

## **How do adolescents with chronic fatigue syndrome perceive their social environment? A quantitative study.**

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### **Abstract**

Some concern has been raised regarding the inappropriateness of the adult Center for Disease Control criteria for use in children. This resulted in a pediatric case definition being published in 2006. Unfortunately, the case definition does not prevent confusion and doubt with regards to the experienced symptoms in school personnel who deal with young persons with chronic fatigue syndrome (CFS). In order to provide more insight into pediatric chronic fatigue syndrome, twenty-seven chronic fatigue syndrome adolescents were interviewed by means of questionnaires. Results showed that it took about one and a half years before children received a diagnosis of chronic fatigue syndrome. Their symptom pattern seems comparable with that of an adult sample, except for stomach aches. The majority experienced conflicts at school due to their condition. Almost every adolescent with chronic fatigue syndrome abandoned their leisure activities. Adolescents with chronic fatigue syndrome were frequently confronted with negative remarks if they attempted their usual leisure activities.

**Key words:** adolescent chronic fatigue syndrome, conflicts, school environment, symptoms

### **How do adolescents with chronic fatigue syndrome perceive their social environment? A quantitative study.**

Chronic Fatigue Syndrome (CFS) is a persistent disabling disorder that is characterized by severe, overwhelming fatigue along with a number of other symptoms (Fukuda et al., 1994; Carruthers et al., 2003). Illnesses that are consistent with CFS definitely occur in adolescents (Van Hoof et al., 2006, Jordan et al., 1997). A number of authors however have raised the concern that the current criteria for CFS were designed for use in adults and that there is relatively little work in assessing how appropriate these criteria are for children and adolescents (Marshall, 1999; Breau et al., 1999; Wright & Beverley, 1998; Jordan et al., 1998; Mears et al., 2004). The discussion on the inappropriateness of the CFS criteria resulted in a specific case definition for pediatric CFS (Jason et al., 2006). These particular criteria address, for instance, the different symptom constellations between adults and children. The case definition presents recommendations developed by the International Association of Chronic Fatigue Syndrome

Pediatric Case Definition Working Group. Epidemiological studies for CFS in children and adolescents are scarce (Richard & Smith, 1998), although in the Netherlands the prevalence in teenagers has been reported as 10-20 per 100 000 inhabitants (De Jong et al., 1997).

To date, there has been limited research on the characteristics of fatigue in adolescents. In CFS, symptom occurrence in children is similar to that seen in adults, and most commonly includes: muscle aches, sore throat, headache, abdominal pain, increased somnolence, concentration difficulties, and depression. A few exceptions, however, are apparent (Oleske et al., 2006, Smith & Carter, 2003). For example, reports of acute onset and viral symptoms appear more frequently in samples including children (Oleske et al., 2006, Smith & Carter, 2003; Carter et al., 1995; Krilov et al., 1998). Therefore, it is possible that an infectious illness at onset may play a role in the development of abnormal fatigue in some adolescents (Oleske et al., 2006). Subsequently, one could argue that to provide enough time for the patient to recover from a possible acute infection, a diagnosis should not be made until there have been two to six months of symptoms. However, some researchers in chronic fatigue suggest intervening after six weeks of complaints (De Jong et al., 1997). Children seemingly differ from adults in that they have a more optimistic prognosis (Joyce et al., 1997). In a systematic review, four studies on children with CFS showed that 54-94% of children recovered in comparison with less than 10% of the adults (Joyce et al., 1997). Most children with CFS also display an impaired school performance and a decrease in social activities (Carter et al., 1995; Krilov et al., 1998; Van Hoof & Maertens, 2002).

The impact of this illness may be profound, and one survey suggested that CFS is responsible for 50% of long term absences from school (Colby, 1994). The criteria for young people with CFS should therefore include significant limitations in educational, social and leisure activities. These limitations can be persistent but can also have a relapsing, remitting character. The inclusion of limitations seems very important as my clinical practice provides evidence that young people with CFS patients stop their favorite activity in order to keep up at school. Giving a diagnosis at an early stage should prevent social isolation (Van Hoof et al., 2006). This indicates that interview data should be gathered concerning the leisure activities because this can also add to a differential diagnosis. Indeed, CFS patients gradually start to eliminate activities due to the experienced complaints. Most commonly, patients start to reduce their leisure activities with friends and peers in order to be able to attend school. Subsequently, their leisure activities are frequently non-existent as CFS patients present themselves when complaints also start to interfere with their performance at school. School phobia, for instance, is characterized by young people who do not attend school but have a lot of leisure activities (Van Hoof & Maertens, 2002). Furthermore, pediatric CFS patients attend a physician when their physical state deteriorates and when their school attendance becomes problematic. At this point, leisure activities will probably be completely abandoned.

Research suggests using a multidisciplinary approach including school personnel and teachers for both assessment and intervention. As pediatric CFS still is a controversial diagnosis, the inclusion of school personnel and teachers can be problematic and entangled with ignorance and skepticism. In order to provide the best optimal guidance for both school personnel and the pediatric CFS patients, one should be aware of the possible areas which may cause problems at school. This study examines these possible problematic areas by interviewing young people about their experiences at school as CFS patients.

## **Methods**

### *Design*

All potential pediatric CFS patients attending the Chronic Fatigue Clinic in Brussels

(Belgium) between January and March 2005 were approached and asked to complete a questionnaire. Inclusion criteria were CFS diagnosis, parental consent and age between 12 and 21 years of age.

To fulfill the CDC criteria for CFS, clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset, should result in a substantial reduction in previous levels of occupational, educational, social or personal activities. Furthermore, at least four of the following symptoms must have persisted or recurred during 6 or more consecutive months and must not have predated the fatigue: impairment in short-term memory or concentration, tender lymph nodes, muscle pain, multi-joint pain, headache, unrefreshing sleep, and post-exertional malaise > 24 hours (Fukuda et al., 1994). Any active medical condition that might explain the persistence of chronic fatigue prohibited the diagnosis of CFS. Hence, all subjects underwent an extensive medical evaluation, consisting of a standard physical examination, medical history, exercise capacity test, and routine laboratory tests. The laboratory tests included a complete blood cell count, determination of the erythrocyte sedimentation rate, serum electrolyte panel, measures of renal, hepatic and thyroid function, as well as rheumatic and viral screens. If the patient's medical history did not exclude a psychiatric problem at the time of disease onset, then a structured psychiatric interview was performed. In a number of cases further neurological, gynaecological, endocrine, cardiac and/ or gastrointestinal evaluations were performed. The medical records were also reviewed to determine if the patient suffered from organic or psychiatric illness that could explain their symptoms. If any of the laboratory/ additional analyses revealed any active medical condition that might explain the presence of the patient's symptoms, then the subject was excluded from the sample.

All eligible patients were phoned in order to acquire parental consent and to inform patients about the study and its procedure. Using a cross-sectional design, all 27 eligible patients with CFS were sent two questionnaires by post. Further data were later obtained from the clinical notes after informed consent was obtained. The only exclusion criterion was a primary diagnosis other than chronic fatigue syndrome. Patient informed consent was taken as implicit on return of completed questionnaires as was stated in the introductory letter. The study protocol was approved by 'Institute for Family Sciences' in Brussels.

### *Questionnaires*

*The School Questionnaire*, which was especially developed for this study, included information on possible professionals such as physiotherapists or psychologists included in their therapeutic plan; attribution; educational degrees, absenteeism, intellectual capacities, problems with fellow students or teachers, and whether they need special consideration of any kind. This self-report questionnaire was completed without parental support and took 15 minutes to complete. Twenty-eight questions examined four areas: chronic fatigue syndrome, school, friends and leisure activities, and family.

*The Complaint Checklist* was derived from previous research and was comprised of the symptoms most frequently reported by CFS patients attending the tertiary clinic (Van Hoof et al., 2006). Items were translated from English to Dutch by two independent physicians. The Dutch version was then presented to a bilingual assistant in order to ensure content-validity. Reliability scores of this derived complaint checklist is good ( $\alpha = 0.867$ ). The checklist consists of 15-items on a 4-point Likert scale indicating how many times a complaint occurred. A high score also reflects severity of the reported symptoms due to its daily presence.

### *Statistical analyses*

Descriptive statistics and frequencies were computed using SPSS 12.0 [SPSS 2003, SPSS

Syntax reference 12.0 SPSS Inc. Chicago, IL, USA]. As the data were largely ordinal, non-parametric testing was appropriate. Results are reported as mean scores with the standard deviation in parentheses. Reliability analyzes were performed using the intraclass correlation coefficient and Cronbach's alpha. A Spearman rank coefficient with a significance test was performed in order to reveal any associations. The significance level was set at 0.01 to help protect against potential Type I errors.

## Results

### *Sample*

Twenty-seven pediatric CFS patients participated, of which 21 were girls (78%) and 6 were boys (22%). Their mean age was 16.27 years ( $\pm 3.08$ ).

Due to the personal approach by the telephone call before the start of the study, there was a 100% response rate which also demonstrates that all parents provided parental consent.

### *Chronic fatigue syndrome*

All participants were diagnosed using the 1994 CDC criteria (Fukuda et al., 1994). The adolescents had the diagnosis of 'CFS' for 35.11 months ( $\pm 23.52$ ), on average, or almost 3 years. However, this same sample described having CFS-like symptoms for a mean period of 51.92 months ( $\pm 32.75$ ) or 4 years, which means they suffered on average 17.42 months ( $\pm 18.09$ ) from complaints without any diagnosis.

Thirteen students (48%) reported a sudden onset while 14 students (52%) displayed a gradual onset.

Table 1 gives an overview of the reported complaints by our sample. Complaints mentioned by at least 75% of our sample were considered as most debilitating as they were systematically reported on a daily basis. Complaints of fatigue, fatigue after exertion, concentration-, mathematical- and memory problems, sleep problems, muscle- and joint pains, and stomach aches significantly influenced their daily activities.

**Table 1: Complaints reported by adolescents suffering from chronic fatigue syndrome**

[0 = absent; 1 = once in a while; 2 = regularly; 3 = daily] (N = 24)

Symptoms	0	1	2	3
Fatigue	-	4.2%	33.3%	62.5%
Fatigue after exertion	-	-	29.2%	70.8%
Concentration problems	4.2%	8.3%	50.0%	37.5%
Mathematical problems	16.7%	16.7%	41.7%	25.0%
Memory problems	25.0%	12.5%	33.3%	29.2%
Problems finding words	37.5%	29.2%	12.5%	20.8%
Depressive feelings	66.7%	16.7%	12.5%	4.2%
Anxiety	54.2%	16.7%	12.5%	4.2%
Emotional liability	25.0%	25.0%	29.2%	20.8%
Sleep problems	4.2%	25.0%	20.8%	50.0%
Headaches	20.8%	33.3%	16.7%	29.2%
Sore throat	29.2%	29.2%	29.2%	12.5%
Lymph nodes	37.5%	8.3%	41.7%	12.5%
Muscle and joint pains	12.5%	20.8%	29.2%	37.5%
Stomach aches	16.7%	16.7%	20.8%	45.8%

### *Attribution*

Eight students (31%) reported a possible psychological influence of their complaints; 12 students (46%) did not acknowledge any psychological influence. Finally, 6 students (23%) did not know if a psychological influence was possible.

### *Multidisciplinary team*

The majority (85%) were followed up by a physician but not by a physiotherapist (82%) or a psychologist (90%). Only 2 students (9%) reported the presence of a multidisciplinary team.

### *School*

Our sample included one person from first, fifth, and sixth grade (respectively 3.7%). Two were in seventh grade (7.4%), one in 9th grade (3.7%), four in tenth grade (10.8%), ten in eleventh grade (37.0%), five in 12th grade (18.5%) Two individuals already started a higher education (7.4%).

In Belgium, students receive one out of three possible certificates after the completion of a grade. An A-attest means a very successful year; the student can attend the next grade. A B-attest indicates a successful year only when the student changes to a technical education instead of an all-round general education. Finally, a C-attest means the student has failed and needs to start the same grade again. The majority (70%) had failed at least one year (C-attest) since the onset of CFS. About half (44%) changed schools since the onset of CFS.

Our sample did experience problems at school that were attributed to CFS. Extreme fatigue, concentration problems, skipping courses due to an exacerbation of complaints, and working at a slower pace in comparison with their fellow students were most reported. Only 6 persons (22%) attend school full-time. Others attended half of the scheduled time.

Twenty-two students (82%) skipped courses on a regular basis, especially physical exercise. However, everyone attended the major courses. Additionally, 8 students (30%) were able to follow the standard exam schedule. The majority, however, completed the exam schedule with special arrangements. Only 9 students (33%) felt that their grades were in accordance with their capacities.

### *Conflict*

About half (52%) experienced conflicts at school due to their condition. Only 9 students (33%) received help from their fellow students. Help was defined by exchanging notes and keeping track of the tasks/ assignments. Only 2 students (8%) obtained class notes from the teacher. Two students (7%) were tutored. About half (13 students – 48%) caught up on their own.

About half (48%) received a special arrangement due to CFS. Sixty percent of the fellow students reacted neutrally, 33% positively and only 11% displayed a negative attitude toward the CFS patients. Most teachers (60%) also reacted neutrally, 33% seemed positive, and only 7% reacted negatively. The vast majority (96%), however, did not believe good agreements/ arrangements were made about courses, assignments and exams. For instance, when it had been agreed with the principal that, in order to rest, some classes could be skipped the teacher himself did not provide any information on the skipped class although this had been discussed with the principal.

### *Extra-curricular activities*

About half of the students (48%) did not participate; 40% did join their fellow students on a trip once in a while, whereas 2 students (7%) always participated in extra-curricular activities. Most fellow students and teachers reacted neutrally concerning non-participation.

### *Friends and leisure activities*

About half (48%) of the students had fewer friends since the onset of CFS. The vast majority of the students with CFS went out with friends once a month. About half (56%) needed to deal with negative comments if they went out to have fun. Twenty-four students (90%) had to quit their hobby due to their condition.

### *Family*

Most parents (70%) displayed an understanding attitude towards their ill child. Nine (33%) reported overprotection, 11% seemed overly demanding, and 26% of the parents seemed overwhelmed by the situation.

### *Correlations*

A positive attitude from the teachers showed a statistically significant association ( $r = .509$ ;  $p = .007$ ) with a positive attitude from the fellow students. Another statistically significant association was apparent between a teacher's positive attitude and providing special arrangements ( $r = .495$ ;  $p = .009$ ) and receiving notes from the teacher ( $r = .592$ ;  $p = .001$ ). Furthermore, a teacher's positive attitude correlated negatively with conflicts at school ( $r = -.411$ ;  $p = .033$ ). No association between absenteeism and attribution was found. No other significant correlations were found.

## **Discussion**

Our sample consisted of 27 adolescents (80% girls and 20% boys) suffering from CFS. Although some literature (Van Hoof & Maertens, 2002) suggests an equal gender ratio in childhood CFS, one can argue given the wide age-range in our sample that results may have been influenced by the onset of hormonal influences on the bodily functions. It has been thought that these hormonal influences create the 70/30 or 80/20 ratio in CFS.

Some data has suggested a gradual onset in childhood CFS to be more common (Patel et al., 2003; Bell et al., 2001). However, our data suggests an equal distribution between gradual versus sudden onset.

In CFS, symptom occurrence in children is similar to that seen in adults, and most commonly includes: muscle aches, sore throat, headaches, abdominal pain, increased somnolence, concentration difficulties, and depression (Van Hoof et al., 2006, Mears et al., 2004) This is validated by our quantitative data.

The length of time it took to obtain a diagnosis is striking. The literature proposes that children and adolescents are diagnosed after 3 to 6 months of symptoms (De Jong et al., 1997). Our results, on the other hand, suggest that these adolescents with CFS suffer symptoms for 17 months before a diagnosis and treatment plan is suggested. Moreover, the quantitative data show they have already become isolated. The results showed fewer friends, no leisure activities, no extracurricular activities with school. Diagnosis at an earlier stage should prevent such social isolation. Rangel, Garralda, Lavin and Roberts' study (2000) reported that when the illness was at its worst, most children with CFS had stopped socializing with their friends, and family relationships had become strained in many instances. This social isolation, however, creates vulnerability in their identity development. At this point in their development, adolescents use peer groups and friends to create a sense of self. Without social interaction this is inhibited. Furthermore, our data reveal that when adolescents with CFS do go out with friends and try to

have fun, they receive a lot of derogatory remarks. Subsequently, clinicians doubt the sincerity of the experienced complaints, leading to psychiatric diagnoses such as Munchausen-by-proxy (Van Hoof et al., 2006).

Functional impairment is a key aspect of the condition and it affects most areas in children's lives. Most striking, according to Rangel, Garralda, Lavin and Roberts (2000) was the impairment caused in school attendance: two-thirds had been totally unable to attend school, with a mean time out of school of one year. In our sample, only 22% went to school full-time and 30% went through a standard exam schedule. Prolonged school absenteeism consequently is included in the definition as a proxy measure for functional impairment and severity (De Jong et al., 1997; Vereker, 1992; Garralda & Rangel, 2004).

Many adolescents in our sample state that they do not believe their grades match their capabilities. In real life, the outcome of education is generally seen as the degree of success at national examinations and entry to further education. These are rarely reported in clinical literature. Furthermore, they experience a lot of conflicts at school and less help and support from the school environment. Summarizing, adolescents with CFS cannot attend school full-time, do not get grades according to their intellectual capacities, and can not participate in a social culture due to their condition. If not supported in a correct fashion, their identity, their sense of self, and their value systems could be affected, and this creates insecurity. Some studies suggested that their attribution towards a viral onset and not psychological factors could influence their absenteeism. Our data did not reveal any association between absenteeism and attribution.

To protect a healthy development of identity and sense of self, more support should be offered at school. Information about this condition should be presented to the school personnel. Moreover, information on development should be given. Subsequently, school personnel and family would be able to integrate education and social development. One could argue that an arbitrary division of the energy for school/education, and of the energy for social activities could improve and protect their identity development.

Correlations revealed that a positive attitude from the teachers could create a positive attitude in fellow students and would result in receiving appropriate assistance. This could diminish the chance of conflicts and would create an adapted school environment for the child with CFS. A balance should be found between education, multidisciplinary counseling and social interaction. In summary the disruption to education, social, and recreational arenas and peer group integration should be minimized (Bell & Van Hoof, 2006).

A legitimate criticism of the study is the number of adolescents with CFS in our sample. Twenty-seven participants is a relative small sample but CFS in young people is still a rare condition (Jordan et al., 2006, De Jong et al., 1997). Our data however, suggest this sample to be comparable with previous studies (Mears et al., 2004; Patel et al., 2003; Garralda & Rangel, 2004).

## **Conclusion**

A significant problem in the literature was the lack of a pediatric case definition of CFS. This deficiency leads to criterion variance problems resulting in studies labeling children with a wide variety of symptoms with CFS. Subsequently, comparisons between articles become difficult, decreasing the possibility of a meta-analysis. In 2006, a pediatric case definition was presented (Jason et al., 2006). One of the main goals of correctly classifying any disease or illness is to

group together patients who have an illness that may have manifestations but a common underlying pathophysiological pathway (Hartz et al., 1998). The benefit of a well-designed case definition is that it facilitates communication among clinicians/ researchers, selection of appropriate treatment methods, and prediction of response to treatment. The proposed pediatric case definition makes sure that clinical, familial, and developmental histories are carefully collected to ensure a diagnosis and subsequent treatment (Jason et al., 2006). This study adds to the current knowledge on pediatric CFS. The most striking result is the length of time it takes to get a diagnosis. Young people with CFS function at a low level before getting a diagnosis. Their social development, however, could be protected if this time could be shortened. Secondly, the results also challenge the more commonly reported acute onset in young people

Finally, this study provides support for the inclusion of restrictions in educational, social and leisure activities into the criteria of pediatric CFS. As restrictions in educational, social and leisure activities are significant and most frequently present in the school environment, the school personnel should be included in the multidisciplinary team.

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