

Diagnosis in chronic illness: disabling or enabling—the case of chronic fatigue syndrome

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J R Soc Med 1995;88:325–329

Keywords: *Diagnosis; doctor-patient relations; chronic fatigue syndrome*

SUMMARY

This paper examines doctors' and patients' views on the consequences of an increasingly common symptomatic diagnosis, chronic fatigue syndrome (CFS). Two studies were conducted: the first comprised interviews with 20 general practitioners; the second was a longitudinal study, comprising three interviews over a period of 2 years with 50 people diagnosed with CFS. Contrasts were apparent between doctors' practical and ethical concerns about articulating a diagnosis of CFS and patients' experiences with and without such a diagnosis. Seventy per cent of the doctors were reluctant to articulate a diagnosis of CFS. They felt constrained by the scientific uncertainty regarding its aetiology and by a concern that diagnosis might become a disabling self-fulfilling prophecy. Patients, by contrast, highlighted the enabling aspects of a singular coherent diagnosis and emphasized the negative effects of having no explanation for their problems.

INTRODUCTION

Patients with seemingly unrelated multiple symptoms which do not correspond to a clear-cut diagnosis represent a major problem in medical care, particularly in general practice. Studies of ambulatory general practice indicate that 68–92% of patients do not have demonstrable evidence of serious physical disorder¹.

What should the patient be told in these circumstances? Many doctors have reservations about committing themselves to a firm diagnosis in the absence of any clearly defined pathophysiology. The possibility of a psychogenic origin always lies in the background and many clinicians are concerned that giving a definite diagnosis may become a disabling self-fulfilling prophecy, influencing patients' perceptions of their symptoms and altering their behaviours and social relationships^{2,3}.

In this paper, doctors' and patients' perspectives on the risks and benefits of symptomatic diagnosis are examined in relation to a condition notable for its chronicity and puzzling constellation of symptoms, chronic fatigue syndrome (CFS). Surrounded as it has been by controversy and uncertainty, CFS supplies a useful focus for the issue of uncertainty and diagnosis in clinical practice. Subject to a variety of interpretations, functional and physiological⁴, and shifting definitions, this is an illness which as yet has no scientifically

established diagnostic tests nor proven treatments. As such, it could be claimed, as several doctors in this study argued, that the diagnosis has little practical value. However, patients' comments and experiences challenge that view. Despite uncertainties associated with CFS as a diagnosis, patients in this study found the diagnosis more enabling than disabling. Indeed, getting a diagnosis appears to have been a turning point for many patients, particularly those who had been without a diagnosis for a long time. This finding poses a dilemma for doctors who are concerned about providing patients with uncertain symptomatic diagnoses like CFS. We conclude with comments about how some doctors have successfully negotiated this dilemma.

METHOD

This paper is based on two related investigations. The first involved 20 general practitioners (11 women and nine men) who were recruited with the assistance of the Canberra branch of the Royal Australian College of General Practitioners (RACGP). During interview, they were asked about their views on CFS and the difficulties it created for them in their practices. These issues were discussed in relation to their beliefs and practices around chronic illness generally.

The second investigation was conducted with 50 people who had been diagnosed by doctors as having CFS. The criteria for a diagnosis of CFS include chronic or relapsing fatigue for more than 6 months and evidence of neuropsychiatric dysfunction. Other possible explanations for the illness must have been examined and rejected⁵. This

group comprised 40 women, ranging in age between 13 and 64 years (mean=36.4 years) and 10 men with an age range between 25 and 53 (mean=39.2 years). These participants were interviewed, in depth, three times over a period of 2 years (1990–1992). They were asked to describe the characteristics of their illness over time, their history of medical investigations, the social consequences of their illness and their own approaches to managing their illness.

Interview schedules for both investigations were provided prior to the interview to allow participants time to reflect on their answers. At the interview, they could speak to their notes if they had made any (60% of the participants with CFS had done so) or discuss the questions in a less structured way. At the end of each interview, the schedule was reviewed to ensure that all questions had been addressed. Interviews were conducted and taped by one interviewer (RW). They were later transcribed, coded and analysed. To ensure reliability and consistency in the coding process, several interviews were recorded some weeks after they were initially coded. Analysis of the qualitative data was facilitated by the use of a computer program designed for that purpose (NUDIST).

RESULTS

Doctors' views on CFS

Only one of the 20 doctors was unaware of an illness called CFS. Almost half were unsure whether they had had patients with it. The other half were generally quite knowledgeable about the condition, although some maintained reservations including: skepticism towards 'fashionable epidemics'; caution about loosely defined 'umbrella terms' such as CFS; and a concern that both doctors and patients may end up 'medicalizing' fatigue when it might well be a case of people simply *doing too much*. A few expressed concern about the legal/professional position of doctors in relation to a diagnosis such as CFS, mentioning their reluctance to become embroiled in controversy or be subject to critical professional scrutiny.

Fourteen of the doctors interviewed were reluctant to diagnose CFS, principally because of scientific uncertainties about the condition, but also because of their beliefs about appropriate professional practice and their uncertainty about the possible impact of the diagnosis on patients' lives. However, they did not express reservations about offering a diagnosis to patients with well-defined conditions and did not speculate on the consequences for patients' lives of not having a diagnosis.

Three of these doctors held very strong views about the most effective style of care for patients with non-specific conditions like CFS. They saw the doctor's role as authoritative and directive, and they expected patients to accept their assessments and comply with their

interventions. All three felt that appropriate care comprised either advice and some *pushing along*, or intensive psychotherapy based on the assumption that the physical symptoms were psychological in origin. One doctor spoke of patients *needing their symptoms*. Another who specialized in patients with chronic pain insisted that diagnosis or the details of pain were unimportant. He made it clear that when he and his patients had differing views about the nature of the problem, his view would prevail. To a lesser degree the other two doctors shared this approach.

Eleven of the doctors who were reluctant to diagnose CFS were less definite about their role. They spoke about the complexity of offering care. Several questioned the extent of the care they could provide, and what it was that patients really wanted from them. They said their confusion was amplified by the way some patients presented their story. In particular, they mentioned the tensions created when patients had already seen several doctors and then presented complicated stories with great emotion or aggression.

These 11 doctors also mentioned reservations about the impact of CFS diagnosis. They were concerned that the diagnosis might become a self-fulfilling prophecy, or disconcerted by the possibility that 'normal' symptoms of fatigue and weakness might become unnecessarily pathologized. One said that she thought it was important to avoid a 'label' so that she would be able to maintain a critical and open mind to a person's problems. Two explained their reluctance by commenting on their dissatisfaction with diagnostic criteria for a wide range of complex chronic conditions. They preferred generic diagnoses, such as 'disorder of the musculoskeletal system' over specific diagnoses.

Six doctors described ways of managing the scientific uncertainties which also accommodated the concerns and needs that patients in this study have identified (*see below*). These doctors adopted a collaborative approach to providing care. They said they were committed to working with patients' views about their health, indicating a desire to understand the world of their clients. They thought it important to affirm their patients' accounts and to learn from their struggles. They tried to develop a relationship with their patients where all aspects of the person's health might be discussed, including the alternative treatments their patient might seek. Each stressed the need for doctors to *understand*; to *offer patients support, knowledge, reassurance and hope*. All but one stressed the importance for any patient of having a diagnosis to explain their distressing symptoms.

Although all six acknowledged the scientific uncertainties about CFS, each had found ways to interpret the uncertainties. Two had become extremely well-informed about current research on CFS. They felt able to make

judgements about the most plausible explanations and the most promising treatments. Four doctors had not followed current research closely, but were comfortable with the idea that medical explanations are often incomplete. As they had read widely, they were aware of the possible treatments for CFS, although they were reluctant, to varying degrees, to experiment with more controversial regimes. Instead they sometimes referred patients to general practitioners or specialists who would offer such treatments, and they encouraged or tolerated their patients seeing alternative practitioners. In effect, they dealt with their concerns about care and accommodated scientific uncertainty either by becoming 'case managers' or 'sounding boards' for their patients. They monitored health changes, gave emotional support and encouragement and passed on any relevant research data or advice based on other patients' experiences. With CFS as a label, the doctors were able to help patients work out their own ways of coping.

These six doctors said they had not learnt these responses in their medical training. Instead, they had learnt to offer this sort of care through exposure to many patients with chronic illness, experience of illness either in themselves or in a family member, or by witnessing the changes due to an unexplained illness in a previously healthy patient.

Patients' views on diagnosis

Ninety per cent of patients nominated diagnosis as the single most helpful event in the course of the illness. Several of these participants were surprised at their own reactions to the diagnosis. They said they had previously shared some of the doctors' reservations about possible adverse consequences of diagnoses until this ongoing illness had disrupted their daily lives.

Although participants had to have a diagnosis of CFS to be included in this study, most had had lengthy periods of illness prior to the diagnosis so they were able to comment on the effects of not having a diagnosis. Only 11 of the participants had a diagnosis within 12 months of becoming ill. In contrast, 33 participants had been ill without a diagnosis for more than 3 years. They had also been ill for some time before the condition was given its current name and definition in 1988⁶.

Patients emphasized the adverse effects of having no diagnosis for their problems, particularly on their day to day health and well-being. They described how fear, anxiety, confusion, self-doubt and bitterness developed. Fear was associated with the nature of the illness as several wondered whether they had an undiagnosed terminal condition such as cancer. Others became anxious and confused when they felt their doctors had been disparaging and dismissive, instead of supplying the information and support they had anticipated. For many, self-doubt and bitterness grew when doctors

interpreted their symptoms as evidence of psychiatric disorder. Women were much more likely to be given this interpretation (85% of women participants) than men (30%).

Those who were severely ill, feeling dismissed by doctors and unsupported by family or friends, were especially undermined. They said they had struggled to maintain their usual social roles or sources of financial support while feeling confused and vulnerable to their own doubts about the nature of their problem, as well as the doubts of their doctors, their families or employers. Several described how they began to lose their sense of identity and purpose. Their perceptions of themselves became fragmented as they saw a different self mirrored in other people's reaction to their illness.

Although it was valued by all, diagnosis meant different things to different participants. Factors influencing their responses included the length of time they had been without a diagnosis, the severity of their illness during that time and the extent of the disruption it had caused in their lives.

The value of diagnosis did not lie primarily in its immediate effects. Many people said they were reluctant to hear that they had a chronic illness. Contrary to the apprehensions of most of the doctors interviewed, no one embraced the idea of long-term illness. More than half sought a second opinion before they were prepared to accept the diagnosis. Those who accepted the diagnosis when it was first proposed usually did so only when there was supporting evidence. For example, the diagnosis was accepted if: the doctor had a good reputation or was trusted; the patient had already suspected the diagnosis; or if numerous tests had been performed so alternative explanations had been eliminated. Approximately a quarter of the participants decided that the doctor's diagnosis fitted only after they read accounts of the illness elsewhere. During the course of the study, only two people continued to have doubts about the appropriateness of this diagnosis for describing and managing their problems.

Nor was diagnosis necessarily associated with social understanding. For most people, it only partially alleviated the social problems that had arisen. The longer people went without the diagnosis, the less likely it was that diagnosis could confer the social legitimacy the patient needed. In part that was because people were having to rely on a controversial diagnosis to overcome long established doubts and disbelief. As one said,

I've got something which no one believes in. Even the doctor who gave me the diagnosis told me he had always thought it was hysteria.

However, the value of diagnosis was a common theme, with its value extending beyond a simple rendering of social and medical legitimacy. For people whose illness had been

long and severely debilitating, but unnamed, the primary value of diagnosis lay in the meaning that it gave to their years of suffering. Without a diagnosis and without affirmation that they were ill, they had struggled to make sense of what was happening to them. Without a name for the condition, they had lacked a language for discussing their complaints with others. A compelling part of their lives could not be shared. They had no way to explain their grief at so many changes in the way they lived their lives. In contrast, with a diagnosis, they had a label that others might understand or recognize, a label that reassured them that others had also shared their form of suffering. Furthermore, this label allowed them to create a linguistic distinction between themselves and their illness. They could begin to say:

I am not crazy; it's this illness that is crazy.

These views vary from those expressed by seven people who had a diagnosis within months of becoming ill. These people appeared to have been less harmed by the experience of ill health. Their comparatively early diagnosis seems to have moderated the harmful social and psychological consequences. Diagnosis did not necessarily diminish the severity of their symptoms, but when they described their experiences, they tended to see their illness as less traumatic than the majority of participants. Even when they had been very sick they used phrases such as:

I don't think there is anything remarkable about my experience. I'm just one of many people who have been through this.

They were able to tell their story without a sense of being wronged and harmed by others, although they, like the majority, had difficulties in relation to work, family and study. It seems likely that these people felt less harmed because they had an explanation from the earliest stages of their illness. As a consequence, they encountered fewer social problems than others. With an early explanation, employers and families generally understood and accepted that the person was ill, even though they did not always understand the effects of the illness.

In the main, diagnosis provided all patients with a rationale for the fundamental change in how they experienced the world. They were able to begin to understand their experience as coherent and meaningful, thus they had the essential preconditions for coping⁷. Armed with this framework for understanding their symptoms, many said they felt more in control of the circumstances of their lives, able to work out meaningful ways of managing their problems.

For 20 years I thought about suicide every day. It's only in the last eight months that I have stopped.

Q: What changed?

Having a diagnosis. It made that much difference after being diagnosed and treated for so many different psychiatric conditions. Not one of those had therapeutic value. Have you read Martin Seligman's book, *Learned Helplessness*? When you feel helpless life doesn't have a lot of promise. But when you find there is rhyme, reason or explanation you don't feel as helpless, even if in fact you are as helpless. Your perception is different.

Despite the uncertainties, once patients were diagnosed, it also seems that the course of their illness moderated. Prior to diagnosis, participants reported deteriorating health. However, few described their health problems as becoming worse after diagnosis. Whatever the significance of their diagnosis, the majority of patients said it had positively influenced the way they managed their symptoms.

Finding out what was going on was very helpful, even if you can do nothing about it. I had doctors saying to me that it didn't matter if I had CFS as there was nothing I'd be able to do about it anyway, so why get diagnosed. But the point of diagnosis is that it enables you to get some idea of what is going on, to work out things that might help or decide what things might be making you worse. I had so much conflicting advice before that.

DISCUSSION

As has been found in studies of terminal and other more readily diagnosed chronic conditions⁸⁻¹³ patients in this study preferred to have a diagnosis, notwithstanding its uncertainties, once their health had become a continuing problem. Given that the majority of doctors in the study expressed reservations about the value of providing people with this diagnosis, these findings about the value to patients of the diagnosis of CFS have important implications for the management and care of this and other chronic conditions where there are scientific uncertainties.

Our findings suggest that doctors need to balance their concerns about symptomatic diagnosis triggering a self-fulfilling prophecy with an appreciation of the possible benefits to patients. In so far as diagnosis gives people a coherent 'framework for interpreting and ordering [their] distressing experiences'¹⁴, it may ease both their distress and contribute to beneficial changes in their health. In this study, instead of contributing to chronicity, as doctors feared, an early diagnosis was associated with a moderation in people's health problems and an improvement in overall well-being. In contrast, lack of a diagnosis was related to deteriorating health and growing feelings of despair and helplessness.

Patients' accounts provide useful pointers to the appropriate structuring of medical care for people who are chronically ill. The most important requirement of the people interviewed in this study was for information that

fitted with their experience and gave them a framework for understanding how they had come to be the way they were, how to manage in the present and how their lives might be in the future. We speculate that some doctors' reservations about articulating the diagnosis of CFS are influenced in part by their own uncertainty in contemplating a diagnosis without a clear aetiology and unsupported by objective tests. Refraining from offering any diagnosis could be one strategy for coping with such uncertainty. However, several of the doctors in this study were able to suggest the diagnosis of CFS to their patients without necessarily abandoning a critical scientific stance. They were ready to acknowledge that medical knowledge has limitations and that diagnoses may have meanings beyond the matching of symptoms to specific aetiological models. They were also committed to supporting their patients in making sense of their illness, collaborating with them in the search for more useful information and better ways of coping.

Acknowledgments We gratefully acknowledge the helpful suggestions of Dr G Bammer, Professor L Broom and Professor R M Douglas.

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(Accepted 17 August 1994)