

Title page

How do hospital doctors manage patients with medically unexplained symptoms:

A qualitative study of physicians

(Short title: Physicians approach to medically unexplained symptoms)

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Keywords

Medically unexplained symptoms, MUS, Somatoform disorders, Functional symptoms

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Funding

AW was funded by an NIHR In-Practice Fellowship. This report is independent research arising from an In-Practice Fellowship supported by the National Institute for Health Research. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research or the Department of Health.

Ethical Approval

Ethical approval was obtained from the North West London NHS Research Ethics Committee Reference number 11/H0720/3. Participants gave their informed consent before taking part.

Guarantor

MB is the guarantor.

Contributors

AW, MB and KW conceived and designed the study. AW conducted the in-depth interviews. All authors participated in data analysis and interpretation and contributed to drafts of the manuscript. All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

Acknowledgements

The study was sponsored by University College London. We would like to thank all the doctors who gave their time to be interviewed for the study.

Abstract

Objectives

Medically unexplained symptoms (MUS) are a common presentation in medical practice, and are associated with significant morbidity and high levels of service use. Most research exploring the attitudes and training of doctors in treating patients with unexplained symptoms has been conducted in primary care. This study aims to explore the ways in which doctors working in secondary care approach and manage patients with medically unexplained symptoms.

Methods

Design

Qualitative study using in-depth interviews and thematic analysis.

Setting

Three hospitals in the North Thames area.

Main outcome measures

Physicians' approach to patients with medically unexplained symptoms and their views on managing these patients

Participants

Twenty consultant and training grade physicians working in cardiology, gastroenterology, rheumatology and neurology.

Results

There was considerable variation in how the physicians approached patients who presented with MUS. Investigations were often ordered without a clear rationale and the explanations given to patients when results of investigations were normal were highly variable, both within and across specialties. The doctor's level of experience appeared to be a more important factor in their investigation and management strategies than their medical specialty. Physicians reported little or no formal training in how to manage such presentations, with no apparent consistency in how they had developed their approach. Doctors described learning from their own experience and from senior role models. Organisational barriers were identified to the effective management of these patients, particularly in terms of continuity of care.

Conclusions

Given the importance of this topic, there is a need for serious consideration as to how the management of patients with MUS is included in medical training and in the planning and delivery of services.

Introduction

Medically unexplained symptoms (MUS) are a common presentation in medical practice. In a study based across a variety of outpatient clinics in two London hospitals, around 50% of patients had not received a biomedical diagnosis for their symptoms three months after they were first seen (1).

Such patients often experience significant morbidity, with increased rates of anxiety, depression and impaired social functioning (2), and high levels of service use and investigation costs (3). The annual additional cost to UK health services of MUS was estimated in 2008-9 at £3 billion, including primary and secondary care use, accounting for approximately 10% of the annual NHS spending for the working age population. Taking into account quality of life and sickness absence, wider costs to the economy were estimated at over £14 billion (4).

There are a variety of possible approaches to the investigation and management of patients presenting with physical symptoms that cannot be adequately explained by a physical disease. Doctors may explore associated psychological, physical and social factors separately or may attempt to integrate them. There is consensus that repeated referral and investigation is not helpful, is likely to be costly and may lead to worse outcomes (5), although clinicians need to balance this with the risks of not detecting a disorder. Recognition of the potential for harm, and the significant cost implications of unnecessary tests and treatment, has led to international efforts to help doctors select appropriate investigations and interventions, such as the *Choosing Wisely* initiative in the USA (6). This encourages carefully considering the most clinically appropriate and cost-effective use of investigations, with implications for the management of MUS.

Most international research exploring the attitudes and training of doctors in treating these patients has been conducted in primary care with general practitioners (GPs)(7),(8). The attitudes of secondary care physicians to MUS have not previously been examined. This study aimed to explore the ways in which doctors working in secondary care approach and manage such patients.

Methods

Study design

Qualitative study with in-depth interviews.

Setting and participants

We approached consultant and training grade physicians working in cardiology, gastroenterology, rheumatology and neurology in three different hospitals in the North Thames area. These four medical specialties were identified from a previous study as having the highest prevalence of clinical cases with MUS (1).

Participants were purposively sampled from staff lists provided by the hospitals, aiming to achieve as wide a variation of views as possible across specialities, level of experience and setting. Participants' gender, ethnicity, and experience in other specialties were also monitored in order to achieve maximum diversity.

Data collection

A topic guide for the interviews was developed by the research team, informed by existing literature. We did not provide a particular definition for MUS, instead seeking to understand participants' own understanding of this issue. Interviews were conducted until saturation on key themes was reached, which occurred after twenty interviews. In recognition of the time spent being interviewed we offered a book token to participants. Written informed consent was obtained from all participants prior to conducting the interview. The interviews were all conducted by one researcher (AW), at the participants' place of work, and lasted for an average of 45 minutes. Interviews were conducted by a doctor, this aimed to maximise participants' willingness to share their views on this issue. Interviews were recorded and transcribed verbatim.

Analysis

The study team was comprised of three academic general practitioners (AW, KW and MB) and one social scientist (KL), with experience in qualitative research and a particular interest in this topic. All members reviewed each transcript independently. A thematic framework was developed and agreed by consensus, identifying key issues, concepts and themes. Data from the interviews was organised using Microsoft Excel charts and analysed using the 'framework' approach, identifying key themes and their meanings. (9). Data were analysed comparatively and disconfirming evidence searched for. The analysis and interpretation remained grounded in the data at all times (9).

Results

In-depth interviews were completed with twenty physicians; 11 consultants and 9 specialty trainees (see Table 1). All worked at least 50% of the week in NHS clinical practice and all were involved in teaching medical students. Trainees were engaged in further training in their particular specialty and all were at their third year of specialist training (ST3) level or above. All participants worked in outpatient clinics, ranging from one to four clinics per week. 32% of physicians invited to participate responded, with no apparent difference in specialty, grade and gender of non-responders as compared with those interviewed.

<Table 1 here>

The physicians interviewed described examples of patients presenting with unexplained symptoms which varied according to specialty (see Box 1), the impact of managing such patients on themselves, their views about their role, strategies for carrying out investigations and for providing explanations, and perceived barriers to effective management.

<Box 1 here>

All the doctors interviewed recognised that presentations with unexplained symptoms were a significant part of their workload. Most estimated that they saw at least one or two such patients in any routine outpatient clinic. Several doctors, from all specialities, described mixed presentations of symptoms that were partly explicable by organic pathology and partly unexplained.

Clinician attitudes and approach

Doctors' perceptions of their role when dealing with such patients varied considerably and there was a range of attitudes relating to the impact of working with patients with MUS. These had often been formed over time and there were clear associations with the level of experience of the clinicians. Most spoke of finding such patients challenging, but this could be in either positive or negative ways.

Some participants who found managing patients with MUS exhausting described them as very time-consuming. Several doctors in training, as well as a few consultants, felt unsatisfied or frustrated at times when they felt unable to treat patients effectively.

Challenging perhaps because it doesn't fit the medical mould... It's harder when it's normal [results] and yet they've still got symptoms, which you can't explain away through a medical process. [Cardiology Registrar 1]

Some felt that their role as a specialist was to exclude causes for a patient's symptoms only relating to their own specialty, and not necessarily to go beyond that. This view was held by doctors from a range of specialties and experience.

I see my main function in the heart clinic as reassuring that it isn't coming from their heart and that it isn't something life threatening, rather than telling them exactly what it is. [Consultant Cardiologist 2]

Several respondents talked about the importance of providing reassurance and many spoke about the importance of building a relationship, developing trust and making sure patients felt their concerns were heard. These were mostly more experienced doctors from all specialties:

I think the key is to have a trusting relationship with the patient, that they're confident, they're happy that you have their best interests at heart. That you're looking at and believing them. [Consultant Gastroenterologist 1]

A distinct group of three more experienced doctors found dealing with such patients a positive challenge. These doctors also perceived difficulties in managing patients with MUS, but said they found it rewarding.

I like them. I think it's a challenge actually...managing them over quite a long period of time you can, you feel as if you're achieving something ...

[Consultant Rheumatologist 3]

These senior consultants considered they had developed particular expertise in working with such patients and so would be likely to 'attract' them or have them referred for advice.

How doctors develop their approach

When asked how they had developed their personal approach to managing patients with MUS, the doctors described a variety of influences. Most commonly, they spoke of learning by example from colleagues they had observed practicing:

You develop it over time through positive and negative role models, what to do and what not to do. [Neurology Registrar 2]

Several more experienced doctors described a process of trial and error and of learning from their own mistakes, with time being important in allowing experience to develop. Almost all those interviewed recalled receiving very little or no teaching about this topic in undergraduate or postgraduate training and relying on informal or 'on the job' experience:

Nobody's ever taught me this. This is all stuff that I've pretty much, it's unstructured and it's pretty much what I've learnt as I've gone along. [Gastroenterology Registrar 3]

Doctors in training posts said they rarely had the opportunity to observe their seniors consulting in outpatient clinics and that they themselves were very rarely observed in clinic as part of their training:

I don't think I've ever been taught anything in an out-patient clinic directly. I might have gone to present a patient to the consultant, but no one's actually sat and watched me consult. No one has shown any interest in my consulting technique.

[Cardiology Registrar 4]

All the clinicians reported receiving no feedback on the effectiveness of their approach to managing patients with MUS and many considered they would find this very useful.

Rationale for Investigations

The doctors described considerable variations in their approach to the investigation of patients presenting with MUS, giving different reasons for their actions, but with a general emphasis on ordering a range of investigations and then discussing the results with the patient rather than being more selective at the outset.

“Standard tests” for all

Some clinicians had a blanket approach to the initial investigation of patients

Everybody gets a full panel of blood tests as standard. And then brain imaging, depending on what we’re looking for... EEG... and so on. [Neurology Registrar 5]

Taking the patient seriously and facilitating further management

[Testing] clears the deck for, in my view, an adult exchange of views where their various concerns, their expectations, their ideas can be systematically examined and discussed [Consultant Gastroenterologist 8]

Providing reassurance for patient, and/or for doctor

I think whether or not you do a test on a patient, to a small degree, is driven by how much a patient needs the reassurance. [Cardiology Registrar 1]

Concern about missing organic pathology

Several of those interviewed, particularly more junior ones, indicated that they were likely to arrange more investigations for patients with unexplained symptoms because of their fear of missing significant organic pathology

... you always do more tests ...you do every test you can think of to make sure you’re not missing anything. People I think are functional cause a great deal of anxiety because I’m nervous about the fact that I think they’re functional and I’m very worried that I’m just missing something. [Neurology Registrar 6]

Threat of litigation

This fear of missing an organic diagnosis was compounded by the perceived threat of litigation if an organic diagnosis was missed

I over-investigate the vast majority of these patients. The number of times I've actually found an abnormality... really minimal...I think if we were in an era where the lawyers weren't so prominent, you know, advertising their services for patients who come out of A&E and that kind of thing, then I probably wouldn't be so defensive.

[Consultant Rheumatologist 7]

Negative aspects of investigations

Several of those interviewed also discussed the potential for negative consequences from performing investigations. For example, that organising tests to reassure the patient could in fact generate more anxiety, particularly where scans revealed incidental findings

...if patients get a lot of tests and just by statistical chance they will have an abnormality... [Consultant Neurologist 5]

They described sharing with patients in advance that tests could be potentially dangerous and unnecessary and that there were limitations on what could be tested for. Some also highlighted the potential for wasting resources.

...you've got to have a strategy ... at some stage be quite firm and say, 'I don't think I want to do any more tests. I think they are unnecessary. I think potentially they're dangerous, every test has a risk. [Consultant Cardiologist 9]

Types of explanations used

Those interviewed described using various strategies to explain what they considered the problem to be, possible underlying mechanisms and ways of taking things forward. We have divided these into three main categories:

Reassurance / Normalising:

Many told patients directly that the cause for their symptoms was unknown, some mentioning the current inadequacies of medicine to provide an explanation. This approach was particularly taken by trainees.

I'm sure you have that symptom but we can't explain it. What we do know is it's not something worrying or dangerous or life threatening...And it's something that I think we can manage conservatively. [Rheumatology Registrar 7]

Physiological / Mechanistic:

Explanations of biological function were frequently given, by both consultants and trainees, aimed at helping patients understand how the potential cause of their symptoms. The doctors aimed to put their symptoms into a context which the patient could understand, for example describing normal responses to stress and hyperventilation. A few mentioned checking the patient's understanding of this explanation. Some made use of leaflets or drew diagrams:

Enabling and improving function

Several clinicians of different levels of experience described using explanatory strategies which aimed to incorporate the importance of promoting functional recovery, helping patients to achieve control over their symptoms

...we've looked at the nerves and the electrics and all the messages are getting through. ...and I always couch it in a positive way...We have to find a way in order to get you to make your leg work again. [Neurology Registrar 4]

Those doctors who had described their role as mainly to exclude organic pathology tended to describe giving normalising explanations and trying to provide reassurance. This was also the case for doctors in training who had mentioned finding such consultations challenging.

However, interviewees who had described finding such patients a positive challenge and those who felt they had developed particular experience in the area tended to describe giving more physiological or enabling explanations. In particular, neurology consultants and trainees reported using enabling explanations, mentioning concepts of relearning, retraining and adaptation.

Barriers to effective management of patients with MUS

Several doctors contrasted their ideal approach to managing these patients with the realities of their current outpatient practice, which they felt impacted negatively in many cases.

Time pressures

Limited time in out-patient settings to form effective relationships with patients was seen as a particular problem

These patients take time...To treat them properly you need to give them more time than anybody else. You need to develop a relationship with them.

[Neurology Registrar 1]

Lack of continuity

Doctors in training particularly found it difficult to see the same patient more than once, so they would have little idea about longer-term patient outcomes.

...the difficulty being a registrar in the NHS is.. you rotate through various clinics, so I will not have a longstanding relationship with this patient, which is extremely unfortunate because I can't really take it any further [Neurology Registrar 2]

Patients were frequently seen once in a clinic and then discharged back to their GP with their results, without having any specialist review to explain any negative results, which they would only hear about by letter or telephone call. This was perceived as a problem in managing such patients.

Limited management options

Some clinicians described a lack of effective therapeutic options. Access to psychology and liaison psychiatry was limited, and even where available several doctors mentioned difficulties in broaching the idea of involving a psychologist with patients.

Discussion

The physicians interviewed identified patients with medically unexplained symptoms (MUS) as forming a significant part of their workload. There was considerable variability in how the doctors approached these patients and their level of experience appeared to be a more

important factor in their investigation and management strategies than their medical specialty. The exception was neurologists, who tended to give enabling explanations at all levels of experience. There was a general tendency to order batches of investigations, although the reasons given varied. Physicians reported little or no formal training in how to manage such patients, with no consistency in how they had developed their approach. Doctors described learning from their own experience and from senior role models. Organisational barriers were identified to the effective management of these patients, particularly in terms of continuity of care.

Comparison with existing literature

Many of those interviewed found the management of patients with MUS challenging, and for some doctors in training this was a source of considerable anxiety, particularly around missing serious pathology. These findings are similar to previous work with GPs (8), and GP trainees (10). However, a recent study of patients seen in a variety of secondary care settings found that in 120 cases diagnosed as having bodily distress syndrome (another term for MUS), none had been wrongly diagnosed, although five had comorbid medical problems which had not been optimally managed (11). A recent study exploring medical student attitudes also found a lack of formal training in MUS, and senior role models to be influential in shaping students' attitudes and approach (12).

Patients' presenting symptoms varied according to specialty, although with some overlap in areas such as pain and fatigue, consistent with other studies (13),(14). Several doctors interviewed highlighted the importance of attempting to understand the patient's expectations, as in a recent review of the literature on effective communication with patients presenting with MUS (15).

Investigations were initiated for a variety of reasons, and might be as much because of doctors' own anxiety about the consequences of missing an organic diagnosis as for clinical indications. While negative results are commonly considered reassuring to patients, a recent systematic review found this may not be the case (16) and that for symptoms with a low risk of serious illness, diagnostic tests do little to reassure patients or reduce anxiety in either the short or long term.

Defensive medicine and fear of litigation affecting clinical practice are widely recognised, as is the potential for incidental findings causing new anxieties for patients as mentioned by several respondents in our study (17). Detsky proposes that clinicians should promote the appropriate use of 'restraint' with investigations and consider all their potential consequences, including iatrogenic harm. He argues that, senior clinicians are well placed to do this and to demonstrate the appropriate use of restraint (18).

Those interviewed described using a variety of explanations to account for patients' symptoms, with several participants suggesting the use of 'empowering explanations' which have been found to be well received by patients (19). However others, in particular doctors in training, reported offering more limited explanations, i.e. giving feedback about negative findings, but without giving any further explanation for the symptoms experienced. The approach of these doctors was consistent with a previous study of physicians that found less patient-centred communication in MUS cases (20).

Strengths and limitations

This is the first study we are aware of exploring the views of hospital physicians across different medical specialties about managing patients with MUS. There was the potential for selection bias with the sampling strategy used, and doctors with a particular interest in this topic may have been more likely to respond to an invitation for interview. There were two experienced clinicians who participated in the study, who stated a special interest in this area. However, a purposive sampling strategy aimed to maximise diversity across experience, setting and demographic characteristics within four medical specialties with a high prevalence of MUS. There was deliberate probing for negative attitudes, and participants expressed a wide range of views. Participants were aware that the interviewer was a doctor, and this may have influenced the attitudes and experiences that they shared. It is possible that doctors who declined to participate have views not represented here.

Meaning and Implications

Inconsistencies in the approach provided by different clinicians risks patients being given contradictory messages and potentially losing confidence in their doctors. A number of experienced consultants were identified who found managing such patients a positive challenge and who felt they had developed effective management strategies, with providing some continuity of care considered important. This needs to be explored further and assessed with objective data on patient outcomes.. However, with the arrangements for clinics and training described, it is unclear how such experience can currently be passed on to colleagues and trainees in any consistent or reliable way. It is potentially beneficial for junior doctors to have the opportunity to observe their seniors consult, to be observed themselves and to receive feedback from both colleagues and patients.

There appeared to be little consistency of approach to such patients, either within or across specialties, and few of the doctors reported receiving any formal training in this area, with a brief mention in a lecture at the most. Given the associated patient morbidity and functional impairment, with the resulting cost implications, serious consideration needs to be given to including the topic in the training and continuing professional development of all doctors. Such training should be provided in an evidence-based and consistent way and the impact on patient outcomes assessed.

We also need to improve our understanding of the perceived indications for the ordering of investigations and recommendations for referrals and interventions , as there is clearly currently considerable variability in current practice, often without a clear underlying rationale. This is particularly important given the potential harm from unnecessary investigations, , as well as the considerable healthcare costs .

Many interviewees identified the current organisation of outpatient clinics as making managing patients with MUS more difficult. In developing models of care, the importance of continuity and the longer term benefits of investing sufficient time to ensure patients receive satisfactory explanations for their symptoms needs to be recognised.

Conclusions

Patients with MUS experience significant morbidity and have high levels of service use and associated health expenditure. Our study reports very variable approaches to their investigation

and management. There is a need for serious consideration of how the management of patients with MUS is included in medical training, and in the planning and delivery of services.

Table 1 – Participant Characteristics

Participant Characteristics		
Specialty	Neurology	5
	Cardiology	5
	Gastroenterology	4
	Rheumatology	6
Hospital	A	6
	B	8
	C	6
Gender	Female	8
	Male	12
Grade	Consultant	11
	Trainee	9
Years post-qualification	Less than 10	5
	10 to 19	8
	20 to 29	5
	Over 30	2

Box 1 Examples of unexplained symptoms reported by specialties

Examples of unexplained symptoms reported by specialties

Gastroenterology

Abdominal pain, nausea, constipation

Rheumatology

Chronic or generalised pain syndromes, Fibromyalgia

Cardiology

Chest pain, palpitations

Neurology

Non-epileptic seizures, weakness, paralysis, movement disorders, sensory disturbance, dizziness, non-organic blindness, loss of consciousness.

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