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Original Research

Investigating undergraduate medical education on myalgic encephalomyelitis/chronic fatigue syndrome

ORIGINAL RESEARCH

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ABSTRACT

Background: Myalgic encephalitis or chronic fatigue syndrome (ME/CFS) is a poorly understood, highly stigmatised condition which significantly reduces patients' quality of life. ME/CFS had been identified as a gap in many health professionals' knowledge, therefore this research aims to explore the understanding of ME/CFS amongst UK medical students.

Methods: An online survey was developed and distributed to participants who were recruited via social media or via medical society's emails. The participants were undergraduate UK medical students.

Results: 106 students responded to the survey and 94 students completed the survey from more than 16 medical schools. 35% of the students did not know what ME/CFS is and 88% say that the disease has not been covered in their course so far. 89% of participants would like to learn more about ME/CFS, specifically through e-learning and videos.

Discussion: Participants were generally unaware of ME/CFS and its symptoms and had not received relevant teaching or exposure to the disease. Education on ME/CFS within undergraduate UK medical schools is currently inadequate and the interest expressed by students in this survey demonstrates a new teaching opportunity for UK medical schools.

BACKGROUND

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, debilitating, multi-system disease which is poorly understood by both patients and professionals. Its prevalence in the UK is approximately 0.2-0.9%, and although the pathophysiology has not yet been determined, many cases are triggered by infection or prodromal incidents such as infection or trauma. (1-3) ME/CFS is characterised by a range of neuro-immune symptoms such as debilitating fatigue, post exertional malaise, orthostatic intolerance, unrefreshing sleep, autonomic dysfunction, temperature hypersensitivity, myoclonic jerks, flu-like symptoms, muscle aches and more. (4, 5) Patients can be stigmatised due to the name of their condition, which is far more extensive than 'fatigue' and also due to the lack of awareness of ME/CFS as a medical condition. (3) Many fail to realise the significantly reduced quality of life which ME/CFS patients and their families face and the physical, psychological and emotional ramifications of the disease. (6) Research into ME/CFS has never been more important as the Covid-19 pandemic has seen an exponential rise in post-COVID-19 Syndrome, also known as 'Long Covid', which presents with similar symptoms and may share similar pathophysiology to ME/CFS. (7) Wong and Weitzer's study revealed that 25 out of 29 symptoms of ME/CFS were also symptoms experienced by Long Covid patients, highlighting the urgent need for more research into the pathogenesis and presentation of these comparable conditions. (8)

The aims of the project were to conduct a small pilot study to explore the understanding of ME/CFS amongst medical students across the UK and to investigate medical schools' curriculums and students' exposure to learning about the disease.

METHODS

Ethical approval was obtained from the Cardiff school of medicine research ethics committee before commencing research. Questions were formulated following an examination of the literature and the NICE 2021 Guidelines, these identify a lack of medical awareness of how common, serious, and physically disabling the condition can be. The questions were designed to identify medical student knowledge on awareness, prevalence, symptoms, and impact on quality of life and an online survey was generated. The purpose of the survey was to investigate the knowledge of ME/CFS amongst medical students across the UK and to discover the extent to which students think ME/CFS teaching is incorporated in the medical school curriculum. Undergraduate deans/clinical leads were made aware of the project and survey through a covering letter explaining the study aims and objectives before the survey was launched. Participants were volunteers recruited via social media or through the university's medical society email. The 5-minute online survey was created via REDCap, a secure web application for building and managing online surveys and databases. The survey collected quantitative data over a 3-week period from 22/03/21 to 12/04/21 when the survey ended. The survey was trialled by four Cardiff medical students and minor adjustments were made before it was distributed. Students were provided with a participant information sheet which they had to read, then select a button to agree to consent to participate and students were able to remain anonymous unless they volunteered their email address. The survey was posted on several medical school social media pages, it was sent via social media messenger to the majority of UK medical school societies and was emailed to undergraduate medical school societies. The survey was open to any student who was willing to respond, however participants were only included if they currently study an undergraduate medicine course at GMC recognised UK medical schools, students were not excluded if the course was graduate entry or intercalated. The results were analysed, and graphs were drawn using Graphpad and excel, and a report was written. 110 undergraduate medical students responded to the survey, however 4 of these responses were not from undergraduate medical students and their responses were discarded .

RESULTS

110 students selected the questionnaire, 106 medical students gave their consent to participate, 94 of whom completed the entire survey. Participants from more than 16 different UK medical schools responded, with 15% (n=16/106) of people not identifying their medical school.

Results revealed that 35% (n=37) of the students did not know what ME/CFS was and 88% (n=93) of participants stated that the topic had not been covered in their course. Additional comments from participants included "I had never even heard of this disease before doing this survey" and "I don't think ME is an illness. It is just a label for a variety of pathology".
78% (n=83) of students declared that they had not been examined on ME/CFS at medical school, 22% (n=23) were 'not sure' and 0% answered 'Yes'.

The results in table 2 display that 48% (n=50) of the students have never met a patient with ME/CFS, and of those that have, 13% (n=14) met the patient on placement and 30% (n=31) met the patient outside of medical school. 86% (n=89) of participants have never taken a history from a patient with ME/CFS.

The majority of students were aware that ME/CFS does not improve with exercise and that there is no blood test to diagnose the disease, 63% (n=60) and 95% (n=91) respectively.
Less than 50% of participants associated orthostatic intolerance, autonomic dysfunction, palpitations, temperature hypersensitivity, feeling hot or cold, myoclonic jerks/ muscle twitching, sore throat, intolerance to alcohol/ food/ chemicals, nausea, pain on touch, eye pain, abdominal pain with ME/CFS.

The majority of participants 52% (n=49) incorrectly estimated the prevalence of ME/CFS in the UK to be 1 in 2000. This is lower than the estimated prevalence of 1 in 200, which 27% (n=26) of students selected. 42% (n=39) of participants believed ME/CFS patients to have a better quality of life than multiple sclerosis patients, 63% (n=59) reported that ME/CFS patients have a worse quality of life than patients with diabetes and 34% (n=31) thought that ME/CFS patients had the same quality of life as those with chronic kidney disease.

Table 1: *A Table to Show the Number of Students from each University*

Medical School	Number of Participants
Cambridge	5
Cardiff	38
Keele	31
Leeds	1
Newcastle	1
Norwich	2
Nottingham	1
Queens Belfast	3
University College London	1
University of East Anglia	1
Liverpool	1
Central Lancashire	1
Dundee	1
Exeter	1
Glasgow	1
Manchester	1
Unknown	16

Table 2: *The proportion of students who have met and taken a history from a ME/CFS patient*

	Yes	No	No response
Have you met a patient with ME/CFS?	54	50	2
If yes, did you meet the patient on placement?	14	40	-
If yes, did you meet the patient outside of medical school?	31	23	-
If yes, have you met ME/CFS patients both on placement and outside of medical school?	9	45	-
Have you taken a history from a patient with ME/CFS?	15	89	2

89% (n=85) of the participants would be interested in learning more about ME/CFS and 55% (n=53) said that the COVID pandemic and 'long covid', had increased their desire to learn more on the topic. The students reported that the teaching methods they found most useful were videos 85% (n=78), interactive elearning 82% (n=78) and lectures 79% (n=75) whilst 26% (n=24) and 15% (n=14) people respectively stated that podcasts and PDF handouts were not helpful.

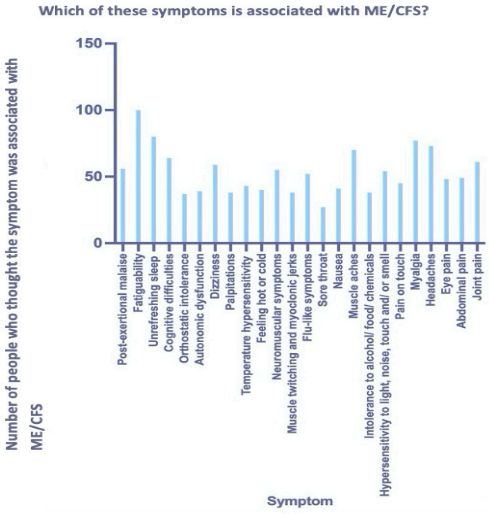

Figure 1: *Which of these symptoms may be associated with ME/CFS?*

DISCUSSION

ME/CFS is a common and serious disease that many medical professionals are uneducated on. The emergence of long covid as a serious global health burden following the covid pandemic has highlighted how the medical profession have underestimated post viral disease. The results of the survey clearly emphasise the need for education on ME/CFS in medical schools in the UK, as 35% of students did not know what it was, 88% of students stated that it had not been covered on their course and none of the students surveyed stated that they had been examined on the topic. Only 13% of students have met a patient with ME/CFS on medical placement and 19% of these people have taken a history. History taking is essential in the diagnosis of ME/CFS and medical students are not being provided with the technical skills or the exposure to patients that is required to diagnose the disease. The symptoms listed in the study are associated with ME/CFS, yet 12 of these symptoms were not selected by more than half of the medical students participating in the survey. (5) Many were unaware of the reduced quality of life the condition has compared to other chronic illnesses . The majority of students would like to learn more about ME/CFS and they demonstrated a preference for an interactive elearning on the topic which could be a useful future initiative to educate medical students .

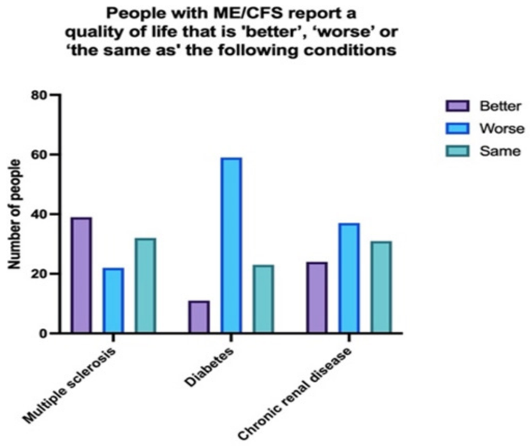

Figure 2: *People with ME/CFS and their quality of life*

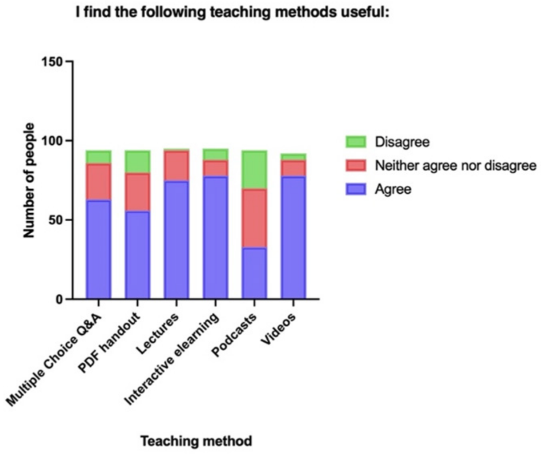

Figure 3: *I find the following teaching methods useful*

The results of this study are supported by the new NICE guidelines which state the need for improved education, training and empathy relating to ME/CFS (5). Research suggests that medical professionals are unsatisfied with their current level of training and need a source of evidence-based education on ME/CFS as the current system has failed to meet their needs. (9) "Understanding medical students' views on chronic fatigue syndrome" demonstrates similar findings to this study; medical students were uncertain of their understanding of ME/CFS, its symptoms and management and often adopt the negative attitudes of doctors' they meet on placement and the cycle of misunderstanding continues. (10) A more recent study focused on surveying medical schools' staff rather than students; they concluded that education on the topic has not improved in 20 years and that 41% of UK medical schools do not teach ME/CFS. (11) Our research revealed that 89% of students would like to receive further education on ME/CFS and compliments earlier findings that 64% of the medical schools understand the importance of improved ME/CFS education and would like to facilitate this education. (11) Therefore, it is clear that both medi-

cal students and their medical schools are interested in developing their knowledge on ME/CFS and that there is a demand for new learning materials on the disease. ME/CFS is not just yet another disease to add to overburdened curricula, it is unique in that there is a worsening of repeat cardiovascular exercise physiology, and exacerbation of disease symptoms on exertion. Patients with ME/CFS are an exception because the usual advice to exercise could cause harm. The lack of current biomarkers for ME/CFS can be used as an educational opportunity to highlight the importance of taking a good history and believing the patient .
There remains a paucity in the literature on this topic and to our knowledge this is the largest study of its kind. The other study of medical students' views on CFS/ME in the literature involved 21 students participating from just one university medical school. (10) This is the first study to survey medical students from multiple UK universities on their understanding of ME/CFS, independently to their university. The informal style of the project may have allowed for more accurate results, as students were given the opportunity to answer honestly without risk of judgement from their university. The Covid pandemic raised awareness of Long Covid and ME/CFS at the time of the survey, which may have made students more interested in participating.

Limitations of the study are the small sample size, the lack of information on students' year group, and the dropout rate of 11.3%. The study should be repeated on a larger scale with a greater sample size and would ideally survey students in their last year of study to give an accurate overview of the whole course. The results are statistically difficult to interpret as there was not an even spread across participating universities, with the greatest number of respondents being from the lead author's university and some medical schools did not respond at all. This could be due to the method of recruitment relying on volunteers from social media or to the short time frame of the research. There remains a paucity in the literature on this topic and to our knowledge this is the largest study of its kind. The other study of medical students' views on CFS/ME in the literature involved 21 students participating from just one university medical school. (10)

This research demonstrates that medical students are not being educated and trained to recognise, diagnose or treat ME/CFS, despite their desire to learn more on the topic. If medical schools addressed this gap in knowledge by delivering teaching which incorporates the evidence based NICE guidelines, medical students would have the skill set to contribute to improving the quality of care for ME/CFS patients in the future.

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