

ORIGINAL ARTICLE

Chronic fatigue syndrome and health control in adolescents and parents

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Aims: To explore the locus of health control in adolescents with chronic fatigue syndrome (CFS) and their parents in comparison with healthy adolescents and their parents.

Methods: In this cross-sectional study 32 adolescents with CFS were compared with 167 healthy controls and their respective parents. The Multidimensional Health Locus of Control (MHLC) questionnaire was applied to all participants.

Results: There was significantly less internal health control in adolescents with CFS than in healthy controls. An increase of internal health control of one standard deviation was associated with a 61% reduced risk for CFS (OR=0.39, 95% CI 0.25 to 0.61). Internal health control of the parents was also protective (OR fathers: 0.57 (95% CI 0.38 to 0.87); OR mothers: 0.74 (95% CI 0.50 to 1.09)). The external loci of health control were higher in adolescents with CFS and in their parents. Increased levels of fatigue (56%) were found in the mothers of the adolescents with CFS, in contrast with the fathers who reported a normal percentage of 13.

Conclusions: In comparison with healthy adolescents, adolescents with CFS and their parents show less internal health control. They attribute their health more to external factors, such as chance and physicians. This outcome is of relevance for treatment strategies such as cognitive behaviour therapy, for which health behaviour is the main focus.

Chronic fatigue syndrome (CFS) is mainly characterised by a complaint of chronic and disabling fatigue in addition to other symptoms. A great variety of explanations have been explored, including infectious, metabolic, immunological, and endocrine causes, but no one factor can be shown to be the single causative agent. Similarly, a single psychiatric cause cannot be established, although comorbidity with depression and anxiety is common in CFS adolescents.¹ There is currently insufficient support for either a purely somatic or psychic chain of causation. CFS is believed to have a multifactorial origin, and a distinction is made between constitutional, initiating, and perpetuating factors on both a biological and psychosocial level.²

Prevalence estimates of CFS vary substantially from 0.02% in the Netherlands³ to 0.2% in the UK⁴ to 0.33% in the USA,⁵ and seem to depend much on criteria and methods. Self-reported CFS yields a higher prevalence rate than physician reported CFS, which is the basis for the prevalence rate in the Netherlands.³ A more recent prevalence study in the UK based on physicians' reports of severe unexplained fatigue of at least three months' duration, reported a prevalence rate of 0.06%.⁶ A recent study showed that two thirds of children with CFS finally recover with a resumption of social activities and school attendance and a marked decrease in number and severity of symptoms.⁷ Although most adolescents recover, disability during illness is high and affects all aspects of life.^{8–12} This disability may have lasting effects and it is therefore important to detect factors that influence the start and the course of the CFS symptomatology.

The lack of a definite aetiology for CFS limits the treatment options to symptomatic and behavioural treatment. A recent randomised controlled trial gave evidence for the effectiveness of cognitive behaviour therapy, but only 60% of the adolescents had made a complete recovery as assessed directly after treatment.¹³ In an uncontrolled study of the

effectiveness of family cognitive behaviour therapy, 83% improved, and this improvement lasted for the follow up time of six months.¹⁴ Multidisciplinary rehabilitative treatment was shown to be effective in another uncontrolled study,¹⁵ but only 43% had complete recovery. The remaining treatment options are restricted to symptomatic treatment, like careful attention to sleeping habits and nutrition.¹⁶ Although health behaviour seems the focus of treatment, very little is known about the beliefs that determine health behaviour in adolescents with CFS, either as predisposing or as maintaining factors. From studies in adults with CFS we know that the patient's illness attribution (the patients' beliefs about the cause of their illness) and coping style contribute to the severity of the illness.¹⁷ However, similar studies in adolescents are lacking. Important motivational factors for health behaviour are beliefs about the locus of health control.¹⁸ An internal locus of health control indicates that patients believe that health is primarily determined by their own behaviour or capacities (for example, "My health depends on how well I take care of myself"). An external locus indicates a belief that health is primarily determined by external factors (chance or physicians; for example, "Most things that affect my health happen to me by accident"; "I can only do what the doctor tells me to do").¹⁹ An individual does not have either an internal or an external locus of health control—they are coexistent to a larger or lesser extent. Individuals who believe that health is a function of personal behaviour (internal locus of control) have been shown to take greater responsibility for their own health than those with an external control orientation.²⁰

Parents reinforce adolescents' behaviour. A recent study confirmed that children with CFS experience even more parental reinforcement of illness behaviour than healthy or chronically ill control cases.²¹ This finding emphasises that research on health beliefs and health related behaviour in adolescents with CFS should be extended to their parents.

The present study aims to examine whether the locus of health control differs between adolescents with CFS and healthy adolescents and their respective parents.

METHODS

A total of 45 adolescents (aged 12–18 years) were referred with severe fatigue to a specific CFS clinic of the University Medical Center, Utrecht between January 2001 and May 2002. All patients were Caucasian; 39 adolescents fulfilled the Centers for Disease Control and Prevention (CDC) criteria for CFS.²² A child psychologist performed psychological examinations, using specific Dutch questionnaires for anxiety and depression in combination with an interview of both child and parent. Additional to the CDC exclusion criteria, patients with lifelong problems of somatisation ($n = 2$) or an established diagnosis of a severe depression or a primary anxiety disorder dependent on pharmaceutical treatment were excluded ($n = 2$). Three adolescents refused to participate (two on account of fatigue, one received no permission from the rehabilitation centre). Individual measurements of the remaining 32 patients took place during two special sessions in May 2002, in separate rooms in the hospital, and at different periods after first diagnosis.

As a reference group, 363 adolescents aged 12–18 years from a general secondary school, “De Breul” (Zeist, Netherlands), were invited to participate. A total of 167 adolescents (46%) agreed to participate and were examined during sessions at school in April 2002. In addition to the adolescents, the parents of both groups were asked to complete questionnaires. In the CFS group, 32 mothers and 30 fathers responded. In the healthy group, 158 mothers and 143 fathers responded.

Measurements

Control beliefs with respect to health and illness in general were measured with the Multidimensional Health Locus of Control (MHLC) questionnaire.²³ The MHLC comprises three subscales corresponding to an internal, chance, or physician locus of health control. All subscales comprised six items scored on a five point Likert scale in accordance with the validated Dutch translation of this questionnaire.²⁴ We determined the psychometric property of the MHLC by the Cronbach’s alpha reliability coefficient, which was 0.80 for the entire MHLC, and for the subscales internal locus 0.82, chance locus 0.75, and physician locus 0.73.

Causal attributions were assessed by asking the adolescents with CFS to write down their ideas about the cause of their complaints. Responses were coded into three categories: physical, psychosocial, and do not know. The MHLC was applied to all participants: adolescents with CFS and healthy adolescents and their respective parents. Causal attributions were only asked of adolescents with CFS.

Fatigue was assessed with the Checklist Individual Strength (CIS-20) in both adolescent groups. The CIS-20 asks about fatigue in the two weeks preceding the assessment. There are four subscales: subjective experience of fatigue with eight items, concentration with five items, motivation with four items, and physical activity with three items, each item scored on a seven point Likert scale. A high score indicates a high level of subjective fatigue and concentration problems and a low level of motivation and physical activity. The internal consistency is high, as is the discriminative validity for CFS.¹⁷

Physical activity was measured in both adolescent groups by a detailed questionnaire asking for the time spent in three different physical activities: cycling to school, school gymnastics, and outdoor sports. Regular physical exercise has been associated positively with internal locus of health control and negatively with external locus of health control.¹⁸

A recent study confirmed decreased physical activity to be an important risk factor for the development of CFS.²⁵

School type and school attendance were assessed in both adolescent groups by a general questionnaire asking about school attendance in the six months preceding the assessment.

A general questionnaire was applied to the parents of all the adolescents regarding sporting activities and fatigue complaints.

The adolescents completed the questionnaires, without their parents’ presence, in an average of 30 minutes. The parents completed the questionnaires at home.

The medical ethics committee of the University Medical Center, Utrecht approved the study. Written informed consent was obtained from adolescents and parents.

Data analysis

Of the relevant variables, group specific means and standard deviations or proportions were calculated for descriptive purposes.

The data were analysed with linear regression using the variable of interest (locus of control) as dependent variable and a group indicator (patient = 1, control = 0) as independent variable to explore group differences. Results are presented as linear regression coefficients representing mean differences between the CFS and the healthy family members for the investigated parameter with their corresponding 95% confidence intervals. The same models were used to adjust for possible confounding factors.

The magnitude of the associations between locus of health control and CFS was quantified by estimating odds ratios (OR) and corresponding 95% confidence intervals (95% CI) using unconditional binary logistic regression, with CFS (yes/no) as dependent variable and the Z scores of the total score on the different subscales as covariates. The adjusted odds ratio was quantified in the same model by adding possible confounding factors as covariates (age and gender of the child).

Statistical significance was considered to be reached when 95% CI did not include the 0 (concerning linear regression coefficients) or 1 (concerning odds ratios) corresponding with a p value < 0.05 .

RESULTS

Table 1 presents clinical characteristics of the adolescents and their parents. There was a significantly higher proportion of girls in the CFS group. Physical activity was reduced in the CFS group by an average of nearly 6 hours per week. School level was the same but school attendance was substantially impaired in the CFS group. The CFS patients showed a higher score on all the subscales of the Checklist Individual Strength (CIS-20) than healthy adolescents, after adjusting for gender and age. Comparison of the parents of both groups showed that the mothers of adolescents with CFS were also less active in sports and complained more about fatigue. The fathers of adolescents with CFS showed the same reduction in physical activity, although not statistically significant, but they lacked the fatigue complaints. All relevant differences between the adolescents with CFS and the healthy adolescents were adjusted for age and gender as possible confounders, but this did not influence the results in table 1.

Table 2 shows the results of comparisons of patients with CFS and controls and their respective parents with regard to MHLC questionnaire scores. Adolescents with CFS and their fathers had significantly lower mean scores for internal locus of health control compared to respective healthy family members. The calculated odds ratio showed a 61% lower risk for CFS per standard deviation higher score for internal locus of health control. The mothers showed the same tendency, but this was of borderline statistical significance. The odds

Table 1 Characteristics of adolescents with and without CFS and their respective parents

	CFS cases (n = 32)	Healthy controls (n = 167)	Mean difference (95% CI)
Age (years)	16.0 (1.7)	15.5 (1.6)	0.5 (-0.1 to 1.2)
Gender (% girls)	88	60	28 (9 to 45)
Median illness duration in months (range)	27 (6–192)	NA	
Mean total hours physical exercise per week (h/wk)	2.3 (3.3)	8.0 (3.9)	-5.7 (-7.2 to -4.2)
School type level 1 (%)	19	20	0 (-15 to 16)
School type level 2 (%)	81	80	0 (-15 to 16)
Minimal school absence (less than 5% last 6 months) (n (%))	4 (13)	149 (89)	-76 (-89 to -65)
Considerable school absence (5–50%) (n (%))	19 (59)	18 (11)	48 (35 to 62)
Almost complete school absence (50–100%) (n (%))	9 (28)	0	28 (21 to 35)
Fatigue assessment: Checklist Individual Strength (20 items, 7-point Likert scale)	45.2 (11.0)	22.9 (11.0)	22.2 (18.0 to 26.4)
Total score subscale subjective fatigue (8 items)	21.6 (8.7)	15.2 (7.0)	6.3 (3.0 to 9.6)
Total score subscale concentration (5 items)	13.5 (5.2)	9.0 (4.0)	4.5 (2.5 to 6.4)
Total score subscale motivation (4 items)	14.4 (4.9)	7.4 (3.8)	7.1 (5.3 to 8.9)
Total score subscale physical activity (3 items)			
Self-reported sporting activities			
Mothers, % active on outdoor sports	47	76	-29 (-46 to -12)
Fathers, % active on outdoor sports	47	62	-15 (-34 to 4)
Prevalence (%) of self-reported fatigue in parents			
Fatigue in mothers	56	21	35 (6 to 64)
Fatigue in fathers	13	17	-4 (-19 to 11)

Values are mean (SD) unless otherwise indicated. 95% CI, 95% confidence interval corresponding with a p value <0.05.

ratios for loci of health control of the adolescents were adjusted for age and gender. There was, on average, significantly more attribution of health to external factors (chance and physicians) by adolescents with CFS. Their respective parents showed the same tendency, although for the physician locus there was no clear difference between the mothers of both groups.

Half the adolescents with CFS indicated that they did not know the cause of CFS, when asked in an open question. Only 20% attributed the CFS illness to mainly physical factors (virus infection, sugar intolerance, weakened immune system, hormones, constitutional), whereas 30% judged psychosocial factors as the main cause (stress, overburdening, negative self-esteem, and instability in daily events).

DISCUSSION

We have established that families with an adolescent with CFS show a reduced internal health control in comparison with healthy families. Their belief in personal control over illness is diminished in favour of a belief in chance or physicians influencing their illness. Our study indicates that this reduced internal health control is one of the psychosocial factors that is involved in the CFS symptom complex, either as a predisposing or maintaining factor or both.

The pattern of health control of the healthy adolescents is similar to findings in previous research in 506 healthy Swedish adolescents, with the same ranking of internal and external locus with comparable scores.²⁰ Although we cannot exclude the possibility of differential non-response—that is, that healthy subjects with lower internal locus of health control would have participated less in our control group, the resemblance in scores with other healthy adolescents is reassuring.

The change in health control to a more external pattern in adolescents with CFS has not been published before. We know from other studies in chronically ill adolescents that the pattern of health control can change into a more external pattern in chronic illnesses, as in adolescents with inflammatory bowel disease.²⁶

Our cross-sectional design does not enable us to make a distinction as to whether illness beliefs were pre-existing or the consequence of living with a chronic, unexplained illness. Previous studies regarding health control indicated that the degree of internal control varied with the realistic controllability of the disease,²⁷ becoming more external when the outcome of disease is hardly influenced by health behaviour. Kellerman *et al* found a more external pattern of health control in adolescents with rheumatologic, cardiologic, and

Table 2 Locus of health control measured with the MHLC*

	Internal locus			Chance locus			Physicians locus		
	Total scores		Odds ratio† (95% CI)	Total scores		Odds ratio† (95% CI)	Total scores		Odds ratio† (95% CI)
	CFS (n = 32)	Healthy (n = 167)		CFS (n = 32)	Healthy (n = 167)		CFS (n = 32)	Healthy (n = 167)	
Adolescents	14.5	19.1	0.38 (0.25 to 0.58) 0.39 (0.25 to 0.61)‡	15.0	13.7	1.34 (0.92 to 1.96) 1.42 (0.95 to 2.10)‡	12.0	10.7	1.47 (1.02 to 2.13) 1.52 (1.02 to 2.24)‡
Fathers	16.8	19.1	0.57 (0.38 to 0.87)	15.4	14.2	1.32 (0.90 to 1.95)	12.8	10.9	1.67 (1.14 to 2.45)
Mothers	16.9	18.2	0.74 (0.50 to 1.09)	15.8	14.2	1.53 (1.04 to 2.26)	10.8	10.5	1.08 (0.74 to 1.57)

*MHLC: Multidimensional Health Locus of Control: three subscales with six items scored on a five point Likert scale (range: 6–30).

†All odds ratios represent one SD shift on the subscale concerned.

‡Adjusted OR for age and gender.

What is already known on this topic

- A lower internal locus of health control has been found to be associated with a worse outcome of CFS in adults
- Knowledge about health beliefs in adolescents with CFS is not available but is expected to be important for treatment strategies

nephrologic disease, characterised by few control possibilities over their illness. Diabetic adolescents, on the other hand, equipped with extensive control possibilities related to outcome, showed a pattern of health control comparable to healthy adolescents.²⁸ Adolescents with cancer were found to have a lower internal health control and a higher reliance on physicians,²⁹ comparable with the pattern we found in CFS families. While this could be well adjusted and advantageous for the adolescent with cancer, where there is a need to adhere to intensive medical treatment, this can be disadvantageous for an illness such as CFS, where the only available treatment options are behavioural.

CFS is characterised by the lack of a uniform illness explanation and well defined treatment possibilities, and this may enhance the feeling that the symptoms cannot be influenced and that control over the illness is therefore impossible. The majority of the adolescents with CFS in our study perceive CFS as a black box providing no clues about the cause. CFS itself might have induced this change in control beliefs to a more external pattern. However, for treatment strategies it does not really matter if these beliefs are pre-existent or the consequence of the illness. Important is the fact that the outcome of chronic illness is improved by increasing patients' involvement and control over their illness.³⁰ Particularly for adults with CFS, a relation between outcome and sense of control over the illness has been shown.³¹ The finding of a reduced internal health control, not only in the adolescents with CFS but also in their parents, and the possible relation to illness outcome, demands more attention to health beliefs within any treatment strategy and within a family systems perspective.

Female gender is a major risk factor for CFS in this study. This corresponds to prevalence data in the Netherlands³ and the UK,⁶ both for adolescents and for adults.

The locus of control might be influenced by undetermined psychosocial factors, such as depression or anxiety. The literature on this aspect is inconsistent. In adults, for example, low internality and high externality of locus of control is related to depression.³² A study in adolescents with inflammatory bowel disease or diabetes showed that an external locus of control correlated with the severity of a physical illness and the presence of psychiatric disorders.²⁶ Another study, however, in adolescent girls with CFS, showed an increased score for depression and anxiety, but the locus of control was in the opposite direction, namely more internal in the CFS group.³³ The last three mentioned studies examined mere locus of control and not the specific *locus of health control*, as was the subject in our study. Insofar as depression might partially be a cofactor for the reduced internal health control, the direction of causation is once more unclear. In our study population, patients with severe depression were excluded, but minor depression might still be a partial explanation for the difference in locus of control, either as one of the causative factors or as an epiphenomenon.

The impact of CFS on the individual adolescents and their families is substantial. In our study only three adolescents were able to follow a (reduced) normal school programme.

What this study adds

- Adolescents with CFS have a lower internal locus of health control, and their parents show the same pattern of health beliefs
- Inclusion of a family perspective in the treatment of the adolescent with CFS is recommended

All others were either total school absentees or required facilities such as home tuition or a school accommodation programme. Moreover, chronic fatigue often involves other family members. Fifty six per cent of the mothers of adolescents with CFS reported feeling fatigue themselves, in comparison with 22% of the working population in the Netherlands,³⁴ corresponding with the percentage we found in the mothers of the healthy adolescents. A positive family history of fatigue may indicate a strong predisposing factor, either on a biological level or on a psychosocial level, or both. Together with the reduction in physical activity in the parents and the shared health beliefs with a reduced internal locus of health control in CFS families, this justifies a family orientated system perspective towards the treatment of adolescents with CFS. The most promising therapy in adolescents with CFS is cognitive behavioural therapy, but full recovery is restricted to 60%. More detailed insight into the familial health beliefs may enable more tailored interventions in an earlier stage of illness development.

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