

# Frequent attenders in secondary care: a 3-year follow-up study of patients with medically unexplained symptoms

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## ABSTRACT

**Background.** There are few longitudinal studies of patients with medically unexplained symptoms. The aim of this study was to investigate outcome in frequent attenders in secondary care who present repeatedly with medically unexplained symptoms.

**Method.** Forty-eight patients presenting with medically unexplained symptoms, from a sample of 61, participated in a 3-year follow-up study. Psychiatric morbidity, functional impairment and use of services were evaluated.

**Results.** At follow-up there was a high prevalence of psychiatric morbidity with 69% having at least one psychiatric diagnosis. The sample continued to be high users of a range of health services and substantial functional impairment was reported.

**Conclusion.** In this group of frequent attenders with medically unexplained symptoms outcome as measured by psychiatric morbidity, service use and functional impairment remained poor after 3 years.

## INTRODUCTION

Medically unexplained symptoms occur frequently in all medical settings, and are associated with psychiatric disorder and reduced functioning (Katon & Walker, 1998). These symptoms are common among frequent attenders to primary care, and in a previous study we found that medically unexplained symptoms accounted for a considerable proportion of consultations by frequent attenders to secondary care (Karlsson *et al.* 1997; Reid *et al.* 2001).

Although patients presenting with unexplained somatic symptoms are often considered to have a poor outcome, longitudinal studies are lacking and those available offer conflicting

findings (Kroenke & Mangelsdorff, 1989; Craig *et al.* 1993; Speckens *et al.* 1996; Crimlisk *et al.* 1998). There is a burgeoning evidence base of effective treatments for medically unexplained symptoms, yet health professionals continue to find these patients difficult to manage (Mayou & Sharpe, 1997). Such patients, who frequently attend services, may undergo extensive investigation and medical treatment but the benefits of this form of management are unclear.

The aim of this study was to measure the outcome of frequent attenders in secondary care with medically unexplained symptoms, by determining rates of psychiatric disorder and their functional disability. We therefore conducted a 3-year follow-up study of frequent attenders to secondary care who presented repeatedly with medically unexplained symptoms. A further aim was to measure the service use and cost of illness in this group of patients at follow-up.

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## METHOD

### Sample

Initially, we undertook a retrospective cohort study of frequent attenders over a 3-year period, 1993–6, selected from the South Thames (West) NHS Region database of out-patient hospital activity (Reid *et al.* 2001). A population was defined in which potential subjects were all patients in the region aged 18–65 years who had a new appointment to secondary medical or surgical care in 1993. The following condition-specific specialities were excluded from the sample because referred patients were unlikely to be presenting with medically unexplained symptoms: obstetrics (but not gynaecology), oncology, clinical genetics, palliative medicine, transplantation surgery and nuclear medicine. Psychiatry was also excluded as in this case medically unexplained symptoms would be the reason for referral.

Patients were followed over a 3-year period to assess their overall service use within the region by counting all out-patient appointments. The population was stratified by two age groups (18–45 years and 46–65 years) to account for the expected increased consultation rates in the older age group. Frequent attenders were then defined as the top 5% of out-patient attenders by number of appointments and 200 patients were randomly selected from each age stratum (24 489 in the 18–45 year age group; 36 743 in the 46–65 year age group) for inclusion in the study. The study was approved by the local research ethics committee.

### Procedures

The medical records of each subject were examined by a medically qualified investigator between September and December, 1998. Every new referral (consultation episode) during the 3-year period was recorded, as were details of appointments, clinical investigations, treatment and disposal. It was then determined whether each episode was medically unexplained, explained, mixed in nature (evidence of both physical and psychological disorder) or factitious. Criteria for a medically unexplained episode consisted of the following: (a) the patient presented with physical symptoms; (b) they received investigations for these; and (c) the investigations and clinical examination revealed no abnormality,

or abnormalities that were thought to be trivial or incidental.

A symptom was designated ‘definitely medically unexplained’ if there was evidence of a thorough investigation of the symptoms, all of which were negative, and either psychosocial reasons were suggested for the presentation or a diagnosis was made which implied a medically unexplained syndrome (e.g. fibromyalgia, irritable bowel syndrome, etc.). An intermediate category, ‘probably medically unexplained’, was used when there was an absence of evidence that a defined organic disease caused the symptom but uncertainty was expressed about the diagnosis, or investigations were inconclusive. This method was evaluated in a pilot study involving both liaison psychiatrists and physicians and was found to have good inter-rater reliability (kappa 0.76–0.88) (Reid *et al.* 1999). It has also been used with similar reliability in a study of hospital admissions (Hotopf *et al.* 1999). For the purpose of analysis those episodes categorized as definitely or probably unexplained were regarded as medically unexplained consultation episodes.

The medical records of 361 (90%) out-patients were obtained for examination and following review 61 (17%) of the sample were identified as presenting repeatedly with medically unexplained symptoms (defined *a priori* as patients having two or more medically unexplained consultation episodes) (Reid *et al.* 2002). These patients were sent a letter in 1999 explaining the purpose of the study and requesting their participation in a follow-up interview that took place at home. Two months later non-respondents were sent a further letter.

### Measures

Psychological morbidity was measured using the Hospital Anxiety and Depression Scale (HADS) – using a score of  $\geq 11$  as a cut-off for caseness (Zigmond & Snaith, 1983), and the somatization subscale of the SCL-90-R questionnaire (Derogatis, 1975), a measure of distress associated with perceived bodily dysfunction. In order to obtain specific psychiatric diagnoses, each patient was interviewed using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) (Wing *et al.* 1990), by a psychiatrist trained in its use. Functional disability was measured using the Short-Form 36 (Ware, Jr. & Sherbourne, 1992), a quality of life schedule.

Finally, service use and costs of illness were collated for the 6-month period prior to the interview. Data were collected on all formal health and social care services used by patients, as well as time taken off work due to illness, personal expenditure and informal care. For this purpose, a specially adapted version of the Client Service Receipt Inventory (CSRI) (Beecham & Knapp, 1992) was developed. For the costing of community-based services, average duration of contact was also taken into account.

Specific costs for health services were obtained from Netten *et al.* (2000). Costs of lost productivity arising from days off work were based on self-reported earnings. The value of social security benefit claims were based on rates published by the Benefits Agency (Benefits Agency, 1999). All costs were based on 1999/2000 prices – the period for which data were collected.

## RESULTS

### Study population

Of the 61 frequent attenders identified presenting repeatedly with medically unexplained symptoms 48 (79%) agreed to participate. Seven patients declined and the remaining six were not traced: 34 (71%) of the sample were women; 34 (71%) were married and four (8%) were separated or divorced; six (13%) patients were of non-White ethnicity; 16 (33%) of the sample were engaged in open employment and almost one in five (19%) were receiving sickness benefit. The non-responders did not differ from the responders with regard to demographic characteristics such as sex, age or marital status. Neither did they differ on number of appointments or medically unexplained consultation episodes.

### Psychiatric disorder

Psychological morbidity was identified in the majority of the sample using the HADS: 69% reached the cut-off score for anxiety and 52% for depression. The mean score on the somatization scale of the SCL-90-R for the sample was 1.5 (s.d. = 1.0). This is comparable to results from a previous study in which 45 patients given explicit diagnoses of functional somatic syndromes had a mean score of 1.3 (s.d. = 0.8). (Bach *et al.* 1994). In a further study of 220 patients with chronic

Table 1. *Current DSM-IV diagnoses (N=48\*)*

Disorders	Current diagnosis	
	N	(%)
No psychiatric diagnosis	12	(25)
Anxiety disorders		
Panic disorder without agoraphobia	5	(10)
Agoraphobia	3	(6)
Specific phobia	2	(4)
Social phobia	1	(2)
Generalized anxiety disorder	14	(29)
Any anxiety disorder	25	(52)
Mood disorders		
Major depression	9	(19)
Dysthymic disorder	2	(4)
Depression not otherwise specified	3	(6)
Adjustment disorder with depressed mood	6	(12)
Any mood disorder	20	(42)
Somatoform disorders		
Somatization disorder	9	(19)
Undifferentiated somatoform disorder	20	(42)
Pain disorder	2	(4)
Hypochondriasis	2	(4)
Any somatoform disorder	33	(69)
Other		
Alcohol dependence	2	(4)
Alcohol abuse	5	(10)
Total no. of diagnoses	85	

\* Three patients refused the SCAN interview, and 12 patients had no formal psychiatric illness.

temporomandibular disorder pain, the mean somatization score was 0.8 (s.d. = 0.7) (Wilson *et al.* 1994).

Of the 48 patients three refused interview with the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) and 12 had no psychiatric diagnosis (Table 1). Thirty-three (69%) patients had at least one current psychiatric diagnosis and 23 (48%) had at least two. Affective disorders were a frequent problem, with almost one-fifth of the patients meeting DSM-IV criteria for a current major depression and almost half meeting DSM-IV criteria for any mood disorder. Similarly, over 50% of the sample met the DSM-IV criteria for an anxiety disorder, most commonly generalized anxiety. Somatoform disorders were the most common psychiatric diagnosis, with somatization disorder being present in 19% of the sample. The high total number of diagnoses demonstrates the degree of overlap with psychiatric disorders in this group. In the 3 years prior to the follow-up interview seven of the sample reported a psychiatric referral and six had been to a counsellor in primary care.

Table 2. *Medical Outcomes Study SF 36 scores in sample, comparison patients with depression, other medical conditions and the general population\**

SF36 Subscale†	Sample Mean (S.E.)	Patients with depression Mean (S.E.)	Patients with arthritis Mean (S.E.)	Patients with heart disease Mean (S.E.)	General population Mean‡
Physical functioning	62 (4)	75 (1)	73 (1)	68 (2)	78
Physical role	42 (6)	47 (1)	49 (2)	50 (3)	74
Freedom from pain	46 (4)	67 (2)	63 (1)	74 (2)	72
General health perception	51 (4)	56 (1)	62 (1)	56 (1)	68
Energy	41 (3)	43 (1)	51 (1)	49 (1)	59
Social functioning	72 (6)	62 (2)	78 (1)	78 (2)	82
Emotional role	43 (3)	44 (2)	63 (2)	67 (3)	80
Mental health	52 (3)	50 (1)	69 (1)	72 (1)	75

\* (Wells &amp; Judd, 1996).

† Low score indicates poor outcome.

‡ General population scores adjusted for demographic characteristics, standard errors unavailable.

### Functional disability

The SF36 health profiles of the sample are compared with reference values in Table 2. Overall, the scores for the study sample indicated high levels of functional disability. Our patients reported poorer physical functioning than all of the comparison groups. They also complained of considerably more pain. Role limitations in daily activities due to emotional problems, and mental health were comparable for the sample and patients with depression, and both were more impaired than the other medically ill patients. Energy levels in the sample were also comparable with patients with depression but notably, they rated their social functioning considerably higher than the depressed group.

### Service use and costs of illness

Of the 16 (33%) patients in full employment, 12 had taken an average of 16.5 days off work due to ill health in the previous 6 months. Of the 14 subjects who were unemployed, many had been so far extended periods of time – between 2–17 years. Table 3 summarizes the proportion of patients using health and social services during the 6-month period prior to assessment and the mean cost per patient. Overall, 43 (90%) patients had made use of at least one healthcare service during this period. The in-patient admission rate during the 6-month period was 15%. Use of out-patient services was considerably higher at 58% and involved a range of specialities. Although most subjects had one out-patient episode, 27% of subjects had had two or three separate

Table 3. *Service use and costs of sample during the 6 months prior to assessment*

	Number using service (%) (N=48)	Mean cost (S.D.) per patient (£) (N=48)
Secondary care		219 (293)
One admission	5 (10.4)	83 (240)
Two admissions	2 (4.2)	
One OP episode	15 (31.3)	136 (154)
Two OP episodes	12 (25.0)	
Three OP episodes	1 (2.1)	
A & E	0	—
Community-based services		168 (241)
GP surgery visit	40 (83.3)	67 (69)
Practice nurse	0	—
District nurse	2 (4.2)	6 (31)
CPN	1 (2.1)	2 (12)
Counselling	5 (10.4)	32 (131)
Psychologist	2 (4.2)	7 (40)
Psychiatrist	5 (10.4)	54 (162)
Total healthcare costs		387 (368)

OP, Out-patient; A &amp; E, accident and emergency; CPN, community psychiatric nurse.

episodes during the 6-month assessment period. Primary care was also heavily used with the 83% of subjects reporting GP attendance having a median rate of four consultations in 6 months, although none of the sample had attended Accident and Emergency departments.

The indirect costs of illness – due to lost productivity and social security benefit claims, were calculated at a mean cost of £854 per patient (standard deviation £832). So, direct costs at £387 per patient accounted for a relatively small

proportion of total cost, but between these, secondary care tended to dominate.

## DISCUSSION

This study shows that patients who present repeatedly to secondary care with medically unexplained symptoms have high rates of psychological morbidity as well as markedly impaired levels of physical and social functioning when followed up in the longer term. They also continue to consult frequently with a wide range of health services. These findings must be considered in the context of methodological shortcomings. As this was a descriptive study no control group was used and any comparisons were made with the results of previous work. The main aim of the study, however, was to describe rates of psychiatric disorder and service use in this specific group of patients. In determining the nature of the original consultations, medical records were used for data collection, but the most important information, details of investigations and final diagnosis, are generally well documented in hospital casenotes. This is the first study of such a patient group that has encompassed a number of secondary care specialties in several hospitals. Despite the follow-up interval of 3 years, 48 (79%) of the original sample participated, which is comparable to previous follow-up studies of unexplained physical symptoms (Speckens *et al.* 1996).

The findings of this study confirm previous work that highlights the association between medically unexplained symptoms and psychological morbidity (Katon *et al.* 1991). The prevalence of DSM-IV disorders emphasizes that many of these patients have defined psychiatric illness and there is evidence to suggest that psychiatric treatment may reduce health care costs and improve functioning in those with somatoform disorders (Smith, Jr. *et al.* 1995).

High levels of functional disability are evident in this sample from the MOS SF36 scores. Compared to patients with depression, rheumatoid arthritis and heart disease, the study participants were markedly impaired in both the physical and psychological domains. This indicates that contrary to a widely held view that they represent the 'worried well', these patients are severely disabled (Bass *et al.* 2001). Also, the disjunction between the patients' experience of

their symptoms and the views of the physician or psychiatrist treating them may, in part, explain their dissatisfaction with management (Lin *et al.* 1991).

This study demonstrates that at least 3 years after their initial identification as frequent attenders of secondary care, this sample continued to consult a large number of different health services. This suggests that the medically unexplained symptoms with which these patients present remain chronic problems. Interestingly, this group reported no attendances at Accident and Emergency departments. The reasons for this are unclear and surprising given the level of consultation elsewhere. One possibility is that frequent scheduled appointments in other settings reduces the perceived need to attend emergency services. Only three (6%) patients incurred no health-related costs during the evaluation period. Furthermore, it can be seen that more than two-thirds of the total cost incurred was accounted for by the cost of lost productivity arising from days off work due to illness and claims for social security benefits. Thus, having accumulated over £18 500 in NHS costs or nearly £60 000 to society in general in 6 months, it is clear that this sample of frequent attenders with medically unexplained symptoms account for a considerable proportion of health and social care expenditure. Also, the frequent attenders identified in this study represent the tip of the iceberg as far as medically unexplained symptoms are concerned.

Several studies have reported on the outcome of patients with medically unexplained symptoms, with mixed results. In a 2-year primary care study the physical symptoms of patients identified as acute somatizers were less likely to improve when compared with others and one-third went on to develop chronic somatoform disorders (Craig *et al.* 1993). Crimlisk *et al.* (1998) followed up 64 patients with medically unexplained motor symptoms admitted to a specialist centre for neurological disorders. After 6 years, 31 experienced at least some symptomatic improvement. A similar rate of improvement was reported in a large primary care study with an average follow up of 11 months (Kroenke & Mangelsdorff, 1989). Speckens *et al.* (1996) surveyed 81 patients with medically unexplained symptoms after an average of 15 months and found that three-quarters of the sample

reported improvement or recovery. However, many patients also reported persisting functional impairment. Other studies (Fowlie *et al.* 1992; Sharpe *et al.* 1992) have shown an association between psychological morbidity and continued high use of medical care services.

In conclusion, after identifying a group of patients that frequently attend secondary care, presenting with symptoms which remain medically unexplained, we found that at 3 year follow up this group of patients had high rates of psychiatric disorder, were severely disabled by their complaints, and continued to consult frequently in a range of settings. Psychiatric disorder is infrequently diagnosed in this group, despite its high prevalence. Further work would be helpful in determining whether identification and treatment of psychiatric illness would be an effective way of reducing service use and costs, as well as improving health outcomes in this group of patients.

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