

The Awareness Of Dystonia Amongst UK Medical Students In Their Clinical Years

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Abstract

Background and aims: dystonia is a neurological movement disorder characterized by patterned, directional and usually sustained muscle contractions, frequently causing repetitive twisting movements or abnormal postures. It affects more than 40,000 people in the UK. Medical students in the UK have only a 5-6 week attachment within a neurology department to come across this important condition. The primary aim of this study is to determine the extent of awareness and knowledge medical students in their clinical years possess about this condition. In addition, as a secondary aim, we also wanted to observe if undertaking a clinical attachment in neurology or observing/clerking patients with dystonia have a significant impact on their knowledge of this condition. Methods: a questionnaire comprising of a range of choice based (single best answer and multiple choice) and mental recall based assessment techniques (short answer questions) were constructed with expert input to assess knowledge of dystonia. Following two pilot studies and revision of the questionnaire, it was administered to a group of medical students. A total of 51 medical students out of 140 who were contacted participated in the study. The outcomes for the secondary aim were analyzed via the Chi-squared test and, where not possible due to sample size, the Fisher's exact test. Results: in terms of the overall knowledge and awareness of dystonia, a large number of students seem to already have a good grasp of what the term dystonia implies, its basic pathology and epidemiology. In addition, there is strong evidence to suggest that undertaking a clinical attachment in neurology or clerking a patient with dystonia does not contribute significantly to developing a sound knowledge base and awareness of this medical condition. However, caution must be applied to interpreting these results, as there was a large difference between the provision of correct answers to choice-based and mental recall based assessment techniques as proven in this study. Conclusion: medical students in their clinical years appear to have an acceptable awareness of dystonia in choice based assessments; however this appears to decline in mental recall based assessments. In addition, a clinical attachment within a neurology department or clerking a patient with dystonia does not appear to significantly increase their overall knowledge of the condition. We conclude by proposing that incorporation of this condition within the curriculum of medical students and exposing them to a patient based lecture on dystonia may help to increase their awareness of this condition

INTRODUCTION

Dystonia is a neurological movement disorder characterized by patterned, directional and usually sustained muscle contractions, frequently causing repetitive twisting movements or abnormal postures'. Hermann Oppenheim (1911) is usually credited with the introduction of the term dystonia when he observed a childhood onset form of generalized dystonia and referred to it as dystonia musculorum deformans'. Several studies have been carried out with regards to the diagnosis, pathophysiology and treatment of this condition and several reviews are also available on these subtopics'. The aim of this study however, is to determine the extent of awareness and knowledge medical students in their clinical years possess

about this condition. As a secondary aim, we also wanted to determine if undertaking a clinical attachment in neurology or observing/clerking patients with dystonia result in a significant improvement on their knowledge of this condition. This study is an important undertaking due to the fact that the majority of medical students usually only undertake a 5-6 week attachment in neurology before heading onto become junior physicians. This is usually one of the best (and almost the only) opportunity for them to become acquainted with an important neurological condition that affects around 40,000 individuals in the United Kingdom'. It is thus essential that they develop some sort of basic understanding and awareness of this condition during their time on and following an attachment in neurology. This

will enable them to deal with patients that suffer from this condition and known some basic facts about the condition and make an appropriate referral if required once they become physicians.

Thus apart from assessing the overall knowledge of dystonia among medical students in their clinical years which was the primary aim of this study, two null (and alternative) hypotheses can also be defined for the secondary aim proposed for this study:

METHODS

Construction of a questionnaire to test awareness of dystonia

A search was undertaken on Medline to locate any studies that attempted to quantify awareness of dystonia among healthcare workers (i.e. physicians, nurses, medical students) through the use of a validated questionnaire. No such studies were found.

The absence of such studies required the construction of a questionnaire that achieved the desired aim with consistency. Initially a pool of eligible questions was constructed using textbooks, posters and journal articles which dealt with various aspects of dystonia¹⁷. These questions were then reviewed by experts in the field of neurology (i.e. consultant neurologists and those neurologists who had an interest in medical education) to determine if they were of the standard required for medical students. This led to the elimination of certain questions and the inclusion of eleven questions which were believed to test, to the required depth, the awareness of dystonia among medical students. The questionnaire was then piloted twice. During the first pilot it was discovered that the questionnaire was too long and as a result, four questions were eliminated. It was then piloted a second time which revealed that the questionnaire was of adequate depth in terms of material tested and was of an acceptable length to the students. This same modified questionnaire was then used in the study. The pilot surveys also revealed that the questionnaire was consistent with more or less all students understanding the questions in the same manner and to the same extent (i.e. it demonstrated an acceptable level of content validity).

The final definitive questionnaire contained seven questions, and was a mixture of three true/false, two single best answer (SBA) and two short answer questions (SAQ). It was decided to use a variety of question types in order to prevent the possibility of guessing the answers.

Following these seven questions Students were also asked to indicate their age, gender, year of study and proposed specialty.

SAQ QUESTIONS

It would be useful to elucidate the marking criteria for these two questions as it was more complex than that of the MCQ and SBA style questions. The first SAQ asked the students to list three different types of dystonia. The accepted answers to this SAQ are shown in Table 1. Any of the major aetiological divisions, including the different types under those divisions, were accepted as a sufficiently correct answer.

The second SAQ asked the students to list any three treatments that they knew of for dystonia. The accepted answers are given in Table 2. The students were given full marks even if all the three treatments were drug therapies. To get marks for drug and surgical therapies students had to mention the particular drug name or surgical procedure. The term “drug” or “surgical” treatment alone was not accepted as a valid answer. However, for botulinum toxin therapy the students did not have to specify which toxin type, A or B, they would use. Marks were awarded for mentioning botulinum toxin alone as a form of treatment.

Figure 1

Table 1 The classification of dystonias . Any one of the terms in this graph was accepted as one of the three answers.

| | | |
|------------------------|---|--|
| 1)Aetiology | Primary (or idiopathic) | <ul style="list-style-type: none"> • Oppenheim's torsion dystonia • Cranio-cervical dystonia • Familial torticollis • Whispering dystonia |
| | Dystonia plus | <ul style="list-style-type: none"> • Myoclonus-dystonia • Rapid-onset dystonia-parkinsonism • Dopa responsive dystonia • Myoclonus dystonia |
| | Heredo-degenerative | <ul style="list-style-type: none"> • Lubag |
| | Secondary | <ul style="list-style-type: none"> • Tardive dystonia |
| | Paroxysmal | <ul style="list-style-type: none"> • Paroxysmal dystonic choreoathetosis • Paroxysmal kinesigenic dyskinesia • Paroxysmal dyskinesias with spasticity |
| 2) Age of onset | Early-onset | |
| | Late-onset | |
| 3)Body region affected | Focal | <ul style="list-style-type: none"> • Oromandibular • Cervical dystonia • Isolated limb dystonia • Craniofacial dystonia • Blepharospasm |
| | Segmental | |
| | Multifocal | |
| | Generalized (Idiopathic torsion dystonia) | |
| | Hemidystonia | |
| 4) Other | Psychogenic dystonia | |
| | Pseudodystonia | |

Figure 2

Table 2 Accepted answers for SAQ 2, list three treatments for dystonia .

| | |
|-------------------------------|---|
| 1)Drug | <ul style="list-style-type: none"> • Trihexyphenidyl • Clonazepam • Diazepam • Baclofen • Carbamazepine • Carbidopa/levodopa • Tetrabenazine |
| 2) Botulinum toxin injections | <ul style="list-style-type: none"> • Botulinum toxin A • Botulinum toxin B |
| 3) Surgical procedures | <ul style="list-style-type: none"> • Deep brain stimulation • Selective peripheral denervation and myectomy • Intrathecal baclofen • Radiofrequency lesions |
| 4) Other | <ul style="list-style-type: none"> • Physical therapy • Occupational therapy • Immobilisation, constraint-induced therapy |

SAMPLE SELECTION AND ADMINISTRATION OF THE QUESTIONNAIRE

Altman's normogram was used to calculate the required sample size'. It was decided to have at least 70 students in each group (for statistical comparison to fulfill the secondary aim of the study) to have an 80% power of detecting a significant difference in awareness of dystonia of 25% between the two groups at the 5% level. The entire sample was drawn from students attending one medical school in London. The author assumed knowledge of 40% of the

material covered in the questionnaire for the group which did not undertake an attachment in neurology. This assumption of 40% was made based on the results obtained in the second piloting of the questionnaire. These students were then e-mailed and invited to attend a lecture theatre on a particular day where the questionnaire would be handed out and they would be requested to complete it. Out of the total of 140 students 68 replied back and were happy to participate in the study.

On the day however only a total of 51 students attended and completed the questionnaire. The students were unaware of what condition was being tested prior to the questionnaire being handed out and had no opportunity to prepare for it.

STATISTICAL ANALYSIS

Statistical analysis of the data was carried out using SPSS (Version 16), a computer software statistical package. The analysis aimed at testing the two above mentioned hypotheses and providing the probability for the null hypotheses by dividing the 51 students into two groups for comparison (attachment in neurology vs. no attachment in neurology and clerked/observed a patient with dystonia vs. not clerked/observed a patient with dystonia). Hypothesis one was tested using the Chi-squared test. The test statistic and corresponding P-value were obtained by computer analysis. Only the three MCQ and two SBA questions were included in the statistical analysis. SAQ questions could have been included in statistical analysis via coding techniques, but were not because deciding which number of correct responses within each SAQ enabled us to code it as correct or wrong to include in statistical analysis would be arbitrary unlike the SAQ and MCQ question styles which had only one correct answer. To clarify, the first SAQ for example required 3 responses for full marks. Would we code it as "correct" if it had 1 correct response or 2 or 3 correct responses? And when would we code it as "wrong"? Due to this difficulty in determining exactly when it could be coded as correct or wrong these questions were not included in the statistical analysis.

Two by two contingency tables were created for each of the 5 questions along with whether the students had undertaken a neurology clinical attachment or clerked a patient with dystonia. This resulted in a total of five test statistics and P-values being generated. An example of a blank contingency table constructed for each of the five questions is shown below in Table 3.

Hypothesis two was also tested in the same way using the

Chi-square test by the construction of contingency tables and the generation of test statistics and corresponding P-values. Whenever the expected (E) frequency in at least one cell in the contingency tables was found to be smaller than 5, the P-value was obtained by the use of Fisher's Exact test. This had to be done in two cases which will be discussed further in the results section. Hypothesis two testing also generated five test statistics and P-values.

Statistical analysis was not performed on the SAQ style questions. However, the answers have been summarized in graph format, showing the percentages of correct and wrong answers.

Figure 3

Table 3 Example of the contingency table created for each question to test hypothesis 1 and 2.

| What is Dystonia? | | Undertaken a clinical attachment? / Clerked or observed a patient with dystonia | | |
|-------------------|--|---|----|-------|
| | | Yes | No | Total |
| Correct | | | | |
| Wrong | | | | |
| Total | | | | |

ETHICAL CONCERNS

The research ethics committee within the institution was consulted with regards to any ethical issues this study might pose. The author was advised that this study did not require ethical approval as it did not involve any intervention that had the potential to cause physical or mental harm to the participants. In addition informed consent was obtained from the participants in the form of a return e-mail to the initial invitation e-mail that was sent. The participants were also assured that their test scores would be kept confidential and their participation anonymized and steps were taken to this effect. They were also given information as to why this study was important.

RESULTS

SBA 1: WHAT IS DYSTONIA?

Figure 4

Table 4 Contingency table for SBA 1 hypothesis 1

| What is Dystonia? | | Undertaken a clinical attachment? | | |
|-------------------|--|-----------------------------------|----|-------|
| | | Yes | No | Total |
| Correct | | 20 | 16 | 36 |
| Wrong | | 9 | 6 | 15 |
| Total | | 29 | 22 | 51 |

Figure 5

Table 5 Contingency table for SBA 1 hypothesis 2

| What is Dystonia? | | Clerked or observed a patient with dystonia | | |
|-------------------|--|---|----|-------|
| | | Yes | No | Total |
| Correct | | 5 | 31 | 36 |
| Wrong | | 8 | 7 | 15 |
| Total | | 13 | 38 | 51 |

Out of the total of 51 students 36 (70.6%) managed to get the answer correct with only 15 (29.4%) getting the answer wrong. This was despite only 29 (56.9%) of them having undertaken a clinical attachment in neurology and only 13 (25.5%) having ever clerked or observed a patient with dystonia. This proves that a sizeable number of clinical year students have a good understanding of the definition of the condition.

SBA 2: THERE ARE CURRENTLY APPROXIMATELY 40,000 PATIENTS IN THE UK WITH DYSTONIA?

Figure 6

Table 6 Contingency table for SBA 2 hypothesis 1

| 40,000 patients in the UK with dystonia? | | Undertaken a clinical attachment? | | |
|--|--|-----------------------------------|----|-------|
| | | Yes | No | Total |
| Correct | | 13 | 10 | 23 |
| Wrong | | 16 | 12 | 28 |
| Total | | 29 | 22 | 51 |

Figure 7

Table 7 Contingency table for SBA 2 hypothesis 2

| 40,000 patients in the UK with dystonia? | | Clerked or observed a patient with dystonia | | |
|--|--|---|----|-------|
| | | Yes | No | Total |
| Correct | | 6 | 17 | 23 |
| Wrong | | 7 | 21 | 28 |
| Total | | 13 | 38 | 51 |

In this case 28 (54.9%) students got the answer wrong and only 23 (45.1%) got the answer correct. Although there might not be a stark contrast between the numbers who got the answer wrong and those who got it correct, what the result does indicate is that the majority of students are unaware of the approximate number of dystonic patients currently in the UK.

MCQ 1: MORE PATIENTS IN THE UK HAVE MOTOR NEURONE DISEASE (MND) THAN DYSTONIA (FALSE).

Figure 8

Table 8 Contingency table for MCQ 1 hypothesis 1

| | | Undertaken a clinical attachment? | | |
|--|---------|-----------------------------------|----|-------|
| | | Yes | No | Total |
| No. of MND suffers greater than those with dystonia? | Correct | 22 | 8 | 30 |
| | Wrong | 7 | 14 | 21 |
| | Total | 29 | 22 | 51 |

Figure 9

Table 9 Contingency table for MCQ 1 hypothesis 2

| | | Clerked or observed a patient with dystonia | | |
|--|---------|---|----|-------|
| | | Yes | No | Total |
| No. of MND suffers greater than those with dystonia? | Correct | 7 | 23 | 30 |
| | Wrong | 6 | 15 | 21 |
| | Total | 13 | 38 | 51 |

This question was added in order to ascertain if students thought that MND, a neurological condition which they receive teaching on and is well covered in most undergraduate textbooks, was more common than dystonia. Thirty (58.8%) students got the answer correct while only 21 (41.2%) got it wrong. This indicates that the majority of students are aware that although they may come across MND more than dystonia in their medical training, it in no way suggests that MND is more common than dystonia.

MCQ 2: CERTAIN FORMS OF DYSTONIA CAN BE GENETICALLY INHERITED (TRUE).

Figure 10

Table 10 Contingency table for MCQ 2 hypothesis 1

| | | Undertaken a clinical attachment? | | |
|--|---------|-----------------------------------|----|-------|
| | | Yes | No | Total |
| Dystonia can be genetically inherited? | Correct | 18 | 13 | 31 |
| | Wrong | 11 | 9 | 20 |
| | Total | 29 | 22 | 51 |

Figure 11

Table 11 Contingency table for MCQ 2 hypothesis 2

| | | Clerked or observed a patient with dystonia? | | |
|--|---------|--|----|-------|
| | | Yes | No | Total |
| Dystonia can be genetically inherited? | Correct | 5 | 26 | 31 |
| | Wrong | 8 | 12 | 20 |
| | Total | 13 | 38 | 51 |

Again the majority of students answered this question correctly. Thirty one (60.8%) students got the answer correct while only 20 (39.2%) got the answer wrong. This again points to the fact that most students are aware that certain forms of dystonia can be inherited genetically.

MCQ 3: BASIC PATHOLOGY OF DYSTONIA INVOLVES DOPAMINE IMBALANCE IN THE BASAL GANGLIA LEADING TO DEFECTIVE

CONTROL OF MUSCLES AND MOVEMENT (TRUE).

Figure 12

Table 12 Contingency table for MCQ 3 hypothesis 1

| | | Undertaken a clinical attachment? | | |
|---------------------|---------|-----------------------------------|----|-------|
| | | Yes | No | Total |
| Dopamine imbalance? | Correct | 21 | 15 | 36 |
| | Wrong | 8 | 7 | 15 |
| | Total | 29 | 22 | 51 |

Figure 13

Table 13 Contingency table for MCQ 3 hypothesis 2

| | | Clerked or observed a patient with dystonia? | | |
|---------------------|---------|--|----|-------|
| | | Yes | No | Total |
| Dopamine imbalance? | Correct | 10 | 26 | 36 |
| | Wrong | 3 | 12 | 15 |
| | Total | 13 | 38 | 51 |

With this question 36 (70.6%) of students got the answer correct with only a mere 15 (29.4%) students getting the answer wrong. This again goes to show that most medical students have a clear understanding of the basic pathological mechanism of dystonia.

STATISTICAL ANALYSIS OF SBA AND MCQ QUESTIONS

Table 14 below summarises the results obtained for hypothesis 1. As can be observed from Table 14, only in one question did undertaking a neurology attachment result in a significant difference ($p < 0.05$) in the ability to answer that particular question correctly (namely in question 3, an MCQ style question where the p-value was 0.005). In all other cases undertaking a clinical attachment did not enhance the student's capability to answer the questions with greater accuracy. Thus we can conclude that in all cases except one we have insufficient evidence to reject the null hypothesis.

Figure 14

Table 14 Summary of cross tabulation results for each question in hypothesis 1.

| Question and type | Pearson Chi-Squared test P-value | Fisher's exact test P-Value (if applicable) |
|--|----------------------------------|---|
| 1) What is dystonia? (SBA) | 0.770 | Not applicable |
| 2) Prevalence of Dystonia in the UK (SBA) | 0.964 | Not applicable |
| 3) Dystonia more prevalent than MND? (MCQ) | 0.005 | Not applicable |
| 4) Can be genetically inherited (MCQ) | 0.829 | Not applicable |
| 5) Basic Pathology (MCQ) | 0.743 | Not applicable |

Table 15 below summarises the results obtained for hypothesis 2. As can be seen from table 15 there is again only a single instance where we obtained a statistically significant p-value ($p < 0.05$). This was in the first question

which was an SBA style question regarding what the term dystonia could be defined as (p-value = 0.011). Thus we can conclude that in all cases except one, clerking or observing a patient with dystonia in a clinical setting did not enable the students to answer a set of questions on dystonia more accurately. Therefore we again have insufficient evidence to reject the null hypothesis except in one case. Note that Fisher’s Exact test was used to derive the P-value for questions 1 and 5 due to the fact that $E < 5$ in one cell in each case when contingency tables were constructed.

Figure 15

Table 15 Summary of cross tabulation results for each question in hypothesis 2.

| Question and type | Pearson Chi-Squared test P-value | Fisher's Exact test P-Value (if applicable) |
|--|----------------------------------|---|
| 1) What is dystonia? (SBA) | $E < 5$ | 0.011 |
| 2) Prevalence of Dystonia in the UK (SBA) | 0.929 | Not applicable |
| 3) Dystonia more prevalent than MND? (MCQ) | 0.673 | Not applicable |
| 4) Can be genetically inherited (MCQ) | 0.056 | Not applicable |
| 5) Basic Pathology (MCQ) | $E < 5$ | 0.730 |

SAQ 1: LIST 3 DIFFERENT TYPES OF DYSTONIA.

Figure 16

Figure 1 Number of students providing correct, incorrect or no response to SAQ 1

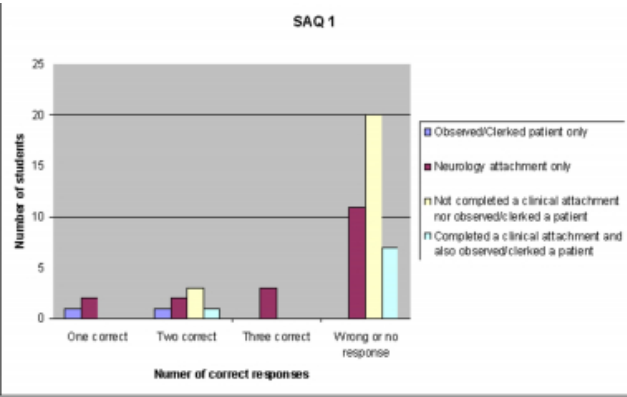
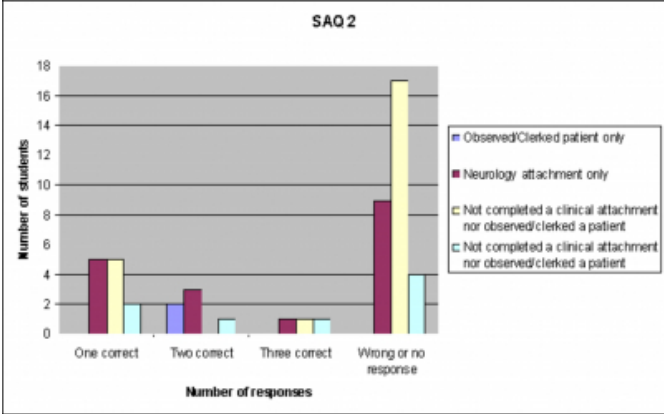


Figure 1 above gives us an idea of how the students dealt with this question. Thirty eight students (74.5%) were unable to list even one type of dystonia leaving the section blank or providing the wrong answer. Only 3 (5.9%) students were able to list three types correctly. Three (5.9%) and 7 (13.7%) students provided one and two correct responses respectively.

SAQ 2: LIST 3 DIFFERENT TREATMENTS FOR DYSTONIA.

Figure 17

Figure 2 Number of students providing correct, incorrect or no response to SAQ 2.



The number of students getting the answer wrong or not responding was 30 (58.8%) for this SAQ. This is a substantial improvement compared to the previous one. However this number is still quite high. Again only 3 (5.9%) students managed to get all three responses correct. More students managed to get one (12 [23.5%]) and two (6[11.8%]) correct responses in this SAQ.

DISCUSSION

To the author’s knowledge this is a pioneering study assessing the awareness and knowledge of dystonia among medical students. In this particular study the focus was on medical students who will eventually go on to become physicians. Thus, because of the preliminary nature of this study, there are no previous reports with which these results could be compared.

In terms of the overall knowledge and awareness of dystonia, a large number of students seem to already have a good grasp of what the term dystonia implies, its basic pathology and epidemiology prior to undertaking a clinical attachment in neurology or observing or clerking a patient with dystonia. However one problem with this conclusion is that because the majority of questions involved choosing an answer it is difficult to say that they definitively possess good knowledge of this condition. It may well have been due to the fact that they made a few “lucky” or “educated” guesses. In fact, when taking into consideration the responses to the two SAQ questions which asked about types and treatment of dystonia, most students were unable to answer correctly, let alone respond. This suggests that guessing may have played a significant part in answering the SBA and MCQ questions.

In terms of the first hypothesis, there is strong evidence that undertaking a clinical attachment in neurology does not contribute much to developing a sound knowledge base and awareness of this medical condition. The same could be said for hypothesis two. Those who had observed or clerked a patient with dystonia had no significant enhancement in their knowledge of this condition. Thus in both cases we have insufficient evidence to reject the null hypothesis. Furthermore in the two instances where there was a significant result it could be pointed out that the non-parametric nature of the Chi-squared test and Fisher's Exact test greatly reduces the power of the results.

One of the major limitations of this study is the small number of participants in it. In addition the fact that only students from one medical institution were invited to participate in the study is another serious limitation. Further to these limitations was also the issue of what exactly medical students are expected to know of this condition and what was considered beyond that. This issue was addressed as best as possible by receiving input from neurologists, yet further discussion needs to be undertaken in order to develop definitive learning objectives for students with regards to dystonia. Infact, there were no particular learning objectives defined for dystonia within the institution in which this study took place.

Another very important limitation is the design of the study itself. Since this is a cross-sectional study it only provides a snapshot of the situation within one particular time-frame. Thus in case a different time of the year was chosen, say closer to examinations, the results may have been different. In addition even if the statistics proved that in all questions a clinical attachment in neurology or observing/clerking a patient improved the number of correct responses it would have still been difficult to make a causal inference. That said cross-sectional studies do have their advantages in that they are inexpensive and can be carried out within a short time frame¹⁴.

Further research into this area should involve more students, more medical institutions and better defined learning objectives for dystonia that students should be tested on. In addition a prospective cohort study design would enable us to determine the variance of knowledge that occurs over a given period, for example whether knowledge of the condition increases prior to exams compared to when students are not facing any imminent examinations.

CONCLUSION

Within its limitations, this study has flagged two important points regarding the knowledge and awareness of dystonia amongst medical students in their clinical years. Firstly, their overall knowledge and awareness of dystonia seems to be at an acceptable standard. Secondly, undertaking a clinical attachment in neurology or observing/clerking a patient with dystonia in a clinical setting does not add anything significant to the knowledge that medical students already possess regarding this condition.

Following these two conclusions we could suggest two ways of further improving their awareness and knowledge of this condition. First is to define certain learning objectives for dystonia that are inline with the standard that is expected for medical students and incorporate them into the syllabus. Second, students undertaking a neurology firm have at least one lecture on dystonia with a patient present (so-called problem based teaching) so that they can gain an idea of what the condition is and what it looks like. However due to the number of limitations within this study these suggestions could only probably be applied to the particular medical school within which this study was carried out and not to any other medical schools within the UK. In order to apply these two schemes nationally we would need to carry out a study involving a much larger number of students and medical institutions within the UK.

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