ABSTRACT

BACKGROUND. It is often surmised that school functioning is significantly impacted in chronic fatigue syndrome (CFS); however, how this phenomenon manifests itself has rarely been characterized.

METHODS. This systematic review synthesized and critically appraised methods, constructs, and instruments used to assess school functioning in students with CFS. Searches were conducted in electronic databases (CINAHL, MEDLINE, PubMed, ERIC and PsycINFO) to locate empirical studies that measured school functioning in children and adolescents with CFS.

RESULTS. A total of 36 papers met the inclusion criteria. By far the most commonly reported school functioning construct measured related to school attendance. This was followed by academic functioning, achievement motivation, and educational services received. Little consistency was found in the measurement of these constructs across studies.

CONCLUSIONS. The current review revealed that the school experiences of children and adolescents with CFS have rarely been characterized beyond school absenteeism. Improvements in current assessment methods are required to comprehensively understand the impact of CFS on school functioning. Fully understanding the multiple aspects of school functioning will help to inform targeted strategies to optimize educational outcomes for students with CFS.

Keywords: Chronic Diseases, Chronic Fatigue Syndrome, Child & Adolescent Health, School Functioning, School Psychology

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Rates of chronic health conditions in childhood and adolescence are rising, and although rates vary across studies, some studies report rates in excess of 30%.^{1,2} As chronic illnesses are not uncommon among students, it is important that schools are well equipped to support students with chronic health conditions. One such chronic health condition which is experienced by many students around the world is that of chronic fatigue syndrome (CFS). CFS, also referred to as Myalgic encephalomyelitis (ME), is a condition characterized by profound, medically unexplained fatigue that involves a range of sleep, pain, cognitive, neuroendocrine, and immune symptoms.³ It is increasingly recognized that CFS can affect children and adolescents. In fact, a recent study suggests that adolescence represents one of 2 age peaks in the incidence of CFS across the life span.⁴ Estimates of the prevalence of CFS in children and adolescents range from 0.003% to 2%,⁵⁻¹⁰ with rates varying depending on the case definition used and methodological design.¹¹ It is less commonly diagnosed in children as compared to adolescents.¹²

Consistent with other similar chronic health conditions, CFS can pose significant limitations to daily functioning for those affected by this condition. A key area of functioning which is impacted by CFS in children and adolescents is that of school functioning. Of note, school absenteeism or school attendance, has frequently been used as a key indicator of severity of illness in adolescents with CFS. It is well recognized that students with CFS miss substantially more school than their peers with frequent school absence being recorded among children and adolescents who suffer from CFS.^{6,13-16} However, rates of school absenteeism in students with CFS vary considerably, as do the presentation of these rates. For instance, Crawley et al⁸ reported in a study of over 2855 adolescents that 1.0% of enrolled students have CFS and miss over 20% of school over a 6-week period. In another study of 211 children and adolescents with CFS, almost half of these students attended school for only 20% or less of the expected attendance.¹⁷ Bould et

al¹⁸ reported that in a sample of 520 adolescents with CFS recruited through a specialist paediatric CFS/ME service a total of 41% had attended less than 40% of school. Variations in rates of school attendance may be attributed to a range of factors including variations in the way that school attendance is measured and the samples being described.

Nonetheless, there is a clear message that for many students with CFS attending school can be difficult. Due to the persistent and chronic nature of CFS, school absenteeism in students with CFS may be an ongoing concern. The average amount of time away from school for students diagnosed with CFS has been estimated to be one year across their school life.¹⁹ The acquisition of core academic skills as well as psychosocial competencies, which are important for life success, may be compromised for students with CFS who miss substantial amounts of school during the formative years of development.

Not only can school attendance be physically and psychologically demanding for those with CFS,³ other symptoms of the condition such as persistent fatigue, difficulty concentrating, and disrupted sleep may also interfere with learning and school functioning. It can therefore be surmised that the burdensome impact of CFS on school functioning extends beyond that of school absenteeism as CFS carries a series of secondary psychological, social and educational consequences. For instance, students with CFS may experience impaired relationships with friends, be worried about schoolwork and may be concerned about expectations about performance on return to school.¹⁴ These students may struggle academically and while this may be in part due to increased school absenteeism, cognitive dysfunction associated with CFS^{3,20} likely further compromises their ability to succeed at school. These collective experiences can make adjusting to the school environment after long or frequent absences difficult for students. Sankey and colleagues²¹ noted that over half of students with CFS involved in their study experienced difficulty

returning to school while almost 70% reported that the condition impacted on their education or career plans. School planning and liaison usually represents a major component of the clinical care of paediatric patients with CFS. This is supported by guidelines from The Royal College of Paediatrics and Child Health that recommend close liaison between paediatricians caring for patients with CFS and their schools.²²

Although school absence is often used as an indicator of the impact of CFS in children and adolescents it is important to be mindful that school absence is an important but broad measure. Measuring the impact of CFS solely on school attendance fails to account for the multiple aspects of school functioning, such as academic and social participation, engagement and academic performance. Studies that have explored school functioning in adolescents with a similar chronic illness, chronic pain, have described school functioning as multi-faceted, encompassing a range of factors such as peer relationships, social skills, academic achievement and participation in extracurricular activities.²³ While it is expected that CFS can have a debilitating effect on school functioning for most children and adolescents with the condition due to high rates of school absenteeism, the extent to which research has explored CFS in relation to different areas of school functioning, including engagement, participation and academic performance is unknown.

The aim of this systematic review was to synthesize and critically appraise the methods used to assess school functioning in children and adolescents with CFS. We aimed to provide an overview of the types of constructs examined, the methodological approaches, and the psychometric properties of the instruments used to assess school functioning in this population.

METHODS

Eligibility Criteria

To be considered eligible for inclusion in this review, each study was required to have empirically examined school functioning in children and adolescents with CFS/ME. More specifically, the study needed to have measured an aspect of school functioning in a sample of children and/or adolescents (d 18 years of age) with a diagnosis of CFS/ME based on published criteria. Purely qualitative studies, narrative reviews, and case studies were excluded from this review.

Study Identification

The objective of the search was to obtain empirical studies that measured school functioning in children and adolescents with CFS. Electronic searches were conducted by a single researcher in CINAHL, MEDLINE, ERIC and PsycINFO using Ebsco. These databases were selected to capture literature across the health and education interface. The reference lists of retrieved articles were also scanned to identify additional research not captured by the standard search strategy. The initial search was restricted to English-language publications in peer-reviewed journals from 1987 to 2014. This time frame was selected as the first universal criteria for CFS were published around this time.²⁴ An electronic search was also conducted in Pubmed as part of the initial search strategy; this search was restricted to 2014 publications, so as to capture potential e-publications ahead of print. The search was re-run across the multiple databases from September 2014 – December 2015, to identify new papers published since the initial search was undertaken.

Searches involved the use of both controlled vocabulary (MeSH or thesaurus terms) and text words. Search terms relating to the population (eg *child* or adol* or paediatric* or pediatric**) were combined with terms describing the condition of interest to this review (eg., *chronic fatigue syndrome or myalgic encephalomyelitis*). These terms were also combined with a range of school

functioning terms (eg *student* or school* or absen* or school attend* or school performance or academic or achievement or academic achievement or school avoidance or school belong* or school connectedness or school functioning or student attitud* or truan* or school refusal or educational status or school adjust* or educational measurement or achievement test* or school membership or school bonding or school attachment or school engagement or student engagement or student disengagement or school disengagement or school dropout or student dropout*) using Boolean operators.

Study Selection

Search results were exported into Endnote X7 after which duplicate records were removed. Titles and abstracts of articles retrieved from the searches were screened against the inclusion criteria by 2 independent reviewers (MT and SK); papers not meeting the inclusion criteria were excluded. For the remaining records, full text articles were located and assessed for eligibility by 2 independent reviewers (MT and SK); high concordance was noted between the reviewer's decisions (90% agreement). Discrepancies between the reviewer's decisions to include articles were discussed between the 2 reviewers to achieve consensus; in all instances, consensus was reached.

Data Extraction (Data Collection Process)

For studies meeting the inclusion criteria, data relating to the study characteristics including the author, year of publication, study design, participant details (number of participants, sex breakdown, age, illness duration, comorbidities), control group details, recruitment information, criteria used for CFS diagnosis and method of diagnosis, and information relating to the

measurement of school functioning including the school functioning construct, instruments/scales used, psychometrics properties of the instrument, format of instrument, and the respondent, were extracted using a data extraction form. Data extraction was conducted by a single reviewer (MT). In the event that information to be extracted was not clearly identified within the study, a second reviewer (SK) also attempted to extract this information.

RESULTS

The search results are depicted in Figure 1. A total of 436 records were identified through the initial database searching and of these 34 met inclusion criteria. Another 65 papers were identified when the searches were re-run from 2014-2015 and of these 2 new studies met inclusion criteria. Reasons for non-inclusion are detailed in Figure 1. A total 36 papers met the inclusion criteria for this review.

[Insert Figure 1]

Study Characteristics

Table 1 presents the study characteristics of the included studies. Most of the studies could be described as experimental or non-experimental control trials (including follow up studies) (N = 8 studies), longitudinal studies (N = 6 studies), prospective and retrospective cross-sectional studies (N = 19 studies). The number of participants with CFS in these studies ranged from N = 10¹⁵ to N = 674.¹⁸ Participants were recruited through a variety of means; primarily from schools, private practices, specialist pediatric services, tertiary clinics and hospitals, practitioners (including psychiatrists and pediatricians), and through newsletter advertisements. The most common

diagnostic criteria used in these studies were the US Centers for Disease Control and Prevention (CDC) (N = 16 studies) and the Oxford Criteria for CFS (N = 6 studies), or both (N = 3 studies).

[Insert table 1]

School Functioning

Table 2 summarizes information pertaining to the different school functioning constructs measured in the included studies. These have been organized according to 4 broad themes: school attendance/absenteeism, academic functioning, educational services, and other.

[Insert table 2]

School attendance/absenteeism. The most commonly reported school functioning construct measured in the included studies related to school attendance. This construct was measured in 34 of the 36 included studies. There was variation in the way that this construct was operationalized and described across these studies with some studies measuring amount of time attending school (eg Crawley et al²⁵) and others measuring time absent from school (eg Walford et al¹⁶). There were also a number of studies which included school absence as a proxy for the functional impact of CFS,²⁶ social handicap,¹⁹ functional impairment,²⁷ psychosocial functioning,¹⁵ or as an indicator of recovery.²⁸

Wide variation in the time frame participants were expected to report school attendance/absence was also noted across these studies with some examples including: in the

previous week,²⁹ in the last month,³⁰ in the past 3 months,³¹ in previous 6 months,³² over the past term,²⁵ when illness was at its worst¹⁴ and on a yearly basis.¹³

Evidently, most studies used questionnaires or semi-structured interviews to collect school attendance data. In 5 studies, reviews of medical notes, diaries, chart reviews, or review of case records were used to collect data about school attendance. Almost all included studies failed to describe whether a validated or reliable scale or instrument was used to measure school attendance. In one study³¹ school attendance was reported by families at a clinic visit and this information was verified with the school over the phone.

Academic functioning. Four studies^{21,33-35} were identified which measured an aspect of academic functioning in students with CFS, although variation existed in the focus of these constructs. Garralda and Rangel³³ measured school performance and scholastic competence using well established and validated subjective questionnaires with parents and students. These included the Child Behavior Checklist³⁶ and the Harter Self-Esteem Questionnaire.^{37,38} Similarly, Van Middendorp et al³⁴ measured perceived competence in scholastic ability among students with CFS using the Self Perception Profile for Adolescents, which according to Van Middendorp et al³⁴ maintains moderate high to high internal consistency. Nijhof et al³⁵ reported educational achievement data based on retrospective review of standardized school assessments (the CITO test) completed by students at age 12 years (prior to diagnosis of CFS). Sankey et al²¹ also measured academic abilities based on a review of case records. No studies conducted an objective and standardized assessment of academic achievement using a prospective research design.

Educational services. Two studies explored whether children or adolescents with CFS had received accommodations to their educational program¹³ or home tuition²¹ through semi-structured

interviews and questionnaires. Information about whether these studies used psychometrically sound instruments to collect this information was not reported.

Other. In 2 instances, studies measured school impairment due to CFS. More specifically, these studies measured difficulty functioning/attending school using a checklist of infectious symptoms,³⁹ and the effect of CFS on school and education measured via semi-structured home interviews.²¹ Sankey and colleagues²¹ also measured difficulty returning to school in students with CFS as reported by parents. Two studies were located which measured achievement motivation^{34,35} using The Achievement Motivation Test for Children;^{40,41} a questionnaire with high internal consistency. Other single studies such as Walford et al¹⁶ measured repeated school level collected via semi-structured interviews with parents, and Winger et al⁴² measured school functioning using the Pediatric Quality of Life Inventory.⁴³

Considerations. Of the included studies, some measured school functioning as part of a broader scale. For example, Chalder et al⁴⁴ measured impairment in school using the Work and Social Adjustment Scale⁴⁵ which is a broad scale which measures one's ability to participate in life. In many of these instances, the results were presented for the broader scale; however, the results were not specifically broken down for the school functioning component of the scale. There were other instances where despite a study measuring a facet of school functioning, the results relating to school functioning were not reported. These studies are outlined in Table 3. These covered constructs about: effect of illness on school life,⁴⁶ impairment to school functioning,^{27,30,44,47-49} academic functioning,¹⁵ educational services,⁵⁰ and school functioning.¹³ Most of these constructs were measured using standardized instruments.

[Insert table 3]

DISCUSSION

This systematic review examined existing CFS literature with the intent of describing how school functioning has been measured in children and adolescents with CFS. The review of the literature identified 36 studies on this topic. Within these studies it was revealed that the most common school functioning construct measured in this population was that of school attendance/absenteeism. A small number of studies measured other aspects of school functioning including academic performance, achievement motivation, and educational services for students with CFS. However, there were considerable variations in approaches to measurement, and well-validated standardised measures were seldom utilised.

Despite there being consensus that school attendance/absence is an important area of study in students with CFS, there has been little agreement about the measurement of this construct, as approaches to assess school absences have not been uniformly adopted. This review revealed little consistency in how school absenteeism/attendance was operationalised and measured including the reporting time frame, the measurement tools, the informant, as well as data collection procedures used to measure school attendance. Such inconsistency in the approaches used to measure school attendance contributes to difficulties in drawing conclusions about the impact of CFS on this aspect of school functioning. Using a more uniform approach to measure school attendance is recommended to aid in the comparison and synthesize of findings across studies. This will provide schools working with these students with a better understanding of the impact of the condition on school attendance.

Although school attendance and school absence were most commonly identified in the included studies of this review, there was a tendency for these studies to fail to report or provide

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sufficient detail about the school attendance measures used in these studies. This limitation was also applicable to most of the other school functioning constructs identified in the review. Information about instruments used, including their validity and reliability, and the accuracy of data being collected was generally not reported. Furthermore, the accuracy and reliability of the information collected in the included studies should be viewed with caution, given the high reliance on retrospective informant estimates and lack of verified self-report data with official data or with schools. It is important to be mindful that the accuracy and validity of self-reported school constructs have come under scrutiny.⁵¹ It is recommended that researchers implement methods for verifying the accuracy of self-report data when collecting school functioning data of this nature in the future. Furthermore, psychometrically sound instruments of school functioning are recommended to be used to measure facets of school functioning in students with CFS when possible. This is consistent with Patel et al⁵² who argue the need for standardized tools for the measurement and reporting of educational outcome data in the context of students with CFS.

In comparison to the number of studies that measured school attendance/absenteeism, fewer studies measured facets of school functioning beyond school attendance, notwithstanding the importance of these different elements of school functioning. Although school absence has been linked to a range of deleterious outcomes⁵³ which emphasizes the importance of measuring this construct, it could be argued that restricting the measurement of school functioning to school attendance somewhat simplifies the potential complexities of school functioning in students with CFS. This provides impetus for collecting and examining information about other aspects of school functioning using standardized, validated and objective measurements in conjunction with school attendance to provide a more comprehensive account of how students with CFS are faring at school. Surprisingly though, few studies were identified in this review which explored multiple aspects of

school functioning simultaneously. It is recommended that future work in this area measures school functioning as a multifaceted construct as part of a more comprehensive evaluation of the impact of CFS on functioning.

A small number of studies included in this review measured academic functioning and educational services; few of these studies used objective testing to gather this information. Interestingly, to the authors' knowledge no studies have measured school engagement or connectedness to school in students with CFS. Similarly, to our knowledge no studies measured emotional attachment to school and learning in this population, despite evidence that school connectedness, emotional attachment, and school engagement is significantly associated with social, emotional, behavioral and academic functioning.^{54,55} Efforts to measure these other emotive engagement responses to school are therefore encouraged to gain an accurate account of students' relationship with school and learning.

Finally, it may be important to gain greater insight into the nature and patterns of school functioning for students with CFS, so that schools are better able to support students with this condition. This review revealed that most studies have been based on cross-sectional designs, which restricts the ability to determine the temporal precedence of CFS and school functioning, and further limits the potential to address the change in school functioning across the course of illness which may be achievable using a longitudinal design. This information would be useful for schools, so that services and support can be provided to students at particularly vulnerable times to have their greatest effect, and may be of great relevance for clinicians, school staff, families, and students with CFS in working towards better management of this condition and the promotion of optimal educational outcomes.

This study is the first study to systematically review the scope and quality of approaches to evaluating school functioning in children and adolescents with CFS. An extensive commentary on the quality of the school functioning measures used in the identified studies was limited due to the scarcity of information about the reliability and validity of existing measures in the included studies. It is also possible that additional studies exist that have been published in books, dissertations, and grey literature sources, however it was beyond the scope of the current review to examine these further. Despite this, the current review had many strengths. This review used a rigorous methodology to systematic search and review an extensive, comprehensive, and up to date body of literature on this topic to answer a definitive predetermined research question. In addition, independent assessment of study inclusion by 2 review authors was considered a strength for reducing potential bias in study selection. Given the strong methodological features of this review, the current study was able to identify significant gaps in ways of comprehensively measuring school functioning in students with CFS, information of which is important for better understanding and supporting students with CFS.

The current review revealed that school experiences of children and adolescents with CFS have rarely been characterized beyond absenteeism. Failure to adopt a broader multifaceted framework for measuring school functioning has contributed to a gap in our understanding of the extent to which school functioning is related to CFS. Filling this gap will be important in informing the management of CFS and intervention efforts to improve school outcomes for this vulnerable population.

IMPLICATIONS FOR SCHOOL HEALTH

To develop tailored interventions to support students whose schooling is affected by CFS, it is important to truly understand the different facets of their school experience; information which is currently limited in CFS literature. Health professionals and educators in schools can make a significant contribution to improving this state of evidence by:

- Collecting prospective, standardized, and comprehensive information about different aspects of school functioning in students with CFS, by administering validated surveys which assess different facets of school functioning such as school engagement, social relationships, and school participation.
- Implementing routine recording systems for consistently reporting and monitoring school attendance, so that students who are frequently absent from school because of illness are identified and supported.
- Conducting research into CFS and multifaceted school functioning in students with CFS and widely disseminating findings. This will be important for building a better understanding of CFS and school functioning in school communities and health sectors alike.

Collecting data about school functioning as a multifaceted construct could be used by schools to support students with CFS by:

- Providing a basis for informing educational modifications and accommodations for students with CFS. Health professionals, school nurses, psychologists, educators, students, and families, may use this data to assist in developing educational learning plans for such students;
- Facilitating the monitoring of students' educational performance and broader areas of school functioning over the course of illness; and

- Be used to examine effectiveness of interventions for these students.

Choosing valid and reliable questionnaires which measure different aspects of school functioning is an important and challenging undertaking for schools. Selecting questionnaires which have been used with students with other similar chronic illness types (for example, chronic pain) or that provide population means, can be useful for comparison purposes.

Finally, the findings of this review revealed that many studies explored CFS and school attendance, and note that students with CFS miss more school than peers. Implementing school reintegration programs to facilitate a smooth school re-entry for these students may be worthwhile.^{56,57} Assigning a liaison person (eg school nurse) who acts as a conduit between school, home and hospital to co-ordinate such programs, may be important for creating linkages between health and education sectors.

Although these implications are applicable to schools supporting students with CFS, it is important to remember that CFS represents one of many chronic health conditions. With rates of chronic health conditions as high as 30%,^{1,2} improving ways of assessing school functioning in all students is important, and may contribute to improving the educational trajectories of students with CFS and other chronic illnesses in the short and longer term.

Humans Subjects Approval Statement

As this is a systematic review, approval from an institutional review board or ethics committee was unnecessary.

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36 papers included in review

Figure 1. **Systematic Search Results**

Table 1. **Study Characteristics**

Author	Year	Study design	No. Participants*	% Female	Age** Mean (SD) Unless otherwise stated	Non CFS Comparison Group Y/N	Criteria used for CFS
Al-Haggar et al	2006 ³⁸	RCT	92	73%	12.52 (3.32)	Yes	CDC
Bell et al	2001 ⁴⁶	Cross-sectional prospective	35 (at follow up)	69%	Not reported (age of illness onset reported: 12.1 years)	No	CDC
Bould et al	2013 ¹⁸	Cross-sectional prospective	542	74.5%	14.8 (1.5)	No	NICE
Brace et al	2000 ¹⁵	Cross-sectional prospective	10	70%	14.10 (2.6)	Yes	CDC
Chalder et al	2002 ⁴⁷	Longitudinal (unclear whether retrospective or prospective)	23	100%	15.0 (14-17) ^M	No	Oxford
Chalder et al	2010 ⁴⁴	RCT	63	68%	15.0 (14-17) ^M	Yes	Oxford or CDC criteria
Crawley et al	2009 ²⁵	Cross-sectional prospective	164	67%	14.2 (12.5-15.7) ^M	Yes	RCPCH

Crawley and Sterne	2009 ¹⁷	Cross-sectional prospective	211	69%	14.6 (12.7-15.9) ^M	No	CDC (but 23 participants did not met criteria as they had fewer than 4 symptoms and 14 did not have illness duration of >6 months)
Crawley et al.	2009 ²⁵	Cross-sectional prospective	164	67%	14.2 (12.5, 15.7) ^M	Yes	RCPCH
Crawley et al	2011 ⁸	Cross-sectional prospective	23 (identified through school project)	74% (identified through school project)	14.6 (1.5) (identified through school project)	No	NICE
			604 (referred to specialist CFS/ME service by health professionals)	70% (referred to specialist CFS/ME service)	14.3 (2.8) (referred to specialist CFS/ME service)		

Crawley et al	2013 ⁵⁰	Pilot RCT	56	75%	14.8 (1.6)	No	NICE
Davies and Crawley	2008 ⁵⁹	Cross-sectional prospective	32	68%	Under age 12	No	RCPCH
Garraalda et al	1999 ³³	Retrospective review of case notes	25	60%	15.6 (2.1)	Yes	Oxford
Garraalda and Rangel	2004 ¹⁴	Cross-sectional prospective	28	79%	15.0 (2.1)	Yes	Oxford and Fukuda
Gray et al	2001 ¹³	Cross-sectional prospective	15	53%	14.3 (2.3)	Yes	CDC
Jason et al	2014 ³⁹	Prospective nested case control longitudinal design	39	90%	16.08 (1.40)	Yes	Jason et al ³
Kennedy et al	2010 ⁶⁰	Cross-sectional prospective	25	72%	15.1 (not reported)	Yes	CDC

Knight et al	2013 ²⁶	Retrospective chart review	59	63%	15.82 (9.5–18.2) ^M	No	Any patient for whom a diagnosis of CFS was made according to any criteria
Knoop et al	2008 ²⁹	Long term follow up of a RCT	66	N/S	18.6 (1.7) (at follow up)	No	CDC
Lim and Lubitz	2002 ⁶¹	Longitudinal – prospective	57 (completed program; N=42 completed follow up) surveys)	88%	15.0 (Not reported)	No	CDC
Lloyd et al	2012 ⁴⁸	Long term follow up of RCT	63 (in trial) 44 (at follow up)	73% (at follow up)	15.0 (1.71)	No	Oxford or CDC

Lloyd et al	2012 ⁴⁹	Non-randomized cohort design	63 (received treatment) 60 (post treatment follow up) 52 (6 month follow up)	63%	15.0 (14.0-16.5) ^M	No	Oxford
May et al	2010 ⁶²	Prospective cross-sectional	333	68%	14.9 (12.9-16) ^M	No	RCPCH
Nijhof et al	2012 ²⁸	RCT	135 131 (6 month follow up) 127	82%	15.9 (1.3): IG 15.8 (1.3): CG	No	CDC

			(12 month follow up)				
Nijhof et al	2011 ⁶	Cross-sectional, retrospective and prospective	184	85%	15.2 (1.9)	Yes	CDC
Nijhof et al	2013 ³²	Follow up of RCT	112 (analyzed)	81%	15.8 (1.4)	Yes	CDC
Nijhof et al	2016 ³⁵	Longitudinal – retrospective	59	78%	15.8 (1.5)	Yes	CDC
Rangel et al	2000 ¹⁹	Cross-sectional prospective	25	60%	15.0 (not reported)	No	Oxford
Richards et al	2005 ²⁷	Cross-sectional prospective	30	57%	16 (not reported) ^M	Yes	CDC and/or Oxford
Sankey et al	2006 ²¹	Cross-sectional prospective	28	46%	13.3 (7.5-17.2) (at symptom onset) ^M 17.2 (9.6-21.4) (at time of interview)	No	Oxford
Stulemeijer et al	2005 ⁶³	RCT	71 (36: IG; 35 Waitlist CG)	87%	15.6 (1.3): IG 15.7 (1.3): CC	No (Waitlist CG)	CDC
Van Geelen et al	2010 ³⁰	Cross-sectional prospective	54	80%	16 (1.5) at initial assessment 18.2 (1.5) at follow up assessment	No	CDC
Van Middendorp	2001 ³⁴	Cross-sectional prospective	36	100%	15.2 (1.4)	Yes	CDC

et al							
Viner et al	2004 ³¹	Longitudinal prospective	78	63%	14.2 (0.2)	No	CDC (>3 month illness duration)
Walford et al	1993 ¹⁶	Cross-sectional prospective	12	50%	13.9 (not reported)	Yes	Oxford
Winger et al	2015 ⁴²	Cross-sectional prospective	120	72%	15.4 (not reported)	Yes	NICE and RCPCH

* Details are based on CFS group only; **age at evaluation/survey/baseline unless specified; IG =Intervention group; CG= Comparison group; ^M = Median (IQR); RCT = Randomized Controlled Trial; CDC =1994 Centers for Disease Control and Prevention [CDC] criteria; RCPCH = Royal College of Paediatrics and Child Health; NICE = National Institute of Health and Clinical Excellence; N/S = Not specified

Table 2. **School Functioning in CFS Literature**

Author	Year	Description	Instrument, scales	Psychometrics as described in paper (evidence of reliability and validity)	Format	Who completed:
Attendance/absenteeism						
Al-Haggar et al	2006 ⁵⁸	School absence: duration of school stay (in hours/month)				Derived from school attendance profiles, participants diaries, or by families
Bell et al	2001 ⁴⁶	School absence: amount of time out of school because of illness			Mailed Questionnaire	Self-report
		Results presented as frequency who had missed “little or no school,” “from 1 to 6 months”, “6-12 months,” “1 to 2 years,” “>2 years” of school				

Bould	2013 ¹⁸	School attendance: time at school	A single self-completed questionnaire item on school attendance over the last term.	Questionnaire	Self-report
		Results presented as “School attendance less than 40%”, “School attendance of 40% or more”			
Brace et al	2000 ¹⁵	School absence: number of days missed from school because of illness over the previous 6 months of the school year		Questionnaire	Self-report with parent
		Note: this was used as a measure of psychosocial functioning			
Chalder et al	2002 ⁴⁷	School attendance: at least 75% of the time		Unclear	Unclear
Chalder et al	2010 ⁴⁴	School attendance/college/work, over 2-week period, as a percentage of what was expected (continuous measure)			Parent report
		School attendance was also dichotomized as:			

$\geq 70\%$ (good outcome) vs $< 70\%$ (bad outcome)					
Crawley et al	2009 ²⁵	School attendance: time at school	A single self-completed questionnaire on time at school over the last term	Questionnaire	Self-report
Crawley and Sterne	2009 ¹⁷	School attendance: attendance as a percentage of expected attendance		Self-completed inventories	Self-report
For analysis, attendance was dichotomized: $\leq 40\%$ or $> 40\%$					
Crawley et al	2009 ²⁵	School attendance: a single self-completed item measuring time at school over the last term		Self-completed questionnaire	Self-report
Crawley et al	2011 ⁸	School attendance: single-item inventory		Follow up questionnaires and by review medical notes	
Results are presented as Mean % school attendance					

Crawley et al	2013 ⁵⁰	School attendance: a single question Results presented as % school attendance in previous week: None, 10%, 20%, 40%, 60%, 80%, 100%, not applicable	Questionnaire	Child report
Davies and Crawley	2008 ⁵⁹	School attendance rates: a single item measuring actual attendance as percentage of possible attendance	Single item	Not reported
Garralda and Rangel	2004 ¹⁴	School attendance: reported school attendance at time of assessment and when illness was at its worst. (Note: was used as part of a measure of degree of associated impairment) Scoring based on none (none or only odd days off school); mild (attending at least 85% of the time); marked (attending between 50 and 85% of the time); severe (less than 50% attendance),	Direct questioning	Parent report

		and extreme (has not attended school at all for at least one academic term)			
Gray et al	2001 ¹³	School attendance: Number of school days missed on yearly basis from: Kindergarten to onset of illness, Onset of illness to time of study	School attendance form developed by study investigators	Questionnaire	Parent and patient report
Kennedy et al	2010 ⁶⁰	School attendance Results for current schooling status presented as number and proportion of students in the following categories: "Full-time", "Part-time (1-8 h/wk)", "Home", "None"		Screening questionnaire	Participants (unclear if this child/adolescent or parent report)
Knight et al	2013 ²⁶	School attendance: Presented as a proxy for impact of CFS: Mild (attending school full-time), Moderate (missing equivalent to ≥ 1 day of school per week), and Severe (housebound)		Chart review	Not applicable

		Note: school attendance was used as a measure of functional impact of CFS at time of initial consultation in accordance with the 2007 NICE guidelines			
Knoop et al	2008 ²⁹	School attendance: percentage of regular school hours attended in previous week		Postal Questionnaire	Patient self-report
Lim and Lubitz	2002 ⁶¹	School attendance: Retrospective account Rated on a scale with 5 options Note: results for school attendance are presented as number of participants (and percentage) reporting degree of school attendance: “Never”, “Occasionally”, “Half-time”, “Occasional absences”, “Full-time”		Postal Questionnaire	Self-report
Lloyd et al	2012 ⁴⁸	School attendance: Hours attended per week as a percentage of expected attendance Note: school attendance was also dichotomized	All measures were reliable, valid, and had been previously used in	Postal questionnaire	Self-report

		for analysis: Good attendance (at least 70% of that expected)	the adolescent clinic.		
		Note: school attendance was also used to form part of recovery indicator	No further details provided		
Lloyd et al	2012 ⁴⁹	School attendance: hours attended per week as a percentage of expected attendance	All measures were reliable, valid, and had been previously used in the adolescent clinic.	Postal questionnaire	Self-report
		Note: school attendance was dichotomized into good and bad outcome: Good outcome = attendance over 70%	No further details provided		
May et al	2010 ⁶²	School attendance: a single item about attendance as percentage of possible time at school		Was collected prior to clinical assessment	Unclear

Note: described also as a marker of severity

Nijhof	2011 ⁶	School absence: in previous 2 weeks and 6 months. Results presented as “Mean (SD)”, “Minimal” (<5%), “Mild (5%-15%)”, “Considerable (15%-50%)”, “Severe (50%-75%)” and “Almost Complete to Complete (75%-100%)”	Short survey via pediatrician	Patient self-report
Nijhof et al	2012 ²⁸	School attendance: proportion of classes attended as percentage of normal school schedule Note: school absence was also used as one of 3 indicators of recovery (school absence of 10% or less in past 2 weeks)	School attendance (past 2 weeks) was validated with a general questionnaire and checked with parents	Recorded daily on a 24-hour timetable of the self-observation list Unclear
Nijhof et al	2013 ³²	School attendance: proportion of classes attended in past 6 months as percentage of	Questionnaire	Patient self-report

		normal school schedule					
		Note: at 12-month assessment a 2-week prospective diary was used, and at long term follow up a retrospective questionnaire was used.					
		Note: some participants at follow up were no longer school age. For these participant's work attendance was recorded					
		Note: school absence was also used as an indicator of recovery (school/work presence of >90%)					
Nijhof et al	2016 ³⁵	School absence	Not described	Not described	Not described	Not described	
		Described as a percentage					

Rangel et al	2000 ¹⁹	School attendance: impairment in school attendance. Recorded as “no impairment (child having only occasional days off school)”, “mild (child attending at least 85% of the time)”, “marked (child attending between 50% and 85% of the time)”, “severe (less than 50% attendance)”, “very severe (child has not attended school at all for at least a month)”	Semi-structured interview	Not clear. Interview was given to parents and children.
		Note: was used as a measure of social handicap		
Richards et al	2005 ²⁷	School attendance: regular school attendance since onset of illness. Response options: Yes/No	Semi-structured interview	Parent report
		A measure of functional impairment		
Sankey et al	2006 ²¹	School absence: time away from school	Review of case records	Unclear

		Results presented as number and percentage who had been away from school for more than 50% of term before diagnosis was made		
Sankey et al	2006 ²¹	School attendance: return to school	Semi-structured home interviews	Parent report
		Results presented as number and percentage who had returned to full-time education, part- time or having home tuition		
Stulemeijer et al	2005 ⁶³	School attendance: calculated by dividing the hours that patient attended lessons in previous week by hours patient should have attended. Results presented as number and percentage with school attendance being “Full” or “Partial” Note: fully attending school at 5-month	Unclear	Unclear

		assessment was also used as one indicator of clinically significant improvement		
Van Geelen et al	2010 ³⁰	School attendance: percentage of classes attended in last month compared with the school schedule of classmates Note: for those no longer attending school, work attendance was calculated	Questionnaire	Adolescent report
Viner et al	2004 ³¹	School attendance: average school attendance in past 3 months Note: used a marker of functional status and ability to participate in normal life Note: was also used to calculate severity score	Recorded at clinic visit	Family report, which was verified with school
Walford et	1993 ¹⁶	School absence	Semi-structure	Parent/s

al					interview	
		Results describe number of participants who had been absent from school based on complete terms missed				
Winger et al	2015 ⁴²	School absence			Not specified	Not specified
		Calculated as the ratio between mean days absent from school and days supposed to be at school in the last month				
Academic functioning						
Garraalda et al	1999 ³³	School performance*: area of competence	Child Behavior Checklist (CBCL) 4-18	CBCL is used extensively, has well-established validity and reliability	Questionnaire	Parent report

Garralda et al	1999 ³³	Scholastic competence	Harter Self-esteem Questionnaire	Questionnaire shows good reliability	Questionnaire	Self-report
Nijhof et al	2016 ³⁵	Cognitive abilities and educational achievement: Collection of standardized school performance assessment at primary school using the CITO	Dutch CITO elementary test. Contains 240 multiple choice items assessing language skills, mathematics skills, information processing skills and world orientation. Administered on 3 days during final grade of primary school, when students are approximately age 12 years	Not reported	Multiple choice test	Student completed test. Reports provided by adolescents or teachers
Sankey et al	2006 ²¹	Academic abilities			Review of case records	Parent report
		Result presented as number and percentage of those functioning at an average or above				

average level						
Van Middelndorp et al	2001 ³⁴	Perceived competence: Scholastic ability	The Dutch version of the Self-Perception Profile for Adolescents containing 8 subscales	Moderate high-to high internal consistency for subscales (Cronbach alpha's range from .63 - .84 for subscales).	Questionnaire	Patient self-report
				Note: alpha for subscale for perceived competence of scholastic ability not reported.		
Educational services						
Gray et al	2001 ¹³	Accommodations to educational programs: special school programs attended (eg half day	School attendance form developed by study investigators		Questionnaire	Parent and patient report

school programs, home and hospital programs,
curriculum modifications)

Sankey et al	2006 ²¹	Home tuition			Semi-structured home interviews	Parent report
Results reported for number and percentage of students that had home tuition						
Other						
Jason et al	2014 ³⁹	Difficulty functioning/attending school	From the checklist of infections symptoms	Has been used in large scale adult studies of CFS following infectious mononucleosis		Self-report
Note: this was measured prior to CFS diagnosis, and was used as a predictor of CFS						

Nijhof et al	2016 ³⁵	Achievement motivation	The Dutch questionnaire: Achievement Motivation Test for Children (PMTK) which assesses performance pressure, negative fear of failure, positive fear of failure, socially desirable behaviour and combined fear of failure	Not described	Questionnaire	Patient self-report
Sankey et al	2006 ²¹	Difficulty retuning to full time education			Semi-structured home interviews	Parent report
		Results presented as number and percentage of students that reported that return to full time education was difficult/very difficult				
Sankey et al	2006 ²¹	Effect of CFS on various aspects of life including education and career plans			Semi-structured home interviews	Parent report
Van	2001 ³⁴	Achievement Motivation: inclination to	The Dutch questionnaire:	Internal	Questionnaire	Patient self-report

Middendorp et al		achieve Higher score indicates higher levels of inclination to achieve	Achievement Motivation Test for Children containing 4 subscales: achievement motivation, positive fear of failure, negative fear of failure and social desirability	consistency of scales is high (Kuder- Richardson -20 varies from .75- .82)		
Walford et al	1993 ¹⁶	Repeated school Number of participants who had to repeat at least one year of schooling			Semi-structure interview	Parent/s
Winger et al	2015 ⁴²	School functioning: 5-item scale The school functioning scale is examined as a single scale, but also forms part of a broader measure of health-related quality of life and psychosocial health. Higher scores indicate better school functioning and health related quality of life	Pediatric Quality of Life Inventory, 4.0 (PedsQL)	Instrument is validated and has good Cronbach's alpha (between 0.77 and 0.88)	Questionnaire	Patient self-report

* Did not exclusively report on academic functioning.

Table 3. **School Functioning Measured as Part of a Broader Scale or Results not Reported**

Author	Year	School functioning description	Limitation
Bell et al	2001 ⁴⁶	Effect of illness on social and educational life	Results did not address effect of illness on educational life
Brace et al	2000 ¹⁵	Academic functioning using The Achenbach Youth Self Report Form and Child Behavior Checklist	Results not presented for academic functioning subscale of the Achenbach Youth Self Report Form and Child Behavior Checklist
Chalder et al	2002 ⁴⁷	School impairment due to fatigue using The Social Adjustment Scale	Social adjustment results provided which describes degree to which fatigue impairs school, home, social and private leisure activities, but results are not broken down for school impairment specifically
Chalder et al	2010 ⁴⁴	Impairment in school using the Work and Social Adjustment Scale	Overall social adjustment score provided – results not broken down for impairment to school
Crawley et al	2013 ⁵⁰	Educational service of relevance to CFS population using an adapted existing health resource questionnaire	Results not presented
Gray et al	2001 ¹³	School functioning using Global Assessment of Functioning	Overall global assessment of functioning was provided, but results for school functioning not provided
Lloyd et al	2012 ⁴⁸	School impairment using the Social Adjustment Scale	Results are not broken down for school impairment specifically
Lloyd et al	2012 ⁴⁹	School impairment using the Social Adjustment Scale	Results are not broken down for school impairment specifically
Richards et al	2005 ²⁷	Functional impairment in school using the Functional Disability Inventory	Results are not broken down for functional school impairment specifically

Van Geelen et al	2010 ³⁰	Functional impairment using the physical role functioning subscale of the Child Health Questionnaire – Child Form which measures limitations in school and daily activities as a result of physical health problems	Results are not broken down for limitations in schoolwork specifically
Van Geelen et al	2010 ³⁰	Emotional impairment using the emotional role functioning subscale of the Child Health Questionnaire – Child Form which measures limitations in school and daily activities as a result of emotional health problems	Results are not broken down for limitations in schoolwork specifically
Van Geelen et al	2010 ³⁰	Behavioral role functioning using the behavioral role functioning subscale of the Child Health Questionnaire – Child Form which measures limitations in school and daily activities as a result of behavioral problems	Results are not broken down for limitations in schoolwork specifically

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