Illness doesn't belong to us

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SUMMARY

There has been little research in Britain into the experiences of doctors who are ill. We conducted in-depth interviews with 64 doctors of all grades with a recent illness lasting one month or more. Whether the illness was physical or psychiatric, many expressed the idea that illness is inappropriate for doctors. This idea is a cultural value among doctors which is reinforced by the organization of medical work. It discourages doctors from seeking and obtaining appropriate help when they are ill.

INTRODUCTION

Illness doesn't belong to us. It belongs to them, the patients. Doctors need to be taught to be ill. We need permission to be ill and to acknowledge that we are not superhuman (Interview 52).

Studies of doctors' health have generally focused on 'sick' or 'impaired' doctors who through substance abuse or psychiatric illness are thought to present a risk to patient safety[1–3]. Another body of research maintains the focus on doctors' psychiatric health, with reports of higher than expected levels of occupational stress and distress among medical students, doctors in training, general practitioners and consultants[4–8]. Other studies have investigated doctors' management of their own health, documenting tendencies to self-diagnose, self-medicate, delay seeking help and bypass formal routes to services[9–11]. Richards[12] highlighted the difficulties doctors face in being ill and obtaining appropriate help, including the idea that doctors deny their own illnesses.

This paper explores the idea that a fundamental barrier to the management of doctors' health lies in the notion that doctors 'may not' or 'should not' get sick. We draw on data collected through in-depth interviews with doctors with a recent history of illness conducted during a study of doctors' health and needs for services[13]. Qualitative methods were used in this part of the study where the aim was to understand doctors' experiences of being ill and seeking help. Such methods are increasingly valued in health research for the development of concepts with which we may understand complex social phenomena[14].

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METHOD

To overcome problems of confidentiality, potential participants were invited to contact the researcher (CM) through notices in the medical press and via an anonymous screening questionnaire sent to general practitioners in two family health service authorities and to hospital doctors in one trust. Over 80 doctors expressed an interest in participating. Those who did not report an illness lasting one month or more in the previous 3 years were excluded.

Face-to-face interviews, lasting from 45 min to more than two hours, were conducted with 32 doctors. Where more convenient, telephone interviews were conducted. These were carried out with 32 doctors, each interview lasting from 30 to 60 min. Interviews were semi-structured, a checklist of questions being used to investigate access to care, mechanisms of support, sick leave, return to work, perceptions of care received, the personal and professional impact of illness and attitudes towards illness. Interviews were audiotape recorded and transcribed. The transcripts were analysed manually to identify recurring themes and develop categories, by recognized procedures for the analysis of qualitative research[14]. Cases were coded according to the disease category reported (physical or psychiatric), and transcripts were scrutinized for reported attitudes towards illness and evidence of behaviours related to these.

FINDINGS

Respondents

We interviewed 18 male and 21 female general practitioners, 6 male and 6 female doctors in training and 8 male and 5 female consultants. They ranged in age from 27 to 65 years. 24 doctors reported a psychiatric illness, 36 a physical illness and 4 both a physical and a psychiatric illness.

We were concerned that this self-selected sample might consist entirely of doctors anxious to report negative experiences of health care but only about one-quarter of respondents could be so classified. Another quarter of respondents reported both positive and negative aspects in equal measure, while about half were generally happy with the standard of care they received from their colleagues.

The stigma of mental illness

Most of the doctors with a psychiatric illness initially lacked the insight needed to recognize the nature of their problem. They described feeling tired, overworked or under stress, but were not necessarily aware that their symptoms might point to a psychiatric diagnosis. Realizing that they had been labelled as mentally ill, all these doctors experienced embarrassment, shame or horror. In addition to discomfort at the stigma which generally attaches to a diagnosis of psychiatric illness, they were dismayed that they as doctors should be so diagnosed.

It felt horrible to be a doctor with an illness. Being a doctor heightened a sense of failure and inadequacy and guilt. Everyone presumes you should be above it and it's seen as a sort of failure.

Doctors with a physical disorder

Doctors with a physical disorder experienced a wider range of reactions. Those with a chronic disorder were particularly likely to report a sense of discomfort at being at once medically qualified and ill. A general practitioner with breast cancer recalled that being ill was

. . . a terrible let down. Not allowed at all . . . you feel that you're somehow, by the nature of your training, set apart from illness . . .

Some doctors with an acute disorder also described embarrassment or guilt and a sense of failure that they as doctors should have succumbed to illness. On the other hand, 6 with acute physical disorders denied experiencing any such feelings. One of these, a surgeon operated on after a car accident, clarified the difference between his own relatively straightforward case and longer term cases:

. . . surgical problems are usually dealt with reasonably swiftly . . . I think a medical or more long term or prolonged illness—that might be more difficult because then you're more reliant on medical care and you must feel then more of a burden to your colleagues.

Two of these doctors determined that fatigue or pain would not prevent them from continuing to work, while another 2, although denying any sense of embarrassment or failure, admitted that they felt judged by their colleagues for being ill.

Reasons the doctor 'may not' get sick

The doctors we interviewed commented on the origins of this notion. First they referred to the importance of *coping* with pressure, stress and illness. This is inculcated during medical training, as a registrar with myalgic encephalomyelitis suggested:

The idea that you have to soldier on is very prevalent while you're training.

Another registrar, with multiple sclerosis, believed that to be seen to be coping despite her illness was necessary because of the competition among medical trainees. She feared that any sign of 'weakness' might disadvantage her career. Another trainee, who eventually left clinical medicine, returned to work after an absence related to a depressive illness. She was told that she would have to learn to cope. For this reason one young doctor ignored symptoms which later led to a diagnosis of diabetes, explaining that training is a period where chronic low levels of health are expected.

Older doctors also used the discourse of coping. A consultant anaesthetist spoke of doctors' belief that illness should not affect them as badly as it does other people and that they should 'work on'—as indeed most in this sample did. One general practitioner felt a sense of failure when diagnosed with atrial fibrillation. He was concerned that this might be seen as due to an inability to cope with the pressures of general practice. Another reiterated that succumbing to illness may be interpreted as inability to cope, with consequences for the older doctor:

There's a definite feeling that if a doctor says, 'I can't cope', that's it. Can't cope, well retire. It's not, 'OK well we will arrange things until you get your spirit back then you can take up'. Can't cope—bugger off.

Doctors also spoke about their tendency to minimize symptoms. Some described how they did not want to be seen to make a fuss, with the implicit or explicit suggestion that this is what characterizes patients. Others spoke of the difficulties of interpreting their own symptoms, concerned that they might be exaggerating them, yet aware that during a consultation they might be expected to have made a diagnosis:

You don't want to be thought of as neurotic, and if you are medical you have a much fuller idea of what all these symptoms mean so it's quite easy to imagine things . . . you're always worried that what you feel you have isn't there and I suppose you worry you'll make a fool of yourself.

The organization of medical work reinforces these attitudes since cover for an unplanned absence is difficult to

arrange. All doctors referred to the 'burden' which their absence placed on colleagues, who would be expected to assume their duties. A doctor with Crohn's disease described the tension between attending to his own health and loyalty to his colleagues:

> Part of you is saying, 'You are ill for God's sake and people get ill'. And then there's another big part saying, 'It really is murder out there on the wards when there's only a reduced complement of staff'.

Many general practitioners spoke of their sense of guilt about inconveniencing their partners by taking sick leave, reasoning that they too might feel annoyed if they had to cover a partner's absence. Some reported that colleagues reinforced the idea that doctors should not get sick, encouraging the unwell doctor to continue working, even exerting overt pressure to return to work.

Consequences for doctors' health care

These attitudes affected the doctors' use of health care services. It was common for the doctors initially to deny that they might be ill and thus in need of medical advice. Like trainees, fully qualified doctors also expressed the idea that low levels of wellbeing, related to fatigue, are the norm. For example, a general practitioner eventually treated for a neuroma dismissed her neurological symptoms as due to stress, reasoning that all general practitioners are stressed. This view was confirmed by her practice colleagues.

Although all interviewees were registered with a general practitioner, many doctors were reluctant to consult a doctor formally. Some tried to deal with the problem themselves through self diagnosis and treatment. In some cases they made errors that led to delays in receiving appropriate help. Doctors with a psychiatric illness were particularly concerned about confidentiality, and most felt there was nowhere they could turn to for help. However, some doctors with a long-term physical disorder, such as multiple sclerosis, were also concerned that their careers were at risk if employers and colleagues learned about their condition.

Many doctors reported difficulties in consultations, related to their problematic status as patients who were also medically qualified. During the consultation between doctor and doctor-patient the ground rules may be unclear and both parties may be uncertain about how to behave. Thus some doctors judged that because of their medical status they were not given adequate information, follow-up or psychological support. Some who were admitted to hospital felt that they received poorer nursing care, being left to fend for themselves, with the expectation that as doctors they would 'know what to do'.

Denial of illness also obviates the need for sickness absence, and a reluctance to take sick leave characterized all the interviewees. One hospital trainee with lupus was absent briefly from work:

> And then I went back to work because I couldn't believe I wasn't better though I didn't feel much better; and I had to say to them 'I'm sorry I can't get through the day' and they said 'You'd better work 10–4' but I felt as if I was making a big thing out of it.

A general practitioner with hepatitis said

> I couldn't allow myself to be ill. I didn't rest as much as I should have. I felt the surgery couldn't cope without me.

Another with thyrotoxicosis was advised by her general practitioner to take two weeks' sick leave but tried to negotiate a reduction:

> It was a busy time in the practice and I was very upset about landing my partners in it. Besides I had been working even before the diagnosis so I couldn't see what difference it made now.

DISCUSSION

Since this sample was self-selected, we must ask how representative are the views and experiences reported. It is not biased towards doctors' anxious to complain about poor medical care since only a minority of respondents believed that the standard of care was poor. Nevertheless, all the respondents distinguished between the technical quality of their care and their experiences as a patient, in a relationship with a treating doctor. Medical audiences to whom the study findings have been presented have indicated that these correspond to their own perceptions and experiences. Thus a limited form of respondent validation has been achieved[15].

The study provides confirmation of earlier findings that doctors' health care may be compromised by their own denial of the problem, fears that they may be thought to be complaining about trivial ailments and concerns for confidentiality[12]. However, we also identified a fundamental concept which gave rise to doctors' reluctance to acknowledge their own illness and to seek appropriate help. This idea, 'illness doesn't belong to doctors', was articulated by doctors with a psychiatric illness, as expected, but also by doctors with physical illness. Of these, doctors with a chronic disorder were most likely to view their illness as inappropriate for a doctor.

According to Parsons, when doctors diagnose and treat disease they are using their professional knowledge and authority to legitimize illness in others. Thereby they sanction an individual's assumption of the 'sick role', transforming that individual into a patient[16]. Medical

power, therefore, can be described as the necessary authority to define and identify illness, and to create the patient. Yet doctors' power to identify illness and to create patients seems diminished when members of the profession are themselves unwell. Doctors who are unwell may refuse and be denied the benefits of patienthood because of the notion that illness does not belong to them.

There is some evidence that this idea is also reinforced by people outside the profession. Interviewees related that their own patients variously expressed surprise, dismay and even anger on learning that their doctor was ill. These reactions suggest that lay people as well as doctors conceive of doctors and patients as separated by their relationship to illness—doctors defined by their power to treat illness and patients defined by having illness and requiring treatment.

The sick or impaired doctor of the literature is one with a psychiatric disorder, and by implication, one whom the stressed doctor is at risk of becoming[17]. Yet the experiences of doctors with a physical illness suggest that the problems associated with the sick or impaired doctor are but one extreme of a continuum. Doctors with a physical illness also expressed ideas about the illegitimacy of illness for them which led to their dealing with their own health problems, instances of delays in getting appropriate help and examples of poor care. Doctors who work while physically ill may present less of a risk to patients than those with a psychiatric disorder, but what is the quality of care delivered by a doctor who is 'soldiering on' with a debilitating physical illness? Questions also arise about the quality of health care medical practitioners can expect. Are their entitlements and needs different from those of lay people?

There has been much debate about how to address ill-health in doctors. First, there have been calls for greater use of existing services, with reminders to doctors that they should be registered with a general practitioner[18]. Except in the case of junior doctors, registration levels seem high but use of formal services appears to be low[13]. Thus registration of itself is insufficient since it does not overcome the barrier of doctors' feeling the need to be 'allowed' to be ill. Similarly, simple encouragement of doctors to make use of occupational health services within hospitals also overlooks the reluctance of doctors to be identified as ill[19,20]. Concerns about confidentiality, linked to reluctance to use existing services, can also be linked to the notion that illness is inappropriate to the doctor.

Second there have been calls to improve working conditions so as to increase job satisfaction[21,22]. Medical training and work have recently undergone substantial changes, some of which have been associated with increased occupational stress[8,23] The 'New Deal' effected a reduction in junior doctors' working hours but its impact on doctors' ability to manage their health is unknown. Some have suggested that, although junior doctors may work fewer hours, the hours worked are more intensive and there is less peer support than previously; locum cover still seems difficult to obtain[24]. Yet the organization of medical work is a crucial factor in the management of doctors' health and the ideas they hold about health. The structures of medical work reinforce cultural values, such as the ideal of doctors' stoicism in the face of illness, even to the point of neglect of their own and colleagues' needs.

There have also been proposals for strategies and structures to meet the particular health needs of doctors, including the need to educate medical students and doctors about the health risks they face[3,25], the development of coherent strategies to promote health at work[26], and most recently the suggestion for a body to oversee provision of health care to doctors at regional level[27]. Implicit in these is a recognition that as a professional group doctors face unique barriers to appropriate help.

This range of proposals reflects the complexity of the problem. Doctors' ideas about their own illnesses are clearly bound up with questions about identity and role; illness appears to compromise both. Such cultural elements may seem ephemeral but they are powerful and pervasive because reinforced by structural factors; for example, during their training, new doctors must either assimilate such concepts or be rejected as unsuitable for membership of the profession. They are also reinforced by the organization of medical work itself, where absences impose a 'burden' on colleagues because cover for unplanned absences is not easily arranged[28]. Solutions must address both aspects. Changing doctors' attitudes to their own health, through the education of medical students, is a necessary first step. However, of itself this will be insufficient if the organization of medical work does not facilitate taking sick leave and if previous generations of doctors, now employers and trainers, continue to transmit the notion that illness does not belong to doctors.

To date there has been insufficient recognition of the difficulties doctors encounter in acknowledging their own illnesses. A recent report from Norway related the success of a pilot health service for doctors to the fact that service providers were trained in issues related to the special needs of doctor-patients[29]. The first of these may be the need for 'permission to be ill': and this permission may be required from individual doctors, from professional and purchasing bodies, and perhaps also from patients.

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