

What's 'difficult'?
**A multi-stage qualitative analysis of secondary care
specialists' experiences with medically unexplained symptoms**

Anke Maatz*, Megan Wainwright*, Andrew J. Russell, Jane Macnaughton, Yan Yiannakou

*both authors have made equal contributions to this manuscript and share first-authorship

Department of Psychiatry, Psychotherapy and Psychosomatics, Psychiatric
University Hospital, Zurich, CH-8032, Switzerland
Anke Maatz
Postdoctoral research fellow

Division of Social and Behavioural Sciences, School of Public Health and Family
Medicine, University of Cape Town, Cape Town, 7925, South Africa
Megan Wainwright
Postdoctoral research fellow

Department of Anthropology, Durham University, Durham, DH1 3LE, United
Kingdom
Andrew J. Russell
Reader

Centre for Medical Humanities, Durham University, Durham DH1 1SZ, United
Kingdom
Jane Macnaughton
Professor

County Durham and Darlington NHS Foundation Trust, Durham DH1 5TW,
United Kingdom
Yan Yiannakou
Professor

Correspondence to: A Maatz anke.maatz@puk.zh.ch

Abstract

Background

The term 'difficult' is pervasively used in relation to medically unexplained symptoms (MUS) and patients with MUS. This article scrutinises the use of the term by analysing interview data from a study of secondary care specialists' experiences with and attitudes towards patients suffering from MUS.

Design

Qualitative design employing semi-structured open-ended interviews systematically analysed in three stages: First, data were analysed according to the principles of content analysis. The analysis subsequently focused on the use of the term 'difficult'. Iterations of the term were extracted by summative analysis and thematic coding revealed its different meanings. Finally, alternative expressions were explored.

Setting

Three NHS trust secondary care hospitals in North-East England.

Participants

17 senior clinicians from seven medical and two surgical specialities.

Results

Unsolicited use of the term 'difficult' was common. 'Difficult' was rarely used as a patient characteristic or to describe the therapeutic relationship. Participants used 'difficult' to describe their experience of diagnosing, [explaining](#), communicating and managing these conditions and their own emotional reactions. Health care system deficits and the conceptual basis for MUS were other facets of 'difficult'. Participants also reported experiences that were rewarding and positive.

Conclusions

This study shows that blanket statements such as 'difficult patients' mask the complexity of doctors' experiences in the context of MUS. [Our](#) nuanced analysis of the use of 'difficult' challenges preconceived attitudes. [This can help counter the unreflexive perpetuation of negative evaluations that stigmatize patients with MUS, encourage greater acknowledgement of doctors' emotions, and lead to more appropriate conceptualizations and management of MUS.](#) ~~This can help counter the unreflexive perpetuation of negative evaluations that stigmatize patients with MUS, encourage greater acknowledgement of doctors' emotions, and improve doctors' confidence.~~

Introduction

It is common in medical practice that people consult for symptoms that elude medical explanation. In the U.K., this phenomenon is currently referred to as 'medically unexplained (physical) symptoms' (MUS) [1], yet the term is contested and a plethora of competing terms exist, e.g. somatisation disorder, somatoform disorder, abnormal illness behaviour or functional symptoms [2]-[7]. The terminological heterogeneity not only mirrors the fact that such conditions often fall between specialities [8], but also reflects the lack of agreement about the conceptual basis of this phenomenon [9]-[11]. This is especially the case regarding questions about mind-body interaction [12]. Some general guidance on clinical management is available [13] - [15] and NICE-guidelines exist to inform treatment for some specific conditions which are included in the MUS-spectrum (on irritable bowel: [16]; on chronic fatigue: [17]). Yet overall, support for doctors to address the specific needs of MUS patients is still in need of enhancement.

In conjunction with this, the doctor-patient interaction is commonly perceived as problematic, marked by mutual dissatisfaction and misunderstanding [19] - [26]. 'Difficult patient', 'problem patient' [27] or 'heart sink' patient [28] all emerge in the literature on MUS. The word 'difficult' is commonly used when describing MUS patients, for example "physicians often perceive patients with MUS as difficult, frustrating and demanding" [29], and "many of these patients are perceived to be difficult, complaining, and to have inflexible attitudes about their symptoms" [30] (p. 704), while GPs are said to need more training "in the area of managing this difficult group of patients" [31] (p. 182). Such negative preconceptions about MUS patients exist even amongst medical students [32].

The shorthand 'difficult patient' is by no means solely used in relation to MUS and MUS patients, but is part of established medical jargon. Several published books feature this expression in their titles [33] - [37]. In these, MUS patients are either referred to directly with this label, or indirectly by referring to characteristics said to be typical of these patients. For example, high utilisation of health care services and diverging disease concepts are mentioned as accounting for doctor perceived difficulty [38] - [40]. This is interesting because it demonstrates that the intersection between 'difficult patient' and 'perceived difficulty for the physician' emanates, in part, from the conceptual basis and service context for these conditions. Often, it remains unclear if the term 'difficult patient' refers to the patient themselves, or to their 'case' or condition. A difficult case or condition points to difficulties that the physician experiences vis-à-vis the role of treating a person consulting for MUS. In articles, reviews and editorials about MUS, the difficult case or condition is commonly referred to in a beginning or concluding statement about their challenging, difficult, or frustrating nature. Typical examples are "this is a clinically, conceptually, and emotionally difficult area." [41] (p. 336), "MUS are challenging to treat and can be frustrating for primary care physicians to address and manage" [5] (p. 664), and "there are a number of characteristic features of MUS that make them particularly difficult to handle scientifically." [9] (p. 2).

The problem with the pervasiveness of the label 'difficult' being associated in a blanket way with all aspects of MUS, is that it has so far concealed the more complex, multi-level structure of difficulties encountered by doctors with regards to MUS patients. Apart from the difference between difficulties experienced by the doctor and those perceived as within the patient, uses of the term do not clearly distinguish between difficulties at different levels - conceptual, clinical and emotional [41]. This confusion is problematic [42], stigmatising and can easily work - as Nimnuan et al. [43] show - to the patient's disadvantage.

Taking seriously the common conceptualization that this is a 'difficult' area of medicine, or a 'difficult' group of patients means that qualitative research which gives voice to the subjective experiences of health professionals is clearly needed. This is important not only for understanding 'the problem' from health professionals' own perspectives in their own words, but also for exploring possible ways of improving these experiences. Some research has already focused on general practitioners [44] - [52], [31] but there is a significant gap when it comes to specialist clinicians despite the fact that MUS make up 30% to 53% of consultations in secondary care [1]. To address this gap we carried out a qualitative interview study with specialists to explore their experiences of and attitudes towards MUS and the patients who present with them. Drawing on the notion of 'difficult', we examined their own use of the term as an innovative analytic strategy for uncovering the multiplicity of meanings underlying the pervasive use of this expression. To the best of our knowledge this is the first empirical study to explore the notion of 'difficult' in relation to MUS.

Methods

Aim of the study

This study aims to fill a gap in the physician-perspective research literature on MUS by (i) identifying what areas of MUS and care for MUS patients secondary care specialists' perceive as problematic, (ii) analysing the structure of the perceived problems, teasing apart different facets of difficult (iii) informing the design of training programmes.

Research Site

The study was conducted on three sites of an NHS trust in the North-East of England including one teaching hospital.

Participants and recruitment

We used a purposive sampling strategy to recruit specialists from different areas of medicine. Consistent with 'purposive' or 'selective sampling' [52], based on the study's aims and the project's timeline, an approximate sample size of 15 was appropriate. AM personally approached senior clinical staff with a letter inviting them to participate. The letter explained the design and overall aim of the study without mentioning that any aspect of the analysis would focus on language use.

Some of the staff were known to AM previously from 8 months of clinical work and participant-observation in the clinic, but most of them were not. None refused participation, yet in some cases a suitable interview date could not be found. We attempted to approach at least one participant from each of the major medical and surgical specialities formally represented in the trust to achieve our intended sample-size.

In total, we recruited 17 clinicians, 16 of them consultants, one a senior registrar. Five were female, 12 male; their average work experience (time since qualifying) was 24.71 years (range 11 to 41 years). They were drawn from seven medical specialities (gastroenterology, respiratory medicine, cardiology, rheumatology, geriatrics and pain management) and two surgical (colorectal surgery and orthopaedic surgery).

Data collection

AM carried-out one semi-structured, open-ended interview with each clinician. Interviews took place in August and September 2012 and were held in private, in clinicians' offices or in a seminar room.

Flexibility of interviews enabled participants to answer freely in their own words and to direct the interview to topics not included in the interview guide [53]. To start with, participants were asked to tell an exemplary case study from their practice. From this they were encouraged to talk about their personal experiences and views. Topics included their perception of and communication with patients, their explanations of the conditions, their therapeutic approach and their suggestions for how to improve care (Figure 1). Interviews were digitally voice recorded and lasted 29 minutes on average (range: 23 to 39 minutes). Notes were taken if and when informal conversation occurred.

QUESTIONS and SUB-QUESTIONS
1) Tell me about a patient whose complaints you couldn't explain. → What made you think it was functional? → I take it that you see a lot of patients with so-called medically unexplained symptoms. Why did you choose this particular patient?
2) What do you think is going on with this patient? → Has your understanding changed over time? → What do you think the patient thinks is going on?
3) Patients often ask for an explanation of the discomfort they feel. What would you say to this patient?
4) What do you think this patient needs? → What do you do for this patient?
5) How do you feel about this patient?
6) How does this patient make you feel?
7) What is the interaction with this patient like?
8) Is there anything you would have found helpful with this patient?
9) Is there anything we've missed or not talked about that you would like to add?

Figure 1: Semi-Structured, Open-Ended Interview Guide

Data analysis

The interviews were transcribed verbatim and transcripts analysed systematically following the principles of content analysis [54]. Content categories were derived directly from the data [55]. The process of analysis can be described as iterative or hermeneutical proceeding in several rounds [56]. All transcripts were read multiple times by AM and MW. On the basis of three sample interviews, a hierarchical coding scheme was developed grouping codes into thematically descriptive and higher-level interpretative codes. This scheme was agreed by all authors before AM applied it to all the interview data. MW co-coded a selection of interviews in order to strengthen interpretation in a qualitative sense by in-depth, interdisciplinary discussion of emergent themes. Rather than member-checking by returning transcripts to participants, a report of the preliminary results of the content analysis was sent to all participants for feedback.

Building on the content analysis, a summative analysis was performed [57]: Transcripts were searched for the term 'difficult', and data segments containing the word were extracted and analysed for emergent themes. The analysis also took into account how the adjective 'difficult' and associated nouns 'difficulty' and 'difficulties' emerged alongside other expressions like 'challenging', 'frustrating', 'hard' and 'tricky'. We considered the focus on 'difficult' appropriate based on its use in the literature and its frequency in interview transcripts compared to other terms. As a crude yet revealing comparison, 'challenging' had two mentions by one participant, 'frustrating' had nine mentions by three participants, 'hard' had 18 mentions by nine participants, and 'tricky' had three mentions by three participants. In contrast, 'difficult' had 102 mentions by 16 participants, 'difficulty' had four mentions by four participants and 'difficulties' appeared once. 'Difficult' was also mentioned by the interviewer (17 times) and 22 times by participants directly following its use by the interviewer; all other instances were produced spontaneously. This unsolicited prevalence (80 times) points to the significance of this term in describing experiences in this area of medicine. The interview guide did not contain any direct questions about 'difficult' or 'difficulty'. Participants were asked to recount exemplary case studies and to speak generally about their experiences and attitudes. 'Difficult' therefore was generally embedded within these narratives in an unsolicited way.

In the third phase of the analysis, terms clinicians used to describe patients and their interactions with patients, and terms they used to describe their emotional response to patients were extracted from the initial content analysis ~~and coded~~ codes 'patient characteristics and attitudes', 'patient communicative behaviour' and 'doctors' emotional response'. These were inputted to the free software *Wordle* [58]. *Wordle* weights words by frequency of mention to produce visual representations or so-called word clouds [59]. This is a common form of data-representation in many qualitative software programmes including QSR International NVivo10 [60]. In a word cloud, the relative frequency of mention is represented by font size. The position of the words is arbitrary. The word counts,

on which the relative font size of words in the word cloud is based, are provided in the supplement section.

Findings

This section reports findings from the summative analysis of 'difficult', followed by the analysis of alternative ways of describing patients with MUS and interactions with them. Quotations from interviews are in italics.

Meanings of 'difficult'

In the following paragraphs, we unpack the notion of 'difficult' by considering the range of its attributions and what the context of these attributions tells us about its meaning. All of these 'difficulties' are the participants' i.e. doctors' notions of 'difficult' solely reflecting their perspectives and experiences.

Unspecific blanket statements

In some instances, 'difficult' was used as a blanket term, e.g.

They can be quite difficult patients to deal with (P15, consultant colorectal surgeon)

Here, the term 'difficult...to deal with' leaves it unclear whether 'difficult' is intended to describe patients' personal characteristics, features of the doctor-patient interaction or whether it refers to the (medical) management of the patient's condition as experienced by the doctor. While such use was observed, it was rare compared to the more specific uses detailed below.

MUS patients as difficult persons?

In some instances, participants spoke of 'difficult patient(s)' or referred to MUS patients as a 'difficult group of patients'. Linguistically, this usage attributes 'difficult' to a person thus suggesting it is a characteristic inherent to the patient:

... generally speaking during training years it is a difficult group ... patients were time wasters who we can't help who are difficult to get through ... (P14, consultant gastroenterologist)

I think you have got to give people extra time when they are proving to be difficult patients and not answering your questions; you have got to be persistent and manage to break down the barriers to find out why they are refusing to give you information, for example (P4, senior registrar in colorectal surgery)

While at first reading this seems a fairly unequivocal and pejorative attribution of the term 'difficult' to patients, contextually speaking, 'difficult' in the above quotations does not seem to be used as a patient characteristic, but is either an

evaluative term reflecting the doctor's perspective (*'patients were time wasters'*), or the quality of the interaction with the patient (*'refusing to give you information'*).

Difficulty experienced by the MUS patients having difficult lives

Sometimes participants used 'difficult' or 'difficulty' to describe what they thought patients experience as precursors or consequences of their condition. These could be bodily consequences like *'difficulty opening their bowels'* (P11, consultant colorectal surgeon), social consequences like a patient finding it *'difficult to have a social life'* (P8, consultant gastroenterologist), but also emotional precursors like *'difficult childhoods and difficult relationships'* (P15, consultant colorectal surgeon) which might have been causally related to the condition.

Another context in which patients were reported to experience 'difficulties' was in coming to understand their condition:

... patients may find it difficult to understand that, although by the time they come and see me they have often learned this, but they may find it at first difficult to understand that this is an illness for which we have no diagnostic tests, for which we have no proper treatment, for which we have no proper understanding ... (P6, consultant respiratory physician)

This quotation, whilst relating to patients, points to some of the areas of difficulty that doctors mentioned experiencing, namely understanding and explaining MUS, i.e. difficulties emerging at the interface of the condition and the communication and interaction about it.

Doctors' difficult task difficulty experienced by doctors

In the vast majority of cases, 'difficult' was attributed to a specific aspect of doctors' perceived roles and tasks vis-à-vis the patient and her/his condition in the context of the health care system they work in. Linguistically, this was often expressed using the construction 'difficult to...'. Seven interrelated themes emerged which are presented here in the chronological order of their occurrence in a typical consultation.

1. Difficult to diagnose

Difficulty was reported to result from the uncertainty of diagnosis:

I think it is quite difficult because it's not like all, you know, cancer or other sorts of common conditions that you can actually say 'yes, this patient has got this', which is a lot easier from a diagnostic point of view than someone with functional symptoms. (P15, consultant colorectal surgeon)

Differentiating MUS from other conditions was perceived as particularly difficult:

I think one of the biggest groups is the non-cardiac chest pains, they are often people who have definitely had cardiac chest pains, and they are very difficult sometimes for the patient and the doctor initially to decide is it cardiac or is it not? (P9, consultant geriatrician)

2. Difficult to make sense of

The absence of a satisfying explanation of MUS conditions in terms of current medical theory was often described as 'difficult'.

Some of the more disease issues, like fibromyalgia are obviously a little bit more difficult to work through because all it is really saying is probably we don't really understand what is going on. (P7, consultant orthopaedic surgeon)

The medical knowledge currently available e.g. on pain pathways was also described as 'difficult', meaning complex and therefore hard to understand:

it is quite difficult to explain which part of the brain is controlling what and what is processing pain and what is receiving and reacting to things by way of either slowing down, [...] (P8, consultant gastroenterologist)

3. Difficult to communicate

Following on from poor understanding in terms of current medical theory, several participants pointed to struggles in conveying the diagnosis, or the lack thereof in some cases:

.... it's difficult to get across that there is no real diagnosis (P14, consultant gastroenterologist)

Another aspect of communication perceived as difficult was trying to explain their condition to the patient and especially to make sense of the possible interaction between body and mind:

It is difficult to know what to say. I try and just relate [the symptom] to an everyday experience, and say well look there is connections that we don't understand and we are never actually going to understand everything about the human body, I don't think we will You look at the body, everyone has had experiences of how emotions and how events in their life have caused symptoms ... (P4, senior registrar in colorectal surgery)

4. Difficult to manage

Management was the consultation segment most frequently characterised as 'difficult'. The following participant, starting from the statement that only complex cases are referred to secondary care, explains:

They are difficult to treat because most of these patients have gone to a few or a reasonable number of doctors before they end up in a speciality gastroenterology clinic. (P8, consultant gastroenterologist)

Time intensiveness and lack of time in routine consultations was mentioned as an impediment to good management of patients with MUS by nearly all participants. Multi-morbidity and lack of improvement were also mentioned as factors contributing to feelings like it's '*difficult in a sense that you are turning over the same ground a lot.*' (P10, consultant cardiologist). In the words of a consultant geriatrician:

They will have symptoms in many areas of the body ... there was a gentleman who came to my clinic and he said he had headaches, aching limbs, his prostate was running up his spine, he had nausea, he was constantly sick and he went through almost every symptom in the body and very difficult to necessarily help because you might help them with one thing and the next time you see them they may have another symptom (P9)

Participants speaking about the potential role of psychotherapy for patients with MUS tended to portray the psychotherapist's task as particularly difficult due to the chronicity of the condition (P17, consultant dermatologist) and the secondary gains it was assumed to offer:

... so somebody trying to sort of therapise them out of that, ... if you like using psychological techniques, will find that very difficult because the patient consciously or otherwise doesn't want it to change, I suspect ... (P10, consultant cardiologist)

5. Difficult emotions

Some participants described having strong emotional responses to patients presenting with MUS:

Most of the time I know that there are treatment options available to them that will actually improve, it is infrequently that we come across someone so severe that they affect you and make you go through all the emotions that you can sometimes experience with difficult patients. (P4, senior registrar in colorectal surgery)

In the vicinity of the term 'difficult', often emotions such as '*frustrated*', '*disappointed*', '*distressed*' or '*mentally exhausted*' were specified. The topic of emotion and experience more specifically is represented in the results of the third phase of analysis.

6. Difficult service structures

'Difficult' was also used with reference to perceived deficits in the health care system, e.g. poor access to clinical psychology services as well as a lack of personal continuity in the care provided by general practitioners.

... a difficult group of patients, not easy to deal with unfortunately lack of time and lack of support services ... (P14, consultant gastroenterologist)

[GPs] don't feel they have got the necessary support ... to look after them in the community and they don't know what else to do with them, so they send them in. So I think it is difficult, but yes, once they start to come into hospital as they say I think it just reinforces to them that there is something organic and serious and real and they need to be in hospital. (P15, consultant colorectal surgeon)

7. Difficult identities

Finally, 'difficulties' were reported with regards to professional identity and medical cultures that do not easily accommodate the skills needed for dealing with patients with MUS nor inspire any interest in them. As one participant put it:

... they are a group of patients who it's difficult to get surgeons and physicians interested in because it is not sexy and it is not perceived that there is an awful lot that you can do for them so it isn't a very satisfying branch of medicine to go into ... (P15, consultant colorectal surgeon)

Not that difficult?

Despite these challenging features being widely agreed upon, some participants explicitly rejected the common description of MUS patients and/or their conditions as difficult:

So I think they can be perceived as difficult, but I don't think they are by and large I don't think I have ever looked after anyone that you couldn't make some changes to. (P9, consultant geriatrician)

I don't think I find them as difficult as some people do. I don't know why that is, but I think I am just natural with most people, you know I give people a little bit of time, I think so yes, I just try to be honest and if you are talking to a patient, they are an individual person I'm just honest with them and I tell them what I think and they can take it or leave it, so why is that hard? (P10, consultant cardiologist)

Difficulty was not always evaluated negatively but was sometimes portrayed as a positive challenge:

So although they are time consuming and they can be quite difficult because it is often, especially if you do touch what the trigger was, because that can sometimes be distressing for the patients, they have to deal with whatever distress that triggered it in the first place, then it can sometimes be quite rewarding. (P5, consultant rheumatologist)

Beyond difficult: emotive descriptors of patients and interactions

Specific analysis of the word difficult demonstrated that it is often accompanied by emotional descriptors. Looking beyond the expression of difficult by analysing the adjectives which emerged in the data coded to a number of themes related to patients and interactions, revealed diverse emotional valuations and experiences. In this vein, most participants cautioned that, as a group, MUS patients and their individual responses to the consultation were *'hugely variable'* (P1, consultant gastroenterologist) and *'heterogeneous'* (P12, consultant gastroenterologist). Negative evaluations of patients, the doctor-patient interaction or the doctors' own emotional response were often confined to a subgroup of patients:

A proportion make me feel quite positive and good because I actually do feel able to explain the situation to them and they are taking it on board and you know, I think that they have actually benefitted from the consultation and will go away with a more sort of, with a greater ability ... and understanding to deal with it. And then there's another small minority I said are just angry people and it's pretty unrewarding and I mean I'm sure they find me unrewarding and I find dealing with them unrewarding because we don't really get anywhere. (P1, consultant gastroenterologist)

Particularly negative evaluations were presented as views held by colleagues rather than by the participant him/herself:

the classic orthopaedic approach ... is 'they're mad.' (P7, consultant orthopaedic surgeon).

The word cloud that follows (Figure 2) gives a visual portrayal of the number and frequency of expressions doctors used to describe patients, and demonstrates the existence of both positive and negative valuations.

Participants most often used the word 'frustrated' when describing their emotional reaction to MUS patients:

I think it is frustrating ... because you like to be able to help people. You like to be able to find a diagnosis and say this is what will make it better, or here is your diagnosis we can't do anything, this won't make it better, but then these people we don't know what the diagnosis is we can't do anything and that is frustrating for me as a doctor. (P10, consultant cardiologist)

But again, participants reported a mix of positive and negative emotions towards MUS patients with some expressing feeling 'happy' about their consultations and 'satisfied' whilst others experienced disappointment and felt neither confident nor equipped.

This participant is particularly reflective of his own emotions and of how, despite being triggered by the patient, difficulty arises from his own expectations and particularly his feeling of helplessness:

... sometimes you can get annoyed; sometimes you can get frustrated, not frustrated with the patient, frustrated that they are not responding to any of the treatments and that is not their fault, it's not your fault either, it is just the way it works out. Other times you just feel really, really upset ... and that lady I mentioned, ... I just feel so upset for her, because you see it in her eyes as she walks in the door and you think you are going to say it, 'I can't help you.' But then you feel guilty almost because the experimental treatment that you didn't promise would work didn't work. So you really have a full list of the different emotions that you experience, but that is with a minority of patients. (P4, senior registrar in colorectal surgery)

Discussion

The term 'difficult' appears and re-appears in the literature on MUS and is often used in an unspecific, general manner. It also bears negative connotations in so far as "patients are not simply 'difficult to treat' in the sense that they are challenging and stimulating for doctors who want to prove their expertise: rather they are 'difficult difficult' patients, who evoke the negative emotional reactions of frustration and helplessness in their doctors ('heart-sink patients') and seem to undermine rather than stimulate the expertise of the doctor." [61] (p. 126) We therefore consider the usage of 'difficult' in the context of MUS problematic and a potential barrier to improving treatment. In order to counteract its potentially negative impact, a closer understanding of its usage and meanings is needed. The analysis presented here differentiates multiple facets of 'difficulty' experienced by secondary care physicians vis-à-vis MUS patients.

'Difficult' was rarely used as a pejorative patient characteristic as the shorthand statement 'difficult patient' seems to imply. Statements of 'difficulty' mostly related to clinicians' tasks of communication, diagnosis, explanation, and management with regard to MUS patients. These specific 'difficulties' are broadly

similar to those identified amongst general practitioners [46], [62] - [64]. Our study also corroborates the claim that dealing with MUS patients is emotionally demanding for physicians [28] [67]. Yet by exploring their emotional responses in detail, our study portrays physicians' experiences with MUS patients as more complex than heretofore reported. The analysis showed more nuanced manifestations of 'difficulty' such as when expressing feelings of guilt, concern, distress or frustration. It also brought to the fore the heterogeneous nature of perceptions of and attitudes toward MUS and patients with MUS with some respondents contradicting blanket negativity, and reporting positive experiences with such patients. 'Difficulty' was also reported with regard to the very concept and understanding of medically unexplained symptoms, to structural aspects of health care provision for MUS patients and with regard to physicians' professional identity.

The shorthand statement 'difficult patient' appears to draw together 'difficulties' experienced by doctors vis-à-vis MUS patients that arise from a number of interacting factors both internal and external to the physician.

The following diagramme represents in visual form these different facets of 'difficulty' as seen from the doctor's perspective (Figure 4). They can broadly be divided into difficulties lying with the patient, the doctor, the condition ~~and the~~ context, and the doctor-patient interaction. All these facets influence each other and manifest in and shape the doctor-patient interaction. This is represented graphically by the intersecting circles. Specific difficulties identified in the findings are placed spatially in relation to whether they are more or less representative of difficulties experienced by, or inherent to, the patient, doctor, condition or context. The facets of difficult in Figure 4 are only those mentioned by our participants, and are not exhaustive of all the possible examples of difficulties. Interviews revolved around prompting doctors to tell exemplary case stories, hence why interaction appears at the centre. All of the examples given of the different facets of difficult relate to, or manifest themselves in the doctor-patient interaction.

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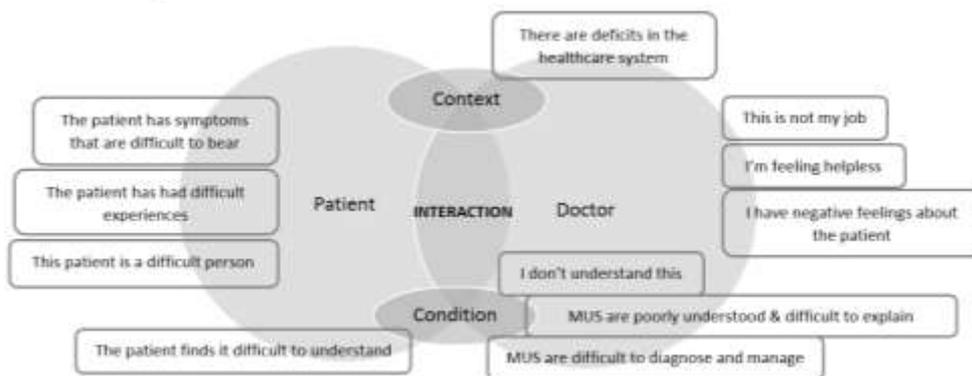


Figure 4: Visual representation of the Framework distinguishing different facets of physician-reported 'difficulty'

The shorthand statement 'difficult patient' thus seems to draw together 'difficulties' experienced by doctors vis-à-vis MUS patients in a variety of areas. According to Henningsen et al. 's overview on barriers to improving treatment [61], these areas can broadly be described as context, comprising understanding of the condition and service organisation, and doctor-patient encounter, comprising doctor-related factors, patient-related factors and interaction-related factors. In a systematic review of barriers to diagnosis of "non-specific, functional, and somatoform disorders" in primary care, [66] through a grounded-theory approach Murray et al. identified that barriers reported in the literature could be interpreted to fall under five very similar thematic categories, namely: patient-related barriers, primary-care physician (PCP) related barriers, interactional barriers, situational barriers, and conceptual and operational barriers. Indeed, a number of the ways in which our participants used the term difficult to describe their experiences, relate to a number of these 'barriers' as can be seen in Figure 4. Interestingly, in Murray et al the emotional experiences of physicians fall largely under PCP-related barriers in the sub-theme "lack of confidence" (p. 5-6). Here, feelings of uncertainty, inadequacy, inability to help, and frustration are reported in the literature. However, Murray et al. do not return to the issue of the emotional experiences of doctors in the discussion except to say that PCP confidence is 'modifiable' (p. 7). The emphasis the discussion places on clinical practice and future research implies that confidence will be modified through better understanding of the conditions and changes in clinical practice.

We agree that improvement for patients and physicians in this area of medicine requires more biomedical as well as conceptual research to inform better service structures, clinical skills and treatment options, but we must also go further to address emotional difficulty in its own right. In light of the design of our study - narrative interviews encouraging doctors to speak from and about their internal perspective - we focus the rest of our discussion on aspects of difficulty that are internal to the doctors, namely their (emotionally) difficult experiences. This is not to negate that difficulty can be due to external factors, e.g. '(difficult) psychophysiology' or '(difficult) health care systems'. But, as some of these external difficulties, especially medical culture or "medical ideology" as Murray et al. call it [66], are slow to change and hard to alter, and the fact that inevitably medicine will never be fully capable of understanding and relieving all forms of human suffering, we believe it is crucial to address experiential, emotional or personal difficulty as its own reality. This aspect is easily neglected in the literature and we believe it is one of the strengths of primary, qualitative research like our study to draw attention to such neglected perspectives and experiences.

In the context of MUS, doctors must interact with patients who suffer from conditions that are poorly understood and for which few if any medical treatment exist. In this regard, we think it is important to encourage doctors to recognize their own emotions and legitimise their 'difficult' experiences [42]. A

[productive way of doing this might be to reflectively use the doctors' emotional reaction as an indicator for where the patient's problems might lie and thus facilitate better understanding and more appropriate psychological management \[69\], \[28\]. Greater awareness of their own emotional reaction might in turn lead to greater awareness for patients' emotional distress which doctors, as Henningsen et al. describe it, tend to 'somatise' – i.e. they pick up emotional cues but respond to them by returning to the bodily complaints \[61\]. Furthermore, it might be helpful to talk more openly about 'difficulties' amongst colleagues rather than, as one participant pointed out informally after the interview \(P2, consultant respiratory physician\), avoid mentioning 'difficulties' for fear of being considered incompetent. A factor also identified in Murray et al.'s review, Implementing Balint groups, which are common practice in some countries in the fields of mental health and primary care, in secondary care in somatic medicine might offer a forum for such open, non-judgemental reflection and help lower doctors' emotional distress when dealing with patients with MUS \[71\] - \[73\].](#)

[Specific training could further help doctors increase their confidence in this area of medicine \[70\]. Figure 2 can be used as a teaching tool for identifying and discussing the different meanings and attributions of the term 'difficult' and help counteract negative preconceptions. In particular, distinguishing 'difficulty' that the physician experiences as lying with patients as persons \(e.g. MUS patients are non-cooperative\), from 'difficulty' that lies within the experience of being the physician providing care to a patient with a MUS condition in a given cultural and structural context \(e.g. I struggle to understand and explain this condition, I find the structural support wanting and this frustrates me\) might help counteract the stigma created by the negative evaluative term 'difficult patient' \[67\]. Medical students and physicians should reflect critically on the use of colloquialisms like 'difficult' for describing patients and conditions. More descriptive language might be more appropriate and more acceptable to patients. A change in language use and a more nuanced picture of doctors' experiences with and attitudes towards MUS as is provided here, may also reduce the lack of confidence some doctors feel because of a word that subtly devalues their ability to deal with MUS patients \[61\] \[68\]. Allowing more room for sharing positive experiences with patients presenting with MUS is also important.](#)

Strengths and weaknesses of the study

Literature heretofore has mostly focussed on the occurrence of MUS in general practice. Our findings contribute to a more nuanced, in-depth understanding of MUS as experienced by secondary care physicians. Whilst not primarily aimed at yielding generalizable results [74], the heterogeneous nature of our sample and the concordance of our basic findings with previous studies in primary care, allows us to assume the experiences and attitudes identified in our study are indeed shared by many secondary care specialists in the U.K. [If we had gathered more detailed sociodemographic data from our participants, we may have been more confident in claiming a greater degree of generalizability. It is also important to note that](#) the situation might well be different in other countries

due to differences in the organisation of health care provision for patients with MUS. In Germany, for example, psychosomatic medicine is much more strongly institutionalised and a specific guideline for “functional and somatoform disorders” exists [75]. It is important to recognize that our findings solely represent physicians’ perspectives and that patients’ perspectives would add additional insight. Finally, it might be that there is a social desirability bias in our findings i.e. that participants held back from expressing negative, stigmatising attitudes in front of the interviewer. Yet even if everyday communication about patients with MUS amongst medical professionals is more unanimously negative than our findings suggest, our study does show that if doctors are offered time and a confidential space where personal insecurity is not judged, they can demonstrate high levels of reflectiveness on their practice and attitudes. These may give rise to the recognition that experiences of patients with MUS may be shaped as much by their own preconceptions and uncertainty as they are by certain patients’ characters or behaviours.

Directions for further research and training

Concerted effort should be undertaken to improve care for MUS patients. To this purpose, future studies should aim to include tertiary care specialists as well as other health professionals working in the area of MUS [76]. Differences between specialities and between traditions of biomedicine in different cultural contexts should also be explored, as others have shown potentially important variations based on region and culture [77] [78]. Studies are needed that include patients and analyse doctor-patient interactions, for example through video-recording [22], [29]. Based on these findings, specific training programmes for MUS in secondary and tertiary care that involve an emphasis on coping with emotional difficulty, could be developed and evaluated. There are only a few of these so far [25] [26]. The same goes for undergraduate medical training [32]. Finally, the conceptual basis of MUS requires further interdisciplinary reflection and clarification to inform clinical practice, language use and the development of services.

Conclusion

Doctors’ perceptions and evaluations of MUS patients, their interactions with them and the emotional responses that ensue vary greatly, contrary to what the blanket term ‘difficult’ might suggest. Whilst negative descriptions of patients and their emotional responses to them predominate, most of these negative evaluations do not follow from unpleasant character traits or adverse behaviours as the shorthand expression ‘difficult patient’ seems to imply. Rather, they have to do with the involvement of emotions that are difficult to bear for doctors and patients alike. Those difficult emotions emerge in the context of the current conceptualization of MUS conditions and the health system, and manifest in the doctor-patient encounter. The

shorthand statement 'difficult patient' thus mostly reflects a difficulty experienced by the doctor, but easily leads to misattributions and, through the powerful interplay of language and (social) perception, to misperceptions. Scrutinizing the notion of 'difficult' can help prevent these misattributions and allows more positive experiences and successes to be acknowledged, thereby helping to overcome stigmatization of patients and leading to the reduction of debilitating self-stigma amongst doctors which takes the form of an important lack of confidence.

Our findings call for greater awareness and acceptance of personal and emotional difficulty amongst medical professionals and emphasise the importance of studying and reflecting on medical culture, including everyday language use. Specific training in these areas is needed [and the analysis and reflections presented here should inform service-development](#)

Footnotes

Competing interests:

All authors declare: no conflict of interests.

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Authors' contributions:

AM contributed to the study design. She collected, analysed and interpreted data and drafted the manuscript.

MW contributed to the study design. She analysed and interpreted data and drafted the manuscript.

AR contributed to the study design. He contributed to the data interpretation and reviewed and commented on the manuscript.

JM contributed to the study design. She contributed to the data interpretation and reviewed and commented on the manuscript.

YY contributed to the study design. He contributed to the data interpretation and reviewed and commented on the manuscript.

All authors, AM, MW, AR, JM and YY agree to be accountable for the integrity of the data and the accuracy of the data analysis. AM is guarantor.

Ethical approval:

The study obtained ethical approval by the Ethics Committee of the Department of Anthropology at Durham University. It was also registered with the NHS Integrated Research Application System (IRAS), but did not require ethical clearance by the NHS ethics committee as the design did not involve research with patients but only with staff. Written consent was obtained from all participants. In the manuscript, all names and identifying details have been omitted in order to protect participants' anonymity.

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