

Primary care

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

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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. Patients often present with symptoms that are diffuse or difficult to characterise. Symptoms, the outlook of patients, and responses to treatment are similar for both conditions.¹ Despite the similarities, some general practitioners are dismissive of chronic fatigue syndrome, whereas irritable bowel syndrome causes them less difficulty.²⁻⁴

Mental health interventions may be effective in both syndromes for patients who don't respond to management of symptoms in primary care.⁵ However, doctors are reluctant to explore psychosocial aspects of patients' lives and to use psychological treatments for irritable bowel syndrome.^{4 6 7} 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 larger research programme which recruited a random sample of clinicians from throughout England. Four nominal groups of general practitioners from the larger research programme of 16 nominal groups were chosen for this analysis. (Nominal groups are a formal method for eliciting opinions in a transparent and explicit way.) The groups comprised between nine and 12 doctors and met between February and October 2002 (see bmj.com).

Procedure

Participants were sent a series of clinical scenarios involving patients with chronic fatigue syndrome or irritable bowel syndrome. They 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. Each group met for a facilitated discussion lasting four hours where they explored differences in opinion for each of the scenarios in turn. The meetings were audiotaped and later transcribed. In addition, field notes were written by one of the authors, who kept a non-attributed "journal." All discussions were conducted according to a protocol that comprised a description of the process to



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be followed, instructions to be given to each group, and explanations of the terms used in the questionnaire.

Analysis of transcripts

Two of the authors independently drew up a preliminary list of themes from the initial transcripts and journal notes. These were then discussed and appraised by all authors. We used a variant of grounded theory for the analysis.⁸ 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 (see bmj.com).⁹

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 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. Secondly, variation over time in the classification of chronic fatigue syndrome delegitimised the diagnosis for some participants. 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. 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. However, they did raise some concerns that patients with irritable bowel syndrome were motivated by pressure groups critical of biomedical views.

The concept of the sick role has been heavily criticised. However, our results support its usefulness in describing normative expectations in the clinical encounter. Participants considered that in 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.

Influence of general practitioners' beliefs on management

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 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).

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 were that these patients "are not as heartsinky as people with chronic fatigue" (GP 18), so doctors were not motivated to shift responsibility 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.

Some doctors did imply that irritable bowel syndrome 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 advocate mental health interventions for chronic fatigue syndrome, because of their experience of positive outcomes ("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.

Discussion

Methodological considerations

Our sampling method allowed us to ascertain views of a range of general practitioners from a variety of practices. We maintained rigour at every level of analysis, and 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 from the larger research programme to confirm the findings reported here. We consider the insights and concepts developed to be widely applicable to general practitioners across the United Kingdom.^{10 11}

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

Other studies

Previous research has shown that doctors tend to negatively stereotype patients who deviate from the sick role.¹² Patients with chronic fatigue syndrome have been described as excessively fixated on illness, leading to doubts about the diagnosis.^{3 13} It has also been argued that pressure groups influence clinical encounters.¹⁴ Consultations have poorer outcomes when patients openly disagree with their doctors.¹⁵ Our findings support this research.

Implications

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.⁵ Our findings indicate that general practitioners' perceptions about patients with either condition may be a barrier to mental health

approaches. A change in perceptions will need to be supplemented by the establishment of locally available effective interventions.

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