



Long Term Sickness Absence due to ME/CFS in UK Schools: An Epidemiological Study With Medical and Educational Implications

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Abstract

Commentary by Dr Elizabeth Dowsett on the research paper published in the Journal of Chronic Fatigue Syndrome in 1997, with an introduction by co-author Jane Colby.

The abstract and introduction of the original paper. The study is the largest epidemiological study of ME available to date.

Does ME Cluster in Schools?

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Introduction

In the United States of America, where ME has now been listed as a Priority One disease, it is well accepted that ME clusters in schools, families and communities. But here in the UK that is not yet so. Yet this fact has been common knowledge amongst parents and teachers for some time, though perhaps not so obvious to doctors because they do not work in educational institutions.

When, back in 1990, Dr Dowsett explained to me that ‘the problem is, we have no statistics showing the pattern of ME in schools’, I said ‘So let’s get them.’ If I had realised then that it would take us five years, during which I was myself still ill with ME from a virus related to polio, I might not have considered it so readily. The exercise was hard, frustrating at times and involved accepting that due to political pressures on the education system (and the near chaos of its re-organisation into new types of institutions) schools were now overtly in competition with one another. Funds depended on pupil numbers, numbers depended on reputation and public image. They still do.

This meant that there was extreme reluctance to reveal statistics to us in some quarters. ME had a controversial image back then, more even than now, and in addition there was a perception that if schools admitted to clusters of cases, there would be a scare that children with ME could transmit it to others. This would drive parents

away. If anyone doubts this assertion, let them try, as many journalists have, to persuade the head of a school to admit - on air - to a cluster of ME and see what response you get. I for one cannot blame them.

When our study was published we explained that this difficulty must indeed have reduced the numbers of returned questionnaires. Logically, however, if it did skew the balance of our statistics in any way, it should have inflated the ‘negative’ reports we got; no school minds submitting a blank return showing no cases of ME at all! And indeed, these came in plentifully.

In fact, we had taken some careful steps in the design of the study, in order to check the reliability of our results. One was to graph out other statistics which came in. Our statistical graph for leukaemia correlated with already known statistics for this disease, indicating that our results were taken from a representative sample. In addition, we checked that we had received a balanced response from schools in both secondary and primary sectors.

The cases of illness on which our study was based were diagnosed cases of ME. No schools were involved in diagnosis, and were asked to list suspected cases separately. We were of course never allowed to see any documents, doctors’ reports etc. on any child or member

of staff, as these are confidential. However, it is part of each school's responsibilities under the 1991 attendance regulations to place any absence from school in one of two categories - authorised or unauthorised. In categorising absences the Head must be satisfied that the explanation is genuine, and will request documentation as proof. We naturally accept the professional competence of senior educational staff to carry out this duty.

In the following paper, Dr Dowsett pays tribute to the education authorities who so kindly assisted us in the face of controversy. It may be that some of the areas which declined to help did so because they already knew they had large numbers of cases. Whether this was the case or not we shall never know, but our study had to take place in those areas we chose for their geographical location and which were also willing to reveal their ME statistics. I should here like to add my thanks to those of Dr Dowsett. Needless to say, we assured them of complete anonymity so that their areas would not be publicly identified with the statistics uncovered; without such assurances we would never have got the study off the ground, like others who have attempted to study schools and failed.

The discoveries we made are many and various, and Dr Dowsett covers most of them below. There are two others, however, which I find particularly interesting - though perhaps not surprising.

One is that where Local Education Authorities are ungenerous in their provision of special arrangements for the education of children with ME, parents are more likely to vote with their feet and take them off the school roll entirely. This is sad because it means they are ineligible for all the help which the state should be giving. This in turn means there is a danger of a two-tier education system for children with ME, one for those whose parents can pay for suitable education, another for those who can't.

The other discovery, rather ironic in its way, is that although ME has often been regarded as, at least in part, a psychological or psychiatric condition, the LEAs we studied provided more home tuition for psychiatric illnesses than for ME. A case of heads you win, tails I lose.

This is not entirely the fault of the LEAs, who have often been following the advice of the 1996 report of the Royal Colleges of Medicine (produced, they now explain, mainly by The Royal College of Psychiatrists). This report is not recommended by the Dept. of Health as a treatment protocol. The Chief Medical Officer's Working Group on CFS/ME (instigated by Sir Kenneth Calman in summer 1998) made recommendations in Chapter 5 of its report (Dept of Health 2002).

ME/CFS in the UK School Population

1 The Problem

Do children and adolescents suffer from ME/CFS? Simple common sense tells most parents, teachers and doctors that they do and often more severely than adults. Yet there remains a sizeable proportion of professionals in Health Care, Education and Social Services who are still prepared to ascribe the numerous, disabling but seemingly unconnected symptoms of this illness in young people to anorexia, depression, school phobia or a dysfunctional family background. All are, at least, agreed that the illness presents a considerable economic, educational and social problem.

2 Market Research

No hopeful salesman can, nowadays, expect to succeed without prior market research and no-one intending to raise a bank loan for such a purpose will be considered without a well-researched business plan. Unfortunately, when we turn our attention to human disease, conclusions are often reached without prior study of the WHO, WHAT, WHERE and WHEN which can lead to effective consideration of WHY. In medical terms, this is called EPIDEMIOLOGY, which means the study of human diseases in relation to their environment rather than, for example, the behaviour of small animals or tissue cultures in laboratory setting.

3 Historical Background [1]

Over 60 years ago, epidemiological studies of ME/CFS were commonplace and usually initiated by doctors who, lacking modern technology, simply used their eyes and ears. Of over 70 recorded epidemics of ME/CFS since that time, 13 clearly mention young people while one is entirely devoted to that age group. These old surveys were small and without government funding but they clearly delineated present day findings such as female predominance of cases, peak incidence at puberty, variable prevalence linked closely to seasonal and geographical features (summer/autumn onset, cool/temperate climates and rural or suburban settings) as well as the key role of schools and similar institutions in the spread of the illness, with clustering of cases within families and schools. The serious disabling potential and chronicity of ME/CFS leading to relapse is always noted.

4 Why did we embark on our schools survey?

To our knowledge, no government anywhere in the world has yet funded an epidemiological survey of this type and scale in schools. Ten years ago, a group of suf-

ferers from ME/CFS who were also teaching professionals, parents or carers of young people similarly affected, conducted a postal survey of sufferers under the age of 25 years which stimulated a response from nearly 600 young people in the UK and abroad. The results were disheartening in what they revealed, but they supplied the initial impetus to seek further information about the WHO, WHAT, WHERE and WHEN with an unexpected bonus in relation to WHY?

What did this survey disclose? There were 3 major findings:

- a) Only 29% of respondents under the age of 25 were in full time education, training or work, while 34% were totally excluded from all three. The remaining 37% were making various compromises, few of which could be considered satisfactory.
- b) An enormous loss of independence and self-esteem was reported, with additional grief at the general disbelief expressed not only by the press and by various professionals but at the loss of support even from friends, colleagues, family members and those in a previously loving relationship.
- c) The bonus was a personal invitation to study, at close hand, the consequences (after 2 years) of a seemingly trivial respiratory/gastro-intestinal infection causing symptoms in 1/3 of a village school roll, leaving some 10% of children so affected, with chronic relapsing energy problems, musculo-skeletal pain and disabling prolonged cognitive disturbance. Early laboratory investigation was missed but relapses in the following year were significantly associated with the viruses then circulating in the school (Influenza A and parvovirus infection).

5 How did we set up the 1991-1995 Survey? [2]

With a clear indication from the young people themselves of what to look for, we set out to find if such a cluster of ME/CFS cases in a single school was a unique event or if (as we already suspected) it would be duplicated elsewhere. We hoped that, if successful, the study might provide clear indication of a cause as well as some helpful pointers to diagnosis, management, treatment and prevention. Since we were not sanguine about the funding of our 'business plan' by medical or charitable agencies, we were grateful for the prompt and unreserved backing of the educational profession, to whose understanding of the importance of this subject, all students and young sufferers from this illness must pay tribute.

6 What methods were used?

A search was made in six English Local Authority (LEA) areas, chosen initially for their widely varied geographical, economic and social mix, for all causes of medically certified long term sickness absence in pupils and staff. Confidentiality was assured in the collection of these details which were handled only by senior educational staff and specifically excluded all personal identification. The information requested included geographical location, age, gender and school class location of sufferers, size of pupil and staff roll and education or management provision while sick, as well as the outcome.

7 What were the most important findings?

Between 1991 and 1995 we were able to collect details of all types of long term medically certified sickness absence from schools with this problem as well as useful information from those without it, and from 63 private schools outside the LEA jurisdiction. Excluding (for cost reasons) the private sector, whose details did not differ significantly from the public one, our survey comprised 1098 schools, 333,024 pupils and 27,327 staff - the largest epidemiological survey of this type made to date.

Significant findings included:

a) Prevalence of ME/CFS in Schools

Over one third of the schools providing information reported long term sickness absence and of these, 2/3 had cases of ME/CFS (230 pupils and 142 staff) suggesting a prevalence in this population of 70/100,000 in pupils and 500/100,000 in staff - a rate two or three times that quoted in other adult population surveys.

b) Types of Illness Which Cause Long Term Sickness Absence

Among the 885 individual sickness records received in 6 LEAs, ME/CFS was by far the commonest cause (42% overall, 33% in staff and 51% in pupils) followed by: cancer and leukaemia (23%); general medical or surgical conditions (13%); musculo-skeletal problems (12%); psychiatric disturbance and virus infections (5% each).

c) Clustering of Cases

Using a definition of 3 or more cases with the same diagnosis in the same school, we looked at all illness falling within this category and found 54 clusters (36 due to ME/CFS, 7 to virus infections, 4 to psychiatric disturbance, 3 each to cancer/leukaemia and musculo-skeletal conditions and one to diabetes).

45 clusters, including all but one of virus infection, occurred in schools with ME/CFS, the exception being one

in close geographical proximity. 4 small clusters (less than 6 cases) of cancer, musculo-skeletal conditions and psychiatric disturbance were noted in schools with no evidence of ME/CFS. This was a noticeable difference from the large clusters of viral infection (variously described as respiratory/gastro-intestinal, 'flu' or 'glandular fever' numbering up to 16 cases each) associated with ME/CFS. Of the 372 ME/CFS cases in pupils and staff, 149 cases (40%) were distributed as single cases, 78 (21%) as pairs and 145 (39%) as clusters of 3-9 cases, a remarkably high prevalence of coincident ME/CFS and viral infection in selected geographical areas.

d) Geographical Prevalence of ME/CFS

Though single instances were noted in all LEA areas but one, we were surprised to find that the majority of ME/CFS case clusters were associated with virus infection grouped in an LEA district which was by no means the largest, but which was characterised by its suburban growth after much recent population influx from the building and expansion of 'New Towns' in green-field sites.

It has always been a characteristic feature of certain epidemic infections (eg poliomyelitis) and of illnesses now suspected to be triggered by environmental factors including infection (eg childhood leukaemia) that, when isolated rural or suburban communities with an established and naturally acquired 'herd immunity' are subjected to an influx of new population, the prevalence of such illnesses increases.

e) The Effect of Age and Gender on the Prevalence of ME/CFS in Schools

Of the 230 pupils certified as suffering from this illness, 157 were female and 73 were male, a F/M ratio of 2:1. The average age was 13 with peak prevalence at 15 years. Sex ratios below puberty were more even, indicating a hormonal influence upon the known frequency and chronicity of the illness in females during child-bearing years. The majority of these sufferers were located in senior schools.

Of the 142 staff with ME/CFS, 111 were female and 31 male, a F/M ratio of 4:1, influenced by the fact that most staff employed in schools are female. This is especially noted in the primary sectors where female staff are more common and there is close personal contact with children suffering from various infections and where the majority of staff suffering from ME/CFS are located.

f) Education and Work Modification for ME/CFS

Although varying education and work management patterns were used in sequence or in combination in all

LEAs surveyed, we consider the following to be key factors in reducing physical over-exertion and mental stress which, together with secondary infection, are the commonest causes of relapse in subjects with ME/CFS in the school environment:

Pupils

Home Tuition for those too ill to attend school (but not generally suitable for the very sick, who make a better recovery if education is postponed until stabilisation of the illness).

Modified Timetable which permits, for example, continued participation in selected school activities (excluding sport) and the taking of examinations sequentially over longer periods.

School Withdrawal which, in the absence of such concessions, may oblige education 'otherwise' at home. There is, however, no evidence that young people educated this way fare worse than in conventional school classes, while many sufferers achieve better results in the absence of school stress and repeated exposure to infection.

In our survey, provision over the 6 LEAs for Home Tuition averaged 48% (range of averages 14-79%), Modified Timetables 57% (range of averages 50-86%) and School Withdrawal 6% (range of averages 0-17%). Though some other medical conditions enjoyed more generous provision, the majority of pupils with ME/CFS were not removed from the school roll. (NB Listing on a school roll does not necessarily imply attendance.)

Staff

The average provision for Official Part-time work was 50% (range of averages 38-80%) but Early Retirement was taken up by 38% on average (range of averages 27-100%) representing a serious and probably avoidable loss of career potential compared with other illnesses.

Commentary

1 Of all the symptoms associated with ME/CFS, disturbance of cognitive function is the most disabling and long lasting in both pupils and staff [3]. It induces prolonged difficulties in maintaining wakefulness and attention, in concentration and memory, in language and mathematical ability and in appreciation of shape and judgement of distance which, combined with motor dysfunction affecting balance and fine motor control interferes with practical tasks and independence. Funding for educational research [4] into the correct management and educational needs of those affected (such as that

already received by individuals with other movement, speech or cognitive disorders) would be well repaid by preventing the loss of educational potential in pupils at an age when brain development is at its peak.

2 Our survey into the clustering of ME/CFS cases in schools and the wide variations in geographical prevalence disclosed suggests that it would not be difficult to identify specific infections which can trigger the onset or relapse of ME/CFS. Epidemiological research directed to the school population, where good records are kept and prolonged follow-up of physical and cognitive problems is possible, would undoubtedly be as economical in terms of diagnosis, management and prevention as it was of the understanding of the true prevalence and mode of transmission of poliomyelitis in the past.

3 The 1996 issue of CR54 [5] and the guidelines relating to management of young people with ME/CFS

(eg discouragement of Home Tuition, encouragement of early return to school, intervention with anti-depressant therapy and graded exercise) may well leave us with a generation of young people suffering from educational deficit and an inability to assist themselves back into work, to meet government targets.

Note: Since the publication of our study, a community paediatrician unaware of our work and unknown to us at the time has, in subsequent years, completed a similar epidemiological survey in just two boroughs of one LEA mentioned in our study, with similar results. This work was published in 1998 [6].

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Long Term Sickness Absence due to ME/CFS in UK Schools

An Epidemiological Study With Medical and Educational Implications

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ABSTRACT

A study was made to determine whether the recognition of multiple cases of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in one school is an unique experience. A five year retrospective period prevalence survey (1991-1995) was collated from sequential reports made in six English Local Education Authority (LEA) areas. By means of a confidential questionnaire circulated to 2942 school principals via internal mail, 1098 schools, comprising 27,327 staff and 333,024 pupils, were investigated. Details were obtained on age, gender, location in school sector, work pattern and morbidity. Forty-two percent of all medically certified long term sickness absence was ascribed to ME/CFS, this figure being well in excess of all other causes. This diagnosis was significantly associated with case clustering, variable geographical prevalence, a marked increase in the female:male case ratio at puberty and prolonged disturbance of educational potential. We conclude that ME/CFS in schools leads to serious economic and career problems. Redirection of research to special educational needs and to early diagnosis of infectious agents which can trigger ME/CFS in schools might prevent, at low cost, much chronic illness and education deficit.

KEY WORDS

CHRONIC FATIGUE SYNDROME, MYALGIC ENCEPHALOMYELITIS, VIRUS INFECTION, SCHOOLS, SICKNESS ABSENCE, EDUCATION DEFICIT.

INTRODUCTION

The current study was prompted by personal experience of an outbreak of 'Summer Flu' with gastroenteritis in a village school. Seventy out of 230 9-11 year old children on the school roll were symptomatic. Following reassembly in the autumn, some 10% of those affected complained of profound fatigue and cognitive disturbance which had not resolved on follow-up two years later. Apart from one child, who had an encephalitic illness and was shown to have had a recent enterovirus infection in July, laboratory investigations were delayed and unhelpful. Relapse of the illness in these same pupils during the following year was demonstrably associated with superimposed infections due to Influenza A and parvovirus then circulating. Only a much larger epidemiological survey in a different setting seemed capable of answering the serious questions then posed.

Excerpt from the Discussion

We conclude that research funding would be highly cost effective if directed specifically to the educational needs of pupils with ME/CFS and to the early investigation of infective agents associated with such a serious illness in schools.

If quoting from the above or from the full research paper, please quote the following reference

Dowsett EG, Colby J. Long-term sickness absence due to ME/CFS in UK schools;
an epidemiological study with medical and educational implications.

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