Prevalence of chronic disabling fatigue in children and adolescents

ANNE FARMER, TOM FOWLER, JANE SCOURFIELD and ANITA THAPAR

Background The epidemiology of chronic fatiguing illnesses in young people is poorly understood.

Aims To estimate the lifetime prevalence of different definitions of chronic fatigue in 8- to 17-year-olds.

Method Participants came from two population-based twin series. Parents completed self-report questionnaires that enquired whether either child had ever experienced more than a few days of disabling fatigue. Telephone interviews were undertaken for individuals who had experienced such an episode.

Results Questionnaires were returned by 1468 families (65% response rate) and telephone interviews were undertaken regarding 99 of the 129 subjects (77%) who had experienced fatigue. The lifetime prevalence estimates ranged from 2.34% (95% CI 1.75–2.94) for disabling fatigue lasting 3 months to 1.29% (95% CI 0.87–1.71) for a disorder resembling adult operationally defined chronic fatigue syndrome.

Conclusions From the age of 11 years, young people have similar rates and types of chronic fatiguing illnesses to adults.

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Chronic fatiguing disorders occurring in adolescence can cause considerable morbidity and severe impairment of educational attainment and social development (Dowsett & Colby, 1997). In a workshop report, Marshall (1999) noted the lack of epidemiological studies in this age group and pointed to the need for population-based samples that avoid referral and treatment-seeking biases. Other recent reviews highlight the lack of research in this age group compared with adults (Garralda & Rangel, 2001). In particular, there is little agreement about the prevalence of disabling fatigue in young people or whether the narrow definitions of chronic fatigue syndrome (CFS) devised to standardise diagnosis in adult populations (Fukuda et al, 1994) are relevant to these younger age groups (Marshall, 1999). In the current study we have used two general population-based twin series to derive lifetime prevalence estimates of different definitions of chronic fatigue in 8- to 17-year-olds.

METHOD

Participants The participants were identified from two population-based twin registers based in South Wales and Greater Manchester. These registers have been amalgamated recently to form the ‘Cardiff Study of All Wales and Northeast England Twins’ twin register (CASTANET). Both registers were set up from birth registers and were originally created from community child health databases. Initially, twin pairs were excluded if one or both twins had severe learning disability, severe physical handicap or if one of the twins had died. Previous studies have shown that the registers are representative of the local population (Scourfield et al, 1999; Thapar et al, 2000).

The combined registers consisted of 3051 pairs of twins aged 8–17 years. The general practitioners of all the twins were first contacted to check for any contraindications to contact by the study team, which led to 34 families not being approached. A further 748 families could not be located at the address listed on the register and further efforts to verify the current address held by a British Telecom database or the electoral register proved unsuccessful. Consequently, the final sample consisted of 2269 twin pairs, of whom 29.8% came from South Wales and 70.2% from Manchester.

Measures The parents were sent questionnaires relating to each child separately, to complete and return by post. Three reminder letters and a further set of questionnaires were sent to non-responders 4 months after the first mailing.

Those who agreed to further contact and where one or both children had experienced more than a few days of fatigue were interviewed by telephone. For those over the age of 11 years, both the main carer and the young person were interviewed. For younger participants, only the parent/main carer was interviewed. In this study we report on the results of the parents’ interviews.

The interview consisted of two parts. The first part obtained further details about the period(s) of fatigue, including the type and degree of impairment in functioning as well as information to determine whether the young person had experienced a similar symptom profile, duration and impairment to the Centers for Disease Control operational criteria for CFS in adults (Fukuda et al, 1994). The second part of the interview consisted of the depression section of the Child and Adolescent Psychiatric Assessment (Angold & Costello, 1995).

Information was sought about the duration of the fatigue and whether it had
been continuous or episodic. The nature
and degree of impairment associated with
the fatigue was assessed by enquiring about
whether the twin needed to rest for at least
1 hour daily, whether there was interfer-
ence with school attendance, and how
the tiredness interfered with the subject’s
usual activities and family and peer
relationships. With regard to school
attendance, the parent was asked whether
the twin needed to take time off from
school and whether the amount of time
off from school meant that the twin had
to repeat a school year, catch up in the
school holidays, have a home tutor, have
work sent home by teachers or have a
reduced timetable. Parents were also asked
about the number of visits to general
practitioners and/or hospital specialists
made regarding the fatigue. The interviewer
also recorded verbatim the diagnoses that
the parent reported had been made by the
general practitioner and/or hospital specia-
list. The physician diagnoses were reviewed
by an independent clinician who deter-
mined those cases where the diagnosis
could entirely explain the chronic fatigue
in the twin. These cases were then excluded
from further analysis. In addition, the parent
was also asked what he or she thought was
the cause of the fatigue. These responses
were also recorded verbatim.

To assess whether the young person’s
fatigue resembled that found in adults
and fulfilled the adult Centers for Disease
Control criteria for CFS (Fukuda et al.,
1994), enquiry was made about symptoms
that sometimes occur with fatigue. These
were lack of energy, need for rest, unref-
reshing sleep, muscle pain, eye strain, poor
memory and concentration, ‘slips’ of the
tongue, difficulty in initiating activities,
fatigueability, headaches, multiple joint
pains, tender lymph nodes, feeling weak,
sores throats, difficulty thinking or post-
exertion malaise associated with the period
of fatigue. These items were rated as ‘less
than usual’, ‘same as usual’, ‘more than
usual’ or ‘a lot more than usual’ for the
episode of chronic fatigue.

The second part of the telephone inter-
view consisted of the depression section of
the Child and Adolescent Psychiatric
Assessment (Angold & Costello, 1995), a
semi-structured investigator-based research
diagnostic interview. The responses to this
were used to apply the DSM–IV (American
Psychiatric Association, 1994) operational
criteria for major depression for the episode
of fatigue.

Analyses
The population-based twin pairs can be
considered as independently sampled, but
each pair contributes two sets of obser-
vations that cannot be classed as in-
dependent (Bland & Kerry, 1997). Conse-
quently, the survey analysis pro-
cedures of Stata Release 6 for PC were
used to adjust the variances of the analy-
ses, which were used in versions of
independent t-tests and χ² tests.

Because not all families where there
were positive replies to the screening
fatigue questions wished to be interviewed,
a mid-range estimate of prevalence was
calculated that assumed that the same pro-
portion of children fulfilled the different
definitions of chronic fatigue in those from
families who did not agree to participate as
among those who did.

RESULTS
Response rates
Parents from 1468 families returned ques-
tionnaires, which is a response rate of
65%. There were no significant socio-
demographic differences between the
responding and non-responding families
(Rice et al., 2002).

One hundred and twenty-nine young
people (4.4%) were identified by the
screening questionnaires as having experi-
enced more than a few days of disabling
fatigue, and telephone interviews were
undertaken for 99 (77%). Of those not
interviewed, 15 had indicated that they
did not wish to participate and a further
15 failed to respond to written requests
for telephone contact. Following the inter-
view, three young people who had
had diagnoses of cerebral palsy, nephrotic
syndrome and thalassaemia were also
excluded following independent paediatric advice
that these disorders could entirely explain
the fatigue. Thus, the following results are
based on 96 young people (see Fig. 1).

Age at interview, gender
and location
For 12 families both twins were reported
as having experienced disabling fatigue,
whereas for 72 families only one twin was
reported as having experienced disabling
fatigue. Thirty-one (32%) of the twins
came from South Wales whereas 65
(68%) came from Greater Manchester.
Two-thirds (64) of the fatigued twins were
female and one-third (32) were male. The
mean age at interview was 14 years 8
months (range: 9 years 5 months to 18
years 5 months).

Characteristics of fatigue
The mean age of onset of fatigue in the 32
boys was 11 years 1 month (s.e.=7.93
months) and for the 64 girls it was 11 years
3 months (s.e.=6.23 months). There were
no significant gender differences for age at
onset.
The mean duration of fatigue in the 32
boys was 9.18 months (s.e.=3.15) and for
the 64 girls it was 13.84 months
(s.e.=3.51). There were no significant
gender differences for duration of fatigue.

Other symptoms associated
with prolonged fatigue
Table 1 shows that the most common asso-
ciated symptoms were lacking energy,
needing to rest, multiple joint pain and
unrefreshing sleep. The Centers for Disease
Control criteria for CFS in adults (Fukuda
et al., 1994) require the presence of at least
four out of eight minor symptoms concomi-
tant with the period of fatigue (these eight

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Fig. 1 Flow chart of subject inclusions and exclu-
sions in the study (Qs, questionnaires; GP, general
practitioner).
symptoms are indicated by asterisks in Table 1). A total of 86% of boys and 77% of girls had at least four concomitant symptoms.

Educational and social impairment
A total of 14 boys (44%) and 34 girls (53%) had to have time off from school because of the fatigue and for 9 boys (28%) and 24 girls (38%) this interference with their education was more severe, requiring extra work in the holidays, work sent home by teachers, a home tutor or a reduced timetable. Boys missed a mean of 9.50 days (s.e. = 2.22) and girls missed a mean of 14.62 days (s.e. = 1.97) per term. Parents of all 96 subjects reported that chronic fatigue had caused impaired relationships with family and friends and reduced participation in leisure activities.

Visits to doctors
General practitioners were consulted about the fatigue for 22 boys (67%) and 44 girls (67%). For 12 (36%) boys and 24 (36%) girls a hospital specialist opinion was also sought. For the boys, the mean number of visits to the general practitioner was 2 (s.e. = 0.26) and for girls it was 4.35 (s.e. = 0.75). Girls had significantly more visits to their general practitioners compared with boys (t = 2.96, d.f. = 64, P = 0.005). In 22 cases general practitioners considered that the tiredness was due to some type of infection, including glandular fever (five cases), but in 21 cases they failed to give an explanation for the fatigue according to the interviewed parent. Psychological causes, age, hormones or puberty were given as causes of the fatigue in nine subjects whereas single causes were given for the remainder. Hospital specialists were more likely to have given a diagnosis for the cause of the fatigue and there was uncertainty only in five cases. Psychological or psychiatric causes were given in five cases and specific infections in four. The general practitioners and specialists were reported to have carried out 42 blood tests, of which eight had positive findings (four indicated an infection and four indicated anaemia). Only in one case was a diagnosis of CFS made by a hospital specialist (a full table of the diagnoses given and tests undertaken by general practitioners and hospital specialists can be obtained from the authors on request). The commonest parental attribution for fatigue in their twin was a psychological cause (28% of fatigued twins) whereas a further 20% of parents thought that their twin’s fatigue was due to an infection. Chronic fatigue syndrome or myalgic encephalomyelitis was not attributed as a cause by any parent (a full table of all the causes cited by parents for fatigue in the twins can be obtained from the authors on request).

Depression and chronic fatigue
Twelve boys (38%) and 25 girls (39%) fulfilled the DSM–IV operational definitions for mild, moderate or severe depression during the episode of fatigue. There were no gender differences for concomitant depression. Table 2 shows that the percentage of subjects with co-occurring depression rises as the duration and severity of the fatigue increases.

Numbers of subjects fulfilling different definitions of chronic fatigue and CFS
Table 2 shows that of the 32 boys and 64 girls with more than a few days of chronic fatigue, for 19 boys and 50 girls this lasted for at least 1 month. For 17 boys (53%) and 44 girls (67%) the chronic fatigue had lasted at least 3 months, of whom 14 boys (44%) and 36 girls (55%) had also had at least four concomitant symptoms. Nine boys (28%) and 26 girls (41%) experienced fatigue lasting 6 months with at least four concomitant symptoms. There were no gender differences for these different severities of fatigue. Table 2 also shows that the mean ages of onset for these different durations of fatigue ranged from 11.13 years to 12.43 years, and that between one-third and a half of the subjects also fulfilled DSM–IV criteria for depression during the period of chronic fatigue.

Prevalence of different definitions of chronic fatigue
The estimated prevalence of fatigue ill-ness lasting 3 months or more was 2.34% (95% CI 1.73–2.94) whereas the prevalence of fatigue lasting 3 months accompanied by at least four minor symptoms from the Centers for Disease Control criteria for CFS was 1.90% (95% CI 1.40–2.40). Lastly, the prevalence of 6 months or more of fatigue with at least four minor symp-toms was 1.29% (95% CI 0.87–1.71).

DISCUSSION
The present study has been undertaken in twin samples that have been shown to be representative of the general populations of South Wales and Greater Manchester. Because there is no evidence that twins are either more or less susceptible to chronic fatigue or CFS than singletons, it is reasonable to use the CASTANET twin sample to derive population prevalence esti-mates (Thapar et al., 2000; Rice et al., 2002).

Frequency, duration and age of onset of chronic disabling fatigue in young people
The results show that disabling fatigue in young people is not rare and that 4.4% of the parents who responded to a question-naire survey reported the symptom lasting for more than a few days in one or both of their children. However, this is less than half the rate in adults where estimates for the rates of ‘persistent fatigue’ complaints to primary care physicians range from 11% to 27% (Wessely et al., 1997; Skapinakis et al., 2000; Sharpe & Wilks, 2002).
study showed that the mean duration of chronic fatigue (9.57 months for boys and 13.49 months for girls) is similar to that reported in studies of CFS in paediatric clinic samples. For example, Carter et al (1995) report a mean duration of 11 months in 20 individuals whose mean age was 13 years, whereas Feder et al (1994) report a mean duration of 7 months in 48 young people whose mean age was 15 years. However, the individuals in the present study were younger than these specialist clinic referrals, with the mean age at onset for both genders around 11 years. This is very similar to that reported in a telephone survey of CFS-like illnesses in children in Chicago where the mean age at onset was 11.6 years (Jordan et al, 2000). Thus, community surveys such as the present study appear to identify fatiguing illness of the same duration as those reported from specialist clinical services, although the children are on average at least 2 years younger.

Our study confirms the findings from other studies that chronic fatigue is rare in children under 10 years old (Marshall, 1999). In addition, the gender ratio of approximately twice as many girls (67%) as boys (33%) reported with the symptom is also similar to other studies both of children and of adults (Carter et al, 1995; Wessely et al, 1997).

### Relationship of chronic fatigue in the twins to operationally defined CFS

Following the telephone interview we have found that chronic fatigue of the same duration, impairment and number of associated symptoms as the adult Centers for Disease Control operational definition of CFS (Fukuda et al, 1994) has an estimated lifetime prevalence of 1.29%, whereas for a broader definition, including those with 3 months of symptom duration, a lifetime prevalence of 1.90% was found. The prevalence estimates for these ‘broad’ (3 months’ duration) and ‘narrow’ (6 months’ duration) definitions of chronic fatigue are not much different, which supports the view that the diagnosis of CFS in this younger age group should be made after 3 months of symptoms with impairment rather than after 6 months as the adult definition requires (Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996).

Despite not being formally diagnosed with CFS, the gender ratio (twice as many girls as boys), number and type of associated symptoms, frequency of co-occurring depression (just under 40%) and duration and impairment of chronic fatigue are little different in our population-based sample compared with those reported for clinical samples of young people diagnosed with CFS (Feder et al, 1994; Carter et al, 1995; Garralda & Rangel, 2001). It is also noteworthy that the percentage of subjects with co-occurring depressive disorder also increased with increasing duration of their chronic disabling fatigue.

### Comparisons with another recently published epidemiological study of chronic fatigue in young people

Our prevalence estimates based on parental accounts are somewhat higher than the rates reported by Chalder and colleagues who undertook telephone interviews with 4240 children aged 11–15 years as part of a large epidemiological study of mental health in this age group (Chalder et al, 2003). They report a chronic fatigue prevalence of 0.57% (95% CI 0.34–0.80) whereas we have a ‘narrow’ definition prevalence of 1.29% (95% CI 0.87–1.71).

However, from the published account of their study it would appear that they have determined point prevalence whereas in our study we have presented lifetime prevalence estimates.

### Limitations of the study

Our study has a number of limitations. First, the results are based on an interview with a parent and not the child. Second, the interviewer was not a clinician so medical exclusions were based on obtaining a verbatim account of what the parent reported a doctor had said was the cause of fatigue in the twin and the advice of an independent clinician that the medical condition listed could entirely explain the chronic fatigue. Other conditions that could have partly explained the fatigue (e.g. viral infections) but not its severity or duration were retained in the analyses. Finally, because of the absence of a clinical examination of the twins, we have only reported on the resemblance of our subjects to CFS as defined by the Centers for Disease Control in terms of morbidity rather than the subjects fulfilling these criteria. Despite these caveats, our study has shown that the symptom pattern and severity, duration and associated impairment associated with chronic fatigue in young people are similar to those found in studies of adults with CFS (Farmer et al, 1996; Wessely et al, 1997) and that prevalence estimates also fall within the range of 0.07–2.6% reported in studies of chronic fatigue in adults (Bates et al, 1993; Buchwald et al, 1995; Wessely et al, 1997).

### REFERENCES

CLINICAL IMPLICATIONS

- From the age of 11 years, young people have the same prevalence, symptom profile, gender distribution, co-occurring depression and severity of fatiguing disorders as do adults.
- Chronic fatigue causes considerable impairment in young people, to both social development and time missed from school.
- Operational criteria for chronic fatigue syndrome (CFS) should require only 3 months' symptom duration in young people and not 6 months as in adults.

LIMITATIONS

- Interviews were carried out by telephone, not face to face.
- The study presents parental accounts of fatigue rather than young people's own accounts.
- Interview questions were not validated in CFS clinic attenders or control subjects.

ANNE FARMER, FRCPsych, MRC Social, Genetic, Developmental Psychiatric Research Centre, Institute of Psychiatry, London; TOM FOWLER, PhD, JANE SCOURFIELD, MRC Psych, ANITA THAPAR, Department of Psychological Medicine, University of Wales College of Medicine, Cardiff

Correspondence: Professor Anne Farmer, MRC Social, Genetic, Developmental Psychiatric Research Centre, Institute of Psychiatry, De Crespigny Park, Camberwell, London SE5 8AF, UK. Tel: +44 (0) 207 848 0940; fax: +44 (0) 207 848 0856; e-mail: spjuaef@iop.kcl.ac.uk

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Anne Farmer, Tom Fowler, Jane Scourfield and Anita Thapar
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