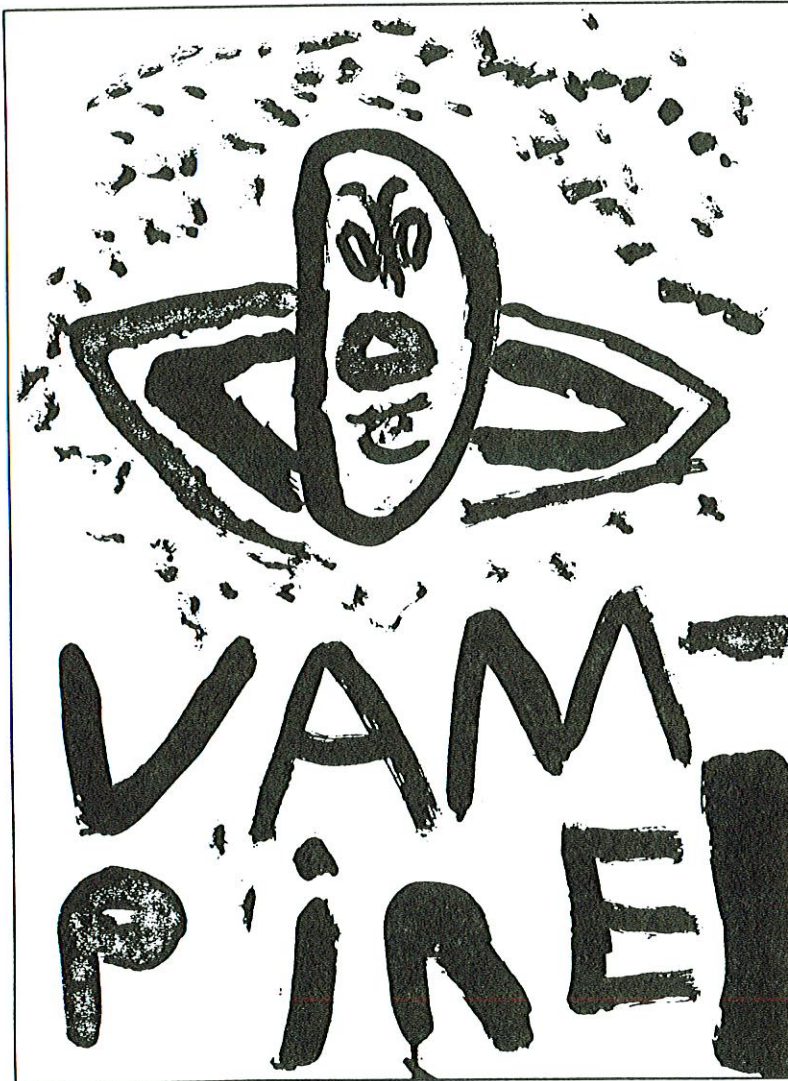


FOCUS & OPINION

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SPECIAL ARTICLE

Chronic Fatigue Syndrome in Children and Adolescents: A Review

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Abstract

Chronic fatigue syndrome (CFS) also called chronic fatigue immune dysfunction syndrome (CFIDS), is an illness characterized by marked functional limitation and a characteristic pattern of somatic symptoms that affects children as well as adults. The symptom complex, physical examination, laboratory evaluation, clinical course, and differential diagnosis are reviewed with particular emphasis on CFS in children.

Clinical management consists of a comprehensive treatment plan including medical, educational, and psychosocial support with the aim of reducing both symptom severity and activity limitation. Although its etiology is unknown, the use of the term "chronic fatigue syndrome" as a clinical diagnosis is appropriate for children with marked functional limitation caused by unexplained fatigue who have the associated symptom complex and physical examination findings characteristic of this condition.

Introduction

Chronic fatigue syndrome is a complex illness characterized by debilitating fatigue and numerous somatic complaints that persist for months or years. Frustrating for both clinician and patient, this illness combines severe activity limitation and symptomatology in an individual who looks relatively well and in whom no biological correlate of fatigue may be found. This paradox—severe activity limitation in a well-appearing adolescent—has generated doubts about the existence of CFS as a specific syndrome, doubts that have been further fostered by conflicting etiologic claims that have proven false. However, the characteristic pattern of symptoms, the typical nature of the fatigue, the frequent postviral onset, and the lack of emotional correlates have argued that CFS is a specific syndrome.

Chronic fatigue syndrome has been described as occurring in clusters or epidemics, and the cause or causes of this illness are unknown. Adults have been the subject of most studies, and several reviews have been published (1–6). Children also have CFS develop, although reviews are less frequent (7–11). In 1988, the Centers for Disease Control and Prevention (CDC) published diagnostic criteria (12) and suggested the term "chronic fatigue syndrome." These criteria

were later modified (13), and new research diagnostic criteria recently have been published (14).

During the past 40 years, CFS has been a controversial illness, with expressed opinions ranging from its being an organic illness (2, 10), a primary emotional illness (15, 16), or "illness behavior" (17). However, regardless of proposed etiology, the symptom complex, dominated by severe fatigue, is being recognized with increased frequency and is receiving more study. With the publication of the 1988 CDC criteria, an increasing number of research studies have been published, including those involving groups of children with the disorder. With the publication of the 1994 CDC criteria and the anticipated improved standardization of patient groups, further research is likely.

Amid the present controversies concerning CFS, numerous issues concerning children stand out. Is CFS a rare or common condition? How frequently does CFS occur in children? Are the clinical manifestations the same as in adults? What are the roles of emotions and family dynamics in children with CFS? And what is the optimal management for children with this disorder? The purpose of this paper is to review the current literature concerning CFS in children and to outline a diagnostic and therapeutic approach to children and adolescents who are seen with chronic fatigue.

Diagnosis

At present, the diagnosis of CFS is entirely clinical: a characteristic pattern of somatic symptoms dominated by unexplained fatigue limiting normal activity. The symptoms follow a relapsing/remitting course that is often exacerbated by exertion or stress and may persist for years. Except in the research setting, laboratory testing is used to rule out other clinical illnesses causing fatigue.

The lack of an objective measurement of fatigue is the greatest methodological difficulty in the diagnosis of CFS. In 1994, the CDC proposed new diagnostic criteria, summarized in Table 1, that require a complete history, physical and mental status examination, and general laboratory screening tests to exclude other clinical conditions. The diagnosis of CFS may be made if there is a new onset of unexplained fatigue that is not the result of ongoing exertion, is not substantially alleviat-

Table 1.—Chronic Fatigue Syndrome Diagnostic Criteria

Diagnostic Steps:
1. History
2. Physical examination
3. Mental status examination
4. Screening laboratory
Fatigue
1. New onset of unexplained fatigue
2. Not the result of ongoing exertion
3. Not substantially alleviated by rest,
4. Results in a substantial reduction in activities
Symptom criteria (at least four of eight)
1) Cognitive dysfunction
2) Sore throat
3) Tender cervical or axillary lymph nodes
4) Myalgia
5) Multijoint arthralgia without swelling or redness
6) Headaches of a new pattern
7) Unrefreshing sleep
8) Postexertional malaise
Documentation of clinical status (research studies)
a) Co-existing psychiatric conditions
b) Current level of fatigue
c) Duration of fatigue
d) Current level of overall functional performance
e) Additional measures of research topic

(Adapted from Fukuda K, Straus SE, Hickie I, et al: *Ann Intern Med* 121:953–959, 1994. Courtesy of Dr. Bell.)

ed by rest, and results in a substantial reduction in activities. Patients must also have at least 4 of the following symptoms: cognitive dysfunction; sore throat; tender cervical or axillary lymph nodes; myalgia; multijoint arthralgia without swelling or redness; headaches of a new pattern; unrefreshing sleep; and postexertional malaise. Those patients meeting the clinical criteria above are given a diagnosis of CFS, whereas those patients not meeting criteria would be given a diagnosis of “idiopathic chronic fatigue.” For research purposes, further documentation is required with subgrouping in 5 categories: coexisting psychiatric conditions, current level of fatigue, duration of fatigue, current level of overall functional performance, and optional additional measures (14).

Previous diagnostic criteria required at least 50% reduction in overall activity along with symptom and physical examination criteria (12). Although these criteria had been helpful in selecting adult groups for research studies, many fatigued patients did not fulfill these criteria and remained with the clinical uncertainty of “unexplained fatigue” (18). The 1988 CDC criteria were not appropriate for children (19–23). Children younger than age 10 years are less able to define degree of fatigue and activity limitation, perhaps because of less well characterized baseline activity level. Research criteria are also used in Great Britain (24) and Australia (25), and criteria based on the symptom pattern of CFS have been proposed (26).

Among the greatest difficulties in diagnosis has been determining the role of depression and somatization, which is a difficulty for both adults and children. In a modification of the early CDC criteria, the diagnosis of CFS could be made if depression occurred after the onset of the symptom pattern,

with no significant history of preexisting emotional illness (13). Pediatricians are accustomed to evaluating families of children with chronic illness, and careful attention should be directed toward family functioning. As in any chronic illness, the degree of emotional symptomatology and family dysfunction, if any, should be correlated to the overall disability and addressed. If the degree of depression is absent or mild, CFS is a useful clinical diagnosis. However, if fatigue or school refusal is linked to a primary gain for the child or family or if depression is severe, the diagnosis of CFS should not be made.

Epidemiology

The incidence of CFS has been a topic of considerable debate that has been complicated by methodological difficulties. Separation of unexplained chronic fatigue from CFS is essential, and the use of different diagnostic criteria has limited data on incidence. Clinical descriptions of early epidemics have been published (10, 27–29), but it has not been fully established that these outbreaks represent the same illness defined by current criteria. Chronic fatigue is common in individuals seen in a primary care clinic, affecting up to 21% of adults (30, 31). Chronic fatigue “syndrome” is clearly less common (18), although the exact incidence is unknown.

In the early outbreaks of CFS involving communities, children were frequently affected and, in some instances, were among the highest attack rates noted. In a review of early epidemics, Acheson noted that community-wide epidemics involved children but rarely children younger than 5 years of age (27). In the outbreak on the northern coast of Iceland in 1949–1950, which involved more than 1,200 persons, 194 children had CFS develop, representing an attack rate of nearly 7% of children in the geographic area. The highest attack rate noted in all age groups in this outbreak was in the 15- to 19-year-old range (32). Several other outbreaks have prominently involved children and have been reviewed (33). Ten to fifteen children with CFS are evaluated each year by the Great Ormond Street Hospital for Sick Children in London (34).

An Australian study noted a prevalence of 31 cases per 100,000 population in the 10- to 19-year age group, with children younger than age 10 years affected infrequently (25). In a 1985 outbreak in Lyndonville, New York, involving both adults and children, an attack rate of 2.3% of the children in the local school district was noted (35). Compared with adults, children younger than age 18 years represented nearly 30% of affected individuals (unpublished data).

Another approach to the question of incidence of CFS in children is to examine the incidence of primary juvenile fibromyalgia, a closely related if not identical illness (1, 36). Fibromyalgia conforming to current diagnostic criteria does occur in children (37), and the relationship between CFS and juvenile fibromyalgia has been reviewed (8). In a recently published study, 8 of 27 children meeting diagnostic criteria for

CFS also met diagnostic criteria for primary juvenile fibromyalgia. In comparing those children with CFS who did and did not meet fibromyalgia criteria there was no difference in age, type of onset, degree of fatigue, and incidence of most symptoms (38).

Juvenile fibromyalgia may be a common condition. In one study, 338 healthy schoolchildren were examined for tender points, with 21 (6.2%) meeting fibromyalgia criteria (39). Children seen at rheumatology clinics for noninflammatory chronic musculoskeletal pain represent a large population (40). Unfortunately, these studies generally do not evaluate the degree of fatigue, activity limitation, or associated somatic symptoms, allowing an estimate of the prevalence of CFS. It is hoped that with the wider use of diagnostic criteria for children and adolescents, this problem will be addressed in the future, and reliable figures of incidence may be obtained.

Clinical Presentation

ONSET CHARACTERISTICS

The general clinical presentation of CFS has been described in several reviews (1–3), but clinical descriptions specific to children are less common (9, 19, 21, 35, 41, 42). In adults, women are more likely to have CFS than men, but some studies in children have indicated a more equal sex distribution (9, 35, 42). The onset may be either acute or gradual.

The acute onset, presenting with a flu-like or “mononucleosis-like” illness, is more common, particularly with onset after puberty. Children aged 6–12 years with “unexplained fatigue” usually have a gradual or insidious onset of symptoms over several months or years. Although younger children with insidious onset may complain less of fatigue, detailed observations of their behavior by parents and school personnel re-

veal reduction in activity similar to that seen in children with acute onset. After the illness has been present for at least 1 year, these 2 modes of onset cannot be distinguished by the pattern of symptoms or physical examination (unpublished observations).

SYMPTOMS

The symptoms of CFS in children are similar to those seen in adults. The pattern is dominated by incapacitating fatigue that is exacerbated by exertion or exercise (21, 23). In a comparison of 5 published studies and an unpublished personal series of children with CFS, the most prominent symptoms in addition to fatigue are headache, abdominal pain, sleep disturbance, myalgia, sore throat, cognitive difficulties, lymph node tenderness, and arthralgia (Table 2). Other symptoms described include the sensation of fever despite a temperature below 100°F, night sweats, rash, dysuria, dizziness, photophobia, and parasthesia. The symptoms resemble the malaise of viral illness.

PHYSICAL EXAMINATION

The ongoing controversy over the legitimacy of CFS as a clinical entity is based on a relatively normal physical examination despite severe functional disability. Studies in adults and personal experience have shown significant adenopathy, occasional splenomegaly, and occasional neurologic findings during the acute onset of CFS (10, 43), but these physical findings resolve despite persistence of lymph node pain and left upper quadrant abdominal pain. Perhaps the most helpful physical finding is tenderness to palpation of lymph nodes without significant adenopathy. Nonexudative pharyngitis,

Table 2.—Clinical Characteristics of Chronic Fatigue Syndrome in Children

Reference	42	9	19	41	35	*	Average
Number in Study	12	32	15	23	21	19	20.3
% with Acute Onset	100	59	73	ND	ND	58	72.5
Male: Female	6:6	13:16	6:9	9:14	11:10	4:15	49:70
Duration of Symptoms**	34m	20m	18m	ND	ND	35m	26.75
Symptoms (%)							
Fatigue	100	100	100	100	100	100	100
Headache	92	97	100	100	100	100	98
Abdominal Symptoms	67	97	73	57	100	68	77
Sleep Disorder	ND	84	ND	ND	38	100	74
Myalgia	92	90	33	<33	100	95	73
Pharyngitis	ND	97	67	43	100	53	72
Memory/Concentration	100	63	40	ND	67	84	71
Lymphatic pain	ND	91	67	<33	95	42	65
Depression	ND	ND	60	ND	ND	68	64
Arthralgia	ND	88	27	<33	91	53	58

*Indicates an unpublished series of 19 children with CDC-defined CFS (Bell 1994).

**Indicates duration in months from onset to study.

Abbreviation: ND, not determined.

(Courtesy of Dr. Bell.)

photophobia elicited on fundoscopic examination, and the presence of tender points on muscle examination may be present.

CLINICAL COURSE AND PROGNOSIS

The clinical course of CFS in children is marked by relapses and remissions without serious medical complications. It is rare that another diagnosis of an illness causing fatigue is discovered in the course of follow-up. Revision of diagnosis has been described in only 1 child subsequently found to have ulcerative colitis (41).

Adequate prognostic studies on children with CFS have not been done. Difficulties with patient selection, varying illness definitions, and lack of biological markers have hampered prognostic efforts. Although a favorable outcome for children seems to be assumed, the improvement noted may in fact be caused more by improved coping with existing disabilities than by a reduction in symptom severity (personal observations). In those studies attempting to look at outcome, 8% to 47% of children with CFS become well, 27% to 46% improve, 12% to 29% remain unchanged, and 6% to 17% become worse on follow-up evaluation (9, 23, 41).

Some children with CFS have a severe course resulting in persistent disability. In these children, the activity limitation and symptom severity are very severe from the onset. The overall pattern of symptoms is the same, with the exception of more severe neurologic symptoms, such as myoclonus, parasthesia, and seizure-like episodes, usually prompting detailed neurologic evaluation. In general, the prognosis in these children is not as favorable (personal observations). At present, there are no adequate studies comparing children who have recovered with those who have more severe morbidity.

Laboratory Evaluation

Although there have been no comprehensive laboratory studies in children published to date, the laboratory evaluation in adults with CFS has been reviewed (1, 3, 6, 44–46). The routine screening is unremarkable except for occasional mild elevations in white blood cells, liver function studies (46), and autoantibodies including low titers of antinuclear antibody (46–47). The sedimentation rate is usually low (44, 46). Abnormal immunology, with decreased natural killer cell cytotoxicity and dysregulated cytokines, has been noted in CFS; although it is useful in the research setting, it is of little value in the clinical evaluation of the individual patient. Elevated antibodies to Epstein-Barr virus have been suspected in the past but are of no value in the evaluation of the individual patient (14). A review of the interesting and complex laboratory findings in CFS is beyond the scope of this review.

The role of the laboratory in CFS in children is straightforward and simple. Beyond routine screening with complete

blood count, sedimentation rate, urinalysis, thyroid assay and standard chemistries, studies should be obtained as indicated by clinical evaluation. Laboratory use in CFS is not different from the evaluation for unexplained abdominal pain or headache, where the laboratory may be involved to a greater or lesser degree depending on clinical circumstances.

Depression

There is little doubt that depression occurs in children with CFS; the question is whether it is the cause of the symptom pattern or the result of it. Nearly 60% to 80% of children with CFS will describe depression among the symptoms (10, 19, 21). In the early outbreaks, emotional (dysphoric) symptoms played a prominent role (48), with affected children showing nervousness (32), crying spells, emotional instability (27), irritability, clinging dependency, and hypochondriasis (10).

Among the more recent studies, systematic attempts have been made to categorize the type and degree of emotional symptoms in children with CFS. In a study by Smith et al. (19), 15 children with chronic fatigue were evaluated and only 5 (33%) were found to have major depression determined by psychiatric interviews with the Schedule for Affective Disorders and Schizophrenia—Children's Version (K-SADS), Children's Depression Inventory (CDI), and the Spielberger State-Trait Anxiety Inventory (STAI). Of interest was that 4 of these 5 subjects had an initial acute, Monospot-positive, febrile illness that initiated their chronic fatigue. Other than isolation, psychosocial interviews revealed significant family problems in only 4 subjects. In comparison with 50 psychiatric clinic adolescents, the depressed adolescents with CFS were less likely to express depressed mood, anhedonia, suicidality, and agitation. There was, however, overlap with the secondary symptoms of depression. The fact that psychological variables did not predict outcome in these children with CFS was also of interest.

The authors note the difficulty in formulating diagnostic criteria around the presence or absence of concurrent depression. Although one third met criteria for major depression, key features and indicators of severity were missing. They state, "it is possible that depression is a consequence of, rather than an antecedent risk factor to, the syndrome."

In another study using the CDI, Walford (42) evaluated 12 children with CFS, 5 of whom (42%) scored above 19, indicating major depression. In comparison to healthy children and children with cystic fibrosis, the CDI was significantly elevated but not to the degree of the differences in the fatigue questionnaire used. The authors note the "hypothesis...that chronic fatigue syndrome may be a misdiagnosed depressive disorder, but the findings in other studies as well as our own ... do not support this view."

In a small, unpublished study comparing 7 children with fatigue who met CDC diagnostic criteria with 12 children with prolonged, unexplained fatigue who did not meet the

criteria, there was no difference in CDI scores (11.7 vs. 10.7). One child with CDC-defined CFS scored in the depressed range on this instrument (personal observations).

In a study evaluating children with CFS with psychiatric interviews and family assessment, Vereker (21) evaluated 10 children, finding 6 children with depressed mood and 2 others with anxiety, although no child met the *Diagnostic and Statistical Manual of Mental Disorders, ed III, Revised* criteria for depressive disorders. No child expressed worthlessness, hopelessness, a sense of guilt, or suicidal ideas. Family evaluation revealed intact families with only 2 families showing evidence of marital disharmony. Neither depression nor somatization disorder were appropriate diagnoses, and the authors suggested the older term "neurasthenia" to describe the pattern of emotional symptoms.

Despite the lack of published studies showing depression or somatization as causes of CFS in children, the perception of its being an emotional illness is widespread (11, 20, 49–53), usually because of normal physical examination and normal routine laboratory testing. A commonly held view is that children experience "lassitude from time to time," but if the fatigue is severe, they "may be suffering from a pathological depression" (11). These children have been said to be "psychologically vulnerable individuals" (49) without evidence being presented in the medical literature. Family dysfunction is particularly important in the development of psychological disturbances in children and adolescents (21, 50, 51), yet little documentation of abnormal family dynamics exists in children with CFS. The argument against depression as a diagnostic label for these children is that primary depression should not be assumed solely on the basis of the symptom of fatigue.

The argument against using CFS as a diagnostic label is that it promotes "learned helplessness" in which children disengage from an active lifestyle (20, 54). The diagnosis (myalgic encephalomyelitis in Great Britain) may "seriously damage a child's health" (55). However, there are as yet no data in the medical literature to support this position. The lack of data demonstrating disturbed family functioning, presence of primary gain, or major depression in a majority of patients would argue in favor of a descriptive diagnostic term such as "CFS" in describing fatigued children in whom no organic or psychiatric etiology is obvious. In evaluating a child with CFS, it is essential to examine family functioning and emotional risk factors objectively.

Münchausen's syndrome by proxy has been described in a fatigued 12-year-old and has been cited as another reason for not formalizing the clinical diagnosis (56). However, this diagnosis should be used with some caution as an increased family incidence of CFS has been noted in some studies (9, 35, 47) as well as in primary juvenile fibromyalgia syndrome (57). Furthermore, adults with CFS who are sensitized to the symptom pattern may misinterpret the normal fatigue and sleep disruption of adolescence with CFS. This becomes an extremely difficult problem in an illness where symptoms are subjective and there are no biological markers for diagnosis.

However, observation of overall activity usually clarifies the diagnosis. In CFS, overall activity is markedly limited, whereas the "normal" fatigue of adolescence does not restrict children in their participation of sports and other vigorous activities. The diagnosis of Münchausen's syndrome by proxy should be made only if there is clear evidence of symptom fabrication.

In summary, a diagnosis of depression and/or somatization has not been able to adequately describe children with CFS, despite emotional symptoms frequently being present. Family dynamics should be an essential part of the evaluation of a child with chronic fatigue. However, the presence of mild depression or indicators of mild family dysfunction should not, any more than the presence of "borderline" anemia, be considered the cause of severe fatigue. However, like anemia, they should be addressed and treated as part of a comprehensive management plan.

Differential Diagnosis

The differential diagnosis of CFS is extensive and is dependent on the pattern of symptoms and their severity. Perhaps the most important differentiating factor between CFS and other fatigue-causing illnesses is the presence of generalized fatigue compared with easy fatigability (50). Anemia, congestive heart disease, and chronic lung disease may cause associated easy fatigability, which is quite different from the overwhelming exhaustion described even at rest in the patient with CFS. Although exertion may cause worsening of the fatigue in CFS, the increased fatigue may follow the exertion by hours rather than fatigability during exertion (21, 23). Pregnancy, drug abuse, juvenile rheumatoid arthritis, lupus erythematosus, hypothyroidism, brain tumor, inflammatory bowel disease, Lyme disease, and HIV infection are among the numerous entities to be excluded. A more comprehensive differential diagnosis for children with fatigue has been presented (8).

After depression, the area of greatest diagnostic confusion is between CFS and separation anxiety disorder, or school phobia. After a "negative" routine laboratory workup, the clinician may be faced with a child complaining of fatigue and other symptoms that prevent school attendance yet have no obvious explanation. There are several factors that should help differentiate the 2 illnesses.

Because school phobia is a manifestation of separation anxiety disorder, symptoms will be most marked by activities that require separation from the parents. The somatic symptoms present in children with school phobia prevent anticipated separation and resolve when separation is not anticipated. The symptoms cause a "secondary gain," the avoidance of separation. In CFS, however, the symptoms are equally present after school and on weekends, causing a marked disruption of social activities, and no secondary gain is found on careful evaluation. In school phobia, disordered relationships within the family may exist, such as the "hostile-dependent"

pattern. An acute anxiety producing event frequently precipitates school refusal (58). In CFS, the onset is often marked by an acute infectious illness with fever and lymphadenopathy, and family relationships are normal.

The pattern of somatic complaints is not the same in the 2 illnesses. Symptoms such as fever, night sweats, arthralgias, lymphodinia, photophobia, and myalgia are not common in school phobia. The pattern of physical examination findings may be different. Findings of lymphatic tenderness, photophobia, rash, and muscle tenderness, when present, are characteristic of CFS.

Management

The medical management of CFS in children usually is not difficult, consisting of symptomatic treatment and vigilance for other medical conditions causing fatigue. However, the psychosocial management requires an understanding of the expected course of the illness, patience, trust between physician and family, clear communication, and, when necessary, confrontation with support. Although pharmacologic therapy may help with certain symptoms of the illness, there is no evidence that it shortens the overall course. A comprehensive treatment plan is necessary to address the many issues to be treated.

SUPPORT AND UNDERSTANDING FROM PHYSICIANS, FAMILY, AND FRIENDS

The child with CFS is usually faced with social and educational isolation because of fatigue and reduced activity level at a time of great importance in identity formation (51). This isolation is compounded by suspicions of malingering, neglect, and primary emotional illness (8), and the child requires support from the treating physician, regardless of whether the ultimate etiology proves to be medical or psychological (59). As in other chronic illnesses, the physician is called on to act as patient advocate, managing both medical and psychosocial issues, providing information and education to the patient, family, and school personnel. Physician support during all phases of the illness will allow greater compliance with treatment suggestions concerning increased activity, an exercise program if appropriate, and counseling if necessary.

FREQUENT DIAGNOSTIC REEVALUATION

Because many of the symptoms of CFS are present early in other disease states, periodic diagnostic reevaluation is essential. Frequent brief office visits are useful to evaluate changes in the symptom pattern, adjust symptomatic treatment, and provide family support, and are probably more valuable than infrequent and more extensive visits. Reevalua-

tion should consist of interval history, physical examination, and ongoing evaluation of psychosocial issues rather than relying on laboratory evaluation. However, new symptoms or changes in the pattern of symptoms should be investigated with laboratory tests as clinically appropriate.

REST AND ACTIVITY

The level of rest necessary for children with CFS varies with illness severity and may fluctuate. Most children are able to assess their activity limits and should be encouraged to be as active as possible. Exceeding these limits may result in a relapse of severe fatigue (21) and begin another period of prolonged bed rest. Therefore, a common sense approach is appropriate to avoid excessive fluctuations in symptomatology by demanding too rapid an improvement in activity.

Many patients will express fears that exercise or exertion would be detrimental to their long-term prognosis and seek excessive rest. If, as some have suggested, CFS is an illness characterized by cycles of viral infection followed by deconditioning (54), rest beyond the immediate needs would be harmful and should be avoided. A balance should be established for the individual child: enough rest to prevent the turmoil and discomfort of frequent relapses and enough activity to prevent deconditioning.

Acceptance of the limitations imposed by the illness and a realistic outlook should be encouraged as part of the overall plan and is facilitated by the usual good prognosis. When anxiety excessively restricts activity, physician support is crucial to helping the child increase activity within tolerable limits. Rehabilitation programs (combined inpatient and outpatient) and behavior modification to increase activity was of value in 6 of 10 children in 1 study of children (21). Unfortunately, the effect of rehabilitation programs on the course of CFS has been inadequately studied. Those adult studies examining treatment with rehabilitation programs have shown mixed results (25, 60).

SCHOLASTIC SUPPORT

Absence from school for prolonged periods of time is frequent in children with CFS and should be addressed in the management plan. Because the long-term prognosis for children with CFS is generally good, it is important to avoid an educational handicap caused by poor educational management during the period of greatest activity restriction. The number of children with prolonged school absence requiring home tutoring ranges from 20% to 44% (9, 19, 35, 41). In one study, school absence was more pronounced in children with CFS than in those with cystic fibrosis (42).

The goal of treatment is to return the child to normal activity as quickly as possible. If a child has severe symptoms and is unable to attend school, home tutoring is appropriate. This may be followed with a half-day program when tolerat-

ed, a full-day program without gym, and finally a normal schedule. Severe relapses may occur in children returning early to full-time school (21), so increased exertion should be gradual and correlated with symptom severity. Flexibility on the part of school personnel is helpful, and some children remain in full-day school if they are able to rest in the nurse's office during periods such as gym and study halls (personal observation).

Cognitive symptoms are described by children with CFS as well as adults. However, adult testing has shown that these cognitive deficits are primarily attentional rather than representing a true dementia (61, 62) and may be viewed as if resulting from fatigue (63). With this in mind, academic achievement is not handicapped other than by the fatigue, and structuring home tutoring and study periods during the periods of least fatigue will usually allow maintenance of academic achievement. If academic abilities decrease more than explained by the fatigue, cognitive testing should be considered.

PSYCHOLOGICAL MANAGEMENT

The term "chronic fatigue syndrome" implies a symptom complex of severe debilitating fatigue and somatic complaints without obvious etiology. The name of this illness as a syndrome does not imply a specific organic or psychiatric etiology and is useful in this regard. Because many patients are resistant to the implication that the illness results from psychopathology, arguments concerning etiology are of little value and undermine follow-up efforts. Family views and experience need to be heard and respected. Differentiation should be made between accurate parental or patient observation and anxiety or fears not based on past experience.

During the initial evaluation and follow-up visits, individual emotional adjustment should be carefully assessed. Type and degree of depression should be noted as well as adequacy of coping skills. Issues involving enmeshment, communication, and emotional support should be monitored. As specific emotional problems, either primary or secondary, are uncovered, they should be addressed with appropriate counseling and/or referral. Medications may be of value in decreasing depression. Despair and suicidal ideation should be carefully evaluated in all children with CFS, but they are uncommon (19, 21).

IMPROVEMENT OF SLEEP HYGIENE

Insomnia, hypersomnia, and nonrefreshing sleep are essential parts of CFS and should be addressed in the treatment plan. Early descriptions in children have emphasized a sleep phase reversal (29). However, few studies have been conducted on sleep disturbance in adults (64, 65) and have rarely been done in children (66). Gradual restructuring of the sleep-wake cycle, good sleep hygiene, as well as cautious use of medication, may be of value in improving sleep quality.

SOCIAL MANAGEMENT

Along with disruption of schooling, social disruption occurs with regularity and should be addressed in the management plan of children with CFS. In the previously mentioned study by Walford et al., social adjustment was compared between children with CFS, healthy controls, and children with cystic fibrosis. The degree of social disruption was higher in children with CFS than in those with cystic fibrosis, despite the fact that the latter condition is frequently fatal in adolescence. All but 1 child with CFS in this study believed that their condition affected social functioning (42). Other studies have noted disrupted social functioning in 38% to 67% of children affected (9, 19).

A management plan should take social functioning into account. For many children, "active time" is limited, and children with CFS are asked to choose between school attendance and social activities. This problem is aggravated if a child needs to "prove" he or she is sick by not going out even when feeling better. Management should include limited social activities, particularly if they can be integrated with school. For a child attending school part-time, arranging the more important classes around the lunch hour may help. Again, because of the expected favorable prognosis, the goal is to maintain social contact so that when recovery occurs, social isolation is not a permanent sequela.

PHARMACOLOGIC TREATMENT

Pharmacologic treatment of adults with CFS has been recently reviewed (1, 67-70) and may be of value in children when accompanied by close follow-up and support. The literature contains few references to drug treatment (antidepressant medication) in children with CFS, and there are no studies critically assessing outcome. It would be hoped that as diagnostic criteria become standardized, further studies will be attempted.

Conclusions

Adolescence is a time of great change and turmoil, and the developmental issues for healthy children are difficult. When a child has a chronic illness, psychosocial development and identity formation are affected. Chronic fatigue syndrome represents a unique and devastating developmental crisis for the adolescent, and the long-term sequelae of the illness may thus be worse for children than for adults.

Bluntly stated, the identity crisis faced by adolescents with CFS is the confusion of whether they are sick or crazy. They experience a constant flu-like malaise, yet physicians tell them they look healthy, that nothing is wrong, and that they should "snap out of it." Over time, identity formation may become affected because these children must decide

whom to trust: their own subjective experience or the advice of the medical professional. Choosing the former may alienate them from professional help. If they choose the latter, they must eliminate their fatigue, somatic symptoms, and activity limitation, a feat that may not be possible. Failure to become "well" may result in guilt and increased identity confusion.

Perhaps the greatest harm to children with CFS is the skeptical undertone of the current medical research. Regardless of whether CFS proves to be a result of an infectious agent, the psyche, or some combination of both, it is an illness that causes great morbidity in children at a crucial period of their development. Chronic fatigue syndrome is a complex illness that lies on the cusp of neurology, immunology, and psychiatry. Oversimplification of the illness is perceived as rejection and is a disservice to children with this condition.

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