Characteristics of patients with persistent severe disability and medically unexplained neurological symptoms: a pilot study

J Allanson, C Bass, D.T Wade

This study audited 25 patients (21 female) from Oxfordshire who had been referred to either the liaison psychiatry or the neurological disability service between 1992 and 1998. They were given a rating of functional impairment using the global assessment of functioning (GAF) scale. Each patient was interviewed at home. The Barthel ADL index score (0–20, 20 being fully independent) and Frenchay activity index score (0–45, where 45 indicates full involvement in domestic tasks, social events, hobbies, and employment) were recorded as measures of dependence and social participation.

RESULTS
Twenty-five patients (21 female) were identified, most from the liaison psychiatry database. The mean (SD) age was 42.4 (12.4) years, and 24 were white. The average (SD) time from onset of symptoms to the assessment was 12.6 (9.5) years and the average duration of their current level of disability was 5.1 (3.7) years.

Methods

Patients were audited patients attending services with significant “physical disability” to characterise them and to estimate a minimum prevalence of this phenomenon.

Abbreviations:
ADL, activities of daily living; GAF, global assessment of functioning; SOMCT, short orientation memory and concentration test

Impairments

The patients had a variety of apparent impairments. During assessment of 11 patients some inconsistencies in performance were observed, both informally and during structured

M any patients are referred to hospital specialists with complaints that cannot be explained by underlying disease. Most patients are referred back to the primary care doctor after investigation but a proportion remain symptomatic and become significantly disabled physically. When these disabilities involve loss of or alteration in limb function patients may be referred to neurological disability services. The problem is of some economic importance to primary and secondary health care services. We audited patients attending services with significant “physical disability” to characterise them and to estimate a minimum prevalence of this phenomenon.

METHODS

Patients were identified from records in the liaison psychiatry department and neurological disability services in Oxford. All patients attending the liaison psychiatry outpatient clinic may be referred to neurological disability services. The problem is of some economic importance to primary and secondary health care services. We audited patients attending services with significant “physical disability” to characterise them and to estimate a minimum prevalence of this phenomenon.

Abbreviations:
ADL, activities of daily living; GAF, global assessment of functioning; SOMCT, short orientation memory and concentration test

J Neurol Neurosurg Psychiatry 2002;73:307–309

www.jnnp.com

Downloaded from http://jnnp.bmj.com/ on June 25, 2017 - Published by group.bmj.com
Eight walked only during therapy sessions. Regular help with bathing, with 22 having daily help. One had reported major day to day variation in their ability, largely as a result of variation in pain and fatigue (largest range 10 points). Three people scored less than 9/20. Of note, all 25 had regular help with bathing, with 22 having daily help.

The mean (SD) Barthel ADL index score was 14.1 (3.3). Eight had abnormal speech. Twelve said that they were unable to walk and declined timing of a 10 m walk. The motricity index was < 50% on the left in four but in none on the right, and nine had bilaterally reduced scores. Laterality of impairments was not related to hand preference. During the nine hole peg test, contralateral tremor improved in one person and abnormal posture recovered in another.

**Disability and dependence**

The mean (SD) Barthel ADL index score was 14.1 (3.3). Eight reported major day to day variation in their ability, largely as a result of variation in pain and fatigue (largest range 10 points). Three people scored less than 9/20. Of note, all 25 had regular help with bathing, with 22 having daily help. One had an indwelling catheter for persisting urgency of micturition. Eight walked only during therapy sessions.

All patients were unemployed. All relied on family and friends to perform domestic tasks. The average (SD) Frenchay activities index score was 12.9 (7.5) out of a possible 45, indicating severe limitation in social activities. There was no correlation between Barthel ADL and Frenchay activities index scores.

The help required with personal care was provided entirely by partners, parents, or other family members in almost all cases. Only three had formal care packages (with Barthel ADL scores of 4, 8, and 10–20) and in two with severe forms of chronic fatigue syndrome carers were arranged to allow respite for other family members. Significant cognitive difficulty was rare, with 24 patients scoring > 22/28 on the SOMC.

**Psychiatric morbidity**

All except one patient had been assessed by a psychiatrist (CB) and assigned a formal psychiatric diagnosis according to criteria in the *International classification of diseases*, 10th revision (1992). Thirteen had a motor conversion disorder, five somatoform pain disorder, three undifferentiated somatoform disorder, three severe chronic fatigue (neuasthenia), and one profound hypochondriasis (delusional type). Ten had scores above 17 on the Beck depression inventory and seven were being treated for depression.

Nine patients had a long history of contact with psychiatric services. Nine had taken drug overdoses, six of whom had repeatedly performed acts of deliberate self harm (over five in four cases). Five of these six patients did not take further overdoses once their level of disability had stabilised, usually once the patient had become a wheelchair user.

Eleven patients (including four of the group who had taken overdoses) gave unequivocal histories of abuse (physical or sexual) either in childhood or by previous partners.

**Use of health care resources and welfare benefits**

A wide range of equipment was used. Twenty had a wheelchair and 13 used it all the time. A further two used a relative’s wheelchair. Eight had had either stair lifts or through floor lifts installed. Most equipment had been provided by social services after assessment by community occupational therapists. The largest grant provided was £18 000 for a downstairs extension with walk in shower.

The patients received some support from statutory services. Eight were admitted for respite care, five attended day centres regularly, two attended mental health centres twice weekly, and three attended young disabled units weekly.

All patients studied were receiving a disability living allowance. Ten were receiving the maximum for care and mobility (£360 a week). Some were also entitled to incapacity benefit (£66 a week) and if their partners were also unemployed patients were entitled to income support (£80.65 a week for a couple). The maximum sum being paid to one patient was £1815 a month (disability living allowance, income support, invalidity benefit, and rent allowance).

**DISCUSSION**

We identified 25 patients with an extreme form of apparent neurological “physical” disability in the absence of any neurological disease. These patients were not rare (derived from a population of 560 000) and were using considerable health and social service resources. The two characteristic features were the variability of diagnosis, both between patients and within patients, and the close involvement of families.
There are three main limitations. Firstly, this was not a community survey, so it is difficult to estimate the true prevalence of this form of severe non-organic disability. Our patient group provides a minimum estimate of those referred to secondary care services and interviewed by a psychiatrist. Secondly, we excluded patients presenting with severe disability who had even minimal pathology detectable on investigation. Thirdly, because the results of our measures of physical impairment and disability are dependent on effort, the data are difficult to interpret. The results reported above are the best scores achieved at any moment during the assessment.

We were surprised to find that most of the care was provided by partners and family members (only three had formal care packages). Most partners were unemployed and fully occupied as carers, which needs to be considered when managing these patients. Moreover, while most patients were receiving substantial financial support and had been provided with many items of complex equipment, only five were using other services regularly.

During this study we became increasingly aware of the lack of adequate service provision for patients with profound “non-organic” disabilities. Psychiatric services generally give low priority to this group of patients and staff in neurology rehabilitation services may become alienated or hostile towards such patients.

We believe that the optimum management of these patients can be provided by a multidisciplinary team with personnel from neurological disability and psychiatry services, in which should make it possible to provide, at the very least, a containing therapeutic environment and, at best, an opportunity for rehabilitation. Such a service may benefit patients and their relatives and save costly NHS resources.

ACKNOWLEDGEMENTS
We thank all the patients for their patience and cooperation.

Authors’ affiliations
J Allanson, Heberden Rehabilitation Unit, Amersham Hospital, Amersham, Buckinghamshire HP7 0JD, UK
C Bass, Department of Psychological Medicine, John Radcliffe Hospital, Oxford OX3 9DU, UK
D T Wade, Oxford Centre for Enablement, Windmill Road, Oxford OX3 7LD, UK

Competing interests: None declared

Contributions: All authors contributed to the formulation and design of the study, interpretation, and writing the paper; JA interviewed all the patients and collected and analysed the data; CB is the guarantor.

Correspondence to: Dr J Allanson; allanson@doctors.org.uk

Received 14 September 2001
In revised form 13 March 2002
Accepted 22 March 2002

REFERENCES
Characteristics of patients with persistent severe disability and medically unexplained neurological symptoms: a pilot study

J Allanson, C Bass and D T Wade

J Neurol Neurosurg Psychiatry 2002 73: 307-309
doi: 10.1136/jnnp.73.3.307

Updated information and services can be found at:
http://jnnp.bmj.com/content/73/3/307

These include:

References
This article cites 13 articles, 5 of which you can access for free at:
http://jnnp.bmj.com/content/73/3/307#BIBL

Email alerting service
Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Topic Collections
Articles on similar topics can be found in the following collections

Disability (194)
Drugs: CNS (not psychiatric) (1945)
Epilepsy and seizures (846)
Immunology (including allergy) (1943)
Multiple sclerosis (934)
Musculoskeletal syndromes (537)
Neuromuscular disease (1311)
Somatoform disorders (52)

Notes

To request permissions go to:
http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to:
http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to:
http://group.bmj.com/subscribe/