

SHORT REPORT

Patients whom neurologists find difficult to help

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Background: All doctors recognise that some patients are more “difficult to help” than others, but the issue has received little systematic investigation in neurological practice.

Objective: To test the hypothesis that patients whose symptoms were less explained by organic disease would be perceived as more difficult to help.

Methods: In a consecutive series of 300 new neurology outpatients, neurologists indicated on four point Likert-type scales how “difficult to help” they found the patient and to what extent the patient’s symptoms were explained by organic disease. The patients’ demographics, health status, number of somatic symptoms, and mental state were also assessed.

Results: The neurologists rated 143 patients (48%) as “not at all difficult” to help, 111 (37%) as “somewhat difficult”, 27 (9%) as “very difficult”, and 18 (6%) as “extremely difficult”. A logistic regression model was constructed and the hypothesis that patients whose symptoms were less explained by organic disease would be perceived as more difficult to help was supported. The only other measured variable that contributed to perceived difficulty was physical disability, but it explained only a small amount of the variance.

Conclusions: Neurologists find patients whose symptoms are not explained by organic disease more difficult to help than their other patients.

All doctors recognise that some patients are more “difficult to help” than others. This phenomenon has also been described as “frustrating patients”, “difficult patients”, and “problem patients”.¹ Over recent years there have been a few studies of difficult to help patients under various labels and in various settings.^{2–13} We are, however, not aware of any studies that have examined this issue in neurological practice.

As part of a prospective cohort study of new neurology outpatients,^{14–15} we aimed to determine how difficult to help neurologists perceived each patient to be, and what patient characteristics were associated with perceived difficulty. Our hypothesis was that patients whose symptoms were unexplained by neurological or other medical disease would be perceived as being more difficult to help than those whose symptoms could be explained by disease.

METHODS

At the time of the study, neurology services in Lothian were provided by eight consultants and their junior staff. All outpatient clinics saw general referrals, which were distributed by clerical staff simply according to available appointments. Clinic templates dictated the number of urgent, semiurgent, and routine appointments available in each clinic.

Sampling

The study was conducted between November 1997 and March 1998 in five of the eight consultant outpatient clinics. Limiting the number of clinics to five allowed one clinic to be studied each weekday. All new patients were included except in one clinic where, because of the large number attending, every alternate new patient was included.

Following the initial consultation with the patient, the neurologists indicated on a four point Likert scale⁸ how difficult to help they found the patient to be: not at all difficult; somewhat difficult; very difficult; extremely difficult.

The rating of the degree to which the patient’s symptoms were considered to be explained by organic disease was also obtained from the neurologist on a four point Likert type scale immediately after the initial consultation: “not at all explained”, “somewhat explained”, “largely explained”, and “completely explained”.¹⁴

After their consultation visit, patients were interviewed by researchers trained in mental state evaluation using the primary care evaluation of mental disorders (PRIME-MD).¹⁶ This brief structured interview of established reliability and validity was used to make diagnoses of anxiety and depression disorders. The interviewers were blind to the neurologists’ ratings.

Patients also completed self rated questionnaires. Perception of health status and disability was measured using the medical outcome study 36 item short form questionnaire (SF-36)¹⁷ which examines health status in eight domains, each assessed by a separate subscale. Physical symptoms were measured using a checklist and emotional distress using the hospital anxiety and depression scale (HADS).¹⁸

Analyses

First, we described the “difficulty” ratings. Second, we examined the association of the difficulty ratings with the neurologists’ opinion of the extent to which the patients’ symptoms were explained by “organic” disease using the χ^2 test. Finally, we examined the relative contribution of the patient variables to the doctors’ perception of difficulty. In order to do this we dichotomised the neurologists’ difficulty rating into low difficulty (“not at all difficult” and “somewhat difficult”) and high difficulty (“very difficult” and “extremely difficult”) and converted age, SF-36 subscales, and HADS total scores into quintile ranges. We then constructed a model for multiple backward logistic regression.

Ethics

The local research ethics committee approved the study and all participating patients gave their informed consent.

Abbreviations: DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition; HADS, hospital anxiety and depression scale; PRIME-MD, primary care evaluation of mental disorders; SF-36, medical outcome study 36 item short form health questionnaire

RESULTS

Of 364 new patients booked in the designated clinics during the study period, 48 did not attend, leaving 316 eligible to participate. Of these, 12 refused, one had too much cognitive impairment, two were lost to assessment, and one reported the assessment to be too distressing and withdrew. This left 300 patients—a participation rate of 96% of attenders and 82% of referrals.

Of the 300 patients assessed, 174 (58%) were female. The mean age was 43 years (range 14 to 88). Table 1 describes the neurologists' final clinical diagnoses of patients in the sample. In some cases these clinical diagnoses were merely symptom descriptions.

Difficulty data were available on 299 patients (one form was not completed). The neurologists described 143 (48%) as "not at all difficult" to help; 111 (37%) as "somewhat difficult"; 27 (9%) as "very difficult", and 18 (6%) as "extremely difficult".

When the scores on the neurologists' difficulty rating were compared across the four groups defined by the rating of how medically explicable the patients' symptoms were, those patients whose symptoms were poorly explained by organic disease were rated as more difficult to help ($\chi^2 = 103.2$, $df = 9$, $p < 0.0005$; fig 1). It is striking that 82% (27/33) of the patients with symptoms rated "not at all explained by disease" were rated as at least somewhat difficult to help, compared with only 25% (32/128) of those whose symptoms were regarded as completely explained.

On the PRIME MD interview, 140 of 299 patients (47%) met DSM-IV criteria for anxiety or depression diagnoses. In 77 of these patients (26%) the diagnosis was a major depressive disorder.

The outcome of the backward logistic regression analyses is shown in table 2. The degree to which symptoms were medically unexplained was the main determinant of patients being perceived as difficult to help. The SF-36 physical function score explained a small additional proportion of the variance.

DISCUSSION

In this prospective study of 300 new general neurology outpatients, almost half were described by the neurologist as at least somewhat difficult to help and 15% as very or extremely difficult. Patients with predominantly unexplained symptoms were perceived as more difficult to help than those whose symptoms were considered to be mostly explained by neurological disease. One other variable—physical disability—was associated with difficulty but explained only a small amount of the variance. Age, sex, pain, number of physical symptoms, and the presence of depression and anxiety diagnoses and symptoms did not influence the neurologists' perception of the patient as being difficult to help.

Table 1 Primary diagnoses*, given to illustrate the case mix (n = 300)

Headache	63 (21%)
Epilepsy/fits/pseudoseizures	43 (14%)
Multiple sclerosis	30 (10%)
Neuropathies (peripheral/entrapment)	25 (8%)
Syncope	22 (7%)
Spinal pathology (cervical/lumbar)	22 (7%)
"Dizziness"	8 (3%)
Parkinson's disease	7 (2%)
Psychiatric diagnosis only	7 (2%)
Other†	73 (26%)

*Diagnoses do not necessarily indicate neurological disease; some are simply symptom descriptions.
 †Diagnoses in the "other" category each had a frequency of less than 2%.

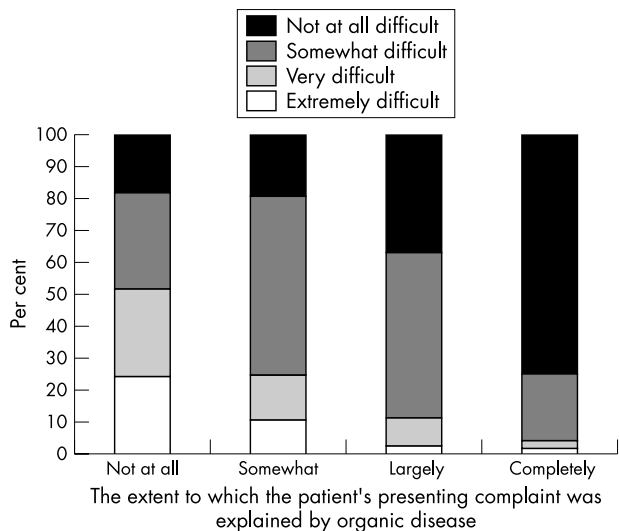


Figure 1 Percentage in each category of degree of "difficulty" (ie, an assessment of how difficult the patient was to help) in relation to the extent to which symptoms were explained by organic disease (n = 299).

Table 2 Stepwise backward multiple logistic regression analyses* of association with a rating of "difficult to help"

Variable	p Value	Wald	df	R
Symptoms explained by organic disease	<0.0005†	37.6	1	-0.4
Physical function (SF-36)	0.07‡	3.3	1	-0.07
Constant	0.003	8.6	1	

*Variables in model: age; sex; extent to which symptoms were explained by organic disease; SF-36 scores (physical function, physical role function, bodily pain, and social function); number of somatic symptoms; PRIME-MD ratings of (1) the presence of any DSM-IV anxiety or depression diagnosis and (2) the presence of major depressive disorder; total HADS score.

†Increased difficulty with symptoms which were poorly explained by organic disease.

‡Increased difficulty with poorer physical function.

DSM-IV, *Diagnostic and Statistical Manual of Mental Disorders, 4th edition*; HADS, hospital anxiety and depression scale; PRIME-MD, primary care evaluation of mental disorders; SF-36, medical outcome study 36 item short form health questionnaire.

We are unaware of any other studies that have examined the factors associated with neurologists finding a patient difficult to help. The question has been systematically examined in primary care in the USA,^{6 8 10 12 13} Canada,² and the United Kingdom.^{2 7} Hospital practice has been studied by general medical and surgical consultants in the United Kingdom⁹ and by rheumatologists in the USA.¹¹ Most of these studies also identified medically unexplained symptoms as an important contributory variable to the patient being perceived as difficult to help. Other reported associations include high service use, personality disorder, and dissatisfaction with the care received.

These findings must be interpreted in the context of methodological limitations. We measured the neurologists' perception of whether a patient was difficult to help using only a simple four point Likert scale rating. This did not allow an in depth exploration of what individual neurologists actually meant when they rated "difficulty". Nor did we examine doctors' characteristics that may have contributed to such difficulty. In particular, we did not compare the perceptions of consultants against senior trainees. The neurologist's rating of the extent to which the patient's

symptoms were explained by disease were made after the history and examination but before investigations were carried out. However, a review of cases after investigation found these initial assessments to be accurate.¹⁴ Finally, we cannot assume that these findings from Lothian consultant neurologists and their patients can be generalised to all neurological consultations.

“Medically unexplained” physical complaints are the single commonest reason for a patient to present to the health service. They account for 30% of neurology outpatient consultations.¹⁴ Neurological services would ideally include appropriate resources to assist neurologists in helping this substantial minority of patients. As a start we suggest that all doctors should be trained in the basic skills of assessing and managing medically unexplained symptoms. Since this study was conducted we have established an ongoing programme of research into such disorders. Our clinical experience is that local neurologists are becoming more confident in discussing the diagnosis, giving advice, and initiating management for these patients. Such patients with symptoms unexplained by neurological disease are gradually being perceived as “interesting” rather than “difficult”. This is to the benefit of both neurologists and their patients.

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