

Article

Medical School Education on Myalgic Encephalomyelitis

Nina Muirhead ^{1*}, John Muirhead ², Grace Lavery ³, Ben Marsh ⁴

1 Miss Nina Muirhead BA(oxon) BMBCh(oxon) MRCS DOHNS MEd PGDipDerm Dermatology Surgeon
Buckinghamshire Healthcare NHS Trust

Amersham Hospital, Whielden Street, Amersham HP7 0JD.

2. John Muirhead MA, FCCA, FCMA (retired) and ME/CFS Patient Carer

3. Miss Grace Lavery Cardiff University Medical School

4. Dr Ben Marsh MBBS BSc MRCPCH Consultant Paediatrician

Consultant in Acute & Neurodisability Paediatrics

Formerly Clinical Director of Community Paediatrics

University Hospitals Plymouth NHS Trust

* Correspondence: nina.muirhead@btinternet.com

Abstract: *Background and objectives:* Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ME/CFS is a common complex multi-system disease with a significant impact on the quality of life of patients and their families, yet the majority of ME/CFS patients go unrecognised or undiagnosed. For two decades the medical education establishment in the UK has been challenged to remedy these failings, but little has changed. This study was designed to ascertain the current UK medical school education on ME/CFS and to identify challenges and opportunities to inform the future of medical education. *Materials and methods:* A questionnaire, developed under the guidance of the Medical Schools Council, was sent to all 34 UK Medical Schools to collect data for the academic year 2018-2019. *Results:* Responses were provided by 22 out of a total of 34 medical schools (65%). 59% of respondents taught ME/CFS, led by specialists drawn from 6 medical disciplines. Teaching delivery was usually by lecture; however, discussion case studies and e-learning were used. 7 schools included questions on ME/CFS in their examinations and 3 schools reported likely clinical exposure to ME/CFS patients. 64% of respondents were interested in receiving further teaching aids in ME/CFS. None of the schools shared details of their teaching syllabus so it was not possible to ascertain what students were being taught. *Conclusions:* UK medical school teaching in ME/CFS is shown to be inadequate. Several medical disciplines, with known differences about the disease, need to set these aside to give greater clarity in teaching undergraduates so they can more easily recognise and diagnose ME/CFS. Improvements are proposed in ME/CFS medical education consistent with the international paradigm shift in biomedical understanding of this disease. Many medical schools (64% of respondents) acknowledge this need by expressing a strong appetite for the development of further teaching aids and materials. The GMC and MSC are called upon to use their considerable influence to bring about the appropriate changes to medical school curricula so future doctors can recognise, diagnose and treat ME/CFS. The GMC should also consider creating a registered speciality encompassing ME/CFS, post viral fatigue and Long Covid.

Keywords: ME/CFS; education; medical school; teaching; patient safety, NICE Guidelines, Health Act 1983, General Medical Council, GMC, Medical Schools Council, MSC, Long Covid.

1. Introduction

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) affects around 250,000 patients in the United Kingdom (UK) alone, it is twice as common as other diseases which do feature in the undergraduate curriculum such as Human Immunodeficiency Virus (HIV) and Multiple Sclerosis (MS). In a recent survey of 4,038 ME/CFS patients 62% stated they are not confident their General Practitioner (GP) understands the condition and 18% of patients wait longer than 6 years for a diagnosis [1]. The impact of this disease on patients and carers' quality of life is significant [2,3] yet it remains poorly understood and recognised by a large proportion of medical practitioners and is often incorrectly dismissed as psychosomatic [4]. Devastatingly, Davenport et al. note that up to 90% of patients are undercounted, undiagnosed and under-treated [5].

ME/CFS is a complex, multi-system disease diagnosed on a history of: significant fatigue impairing function, post exertional malaise, unrefreshing sleep, orthostatic intolerance and/or cognitive impairment. Unlike any other illness and disease, exercise in ME/CFS has been shown to result in deterioration of cellular bioenergetics and increased disability. A growing number of recent studies demonstrate abnormalities in cognition, brain changes on spectroscopy scans, lower metabolic energy generation and altered immune system response as well as brain inflammation and compromised physiology following repeated exercise [6].

In 1998 The Chief Medical Officer (CMO) of the UK appointed an Independent Working Group (IWG) to investigate divergent clinical views of ME/CFS and dissatisfaction among patients and patient support groups about the paucity of medical services to deal with this disease [7]. The IWG, which was first to acknowledge the importance of the patient voice, published their report in 2002 recommending that: improvements were needed in the education and training of doctors, nurses and healthcare professionals, especially in primary care; CFS/ME should be considered as a differential diagnosis and GPs and medical specialists should be able to provide basic guidance after diagnosing this condition.

Given that 20 years later patients and patient support groups continue to be dissatisfied with the healthcare community's response to ME/CFS, this study was undertaken to establish the extent to which medical schools are covering this subject in their curricula and, if possible, why, seemingly, healthcare professionals still struggle to understand ME/CFS or, in some cases, to deny the existence of this disease other than as a mental health condition.

In November 2020 the UK's National Institute for Health and Care Excellence (NICE) issued new draft guidelines [8] on ME/CFS. These acknowledge that ME/CFS is a chronic multi-system medical condition with distinct clinical diagnostic criteria. Echoing the 2002 CFS/ME IWG report, NICE calls for significant improvements in the education of healthcare professionals with greater emphasis on delivery of evidence based training by specialists based upon current knowledge and representing the experiences of people with ME/CFS.

The fact that the NICE report in 2020 makes virtually the same recommendations as the IWG in 2002 demonstrates serious failures in medical education in CFS/ME over the past almost 20 years.

This study establishes a baseline of how and to what extent the subject of ME/CFS is being taught in UK Medical Schools and opens an opportunity to research the pedagogy surrounding the challenges of teaching a paradigm shift in the biomedical narrative of a complex multi-system disease, an outdated narrative and paucity of experts. Improved medical education on the topic of ME/CFS is urgently required to improve patient safety.

2. Materials and Methods

Approval of the UK Medical Schools Council was obtained before this study was undertaken. The study was advocated by Forward ME, Cardiff University and the CFS/ME research collaborative (CMRC).

A questionnaire comprising 10 questions was developed to ascertain the extent of current teaching ME/CFS in all UK medical schools. The Medical Schools Council circulated a request to all 34 schools in the UK in October 2018 asking them to participate in the study and providing them with a link to the online questionnaire (using Survey Monkey). E-mail reminders were sent in February and March 2019. Not all schools responded, and some responded anonymously.

3. Results

Out of a total of 34 schools, 22 responded (65%) of those 13 schools taught ME/CFS in their syllabuses (59%) leaving 9 schools (41%) that did not.

3.1. Teaching Methodology

As Figure 1 shows, 9 schools out of 13 (69%) taught by lecture, 5 used discussion and/or case study methods and some stated that the “Unrest” video had been shown and formed a part of their discussions. E-Learning, tutorial and handouts were less frequently used. Some schools use more than one method.

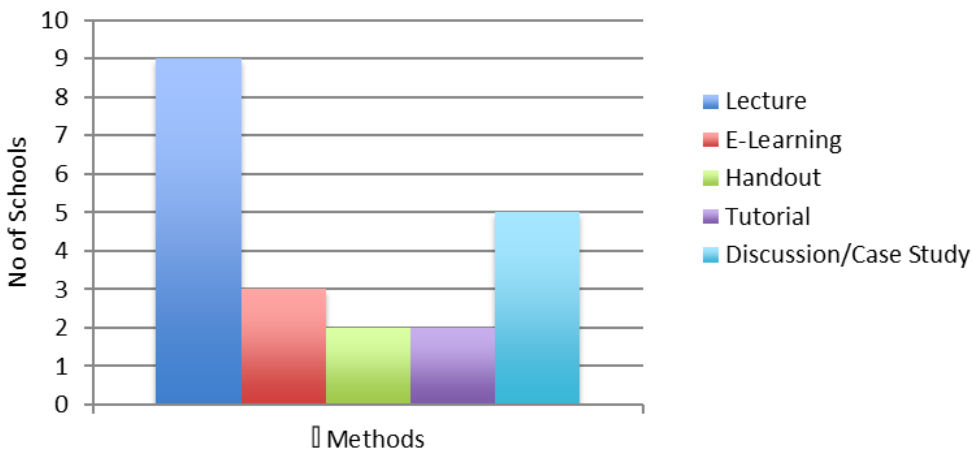


Figure 1: Teaching Methodology

3.2. Teaching Duration

Two-thirds of respondents, 8 out of 13 schools (61%) devoted between 1 and 2 hours to teaching ME/CFS; 2 schools (17%) devoted more than 3 hours while only 1 school (8%) devoted less than 1 hour to the subject. 1 school was unable to quantify teaching duration. See Figure 2.

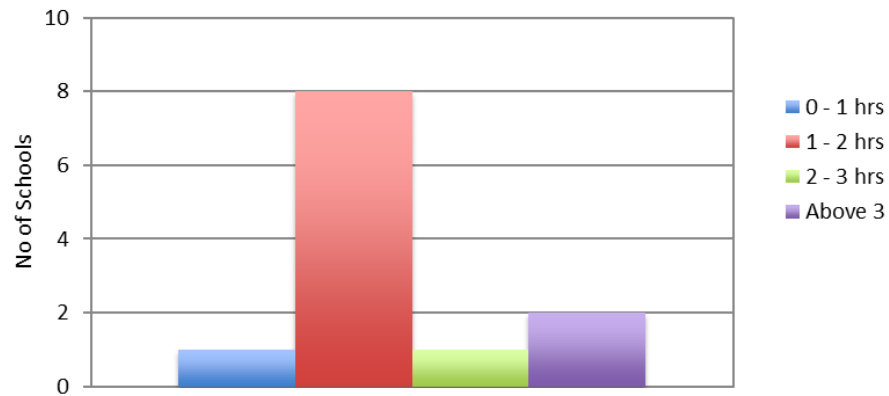


Figure 2: Teaching Duration

3.3. Disciplines Providing ME/CFS Teaching

On average, ME/CFS was taught by two medical disciplines for each of the 13 schools which taught the subject. Figure 3 shows that ME/CFS across the 13 schools was taught by 6 different medical disciplines. The most common was General Practice (n=5); followed by Chronic Disease, Neurology and Psychiatry (all n=4); Rheumatology (n=3) and from within Paediatrics (n=1).

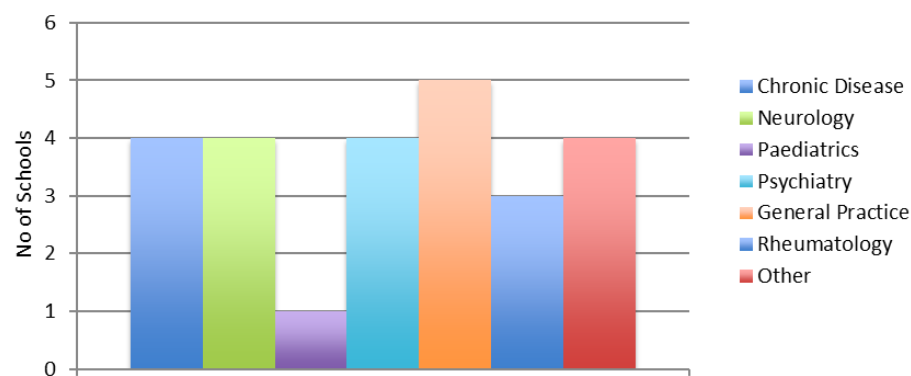


Figure 3: Disciplines Providing ME/CFS Teaching

3.4. Medical Specialists Leading Teaching of ME/CFS

Various specialists provided the core of teaching for ME/CFS as shown in Figure 4. Some supplied more than one specialist to teach the subject. 7 schools referred to professors or senior teaching fellows without stating their area of expertise. General practitioners and psychiatrists were leading ME/CFS teaching (n=4) followed by rheumatologists (n=3) and neurologists (n=2).

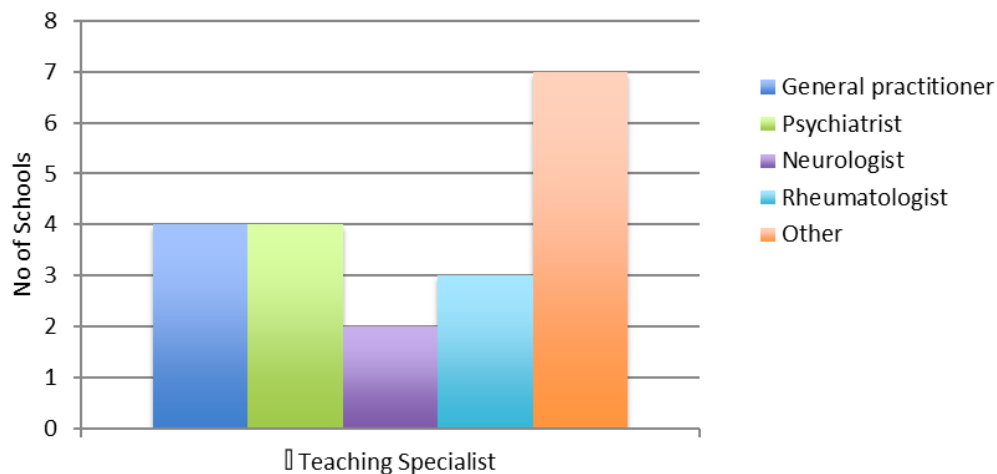


Figure 4: Medical Specialists Leading Teaching of ME/CFS

3.5. Clinical Contact with ME/CFS Patients

Only 3 schools out of 13 (23%) responded affirmatively to the inclusion of contact with ME/CFS patients as part of their curriculum.

3.6. Examination Practices

Of the 13 respondents who taught ME/CFS, 7 schools (54%) stated that they set questions on the subject in their examinations.

3.7. Interest in Further Teaching Aids

The following results relate to all 22 respondents irrespective of whether they taught ME/CFS in their curriculum.

14 schools (64%) stated that they were interested in receiving further teaching aids on the subject of ME/CFS. Of the 9 schools that do not teach ME/CFS, 7 schools (78%) said they were interested in receiving further teaching aids or materials.

The most common teaching aid of interest was educational videos of 20-30 minutes duration, followed by e-learning module of 30-60 minutes duration or lecture with patient volunteers of 30 - 60 minutes duration. Each of these options was preferred by 5 schools apiece (note: not necessarily by the same five schools). 3 schools showed an interest in a lecture of 30 - 60 minutes duration. A total of 27 options were chosen by 14 schools, an average of almost 2 per school, see Figure 5.

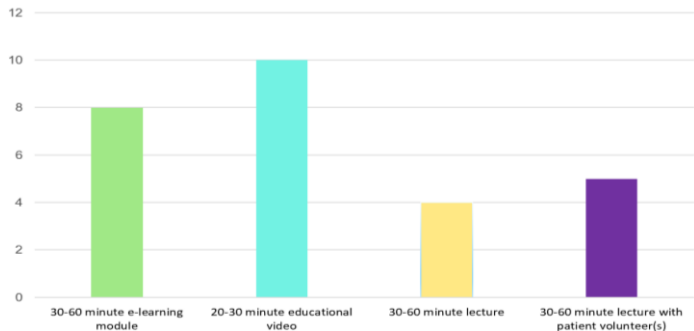


Figure 5: Interest in Further Teaching Aids

4. Discussion

4.1. Potential Bias

The 64% response rate across the UK is considered to be significant and sufficient to draw valid conclusions. It compares well against the 54% response rate in published research on ME/CFS teaching in Medical Schools in the United States [9]. The lack of response from some medical schools could bias the results of this study to overestimate the current teaching.

4.2. Teaching Time and Methodology

Given the present high level of undiagnosed sufferers with ME/CFS, the low level of confidence among GPs to be able to diagnose this disease and the absence of patient satisfaction in the medical profession, it is not surprising to see that 41% of medical schools responding do not teach ME/CFS. Of those that do, i.e. 59%, teaching duration is usually about 1 hour, is not always examinable, and few augment their teaching with exposure to patients with the disease.

Little seems to have changed since a study in 2008 [9] which revealed “Family physicians obtain information about CFS/ME from their nonprofessional world which they incorporate into their professional realm”. Moreover, an analysis of ME/CFS teaching in UK Medical Schools as recently as 2015. [10] concluded that “Students acquired their knowledge and attitudes largely from informal sources and expressed difficulty understanding [ME/CFS] within a traditional biomedical framework”.

4.3 Medical School Curriculum

Respondents were invited to send their syllabuses to enable a more detailed analysis of what is being taught about ME/CFS in their respective schools. A similar study undertaken in the United States revealed only 5.6% of medical schools were judged to deliver sufficient clinical, curricula and research on ME/CFS [11]. However, as no syllabus details were provided by any of the respondents, and no explanations given, it has not been possible to throw any light on why many healthcare professionals in the UK still struggle to: recognise this disease, be able to diagnose it or agree upon suitable management or treatments.

The medical profession furthermore is well known to be split on the aetiology or pathogenesis of ME/CFS [7] and without details on curricula it has not been possible to elicit whether this is a factor in why healthcare professionals continue to struggle with this disease.

The wide spectrum of medical disciplines and beliefs that are involved in teaching ME/CFS, as revealed by this study, could explain why healthcare professionals remain confused. Whilst ME/CFS is a complex, multi-system disease that will continue to attract divergent clinical and academic beliefs at a research level, there is no apparent reason why undergraduate medical students cannot be taught how to recognise and diagnose this disease and be able to make recommendations on its management. The over-riding priority in undergraduate teaching is to improve attitudes towards patients and acknowledgement of genuineness of the patient experience and validity of the disease. Treatment approaches that are shown to cause patient harm, delayed diagnosis, unsafe advice to exercise and outdated assumptions such that dysfunctional beliefs, behaviours, or even personality traits are responsible for causing or perpetuating this illness [12] should have no place in undergraduate teaching.

4.4 Medical Education Challenges

Despite almost twenty years of stagnation there is, as this study reveals from the attitudes of the majority (64%) of respondents in favour of more teaching aids and materials, now a substantial need for medical education in ME/CFS to “move on”. It is proposed that the paradigm shift in international understanding of this condition is an opportunity for medical educators to develop clear teaching materials for medical schools to use in a flipped classroom model. Such materials, updated to reflect the latest biomedical science developments, and patient perspectives, would transform what is taught regarding diagnosis and management of ME/CFS [13]. Teaching could be augmented with patient and specialist podcast interviews to convey both the complexity and patient experience of this disease.

This proposal would, furthermore, comply with the new NICE draft guidelines [8] which call for improvements in evidence based education and training of healthcare professionals and better acknowledgment of the patient experience.

Based upon the findings in this study, the UK General Medical Council (GMC), which has statutory responsibilities under the Health Act 1983 for medical education curricula and standards, and the Medical Schools Council (MSC), which represents medical schools in various areas of common interest, are called upon to use their considerable influence to bring about changes in medical schools undergraduate and postgraduate curricula such that doctors of the future are more capable of recognising, diagnosing and treating ME/CFS. Additionally the GMC may also wish to consider recognition of ME/CFS as a registered speciality which could also encompass post viral fatigue and the growing cohort of Long Covid patients.

The authors are not aware of any earlier study into the extent and nature of ME/CFS medical education across UK medical schools. This study therefore provides a baseline as to where UK medical education currently stands in relation to quantity, but it is difficult to comment on the content, quality or nature, of teaching in this subject. The evolving biomedical and patient narrative in relation to this disease must drive the development of updated guidelines, curricula and intended outcomes for what should be taught about ME/CFS and how it can be assessed.

5. Conclusions

UK medical education in ME/CFS is currently inadequate and appears not to have progressed over the past two decades. 41% of medical schools responding do not teach the subject at all. The teaching in those medical schools that do, 59%, is performed by multiple medical specialists, mostly by lecture of one-hour duration, is not always examinable, and mostly takes place without any exposure to patients with the disease.

Differences in beliefs of medical specialists concerning the aetiology or pathogenesis of ME/CFS need to be set aside in the interests of improving the clarity of what is taught at undergraduate level relating to the identification and diagnosis of this disease and its management. This study proposes that educators could sharpen focus and deliver a more coherent evidence-based message to enable healthcare professionals in the recognition, diagnosis and treatment of this disease.

Most medical schools (64% of respondents) acknowledge the need to improve education and training of healthcare professionals by expressing a strong appetite for more teaching aids and materials which convey the complexity of this disease. The GMC and MSC are encouraged to use their considerable influence to bring about change in medical schools curricula in ME/CFS.

Affiliations: 1. Miss Nina Muirhead BA(oxon) BMBCh(oxon) MRCS DOHNS MEd PGDipDerm 2. John Muirhead MA, FCCA, FCMA (retired) and ME/CFS Carer 3. Miss Grace Lavery Cardiff University Medical School Finalist 4. Dr Ben Marsh MBBS BSc MRCPCH Consultant Paediatrician

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Ethics: This study relates to medical education and data collected do not directly relate to human subjects, material or data (as per the Helsinki Accord) or to living persons (as per the UK Data Protection Act). No respondent has withdrawn informed consent to the Survey Monkey questionnaire.

Conflicts of Interest: N.M. is a member of Forward ME, chair of the Education working group of the CMRC (CFS/ME research collaborative) and author of the online education module with StudyPRN. B.M. is a patient member of the ME/CFS Priority Setting Partnership steering group. There are no financial conflicts of interest to declare.

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