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Raine, Rosalind; Carter, Simon; Sensky, Tom and Black, Nick (2004). General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study. *British Medical Journal*, 328 pp. 1354–1357.

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Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.1136/bmj.38078.503819.EE>

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BMJ

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BMJ 2004;328:1354-1357; originally published online 28 May 2004;
doi:10.1136/bmj.38078.503819.EE

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General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study

Rosalind Raine, Simon Carter, Tom Sensky, Nick Black

Abstract

Objectives To compare general practitioners' perceptions of chronic fatigue syndrome and irritable bowel syndrome and to consider the implications of their perceptions for treatment.

Design Qualitative analysis of transcripts of group discussions.

Participants and setting A randomly selected sample of 46 general practitioners in England.

Results The participants tended to stereotype patients with chronic fatigue syndrome as having certain undesirable traits. This stereotyping was due to the lack of a precise bodily location; the reclassification of the syndrome over time; transgression of social roles, with patients seen as failing to conform to the work ethic and "sick role"; and conflict between doctor and patient over causes and management. These factors led to difficulties for many general practitioners in managing patients with chronic fatigue syndrome. For both conditions many participants would not consider referral for mental health interventions, even though the doctors recognised social and psychological factors, because they were not familiar with the interventions or thought them unavailable or unnecessary.

Conclusions Barriers to the effective clinical management of patients with irritable bowel syndrome and chronic fatigue syndrome are partly due to doctors' beliefs, which result in negative stereotyping of patients with chronic fatigue syndrome and the use of management strategies for both syndromes that may not take into account the best available evidence.

Introduction

Chronic fatigue syndrome and irritable bowel syndrome have complex, poorly understood causes that are thought to include biological, psychological, and social factors, and patients often present with symptoms that are diffuse or difficult to characterise.¹⁻³ Symptoms, the outlook of patients, and responses to treatment are also similar for both conditions.⁴ Despite the similarities, some general practitioners seem to be dismissive of chronic fatigue syndrome, whereas irritable bowel syndrome causes them less difficulty.⁵⁻⁷

Mental health interventions may be effective in both syndromes for patients who don't respond to management of symptoms in primary care.⁸ Although doctors recognise that psychological factors can initiate or perpetuate symptoms of irritable bowel syndrome, they are reluctant to explore psychosocial aspects of patients' lives and to use psychological treatments.⁷⁻¹⁰ We aimed to compare general practitioners' beliefs and attitudes about chronic fatigue syndrome and

irritable bowel syndrome to explain differences in their perceptions of the two conditions and to explore the implications of their perceptions for the use of psychological treatments.

Methods and participants

Sample

The study arose out of a programme of research into factors affecting group decision making for the development of clinical guidelines. A random sample of clinicians from throughout England were invited to participate in research into the process and outcomes of decision making by first completing a questionnaire and then attending a nominal group meeting to discuss their views. (Nominal groups are a formal method for eliciting opinions in a transparent and explicit way and are often used in the development of clinical guidelines.) We used computer generated random numbers to select individuals from the Department of Health's general practitioner database.¹¹ Each individual was randomly selected without being replaced. The aim was to establish 16 nominal groups of 11 participants, some comprising only general practitioners, others also including psychiatrists and other mental health specialists (sampled from databases of mental health professionals). Assuming a response rate of 4% (based on the response rate for the first group) and a provisional group size of 14 participants, to allow for attrition, we initially invited 350 general practitioners to take part in each nominal group meeting. A total of 135 general practitioners and 42 mental health professionals participated in the programme. A subset of nominal groups comprising only general practitioners was chosen for this analysis. No new major themes had emerged after analysis of the transcripts of four of the nominal groups, implying that theoretical saturation had been reached. The four groups analysed in this paper met between February and October 2002, and by the time the groups met they comprised between nine and 12 doctors.

Procedure

The participants were each sent a series of clinical scenarios involving patients with chronic fatigue syndrome or irritable bowel syndrome—for example, one scenario concerned the appropriateness of behavioural therapy in a patient who believes that chronic fatigue syndrome has an organic cause. The doctors were asked to rate their level of agreement with using mental health interventions. Two of the four groups were also given a systematic review of the effectiveness of mental health interventions for chronic fatigue syndrome and irritable bowel syndrome. The participants of each group met for a facilitated discussion where they explored any differences in opinion for

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each of the scenarios in turn. Each meeting lasted approximately four hours, giving sufficient time to explore in depth all the issues raised and to clarify any ambiguities. The meetings were audiotaped and later transcribed. In addition, field notes were written by one of the authors (RR), who kept a non-attributed "journal" of the group processes. The first group was facilitated by one author (NB) and the rest of the groups by another (RR), but all discussions were conducted according to a protocol. The protocol was written by two of the authors (RR and NB), one of whom (NB) had extensive experience in facilitating nominal groups. The protocol comprised a description of the nominal group process to be followed, instructions to be given to each group, and explanations of the terms used in the questionnaire. The meetings were all held at the same venue.

Analysis of transcripts

The analysis of the transcribed data involved independent scrutiny by two of the authors (RR and SC) of the initial transcripts and journal notes to draw up a preliminary list of themes. The two authors then met to compare and discuss identified themes. These interpretations were also appraised by the other authors. We used a variant of grounded theory in which we firstly identified provisional themes by using the respondents' own concepts. We then used these themes iteratively, applying them to later transcripts to allow the emergence of an analytical theory suited to the context.¹² In particular, we used a representational approach that allowed analysis of participants' discussions of the potential tensions and ambiguities in their roles as general practitioners.¹³ We were constantly vigilant for deviant cases that might question the emerging thematic and conceptual relations. This form of analysis, together with the use of the scenarios, allowed us insights into how the participating general practitioners responded to the key institutional and cultural conditions relevant to them.¹³

Results

The four groups comprised 46 participants. Twenty nine were men, and 37 were white. Their mean age was 46.9 years. They had worked for an average of 14.8 years in general practice, and nine were affiliated to a medical school.

Different perceptions of chronic fatigue syndrome and irritable bowel syndrome

Some general practitioners tended to see patients with chronic fatigue syndrome as having "a certain personality trait that is chronic fatigue syndrome waiting to happen" (general practitioner 4). This trait was often described pejoratively, such as being "introspective" and having a "low symptom threshold." Such stereotyping of patients with irritable bowel syndrome did not tend to occur, for five reasons. Firstly, the specific anatomical location of irritable bowel syndrome meant that a plausible pathological mechanism could be constructed, in contrast to chronic fatigue syndrome, which could not be ascribed to a precise location ("It isn't like a broken leg" (GP 7)) and which was difficult to conceptualise. Secondly, variation over time in the classification of chronic fatigue syndrome delegitimised the diagnosis for some participants ("Through the centuries [chronic fatigue syndrome] is called different things at different times" (GP 83)), although others questioned the logic of this argument. Thirdly, patients with chronic fatigue syndrome were seen as transgressing the work ethic ("One patient who had a particularly stressful job is very happy now that he is avoiding stress" (GP 78)). Fourthly, they were also seen as lacking in stoicism. Participants saw such an attitude as a problem because

patients seemed to ignore the normal obligation of the "sick role" to make every effort to get well as quickly as possible.¹⁴ In contrast, patients with irritable bowel syndrome "seem to battle through it" (GP 12) and were rarely "debilitated to such an extent that they were off work" (GP 10). Finally, general practitioners reported many conflicts with their patients about the causes of chronic fatigue syndrome and the options for its management. The doctors felt that they were subjected to criticism that called their own expertise into question: "It's much more adversarial than irritable bowel syndrome" (GP 11). However, the doctors did raise occasional concerns that patients with irritable bowel syndrome were also motivated by pressure groups critical of biomedical views.

The concept of the sick role in sociological analyses of the clinical encounter has been heavily criticised.^{15 16} However, our results support the continuing usefulness of the concept in describing normative expectations and ideals in the clinical encounter. Participants considered that in the case of irritable bowel syndrome most patients and doctors abided by the obligations of the sick role. However, often in chronic fatigue syndrome both doctor and patient seemed to violate their expected roles. The patient was often characterised as coming to the consultation with preconceived ideas about causes and treatment and sometimes rejecting the doctor's explanations and advice. In these cases general practitioners felt that their impartiality and authority were challenged.

Influence of general practitioners' beliefs on management

The doctors' stereotyping of patients with chronic fatigue syndrome meant that the condition ceased to be seen as a discrete disorder and became the defining feature of that patient. This value laden approach may have prevented general practitioners from assessing each patient as objectively as possible. It was not surprising that this attitude, sometimes combined with a breakdown of the relationship between doctor and patient, led to ambivalence towards treatment options. For most of the participants, choosing appropriate treatments for chronic fatigue syndrome was like groping in the dark—either not knowing who to refer to (GP 86) or just "feeling hopeless and more hopeless" (GP 14). They might therefore consider mental health interventions only as part of a process of trying a range of treatments: "You would do anything for these patients" (GP 45). So it is not surprising that general practitioners described caring for patients with chronic fatigue syndrome as a "burden" (GP 18): "I would rather treat a whole surgery full of people with irritable bowel syndrome than people with chronic fatigue" (GP 84).

Doctors who believed that both conditions are influenced by a combination of biological, social, and psychological factors often did not translate this belief into an awareness of the need to consider mental health interventions. Five main reasons for not referring patients for mental health interventions were identified: lack of familiarity with mental health treatments ("Medics don't really understand what psychologists do" (GP 82)); the belief that the conditions could be effectively and adequately managed in primary care with empathy and conventional drug treatment; perceived resistance among patients to psychological treatments ("Their shutters will go up" (GP 84)); a lack of local mental health resources; and doubts about the strength of evidence for the effectiveness of mental health interventions. In irritable bowel syndrome, other reasons for preferring treatment with drugs to mental health interventions were that these patients "are not as heartsinky as people with chronic fatigue" (GP 18), so doctors were not motivated to shift responsibility for management to other professionals; patients

were able to manage themselves with “their own cack-handed CBT [cognitive behaviour therapy]” (GP 13); patients did not demand referral; and many doctors had never thought about mental health interventions as an option.

Despite their contentment with their management of irritable bowel syndrome, some doctors did imply that it is not always managed effectively in primary care: “Most patients with irritable bowel syndrome actually keep coming back but not necessarily for the same stressor” (GP 11). Mostly this did not seem to concern the participants: “It is so easy to write a prescription” (GP 46). But some did see the potential for psychological treatment: “Most of irritable bowel syndrome is aggravated by psychological causes, so it is not surprising to see that CBT could be a partial answer” (GP 4). Some doctors did advocate mental health interventions for chronic fatigue syndrome, because of their experience of positive outcomes of treatment (“I must admit, my patients who have managed to get to CBT do seem to have done very well” (GP 17)) or because the treatments challenged the patients’ views of their own illness (“It’s a way of making the patient reassess what their view of it is” (GP 9)).

Discussion

Methodological considerations

We used our sampling method in preference to purposive sampling to meet the requirements of the larger research programme of which this study was part. This method allowed us to ascertain beliefs and views of a range of general practitioners from a variety of practices. We maintained rigour at every level of analysis—from the conduct of the nominal groups, through the transcription and initial data coding, to final analysis—by a thorough contextualisation of data extracts, a reflexive thematic analysis involving attention to all perspectives, and careful attention to deviant cases. The written protocol minimised any potential investigator bias. The themes that emerged from the analysis of the initial four transcripts were examined against field notes taken in the other 12 groups to confirm the findings reported here. We consider the insights and concepts developed to be widely applicable to general practitioners across the United Kingdom.^{17 18}

Other studies

Previous research has shown that doctors tend to negatively stereotype patients who deviate from the sick role.¹⁹ Patients with chronic fatigue syndrome have been described as excessively fixated on illness, leading to doubts about the diagnosis.^{6 20} It has also been argued that pressure groups influence clinical encounters.²¹ These influences may make it harder for doctors to legitimise the symptoms of chronic fatigue syndrome.

Consultations have poorer outcomes when patients openly disagree with their doctors.²² Our findings support this research, indicating that where doctors find it difficult to make a satisfactory diagnosis or are influenced by negative encounters with patients difficulties in management are likely to escalate, potentially creating a vicious spiral of alienation between doctor and patient.

Implications

Effective clinical management at least partly depends on the development of a collaborative doctor-patient relationship.^{23–25} For chronic fatigue syndrome and irritable bowel syndrome, effective management includes discussion about mental health interventions, particularly for patients who have responded poorly to other management options.^{3 8} Our findings indicate that general practitioners’ perceptions about patients with either

What is already known

General practitioners are more uncertain or dismissive of chronic fatigue syndrome than they are of irritable bowel syndrome

Mental health interventions may be effective for patients with chronic fatigue syndrome or irritable bowel syndrome who don’t respond to management of symptoms in primary care

What this study adds

Differences in general practitioners’ perceptions of the two conditions are due, in chronic fatigue syndrome, to the lack of a precise bodily location of the illness, the changing classification of the syndrome over time, patients’ transgression of the sick role and lack of stoicism, and conflict with doctors over management

Even when doctors recognise psychological or social factors, many do not consider referral for mental health interventions because they are unfamiliar with the interventions or think them unavailable or unnecessary

condition may be a barrier to the implementation of mental health approaches. To overcome these barriers doctors must recognise their deeply held beliefs that mediate their understandings of complex disease mechanisms. Only then can they engage with a complex, multifactorial model of illness and its implications for treatment. Such a change in perceptions will need to be supplemented by the establishment of locally available effective interventions.

This study is part of a research programme examining the methodology of group decision making for the development of clinical guidelines, funded by the Medical Research Council. This programme is overseen by a steering committee comprising SC, NB, TS, Andy Haines, Colin Sanderson, and Theresa Marteau. Andy Haines also provided valuable comments on the drafts of this paper. We thank Kirsten Larkin for formatting the questionnaire, providing administrative support, recording the meetings, and transcribing the data. We thank the general practitioners who took part in the study.

RR and NB designed the study. RR collected the data, with the help of Kirsten Larkin, and did the analysis, with SC. All authors contributed to the interpretation of the data. RR drafted the paper, and all authors critically revised it.

Funding: None.

Competing interests: None declared.

Ethical approval: Not needed.

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(Accepted 12 March 2004)

doi 10.1136/bmj.38078.503819.EE

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