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Distress: Developing Better Clinical Services

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Excerpt

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Chapter

1

Epidemiology: prevalence, causes and consequences

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Introduction

The epidemiology of medically unexplained symptoms will be considered under the following headings: prevalence, causes and consequences. For the first and last of these headings the data will be considered in three categories: medically unexplained symptoms, somatoform disorders and functional somatic syndromes (see Chapter 2). These 'diagnostic' labels describe different groups of patients but they also overlap considerably. The term 'medically unexplained symptoms' is a broad one; somatoform disorders and functional somatic syndromes are subgroups within it. These subgroups are represented diagrammatically in Figure 1.1 and are described below.

Prevalence

For each of the three groups, medically unexplained symptoms, somatoform disorders and functional somatic syndromes, the nature of the group will be described briefly and then the prevalence of these will be described in cross-sectional studies in primary, secondary care and population-based studies. Then each section will include data from longitudinal studies that show the outcome of medically unexplained symptoms.

Medically unexplained symptoms

The term 'medically unexplained symptoms' has been used widely and there is a considerable amount of data concerning the prevalence and outcome of these symptoms. The findings from secondary care will be considered first as this is where the concept was developed. It arose because many patients attending secondary care clinics had symptoms that, after appropriate (and sometimes very extensive) investigation, could not be explained by organic pathology or well-recognised physiological dysfunction [1;11]. In this way the term 'medically unexplained symptoms' describes a group of patients by what they do not have. The next section examines how often this occurs.

Prevalence of medically unexplained symptoms in secondary care

Secondary care studies in the Netherlands, UK and Germany have shown that medically unexplained symptoms are the presenting problem for 35–53% of new outpatients at specialist medical clinics (Table 1.1). The most common symptoms are: headache; back, joint, abdominal, chest and limb pains; fatigue; dizziness; bloating; palpitations; hot or cold sweats;

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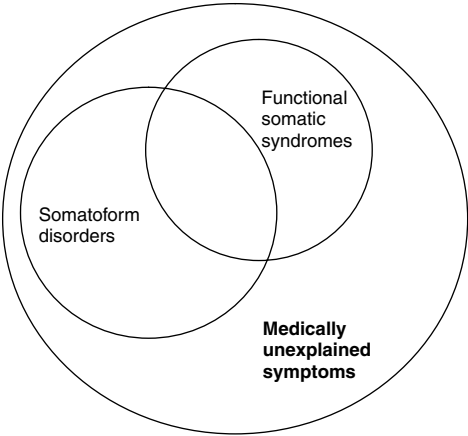


Figure 1.1 Diagram to show how the term ‘medically unexplained symptoms’ embraces a wide group of patients, and that somatoform disorders and functional somatic syndromes are smaller subgroups within the wider group.

Table 1.1 Proportion of patients attending secondary care clinics whose presenting complaint is diagnosed as ‘medically unexplained’

Study	Type of clinic	Number of patients included in the study	Per cent diagnosed with ‘medically unexplained symptoms’
Van Hemert <i>et al.</i> , 1993 [2]	General medical	191	52
Hamilton <i>et al.</i> , 1996 [3]	Gastroenterology, neurology and cardiology	324	35
Nimnuan <i>et al.</i> , 2001 [4]	Seven different specialties	550	52
Fiddler <i>et al.</i> , 2004 [5]	Gastroenterology, neurology and cardiology	295	39
Kooiman <i>et al.</i> , 2004 [6]	General medical	321	53
Targosz <i>et al.</i> , 2001 [7]	Neurology	57	30
Carson <i>et al.</i> , 2000 [8]	Neurology	300	30
Stone <i>et al.</i> , 2009 [9]	Neurology	3781	30
Mangwana <i>et al.</i> , 2009 [10]	General medical	200	50

nausea; trembling or shaking; and numbness or tingling sensations [11;12] In seven clinics in one UK hospital, the proportion of patients with medically unexplained symptoms varied between 24% in the chest clinic to 64% in the neurology clinic (mean 52%) [4].

The high prevalence of medically unexplained symptoms in neurology clinics has led to numerous studies and a summary of data from seven neurology clinics showed prevalence rates between 26% and 45% (median 30%) [9]. In the largest survey, the most common categories of diagnosis were: (i) headache disorders (26%); (ii) an organic

Table 1.2 Proportion of patients attending primary care whose presenting complaint is diagnosed as ‘medically unexplained’

	Clinics	Number of patients	Per cent diagnosed with ‘medically unexplained symptoms’
Mumford <i>et al.</i> , 1991 [14]	Primary care patients consulting with illness (i.e. excluding ‘routine’ visits)	554	7–12.6
Peveler <i>et al.</i> , 1997 [15]	Booked consultations	170	19
Kirmayer and Robbins, 1991 [16]	Primary care attenders	685	23.6
Palsson, 1988 [17]	Sweden		16
Kisely <i>et al.</i> , 1997 [18]	Weighted sample of primary care attenders	5447	15.4 Had 5+ medically unexplained symptoms
Duddu <i>et al.</i> , 2008 [19]	119	119	33

neurological disease was present but the presenting symptoms were not explained by it (26%); and (iii) conversion symptoms (motor, sensory or non-epileptic attacks) (18%) [13]. The second category is important as it indicates that medically unexplained symptoms commonly occur in people who have physical illness but the presenting symptoms cannot be explained by that physical illness. Examples include non-epileptic attacks, which occur in people who also have epilepsy, and non-cardiac chest pain in people with heart disease.

Prevalence of medically unexplained symptoms in primary care

In primary care, the general practitioner (GP) will usually make a clinical judgement that a symptom is not explained by organic disease, without necessarily using special investigations. Such symptoms generally form between 10% and 33% of presenting complaints in primary care (Table 1.2). A systematic review concluded that medically unexplained symptoms constitute the primary reason for consulting the GP in 15–19% of patients [20].

The proportion of all patients whose symptoms are classified as ‘medically unexplained’ varies greatly between GPs and this variation cannot be attributed to variation in the GPs’ patient populations; instead it reflects GPs’ tendency to use this categorisation [21]. There is, however, a relevant diagnostic category in the *International Classification of Diseases* (ICD), under which many of these patients may be classified: ‘Signs, symptom and ill-defined conditions’ (ICD code 780–789). In the UK, this accounts for the one of the largest diagnostic categories of hospital outpatients and the fourth largest category in primary care. In USA, it is the fifth most frequent reason for visiting a doctor (60 million per annum) – see Table 1.3 [22].

Table 1.3 Number of visits to the doctor in USA by diagnostic group (2005) [22]

Diseases of	Million visits per annum	Per cent of total
Respiratory system	110	11.5
Nervous system	86	8.9
Circulatory system	81	8.5
Musculoskeletal	80	8.4
Symptoms, signs; ill-defined conditions	60	6.3
Endocrine, nutritional and metabolic	56	5.9
Mental disorders	47	4.9

Prevalence of medically unexplained symptoms in population-based studies

Surveys in the general population show that pain is the most common medically unexplained symptom – headache and back, joint, abdominal and limb pain being the most common; fatigue, dizziness, bloating, food intolerance and sexual difficulties are also common [23;24]. These symptoms are reported by over a fifth of the population but only a small proportion report that they are severe [24].

Outcome of medically unexplained symptoms

Prospective studies are concerned usually with one of two outcomes: Does an organic disease come to light that explains the symptom(s)? Do the symptoms persist over time?

With regard to the first question, follow-up studies have been performed to assess whether medically unexplained symptoms turn out to have a medical cause after a period of time. In fact, this rarely occurs even though it is uppermost in some doctors’ minds and contributes to their decision to perform repeated investigations. In a German one-year follow-up study, five out of 284 patients classified as having medically unexplained physical symptoms later turned out to have a physical illness that could explain their symptoms [6]. In the largest neurology survey, only four out of 1030 patients (0.4%) had acquired an organic disease diagnosis that was unexpected at initial assessment and could plausibly be the cause of the patient’s original symptoms [9].

With regard to the second question, population-based studies suggest that most medically unexplained symptoms wane over time; fewer than half persist over one year [24;25;26;27] and two-thirds recede over a longer period [28]. The long Norwegian study reported that painful medically unexplained symptoms may persistent over many years in approximately 8% of the general population, mostly women [28].

Although up to a fifth of new symptoms presented to GPs are medically unexplained [15;29], only 10% of these (i.e. 2.5% of all patients attending the GP) had persistent symptoms that led to repeated consultation – the rest consulted for a single episode only [30]. In secondary care clinics symptoms tend to be more severe and persistent than those seen in primary care. Over a one-year follow-up period, approximately two-thirds of patients report improvement in medically unexplained symptoms but about 40% report some continued symptoms causing ill health [6;31]. The proportion may be higher in neurology clinics [9].

Therefore, we can conclude that medically unexplained symptoms are very common both in the general population and in primary and secondary care, but at least in the first two settings most are transient. These may not require medical intervention other than reassurance about their frequency in healthy people and a check that they do not indicate physical disease. In secondary care the symptoms tend to be more persistent and may have more severe consequences (see below). In both primary and secondary care, doctors need to use appropriate strategies in managing patients with these symptoms. The rest of this section is concerned with medically unexplained symptoms that persist over six months or more.

Somatoform disorders

This term includes several disorders where a high number of medically unexplained symptoms is the main feature. It is a diagnostic category in both the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-IV and ICD-10 classification systems [32;33], where it also includes several other diagnoses (see below). This book is concerned with the first two main categories (a and b below) but there have been several modifications, two of which (c and d) are also included here. In this chapter we used 'somatoform disorder' as an umbrella term to include the following disorders:

- (a) 'somatisation disorder', defined by numerous bodily symptoms that are disabling and/or lead to medical help-seeking [32]; there are slight differences in the way the two diagnostic systems define this disorder but both require multiple somatic symptoms spread throughout the body (Table 1.4)
- (b) 'undifferentiated somatoform disorder', which requires presence of one or more unexplained physical symptoms causing clinically significant distress or impairment for six months [32]
- (c) 'abridged somatisation disorder', which is defined by the somatoform symptom index (SSI) either as four medically unexplained symptoms in men and six in women (SSI-4/6) or by three medically unexplained in men and five in women (SSI-3/5) [34;35]
- (d) 'multisomatoform disorder', which requires presence of three current medically unexplained symptoms, one of which must have been present for two years [36].

This large number of diagnoses reflects the fact that 'somatisation disorder' as originally defined, had a very high number of medically unexplained symptoms, which meant that this disorder was very rare in population-based studies [37]. The other diagnoses have been developed as they have a lower threshold and are more relevant in primary care and population settings.

The remaining major group of disorders concerns high health anxiety (hypochondriasis), which also has rather a high threshold. Persistent disease conviction (the worry that one has a serious illness) occurs in approximately 6.5% of the population but the additional criteria of seeking medical help and refusal to accept appropriate medical reassurance reduces the prevalence of the diagnosis in population-based samples to less than 1% [37;38;39].

The diagnostic category 'somatoform disorders' includes also the diagnoses of pain disorder (pain not fully explained by organic disease and associated with psychological factors) and conversion disorder, which refers to sensory or motor symptoms for which no medical explanation can be found, but which are disabling and lead to medical help-seeking [32;33]. Pain disorder is not considered separately from the somatoform disorders as the epidemiology is similar; many people have multiple pains [40]. Conversion disorder

Table 1.4 Selected somatoform disorders in DSM-IV and ICD-10 [32; 33]

DSM-IV		ICD-10	F45
Somatisation disorder:	300.81	Somatisation disorder:	F45.0
– a history of many medically unexplained symptoms before age 30		– at least two-year history of medically unexplained symptoms	
– resulting in treatment sought or psychosocial impairment		– resulting in repeated (three or more) primary care or specialist consultations	
– a total of eight or more medically unexplained symptoms from across the four groups:		– a total of six or more medically unexplained symptoms, from at least two separate organ groups (gastrointestinal, cardiovascular, genitourinary, skin and pain)	
• at least four pain			
• two gastrointestinal			
• one sexual			
• one pseudoneurological			
Undifferentiated somatoform disorder	300.81	Undifferentiated somatoform disorder	F45.1
Hypochondriasis	300.7	Hypochondriacal disorders	F45.2
Pain disorder associated with psychological factors	307.80	Persistent somatoform pain disorder	F45.4
		Somatoform autonomic dysfunction	F45.3
Body dysmorphic disorder	300.7	Hypochondriacal – dysmorphophobia	F45.2
		Neurasthenia	F48.1

is not considered in detail in this book as it is rare in clinical practice and has not been studied widely [41;42]. Body dysmorphic disorder is a condition characterised by a distressing and disabling preoccupation with an imagined or slight defect in appearance [43;44;45]. It differs considerably from the very common disorders which are the main concern of this book.

ICD-10 includes neurasthenia (chronic fatigue), as one of the somatoform disorders. This is considered here as chronic fatigue syndrome under the heading of functional somatic syndromes. ICD-10 also includes somatoform autonomic dysfunction, which refers to symptoms of autonomic arousal with preoccupation and distress relating to a particular organ [33].

Prevalence of somatoform disorders in primary and secondary care

The prevalence of somatoform disorders in primary care studies is shown in Table 1.5. The third column of Table 1.5 shows the prevalence of somatoform disorders as a whole, i.e. somatisation disorder, undifferentiated somatoform disorder, somatoform disorder, not otherwise specified, pain disorder, hypochondriasis, conversion and abridged somatisation (SSI-4/6) and multisomatoform disorder. It can be seen in the last column that the

diagnoses undifferentiated somatoform disorder, somatoform disorder, not otherwise specified, abridged somatisation (SSI 4/6) and multisomatoform disorder are much more frequent than the other disorders, reflecting their lower threshold.

Most of the studies have used a standardised research interview to assess diagnosis. The most commonly used interviews are the Schedule for Clinical Assessment in Neuropsychiatry (SCAN)[55], the Primary Care Evaluation of Mental Disorders (PRIME-MD) [56], and, in population-based studies, the Composite International Diagnostic Interview (CIDI) [57]. During these interviews respondents are asked about each of many bodily symptoms and, for each symptom reported, whether a doctor has declared that it is ‘medically unexplained’ and that it causes distress or impairment. A few studies, however, have simply used a self-administered questionnaire (e.g. the Personal Health Questionnaire (PHQ-15)) to ask respondents to tick on a checklist those bodily symptoms that they have experienced recently and found bothersome. This approach counts all bodily symptoms, regardless of whether they are medically explained or unexplained. It cannot lead to a formal diagnosis but it has been found that a high score on such a questionnaire is associated with impaired functioning and high healthcare use even after adjusting for concurrent psychiatric and physical disorders [53;54;58]. Patients scoring in the top 10–20% on this questionnaire were given a provisional diagnosis of ‘probable somatisation’ [53] and are represented in the bottom three rows of Table 1.5.

The use of different measures and different samples leads to considerable variation in the prevalence rates reported in Table 1.5, but most studies provide an overall prevalence in the range of 8–20%. The median for abridged somatisation SSI-4/6 is 16% which concurs with a systematic review [37] (Table 1.6).

One systematic review examined the prevalence of somatisation and hypochondriasis in primary care using abridged forms of both diagnoses (Table 1.6) [37]. It can be seen that the median prevalence figure for abridged somatisation was 16% in primary care and this concurs with a further systematic review which found that between 16% and 22% of patients had abridged somatisation [20]. The median prevalence rate for hypochondriasis is approximately 10% of patients attending primary care.

Very few primary care studies reporting prevalence of somatoform disorders provide clear data regarding concurrent physical illnesses. One study reported that 42% of patients with somatoform disorders had diseases of the circulatory system, 29% of the musculoskeletal/connective, 20% respiratory, and 18% endocrine, nutritional and metabolic diseases [49]. Another showed that 58% of patients with medically unexplained symptoms had two or more chronic diseases, most commonly chronic chest and cardiovascular diseases [59]. Of the last two studies in Table 1.5, one reported that the mean number of physical disorders was approximately 1 in the patients with high somatic symptoms score [54]. The other reported that 41% had at least one serious concurrent medical illness [53]. This shows clearly that somatoform disorders coexist with recognised physical diseases.

There have been fewer studies of somatoform disorders in secondary care. In patients newly referred to a neurology clinic, the most frequent current diagnoses were somatoform disorders (33.8%; 95% confidence interval (CI) 25.9–42.7%) [12]. In two-thirds of these patients the somatoform disorder occurred in addition to a clear organic neurological disorder, emphasising the frequency with which somatoform and organic disorders can co-occur. A study of medical inpatients, most of whom would have had serious physical illness, found 1.5% had somatisation disorder and 10% had undifferentiated somatoform disorder,

Table 1.5 Prevalence of somatoform disorders in primary care

Study	Sample (N) and measure ^a	Proportion with any somatoform disorder, ^b % (95% CI) or median % and range (R)	Prevalence (rate %) of individual somatoform disorders (see text) and further data concerning incidence or persistence
Fink <i>et al.</i> , 1999 [46]	Denmark (18–60 yrs) (SCAN 2.1) N = 199	Any somatoform disorder: 22.3% (16.4–28.1%) for ICD-10 57.5% (50.5–64.5%) for DSM-IV	Prevalence: (DSM-IV): 30.3% (23.8–36.9) if somatoform disorder, NOS excluded 12.6% (7.9–17.4) if somatoform disorder, NOS and undifferentiated somatoform disorder excluded
de Waal <i>et al.</i> , 2004 [47]	The Netherlands (25–80 yrs) (SCAN 2.1) N = 473	Any somatoform disorder: 16.1% (12.8–19.4%)	Somatisation disorder: 0.5% (0.0–0.9) Undifferentiated somatoform disorder : 13.0% (9.8–16.2) Pain disorder: 1.6% (0.7–2.4) Hypochondriasis: 1.1% (0.4–1.8) Conversion disorder: 0.2% (0–0.6)
Toft <i>et al.</i> , 2005 [48]	Denmark (18–65 yrs) (SCAN) (Present state rate) N = 701	Any somatoform disorder (using ICD-10) Total: 35.9% (30.4–41.9%) F: 38.3% (31.5–45.6%) M: 31.7% (22.6–42.4%)	Diagnoses by ICD -10: F44.4–48.0 Somatisation: 10.1% (7.5–13.5) Undifferentiated somatoform disorder: 1.7% (0.7–4.0) Hypochondriasis : 2.4% (1.1–5.2) Seasonal affective disorder: 4.3% (2.8–6.7) Pain disorder: 4.4% (2.7–6.9)
Hanel <i>et al.</i> , 2009 [49]	Germany (18–65 yrs) N = 1751	18.4%	Somatoform disorders/ functional disorder diagnoses by 75 GPs

Table 1.5 (cont.)

Study	Sample (N) and measure ^a	Proportion with any somatoform disorder, ^b % (95% CI) or median % and range (R)	Prevalence (rate %) of individual somatoform disorders (see text) and further data concerning incidence or persistence
Kroenke <i>et al.</i> , 1997 [36]	USA (18–91 yrs) (PRIME-MD) (PHQ-15) N = 1000	Any somatoform disorder 14%	Multisomatoform disorder: 8.2% Somatoform disorder, NOS: 4.2% Hypochondriasis: 2.2%
Jackson <i>et al.</i> , 2008 [50]	USA (Follow-up 5 yrs) (PRIME-MD) (PHQ-15) N = 500 (baseline)		Multisomatoform disorder: 8% (at baseline) Stability: 22% (7/32) had multisomatoform disorder at five-year follow-up)
Ustun and Sartorius, 1995 [51]	6 European sites PSE/SCAN/ CIDI/SCID		Somatisation disorder: median = 1.7% (range: 0.4–3.0) Hypochondriasis: median = 0.5% (range: 0.1–1.0) Neurasthenia: median = 9.3% (range: 4.6–10.5)
Lowe <i>et al.</i> , 2008 [52]	Germany (18–95 yrs) (PRIME-MD) (PHQ-15) N = 2091	9.5% (PHQ-15 score ≥15)	
Barsky <i>et al.</i> , 2005 [53]	USA (PHQ-15) N = 1546	20.5% (PHQ-15 high score)	
Kroenke <i>et al.</i> , 2002 [54]	USA (PHQ-15) N = 3000	10% (PHQ-15 score ≥15)	

^a Adults >18 years, unless otherwise specified.

^b Total and M and F.

M, male; F, female; CI, confidence interval; NOS, not otherwise specified; DSM, *Diagnostic and Statistical Manual of Mental Disorders*; ICD, International Classification of Diseases; SCAN, Schedule for Clinical Assessment in Neuropsychiatry; PRIME-MD, Primary Care Evaluation of Mental Disorders; PHQ, Patient Health Questionnaire; CIDI/SCID, Composite International Diagnostic Interview/Structured Clinical Interview for DSM.

Table 1.6 Summary of findings regarding prevalence of abridged somatisation and abridged definition of hypochondriasis [37]

	Abridged somatisation	Abridged hypochondriasis
Population-based	Median = 14% (range: 4.4–19%) Four studies	Median = approx. 7% (range: 1.3–10.7%) Four studies
Primary care attenders	Median = 16.6% (range: 7.3–35%) Six studies	Median = 10.7% (range: 2.2–14%) Eight studies

using DSM-IV criteria [60]. In a larger study of patients with serious physical illnesses the prevalence of somatoform disorders (15.3%) was significantly higher than in a population-based sample of healthy controls (5.7%) [61].

Prevalence of somatoform disorders in population studies

The prevalence of somatoform disorders in population-based studies is summarized in Table 1.7. Once again, there is considerable variation in the prevalence rates reflecting the use of different measurement instruments. One systematic review of population-based studies included only somatoform disorders diagnosed using the standardised CIDI. In seven studies, with a total of 18 894 respondents, the 12-months prevalence ranged from 1.1% to 11% (median = 6.3; 95% CI 2.1–7.8) [62]. The authors of this study estimated that the number of residents aged 18–65 years in the European Union (EU) (total 301 million) affected by somatoform disorders within the previous 12 months was 18.9 million (95% CI 12.7–21.2).

Outcome of somatoform disorders

There have been remarkably few prospective studies of somatoform disorders [27;37;74]. From the results of two systematic reviews it appears that half of patients with abridged somatisation reported remission of the disorder over one year and in half the symptoms persist [27;74]. The same is true of patients with hypochondriasis [27].

Symptoms are more persistent in those studies which have selected patients with particularly severe or chronic symptoms [74]. In adolescents, where symptoms tend to be of recent onset, symptoms of somatoform disorders persisted in approximately one-third of participants over a 15-month follow-up period [62]. In another study of adolescents, approximately 45% of those with undifferentiated somatoform disorder continued to have the disorder one year later, but the proportion was larger (two-thirds to three-quarters) in those with pain disorder or abridged somatisation disorder [64;65].

Functional somatic syndromes

The term functional somatic syndromes covers the individual, well-recognised medical syndromes such as irritable bowel syndrome, fibromyalgia (chronic widespread pain), chronic fatigue syndrome, temporomandibular joint pain and multiple chemical sensitivity. These diagnoses are made frequently in clinical practice but their cause is unclear so they are generally regarded as ‘medically unexplained’ syndromes. Each syndrome has clear diagnostic features that have been refined by expert committees[75;76;77]. These detailed diagnostic