



# Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'

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## ABSTRACT

**Objectives** To determine the disability, distress and employment status of new neurology outpatients with physical symptoms unexplained by organic disease and to compare them with patients with symptoms explained by organic disease.

**Methods** As part of a cohort study (the Scottish Neurological Symptoms Study) neurologists rated the extent to which each new patient's symptoms were explained by organic disease. Patients whose symptoms were rated as 'not at all' or only 'somewhat' explained by disease were considered cases, and those whose symptoms were 'largely' or 'completely' explained by disease were considered controls. All patients completed self-ratings of disability, health status (Medical Outcomes Study Short Form 12-Item Scale (SF-12)) and emotional distress (Hospital Anxiety and Depression Scale) and also reported their employment and state financial benefit status.

**Results** 3781 patients were recruited: 1144 (30%) cases and 2637 (70%) controls. Cases had worse physical health status (SF-12 score 42 vs 44; difference in means 1.7 (95% CI -2.5 to 0.9)) and worse mental health status (SF-12 score 43 vs 47; difference in means -3.5 (95% CI -4.3 to 2.7)). Unemployment was similar in cases and controls (50% vs 50%) but cases were more likely not to be working for health reasons (54% vs 37% of the 50% not working; OR 2.0 (95% CI 1.6 to 2.4)) and also more likely to be receiving disability-related state financial benefits (27% vs 22%; (OR 1.3, 95% CI 1.1 to 1.6)).

**Conclusions** New neurology patients with symptoms unexplained by organic disease have more disability-, distress- and disability-related state financial benefits than patients with symptoms explained by disease.

## INTRODUCTION

We know that one-third of neurology outpatients have symptoms, such as pain, weakness and sensory disturbance, that are not explained by recognised 'organic' disease.<sup>1-4</sup> But are these patients really ill? In other words, do they just have symptoms, or are such symptoms actually associated with disability and distress, and is this reflected in their employment status and receipt of disability-related state financial benefits?

A previous study we conducted of symptoms unexplained by organic disease suggested that neurology patients with this problem were at least as disabled and distressed as patients with neurological

disease, but it was of only a small sample (90 patients with unexplained symptoms) recruited from only one service.<sup>1</sup> In this study, we aimed to determine the disability, distress and employment status of more than 1000 consecutive cases with symptoms unexplained by disease, who were prospectively identified as part of a large multicentre study of new neurology outpatients, and to compare these with those of controls from the same cohort whose symptoms were explained by neurological disease.

## METHODS

The Scottish Neurological Symptoms Study was a prospective, multicentre, cohort study of NHS neurology outpatients in Scotland. Ethical approval for the study was granted by a Multicentre Research Ethics Committee. This paper reports a case control analysis of study baseline data.

## Participating clinics

Thirty-six out of 38 consultant neurologists, working across all four Scottish NHS neurology centres, participated. Patients were recruited from their general neurology clinics (including their supervised trainee clinics) in the main Scottish neurological centres—Aberdeen, Dundee, Edinburgh and Glasgow, and associated peripheral clinics in Airdrie, East Kilbride, Falkirk, Inverness, Perth, Stirling, Vale of Leven and Wishaw—between December 2002 and February 2004. All the clinics sampled took mainly general practice referrals with patients allocated by medical records staff according to availability of appointment. Tertiary clinics, where patients required a verified diagnosis to attend (such as multiple sclerosis clinics), and emergency clinics were excluded.

## Patients

All newly referred patients at the participating clinics were potentially eligible for inclusion. The exclusion criteria were: age less than 16, cognitive or physical impairment of a degree that precluded informed consent, inability to read English or if the neurologist identified the patient as unsuitable for the study (eg, too distressed, terminally ill). New patients included patients with existing neurological diagnoses who had been re-referred from primary care. Patients were sent information about the study prior to their appointment with the neurologist. After the consultation, they were invited by their neurologist to speak to a research

assistant. Consent was obtained from patients willing to participate.

Immediately following the initial consultation, neurologists were asked to complete a four-point Likert scale: 'To what extent do you think this patient's clinical symptoms are explained by organic disease?'—'not at all,' 'somewhat,' 'largely' or 'completely.'<sup>1</sup> Operational criteria were provided to guide ratings (supplementary figure 1).

### Measures

Following the initial neurological consultation, all participating patients completed a self-report questionnaire which included the following measures:

- ▶ Demographics including age and sex.
- ▶ Reported disability (Health status): using the Medical Outcomes Study Short Form 12-item Scale (SF-12),<sup>5</sup> which examines health status across eight domains and in two composite scores of physical and mental health status. We calculated the 'raw' score in each of the domains as a percentage and also the two composite scores as recommended by the authors.
- ▶ Emotional distress using the Hospital Anxiety and Depression scale (HAD).<sup>6,7</sup>
- ▶ Employment Status and receipt of state financial benefits by patient self-report. We asked specifically whether patients were (a) in paid employment (and, if not, whether this was because of health problems); (b) in receipt of income support, unemployment benefits, disability living allowance or incapacity benefit.

### Analysis

First, we calculated the number of patients in each of the four 'organicity' groups. We then amalgamated those patients whose symptoms were rated as 'not at all explained' and 'somewhat explained' by organic disease and classified them as having symptoms 'unexplained' by disease (cases) and patients who were rated as having symptoms 'largely' and 'completely' explained by disease as having 'explained' symptoms (controls). We then compared the cases and controls using the difference in means and ORs.

### RESULTS

Patients were recruited between 16 December 2002 and 26 February 2004. During this period, a total of 4299 new patients attended the designated clinics. Recruitment to the study is summarised in figure 1. The final sample was of 3781 patients (88% of all attendees and 91% of all eligible outpatients), of whom 1144 patients (30% of the total) were rated by neurologists as having symptoms 'not at all' (n=446; 12%) or only 'somewhat explained' (n=698; 18%) by disease; they were the 'unexplained' cases. The medical diagnoses given to the cases have been described in detail elsewhere.<sup>7,8</sup> The remaining 2637 patients had symptoms which were 'largely' (n=940; 25%) or 'completely explained' (n=1697; 45%) by organic disease; they were the 'explained' controls. (We have also analysed the data across all four groups and include this as supplementary table 1).

Cases were, on average, 4 years younger and more likely to be female than controls (table 1). They had lower scores in all SF-12 individual domains, including all the disability domains including physical and social function, and physical and emotional role function. Cases also had a higher level of emotional distress on the SF-12 mental health scale and on the Hospital Anxiety and Depression Scale.

A similarly large proportion of both cases and controls reported not being in paid employment (50% vs 50%). However,

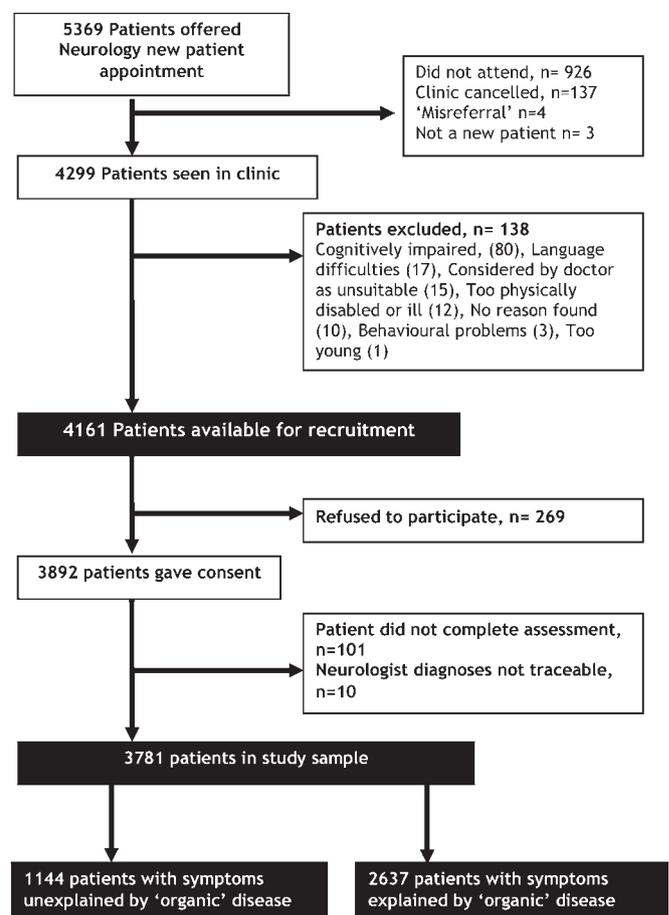


Figure 1 Flow chart of patient recruitment into study.

of those, unemployed cases were more likely to report that they were not working because of ill health (26% vs 18%). This difference was reflected in the finding that cases were also more likely to be in receipt of disability-related state financial benefits (27% vs 22%; OR 1.3, 95% CI 1.1 to 1.5).

### DISCUSSION

We found substantial self-reported disability, distress and unemployment in patients with symptoms 'unexplained' by 'organic' disease. All these variables were more severe in cases than controls. Furthermore, the cases were more likely to report unemployment for reasons of ill health and to be in receipt of disability-related state financial benefits.

These findings clearly indicate that patients with symptoms 'unexplained' by organic disease are not merely the 'worried well.' Rather, they have substantive self-reported disability, distress and associated unemployment. While their degree of disability and distress was actually statistically greater than that of controls with neurological disease, this difference is around the minimum considered clinically significant.<sup>9,10</sup> A more conservative interpretation of these data would therefore be that they are similar to patients with neurological disease on these characteristics.

Although cases had greater rates of health-related unemployment and disability-related state financial benefits than controls, the majority of patients with symptoms unexplained by organic disease were actually in work. This observation does not support anecdotal suggestions that all such patients are motivated by work avoidance and receipt of benefits.

**Table 1** Disability, distress and employment status of cases with symptoms 'unexplained by organic disease' and controls with symptoms 'explained by organic disease'

	Cases	Controls	OR difference in means (95% CI)
Age, mean (SD)	43.6 (14.4)	47.5 (17.0)	-3.85 (-4.98 to -2.72)
Female, % (n/N)	65.3 (747/1144)	53.6 (1414/2637)	1.63 (1.41 to 1.88)
Medical Outcomes Study Short Form 12-Item Scale, mean (SD)*			
General health	42.6 (26.0)	48.7 (24.7)	-6.15 (-7.90 to -4.41)
Physical functioning	63.9 (38.4)	66.9 (36.8)	-2.99 (-5.58 to -0.40)
Role physical	50.0 (46.7)	56.1 (45.0)	-6.02 (-9.18 to -2.86)
Bodily pain	58.0 (35.8)	67.2 (34.5)	-9.23 (-11.66 to -6.81)
Social functioning	62.3 (34.7)	69.2 (33.6)	-6.91 (-9.27 to -4.56)
Vitality	39.5 (27.7)	44.4 (28.0)	-4.90 (-6.85 to -2.96)
Mental health	54.5 (25.5)	61.4 (24.0)	-6.94 (-8.63 to -5.24)
Role emotional	64.7 (43.1)	75.2 (38.9)	-10.48 (-13.28 to -7.69)
Composite score—physical health status	42.2 (12.5)	43.9 (11.7)	-1.72 (-2.55 to -0.89)
Composite score—mental health status	43.4 (12.1)	46.9 (11.3)	-3.53 (-4.33 to -2.73)
Hospital Anxiety and Depression Scale, mean (SD)*			
Anxiety subscale	7.9 (5.0)	6.4 (4.5)	1.51 (1.19 to 1.84)
Depression subscale	5.9 (4.9)	4.7 (4.2)	1.21 (0.91 to 1.52)
Total score	13.8 (8.9)	11.1 (7.8)	2.73 (2.16 to 3.30)
Not in paid employment, % (n/N)	49.5 (563/1137)	49.9 (1313/2629)	0.98 (0.86 to 1.13)
If not, was this because of health, % (n/N)†	54.2 (297/548)	37.4 (470/1258)	1.98 (1.62 to 2.43)
On income support/unemployment benefit, % (n/N)	19.7 (224/1135)	16.0 (417/2612)	1.29 (1.08 to 1.55)
In receipt of incapacity benefit or disability living allowance, % (n/N)	27.0 (307/1137)	21.9 (573/2614)	1.32 (1.12 to 1.55)

\*Sample size varies between 1134 and 1143 in the not at all/somewhat explained group, and between 2612 and 2633 in the largely/completely explained group.

†Denominator is those who reported not being in paid employment n=1806.

This study has the strength of being of a large and representative sample of neurology patients. However, it also has limitations: although almost all Scottish neurologists participated in the study, not all their clinics were sampled, and specialised clinics such as neurovascular and memory clinics were not included; consequently, patients with these disorders may be under-represented. Similarly we cannot be certain that Scottish neurological practice is similar to neurological practice round the world, although the prevalence rates of the common neurological disorders in patients attending the clinics sampled would suggest it was.

Although disability-related state financial benefits are subject to independent assessment and, in a small number of cases, antifraud investigations, much of the information used to assess such claims is still based upon self-report and cannot therefore be regarded as completely objective. Furthermore, absolute rates of health-related unemployment and the uptake of financial benefits may be influenced by economic conditions as well as by illness.

Among other limitations was our approach of 'lumping' patients with symptoms unexplained by organic disease into one group. While we believe that there are sound theoretical reasons for doing this,<sup>11</sup> others may prefer to 'split' this group into many separate conditions. Furthermore, we did not seek to determine the factors causing the observed disability; these are likely to include a variety of factors including, but not exclusively, psychiatric illness. Finally, our 'unexplained' cases were slightly younger and more likely to be female; this may influence the reported rates of disability and distress.

Previous studies of specific diagnostic groups including psychogenic seizures,<sup>12–14</sup> psychogenic sensory loss<sup>15</sup> and psychogenic movement disorders<sup>16–17</sup> have also found that these patients have a degree of physical disability similar to that of patients with neurological disease. A retrospective Dutch study of a consultation liaison psychiatry service<sup>18</sup> included 544

patients who had been diagnosed as having a somatoform disorder, of whom 215 had a conversion disorder, and found a high rate of unemployment among the older patients with somatoform symptoms but not among younger patients. Crimlisk *et al*, in a study of 64 patients with motor conversion disorder at a tertiary centre, found that 77% of their cohort had held jobs prior to symptom onset, but only 11% were still working at 6 years' follow-up.<sup>19</sup> A recent cohort study of psychogenic seizures in the West of Scotland described very high rates of unemployment (90%) and uptake of benefits (62%).<sup>20</sup> We found a lower rate of unemployment in our cohort. We suspect this was due to two factors: first, we distinguished between those whose unemployment was due to their health complaint and those who were unemployed for other reasons; second, we studied a sample more representative of general neurology clinic attenders.

In summary, our data indicates that neurology patients with symptoms unexplained by disease are not merely the 'worried well' but are demonstrably ill by the usually applied criteria of disability and distress. These data make a strong case for the development and implementation of targeted interventions for this group of patients. It is however imperative that such potentially complex interventions are properly tested in well-designed randomised controlled trials before they are implemented. Researchers should consider including economic measures into trials as successful treatment could not only improve the quality of patients lives but also help them to return to work.

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**Competing interests** None.

**Ethics approval** Ethics approval was provided by the Multi-centre Research Ethics Committee Scotland.

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## Information for patients from JNNP

# Unexplained nerve symptoms often linked to ill health

When a nerve symptom such as pain doesn't have a clear cause, is a person truly ill? Quite often, yes, reports a new study, which found that people with unexplained symptoms often have more severe signs of ill health - such as distress and disability - than those whose nerve symptoms have a known cause.

## What do we know already?

About 1 in 3 people who see a doctor specialising in nerve problems (a neurologist) have symptoms that can't be explained by known illnesses. These symptoms often involve pain, weakness, or disturbances in a person's vision, hearing, or other senses. Such patients are sometimes described as being 'worried well'. This suggests that although they have symptoms, these problems aren't caused by an actual illness and are unlikely to lead to serious problems.

But is this a fair assessment? Some research suggests not, although most studies so far have been fairly small.

To learn more, researchers in Scotland recruited nearly 3,800 people who'd started seeing a neurologist between December 2002 and February 2004. The neurologists noted to what extent people's symptoms could be explained by known conditions. And participants filled out standardised questionnaires rating their level of emotional and physical distress and disability. They were also asked whether they were employed and whether they were receiving any government benefits.

## What does the new study say?

Overall, 1,144 people had symptoms that were unexplained, or only somewhat explained, by known conditions.

Compared with people who had clearer diagnoses, this group consistently scored worse on scales rating their physical and mental health, and level of disability. They were also more likely to be unemployed because of ill health, and were more likely to be receiving disability benefits.

However, the differences between the groups were fairly small, say the researchers. So, a more accurate reading of their findings might be that

people with unexplained symptoms are just as likely to have signs of ill health as those with known conditions.

## How reliable are the findings?

This was a well-conducted study, and its results should be fairly reliable. However, we can't be certain that people's ill health and unemployment were directly related to their unexplained symptoms. This is because other factors might also have played a role, including whether people had other health problems.

## Where does the study come from?

The study was conducted by researchers with universities and hospitals in Scotland. It was funded by NHS Quality Improvement Scotland.

## What does this mean for me?

Not knowing what's causing a nerve symptom such as pain or weakness can be distressing. And this can be compounded if you feel that your doctor isn't taking your symptoms seriously.

These findings suggests that doctors should take heed of these unexplained symptoms, as they are just as likely to be linked to ill health as symptoms with known causes. The researchers hope their findings lead to more research into treatments for people with these unexplained symptoms.

## What should I do now?

Good communication with your doctor is essential, whether you're dealing with unexplained pain or another health problem. If you feel that your doctor isn't adequately addressing your symptoms or concerns, it's important to raise this. You might mention this study as part of your discussion.

Carson A, Stone J, Hibberd C, et al. Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'. *Journal of Neurology, Neurosurgery, and Psychiatry* 2011;**82**:810–13. <http://jnnp.bmj.com/content/82/7/810.full>

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