Scottish Neurological Symptoms Study

Executive Summary
Phase 1
Scottish Neurological Symptoms Study

EXECUTIVE SUMMARY

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On behalf of the SNSS Study Group:

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Introduction

Contrary to lay opinion many physical symptoms such as pain, weakness and fatigue are found to be unexplained by disease, even after extensive medical assessment. There is now increasing evidence that such medically unexplained symptoms (MUS) are a major cause of disability, and place a very substantial burden on both the NHS and the economy in general [1,2]. However we have very limited information to inform better management. This knowledge gap includes associated illness related beliefs and behaviours, outcome, what predicts poor outcome and how these patients are currently managed. This study aimed to address these questions.

Aims and Objectives

These may be divided into phase 1 and 2. Phase 1 was funded by NHS Quality Improvement Scotland (NHS QIS) and is reported here. Phase 2 is funded by the Chief Scientist Office and will be reported separately.

Phase 1 questions:

1. What proportion of new patients attending Scottish Neurology Clinics have MUS?

2. What is the age, sex, health status, degree of distress, illness beliefs and satisfaction with care received of patients with MUS and how does this compare with those whose symptoms are medically explained?

Methods

This was a cross-sectional survey to be followed by a prospective cohort study.

Subjects

All new patients at the participating neurology outpatient clinics were eligible for inclusion. Sampling took place in the four main Scottish Neurology departments and from related satellite clinics allowing a representative spread of clinical activity. The only exclusion criteria were: age less than 16 and cognitive impairment such that the subject could not give informed consent. We aimed to screen a minimum of 3500 new patients (1000 Edinburgh including Falkirk and Stirling; 1000 Glasgow including Lanarkshire; 750 Aberdeen including Grampian; 750 Dundee including Tayside).

Diagnosis of symptoms as medically unexplained

This was made by the consultant neurologist following the initial assessment of the patient according to explicit criteria and rated on a four point Likert-type ‘organicity’ scale [3]. Patients whose symptoms were rated as “not at all explained” or only “somewhat explained” were classified as having 'MUS' and those with symptoms rated as "largely" or "completely" explained as having 'explained' symptoms. The diagnosis of MUS will be reviewed at the time of follow up via GP survey, with case record review and consultation with treating clinician as required.

Procedure for Phase 1 (Baseline Survey)

Patients were sent information about the study prior to their appointment. They were invited to speak to the researchers by the treating neurologist after their initial
appointment. The researchers then took informed consent from those patients willing to participate. Those who consented then completed the baseline questionnaires.

**Baseline Measures:**

*Demographics:* Age, sex, marital status, CHI number, post code.

*Symptoms:* Patient Health Questionnaire (PHQ) checklist [4] of the 15 commonest physical symptoms supplemented by a list of the 15 commonest neurological symptoms [5].

*Health status and disability:* Medical Outcomes Study Short Form 12-item Scale (MOS SF-12). The MOS scales of health status are the most widely used self-report measures of health status and disability in medical research and provide reliable estimates of quality of life and health status in both physical and mental domains [6].

*Emotional distress:* 25-item Patient Health Questionnaire (PHQ) provides diagnostic information [4] and the Hospital Anxiety and Depression scale (HAD) gives continuous measurement of distress [7]. Both scales have proven reliability and validity.

*Patients' understanding of their illness:* This was measured using items from the Illness Perceptions Questionnaire [8] and the Whitley Index [9].

*Patients' satisfaction with neurology service:* This was measured using the Medical Outcomes Study Satisfaction Scale [10].

**Analyses**

First, we calculated the prevalence of MUS from the neurologist’s ‘organicity’ ratings. Second, we compared groups defined by the ‘organicity’ ratings for demographic statistics, health status, and distress and illness beliefs.

The study sample was planned to provide a high degree of precision around estimates of prevalence and characteristics and provided more than adequate power for the proposed comparisons. The sample was planned to be large enough to conduct logistic regression analysis using up to 30 variable models, assuming the conservative measure of 20 patients per variable. There are enough patients in each individual centre to allow for a definitive description of current Scottish practice, which may be subject to inter-region variation.

**Results - Phase 1**

The study ran from 16/12/2002 to 26/02/2004. During this period 5405 patients were due to attend the designated neurology clinics. Of these patients 927 failed to attend the clinic. Staff problems, such as unplanned absence through sickness, led to a further 138 patients attending but there being no clinic. Of the remaining patients, 180 were excluded from participation. This left 4160 patients available for inclusion in the study. Of the 4160 patients, 3908 gave consent to participate; 89 of these patients failed to complete the assessment, 23 completed assessment but changed their mind and withdrew consent, and the neurologists' organicity ratings had not been completed on 48 patients. In summary 3748 patients participated and the participation rate was 90%.

Of the 3748 participating patients, 450 (12%) had symptoms which were considered to be 'not at all' explained by organic disease and a further 725 (19%) symptoms only 'somewhat' explained by organic disease. This compared with 887 (24%) who had symptoms 'largely' explained and 1686 (45%) whose symptoms were 'completely' explained by organic disease. In summary, nearly a third (31%) of patients attending
Scottish neurology clinics have medically unexplained symptoms. Taken as a whole they are the largest single group attending the services. There were statistically significant variations in prevalence of MUS between centres but the differences were not marked. Further statistical exploration is required and potential confounding factors may include age, sex and deprivation of the clinic attenders. This will be the subject of further analysis.

The patients' mean age was 46 years, and 1749 (47 %) were male. Patients whose symptoms were less explained by disease were more likely to be younger and to be female. Patients whose symptoms were less explained by disease reported slightly greater physical disability, but although this was statistically significant the mean three-point difference in scores on the SF12 was not clinically substantial. Patients whose symptoms were less explained by disease reported greater mental disability and distress measured by the SF12 and by the HAD. This difference was both statistically and clinically significant.

Patients whose symptoms were less explained by disease described higher rates for most, but not all symptoms. The reported rates of blindness, deafness and seizures or fits were similar across all symptom groups. The differences between groups appeared most marked where the somatic symptoms were those potentially associated with anxiety.

There was no difference between the 'organicity' groups regarding beliefs surrounding genetics, smoking, accidents or medication as a cause for their symptoms. Patients whose symptoms were less explained by disease were however more likely to blame stress, overwork, their emotional state or poor medical care. By contrast patients whose symptoms were more explained by disease tended to blame chance or ageing. There were also statistically significant differences between the groups in the degree to which they blamed viruses and diet, but these differences did not systematically increase or decrease in accordance with organicity score.

Patients whose symptoms were less explained by disease were more likely to report that their symptoms were 'a mystery' to them and were less likely to believe that their doctor understood the cause. They were however more likely to believe that their symptoms would be temporary. When they thought about their symptoms they were more likely to get angry or upset. The majority of patients believed that they had the ability to influence their symptoms and there were no differences between groups in this regard.

Patients whose symptoms were less explained by organic disease had increased health anxiety. Although they were no more likely to believe that there was something seriously wrong with their body, they did worry more about this possibility and about their health in general. They were more likely to be bothered by many different symptoms, aches and pains and reported that they were more likely to worry about a disease if it was brought to their attention. Unfortunately they also found it harder to believe their doctor when he/she told them there was nothing to worry about. This pattern of beliefs has been termed hypochondriasis.

Approximately half the patients in the sample were in paid employment. There was no difference in employment status across the groups. However, there was an excess of patients whose symptoms were less explained by disease among those patients in employment, but currently off work sick. Of patients who were not in employment, this was more likely to be as a result of health problems if the patients' symptoms were less
explained by organic disease. Similarly they were more likely to be in receipt of benefits including income support, incapacity benefit and disability living allowance.

Overall satisfaction with the neurology service was very high. Three quarters of patients thought that the overall visit was either excellent or very good. Four fifths of patients gave these ratings to the competence of the neurologist and their personal manner. By contrast only around one third of patients were satisfied with the length of waiting lists and with the convenience of clinics; there was no difference between the four organicity groups on these two ratings. However, there was a tendency for patients whose symptoms were less explained by disease to be less satisfied with the actual consultation giving them slightly lower scores for competence, personal manner and the length of time spent with the neurologist. It is particularly notable that these patients were significantly less satisfied with the explanation given by the neurologist for their symptoms.

Conclusions

The Scottish Neurological Symptoms Study Group set out to conduct a large scale epidemiological study of the prevalence of medically unexplained neurological symptoms in newly presenting patients to Scottish Neurology Clinics. We have found that 31% of new patients attending clinic have MUS. Patients with MUS are younger and more likely to be female. They report a slightly greater physical disability and much greater mental disability and distress than patients with neurological disease. They report a large number of symptoms. They attribute their symptoms to stress, worry and overwork. They get upset and angry about their symptoms and have marked health anxiety. The associated social benefits costs are considerable. They are less satisfied with the care they received than are other patients.

Our ongoing follow up of this cohort is progressing well and will report next year. Having demonstrated that MUS in neurological clinics are a major clinical and public health problem we have sought and obtained competitive grant funding from the Medical Research Council in order to create and conduct preliminary evaluations of cost-effective solutions.

Action(s) Required/Recommendations for the Future

We consider that Medically Unexplained Symptoms are a significant public health problem and account for a large burden of disability. As a result they are associated with significant financial cost in particular relating to sickness absence and benefits. Although treatment, using drugs or psychotherapy, is theoretically possible, few patients have access to clinicians with the necessary skills and resources. In particular, although many community mental health teams have nurse therapists trained in CBT, the model of therapy they use cannot be simply transferred to patients with MUS. Furthermore, the numbers of therapists are inadequate to the task. We need to devise novel and cost effective interventions that will help this group of patients. It is imperative that such interventions are properly tested in randomised controlled trials if they are to be accepted by patients and clinicians. We consider this to be a priority if the government's waiting list targets are to be achieved.
References

Acknowledgements

The study team comprised of the following members:

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We wish to thank NHS QIS and the CSO for their support of the study. In particular we are grateful for their continuing support as the scope of the project grew in size. We hope they will feel that this flexibility has been justified by the results. We also wish to thank the Clinical Neurosciences Department of the University of Edinburgh who provided a physical base for the study and the four neurology departments across Scotland for hosting the research assistants. We are especially grateful to our colleagues in the neurology clinics across Scotland who have been supportive of this study and patiently completed rating scales and recruited patients. Similarly, our thanks go to all the nursing, clerical and administrative staff who have supported the project and tolerated the disruptions it has caused. Most importantly we thank all the patients and their relatives who have freely given up their time to participate.