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Unidentified Chronic Fatigue Syndrome (CFS/ME) is a major cause of school absence: school based surveillance study

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Unidentified Chronic Fatigue Syndrome (CFS/ME) is a major cause of school absence: school based surveillance study

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Key words

Chronic fatigue syndrome, ME, CFS/ME, school, prevalence, paediatrics

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ABSTRACT

Objective: To investigate the feasibility of conducting surveillance for Chronic Fatigue Syndrome (CFS/ME) in schools.

Design: School based surveillance project

Participants: Children aged 11 to 16 years enrolled in 3 state secondary schools in England.

Main outcome measures: Number of children newly diagnosed with CFS/ME.

Methods: Attendance officers identified children missing 20% or more of school in a 6 week term without a known cause, excluding those with a single episode off school, a known medical illness explaining the absence, or known to be truanting. Children with fatigue were referred to a specialist CFS/ME service for further assessment. We compared children with CFS/ME identified through school based surveillance with those referred via health services. Outcomes of CFS/ME were evaluated at 6 weeks and 6 months.

Results: 461 of 2855 enrolled children had missed 20% or more school over a 6 week period. In 315, of whom 3 had CFS/ME, the reason for absence was known. 112 of 146 children with unexplained absence attended surveillance meetings, of whom 2 had been previously diagnosed with CFS/ME and 42 were referred to a specialist clinic where 23 were newly diagnosed with CFS/ME. Therefore 28/2855 (1.0%) children had CFS/ME. Children with CFS/ME identified through surveillance had been ill for an amount of time comparable to those referred via health services, but had less fatigue (mean difference 4.4, 95% CI 2.2, 6.6), less disability (-5.7, 95% CI -7.9, -3.5) and fewer symptoms (1.86, 95% CI 0.8, 2.93). Of 19 children followed up, 6 had fully recovered at 6 weeks and a further 6 at 6 months.

Conclusions: Chronic fatigue is an important cause of unexplained absence from school. Children diagnosed through school based surveillance are less severely affected than those referred to specialist services, and appear to make rapid progress when they access treatment.

ARTICLE SUMMARY

Article focus

- Hypothesis: many children with CFS/ME remain undiagnosed and untreated, despite evidence that treatment is effective in children.
- Research question: is school based surveillance a feasible way to identify children with CFS/ME and offer treatment.

Key messages

- 1.0% of enrolled children missed 20% or more of school because of CFS/ME.
- Fewer than 1 in 5 children with CFS/ME had received a diagnosis and been offered treatment.
- Children with CFS/ME who were detected through school based surveillance were less severely affected than children referred via health services, and appeared to do well once treated.

Strengths and limitations

- Children were offered assessment regardless of how their absence had been classified.
- All children given a diagnosis of CFS/ME were screened for other medical and emotional causes of fatigue and were prospectively characterised and followed up.
- Surveillance was conducted in 3 schools in the south West which has a well established specialist CFS/ME service. Results may not be generalisable to regions without a CFS/ME service or to regions with different socio-economic factors that impact on school attendance.

INTRODUCTION

Estimates of the prevalence of paediatric CFS/ME show considerable variation according to survey methodology and diagnostic criteria. A postal survey of 1024 UK general practices estimated the prevalence using the Royal College of Paediatrics and Child Health Guidelines[1] to be only 0.06% in children aged 5 to 19 years old[2], whilst population based surveys suggest that prevalence is between 0.1% and 0.5%[3-5]. These differences could be due to difficulties in diagnosis, non attendance at medical services or differences in the type of CFS/ME identified by general practitioners compared with the spectrum of the condition in the childhood population. Only 52% of GPs feel confident in making the diagnosis in adults[6], let alone children. It is therefore likely that many children with CFS/ME remain undiagnosed and untreated, despite evidence that treatment is effective in children[7-11].

In this paper, we report results from a school based surveillance project for CFS/ME among children missing school, in order to identify undiagnosed CFS/ME, and hence improve access to a paediatric CFS/ME service.

METHODS

Surveillance was conducted in three state secondary schools (two mixed gender and one girls only) that were actively working to improve attendance. The attendance officer in each school identified all children in years 7 to 11 (ages 11 to 16 years) who had missed 20% or more of school over a 6 week term. Children were excluded if they only had a single episode of absence (for example, a two week illness), a medical illness that could reasonably explain the absence, a known hospital admission or were known to have been on holiday or to be truanting. Families of the remaining children were sent a letter from the school that invited them to meet with a paediatrician from the Bath specialist CFS/ME team (EC) and a member of school staff, to discuss why their child was missing school.

Diagnosis and management of CFS/ME

Children identified in school surveillance as having fatigue were invited to attend the Bath Specialist CFS/ME service[12] at the Royal National Hospital for Rheumatic Diseases for assessment. The following self-completed inventories were collected prior to assessment at 6 weeks and 6 months: the 11 question Chalder fatigue scale[13]; the 10-question physical function subscale of the SF36[14] (a well validated health survey questionnaire where the worst physical function scored 10 and good physical function scored 30) a visual analogue pain scale; the Spence Children's Anxiety Scale (SCAS)[15] and the Hospital Anxiety and Depression Scale (HADS)[16]. School attendance was recorded at the time of assessment using a single item inventory.

Inventories were coded as missing if >1 question was missing, apart from the SCAS, which was coded as missing when there were >2 missing items. On the HADS, each 7 item subscale was excluded if there was more than 1 question missing. Questions

for which two answers were given were coded as missing. Total scores were corrected for the number of missing items.

Children who attended the specialist service had a full paediatric assessment including a medical history, examination and screening blood tests as recommended in the NICE guidelines[17] to exclude other causes of fatigue. A diagnosis of CFS/ME was given to children who had disabling fatigue lasting 3 months or longer with one additional symptom, where no other cause for the fatigue could be established.

Children with CFS/ME were offered specialist medical care, following NICE guidance[17], by the CFS/ME specialist service. All children who access the specialist service receive advice and help with sleep and activity management. Some children receive CBT while others receive Graded Exercise Therapy[17]. We used school attendance at 6 months, ascertained through follow-up questionnaires and by review of medical notes, as our primary outcome.

Statistical methods

We derived exact binomial confidence intervals for proportions. We compared characteristics of children diagnosed with CFS/ME through the school surveillance programme with those referred via health services using unpaired t-tests.

Ethics

The North Somerset & South Bristol Research Ethics Committee decided that the collection and analysis of data from children and young people seen by the CFS/ME specialist service was part of service evaluation and as such did not require ethical review by a NHS Research Ethics committee or approval from the NHS R&D office (REC reference number 07/Q2006/48).

RESULTS

Identification of children with fatigue

The project was carried out over three school terms between 3/9/07 and 15/2/08 for school 1 and over two terms between 31/10/07 and 15/2/08 for schools 2 and 3. The school rolls for children in years 7 to 11 at the time of the study were 925; 1055 and 875 children respectively (total 2855).

Figure 1 shows the flow of children through the study. A total of 461 (16.1%) children were reported to have missed 20% or more of school over a 6 week period during one or more terms. Of these, 315 (68.3%) had only a single episode off school, had a known medical illness that could explain the absence (three of these had CFS/ME and were being seen by the specialist CFS/ME service), or were known to have been on holiday or to have been truanting. The remaining 146 children (5.1% of school roll) had missed 20% or more school without an identifiable cause and were invited to a surveillance meeting. Of these, 112 (76.7%) attended.

Forty eight children (42.9% of those assessed, 2.1% of the school roll) described significant fatigue as a major cause of their absence and were given appointments for more detailed assessments at the specialist service. Of the remaining 64 children assessed, 30 had medical problems that explained their absence. This included recurrent headaches/migraines in 9 children and infections (e.g. tonsillitis, diarrhoea and vomiting or viral upper respiratory tract infections) in 8 children. 24 children were missing school because of social or emotional problems; 8 because they were truanting and 2 had a diagnosis of CFS/ME confirmed by a paediatrician but had not been referred to the specialist service.

Forty one children attended further outpatient assessment by the specialist service, while one child was severely affected so was assessed at home. Of these, 23 were diagnosed with CFS/ME that was thought to be the main reason for their reduced school attendance, and were offered rehabilitation. Of the 19 children assessed but not diagnosed with CFS/ME, 14 had fatigue secondary to mood disorders (mostly anxiety and depression). Of these, 11 were referred to local Child and Adolescent Mental Health Services. Five children had other medical problems that were thought to be the cause of their fatigue (sleep apnoea (2), recurrent tonsillitis (1), migraine (1), undiagnosed sleep disorder not CFS/ME (1)).

In summary, a total of 28 children (6.1% of the 461 children missing 20% or more of school) had CFS/ME. These included 23 (82.1%) new cases of CFS/ME identified through surveillance, and 2 (7.1%) children identified during surveillance as having CFS/ME previously diagnosed by a paediatrician but not known to the school or to the specialist service. Only 3 (10.7%) children with CFS/ME were already being seen by the CFS/ME service and so were not offered further assessment. The estimated prevalence of CFS/ME sufficiently severe to cause a child to miss 20% or more of school was 28/2855 = 0.98% (95% CI 0.65% to 1.41%). This is likely to be an underestimate as some of the 39 children who were invited to but did not attend surveillance meetings are likely to have had CFS/ME.

Comparison of children with CFS/ME identified through school surveillance with those referred by health services

Table 1 compares the characteristics of the 23 children identified as having CFS/ME through school surveillance and who attended the specialist service with those of 604 children with CFS/ME referred to the specialist service by a health professional.

Children identified through surveillance were less fatigued, had less pain, had fewer symptoms and were less physically disabled than those referred to the specialist service. However, the length of time for which children had been unwell (mean 20.2 months, SD 17.1) was comparable. There was little evidence that levels of anxiety and depression differed between the two groups.

Outcomes of treated CFS/ME in children identified through surveillance

Of the 23 children diagnosed as having CFS/ME, 4 were given advice about managing CFS/ME but did not attend follow up appointments or return follow up inventories. Of the remaining 19 children, 12 (63.2%) were attending full time school by 6 months, of whom 6 had made a full recovery and were attending full time school with minimal advice after 6 weeks. One housebound child improved and was attending school part time every day by 3 months. For the remaining 6 children, school attendance did not alter significantly at 6 months.

DISCUSSION

In a school based surveillance project, 28/2855 (0.98%) of children aged 11 to 16 years were missing 20% or more of school and were diagnosed with CFS/ME. Only 3/28 (10.7%) of these had received a diagnosis and accessed specialist treatment. The duration of symptoms in those identified through surveillance was comparable to those referred to via health services, but they were not as severely affected. Outcomes following treatment were encouraging.

There are several possible reasons why children missing significant amounts of school with CFS/ME are not identified. Those with mild or moderate CFS/ME may not see their GP, or may not be recognised as having CFS/ME if they are seen. Alternatively, GPs and paediatricians may not be aware of specialist CFS/ME services or may feel that the child's CFS/ME is not sufficiently serious to warrant a referral. Children referred to the Bath Specialist CFS/ME service are more severely affected then those described by other specialist services[12]. Differences in characteristics at referral did not appear to be explained by the length of time from symptom onset or co-morbid mood problems.

Strengths and Weaknesses

Children were offered assessment regardless of whether their absence had been classified as "authorised" or "unauthorised". This is because fatigue that is causing a child to miss school may have been ascribed to social or educational problems, leading her absence to be classified as unauthorised. All children given a diagnosis of CFS/ME had been screened for other medical and emotional causes of fatigue; were prospectively characterised and followed up with well validated inventories.

Our surveillance was conducted in three schools in one city in the South West of England in which there is already a well established specialist CFS/ME service. The prevalence of CFS/ME, and reasons for school absence, may be different in regions

where there is no specialist service and may vary according to the prevalence of socio-economic factors that impact on school attendance. We were not able to obtain information on children who did not attend the specialist service for assessment.

Results in context with previous literature

The prevalence of diagnosed CFS/ME in this study (3/2855 = 0.11%) is similar to the prevalence of 0.07% reported in two other school surveys[18] and the prevalence of CFS/ME diagnosed in primary care (0.06%)[2]. We identified more children with CFS/ME than a recent British study which identified chronic fatigue syndrome in only 7 of 8839 children enrolled in 10 schools[19]. However that study screened children who missed 20% of school and whose absence was recorded as "medical absence" whereas we screened children who missed school for any reason, including those whose absence was classified as unauthorised. Our prevalence estimate was also higher than estimates of between 0.1% and 0.5% from population based studies[3-5], perhaps because these used the adult definition of CFS/ME, which requires 6 months of fatigue and four additional symptoms. Our prevalence estimate is lower than that of 2.3% for CFS/ME with three months' duration, from a study in twins[20].

Implications

Surveillance is particularly important for diseases, such as CFS/ME, where there may be poor parental recognition of symptoms and presentation for assessment[21]. This project suggests that undiagnosed CFS/ME can be identified through school based surveillance, and may be an important and under-appreciated cause of school absence in children aged 11-16 years. We also identified potential medical or psychological causes of fatigue in children who were not diagnosed with CFS/ME. Although we do not have outcome data for these children, surveillance is also of

potential benefit in this group. Reduced school attendance is associated with worse educational attainment, and may increase the risk of unemployment[22].

Surveillance can be justified when improved outcomes in those identified and treated outweigh both harms and costs. The UK NICE guidelines[17] recommend that even those children who have mild CFS/ME should be referred to a specialist CFS/ME service after 6 months. There is some evidence that particular treatments (graded exercise therapy (GET) and cognitive behaviour therapy (CBT) are moderately effective in children[8-11], while the recently reported PACE trial provided strong evidence that these treatments are moderately effective in adults[23]. Our finding that more than half (12/23) of children with surveillance-diagnosed CFS/ME returned to full time school within six months of the start of treatment compares well with results from follow up studies[24], suggesting that offering specialist services to children with CFS/ME identified through surveillance may reduce school absence. Nonetheless, it would be of interest to evaluate whether school nurses, rather than doctors, can implement surveillance and to conduct randomised controlled trials evaluating the effectiveness and cost-effectiveness of school based surveillance programmes for CFS/ME. Further studies are needed to investigate the potential for harm in offering surveillance for fatigue to children who do not have a medical diagnosis to explain their absence from school.

In conclusion, school based surveillance for fatigue is feasible and has the potential to reduce school absence and its harmful effects. Together with referral to specialist services, such surveillance has the potential to improve overall school attendance.

Table 1 Characteristics of children with CFS/ME identified through school surveillance project (school CFS/ME) compared to those with CFS/ME referred to a specialist CFS/ME service (service CFS/ME)

	School CFS/ME		*Service CFS/ME*		Mean Difference (95% CI)	P value
	N		N			
Age yrs: mean (SD)	23	14.6(1.5)	604	14.3 (2.8)	-0.38 (-1.5, 0.8)	0.53
Female N (%)	23	17 (74)	607	422 (69.5)		0.20
Fatigue score: mean (SD)	22	20 (5.7)	541	24.4 (5.1)	4.4 (2.2, 6.6)	<0.001
Pain score: mean (SD)	16	37.4 (29.4)	503	46.9 (29.7)	9.5 (-5.3, 24.3)	0.21
SF36: mean (SD)	22	25.5 (3.9)	526	19.8 (5.2)	-5.7 (-7.9, -3.5)	<0.001
Number of symptoms: mean (SD)	22	6.6 (2.2)	582	8.5 (2.5)	1.86 (0.80, 2.93)	<0.001
Depression (HADS): mean (SD)	23	6.7 (2.2)	399	7.3 (3.7)	0.6 (-0.9, 2.16)	0.43
Anxiety(HADS): mean (SD)	23	9.4 (4.0)	400	8.4 (4.3)	-1.0(-2.8, 0.78)	0.27
Anxiety(SCAS): mean (SD)	22	35.2 (20.1)	471	29.3 (17.8)	-6.0 (-13.6, 1.7)	0.13
% school attendance: mean(SD)	23	65.9 (28.7)	569	38.6 (36.1)	-27.3 (-42.6, -12.01)	<0.001
Time to assessment (months): mean (SD)	21	22.5 (18.3)	590	25.3 (25.3)	2.7 (-8.2, 13.7))	0.62

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Competing Interests

The authors declare that (1) EC, AE and JS did not receive any financial support from companies for the submitted work (2) EC, AE and JS have no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AE and JS have no non-financial interest that may be relevant to the submitted work. EC is a medical advisor for the Association for Young people with ME (AYME).

Authors contributions

EC conceived the idea for this study; conducted the surveillance with schools; analysed the data with support from JS and wrote the first draft of the paper. AE contributed to the interpretation of the data. JS helped with the analyses and contributed to writing the paper. All authors read and approved the final manuscript. All authors had full access to all of the data in the study. Dr Crawley will act as Guarantor for this paper.

Data sharing: no additional data available.

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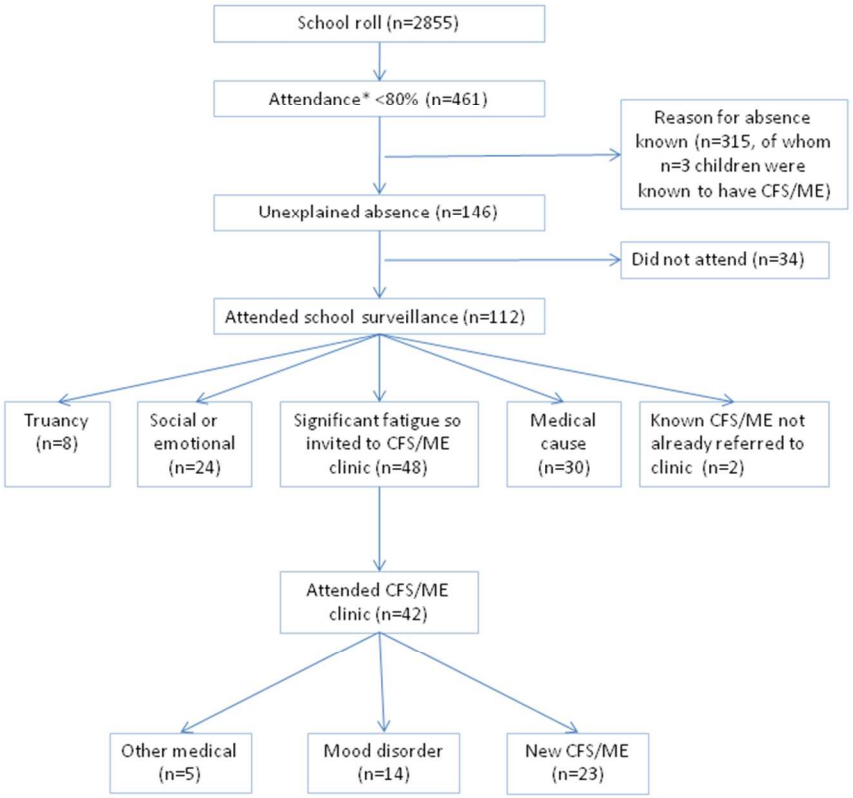
STROBE STATEMENT: **Unidentified Chronic Fatigue Syndrome (CFS/ME) is a major cause of school absence: school based surveillance study**

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	√
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	√
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	√
Objectives	3	State specific objectives, including any prespecified hypotheses	√
Methods			
Study design	4	Present key elements of study design early in the paper	√
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	√
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	√
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	NA
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	√
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	√
Bias	9	Describe any efforts to address potential sources of bias	√
Study size	10	Explain how the study size was arrived at	
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	√
		(*b*) Describe any methods used to examine subgroups and interactions	

		(*c*) Explain how missing data were addressed	
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	√
		(b) Give reasons for non-participation at each stage	√
		(c) Consider use of a flow diagram	√
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	√
		(b) Indicate number of participants with missing data for each variable of interest	√
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	√
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	√
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	√
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	√
Generalisability	21	Discuss the generalisability (external validity) of the study results	√
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	√

Figure 1: Flow of children through project



* Attendance <80% for at least 6 weeks in any term over 3 terms

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Key words

Chronic fatigue syndrome, ME, CFS/ME, school, prevalence, paediatrics

Word Count: 2488

Abstract: 300

ABSTRACT

Objective: To investigate the feasibility of conducting clinics for Chronic Fatigue Syndrome (CFS/ME) in schools.

Design: School based clinical project

Participants: Children aged 11 to 16 years enrolled in 3 state secondary schools in England.

Main outcome measures: Number of children newly diagnosed with CFS/ME.

Methods: Attendance officers identified children missing 20% or more of school in a 6 week term without a known cause, excluding those with a single episode off school, a known medical illness explaining the absence, or known to be truanting. Children with fatigue were referred to a specialist CFS/ME service for further assessment. We compared children with CFS/ME identified through school based clinics with those referred via health services. Outcomes of CFS/ME were evaluated at 6 weeks and 6 months.

Results: 461 of 2855 enrolled children had missed 20% or more school over a 6 week period. In 315, of whom 3 had CFS/ME, the reason for absence was known. 112 of 146 children with unexplained absence attended clinical review at school; 2 had been previously diagnosed with CFS/ME and 42 were referred on to a specialist clinic, where 23 were newly diagnosed with CFS/ME. Therefore 28/2855 (1.0%) children had CFS/ME. Children with CFS/ME identified through surveillance had been ill for an amount of time comparable to those referred via health services, but had less fatigue (mean difference 4.4, 95% CI 2.2, 6.6), less disability (-5.7, 95% CI -7.9, -3.5) and fewer symptoms (1.86, 95% CI 0.8, 2.93). Of 19 children followed up, 6 had fully recovered at 6 weeks and a further 6 at 6 months.

Conclusions: Chronic fatigue is an important cause of unexplained absence from school. Children diagnosed through school based clinics are less severely affected than those referred to specialist services, and appear to make rapid progress when they access treatment.

ARTICLE SUMMARY

Article focus

- Hypothesis: many children with CFS/ME remain undiagnosed and untreated, despite evidence that treatment is effective in children.
- Research question: are school based clinics a feasible way to identify children with CFS/ME and offer treatment?

Key messages

- 1.0% of enrolled children missed 20% or more of school because of CFS/ME.
- Fewer than 1 in 5 children with CFS/ME had received a diagnosis and been offered treatment.
- Children with CFS/ME who were detected through school based clinics were less severely affected than children referred via health services, and appeared to do well once treated.

Strengths and limitations

- Children were offered assessment regardless of how their absence had been classified.
- All children given a diagnosis of CFS/ME were screened for other medical and emotional causes of fatigue and were prospectively characterised and followed up.
- School clinics were conducted in 3 schools in the South West, which has a well established specialist CFS/ME service. Results may not be generalisable to regions without a CFS/ME service or to regions with different socio-economic factors that impact on school attendance.

INTRODUCTION

Estimates of the prevalence of paediatric CFS/ME show considerable variation according to survey methodology and diagnostic criteria. A postal survey of 1024 UK general practices estimated the prevalence using the Royal College of Paediatrics and Child Health Guidelines[1] to be only 0.06% in children aged 5 to 19 years old[2], whilst population- based surveys suggest that the prevalence is between 0.1% and 0.5%[3-5]. These differences could be due to difficulties in diagnosis, non attendance at medical services or differences in the type of CFS/ME identified by general practitioners compared with the spectrum of the condition in the childhood population. Only 52% of GPs feel confident in making the diagnosis in adults[6], let alone children. It is therefore likely that many children with CFS/ME remain undiagnosed and untreated, despite evidence that treatment is effective in children[7-11].

In this paper, we report results from a school based clinical project to assess children missing school, in order to identify undiagnosed CFS/ME, and hence improve access to a paediatric CFS/ME service.

METHODS

This study reports on a pilot clinical service set up with the school attendance service in Bath to try and improve school attendance. The service was offered in three state secondary schools (two mixed gender and one girls only) that were actively working to improve attendance. The attendance officer in each school identified all children in years 7 to 11 (ages 11 to 16 years) who had missed 20% or more of school over a 6 week term. Children were excluded if they only had a single episode of absence (for example, a two week illness), a medical illness that could reasonably explain the absence, a known hospital admission or were known to have been on holiday or to be truanting. Families of the remaining children were sent a letter from the school that invited them to meet with a paediatrician from the Bath specialist CFS/ME team (EC) and a member of school staff, to discuss why their child was missing school.

Diagnosis and management of CFS/ME

Children identified in school clinics as having fatigue were invited to attend the Bath Specialist CFS/ME service[12] at the Royal National Hospital for Rheumatic Diseases for assessment. The Bath specialist paediatric CFS/ME service covers a region in the south west of England with a population of some 400,000 children aged 5 to 19 years (2001 census) and accepts referrals from schools, General Practitioners and paediatricians. Each year, more than 200 children and young people are assessed and treated following NICE guidance[13] in out patient clinics unless they are too severely affected to attend clinic, in which case they are seen at home. The following self-completed inventories were collected prior to assessment at 6 weeks and 6 months: the 11 question Chalder fatigue scale[14]; the 10-question physical function subscale of the SF36[15] (a well validated health survey questionnaire where the worst physical function scored 10 and good physical function scored 30), a visual analogue pain scale; the Spence Children's Anxiety Scale (SCAS)[16] and the Hospital Anxiety

and Depression Scale (HADS)[17]. School attendance was recorded at the time of assessment using a single item inventory.

Inventories were coded as missing if >1 question was missing, apart from the SCAS, which was coded as missing when there were >2 missing items. On the HADS, each 7 item subscale was excluded if there was more than 1 question missing. Questions for which two answers were given were coded as missing. Total scores were corrected for the number of missing items.

Children who attended the specialist service had a full paediatric assessment including a medical history, examination and screening blood tests as recommended in the NICE guidelines[13] to exclude other causes of fatigue. A diagnosis of CFS/ME was given using diagnostic criteria recommended in the NICE guidelines[13] to children who had disabling fatigue lasting 3 months or longer with one additional symptom, where no other cause for the fatigue could be established.

Children with CFS/ME were offered specialist medical care, following NICE guidance[13], by the CFS/ME specialist service. All children who accessed the specialist service received advice and help with sleep and activity management. Some children received CBT while others received Graded Exercise Therapy[13]. We used school attendance at 6 months, ascertained through follow-up questionnaires and by review of medical notes, as our primary outcome.

Statistical methods

We derived exact binomial confidence intervals for proportions. We compared characteristics of children diagnosed with CFS/ME through the school surveillance programme with those referred via health services using unpaired t-tests. Gender between the two groups was compared using the χ^2 test.

Ethics

The clinical service in this study was provided as an outreach from the Bath Specialist CFS/ME service. The North Somerset & South Bristol Research Ethics Committee decided that the collection and analysis of data from children and young people seen by the CFS/ME specialist service was part of service evaluation and as such did not require ethical review by a NHS Research Ethics committee or approval from the NHS R&D office (REC reference number 07/Q2006/48).

RESULTS

Identification of children with fatigue

The project was carried out over three school terms between 3/9/07 and 15/2/08 for school 1 and over two terms between 31/10/07 and 15/2/08 for schools 2 and 3. The school rolls for children in years 7 to 11 at the time of the study were 925; 1055 and 875 children respectively (total 2855).

Figure 1 shows the flow of children through the study. A total of 461 (16.1%) children were reported to have missed 20% or more of school over a 6 week period during one or more terms. Of these, 315 (68.3%) had only a single episode off school, had a known medical illness that could explain the absence (three of these had CFS/ME and were being seen by the specialist CFS/ME service), or were known to have been on holiday or to have been truanting. The remaining 146 children (5.1% of school roll) had missed 20% or more school without an identifiable cause and were invited to a clinical review at school. Of these, 112 (76.7%) attended the school clinic.

Forty eight children (42.9% of those assessed, 2.1% of the school roll) described significant fatigue as a major cause of their absence and were given appointments for more detailed assessments at the specialist service. Of the remaining 64 children assessed, 30 had medical problems that explained their absence. These included recurrent headaches/migraines in 9 children; infections (e.g. tonsillitis, diarrhoea and vomiting or viral upper respiratory tract infections) in 8 children; 24 children were missing school because of social or emotional problems; 8 because they were truanting and 2 had a diagnosis of CFS/ME confirmed by a paediatrician but had not been referred to the specialist service.

Forty one children with fatigue attended further outpatient assessment by the specialist service, while one child was severely affected so was assessed at home. Of these, 23 were diagnosed with CFS/ME that was thought to be the main reason for their reduced school attendance, and were offered rehabilitation. Of the 19 children assessed but not diagnosed with CFS/ME, 14 had fatigue secondary to mood disorders (mostly anxiety and depression). Of these, 11 were referred to local Child and Adolescent Mental Health Services. Five children had other medical problems that were thought to be the cause of their fatigue (sleep apnoea (2), recurrent tonsillitis (1), migraine (1), undiagnosed sleep disorder not CFS/ME (1)).

In summary, a total of 28 children (6.1% of the 461 children who were missing 20% or more of school) had CFS/ME. These included 23 (82.1%) new cases of CFS/ME identified through school clinics, and 2 (7.1%) children identified as having CFS/ME previously diagnosed by a paediatrician but not known to the school or to the specialist service. Only 3 (10.7%) children with CFS/ME were already being seen by the CFS/ME service and so were not offered further assessment. The estimated prevalence of CFS/ME sufficiently severe to cause a child to miss 20% or more of school was 28/2855 = 0.98% (95% CI 0.65% to 1.41%). This is likely to be an underestimate as some of the 39 children who were invited to but did not attend school clinics were likely to have had CFS/ME.

Comparison of children with CFS/ME identified through school with those referred by health services

Table 1 compares the characteristics of the 23 children identified as having CFS/ME through school surveillance and who attended the specialist service with those of 604 children with CFS/ME referred to the specialist service by a health professional.

Children identified through surveillance were less fatigued, had less pain, had fewer symptoms and were less physically disabled than those referred to the specialist service. However, the length of time for which children had been unwell (mean 20.2 months, SD 17.1) was comparable. There was little evidence that levels of anxiety and depression differed between the two groups.

Outcomes of treated CFS/ME in children identified through school

Of the 23 children diagnosed as having CFS/ME, 4 were given advice about managing CFS/ME but did not attend follow up appointments or return follow up inventories. Of the remaining 19 children, 12 (63.2%) were attending full time school by 6 months, of whom 6 had made a full recovery and were attending full time school with minimal advice after 6 weeks. One housebound child improved and was attending school part time every day by 3 months. For the remaining 6 children, school attendance did not alter significantly at 6 months.

DISCUSSION

In school based clinics, 28/2855 (0.98%) of children aged 11 to 16 years were missing 20% or more of school and were diagnosed with CFS/ME. Only 3/28 (10.7%) of these had received a diagnosis and accessed specialist treatment. The duration of symptoms in those identified through clinics was comparable to those referred to via health services, but they were not as severely affected. Outcomes following treatment were encouraging.

There are several possible reasons why children missing significant amounts of school with CFS/ME are not identified. Those with mild or moderate CFS/ME may not see their GP, or may not be recognised as having CFS/ME if they are seen. Alternatively, GPs and paediatricians may not be aware of specialist CFS/ME services or may feel that the child's CFS/ME is not sufficiently serious to warrant a referral. Children referred to the Bath Specialist CFS/ME service are more severely affected then those described by other specialist services[12]. Differences in characteristics at referral did not appear to be explained by the length of time from symptom onset or co-morbid mood problems.

Strengths and Weaknesses

Children were offered assessment regardless of whether their absence had been classified as "authorised" or "unauthorised". This is because fatigue that is causing a child to miss school may have been ascribed to social or educational problems, leading her absence to be classified as unauthorised. All children given a diagnosis of CFS/ME had been screened for other medical and emotional causes of fatigue, were prospectively characterised and followed up with well validated inventories.

Our clinics were conducted in three schools in one city in the South West of England in which there is already a well established specialist CFS/ME service. The prevalence of CFS/ME, and reasons for school absence, may be different in regions

where there is no specialist service and may vary according to the prevalence of socio-economic factors that impact on school attendance. One of the schools was a girls only school. A cross sectional study of British children found little evidence that female gender was a risk factor for CFS/ME diagnosed using the CDC criteria or parental report[3] although adult CFS/ME is more common in women than in men[18]. If the prevalence of CFS/ME were higher in girls than boys aged 11-16 then we would have overestimated the overall prevalence. We were not able to obtain information on children who did not attend the specialist service for assessment.

Results in context with previous literature

The prevalence of diagnosed CFS/ME in this study (3/2855 = 0.11%) is similar to the prevalence of 0.07% reported in two other school surveys[19] and the prevalence of CFS/ME diagnosed in primary care (0.06%)[2]. We identified more children with CFS/ME than a recent British study which identified chronic fatigue syndrome in only 7 of 8839 children enrolled in 10 schools[20]. However that study screened children who missed 20% of school and whose absence was recorded as “medical absence” whereas we assessed children who missed school for any reason, including those whose absence was classified as unauthorised. Our prevalence estimate was also higher than estimates of between 0.1% and 0.5% from population based studies[3-5], perhaps because these used the adult definition of CFS/ME, which requires 6 months of fatigue and four additional symptoms. Our prevalence estimate is lower than that of 2.3% for CFS/ME with three months’ duration, from a study in twins[21].

Implications

Surveillance is particularly important for diseases, such as CFS/ME, where there may be poor parental recognition of symptoms and presentation for assessment[22]. This

project suggests that undiagnosed CFS/ME can be identified through school based clinics, and may be an important and under-appreciated cause of school absence in children aged 11-16 years. We also identified potential medical or psychological causes of fatigue in children who were not diagnosed with CFS/ME. Although we do not have outcome data for these children, the identification of a potential cause is likely to be of benefit in this group. Reduced school attendance is associated with worse educational attainment, and may increase the risk of unemployment[23].

Surveillance can be justified when improved outcomes in those identified and treated outweigh both harms and costs. The NICE guidelines[13] recommend that even those children who have mild CFS/ME should be referred to a specialist CFS/ME service after 6 months. There is some evidence that particular treatments (graded exercise therapy (GET) and cognitive behaviour therapy (CBT) are moderately effective in children[8-11], while the recently reported PACE trial provided strong evidence that these treatments are moderately effective in adults[24]. Large scale randomised controlled trials are needed in children, however our finding that more than half (12/23) of children with school-clinic-diagnosed CFS/ME returned to full time school within six months of the start of treatment compares well with results from other follow up studies[25], suggesting that offering specialist services to children with CFS/ME identified through surveillance may reduce school absence. Nonetheless, it would be of interest to evaluate whether school nurses, rather than doctors, can undertake the initial assessments in school clinics, and to conduct randomised controlled trials evaluating the effectiveness and cost-effectiveness of school based surveillance programmes for CFS/ME. Further studies are needed to investigate the potential for harm in offering surveillance for fatigue to children who do not have a medical diagnosis to explain their absence from school.

In conclusion, school based clinics are feasible and have the potential to identify children with CFS/ME, which may reduce school absence and its harmful consequences. Together with referral to specialist services, school based clinics have the potential to improve overall school attendance.

Table 1 Characteristics of children with CFS/ME identified through school project (school CFS/ME) compared to those with CFS/ME referred to a specialist CFS/ME service (service CFS/ME)

	School CFS/ME		*Service CFS/ME*		Mean Difference (95% CI)	P value
	N		N			
Age yrs: mean (SD)	23	14.6(1.5)	604	14.3 (2.8)	-0.38 (-1.5, 0.8)	0.53
Female N (%)	23	17 (74)	607	422 (69.5)		0.20
Fatigue score: mean (SD)	22	20 (5.7)	541	24.4 (5.1)	4.4 (2.2, 6.6)	<0.001
Pain score: mean (SD)	16	37.4 (29.4)	503	46.9 (29.7)	9.5 (-5.3, 24.3)	0.21
SF36: mean (SD)	22	25.5 (3.9)	526	19.8 (5.2)	-5.7 (-7.9, -3.5)	<0.001
Number of symptoms: mean (SD)	22	6.6 (2.2)	582	8.5 (2.5)	1.86 (0.80, 2.93)	<0.001
Depression (HADS): mean (SD)	23	6.7 (2.2)	399	7.3 (3.7)	0.6 (-0.9, 2.16)	0.43
Anxiety(HADS): mean (SD)	23	9.4 (4.0)	400	8.4 (4.3)	-1.0(-2.8, 0.78)	0.27
Anxiety(SCAS): mean (SD)	22	35.2 (20.1)	471	29.3 (17.8)	-6.0 (-13.6, 1.7)	0.13
% school attendance: mean(SD)	23	65.9 (28.7)	569	38.6 (36.1)	-27.3 (-42.6, -12.01)	<0.001
Time to assessment (months): mean (SD)	21	22.5 (18.3)	590	25.3 (25.3)	2.7 (-8.2, 13.7))	0.62

Acknowledgments

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Competing Interests

The authors declare that (1) EC, AE and JS did not receive any financial support from companies for the submitted work (2) EC, AE and JS have no relationships with any companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AE and JS have no non-financial interest that may be relevant to the submitted work. EC is a medical advisor for the Association for Young people with ME (AYME).

Authors contributions

EC conceived the idea for this study; conducted the school clinics; analysed the data with support from JS and wrote the first draft of the paper. AE contributed to writing, and the interpretation of the data helping to critically revise the paper. JS helped with the analyses and contributed to writing the paper. All authors read and approved the final manuscript. All authors had full access to all of the data in the study. Dr Crawley will act as Guarantor for this paper.

Data sharing: no additional data available.

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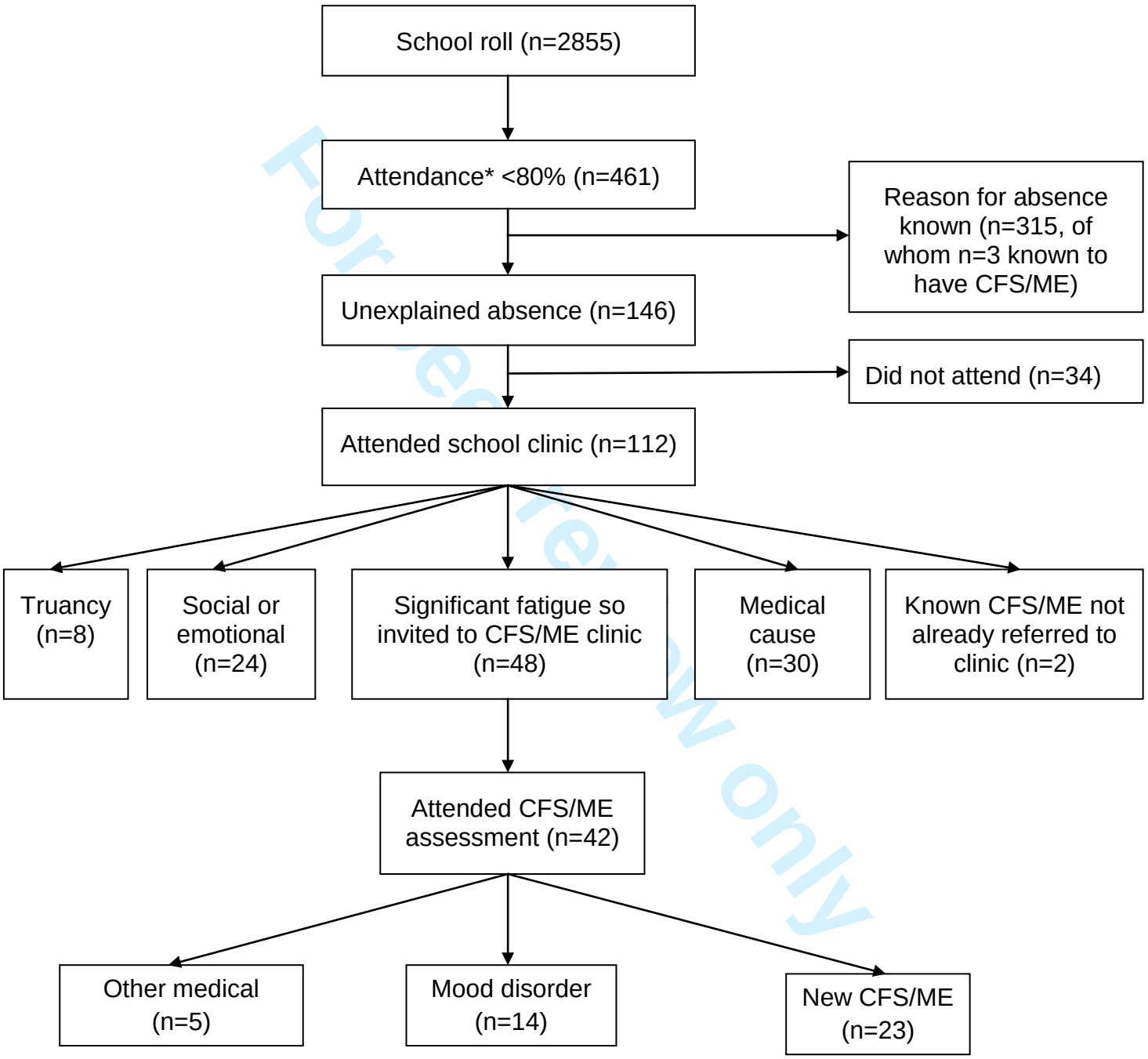
Figure 1: Flow of children through study



*attendance <80% for at least 6 weeks in any term over 3 terms

STROBE STATEMENT: **Unidentified Chronic Fatigue Syndrome (CFS/ME) is a major cause of school absence: school based surveillance study**

	Item No	Recommendation	
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	√
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	√
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	√
Objectives	3	State specific objectives, including any prespecified hypotheses	√
Methods			
Study design	4	Present key elements of study design early in the paper	√
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	√
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	√
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	NA
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	√
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	√
Bias	9	Describe any efforts to address potential sources of bias	√
Study size	10	Explain how the study size was arrived at	
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	√
		(*b*) Describe any methods used to examine subgroups and interactions	

		(*c*) Explain how missing data were addressed	
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	√
		(b) Give reasons for non-participation at each stage	√
		(c) Consider use of a flow diagram	√
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	√
		(b) Indicate number of participants with missing data for each variable of interest	√
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	√
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	√
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	√
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	√
Generalisability	21	Discuss the generalisability (external validity) of the study results	√
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	√

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