

**Doctors' knowledge and
understanding of
Myalgic Encephalomyelitis
United Kingdom
2018**

by Dr. K.N. Hng, November 2018

Full report at <https://bit.ly/2yFAtY8>
Appendix 1 at <https://bit.ly/3byfwga>

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Introduction

It has long been the experience of patients with Myalgic Encephalomyelitis (ME) that their doctors have little knowledge and understanding of the condition, and are largely unable to help. Worse, many report that their doctors do not appear to believe their illness is real, resulting in tragic lack of support.^{1,2,3} Examination of sample medical curriculums in the United Kingdom in 2018 confirmed that as far as could be determined, Myalgic Encephalomyelitis was not in the syllabus at either undergraduate or postgraduate levels. It is therefore quite conceivable that patients' widely reported impression is indeed true.

Methods

In this exercise we attempt to quantify doctors' knowledge and understanding of Myalgic Encephalomyelitis. A questionnaire was developed with input from experts in the field (Appendix 1). At a unique regional training event, where physicians at ST3-8 level were scheduled to receive a short introductory lecture on Myalgic Encephalomyelitis, the questionnaires were handed out and returned on the same day.

In order to capture baseline data, respondents were asked to base their answers on their knowledge before hearing the lecture. The results are analysed below. Apart from the last question, about further education on ME, questions left unanswered are counted as "Don't know".

Results

1. Education, experience and confidence

44 questionnaires were returned and analysed. The first part of the questionnaire examined respondents' previous education on ME, experience of ME, and level of confidence with ME. Results are tabulated in Figure 1.

Education and Confidence:	Yes	No	
Have received some formal teaching on ME	12 (27%)	32 (73%)	
Have seen some ME patients	31 (70%)	13 (30%)	
		Neither 10 (23%)	
<hr/>			
I know how to diagnose ME	5 (11%)	39 (89%)	
I feel confident dealing with ME patients	3 (7%)	41 (93%)	
	Both 2 (5%)	Neither 38 (86%)	Just one 4
Confident to diagnose but not to manage			3
Don't know how to diagnose but apparently confident to manage!			1

Fig 1. Education, Experience and Confidence

Only 27% of respondents reported having previously received formal teaching on ME. Most of this was in the form of undergraduate or postgraduate lectures. 70% reported having had some experience of ME patients. This was in GP clinics, specialty clinics, or in hospitals. 23% had had neither formal teaching on ME nor any experience of it.

89% of respondents did not know how to diagnose ME. 93% did not feel confident dealing with ME patients. Only two respondents (5%) said they knew how to diagnose ME and also felt confident managing ME patients. However, one

of them annotated "ish" against the answers indicating he/she was not fully confident, and the other annotated "If by ME Chronic Fatigue Syndrome is meant," indicating he/she did not understand the difference between the terms.

2. General epidemiology and understanding chronicity

Respondents performed fairly well on questions relating to the general epidemiology and the chronicity of the illness. These answers are displayed in Figure 2.

Response to one particular question raises some concern. Asked whether, "Children with ME miss school because their parents support their sick role and this should be discouraged", the majority answered correctly (false), but 30% thought this was true. Given the high incidence of unjustified Child Protection and Safeguarding proceedings instigated against families of children with ME, often with disastrous consequences to the health of these children, this misconception is of grave concern.³

3. Definitions and diagnosis

Unsurprisingly given that 89% of respondents had said they did not know how to diagnose ME, results in this area are unsatisfactory. They can be seen in Figures 3 to 7.

82% of respondents believed ME to be at least in part psychological or psychosomatic, with only 9% understanding that ME is a real, physical illness (Figures 3,5). Interestingly, all four respondents who answered this question correctly are among the ten who have received no formal teaching on ME, nor ever seen any ME patients (Figure 4). Therefore, 40% of this group correctly recognised ME as a

General Epidemiology and Understanding Chronicity

■ Right answer
 ■ Don't know
 ■ Wrong answer

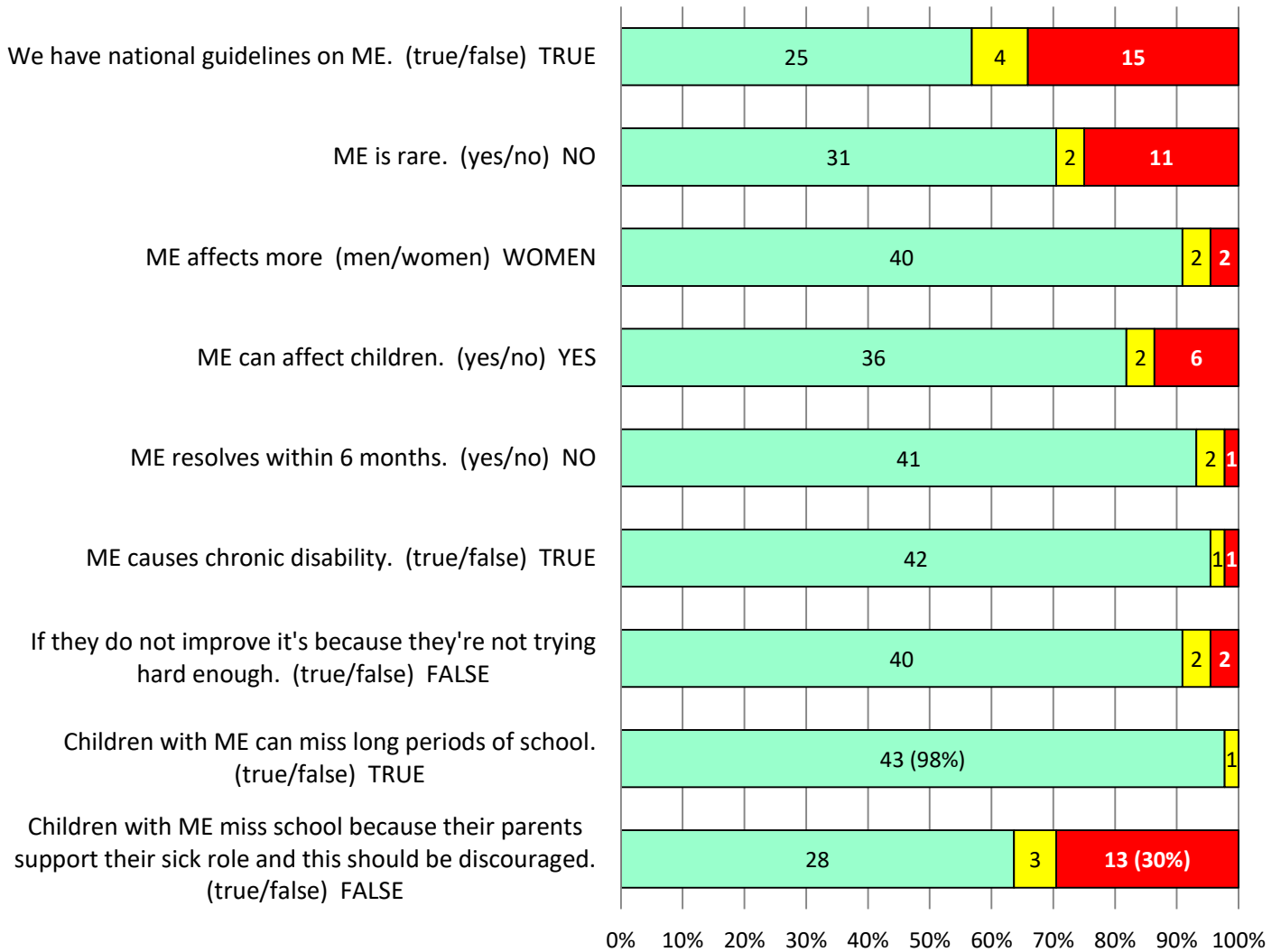


Figure 2. General Epidemiology and Understanding Chronicity

physical illness, compared to 0% among doctors who have received any formal teaching on ME or previously seen any ME patients (Figure 4).

This begs the question: what are doctors being taught on ME, and what are they

being told by their colleagues when they come across ME patients in the clinical setting?

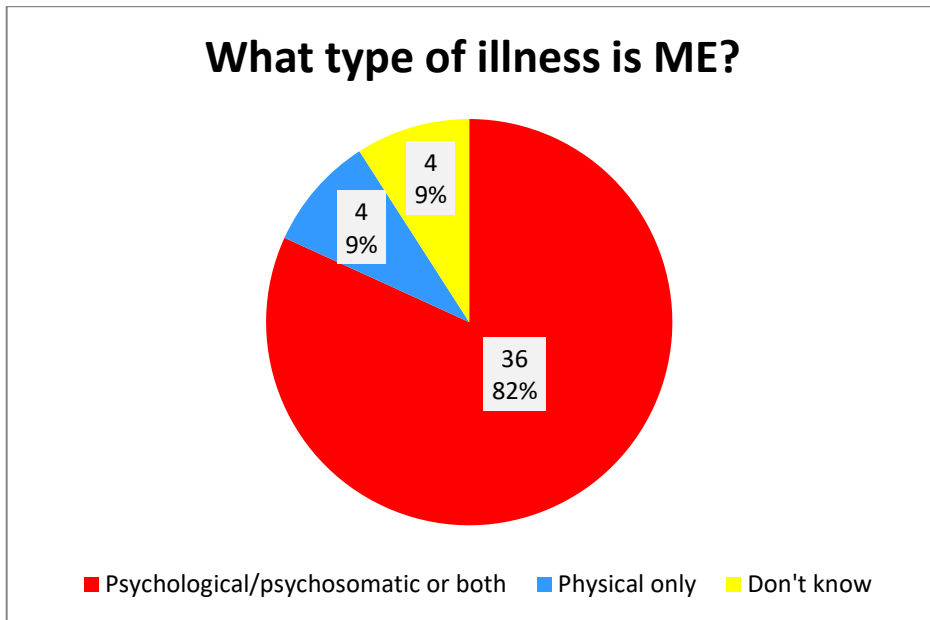


Figure 3. Nature of ME

Effect of previous teaching or experience on understanding of ME			
Total respondents 44			
Had received teaching on ME or Have seen some ME patients 34		Not had teaching on ME and Not seen any ME patients 10	
Thinks ME is at least in part psychological 34 100%	Knows ME is physical 0 0%	Thinks ME is at least in part psychological 6 60%	Knows ME is physical 4 40%

Figure 4. Effect of previous teaching or experience

Definitions and Clinical Understanding

■ Right answer
 ■ Don't know
 ■ Wrong answer

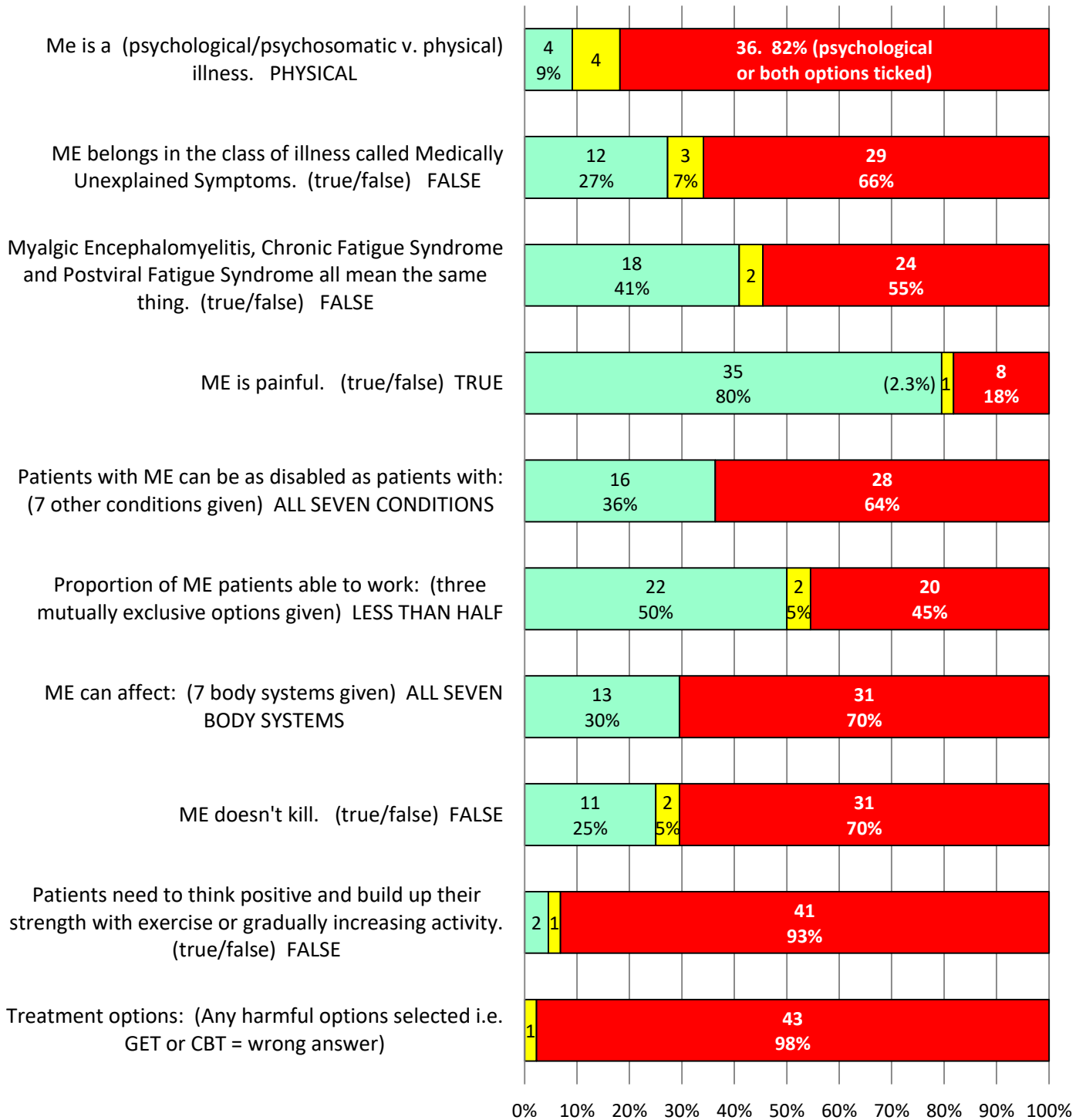


Figure 5. Definitions and Clinical Understanding

Respondents performed poorly on definitions, with 66% of them wrongly believing that ME belonged in the class of illness called Medically Unexplained Symptoms, and 59% of them not knowing the difference between ME, Chronic Fatigue Syndrome and Post Viral Fatigue Syndrome (Figure 5).

When it came to making the diagnosis, 39% of respondents incorrectly thought a psychiatric history was important (Figure 6). This is in line with the misconception that ME is a psychological or psychosomatic problem.

ME is mainly diagnosed with: (multiple options allowed)		
A careful history	40	91%
A psychiatric history	17	39%
A thorough physical examination	30	68%
Investigations	28	64%

Figure 6. Diagnostic methods

The diagnosis of ME requires:		
Six months of fatigue	38	86%
Psychiatric symptoms	11	25%
Post exertional malaise	27	61%
Symptoms from multiple systems	31	70%
Signs of anxiety or depression	15	34%
Certain physical signs	13	30%
Don't know	3	7%
Any red	17	39%

Figure 7. Diagnostic criteria

On diagnostic criteria, a significant 39% of respondents did not realise that **Post Exertional Malaise** is an essential requirement for a diagnosis of ME (only 61% ticked this box - Figure 7).^{1,4-7} These doctors could erroneously diagnose ME while

missing other pathologies. Also, 39% of respondents incorrectly believed that psychiatric symptoms, or signs of anxiety or depression, are necessary for a diagnosis of ME. These doctors could misdiagnose depression or other mental health problems as ME, depriving patients of necessary treatment. They could also miss the diagnosis of ME, depriving patients of crucial recognition, medical advice and support.

In addition, 86% of respondents believed six months of fatigue is necessary for diagnosis (Figure 7). However the **MYALGIC ENCEPHALOMYELITIS – Adult and Paediatric: International Consensus Primer for Medical Practitioners** allows one to make a positive diagnosis based on symptom constellation, without having to wait six months.⁴ This is important as it allows timely diagnosis and management. Diagnostic delay and lack of crucial medical advice in the early part of the illness frequently result in significant harm and increased severity of illness.

4. Disability and impact

When asked about the level of disability suffered by ME patients, 64% of respondents under-estimated the level of disability compared to other common or serious illnesses (Figures 5,8). Only 36% of respondents correctly recognised that ME patients can be as disabled as patients with all seven of the other conditions named. These are Multiple Sclerosis, Cancer, Advanced HIV, Chronic Respiratory Disease, End Stage Renal Failure, Heart Failure and a broken leg. All these conditions have previously been identified in the literature or described by expert clinicians as having comparable levels of disability to ME.^{1,2,6}

45% over-estimated the ability of ME patients to stay in work (Figure 5).⁸ The vast majority (98%) did however recognise that children with ME can miss long periods of school (Figure 2).

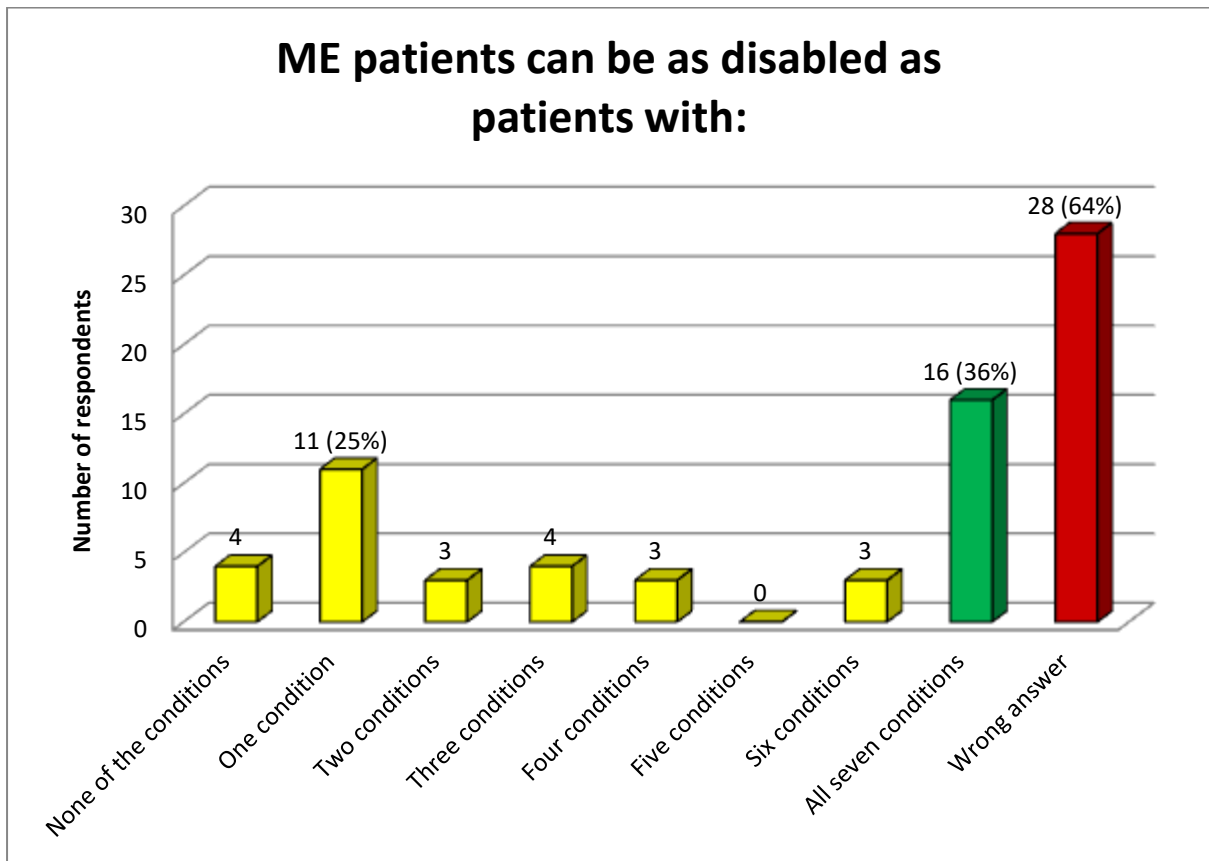


Figure 8. Level of disability

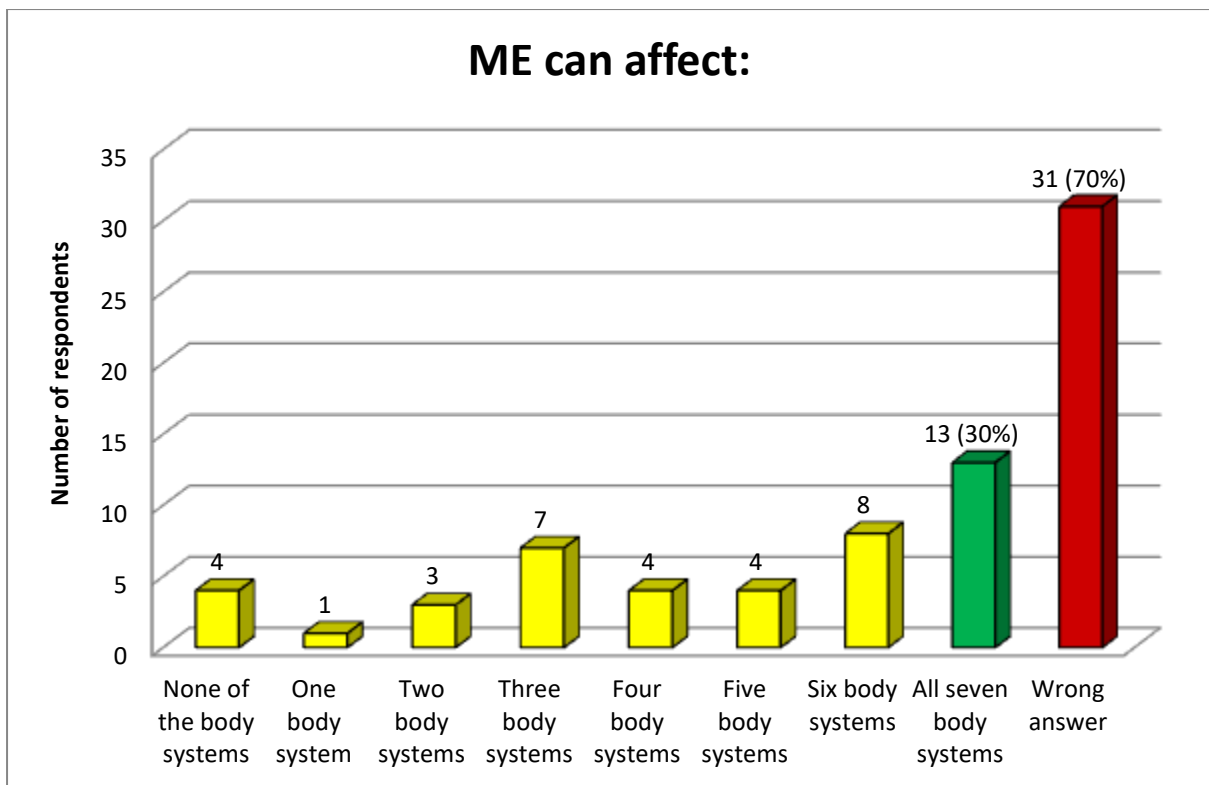


Figure 9. Clinical manifestations

5. Clinical manifestations

The majority of respondents (80%) indicated that ME is painful but only 25% knew that ME can kill (Figure 5).⁹⁻¹² 70% did not realise the breadth of manifestation and symptoms in ME (Figures 5,9). Seven body systems very commonly affected in ME were listed, and only 30% of respondents indicated that ME can affect all seven body systems. These are the nervous system, the cardiovascular system, the endocrine system, the musculoskeletal system, the gastrointestinal system, the immune system and cellular metabolism.^{1,4-7}

6. Treatment

Answers here are most alarming (Figures 5,10,11). 98% of respondents believed that Graded Exercise Therapy (GET),¹³ a most harmful practice indeed in ME,¹⁴⁻¹⁹ is a suitable treatment. 61% believed that Cognitive Behavioural Therapy (CBT)²⁰ to help patients get out of the sick role is also a treatment.

ME is a serious and debilitating multi-system neuro-immune condition.^{1,4-7} As such, CBT attempting to convince patients that they are not actually sick is no more a useful treatment than it is for Cancer.^{20,21} Instead, by convincing patients that they are not ill, it will very likely cause harm, for patients who over-exert themselves will suffer a deterioration in their illness. Even without the behavioural effects, just travelling to and sitting through unhelpful CBT sessions can be harmful to ME patients whose energy is in short supply and who already struggle to manage minimum essential daily activities. Patient evidence suggest adverse outcomes in 20% of cases when treated with CBT.²¹

Even more dangerous is Graded Exercise Therapy (GET).¹³⁻¹⁹ Due to the unique

ME can be treated with:		
Antivirals	3	7%
Graded Exercise Therapy	43	98%
CBT to help patients get out of the sick role	27	61%
Vitamin supplements	7	16%
No answer	1	2%
Any red	43	98%

Figure 10. Treatment options

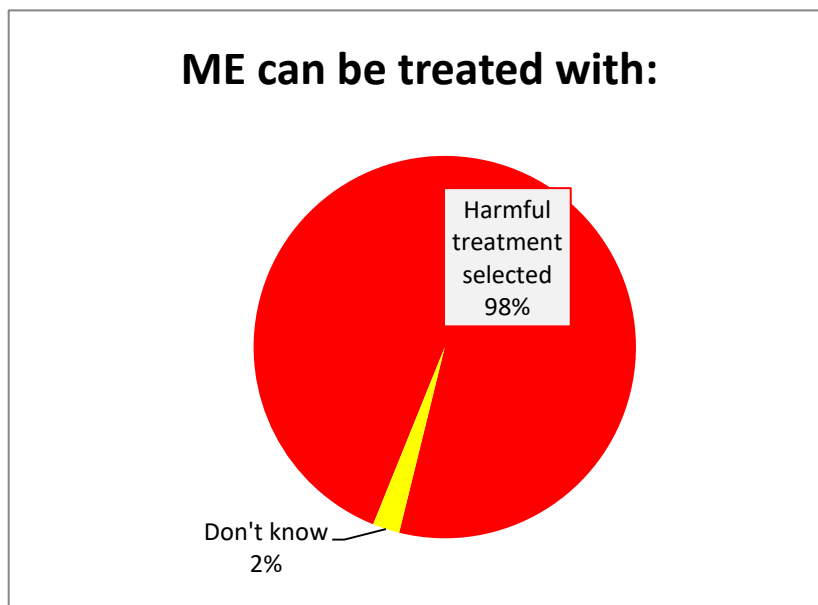


Figure 11. Treatment

and defining characteristic of ME of **Post Exertional Malaise**,^{1,5-7} also known as **Post-Exertional Neuroimmune Exhaustion (PENE)**,⁴ patients suffer the hallmark feature of a prolonged worsening of all symptoms, sometimes with the emergence of new symptoms or symptoms not normally present, if any activity over their individual safe limit is attempted. This is commonly called "a crash". GET harms 54% to 82% of patients,^{14,17} yet based on this survey, 98% of this cohort of doctors would prescribe this highly dangerous therapy (Figure 10,11).

7. Further education on ME

The response to this was very positive. Participants were asked, "After today's introductory lecture, I would like further more in-depth teaching on Myalgic Encephalomyelitis." Answer options were Yes, No and Neutral.

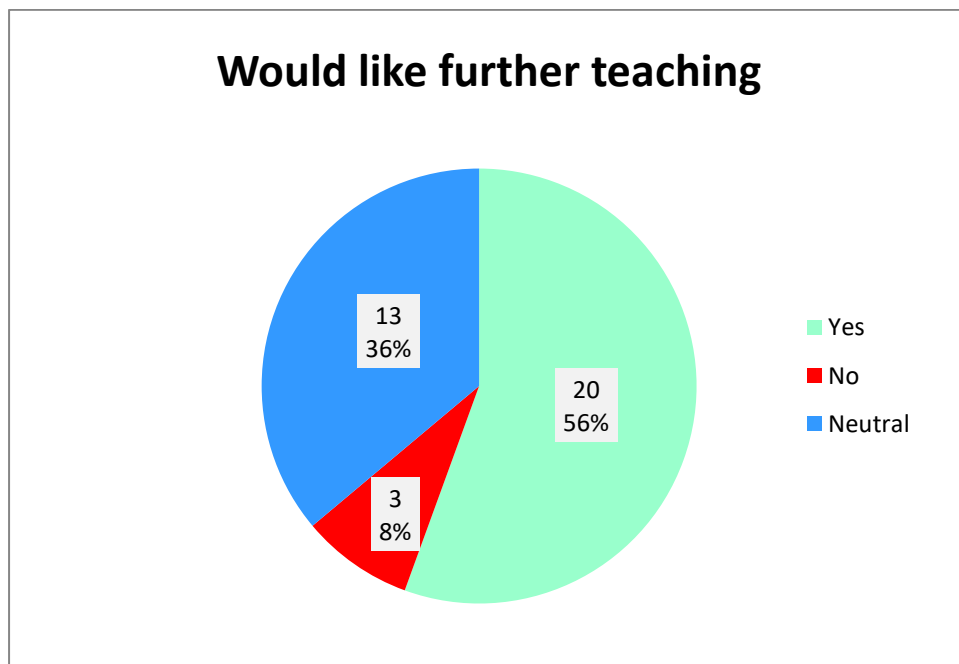


Figure 12. Interest in further education on ME.

36 doctors answered this question. The lower response rate may relate to having had to wait until after they had had the lecture before answering. Of those who responded, 20 said Yes, 3 said No, and 13 were Neutral (Figure 12). Therefore only a very small minority (8%) did not want further teaching on ME. Over half of the respondents (56%) would welcome further education on ME, and the rest (36%) are presumably amenable to it, making a total of 92% who would be amenable to further education on ME.

Conclusions and Discussion

This survey is probably the first attempt in decades in the United Kingdom at formally quantifying doctors' knowledge and understanding of Myalgic Encephalomyelitis. It captures baseline data which sadly confirms patients' perception that their doctors know little about ME and that many do not even believe it is real. It highlights errors in basic fundamental understanding, such as the misconception that ME is partly or wholly psychological or psychosomatic. It also highlights large deficiencies in education and clinical knowledge on ME, as well as dangerous prevailing ideas on treatment. **Nearly all participants (98%) believe ME can be treated with highly dangerous Graded Exercise Therapy.**

The results of this survey make a strong case for putting Myalgic Encephalomyelitis into formal medical education in the UK. We would argue that with ME being more than twice as common as Multiple Sclerosis²² and as debilitating or worse than most other chronic illnesses such as Heart Failure or End Stage Renal Disease,^{1,2,6} causing an estimated economic burden of £3.3 billion per annum to the country excluding productivity losses among carers,² and being the single greatest cause of long term school absence in children,²³ the medical profession cannot afford to be so ignorant, and so misinformed, about ME. This becomes even more evident when considering the danger of currently favoured therapies¹³⁻²¹ in conjunction with the rising costs of clinical negligence.²⁴

Doctors need to be able to recognise ME regardless of their speciality, as it has such a wide range of symptoms and presentations. One anecdotal case, a British surgeon with ME, describes seeing thirteen different doctors including five ENT surgeons, before finally being diagnosed.²⁵ Another case, an experienced British physician now housebound and unable to care for her two young children, describes failing to recognise her own illness for years, despite having several postgraduate clinical and

teaching qualifications, including the Membership of the Royal Colleges of Physicians.²⁶

Not only does this survey and above examples demonstrate the great and urgent need for medical education on ME, which must be factually correct and up-to-date, responses also demonstrate the appetite for it. More than half the respondents (56%) who answered this question wished to have more in-depth teaching on ME, and a total of 92% were amenable to it (Figure 12). Medical Royal Colleges and Medical Schools should take heed.

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