

# BMJ Open Complaints from patients with functional neurological disorders: a cross-sectional UK survey of why patients complain and the effect on the clinicians who look after them

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## ABSTRACT

**Objective** To evaluate the nature of complaints from patients with functional neurological disorders and understand the reaction of UK neurology consultants to receiving complaints from this patient group.

**Methods** A voluntary online retrospective survey was advertised to UK consultant neurologists. Questions asked about the nature of the complaint, how it was dealt with, how it affected their emotional well-being and attitude to work, and whether it influenced their clinical practice. Responses were anonymised. The frequency of responses and percentage of total responses were analysed.

Respondents were also given opportunities to add personal comments.

**Results** Responses from 58 clinicians were received. Patient disagreement with the diagnosis was a factor in 90% of complaints received. Only 77% of complaints were resolved within 6 months and 61% of clinicians received no feedback about the outcome. 31% of clinicians reported their most problematic complaint had an adverse effect on their mood. 67% of respondents changed their practice following the complaint with 59% investigating more frequently or due to perceived pressure from patients.

**Conclusions** Complaints from patients with functional neurological disorders appear to be primarily due to disagreement with the diagnosis. They are more difficult to resolve than other complaints, and clinicians who deal with them often become the 'second victim' in the process leading to potentially adverse effects on patient care. Strategies to tackle these issues are discussed.

## INTRODUCTION

In the UK, there is a mismatch between the fact that the rate of complaints has increased despite a decreased medical error rate. This is set against a backdrop of government initiatives to improve healthcare quality.<sup>1 2</sup> Understanding the purpose and use of the complaints process, its positives and any unintended consequences, is important. Reasons for complaints are wide ranging<sup>1 2</sup>: at one end of the spectrum complaints may highlight significant failings in the health service, while

## Strengths and limitations of this study

- This is the first study to look specifically at the reasons behind complaints from patient with functional neurological disorders and the secondary effects on clinicians.
- The questionnaire assessed in depth a wide range of details about the nature and duration of the effect of a complaint on clinicians.
- Participants were self-selecting and thus may over-represent clinicians who have been adversely affected.

at the other, the patient may disagree with an aspect of their care, but no objective evidence of clinical failure is found.

Currently in the UK, complaints are initially dealt with by local healthcare providers who investigate and try to resolve the issue. In England, if this process fails, the matter can be escalated to the Parliamentary and Health Service Ombudsman. The doctor may become caught in a situation of multiple medicolegal jeopardy as, regardless of the outcome of the complaints process, a patient may also initiate a medicolegal claim and refer a doctor to the General Medical Council (GMC— the UK body that licenses and regulates doctors). This may result in an investigation by the GMC and potentially a Fitness to Practice Tribunal hearing. Some doctors may also find themselves under public scrutiny in the media or investigated by their employer and also the police.

Major changes in the approach to patient safety and learning came into effect in the National Health Service (NHS) in 2009 following high-profile cases where significant failings in patient care had occurred.<sup>3–5</sup> It is generally considered that these have had a positive effect. However, for the

complaints component of these changes, studies examining the reaction of healthcare professionals have found that for many, receiving a complaint can have a negative impact on emotional well-being,<sup>6–10</sup> resulting in them becoming the ‘second victim’ in the complaint process.<sup>11 12</sup> Following complaints, clinicians are more likely to avoid high-risk patients and to display defensive behaviours known as ‘hedging’ tactics,<sup>6 8 9</sup> which ultimately may put patients at increased risk of harm and worsen patient care.

Understanding these factors is important because while complaints and medicolegal investigations are vital in highlighting areas of patient care that can be improved, the process uses a significant amount of NHS resources and therefore minimising any negative impact is essential. Following recent Parliamentary reports into the quality of complaints investigations,<sup>13–15</sup> strategies such as the ‘safe spaces’ initiative<sup>16–18</sup> will hopefully tackle some of these issues.

Previous studies<sup>6–10</sup> looking at the impact of complaints on healthcare professionals have sampled patients with a wide range of disorders from a variety of specialties. However, focusing on a particular patient group allows a more in-depth perspective, potentially highlighting specific areas of service provision where improvements can be made.

Patients with functional disorders (sometimes also referred to as medically unexplained symptoms) have symptoms that are caused by maladaptive functioning of one or more particular body system(s), without any underlying tissue or organ damage. In neurological practice, patients whose presentation includes at least a functional element make up approximately one-third of the workload.<sup>19</sup> Common presentations include dissociative attacks, functional weakness and functional movement disorders. Optimal management has advanced considerably in recent years, with the importance of making a positive diagnosis being key, rather than telling a patient what they do not have and perpetuating disability. Psychological and physical therapy is recommended.<sup>20 21</sup> However, awareness of functional neurological disorders among non-specialists and the general public is still relatively low.<sup>22</sup>

Patients with functional conditions tend to show more dissatisfaction with healthcare services,<sup>23–25</sup> and anecdotally, functional disorders feature prominently in some of the most problematic and involved complaints. However, there is a dearth of literature in this area.

The aim of this retrospective study was therefore to explore the complaints received from patients diagnosed with functional neurological disorders to understand (1) the nature of complaints from this patient group, (2) the emotional impact on clinicians and whether such complaints have any effect on their clinical practice, and (3) whether there are lessons that can be learnt to improve the care of patients with functional neurological disorders. Given recent UK Parliamentary reviews highlighting problems with the current system,<sup>13 14 16</sup> and

commitments to make improvements,<sup>15 16</sup> this work is timely.

## METHODS

An online questionnaire, designed by the authors, was included in the March and April 2016 copies of *Association of British Neurologists* newsletters. In addition, previous NHS England Clinical Network neurology leads were contacted by email and asked to disseminate information about the survey to local consultant neurologists. For our local Clinical Network area, neurologists were contacted directly by the first author. The online survey was open from March to September 2016.

Background information was gained about geographical location, duration of consultancy and experience in working with patients with functional neurological disorders. Regarding complaints, respondents were first asked how many complaints they had received from patients with functional neurological disorders in the previous 12 months. In order to ascertain an unbiased representation of the complaints from this patient group, respondents were asked to consider the most recent complaint they had received from a patient with a functional neurological disorder. Questions covered information about the nature of the complaint, time taken to deal with it, how far it was escalated, whether the media and/or GMC were involved, and whether they knew if the complainant was satisfied with the outcome (a copy of the questionnaire is shown in online online supplementary file).

To explore clinicians’ reactions to complaints, respondents were asked to consider the complaint from a patient with a functional neurological disorder that had caused them most distress during their career. Subsequent questions enquired about the effect of the complaint on their mental well-being and attitude to work. Respondents were also asked about any changes in clinical practice following the complaint. The questionnaire was initially trialled on two local consultant neurologists who gave feedback prior to being advertised nationally.

For each question, respondents were asked to select one or more options from a multiple-choice panel, with opportunities to expand on answers. Since it was envisaged that some clinicians might not answer every question, for each question, the total number of clinicians selecting at least one response option was calculated (described as  $n=x$ ). The frequency of responses to each option was then expressed as a percentage of the total number of clinicians responding to that question. Responses to each question are presented as frequency distributions. Further analyses of the data were not performed since the aim of the study was to provide a detailed description of the nature of complaints and the effect on clinicians rather than investigate associations between variables.

Respondents were never asked for any personal identification and were reassured that their answers would remain anonymous.

**Table 1** Frequency of the number of complaints received from patients with functional neurological disorders in the 12 months prior to the survey (n=55)

Number of complaints	Frequency of responses (%)
0	23 (42)
1	15 (27)
2	12 (22)
3	3 (5)
4	1 (2)
5	1 (2)

Neither patients nor members of the public were involved in this study.

### Patient and public involvement

Patients were not involved during the study and no patient details were collected.

## RESULTS

### Background

Sixty-four consultant neurologists accessed the questionnaire (corresponding to 9% of consultant neurologists in the *Association of British Neurologists* and 8% of all consultant neurologists in the UK). Six respondents did not respond to any of the questions, leaving 58 who answered at least one question and were included in the study.

Details of respondents' geographical location, duration of consultancy and experience in managing functional neurological disorders are shown in online supplementary table 1.

**Table 1** describes the number of complaints from functional disorders respondents received in the 12 months prior to the survey. The proportion of all complaints

that these make up are shown in online supplementary table 2.

### Why patients complain

When asked to consider the most recent complaint from a patient with a functional neurological disorder, out of 42 respondents, the most common reason by far was disagreement with the diagnosis. This was mentioned in 90% of complaints received. Dissatisfaction with investigations was frequently mentioned, as well as communication style of the consultant and lack of time (**figure 1**).

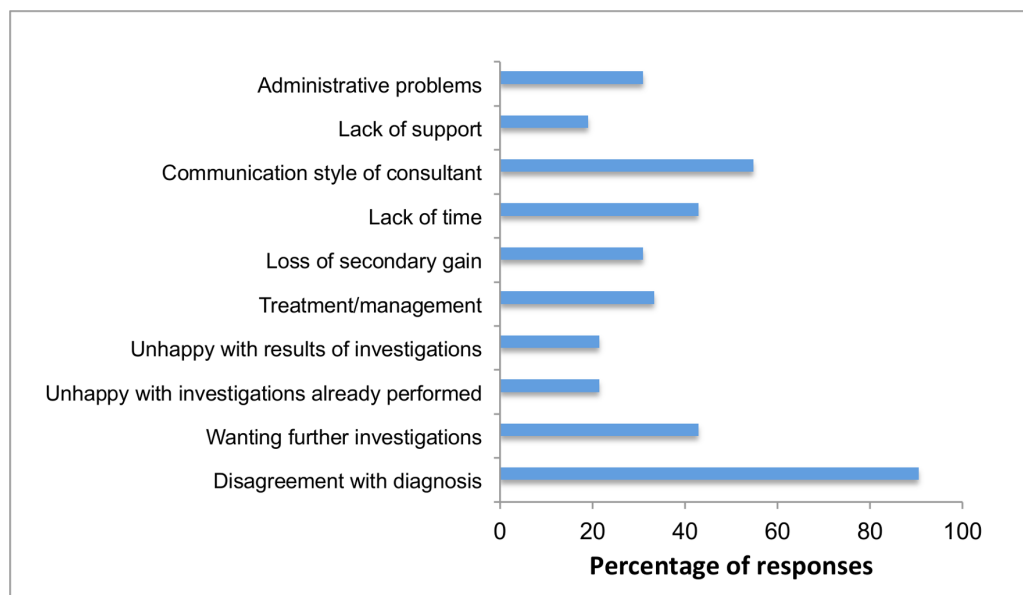
Respondents suggested that at least part of the reason for complaints is the fact that patients receive conflicting information, with general practitioners and/or clinicians from other disciplines often 'colluding' with the patient about the cause of their symptoms, and a 'lack of responsibility' among some in making a diagnosis of a functional disorder. Respondents suggested that this makes it difficult for neurologists to 'un-diagnose' patients who then become angry when they are told that their prior beliefs about the cause of their symptoms are incorrect.

### Dealing with the complaint: escalation and resolution

Details of how far the complaints were escalated are shown in **table 2**.

In 77% of cases, the complaint was dealt with within 6 months. However, 7% of cases took more than a year to resolve (online supplementary figure 1). Respondents felt annoyed at the time spent on dealing with the complaint, with one respondent feeling it was a 'waste of time'.

Out of 46 respondents, 61% did not receive any feedback about the outcome of the complaint. For those who were aware of the outcome (n=18), in 78% of cases patients were not satisfied with the outcome of the complaints process.



**Figure 1** Reasons for dissatisfaction mentioned in complaints (n=42).

**Table 2** Escalation of complaints and involvement of other organisations (n=47)

Escalation of complaint	n (%)
Written correspondence	34 (72)
Local resolution	9 (19)
Ombudsman	4 (9)
Involvement of other organisations	
GMC referral	2
Medicolegal claim	0

GMC, General Medical Council.

### Clinicians' reactions to receiving complaints

Many respondents described an 'inevitability' and a 'lack of surprise' at receiving complaints from patients with functional neurological disorders, with one clinician suggesting this was due to a 'defensive agenda' by patients and another suggesting it was part of a 'pathological behaviour pattern' causing them to 'jump to conclusions'.

Of 48 respondents, 58% thought the complaint was unjustified. Many clinicians explained they had already taken extra time and effort to explain the diagnosis and explore management options, and despite this, the patient still complained. Many felt the complaint was a personal attack, describing the complaint as 'vindictive', 'personally critical', and 'calculated to damage (my) reputation'. One respondent described the situation as 'irretrievable' once the patient had 'turned against you'. Some complaints apparently included false accusations against clinicians. Respondents described cases in which patients appeared manipulative, repeatedly complaining despite input from senior managers on a regular basis.

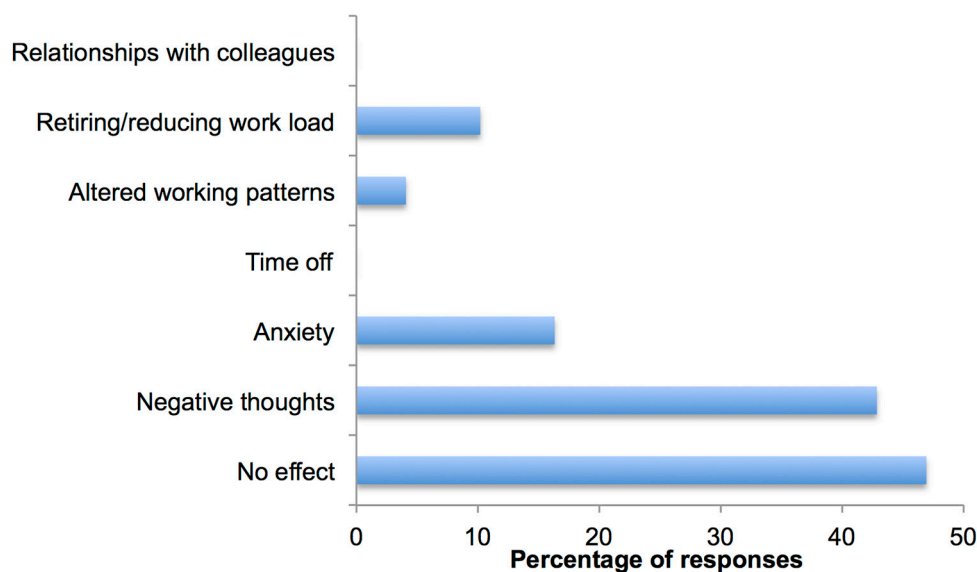
Regarding effect on emotional well-being, of 48 respondents, the majority reported no effect. However, 31% reported suffering from anxiety or depression following

the complaint (online supplementary figure 2). Others commented on a loss of self-esteem and feeling 'disillusioned'. In 45% of respondents (n=47), the complaint had a moderate or severe effect on emotional well-being (online supplementary figure 3). Of 34 respondents, 50% recovered from any negative effects on emotional well-being within days, but 18% suffered for months or years.

Effects of the complaint on attitude to work are shown in figure 2. Additionally, one respondent described how he/she had decreased their workload and limited requests for overbooking clinics; another described how they had considered leaving medicine 'more than usual'.

Of 48 clinicians, 67% (n=22) described changes in practice following their most recent complaint (table 3). The most common alterations were being more upfront with patients about the diagnosis and being more likely to refer patients to psychology. Moreover, 59% of those who had changed their practice (13/22 respondents) investigated more frequently or investigated if there was perceived pressure from patients.

Regarding follow-up, most commonly, respondents avoided follow-up or limited it to one further appointment. However, four respondents arranged more frequent appointments to avoid the patient seeking multiple clinical opinions with the risk of 'iatrogenic' harm and to allow the patient to 'close the book' on the diagnoses. Many respondents felt 'frustrated' and had feelings of 'despair' about the lack of effective or integrated psychological services for functional neurological disorders. One respondent explained they had received fewer complaints while working in a trust that did have an integrated neuropsychiatric service. Lack of national guidelines and knowledge among non-specialists about the diagnoses were also mentioned.



**Figure 2** Effect of the complaint on attitude to work (n=49).

**Table 3** Changes in practice made following complaints (n=22)

Type of change	Number of respondents
<b>Appointment length</b>	
Longer consultations	3
Tried but failed to alter appointment times	5
Adaptations to appointment times	4
<b>Explanation about diagnosis</b>	
More direct about diagnosis	16
Less direct about diagnosis	6
Leave diagnosis open	1
Use an appeasing diagnosis	0
<b>Investigations arranged</b>	
More	6
Fewer	9
Investigate due to pressure from patients	7
<b>Management</b>	
Arranging treatments that were not indicated	0
Low threshold to refer to neurology colleagues for second opinion	9
More likely to refer to psychology	15
Less likely to refer to psychology	2
<b>Follow-up appointments</b>	
More frequent	4
Avoid follow-up	5
Single follow-up	6
Unchanged	16

## DISCUSSION

This study is, as far as we know, the first to examine complaints from functional neurological disorders. The main findings were (1) that most complaints from patients were related to disagreement with the diagnoses or investigations rather than medical error; (2) that receiving a complaint had a substantial impact on mental well-being in a significant proportion of clinicians; (3) complaints from patients with functional neurological disorders can have a long-term negative impact on attitude towards work and clinical judgement, overall reducing quality of care for this group of patients; (4) there are problems with the current system of how complaints are dealt with.

### Nature of complaints from patients with functional neurological disorders

The study suggests that complaints from patients with functional disorders may be more difficult to deal with than complaints from patients with other conditions. First, a key observation from our study is that 90% of cases involved patients disagreeing with their diagnosis. Disagreement with the extent or results of investigations were other common issues, as well as lack of time given to their appointment,

and perceived manner of the clinician. These factors are comparable with those mentioned in previous studies of dissatisfaction among patients with ‘medically unexplained symptoms’,<sup>23–25</sup> and likely reflect anxiety at being given a diagnosis, which may challenge patients’ desire for a ‘medical’ explanation of their symptoms, frustration about receiving differing opinions regarding the cause of their symptoms, and disappointment in the availability and type of treatment options offered.

Second, respondents often commented that complaints from functional neurological disorders were more of a ‘personal attack’ than those from patients with other disorders and suggested underlying psychopathology may be a contributing factor. Mental health problems, which are more prevalent in functional neurological disorders compared with those without,<sup>26</sup> may generate maladaptive cognitive processing patterns.<sup>27–29</sup> This may partly explain why some patients have difficulty accepting differing opinions regarding the diagnosis and drive the emotionally laden character of complaints that clinicians describe.

Third, 9% of complaints were referred to the Ombudsman. This is higher than the overall frequency of complaints that the Ombudsman assesses (3%) or investigates (1.6%),<sup>1,30</sup> and concurs with the study’s finding that patients often remain dissatisfied even after receiving a reasonable explanation.

### Clinicians’ reactions to complaints

*Effect on mental health:* In line with previous work,<sup>6</sup> a significant proportion of respondents became the ‘secondary victim’ in the complaint process with long-lasting detrimental effects on mental well-being: in 45%, the complaint had at least a moderate effect on mental well-being. Anxiety and depression were reported in 31% of respondents, and in 18% of cases, effects were long lasting. These figures are similar to previous work.<sup>6</sup> However, 62% of respondents denied any detrimental effect on their mental health and 50% of clinicians recovered within days. Previous work highlights several factors influencing the response of clinicians after receiving a complaint.<sup>7</sup> Our study suggests specific influences that may help understand reactions to complaints from patients with functional neurological disorders. For example, respondents who are adversely affected may be particularly sensitive to personal criticism or ongoing patient dissatisfaction. Conversely, clinicians who are not significantly affected may find it easier to ‘externalise’ the cause for the complaint, reasoning that patient psychopathology and diagnostic confusion by other clinicians are more relevant than any failure on their part. Interestingly, those clinicians who received at least three complaints (n=5) were more likely to be moderately or severely affected than those who received fewer complaints (n=50; 80% vs 45%) and more affected by depression and anxiety (60% vs 25%). There was no difference in demographics or experience in dealing with this group of patients. These complaints were either settled by written correspondence or local resolution.

*Effect on working practice.* While there was significant variety in responses, defensive practice was more prevalent following a complaint, and some respondents reduced their workload or considered retiring. These reactions may adversely affect care for this patient group and ultimately have detrimental effects on neurological services as a whole.

Many respondents felt annoyed at the time taken for the complaint to be resolved. In our study, 23% of respondents waited longer than the suggested target of 6 months<sup>3</sup> despite the fact that many cases were felt to reflect patients' resentment towards the medical profession rather than highlighting any faults in the management of their condition.

### Managing complaints from patients with functional neurological disorders

There is little study of 'difficult' complaints outside of the psychiatry domain,<sup>31 32</sup> and within this literature, most of the studies are old, reflecting the sensitivity and caution when considering biopsychosocial factors in social processes such as complaining.<sup>32</sup> However, identifying 'difficult' complainants at an early stage and clarifying upfront whether the desired outcome is realistically achievable through the complaints system are suggestions that might limit escalating detrimental effects on both complainant and clinician.<sup>32</sup>

Within Government plans to improve the complaint process,<sup>14-18</sup> providing greater expertise at a local level is a welcome step that may enable local teams to better prioritise complaints where lessons can be learnt and minimise any secondary untoward effects on clinical behaviour. Categorising complaints, separating out those where all or part of the complaint is in disagreement with the diagnosis (if the correct diagnosis has indeed been made) and rapidly closing such complaints rather than engaging in complex diagnostic argument could be one simple and helpful move.

However, there are still concerns about how the Government's plans will be put into practice, as well as uncertainties about the future of complaints investigations both at the local and national levels.<sup>33</sup> How complaint handling fits in with wider reforms,<sup>13-18</sup> and the Government's aim of creating a 'learning not blaming' culture in the NHS,<sup>15 17</sup> is a work in progress.

Providing support for clinicians who are the subject of a complaint is something that psychiatry colleagues are already used to doing,<sup>34</sup> but needs developing in other specialties.<sup>7</sup> Help from colleagues, team debriefings about the systemic causes of any error, and timely involvement of professional psychological services can be beneficial.<sup>7 35 36</sup> The three-tiered model of second victim support<sup>37</sup> would be an excellent framework on which to base such a service.

### Management of patients with functional neurological disorders

Clinicians in the survey felt frustrated at the relative lack of service provision for patients with functional neurological disorders. These conditions are often under-recognised by non-specialists leading to delay in diagnosis, unnecessary investigations and increased patient anxiety.<sup>20 26</sup> Respondents suggested educational initiatives targeting

other medical professionals and inclusion of the topic in medical school curricula to reduce this problem. Furthermore, despite experts advocating specialist psychological and physiotherapy input,<sup>20 21</sup> often patients wait months or sometimes years for therapy with detrimental effects on prognosis.<sup>20</sup> Budget constraints and lack of awareness of the nature of the disorder among policy-makers mean this area may not be a priority for many commissioning groups (the NHS bodies that 'buy' services from providers). However, given the high prevalence of functional neurological disorders,<sup>19 22</sup> expanding services may reap long-term benefits.

The study has a number of limitations. First, it was retrospective so responses may have been tainted by recollection bias. Second, although responses were non-identifiable and confidential, clinicians may have been reluctant to fully disclose the impact of the complaint on their mental well-being and attitude to work. Third, respondents were asked to comment on their reaction to the complaint that had caused them most distress. The findings may therefore represent the extreme end of how neurologists react rather than reflect the variety of clinicians' responses. The respondents were a self-selected group, so the results may not reflect how neurologists as a whole react to complaints from this group of patients. Finally, the number of respondents was limited, and not all respondents answered all questions.

Future work should include comparative studies to explore further the suggestion from this study that there are differences in the type of issues mentioned in complaints from patients with functional neurological disorders compared with those from patients with organic pathology. Studies looking at the support networks for clinicians dealing with a complaint against them would be welcome. Following recent government initiatives to improve the complaints system, it will be important to examine whether changes lead to expected benefits in patient care and clinician well-being.

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**Contributors** CB designed the survey, collected and analysed the data, and is lead author for the article. PG proposed the idea for the article, provided advice on revising the content of the survey, the intellectual content of the article and presentation of the data, and helped proof-read the manuscript.

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**Competing interests** None declared.

**Patient consent** Not required.

**Ethics approval** Ethical approval was not required for this study because all participants were consultant neurologists who voluntarily chose whether or not to complete a questionnaire, the results of which were anonymised. Patients were not involved during the study and no patient details were collected.

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