# **ORIGINAL ARTICLE**

# What Do Patients Choose to Tell Their Doctors? Qualitative Analysis of Potential Barriers to Reattributing Medically Unexplained Symptoms

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**BACKGROUND:** Despite both parties often expressing dissatisfaction with consultations, patients with medically unexplained symptoms (MUS) prefer to consult their general practitioners (GPs) rather than any other health professional. Training GPs to explain how symptoms can relate to psychosocial problems (reattribution) improves the quality of doctor-patient communication, though not necessarily patient health.

**OBJECTIVE:** To examine patient experiences of GPs' attempts to reattribute MUS in order to identify potential barriers to primary care management of MUS and improvement in outcome.

DESIGN: Qualitative study.

**PARTICIPANTS:** Patients consulting with MUS whose GPs had been trained in reattribution. A secondary sample of patients of control GPs was also interviewed to ascertain if barriers identified were specific to reattribution or common to consultations about MUS in general.

APPROACH: Thematic analysis of in-depth interviews.

**RESULTS:** Potential barriers include the complexity of patients' problems and patients' judgements about how to manage their presentation of this complexity. Many did not trust doctors with discussion of emotional aspects of their problems and chose not to present them. The same barriers were seen amongst patients whose GPs were not trained, suggesting the barriers are not particular to reattribution.

**CONCLUSIONS:** Improving GP explanation of unexplained symptoms is insufficient to reduce patients' concerns. GPs need to (1) help patients to make sense of the complex nature of their presenting problems, (2) communicate that attention to psychosocial factors will not preclude vigilance to physical disease and (3) ensure a quality of doctor-patient relationship in which patients can perceive psychosocial enquiry as appropriate.

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# INTRODUCTION

Effective management of medically unexplained symptoms (MUS) poses a challenge to doctor-patient communication. Presentations challenge medical understanding of symptoms, and it is often assumed that patients deny underlying psychological causes of their illness. Patients are often dissatisfied with explanations provided,<sup>1</sup> and despite escalating health-care seeking, management may be inappropriate because it does not match the purpose of patient help-seeking and problems persist. Together these consequences potentially damage the doctor-patient relationship. Nevertheless, patients with MUS prefer to consult their general practitioner (GP) rather than any other health professional.<sup>2,3</sup> Consequently interventions have been targeted at GP communication and consultation behavior.

One method, reattribution, provides physicians with a fourstage communication framework (see Table 1) to structure a routine consultation, or a series of consultations, with the goal of providing patients with an explanation that links their physical symptoms to psychosocial issues.<sup>4–6</sup> It is informed by a patient-centred perspective and was developed from health professionals' experiences of successfully managing patients with somatization disorder. It has been widely adopted internationally.<sup>7–14</sup> Features of reattribution are that: psychological context can help explain physical symptoms; attributions for symptoms held by patients are unhelpful; broadening patients' attributions will resolve/improve symptoms or enable GPs to treat any underlying psychological or social problems.

Substantial evidence demonstrates that reattribution improves patient satisfaction, but evidence of improved clinical outcome is equivocal.<sup>7–14</sup> A recent UK primary care trial (MUST) demonstrated that GPs can be taught by non-expert trainers to deliver reattribution within routine consultations.<sup>5</sup> GPs' communication changed significantly; trained physicians elicited more patient concerns/beliefs and provided richer symptom explanations that linked physical symptoms to psychosocial issues.<sup>15</sup> However, the marked change in GP behaviors did not translate into predicted improvements in

Stage of reattribution	Task for GP	Topics probed within interview
Feeling understood	<ul><li>Obtain all relevant information on complaint</li><li>Explore illness beliefs</li></ul>	<ul> <li>Experience and view of GP's response to patient cues</li> <li>Experience of exploration of illness beliefs and sharing of beliefs</li> </ul>
	• Respond to emotional cues	• Experience of GP expression of empathy
Broadening the agenda	• Summarise physical and psychosocial findings.	• Experience of exploration of emotional aspects of illness
	• Explore patient's openness to idea of linking bodily complaint to psychosocial issue	Acceptability of discussion of emotional concerns
Making the link	• Give explanation relating physical symptom to psychosocial problems because of link in time or physiological mechanism	• View of any link presented
		• Subsequent embellishment of illness explanation by patient
Negotiating further treatment	• Establish if further treatment is required and its nature	• Experience of treatment
	<ul> <li>If necessary, arrange treatment of symptoms, psychosocial problems or mental disorder</li> </ul>	• Involvement in treatment negotiation
		<ul> <li>Modification/adaptation of explanation</li> <li>Self-management</li> </ul>

#### Table 1. Reattribution Model<sup>6</sup>

patient outcomes: despite a trend for improved satisfaction with care, patients rated their overall health as worse.  $^{\rm 15}$ 

Why did this occur? The aim of the current study was to identify potential barriers to reattribution and the improvement of clinical outcome by analysing patients' experiences of consultations, and furthermore, to establish if barriers are particular to the reattribution model or to MUS management more generally. In a complex intervention such as GP training, identifying potential barriers is an essential step in further development of communication interventions and implementing findings into clinical practice.<sup>16–19</sup>

#### **METHODS**

Participants were drawn from patients involved in the MUST Trial <sup>5,15</sup>, a cluster randomised controlled trial of reattribution training for GPs within the UK. Sixteen GP practices were recruited to the trial (n=74 GPs), of which 8 practices were randomly selected. All GPs within these practices received 6 hours of training, which involved DVD explanation and modelling of reattribution, followed by role-play and video feedback. Following training, 141 consecutive patients were identified in control and training practice waiting rooms. Inclusion criteria were (1) aged over 18 years, (2) physical complaint of at least 3 months' duration as the primary reason for consultation and (3) participants' GPs and an independent research GP (blinded to training condition) determined that symptoms and disability were unexplained by physical pathology. Consultations of consenting patients were audiotaped. Full details of the trial and recruitment procedures are found here.<sup>5,15</sup>

Sampling for this qualitative study was purposive. A matrix was developed to help achieve maximum variation when selecting participants in relation to key sampling variables: age, presenting complaint and ratings of satisfaction with consultation three months later.<sup>10</sup> Patients were recruited from GPs who had been trained in reattribution. The initial analysis revealed emerging barriers that were not necessarily specific to reattribution training. To examine if the potential

barriers could also be features of consultation about MUS more generally, a subsequent sample of patients from control GPs (untrained in reattribution) was sought. Again, participants were selected in an attempt to ensure as full variation as possible on sampling variables. Sampling within both groups continued in parallel with the analysis until thematic saturation was achieved. All participants approached agreed to take part.

Twenty-three patients were interviewed. Twenty were female, and ages ranged from 32–84 years (mean=53). At the time of interview, 16 patients' GPs had been trained in reattribution and a further 7 had not. Since the secondary sample was only recruited to test ideas emerging from the initial analysis, fewer participants were necessary. The time since the index consultation ranged from 8–55 weeks (mean=32). Participants' were drawn from 15 GPs (9 trained and 6 untrained). Eight GPs were male.

Semi-structured interviews were conducted in patients' homes, audiotaped and transcribed. An interview guide provided a flexible framework and questioning explored aspects of the index consultation, beginning with patients' reasons for, and expectations of, consulting. The interviewer prompted patients about their consultation experience in relation to each of stage of reattribution<sup>6</sup> (see Table 1), e.g., 'How has the doctor explained your problem'. Patients' wider views of GP-patient relationships and communication were also explored. Interviewers combined open questions to elicit free responses with focussed questions for probing.

Analysis, which proceeded in parallel with the interviews, was inductive, taking a grounded approach.<sup>20</sup> All transcripts were read and discussed by team members (SP, MT, RC, PS, AR). Coding was informed by the accumulating data and continuing analysis. Thematic categories and ideas identified in initial interviews were tested or explored in subsequent interviews where disconfirmatory evidence was sought to establish the robustness of analysis. For example, patients of untrained GPs were sought to test if themes emerging were particular to reattribution management. Periodically, the analysis was referred to the broader group involved in the trial (LG, RM, CD). The multidisciplinary team comprised researchers from psychology, psychiatry, primary care and sociology. Cycling between data and the developing analysis, the use of authors from different disciplinary backgrounds, and presentation of relevant transcript are established procedures for increasing trustworthiness of analysis.<sup>21,22</sup> In reporting the final analysis, we present data from patients whose GPs were in the treatment (T) and control (C) groups to illustrate the range and commonality of meaning of each category of the analysis. Only themes that were present across both groups of participants were included within the analysis.

#### RESULTS

Barriers to reattribution arose from the perceived complexity of patients' problems and the ways in which they chose to reveal this complexity to the GP.

#### Patients' Problems and Needs are Complex

Patients' explanatory models were multifaceted, simultaneously incorporating disease and non-disease causes and the interaction between them (see Text Box 1). At times, their narratives were fragmented and chaotic, presenting multiple, seemingly unconnected and incoherent problems with no clear beginning or end. In this respect some viewed GPs as holding more uni-dimensional, dualistic and hence simplistic models about cause and resolution of problems than their own.

Text Box 1. Working with complexity

Chaotic narratives

I'd forgotten how I'd come starting to talking to her about, I think it was an overall general health and then she asked me and I mentioned I had different things, my hands and then I was having trouble going to the toilet and then I did tell her I had depression and I've got thyroid as well, so she more or less had an idea that it was a little bit of everything going on at the same time (22040 T)

Examples of range of agendas

- There wasn't a lot that I knew she could do for me...she can't give me a tablet which will make it all go away...but sometimes a sympathetic ear can help...nice to know that someone like Dr X, who is understanding, is there for me to call on, or even to go back to if and when I have...bad times (31039 T)
- The X-ray was important to me because at least it proved that everything was clear inside because I was worried there was a blockage (31031 T)
- I suppose it's basically reassurance that I haven't got anything nasty. My mum died of motor neurone disease and it's always at the back of my mind that if I start getting lots of symptoms because it's something like that (21066 T)

I've seen him for over 20 years you see and he's sorted me out every time (31031 T)

She wasn't getting me...just treating all these little bits separately...had me written down as a neurotic...she thought it was all me and all in my head. (31039 T) [Shortly after this, patient changed doctor] Most patients described long-standing, pre-existing problems which in, many cases, were simultaneously being managed by a range of health and social services. Therefore, the context of the consultation was a complex amalgam of a history of symptoms, investigations, diagnoses, explanations and treatments that shaped their expectations of what the GP could achieve.

Patients had a range of reasons for consulting the GP. As predicted by reattribution theory, some sought an explanation for their symptoms. However, several already held explanations that they wanted confirmed, for example, by trying a particular investigation or medication. Others sought, not explanation, but support with self-managing their problems.

I need how to learn how to cope. I want to go somewhere where I can to talk to people who are genuinely interested in caring. (30175 T)

Others wanted comfort from simply sharing their problems.

There's nothing particularly I wanted out of it [consultation] except...to tell her that it had happened. (31039 T)

Often agendas were unmet.

Many times I've come away and I've nearly cried thinking I've gone there and waited, come out and got nowhere. (31106 C)

Some patients' reasons for consulting reflected the particular history of their long-standing relationship with the GP. This fostered expectations that they would be given tangible help, such as prescription or advice or, conversely, that the doctor would avoid challenging their current ways of managing their problems.

He knows I like to keep myself to myself, knows I believe in self-help...knows I'm somebody that likes to work it out for myself. (20757 T)

### Patients' Management of Their Presentation: Selecting What to Say

Keenly aware of the limited time available in any consultation, patients struggled to convey the complexity of their illness and expressed frustration that their GPs couldn't appreciate the full picture of their problems and various avenues that had been pursued in trying to resolve them.

When I come in I don't know what's started it. I just know what's happening to me...I just know within my body that its something that's not right...It's such a difficult thing for a patient to describe. (20792 C)

Therefore, they often simplified their problems or focused on one element to fit in with their expectations of consultation and the capacity of the GP to help.

You do bottle up sometimes when you've only got ten minutes, because sometimes I do think a lot of my problems are related to other things. (30231 C)

Complex explanations

They say it's this fibromyalgia rolled into sort of rheumatism, and I suppose bits and pieces wearing out. Dr X did say it was definitely arthritis in my knees (21066 T)

I think my problem is the link between my existing thyroid problems... when I'm under extreme pressure and stress the thyroid doesn't output enough thyroxin so considering all the stress I was under, which was tremendous, I know that my thyroid's not going to give me the right output (10611 T)

<sup>•</sup> Historical context of the interaction

They particularly valued GPs who showed awareness of the breadth of their problems and helped them structure and make sense of these:

You sort of...get a bit incoherent and rambling on. She'll say 'so what you mean is you feel like this?' and she's got it. She's got to the heart of the matter. (31039 T)

## Patients' Management of Their Presentation: Withholding Psychosocial Disclosure

Contrary to the widespread assumption, on which reattribution and similar communication interventions are based, that MUS patients don't recognise the role of emotional factors in their problems, most patients' explanations already incorporated psychosocial factors.

I used to work for a living and it seriously damaged my health...It was all stress related, it was reactive...in fact I'll tell you how stressful it was - I lost my voice for 7 weeks. (31031 T)

Moreover, imposing a dichotomy between psyche and soma felt artificial.

It's very difficult for me to...differentiate between what is a symptom physically ... and what is something more, you could call it mental. (20700, T)

Again, patients regarded GPs as having less sophisticated views than their own. Specifically, they described their doctors as having dualistic explanations where psychosocial factors couldn't coexist with physical ones. By disclosing psychosocial concerns, patients thought they risked diverting GPs from thoroughly considering physical causes. Moreover, they feared that explicitly discussing the possibility that a symptom has a psychosocial cause would lead GPs to attribute any future symptoms to psychosocial causes, without investigation. Many patients therefore consciously withheld psychosocial issues from their GPs (see Text Box 2).

Text Box 2. Patients' management of presentation: Reasons for withholding psychosocial disclosure

· Stigma of psychosocial explanations

Its not that I don't want to work, it's just that I've been ill...It's like I get the impression that he thinks I'm deliberately getting out of it (20792 C) She didn't believe me basically and she thought I was a neurotic housewife with time on my hands who had nothing to do but worry

- about my own problems (31039 T) Desire to protect GP from burden

It's hard, they must see lots of people with so many different things and I suppose they can only take so much as well...they've got so much on their plate and hearing so many problems all day. My friend said her GP committed suicide and she was lovely, always took time and you wonder how much time she did take on board and worried about it (30231 C)

· GPs unskilled at treating psychosocial problems

The doctor has got really good at identifying stress...but not doing anything about it...it's positive that it's being recognised, but it's like saying 'yeah, you've got gangrene in your arm; I've diagnosed it now go away. You find out what to do about your gangrene yourself' (10611 T) What could he do anyway?...Apart from maybe give me another tablet (30847 T)

- Psychological problems can be managed by patients
- I need to start coming back slowly and I've started walking [the dog] shorter walks just to start building up...I feel more able to cope now. I'm aoina back to work (10611 T)
- I'm going to bed earlier and I'm trying to do more. I found sitting around I'm still just as tired not doing anything, so I've tried to get up early...I'm not taking any vitamins because I've bought a juicer...so instead I'm juicing carrots and apples...just trying to get up and have these juice drinks and truing to be healthier eating (10523 C) I've started knitting — gets my mind occupied (30175 T)

GPs were viewed as having a limited role in the management of psychosocial problems. Stress was viewed, not as a 'disease', but as a feature of patients' environment, personal characteristics or history. Hence, it was largely seen as a normal response to everyday adversity, and discussing it with the GP was considered fruitless and inappropriate. GPs' enquiries about psychosocial issues also had the potential to be viewed as intrusive, by assuming a level of intimacy that patients did not always feel. This was even true within longstanding relationships.

Unless it's relevant to your problems, I don't think they should ask [about psychosocial issues]. I remember my GP when I was little and he knew my whole family, but even so, there was never that bond...there needs to be that distance. (20792 C)

Patients also felt that discussing emotional problems was uncomfortable for both themselves and their GP. Several explained that they avoided disclosing emotional problems so as to avoid 'burdening' their GP.

Even when GPs were considered to have a potential role to help, for example, when patients wished to disclose an emotional component of their illness, they were viewed as unskilled and only being able to offer pharmacological treatments. Medication not only contradicted patients' illness beliefs, but was thought to mask an underlying problem and so had potential to harm. Instead, patients described attempts to self-manage their psychosocial problems, often with success, using an array of cognitive and behavioral strategies not requiring recourse to a health-care provider (see Text Box 2).

#### DISCUSSION

By analysing patients' experiences of consultations with doctors who were trained and untrained in a specific commu-

<sup>•</sup> GPs' explanations are more simplistic than patients'

They're just saying that to everyone and it's all inconclusive and doctors can't comment. So they all just say it's all in the mind...that's why I've not gone back to the doctors (10573 C)

<sup>·</sup> GP will generalise psychosocial cause to future symptoms

I think once that [stress] comes up they tend to think that's it then (10788 T) It's mentioned too quickly. I think instead of saying 'what's going on?', [it's] 'how's your stress?' immediately, which then sometimes causes you to think 'I'm an intelligent human being, I know when I'm under stress, just listen to what I'm saying' (16011 T)

<sup>·</sup> GP management of psychosocial problems is inappropriate

Everyone's got a bit of stress in their life. You know, no-one's stress-free (30847 T)

If she would have asked me how was things at home...I wouldn't have liked that actually because if I wanted anybody to know I would say (10788 C)

You go in and feel everyone's got problems and they're not there to cure your problems (30231 C)

nication model, we identified potential barriers to the effectiveness of GPs' attempts to manage MUS and improve clinical outcomes. Barriers included the perceived complexity of patients' experiences, their simplification of their presentation and caution about disclosing psychosocial issues. The barriers identified within the study were not particular to patients of reattribution trained GPs, suggesting that they are features of interactions more generally and so may compromise a broader range of ways than reattribution for engaging with and managing MUS.

Patients' beliefs and reasons for consulting were complex and multifaceted, and they found it hard to convey this complexity in the consultation. Nevertheless, they wanted GPs to understand the extent of their problems and valued those who helped them make sense of their (often) chaotic narrative. This suggests that the 'feeling understood' stage of reattribution is more challenging and central than envisaged hitherto. It also suggests that continuity of care is desirable so that GP and patient have the opportunity to understand the complexity of the problem over a series of consultations. Continuity of care is highly valued by patients<sup>23</sup> and in the US has been shown to be associated with the confidence felt by primary care physicians in managing MUS.<sup>24</sup> Current policy within UK primary care values access before continuity, meaning that it is now more difficult for people with complex chronic problems to achieve continuity of care with an individual provider.

Whilst a central goal of reattribution is to develop a shared new understanding of the illness, analysis revealed this was rarely the patient's agenda; rather than explanation, many sought confirmation and/or support of their ideas. This suggests the potential for mismatch between GP and patient consultation agendas, which may act as an important obstacle to therapeutic alliance. Consultation agendas frequently go unspoken, leading to misunderstandings and frustration<sup>25</sup>. Previous studies have found similar differences in patients' and doctors' goals, with patients primarily seeking support, whilst physicians primary goal is symptom alleviation.<sup>26</sup> Together this suggests a necessary task of patient-centred communication is for doctors to negotiate a common agenda for the consultation or series of consultations prior to embarking on therapeutic intervention.

Although patients were presenting with 'unexplained' symptoms, findings revealed patients had developed sophisticated models of their illness, which they contrasted with those held (or at least as communicated to the patients) by GPs. A misunderstanding of MUS is that patients hold physical attributions for their symptoms, a view that prompted the early developmental work for interventions such as reattribution.<sup>4</sup> However, contrary to this, both groups of patients described illness models rich in psychosocial components and had often considered how these impacted on their physical symptoms. Despite this, participants discussed how they elected not to share these aspects of their model with GPs. Hence, the task for the physician is not necessarily to change illness beliefs, but to develop a greater awareness of patients' present and past help seeking and self-management strategies in problem resolution, and thereby greater ability to incorporate and relate to patients models of psychosocial distress.

There were a number of reasons why patients chose not to disclose psychosocial issues. Firstly, the belief that GPs were dualistic in their thinking about illness, making distinctions between 'psyche' and 'soma'. This contrasted with patients' own rich illness models. For psychosocial discussion to be possible, patients also needed to trust GPs to look after their physical health and not to generalise psychological distress as the cause of all current and future symptoms. Since many MUS patients also have co-existing physical illnesses, this is a reasonable and important concern. Factors that influence how trusted GPs are include feeling one's individual experience has been understood and the perceived thoroughness of the evaluation.<sup>27</sup> This is likely to be particularly important in MUS where individuals recognise that their condition is at the limits of medical knowledge<sup>28</sup>, describe the effort involved in presenting as credible and legitimate<sup>29</sup> and believe they are taken less seriously than their counterparts with explained symptoms.<sup>30</sup> Elsewhere, it has been shown that in order for patients to feel able to disclose psychological problems, GPs must first provide a safe place in which they feel listened to and understood.<sup>31</sup> Our findings resonate with this as some were willing to share psychosocial information, but only when a level of intimacy had been established. Furthermore, they preferred to initiate these discussions. GPs have many opportunities with MUS patients to respond to psychosocial patientinitiated cues, and by offering these, patients are seeking emotional rather than somatic support<sup>32</sup>; moreover, when GPs do respond to such cues, the likelihood of somatic outcomes decreases significantly.<sup>33</sup> There is evidently scope for GPs to become more alert and responsive to these cues. However, in order to navigate the barriers to sharing their psychosocial formulation and to reduce the potential for the GP to be intrusive and offensive, there is also a need to first establish a productive and mutually beneficial relationship.

Gaining any patients' trust is an important goal for physicians since it predicts adherence to medical recommendations and health behaviours.34 Trusting one's doctor is also associated with having a commitment to this relationship<sup>34</sup>, which may help explain the paradox that MUS patients persist with GPs despite an impasse in treatment. It follows that developing trust between patient and physician allows for less conflictual discussion over issues such as uncertainty, disclosure of emotional distress and psychosocial issues. In a rare experimental study, empathic responses to emotional cues was associated with higher reports of trust for unexplained, but not explained symptoms.<sup>35</sup> This suggests that increasing GPs ability to recognise and respond to cues may be particularly important in gaining the trust of MUS patients, an important outcome in itself. To date, intervention studies aimed at GPs to specifically promote patient trust have been largely unsuccessful.<sup>36</sup> Our findings suggest that the initial stage of the reattribution model has potential to increase patients' trust.

Perhaps because of these problems, patients largely did not perceive GPs as having a role in managing psychological problems. They described being engaged in a range of (often successful) non-medical strategies. It is unclear what role GPs can offer here, although patients did describe one function of seeing the GP was to seek support with self management. Evidently more work needs to address how this can be effectively facilitated in the primary care setting.<sup>37</sup>

A number of study limitations should be acknowledged. In recruiting our sample we didn't seek a representative sample, rather to achieve variance in a number of key variables (physical complaint, training of GP, satisfaction with GP), thereby maximising the range of available views. This led to uneven subgroups, e.g., only 15% were male. This is unlikely to reveal a recruitment bias per se, due to our 100% recruitment rate and that the imbalance reflects the sample from which it was drawn where most participants (70%) were female.<sup>15</sup> Elsewhere, the literature demonstrates that woman are more likely than men to experience symptoms, including unexplained symptoms, although this is likely to be partly explained by increased rates of anxiety and depression in women<sup>38</sup>. A further limitation of the study is that several weeks had passed since the index consultation. Interviewers made particular attempts to focus patients on the experience of the specific consultation, and in most cases, the audiotaped consultation was easily recalled. However, for some frequent consulters, it proved difficult to distinguish the index from subsequent consultations. Hence, we cannot be confident whether patients' reasoning about what information they shared with GPs occurred at the same time as the audiotaped consultation or whether these views had evolved subsequently. A further limitation of the study is that participants' GPs were taking part in training in MUS management (though those within the control arm were untrained at the time of interviewing). Such GPs (and hence their patients' experiences) are not necessarily typical. It is however unlikely that the lack of trust described by patients in their GPs is overrepresented since elsewhere we found that clinicians who choose to take up offers of MUS training are more likely to value such patients and their own ability to manage such problems.<sup>39</sup>

#### CONCLUSIONS

Patients' decisions over how much, and what, information they present to GPs limits the effectiveness of communication training. In order to overcome this barrier, future interventions need to help GPs to (1) help patients to make sense of the complex nature of their problems, (2) reassure patients that medical attention to psychosocial factors does not preclude vigilance to physical disease and (3) establish a quality of relationship in which patients do not perceive psychosocial enquiry as inappropriate and that fosters an environment in which doctors can support patient self-management.

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