

Patients with medically unexplained symptoms and somatisation – a challenge for European health care systems

Draft – prepared by: Peter Henningsen and Francis Creed January 2009

A white paper of the EACLPP MUS study group*

Contents	Page
THE REPORT (brief version)	2
EXTENDED VERSION OF REPORT WITH SUPPORTING DATA	
1 Background to report and its intended use.....	14
2 Definitions, classifications and models of MUS and somatisation.....	16
3 Epidemiology: Prevalence and Consequences.....	17
4 Evidence based management of MUS and somatisation.....	31
5 Current models of care.....	33
6 Barriers to improved treatment.....	39
7 Improved care for patients with medically unexplained symptoms.....	44
8 Medically unexplained symptoms in children and adolescents	50
9 Conclusions and suggestions for further action .. to be written.....	54
Appendix A : <i>Medically Unexplained Symptoms/ Somatisation in different specialities</i> page 55	
Appendix B : Teaching primary care physicians and other non-psychiatrists to diagnose and manage MUS / functional disorders (per Fink) page 61	
Appendix C: Current national guidelines page 65	
Appendix D: Treatment of MUS in the General Hospital (non-systematic review) page 67	
Appendix E: Problems with terminology and definitions page 69	

* An extended version (source text) can be found in the Appendix

Brief version of the report

1 The intention of the white paper

Patients with severe bodily distress like pains, functional bodily disturbances and fatigue, but without significant organic disease explaining this distress, are one of the most frequent groups of patients in all areas of health care across Europe. There is good evidence that they are frequently disabled, incur high costs and high levels of lost productivity. Nevertheless, the care for these patients suffers from a wide range of significant deficits. Some of the important ones are

- lack of generally agreed terms and definitions for severe bodily distress
- lack of awareness of the problem among health care professionals and health care planners
- general tendency to consider only organic explanations for bodily symptoms, leading to long, expensive and frustrating organic work-ups and treatments
- unsubstantiated practice to classify symptoms as *either* physical *or* mental
- lack of specialized care for patients with unexplained bodily symptoms who often “fall between” the largely separate health care systems provided for somatically and mentally ill patients
- high, yet largely ignored influence of context, especially work-related, compensation-related and cultural factors, on incidence and severity of physical symptoms and bodily distress
- lack of adequate training for medical students, doctors and other health care professionals for dealing with these issues

Against this background, the intention of this white paper is to support the claim

- that the suffering of patients with unexplained bodily symptoms is a significant issue for health care policy in Europe
- that there are significant deficits in the care for these patients
- to give examples and make suggestions for improved care for these patients

2 Definitions, classifications, aetiological factors and models

Definition of key terms used in this document

Since distressing unexplained bodily symptoms have been largely ignored in clinical and scientific medicine for a long time, terminology in this field is inconsistent and is still developing as knowledge increases. In the following, we specify the two most important currently used key terms.

Medically unexplained symptoms (MUS)

This is the most general term used to describe patients' complaints about one or more enduring and distressing bodily symptoms which can neither be sufficiently explained by structural organic disease nor by psychiatric disorders like depression or anxiety. The term's strength is that it is purely descriptive and easy to understand also for laypersons. It does, however, cover a very large group of patients since it

does not include information about severity and duration of symptoms and thus clinical significance.

Importantly, the term does not imply absence of a physical basis for the complaints as current models assume that central nervous dysfunctions in the processing of stimuli from the body and in their interaction with emotional and cognitive processes underlie the experience of these bodily symptoms (see: Models). Hence, a truly bio-psycho-social model and neither a purely psychogenic nor a purely mechanistic organic approach is adequate in understanding all of the clinical phenomena discussed here.

Somatisation

This term has several meanings but will be used here to refer to the reporting of *numerous MUS*, i.e. it is seen as a more severe subgroup of all patients with MUS, independent of whether they also carry a Functional Somatic Syndrome description or not. The reporting of bodily symptoms may be on a self-report checklist, or in response to direct questions at a research interview – most patients report a few symptoms only. Somatisation usually refers to a large number of bodily symptoms reported to a doctor.

A related, but less frequent problem is excessive concern about health and illness “health anxiety” (previously known as Hypochondriasis”). People with this problem are preoccupied with fears that they may have a serious disease, a notion that is based on the misinterpretation of bodily symptoms. This preoccupation persists despite appropriate medical evaluation and reassurance and leads to clinically significant distress. The problem overlaps with, but is distinct from, somatisation.

Note that the terms used in this area of medicine are not mutually exclusive. Thus a patient’s symptom may be described simply as a single specific symptom like backache, dizziness, fatigue etc. It may be described as “medically unexplained” if no organic cause is thought to be present and it may be described as somatisation if there are many other bodily symptoms. If the symptoms fall into a recognised pattern there may also be a diagnosis of a functional somatic syndrome (see below). Doctors vary in the extent to which they elicit the extent of a patient’s symptoms and any accompanying distress. As medicine has become increasingly specialised there is a tendency for specialist physicians to concentrate only on symptoms relevant to their area – chest pain for the cardiologist, abdominal pain for the gastroenterologist etc. Identifying the large number of bodily symptoms, spread throughout the body, is a decisive first step in making a correct diagnosis of somatisation, communicating it to the patient and initiating successful treatment.

Classifications

There is no simple way to classify MUS in medicine and many doctors, especially in primary care, are rather reluctant to code them at all. These facts seriously hamper recognition, research and treatment of MUS and somatisation and communication with patients and among health professionals about them.

Classification depends on two related differentiations: classification on the level of either symptoms, syndromes or disorders and classification either as physical, mental or unspecified.

- Classification as a *single symptom* is done for instance with the ICD-9 code 780-789 “Signs, symptom and ill-defined conditions” or its equivalent in ICD-10, chapter XVIII (R00-R99). This classification is easy to use and respects the fact that, at least early in its course, it is hard to tell whether a symptom can be organically explained, or has a physical or mental nature. But it is therefore very unspecific, and it is not adequate for multiple symptoms and severe accompanying distress.
- Classification as a specific *functional somatic syndrome* (FSS) is possible for those patients who have a constellation of (usually more than one) medically unexplained symptoms that fit with the description of this FSS. Examples are Irritable bowel syndrome (IBS), fibromyalgia (now called chronic widespread pain), chronic fatigue syndrome (CFS), temporomandibular joint pain. A large proportion of patients with one FSS also meet the criteria for one or more other FSS (see: Comorbidity); fatigue, for example, is a recognised feature of both chronic fatigue syndrome and fibromyalgia. This classification is used widely in somatic special care, where a major proportion of new patients are found to have a functional somatic syndrome – irritable bowel syndrome in gastroenterology, chronic widespread pain in rheumatology etc. One major advantage of terms like “FSS”, “IBS”, or “CFS” is that they are less stigmatising than the terms “somatisation” and “somatoform disorders”. It is important to note, however, that gradation of severity and a description of psychological and behavioural characteristics are not part of the description of Functional somatic syndromes.
- Classification as a *somatoform disorder* (SFD) within the ICD-10 chapter V (F) on mental disorders and the DSM-IV. In contrast to classification as FSS, subgroups of somatoform disorders allow some gradation according to number of symptoms/ severity and delineation of the subgroup with predominant health anxiety. The SFD classifications mention psychological and behavioural characteristics like preoccupation with organic disease or dysfunctional illness behaviour, but they are not operationalized for single disorder categories. This classification is more difficult to use because it requires judgements about the fact that symptoms are medically unexplained and not part of another mental disorder like depression or anxiety. The term encourages a “lumping” perspective compared to the “splitting” tendency of FSS. It is, however, disliked by many patients, in some countries more than in others, because of its implication that the MUS are part of a mental disorder. New editions of the SFD classifications in ICD-11 and DSM-V are currently under way.

Gender, age and transcultural aspects of MUS, FSS and SFD

Gender

Studies on the prevalence of physical and psychological symptoms including studies on MUS almost unanimously find a female preponderance of about 70%.

Accordingly, about 60 to 80% of patients with a diagnosed Somatoform disorders or Functional somatic symptoms are women. The reason for this gender difference is unclear; but the following are contributory factors: anxiety and depression are more

common in women than men, the sick role is generally more accepted in women because of gender role stereotypes. Women have lower thresholds for many sensations and more readily seek medical care; they experience more childhood and adult abuse and specific stressors such as “reproductive life events” and “double-work” situations, which are associated with medically unexplained symptoms and somatisation. Women’s symptoms and illnesses are more likely to be seen as “psychiatric” or “psychosocial”.

Children, adolescents and elderly people

The prevalence of MUS and somatisation, SFD and FSS peaks around mid-life, but on a closer look, the phenomenon also affects children, adolescents, and elderly people. The spectrum of physical symptoms is broad, and most FSS (such as CFS and FM) have been described in young children (Eminson, 2007). In younger children, unexplained abdominal pain is an especially prevalent problem, whereas, in adolescents, unexplained headaches dominate (Eminson, 2007). Systematic studies are rare, but altogether the prevalence for somatoform syndromes among schoolchildren can be estimated around 10%. It is important to know that there are family accumulations of MUS, possibly resulting from social learning or genetic transmission (Johnson, 2008).

Little is known about MUS in elderly people, since many studies exclude persons above 60 or 65. Due to the effects of normal ageing and increasing somatic comorbidity it is much more difficult to rate a symptom as “medically unexplained” in older patients. Even if the frequency of SFD and FSS diagnoses appears to decrease with age, it still reaches around 15% in clinical populations, with pains of different locations becoming the most prevalent symptoms (Fink et al., 2007).

Transcultural aspects

MUS and somatisation are transculturally and historically ubiquitous phenomena, but symptom types and interpretations vary (Kirmayer et al., 2004). It might be only due to the body-mind-dualism in western academic medicine that MUS, FSS and SFD are so difficult to integrate in medical categories. For example, the traditional Japanese concept of a common form of „nerval weakness“ (shenjing shuairuo) is a combination of fatigue, pain, and psychological symptoms (Lee et al., 2000) and thus integrates “physical” and “mental” complaints.

Ethnic minorities, migrants or refugees, however, appear to have raised prevalences of MUS, FSS and SFD, probably due to increased life stressors and trauma (Castillo et al., 1995; Hsu 1999). Thus, knowledge of explanatory models of bodily distress as well as individual psychosocial strains is useful for the management of unexplained bodily symptoms in patients from different cultural backgrounds.

Evidence based aetiological factors

Although we do not fully understand the causes of medically unexplained symptoms and somatisation, there is now good evidence for several associated factors (Rief and Broadbent, 2007). Note that these factors interact and may play an aetiological, and prognostic role at the same time. In the individual patient it will be hard to tell „what was first“, let alone develop a linear model of causation.

Among *individual* factors, traumatisation (through neglect, physical or sexual abuse), possibly alexithymia (i.e. difficulties realizing and expressing emotions) and insecure attachment, have been found to be associated with MUS and somatisation. Certain personality factors such as neuroticism are more prominent in individuals with MUS. MUS in the family and during childhood as well as prior mental and physical illnesses or accidents raise the stakes to suffer from MUS. *Individual biological* factors are not well described, but there is good evidence of the role of prior organic illness and there are reports on psychoneuroimmunological, endocrinological or neurotransmission changes.

Iatrogenic factors play a crucial role. A purely “organic” argumentation, overinvestigation and overinterpretation of minor findings, ignorance of emotional cues (and sometimes even of full-blown mental illness), and solely somatic treatment offers appear to promote somatic illness beliefs and behaviours in patients with MUS and somatisation.

Relevant *sociocultural* factors are the questionable social legitimacy and the stigma of MUS, urging sufferers to overemphasise rather than relativise their complaints. The possibility of compensation and health insurance coverage may further promote MUS. In western society, the high emphasis on performance and output may lead to individual and collective job strain and effort-reward-imbalance; physical symptoms, culturally labeled as signs of general distress, may represent the only “way out” - either for employees or for employers who can thereby lay-off work force.

Models

Currently, hypotheses on the aetiopathology of MUS aim to re-integrate physical and psychological mechanisms into non-linear multicausal and dynamic models. Central sensitization, cognitive processing and appraisal of current sensory stimuli, CNS representation of past experiences, and environmental factors are thought to play important roles. (Barsky and Wyshak 1990, Kirmayer and Taillefer, 1997; Rief and Nanke, 1999; Henningsen 2003, Brown 2004; Thayer and Brosschot, 2005; Rief and Broadbent, 2007). Hopefully, the growing interest in MUS and somatisation will promote research to test these hypotheses – by now, they all lack sufficient evidence.

3 Epidemiology

Prevalence

Cross sectional

As stated above, the different terms for which prevalence rates are given primarily refer to different settings and perspectives on one and the same phenomenon, not to different diseases. It is reasonable to assume that a large proportion of prevalence of MUS and somatisation usually is hidden behind other terms like “musculoskeletal pain” etc. Note that, due to the vagueness of terminology, prevalence rates differ widely between studies and therefore can only be roughly estimated.

Medically unexplained symptoms

Secondary care studies in Netherlands, UK, and Germany have shown that symptoms judged as medically unexplained after adequate examination occur in 39-52% of new out-patients at specialist medical clinics - from general

medicine over gynecology to neurology (Van Hemert et al., 1993; Hamilton et al., 1996; Nimnuan et al., 2001; Reid et al., 2001; Fiddler et al., 2004; Kooimanet al., 2004). In primary care, such symptoms occur in 15-25% of patients (Kirmayer et al., 2004).

- *Functional somatic syndromes*
In the population, prevalence of specific FSS like irritable bowel syndrome reaches up to 15% (Drossman et al., 2002), but many of these people do not go to doctors. In primary care 2-3% of patients have IBS but in specialist gastroenterology clinics the proportion is approximately one third. Small variations in the criteria can produce wide variations in prevalence rates, for example, whereas The prevalence of chronic fatigue syndrome (CFS) in the population has been estimated to be 0.2% but persistent disabling fatigue, often seen in primary care but not fulfilling all the criteria for CFS, occurs in 9% of the population (Sullivan et al 2005). In selected clinical populations (usually attenders of specialist clinics) as many as half of all new patients have Functional somatic syndromes.
- *Somatoform disorders*
Population-based studies indicate that DSM somatisation disorder occurs in 0.4% of the population. Other types of Somatoform disorders are clearly more frequent: For example, abridged somatisation disorder occurs in 13% (range 3.1%-19%) (Creed and Barsky 2004), somatoform pain disorder in 5.4%-8.1% (Grabe et al., 2003; Fröhlich et al., 2006). In primary care and somatic specialist settings, various somatoform disorders occur in up to 58% (Kroenke et al., 1997; Fink et al., 1999; Fink et al., 2004; Fink et al., 2005).
- *Health anxiety (hypochondriasis)*
The median prevalence of hypochondriasis (DSM-III or IV, ICD-10) in primary care is 4.2% (range 0.8%-8.5%) (Creed and Barsky, 2004). The median prevalence of less strictly defined, abridged hypochondriasis is 6.7% (2.2%-9.0%). Population-based studies describe prevalences between 0.02% and 7.7% (Creed and Barsky, 2004)

Persistence

In one primary care study 25% of patients visiting the GP had medically unexplained symptoms and only 10% of these (i.e.2.5% of all patients attending the GP had persistent symptoms – the rest consulted for a single episode only (Verhaak et al., 2006). In an 11 year prospective study, 8% of people had medically unexplained pain at both times – this group was nearly all women and many had depression also (Leiknes et al., 2007).

Longitudinal studies have shown that bothersome bodily symptoms wax and wane over time. Single symptoms may not be remembered at subsequent interviews (Leiknes *et al.* 2006c; Simon and Gureje 1999a), making exact measurements of life time symptom burden unreliable. Nevertheless, among “high utilizers”, i.e. patients who frequently over years consult for health problems, between 20 and 25% have been shown to have medically unexplained symptoms as main reason for their persistent health utilization (Fink 1992; Reid et al., 2001).

Comorbidity

This term refers to the co-occurrence of one disorder with another. There are several important comorbidities that frequently occur with MUS and somatisation:

a) with *organically defined illnesses*: patients with unexplained bodily symptoms can suffer concomitantly from these. For example, chronic widespread pain frequently occurs with rheumatoid arthritis.

b) Many patients with an FSS, however, *fulfil criteria for at least one other FSS*. The extent of this empirical overlap is from around ten percent in the general population up to ninety percent in clinic populations (Aaron and Buchwald, 2001; Henningsen et al., 2007, Kanaan et al., 2007). Symptoms overlap even more often: For example, all patients with chronic fatigue syndrome report fatigue, but eighty six percent of patients with fibromyalgia do also; conversely, although all fibromyalgia patients report arthralgia, so do eighty eight percent of chronic fatigue syndrome patients. Thus, the apparent diversity of syndromes may be no more than an artefact of medical specialisation.

c) MUS, FSS and SFD frequently *co-occur with depressive and anxiety disorders*, with a linear increase of this co-morbidity with rising somatisation (LIT). The overlap with anxiety and depression is higher in SFD or FSS than in comparable, organically explained diseases (for example approximately 50% of clinic patients with irritable bowel syndrome have concomitant anxiety or depression but this only occurs in 10-15% of inflammatory bowel disease patients).

Importantly, however, more than 50% of the cases occur *without accompanying depression, anxiety or PTSD* (Henningsen et al. 2003; Lieb et al., 2007; Leiknes et al., 2007) and there is increasing recognition of the unique contribution that somatisation makes to outcomes. For example, somatisation, depression and anxiety each make their independent contribution to aspects of impairment, in addition to the contribution of the overlap of all three conditions (Löwe et al 2008). Thus it is not the case that all somatisation is really a manifestation of depressive or anxiety disorders.

Consequences

Impairment

Measurements of somatisation as a continuous variable with a self report questionnaire have consistently shown a linear decrease of health related quality of life (HRQOL) with increasing numbers of MUS. Also in early stages, before the end of diagnostic investigations, MUS are associated with a poor HRQOL (Koch et al., 2007; Duddu et al., 2008; XXX). In a sample of 2900 primary care patients, the top 30% in the distribution of numbers of MUS had a HRQOL significantly below the norm, with the top 10% achieving ratings well below what is seen in most patients with chronic organic illnesses (LIT).

Health care utilisation

Doctor visits linearly increase with rising numbers of MUS. E.g., in the study mentioned above, the 10% of patients in the highest range of MUS showed around 4 times more visits to doctors than the 35% in the lowest range (LIT).

In a US study of 1546 primary care out-patients adjustments were made for demographic features, concurrent medical illnesses and, in addition, psychiatric disorders that often accompany somatisation (mostly depressive, anxiety and panic disorders) (Barsky et al. 2005). The patients with highest degree of somatisation (top 14% on somatisation questionnaire) made more primary care and medical specialist

visits, more visits to the emergency department and had more hospital admissions than the whole rest of the patients.

Disability days/ time off work

In the same primary care study mentioned above, disability days of patients again increased linearly with increasing number of MUS. Patients in the top10% had more than 15 disability days, patients in the lowest group approximately 1 day (Barsky et al., 2005).

Costs

“Signs, symptoms and ill-defined conditions” (ICD-9 code 780-789)

account for the most costly diagnostic category of out-patients and the 4th most expensive category in primary care in the UK (LIT). In the Netherlands this diagnostic category is the 5th most expensive diagnostic category (LIT).

In the US study mentioned above, the high health care utilization of the top 14% also lead to higher in-patient and out-patient costs. This study estimated that if these findings were extrapolated to the whole of USA then US\$ 256 billion a year in medical costs could be attributed to the effect of somatisation alone – i.e. after adjusting for the effect of concurrent medical and psychiatric illnesses (Barsky et al., 2005).

In a UK study on patients with severe Irritable bowel syndrome, the group scoring in the top 25% of somatisation ratings incurred double the health care costs of the lower groups (Creed et al., 2008)

4 Evidence based management of MUS and somatisation

Currently there is no consensus on the best criteria to evaluate the effect of interventions aimed at MUS and somatisation, FSS and SFD. From a traditional biomedical perspective, alleviation of symptoms is most important, whereas from a broader perspective on experience and behaviour of patients, other criteria like quality of life, functioning, health care use and time off work are seen as equally important. There are several recommendations to handle unexplained bodily symptoms in the different health care settings, but evidence is still limited.

Management in primary care

In primary care, it is probably most important to *listen* to any clues indicating bodily or emotional distress beyond the current lead symptom, to *think of the possibility* of an SFD or FSS in patients with enduring physical symptoms, and not to equate them with malingering. On the basis of these additional information it has been suggested to decide whether the patient has “uncomplicated” or “complicated” unexplained bodily symptoms (Henningsen et al., 2007). In uncomplicated cases, reassurance with positive explanation such as transient functional disturbances or stress related symptoms will usually do - do not only convey negative test results. Proposal or performance of repetitive somatic investigations only to calm the patient (or the doctor) should be avoided as they have been shown to carry a “somatising effect” on their own (Ring et al., 2005). Symptomatic measures like pain relief should be offered where appropriate, together with graded activation or exercise rather than rest. In complicated MUS, the patient should be advised on dysfunctional attributions and illness behaviour and encouraged to reframe symptoms within a biopsychosocial framework (ie, incorporate both the patients’ beliefs about the organic nature of their

symptoms and how these can be affected by a range of psychological and contextual factors); additionally, antidepressant treatment should be considered and discussed. Appointments should be scheduled at regular intervals rather than patient-initiated (Henningsen et al., 2007).

Several recent randomized controlled trials have tested the effect of short courses training General Practitioners in recognizing and managing MUS and somatisation (a popular term used for the models taught in these courses is "(extended) reattribution"). When comparing the results of GPs who have taken part in such a course with those who provided usual care, it emerges across different studies and countries that the effects on the level of patient's symptoms and impairment are modest/ not significant, whereas there is a consistent positive effect on GPs' satisfaction with these patients and their work with them. (Rosendal et al., 2005; Rosendal et al., 2007).

Management in somatic secondary/ specialist care

All recommendations for the primary care setting also apply to somatic secondary/specialist setting. The evidence base for management of specific symptoms or syndromes in secondary care is almost exclusively for FSS. It is dominated by studies on the effect of passive pharmacological and physical interventions aiming at a restoration of peripheral organ function (drugs, injections, manipulations, operations etc.). A smaller proportion of studies has looked at the effect of activating interventions aimed at central nervous system/ mental/ behavioural functions (graded activation, psychotherapy, antidepressant therapy, multimodal therapies). A review of systematic reviews of studies performed until 2006 has demonstrated that across all FSS, the activating, centrally acting treatments are more effective in terms of symptoms and function than the ones aiming at the restoration of peripheral function (Henningsen et al 2007).

Management by mental health professionals

As only a small proportion of patients with MUS/ somatisation will primarily turn to mental health institutions for treatments, most studies performed by mental health professionals are done in close collaboration with secondary/ specialist care (see centrally acting treatments, above).

Of the typical mental health treatments, efficacy has most consistently been demonstrated for cognitive behavioural psychotherapy (CBT) and, to a slightly lesser extent, for antidepressant therapy. Almost all studies in which it was looked at demonstrated reductions of costs (by approximately 50%) and/ or health care utilization apart from reductions of symptoms or increases in functioning (Creed et al., 2007; Kroenke 2007). Occasional studies have demonstrated superior effects of in-patient as opposed to outpatient-treatment of patients with somatisation also in terms of costs and days lost from work (Hiller et al 2003).

5 Current and future models of care

Successful treatment of patients with MUS and somatisation requires stepped care models in close cooperation of primary care, somatic and mental health specialists. Currently, however, patients with MUS and somatisation are cared for in multiple (and often incompatible) ways and by various medical specialties and health professionals due to the different ways of presenting, the lack of conceptual clarity and diagnostic agreement.

There is a huge heterogeneity in how services are operating and which patients are cared for across Europe. Care may be rooted in local traditions and possibilities, political factors, but also in personal relationships and networks between different doctors. This means that the service delivery across Europe has been and still is unsystematic, random and heterogeneous.

Primary care

- special courses, “psychosomatic basic care” (Denmark, Germany)
- collaborative care models between GPs and psychiatrists (Netherlands)

Somatic/ specialist care

- collaboration with consultation-liaison (CL)-psychiatry/ psychosomatics (country ?)
- special clinics with multimodal treatments for specific symptoms/ syndromes: chronic pain, fatigue, dizziness, headache etc.) (Country?)

Special units for treatment of MUS/ functional disorders/ somatisation

- Research Clinic for Functional Disorders and Psychosomatics (Denmark)
- So-called integrative Psychosomatic Medicine units within Internal Medicine (Germany, a minority of all depts of Psychosomatic Medicine)

Mental health care

- Special units for MUS/ somatoform disorders (Belgium)
- Depts of Psychosomatic Medicine (Germany, mostly independent of psychiatry, but also of somatic specialists)

6 Barriers to and suggestions for improved treatment

- *Currently*, MUS and somatisation hardly play a role in medical and specialist training.
In the future, the reality of MUS and somatisation and their significant impact on suffering and costs must be recognized and responded to.
- *Currently*, dualistic models of illnesses as either somatic or psychological in origin dominate conceptual/ medical trainings.
In the future, the complex interactions between physical and psychological processes and their intrinsic inseparability should be recognized in medical research and training.
- *Currently*, there is a misleading concentration on “single-organism-physiology” and neglect of brain-body-environment interactions as basic constellation also for all patho(psycho)physiology.
In the future, the dynamics and reciprocity of individual-environment interactions should be incorporated in medical paradigms.
- *Currently*, routine medical practice puts too much emphasis (and hence resources) on finding out organic backgrounds, and considers psychosocial factors too late.
In the future, organic and psychosocial context factors should be considered equally from the outset.
- *Currently*, treatment models are still too much oriented on an either-or of somatic versus psychogenic treatments.

- In the future*, multimodal treatments should be favoured and psychological sequelae of “organic treatments” as much as organic sequelae of “psychological treatments” should be realised and further investigated.
- *Currently*, medical and specialist training is often insufficient in patient-doctor-communication.
In the future, patient-doctor-communication should be a fundamental part of any medical education, not only in respect of MUS.
 - *Currently*, specialist management involves unclear responsibilities for functional somatic syndromes and neglects collaboration of psychiatry/ psychosomatic medicine with the rest of medicine.
In the future, a low threshold interdisciplinary consultation and cooperation with psychiatry/psychosomatic should be established.
 - *Currently*, professional politics is dominated by claims of somatic and mental health specialists to keep MUS/somatisation patients as “their and only their patients”.
In the future, interdisciplinary case management should be encouraged politically and financially.
 - *Currently*, health services primarily provide reimbursements for technical diagnostic tests and somatic treatments, less or not for communication skills and/ or for secondary prevention. Especially the DRG reimbursement system for inpatient treatment favours false labelling and reduction of CL-work.
In the future, communicative and preventive measures should be valued and payed appropriately, noxious effects of all-too technical approaches especially in MUS should be discussed openly.
 - *Currently*, there is no interest of politics and industry in the field leading to insufficient research funding. Partly, this is rooted in the (currently) missing connection to basic science (genetics, neuroscience etc.) which gets most funding.
In the future, funding should support research “from lab to life” and turn towards subjects and their individual environments.
 - *Currently*, health policy and social policy use MUS as a pseudo-medical tool for laying off work force; insurances function as risk factors for chronification of MUS.
In the future, management of MUS should become resource-oriented with the major goal of restoring individual quality of life and functioning (including an adequate integration in the job market).

7 Summary and Conclusions

Medically unexplained symptoms and somatisation are extremely common and yet neglected phenomena that come along with considerable suffering and costs. No matter what terminology is chosen, it is crucial to get an idea of the *whole picture*, i.e. symptoms in other organ systems, anxiety, depression, the psychosocial context of the complaints, and functional impairment. It is of no help for the patient to look for either an entirely mental or an entirely physical explanation for the symptoms: Often, especially after a long course or with relevant comorbidity, causation can never be elicited. For one or more persistent MUS with distress and reduced functioning the diagnosis of a somatoform disorder must be considered. Management of MUS and somatisation consists of a transparent and empathetic doctor-patient-relationship, good interdisciplinary

cooperation, active rather than passive and centrally acting rather than peripheral measures. In motivated patients with complicated courses, psychotherapy and/or psychopharmacotherapy should be considered.

These measures will hopefully lead to less frustrated patients and doctors, a better cost-benefit ratio, and growing scientific awareness of the complex connections between body, mind, and environment, which are so impressively typified by unexplained bodily symptoms.

EXTENDED VERSION OF REPORT WITH SUPPORTING DATA

Draft January 10th 2009

1 THE INTENTION OF THE WHITE PAPER

Patients with bodily symptoms like pains, functional bodily disturbances and fatigue, but without significant organic disease explaining them, are one of the most frequent group of patients in all areas of health care across Europe. There is good evidence that those patients who have severe /persistent unexplained symptoms are frequently disabled, incur high costs and high levels of lost productivity. Nevertheless, the care for these patients suffers from a wide range of significant deficits. Some of the important ones are

- lack of awareness for the problem among health care professionals and health care planners
- lack of generally agreed terms and definitions for severe bodily distress
- widespread wrong allocation of purely somatic diagnostic and therapeutic interventions
- lack of specialized care for patients with severe somatisation who “fall between” the largely separate health care systems provided for somatically and mentally ill patients
- lack of adequate training for medical students, doctors and other health care professionals for dealing with these issues
- high, yet largely ignored influence of context, especially work-related, compensation-related and cultural factors, on incidence and severity of somatisation

Against this background, the intention of this white paper is to support the claim

- that the suffering of patients with medically unexplained symptoms and somatisation is a significant issue for health care policy in Europe
- that there are significant deficits in the care for these patients
- to give examples and make suggestions for improved care for these patients

The report is aimed primarily at healthcare planners and healthcare professionals (of all disciplines) who might be in a position to influence the care received by patients with medically unexplained symptoms. It seeks to provide robust evidence of the nature of the problem, the difficulties faced by patients and by those healthcare providers who are trying to improve services for this group of patients and to demonstrate cost effective solutions to these difficulties.

The report arises from the EACLPP working group “Improving the management of patients with medically unexplained symptoms/somatisation”. The group is open to all EACLPP members but a core group have been responsible for the first draft of this report. The core group (listed below) includes (24 – to be revised?) members, who have contributed so far. They represent 9 EU countries (currently – increase?). All have a special interest in the treatment of patients with medically unexplained symptoms; most have a research interest as well as clinical one and all are motivated to see an improvement in the treatment of these patients who are served poorly by most, if not all, health care systems across Europe.

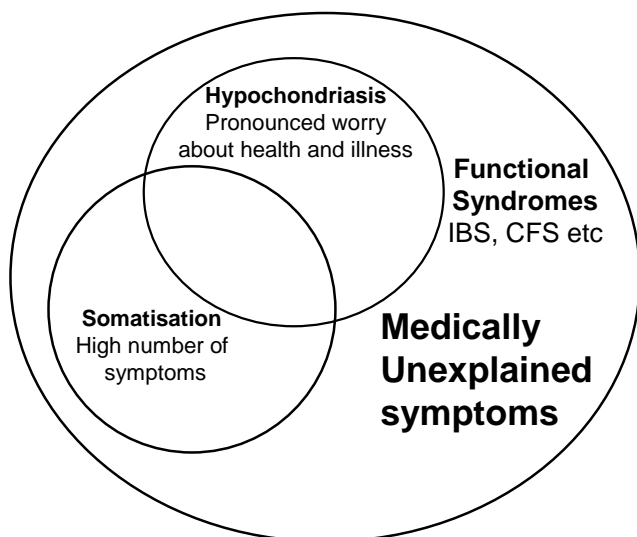
Francis Creed (UK), Peter Henningsen (Germany) & Per Fink (Denmark) ; co-ordinators of the group.

Klars Hui Bregts (Netherlands), Olivier Bollen (Belgium), Christine Bringager (Norway), Chris Burton (UK), Toril Dammen (Norway), Jef De Brie (Belgium), Sylvia Ferrari (Italy), Kurt Fritzsche (Germany) Javier Garcia Campayo (Spain)
| Janna Gol (Netherlands), Constanze Hausteiner (Germany), Peter Hindley (UK),
Klaas Huijbregts (Netherlands Kari Ann Leiknes (Norway), Anders Lundin (Sweden),Charlotte Rask (UK), Marianne Rosendal (Denmark), Judith Rosmalen (Netherlands) Ilaria Tarricone (Italy), Christina van der Feltz-Cornelis (Netherlands), Emma Weisblatt (UK),

2 DEFINITIONS, CLASSIFICATIONS AND MODELS OF MUS AND SOMATISATION

This document is concerned with a large group of patients who have medically unexplained symptoms. The definition of medically unexplained symptoms is not precise but most doctors agree that many patients seen in primary and secondary care have bodily symptoms that cannot be understood on the basis of organic disease. This may occur alone or in conjunction with organic disease. For example, headache, back ache or abdominal pain, which cannot be explained by underlying physical disease, may occur in an otherwise healthy person but they may also develop in a person who has recognised physical disease. In the latter case, after suitable investigations, these painful symptoms cannot be explained by the existing physical disease.

Within the large group of patients with medically unexplained symptoms there are recognised subgroups which will be described in this section. These include the recognised “*functional somatic syndromes*” that are generally included in this group because their cause (aetiology) is incompletely understood; this includes chronic fatigue syndrome, irritable bowel syndrome and chronic widespread pain (also known as “fibromyalgia”). There are also groups known as *somatisation & health anxiety*, which are characterised respectively by the pronounced features of numerous bodily symptoms and marked worry about health and illness. These subgroups are represented diagrammatically in figure 1



3 EPIDEMIOLOGY: PREVALENCE, CAUSES AND CONSEQUENCES

A) Prevalence

a) *Medically Unexplained symptoms*

Secondary care studies in Netherlands, UK and Germany have shown that medically unexplained symptoms occur in 39-52% of new out-patients at specialist medical clinics (Van Hemert 1993. Hamilton 1996, Nimnuan 2001, Fiddler 2004, Kooiman 2004). It is usual, in the secondary care setting, that patients undergo a series of investigations before the doctor concludes that there is no medical disease which explains the symptom(s).

In primary care the GP will usually make a clinical judgement that a symptom is not explained by organic disease. Such symptoms form 15-19%<25% of primary care patients [concur with Burton's text below]

There is a diagnostic category in the International Classification of Disease (ICD), under which many of these patients may be classified: "*Signs, symptom and ill-defined conditions*" (ICD diagnosis ICD code 780-789). In UK this accounts for the most costly diagnostic category of out-patients and the 4th most expensive category in primary care. In USA this is the 5th most frequent reason for visiting a doctor (60 million per annum); the number of doctor visits per diagnostic category during 2005 is shown in table 1.

Table 1 showing the number of visits to the doctor in USA by diagnostic group 2005

<u>Diseases of:</u>	<u>Million visits pa</u>	<u>% of total</u>
Respiratory system	110 million	11.5%
Nervous system	86 m	8.9%
Circulatory system	81 m	8.5%
Musculoskeletal	80 m	8.4%
Symptoms, signs & ill-defined conditions	60 m	6.3%
Endocrine, nutritional & metabolic	56m	5.9%
Mental disorders	47m	4.9%

Transient v persistent medically unexplained symptoms:

There is a wide variation in the presentation of medically unexplained symptoms. Healthy people experience headaches and other aches and pains and fatigue but most do not go to the doctor with them. A German study found that, at any one time, 22% of the population have a single medically unexplained symptom that causes impairment (Hiller). Pain is the most common medically unexplained symptom – headache, back, joint, abdominal and limb pain are the most common; fatigue, dizziness and bloating are also common. These are usually transient and subside spontaneously.

Many people attend the doctor with such complaints only once but they are reassured by the doctor that no serious disease is present and the symptoms subside. For a few people, however, these symptoms are persistent, lead to distress and limitation of normal activities and result in frequent consultations with the doctor. It is these patients who are most likely to be referred to specialists, undergo increasingly expensive investigations and are given medication for their symptoms. A Norwegian study reported that painful medically unexplained symptoms are persistent over many years in approximately 8% of the general population, mostly women (Leiknes J Psychosom Res 2008). Persistent symptoms are more likely if they are numerous and there are high health anxiety or continued depression (Kooiman Psychosom Med 2004).

MUS in primary care

Persistent medically unexplained symptoms in primary and secondary care

Studies of new symptoms presented to general practitioners (GPs) suggest that approximately 25% of these are medically unexplained (Peveler *et al.* 1997b) but in most cases are self limiting and do not lead to repeat consultation. In one primary care study only 10% of these (i.e. 2.5% of all patients attending the GP) had persistent symptoms – the rest consulted for a single episode only (Verhaark 2006). Repeated attendance is related to a combination of symptom severity and patients' perceptions of their need for diagnosis or treatment (Mewes *et al.* 2008b).

One secondary care study examined the 5% of all medical out-patients who attend most frequently. These patients made a median of 18 visits over 3 years (range 13-45). A quarter of these patients who attended frequently had consulted for medically unexplained symptoms (Reid BMJ 2001). The most frequent medically unexplained reasons for consultation were abdominal and pelvic pain, neurological complaints, including headache, and back pain.

A similar study in primary care identified 112 patients who had attended their GP 8 or more times in a 12 months period. About one third were people who has numerous bodily symptom (somatisation). These patients spent more days in hospital than the other frequent attenders; they had more anxiety about their health, rated their health

as poorer and were more distressed than the other frequent attenders. They also had more chronic illnesses, which may partly explain these results.

Medically unexplained symptoms may lead to repeated admission to hospital. One detailed study of such people found that one fifth of people admitted frequently to hospital over an 8 year period were being admitted for medically unexplained symptoms (Fink 1992).

b) *Functional somatic symptoms*

The term *Functional Somatic Syndromes (FSS)* covers diverse single functional syndromes like irritable bowel syndrome, fibromyalgia or chronic fatigue syndrome. Typically, the single functional syndrome terms are used by somatic specialists for patients with MUS in their field of specialization (for the examples above: gastroenterology, rheumatology, infectious diseases/ neurology respectively).

More needed on types and prevalence of FSS

c) *Somatisation and health anxiety*

The people who are most likely to visit doctors frequently and undergo numerous investigations are those with very many bodily symptoms and those who worry most that their symptoms might indicate serious disease. These processes are known as “Somatisation” and “health anxiety (formerly hypochondriasis); they often occur together.

Somatisation

This term has several meanings but will be used here to refer to the reporting of numerous bodily symptoms. This may be on a self-report checklist, or in response to direct questions at a research interview. It also refers to a large number of symptoms reported to a doctor. The number of bodily symptoms is distributed in the population as a continuous variable, like blood pressure. There are two approaches to the definition of somatisation. One regards it a continuous variable and categorises patients as low, medium and high scorers on a questionnaire; others define patients as having somatisation “disorder” if they score above a particular “cut-off” point, the symptoms interfere with ordinary life and they seek help from doctors for their symptoms. Both approaches agree that a high number of bodily symptoms is associated with frequent doctor visits and impaired functioning.

The prevalence of somatisation measured by questionnaire can be illustrated by the Personal Health Questionnaire (PHQ15) with scores divided into 4 groups (see figures 3 & 4) (page 23) (Kroenke). The patients who score in the top 10% on this questionnaire are regarded as “high scorers” and represent “somatisation”. Other researchers have chosen to identify the top 14% on this measure as having “probable somatisation” (Barsky).

Different definitions of somatisation disorder have led to different prevalence figures. Population-based studies indicate that the very restrictive DSM Somatisation disorder occurs in 0.4% of the population, whereas abridged somatisation disorder, with a lower threshold, occurs in 13% (range 3.1%-19%) (Creed & Barsky) (see table 3).

The wider group of “somatoform disorders” (defined by the presence of more than a threshold number of physical symptoms) are common, occurring in as many as 35% of GP attenders (Toft *et al.* 2005b)

How do we square this with studies reported above with lower prevalence???

One study of medical in-patients found that 5% had somatisation disorder and 3.6% had hypochondriasis (Health anxiety) (Fink JPR 2004).

Health Anxiety (hypochondriasis)

The essence of this problem is excessive concern about health and illness. People with this problem are preoccupied with fears that they may have a serious disease, a notion that is based on the misinterpretation of bodily symptoms. Normal bodily sensations are interpreted as signs of disease. This preoccupation persists despite appropriate medical evaluation and reassurance and leads to clinically significant distress

The median prevalence of hypochondriasis (DSM-III or IV, ICD-10) in primary care = 4.2% (range 0.8%-8.5%) (Creed & Barsky). Median prevalence of abridged hypochondriasis = 6.7% (2.2%-9.0%). Using other definitions, prevalence= 10.6%-14% (Creed & Barsky 2004).

(*Somatoform disorders* - should we include this term or does it confuse the reader here?)

Include here a simplified version of table 3

NB see critique of these definitions in Appendix E page 67.

Prevalence of MUS worldwide

It has been assumed for a long time that somatisation in Non-Western cultures, particularly in Asia and Africa, is characteristic for the presentation of psychological disorders. However, recent research results show that somatisation is ubiquitous, although there are significant differences in prevalence and clinical presentation of physical symptoms. But in all cultures the somatic presentation of psychosocial stress is common (Isaac *et al.* 1996).

Table 3 : Prevalence of somatisation “disorder” (incomplete) (Adults >18 years) to be abbreviated and simplified

	Somatisation disorder	undifferentiated somatoform disorder	abridged somatisation	Somatoform disorder not otherwise specified*	multisomatoform disorder	Overall “pooled” prevalence rates (the whole somatoform disorder category)

Primary care						
De Waal 2004	0.5%	13.0%				
Toft 2005	35.9 %	10.1%				
Burton 2003 (syst review)			16-22%			
Lowe 2008			9.5% (PHQ 15 score >14)			
Barsky 2005 (USA)			20.5% (PHQ 15 score)			
Wittchen 2005 (Wittchen and Jacobi 2005)						18.7%
Kringlen 2006 (Kringlen <i>et al.</i> 2006)						2.2%
Sandanger (Sandanger <i>et al.</i> 1999)						5.9%
Leiknes 2007 (Leiknes <i>et al.</i> 2007)				19.2%	14.1%	
Jackson 2008			8% (PHQ-15)			
Medical patients						
Fink 2003 Neurology						
Sharpe (neurology)						
Simon			SSI 6/4 Mean 19.4% 7.6 - 36.8%			

* at least one clinically significant medically unexplained symptom prevalent in the last 6 months

B) Evidence based aetiological factors

Somatisation is associated with female sex, older age, few years of education, low socio-economic status and with other psychiatric disorders (especially anxiety and depressive disorders).

Other risk factors are listed below:

Individual, e.g.

- Genetics, trauma/ abuse, personality factors, prior depression/ anxiety
- Prior somatic illnesses and accidents

Iatrogenic, e.g.

- Communication deficits like neglect of emotional cues, lack of positive explanation
- Overinvestigation and somatic treatment

Social and cultural, e.g.

- work-related factors like job strain, effort-reward imbalance
- compensation and other “secondary gain”
- cultural labelling for general distress

.....more on aetiology

C) Consequences of persistent medically unexplained symptoms / somatisation

Impairment of function

Measurement of number of bodily symptoms (somatisation) using a self report questionnaire consistently shows a linear relationship between number of symptoms and health status – a decrease of health related quality of life (QOL) occurs with increasing number of medically unexplained symptoms.

Figure 2 shows a sample of 2917 primary care patients divided into 4 groups according to number of bodily symptoms rated as bothersome on the PHQ15 questionnaire (Kroenke). The two lowest scoring groups each represent 35% of the population. The top third has been divided into those who score between 10 and 14 (20% of the patients) and the remainder (approximately 10% of the whole sample) who scored 15 or more, representing marked somatisation. It can be seen that general, painful and physical dimensions of health status all decline as number of bodily symptoms increases. Patients in the top 10 or 20% have health status scores that are greatly reduced compared to the respondents who reported few or no bothersome bodily symptoms, indicating very considerable impairment of social and occupational functioning.

Figures 3 & 4 show how the respondents in the top 10% also make more doctor visits and have far more days “off sick” (number of disability days).

Figure 2. Health status (SF20) scores for general, pain and physical subscales by four groups of patients based on somatisation score (Low SF20 score represents impairment)

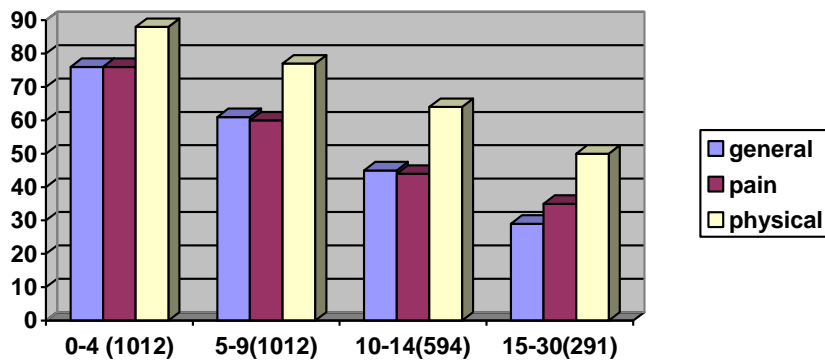


Fig 3: Number of doctor visits over 3 months made by four groups of patients based on somatisation score (as figure 2)

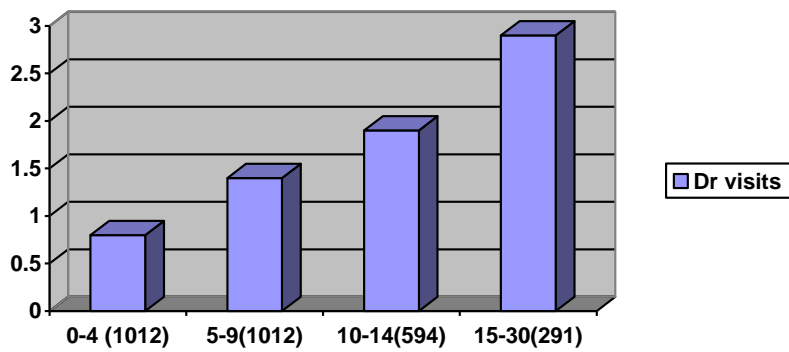


Figure 4: Number of disability days reported by four groups of patients based on somatisation score (as figure 2)

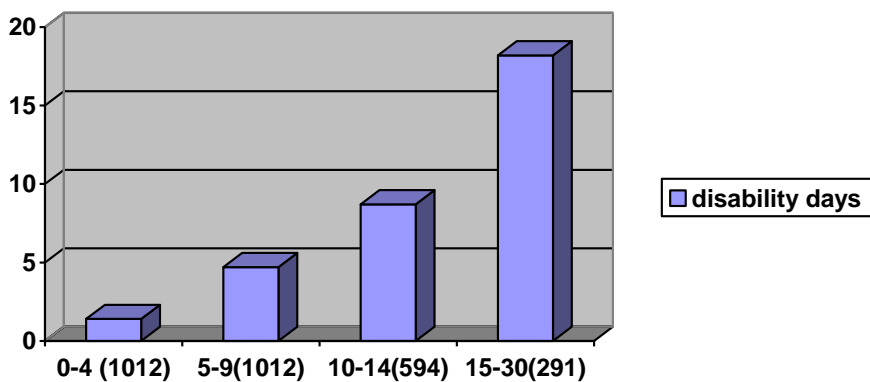
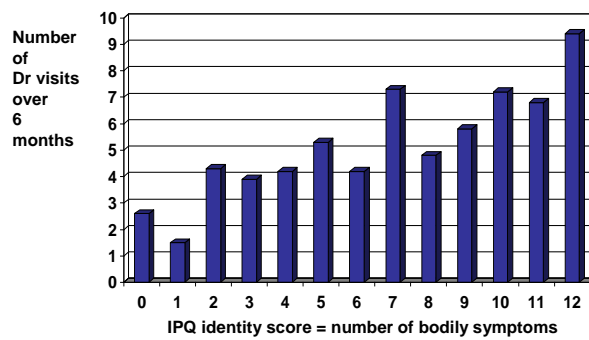


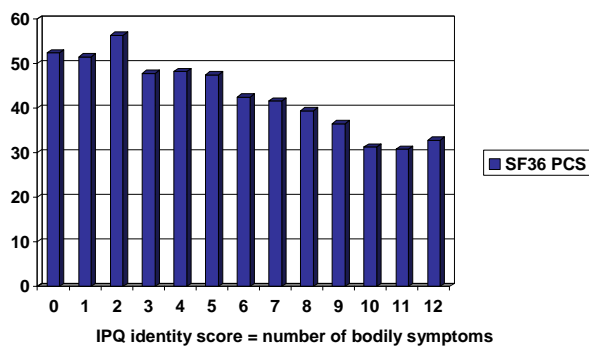
Figure 5 shows the same pattern for a different measure of somatisation in a UK study. The pattern is almost identical; as number of bodily symptoms (IPQ identity score) increases health status becomes more impaired (fig 5b) and number of doctor visits increase (fig 5a) .

Figure 5 a & b

Number of consultations by IPQ identity score



SF36 physical component score by IPQ identity score



Impairment of function and concurrent anxiety and depression

In a meta-analysis Henningsen et al have shown that a significantly greater proportion of patients attending medical clinics with functional somatic syndromes (Irritable bowel syndrome, functional dyspepsia, chronic widespread pain and chronic fatigue syndrome) have well documented anxiety or depressive disorders than patients with comparable organic diseases or healthy controls.

The impairment of function observed above could be due, in part, to concomitant anxiety or depression, which commonly co-exist with marked somatisation. It has been demonstrated, however, that somatisation makes an important independent contribution to impaired functioning in primary care patients in addition to that explained by anxiety and depression (Lowe Gen Hosp Psychiatry 2008)

Figure 6 shows data for the impairment of functioning that is associated with medically unexplained symptom patients (in primary and secondary care) compared with similar data from the general population and people with major depressive disorder. The data concern results on the SF36 questionnaire, which is a widely used measure of health status. The two scales shown in figure 6 are:

- Physical functioning [PF]- how much does the illness affect walking upstairs, carrying shopping etc ?
- Role limitation: physical [RLP] – how much does the illness affect daily life?

High scores represent good health status. low scores indicate impairment

Figure 6: SF-36 scores indicate impaired functioning in medically unexplained patients (primary care in light blue and secondary care in dark blue) and comparison groups: general population [green] and people with major depressive disorder [red] (data from Koch 2007 and Jackson 2006).

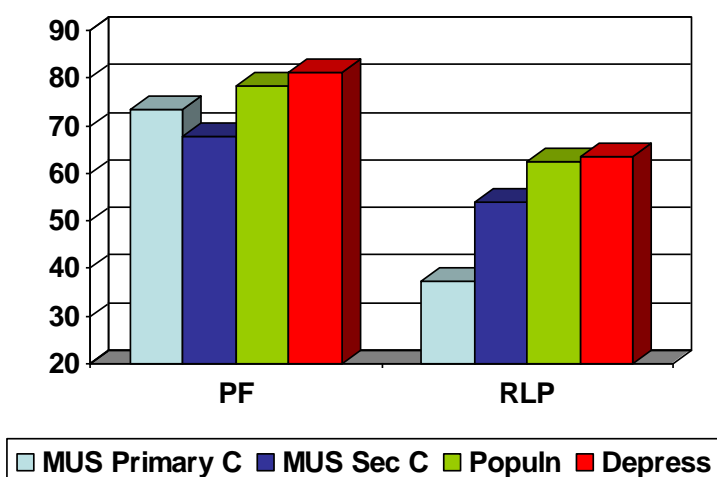


Figure 6 shows that patients with medically unexplained symptoms presenting in primary or secondary care have worse physical functioning (PF) and role limitation functioning (physical- RLP) than the general population or people with major depressive disorder. The particularly low score for role limitation functioning (physical) in the primary care sample represents the large number of patients with chronic fatigue, which is has a marked effect on this aspect of health status. It can be seen that the impairment of physical aspects of functioning are greater in patients with medically unexplained symptoms than in depression (in mental aspects of functioning it is the other way round)

Primary care patients who consult their doctor *frequently* for medically unexplained symptoms have impairment on SF36 physical component score as severe as patients seen in secondary/tertiary settings (Mean PCS = 36.4 (sd=10.3) (Smith GR Psychosom Med 2005)

Healthcare use and costs

We have noted above that the diagnosis of: “*Signs, symptom and ill-defined conditions*” (ICD diagnosis ICD code 780-789) accounts for the most costly diagnostic category of out-patients in UK and the 4th most expensive category in primary care. In USA this is the 5th most frequent reason for visiting a doctor.

In Netherlands this diagnostic category is the 5th most expensive diagnostic category Table 2) (Meering BMJ 1998). The high healthcare costs are accounted for by frequent consultations, investigations (blood tests, X-rays. Scans etc.) and medications. These data do not include time lost from work and the reduced productivity or time of carers.

Table 2 showing the 5 most frequent expensive diagnostic groups in Netherlands. Costs are shown as % of total healthcare cost

<u>Diagnostic groups:</u>	<u>% of total</u>
Mental handicap/ Down’s syndrome	8.1%
Musculoskeletal	6.0%
Dementia	5.6%
Other mental disorders	5.0%
Symptoms, signs & ill-defined conditions	4.8%

Figure 3 (page 23) showed that the number of doctor visits increases linearly with number of bodily symptoms in a USA study and figure 5a shows the same pattern for a different measure of somatisation in a UK study; In both studies patients in the top 10% of somatisation score make approximately 4 times as many doctor visits as patients with a very low somatisation score.

In the UK study of frequent attenders at medical clinics mentioned above (Reid et al 2001) it was noted that one fifth of all frequent attenders had medically unexplained symptoms. The costs of investigations were twice as high in the frequent attenders with medically unexplained symptoms than the other frequent attenders whose symptoms were explained by organic disease (mean = £244 v £124) (Reid et al 2001 & 2). Thus, compared to patients with symptoms explained by organic disease, patients with medically unexplained symptoms incurred significantly higher costs for:

- CT brain scan,
- exercise ECG,
- endoscopy and
- abdominal ultrasound

reflecting the fact that headaches, chest and abdominal pains are common medically unexplained symptoms.

Shaw found, among patients referred to a psychiatrist because of medically unexplained symptoms, the range of expenditure on investigations for possible organic disease ranged from £25-£2,300 (median £286). The determinants of costs included the diagnostic difficulties of the presenting symptom, the attitudes of both patient and physician towards organic disease as an explanation for symptoms and any resistance on either part to adopting a psychological view of the symptoms. It was independent of the view expressed in the general practitioner's referral letter. (*discussed below under barriers*)

Two large studies from USA are informative but only directly relevant to those European countries which have a system of primary and secondary healthcare similar to USA.

In a cohort of 876 out-patients at a primary care clinic the 14% who had highest scores on a questionnaire of somatisation and health anxiety incurred higher costs than the remainder (Barsky 2001). After adjustment for the effect of demographic factors and concurrent medical illnesses the patients with somatisation made approximately 3 out-patient visits per year more than the remainder and total out-patient costs were approximately US\$300 greater per year.

In a similar USA study at the same hospital 1546 out-patients were included and adjustments were made for demographic features, concurrent medical illnesses and, in addition, psychiatric disorders that often accompany somatisation (mostly depressive, anxiety and panic disorders) (Barsky 2005). Compared to the remainder, the patients with somatisation (top 14% on somatisation questionnaire) made more primary care and medical specialist visits, more visits to the emergency department and had more hospital admissions; they therefore incurred higher in-patient and out-patient costs. This study estimated that if these findings were extrapolated to the whole of USA then US\$ 256 billion a year in medical costs could be attributed to the effect of somatisation alone – i.e. after adjusting for the effect of concurrent medical and psychiatric illnesses.

In UK, where general practitioners act as “gatekeepers” a similar picture emerged (Jackson J et al 2005). In one study of medical out-patients at a large teaching hospital, patients who scored in the top 25% of somatisation made an additional 7 more visits to primary and secondary care over an 18 months period compared to those with lower somatisation score (12.7 [sd= 8.9] v 19.7 [12.1]).

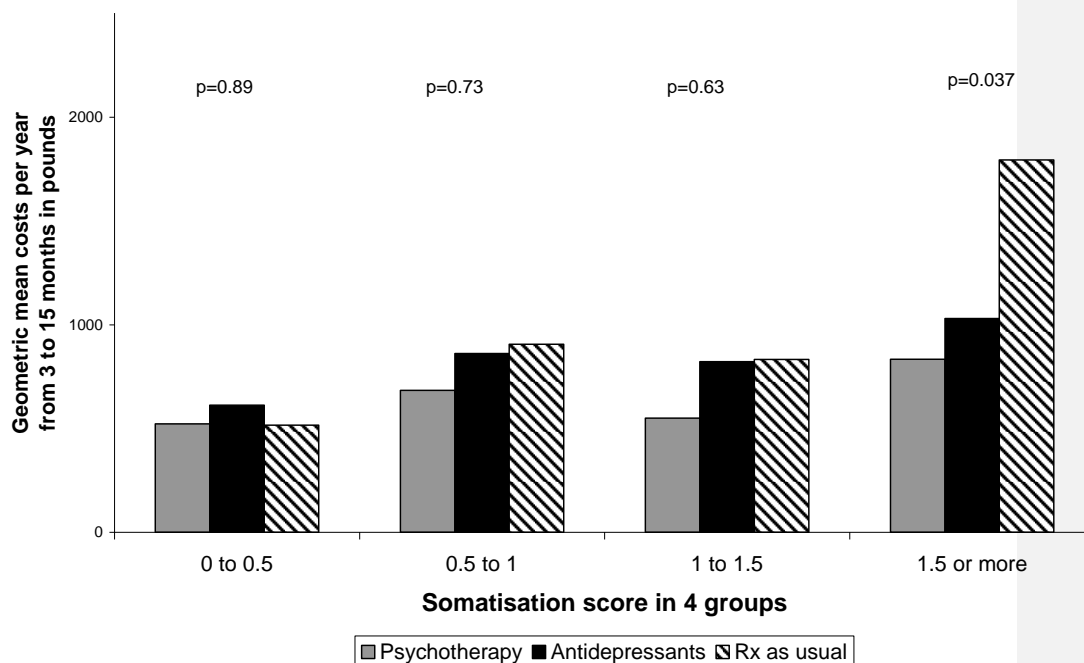
Healthcare and other costs in Functional somatic symptoms

A similar UK study of patients with severe irritable bowel syndrome was undertaken at 7 gastroenterology out-patients department at different hospitals (Creed et al 2008). The quarter of patients who scored highest on the somatisation questionnaire incurred total costs for the year prior to entering a trial of £ 2,010 [se=£214] compared to £1,080 [se=124] for the remainder after adjusting for demographic features and concurrent medical illnesses (Creed et al 2008). Abdominal pain, depression and number of other medical costs were independent predictors of high costs (Creed 2005).

In this study the largest costs were incurred in hospital services (out-patient visits, laboratory and other hospital services and in-patient costs); £1227 v £689 ($p=0.005$) for high somatisation patients v the rest. Primary care costs were less but still different across the two groups: £317 v £226 ($p=0.010$) as were productivity costs (time lost from work): £377 v £149 ($p=0.018$). What was most instructive about this study was the reduction in costs for those who received active treatment (see figure 7).

Figure 7 showing the total costs over 15 months after entry into a trial. The sample has been divided into 4 quartiles according to somatisation score at baseline (0-0.5 represents the low scores, 1.5 or more represents the patients with highest somatisation scores). The costs are shown by treatment group for each quartile. In the highest somatisation group (right hand side of figure) costs remain very high (at pre-trial levels) in the usual treatment group whereas they are reduced in the psychotherapy and antidepressant groups to levels comparable with the lower somatisation groups (need permission to reprint JPR).

Figure 7 – see next page.



A large USA study demonstrated the healthcare costs incurred by patients with irritable bowel syndrome during the year before they attended a tertiary care facility. There was a linear relationship between the number of bodily symptoms and costs incurred (Speigel AM J Gastro 2005). Patients with a level of somatisation 2 standard deviations above the mean incurred healthcare costs of \$2,481 more than average and those with very few bodily symptoms (i.e. had IBS but no additional bodily symptoms) 1,699 less than the average costs. (figure needed).

In some studies it is not direct healthcare costs that are the major costs but informal care, from relatives or other carers. These amounted to over £1,500 per 3 months in chronic fatigue syndrome (McCrone 2004).

In Germany, the direct costs (-36.7%) and indirect costs (-35.3%) could be reduced tremendously in a controlled study with somatoform patients undergoing an inpatient treatment with CBT (Hiller et al. 2004).

The highly complex and cost intensive treatments to diagnose organic diseases are responsible for some of the high costs incurred by these patients. In addition, these tests can reinforce the somatic fixation and the physical attribution to the illness – the related psychosocial problems remain undetected.

More on healthcare and societal Costs needed?

Editor's note: We need to try and explain to the reader how we identify patients with medically unexplained symptoms and provide means of defining/ detecting those who will become high utilisers of health services and incur high healthcare costs.

4. EVIDENCE BASED MANAGEMENT OF MUS AND SOMATISATION

The context of managing medically unexplained symptoms in primary and secondary care

Primary care:

In many European countries primary care represents the main contact with healthcare systems for many patients with new or persistent symptoms. Practitioners are accustomed to dealing with symptoms relating to any body system and ranging in severity from minor to potentially life-threatening. They also have to work in a situation where they may have limited access to diagnostic investigations and only generalist, rather than specialist, knowledge. On the other hand, primary care is also characterised by longitudinal patient-doctor relationships over time in which considerable effort and trust may be invested by both parties and which have real therapeutic potential.

Secondary care

The context of secondary care is quite different from that of primary care. It is the norm that patients will undergo investigations for possible organic disease and the results of such investigations are discussed with the physician. By definition these results do not show evidence of organic disease that explains the symptoms if these are “medically unexplained” and the way this is explained by the physician to the patients is an important issue. Most doctor-patient contacts in secondary care tend to be brief and patients with medically unexplained symptoms are often referred on to another specialist if the search for an organic cause of the symptom continues. Alternatively the patients may be referred back to the GP, who has primary responsibility for ongoing care, at least in some healthcare systems.

Studies of the effectiveness of interventions for medically unexplained symptoms tend to be rather different in the two settings.

Raine et al (2002) found that patients with functional somatic syndromes did better in interventions conducted in secondary care than primary care, possibly because the patients in secondary care have more severe disorders or because of different, and more intensive treatment regimens used in secondary care compared to primary care.

We present here the results of the most important systematic reviews. More details appear in the Appendix D

Interventions for medically unexplained symptoms and somatisation

Kroenke reviewed 10 randomised controlled trials for medically unexplained symptoms. 6 involved Cognitive Behaviour treatment, 1 each exercise or psychotherapy and 2 involved training GPs. Although some trials showed greater benefit for those patients treated in this way, there was no overall clear advantage of such treatments in this group of patients.

By contrast, 13 studies included patients with some form of somatisation disorder (including the abridged or multisomatoform types); these patients would generally have rather more bodily symptoms than those included in the medically unexplained

symptoms group described in the previous paragraph. Overall there was a reasonably clear pattern that the patients in the treated groups – including CBT, antidepressant drugs and letter to the GP – had better outcomes than the patients in the comparison groups – either usual care or placebo. One of the larger studies showed that CBT was followed by reduction of symptoms, health care costs and improved self-rated functioning (Allen 2006)

Both the Kroenke review and a Cochrane review (Thompson & Page 2008) found that psychological treatment – usually some form of cognitive behaviour therapy – to be effective for hypochondriasis (health anxiety) although the evidence is limited by the fact that the comparison intervention was often waiting list control. The largest study to date (Barsky 2004) found that a 6 session individual CBT intervention led to long-term improvement of health anxiety, social functioning and activities of daily living even though bodily symptoms changed little. This result was adjusted for co-existing anxiety and depression.

A systematic review of psychosocial interventions in primary care (Huiber et al Cochrane review 2007) concluded that there is limited evidence that reattribution intervention by a GP is more effective than usual care on consumption of medical resources, subjective health, sick leave and somatisation but recent studies show....

Comment [fh1]: To be completed

Interventions for functional somatic symptoms

A systematic review of the use of antidepressants in functional somatic syndromes found good evidence that they are effective in reducing symptoms and increasing function compared to placebo (O'Malley et al Fam Pract 1999). These authors noted that the improvement in bodily symptom complaints was unrelated to reduction of depression. The same conclusion was reached in a systematic review of studies using cognitive behaviour therapy for somatisation and symptom syndromes (Kroenke Psychother & Psychosom 2000).

5 CURRENT MODELS OF CARE of medically unexplained symptoms and somatisation across Europe.

Service delivery for people with Medically Unexplained Symptoms

a) Overview of current care

Patients with medically unexplained symptoms are cared for in multiple ways and by various medical specialties and health professionals due to the different ways of presenting, the lack of conceptual clarity and diagnostic agreement.

There is huge heterogeneity in how services operate and the patients they care for across Europe. Care may be rooted in local traditions and possibilities, political factors, but also in personal relationships and networks between different doctors. For instance, if a prominent cardiologist is interested in psychological issues, it could promote development of a service for 'non-cardiogenic chest pain', or a gastroenterologist could be promoting a service for IBS. In Germany, the psychosomatic movement has its roots in the environment that existed in the post-war era.

This means that the service delivery across Europe has been and still is unsystematic, random and heterogeneous.

Service delivery can be divided into a) (sub) specialised care for MUS or b) non-specialised general services. a) can furthermore be divided into, a1) services for individual sub-syndromes or diagnoses (i.e. various functional somatic syndromes like CFS, fibromyalgia, somatoform disorders) and a2) services for all types of MUS combined, i.e. including functional somatic syndromes and somatoform disorders as a common phenomenon under one hat. The last type of specialised service is based on the view that it may be the same treatment methods that are effective regardless of the patient's label, and hence only a small adaptation of the therapy is needed for each patient.

Non-specialised services

Primary care

Most medically unexplained symptoms patients are seen in primary care. Some places have developed services with primary care physicians subspecialised in treatment of MUS, and so it is actually a subspecialisation within primary care. [This seems to me to be a curious approach, why not use real specialists].

Service delivery in secondary care

General psychiatric services

Patients with medically unexplained symptoms /somatoform or functional disorders are rarely seen in general psychiatric services, and only patients displaying prominent emotional symptoms or have a comorbid mental disorder besides their medically unexplained symptoms /somatoform or functional disorders are seen. However, patients with health anxiety may be included in programmes for anxiety.

CL psychiatry / psychosomatics (US meaning!) approach

CL psychiatry / psychosomatics is the only medical subspeciality having medically unexplained symptoms / somatoform or functional disorders as a target group. However, as practiced today, medically unexplained symptoms / functional disorders are only part of the service delivered by CL services, and some services do not care for this patient group at all. A European multicentre study included 14,717 patients in general hospitals referred to consultation-liaison psychiatrists. This revealed that, on average 19% of the referred patients had medically unexplained symptoms (Huyse *et al.* 2001). In some services the proportion was 65%, principally psychosomatic services in Germany, indicating that some services specialise in this type of work. The other major groups of referred patients had psychiatric symptoms (40%) (mostly depression accompanying medical illnesses), deliberate self harm (17%) and substance abuse (7%).

For more details of services in each specialty see Appendix A - page 53

b) do current models of care provide a satisfactory service? – unmet needs

In spite of the evidence of effective interventions the evidence suggests that most patients with medically unexplained symptoms receive very little appropriate treatment. The term “unmet need” usually refers to a recognised disorder, which is not receiving adequate treatment and where the person concerned is also suffering impairment of daily function, or disability, because of the untreated disorder.

With regard to patients who have medically unexplained symptoms, functional somatic syndromes or somatisation the evidence of unmet need comes from three sets of findings; evidence that specific appropriate treatment is not being offered, evidence of continuing symptoms with accompanying disability/ high healthcare use and patients’ views on the offer of appropriate treatment.

It is important to note, however, that not all patients presenting to doctors with medically unexplained symptoms have unmet needs. Some, most usually seen in primary care, have transient symptoms that resolve spontaneously – they do not have a need for treatment so they are not regarded as having unmet need.

Few patients are given specific treatment

It is not easy to assess the extent to which doctors offer appropriate help to patients in routine consultation since so much of this depends on what is said by the doctor.

A case notes study of patients with irritable bowel syndrome found that improved symptoms at follow-up and fewer subsequent visits were associated with a positive patient-physician interaction. A positive interaction was one in which the doctor had taken a brief psychosocial history, investigated the reasons for seeking medical help and a detailed discussion of diagnosis and treatment (Owen 1997). These indicators of a positive interaction were present in less than a half of the doctor-patient encounters that were studied.

The reduction in number of visits following a positive interaction with a physician for patients with irritable bowel syndrome can be explained by the fact that it leads to less anxiety, reduced fear of cancer and less preoccupation with pain (van Dulmen 1995). Thus a continued high rate of medical consultations indicates lack of reassurance. The other main factors associated with continued high healthcare use are continuing depression and persistent high number of bodily symptoms (Barsky 1986). Depression is also responsible for a major part of the disability associated with functional somatic syndromes (Creed BJPsych 2005).

Approximately half of patients with depressive disorder seen in primary care present to their GP with numerous medically unexplained symptoms (Simon NEJM 1999). Such depression often goes unrecognised and untreated and the risk of this happening is greater when the patient presents with numerous bodily symptoms (Wittchen & Pitrow 2001; Goldberg 1979). Thus many patients with numerous bodily symptoms have depression that goes untreated and the bodily symptoms persist.

In secondary care clinics it has been documented that less than 10% of patients with medically unexplained symptoms receive specific treatment with antidepressant or psychological treatment ((Hamilton et al 1996, Mangwana et al 2009).

Although patients with medically unexplained symptoms are rarely admitted now, one study found that anxiety and somatoform disorders to be the two most common psychiatric diagnoses among medical inpatients. Of all those with psychiatric disorder, only 2.7% were referred to the consultation-liaison psychiatrist and 5.1% were already receiving psychiatric treatment (Hansen 2001). The vast majority of patients with somatisation and other psychiatric disorders remained untreated.

Another study detected psychiatric disorders among medical in-patients by screening and, when appropriate it was recommended to the physician that antidepressants or other treatment be offered. The system fell down, though, as the discharge summaries of such patients rarely included this fact so the antidepressant was discontinued at discharge as the GP had no knowledge of the depression or antidepressants (Gater J Psychosom Res 1997)

There is some evidence pertaining to patients in neurology units. In the ECLW study there were data available on 34,500 patients admitted to the neurology wards of many hospitals. Only 61 patients (0.002%) with somatoform disorders were referred to a C-L service. This contrasts with a prevalence of somatoform disorder of 14% or more. (Per??).

In a UK study approximately half of patients admitted to a neurology ward had medically unexplained symptoms (with or without concomitant organic disease) and for 60% of these there was evidence of underlying psychiatric disorder (Creed 1990). The majority of these had medically unexplained symptoms but few were routinely referred to psychiatrists.

It can be concluded that the vast majority of patients with somatisation on neurology wards do not get referred to a C-L psychiatric service. This represents unmet need.

Evidence of continuing symptoms with accompanying disability.

Follow-up studies have shown that primary care patients with a moderate number of medically unexplained symptoms continue to have disability over a 5 years period (Jackson & Kroenke Psychosom Med 2008). This was often associated with continuing depression.

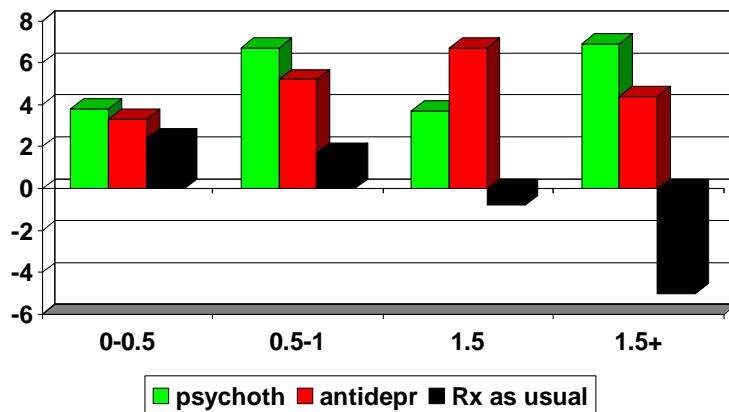
Fink follow-up study of hypochondriasis shows persistent impairment and high healthcare costs?...??

In a German follow-up study of people who had been investigated at a medical clinic and found to have medically unexplained symptoms 63% reported some improvement of their symptoms but only 38% considered themselves to be in good health (Kooiman Psychosom Med). A similar study of patients with medically unexplained symptoms attending hospital clinics in UK reported that at follow-up, 6 months later, 40% said their symptoms had improved although their health status was still impaired. For the remaining 60%, who said their symptoms were the same or worse, their health status remained 1 standard deviation below the population norm.(Jackson J JPR 2006).

Unmet need in functional somatic syndrome – could treatment make a difference?

This can be illustrated by data from the large randomised controlled trial of patients with severe irritable bowel syndrome described above (pp 28-29). The sample was divided into 4 groups according to somatisation score. The group with the highest number of bodily symptoms (1.5 or more on this scale) may be regarded as having somatisation (8 or more bodily symptoms reported). Over the 15 months following the start of the trial patients who received either psychotherapy or antidepressants improved in their health status score by 4- 6 points (equivalent to one standard deviation on this measure) whereas those who received usual treatment experienced a deterioration of their health status of approximately 5 points (right hand column in figure 8).

Figure 8 Change in health status of patients with severe irritable bowel syndrome between from baseline and 15 months later. Increase in SF36 physical component score (representing improved health status) and vice versa. Patients treated with psychotherapy (green) or antidepressants (red) generally showed improvement even if they were in the high somatisation group (1.5 plus). Patients receiving treatment as usual experienced considerable deterioration in their health status.



Patient centred approaches to unmet need.

Comment [fh2]: This section needs to be rewritten

The most sophisticated approach to unmet need includes a dimension that is usually ignored – does the person who has unmet need want help from the medical or related professional? (Andrews 2001). In a study of psychiatric disorders in a neurology ward (the majority would have medically unexplained symptoms) only half of patients with a psychiatric disorder would have wished that the neurologist had asked them about their mood (Bridges & Goldberg BMJ 1984). This had rarely happened. The reasons given for not wanting this included:

- Many felt that the neurologist was a doctor who investigated only physical causes for their symptoms and this had been done.
- Most saw their doctors as very busy and did not wish to burden them with further problems
- Many criticised the lack of privacy on the ward which prevented discussion of sensitive issues. This included the fact that conversations were overhead even when curtains were drawn around the bed and the fact that the neurologist only attended with several other doctors preventing private conversations.
- Some patients were critical of the neurologists for not spending more time with them, seeing the neurologist only to do a physical examination or for a teaching session with medical students. Furthermore if the patient was undressed and lying on the bed this hindered private conversations.

- Some patients complained that the neurologist used technical jargon in their explanation that the patient did not understand and were evasive or vague when asked specific questions.

This list of reasons would hold for patients with medically unexplained symptoms in many medical units.

Unmet need based on patient perception has been infrequently studied in mental health and not at all as far as I am aware for MUS. Mechanic (?) and colleagues used a simple question “over the last 6 months have there been things your health care provider might have done to help but did not” and found a smaller proportion of patients with unmet needs than by using a diagnosis centred approach. While unmet need may be related to low satisfaction a number of studies (e.g. Jackson 2005), have suggested that satisfaction levels in patients with MUS are no worse than those in patients with organically explained disorders.

Comment [fh3]: Redo these paragraphs

Two small studies have taken a patient centred approach, not so much to needs as to goals, with similar results. Zautra (?) studied goals in women with fibromyalgia and found that only around 20% sought recovery, the remainder being equally split between support living with their condition and acceptance by others. Nordin (2006) interviewed patients with MUS and their physicians: patient centred clinician support was most common (62% of respondents) with improvement in function and coping reported by around 40% each.

Reasons for unmet needs

A number of psychiatric studies have explored why patients do not have needs met. Perceived stigma concerning using services inhibits patients while good social support seems to reduce the perceived need for professional help. (develop in barrier section below)

Conclusion:

Although measurement of unmet need for MUS patients is indirect and may be inaccurate it is very likely that the majority of patients with persistent medically unexplained symptoms have considerable unmet need – efficacious treatment exists but they do not enter such treatment largely because it is not offered to them. There are other reasons that will be discussed below.

1. Because these disorders are defined by symptoms, if these are persistent and disabling, all patients with MUS have unmet need using externally applied criteria.
2. As depression and health related anxiety, which appear to be fundamental processes in most patients with medically unexplained symptoms, impair quality of life and perpetuate disability appropriate psychological treatment is required. This is not available in many medical units where these patients are seen.
3. Many but not all of patients with medically unexplained symptoms will have one or more mental health problem (anxiety, panic and depression being commonest) but the need for treatment for these disorder is not recognised and acted upon. A proportion of patients may not wish for this kind of help, especially if it is only available in a psychiatric unit.

4. Patient centred measures of unmet need or goals (for support and recognition) are commonly at odds with physician centred aims (removal of symptoms and “recovery”)

6) BARRIERS TO IMPROVING TREATMENT

Negative attitudes – dissatisfaction expressed by staff and “difficult” patients”

Henningsen and Priebe (1999) describe the social and ethical problems physicians and patients experience when complaints cannot be explained by biomedicine. Salmon (2007) describes the communication problems which come along with MUS in medical routine practice. Various studies show that the interaction between patients and physicians in the case of MUS take an unsatisfying course in primary care for all involved.

Studies have shown that doctors describe patients with medically unexplained symptoms as “difficult to treat” (Carson et al., 2004; Sharpe et al., 1994) and “difficult and frustrating” (Chew-Graham & May, 1999; Wileman et al, 2002; Woivalin et al 2004) and in these descriptions one can find negative typecasts (Kenny 2004; Salmon et al 2007).

The difficulties are apparently connected with diverging concepts of aetiology and treatment on the physicians’ and patients’ sides (Sharpe et al, 1994). While the patients appear to insist on a physical cause for their problems, even in the absence of organic findings, physicians tend to assume that a repressed psychological conflict or other psychological factors cause the symptoms, (Kenny, 2004; Wileman et al, 2002).

Physicians express their incomprehension and anger for patients who insist on their notions (Kenny 2002), and they feel pressurised into somatic interventions (Wileman et al., 2002). The patients’ constant hustle for further treatments can influence the physicians’ actions significantly (Armstrong et al 1991; Little et al., 2004). Further reasons for the negative attitude towards patients with MUS and for further fruitless examinations, prescriptions, and referrals might be explained by the physicians’ anxiety to overlook a physical indisposition – which actually happens only in 3 - 4 % of the cases according to long-term-studies (Crimlisk et al, 1998) – to get involved in a mudslinging media affair or to get sued by patients (Williamson et al., 1981).

However, in surveys the physicians also express their interest in a better management of patients with MUS. They thematize repeatedly their own insecurity and incapability to live up to the patients’ and their own expectations (Hartz et al., 2000; Wileman et al., 2002). Kenny shows (2004) that, on the one hand, physicians suggest psychological causes for the not visible pain to the patients, but, on the other hand, they have at the same time problems to bear the consequences for such a diagnosis and thereby to support the patients psychologically.

They stated not to be able to help adequately and wished for their patients’ psychological support (Sharpe et al, 1994). However, the physicians are, as previously mentioned, indecisive in their judgement regarding the value of their own

commitment to these patients (Wileman et al, 2002). Even physicians who declined training for the treatment of MUS-patients worked in an intuitive, but nevertheless elaborated psychological fashion with the MUS-patients. However, these physicians devaluated their own psychological skills. The authors conclude that not only the devaluation of the patients is a barrier to a better care for MUS-patients but also the physicians' devaluation of their own psychological expertise (Salmon et al., 2007b).

Physicians suggest more often somatic interventions than patients do (Ring et al., 2004, 2005), possibly a reaction to extended and complex symptom descriptions by the patients (Ring et al., 2004, Salmon et al., 2007a). With duration of the consultation the chances for a somatic intervention increase (Salmon et al., 2007a). Physicians possibly use this strategy to put an end to a consultation. Somatic interventions are even prescribed regardless of the patients' attributions regarding their medical condition and their demands for treatment. Somatic interventions become more probable when patients describe their symptoms at length, and more improbable after patients alluded to psychosocial difficulties (Salmon et al., 2006, 2007a).

The role of normalizing strategies of physicians interacting with MUS-patients is controversial. On the one hand, there is evidence that with normalization of the physical symptoms the chances for a somatic intervention decrease (Salmon et al., 2007a). Contrary to this quantitative analysis, a qualitative-content-analytic analysis of consultations with MUS showed that physicians react frequently with a normalizing interpretation to the patients' concerns (Dowrick et al., 2004), but that these interpretations are not effective and amplify the patients' presentation of their symptoms.

In the „normalization with effective explanation“ the physicians linked the explanations to the patients' concerns and partly revealed a connection between physical and psychological factors. These explanations were accepted by the patients. Salmon (2007) suggests the following model for the dynamics of consultations with MUS in synthesis of the above mentioned studies: physicians respond to the patients' demonstration of symptoms with normalizations and pass over psychosocial hints. This provokes patients to intensify and magnify the account of their complaints in order to claim their physicians' commitment and understanding. In response to these intensified accounts physicians resort to somatic interventions.

The development of a common explanation model, of a „common reality“, of a „common ground“ seems more important to patients than a cure for their complaints (Glenton 2003, Salmon 2007). Patients who obtain an explanation for their complaints are more open to a discussion about psychosocial stress and show an improvement of their symptoms as well (Burton et al. 1999, Salmon et al. 1999, Petrie et al 2007, Salmon 2007).

See also: A patient-doctor relationship questionnaire (PDRQ-9) in primary Care: Van der Feltz-Cornelis et al Gen Hosp Psychiatry 2004 .

Medically unexplained symptoms in primary care consultations

Understanding of the processes which occur as patients present medically unexplained symptoms has evolved from early models which viewed physical symptoms as a culturally acceptable way of seeking help for mental distress (Bridges and Goldberg 1985) to one in which patients bring multiple possible explanations for their symptoms (Dominice Dao *et al.* 2006b). These explanations may be either

adopted or ignored by the practitioner (Salmon *et al.* 2007b). While practitioners commonly normalise symptoms (Dowrick *et al.* 2004b) (a strategy for reducing implicit threat, for instance with phrases such as “I’m sure it will clear up in the next few weeks”) for some patients this appears counter-productive and can lead to contested consultations which both doctor and patient find difficult (Wileman *et al.* 2002b) and as a result lead to unnecessary investigations, referral and treatment (Salmon *et al.* 2006b).

The difficulties described above can be broken down into a number of key issues, which must be addressed if we are to improve the situation.

Conceptual difficulties – dualistic view of disease

- Conceptual/ medical training 1: dualistic model of illnesses as either somatic or psychological in origin
- Conceptual/ medical training 2: negative effects of an all too broad use of the term “bio-psycho-social model” without specifications – it has created more damage than use as it has not really entered medical practice in this way, is only used for Sunday speeches.
- Conceptual/ medical training 3: misleading concentration on “single-organism-physiology” and neglect of brain-body-environment interactions as basic constellation also for all patho(psycho)physiology

No agreed terminology

We have seen in the earlier sections of this document that different and overlapping terms are used in this area of medicine reflecting lack of knowledge and the lack of an agreed terminology. This confusion arises for many reasons including conceptual problems, lack of knowledge, different medical specialties, professional stances and backgrounds

The lack of agreed terminology is illustrated well in primary care. This topic is discussed further in Appendix E (page 67).

“Hidden” medically unexplained symptoms in primary care

Despite the high prevalence of somatoform disorders and the moderate prevalence of repeat consulting with medically unexplained symptoms described above, most GPs appear to think of labelling only a few of their patients with medically unexplained symptoms. Partly this may arise because GPs regard many of the medically unexplained symptoms as well recognised medical disorders and use a diagnosis like “irritable bowel syndrome” (IBS) (and to a more variable degree) Chronic Fatigue Syndrome. Such diagnoses may be regarded as “real” disorders rather than “medically unexplained” and thus belonging within taxonomies of medical illness. Equally, however, it is likely that psychiatric labels, such as somatisation, are reserved for patients with the most bizarre symptoms or difficult behaviour. This is not just a medical view, much of the narrative work of patients with medically unexplained symptoms is to present themselves as morally strong individuals worthy of normal attention (Werner *et al.* 2004b).

Medically unexplained symptoms and primary care diagnoses and coding

When it comes to recording information about a patient with MUS, GPs have two ways of doing this: in structured codes or as descriptive text. Most current practice databases offer a combination of the two and practitioners vary in their willingness to condense free-text into more rigid codes. Most health systems allow the GP to decide whether coding is of itself worthwhile.

Should GPs code, they have three options: to code as a *physical symptom* (eg muscle pain), as a *physical syndrome* (eg fibromyalgia) or as a *psychiatric diagnosis* (e.g. somatoform disorder). In the case of a woman with typical widespread muscular pain and disturbed sleep, this may be fairly straightforward, and it is reasonable to view the syndrome term as overlapping with both the physical symptoms and the psychiatric label. However this becomes more difficult when there is no intermediate syndrome: for instance a patient may have abdominal pain, dizziness and headache. Here the somatoform disorder may well be correct but it is much more likely that if anything was coded it would simply be one or more of the physical symptoms. Even where there is a syndrome code this may not be applied by the GP until used by a specialist. Robust diagnostic criteria such as the Rome criteria for irritable bowel syndrome, are not in common use by GPs, who may be reluctant to formally make these diagnoses to the level of certainty that they would code them on their clinical databases.

Coding frameworks differ between EU states: many (including the Netherlands and Scandinavian countries) use the ICPC classification (need details) but the UK uses Read codes with plans to move to SnoMed. Anecdotally, primary care physicians in several more southern European states appear less keen to apply what is seen as reductive coding to patients' complex problems.

Developments in primary care classification

Three recent classification developments are worth noting: first, Rosendal and colleagues have proposed an amendment to the ICPC classification, creating codes covering the full range of severity seen in primary care (Rosendal *et al.* 2007); second, Smith in the USA has developed case review criteria, allocating conditions to either physical disease, minor acute illness or MUS (Smith *et al.* 2004); and third, Barsky identified patterns of healthcare activity from administrative databases which aided detection of patients with MUS (Barsky *et al.* 2006). While each is different, each offers ways of bridging the conceptual gaps between individual symptoms and the broader concept of MUS and has the potential to identify patients who may benefit from interventions.

Dualistic service - medical and psychiatric separated

The medical and psychiatric services have become totally separate in many European countries. This means that the mind and body are artificially separated and patients have difficulty getting psychological/psychiatric help in a general medical setting and vice versa. Doctors in the two systems of medicine rarely see each other and influence each others' thinking.

In routine medical practice there is great emphasis on investigating possible organic causes for symptoms, even those which are very commonly related to stress. Consideration of psychosocial factors late in the diagnostic search leads patients to

doubt a doctor's competence or feel dismissed. In that situation many patients seek help from another doctor.

There are few services where a patient's mental and physical state can be investigated with equal vigour, which is the setting where somatisation is best investigated. Specialist management: unclear responsibilities for functional somatic syndromes, collaboration of psychiatry/ psychosomatic medicine with the rest of medicine not close enough

Treatment models, like those of investigation are still too much oriented on an either-or of somatic versus psychogenic treatments

Training Issues

Much of the discomfort felt by many doctors in their consultations with patients who have medically unexplained symptoms are due to lack of appropriate training. For example many doctors have had insufficient training in patient-doctor-communication, and especially how to approach patients with marked somatisation. This may be true of general psychiatrists as well as internists and surgeons.

Recent research highlights how doctors use the ordering of investigations as a way of ending a consultation, which s/he finds difficult.

There are important clinical skills that are rarely taught adequately, including the feeding back to patients the negative results of investigation. This may be the defining moment when the patient is confronted with the fact that there appears to be no medical cause for their symptoms, however severe or distressing. If this is not done skilfully the chance of further appropriate management may be lost.

Lack of awareness of the problem among healthcare planners

.....text needed

Social factors reinforce disability – an important aspects of society's response to medically unexplained symptoms

- Health services reimburse hospital for technical diagnostic tests and treatments but not for high quality communication skills and/ or for secondary prevention.
- Health policy/ social policy: use of MUS as pseudo-medical tool for laying off work force; insurances as risk factors for chronification of MUS
- Reinforcement of the need to have a "physical" cause for symptoms in order to gain benefits.

Social Context 1and 2ary care

Inadequate research

- Research funding: no interest of industry in the field; no direct connection to basic science which gets most funding (genetics, neuroscience etc.)

7 IMPROVED CARE FOR PATIENTS WITH MEDICALLY UNEXPLAINED SYMPTOMS

a) *Improved models of care*

There have been several different types of care that have evolved at a few centres around Europe in an attempt to improve the quality of care offered to patients with medically unexplained symptoms.

Specialised clinics or units for functional somatic symptoms or syndromes

Many countries have developed sub-specialised services for functional somatic syndromes as for example pain clinics, clinics for CFS, Fibromyalgia and IBS. (I don't know if this information should appear from a table or if each type should be described. I believe that a short introduction to each syndrome and then one typical example from a European country for each type of service would be best??)

Pain clinics

Clinics for Headache

Clinics for CFS (example from UK to follow)

Clinics for Fibromyalgia

Clinics for MCS

Clinics for IBS

Clinics for amalgam

Clinics for dizziness

Others ???

Specialised units for patients with medically unexplained symptoms

Specialised units for MUS, i.e. functional somatic syndromes and somatoform disorders only

A new (are there other departments than ours in Aarhus?) approach is to view MUS / functional somatic syndromes and somatoform disorders as a disorder of its own but with different subtypes. Studies have indicated a huge overlap in symptoms and illness pictures between patients, although different diagnostic labels are given. Furthermore, the same treatment methods, such as CBT, antidepressants and physical activation, have proven to be effective for the patients regardless of their diagnosis, whereas somatic treatment has shown no effect. As there seems to be more similarities than differences between the patients, it therefore appears rational to treat them within the same service. This may prevent simultaneous treatment by different services or one treatment after the other, and it would also make referrals much easier for the GPs.

An example:

The Research Clinic for Functional Disorders and Psychosomatics at Aarhus University Hospital, Denmark.
(description as an appendix)

The Research Clinic for Functional Disorders was established in 1999. The research clinic was established on initiative by the director of Aarhus County's hospital services, the most powerful person in the county's health care organisation referring directly to the political county board. He had become aware that research on MUS had documented heavy health care use in this patient group. Health care professionals who could be interested in the field were invited to a brainstorm meeting, and there was general support for the idea of establishing a service for MUS patients. A small working group was established including a professor in primary care, a professor in psychiatrics, the head of the county administration, the primary researcher in the field and an academic administration secretary from the county. They came up with the suggestion to establish a multidisciplinary research clinic at the University Hospital. The group agreed solely to focus on functional disorders, i.e. somatoform disorders and functional somatic syndromes or MUS. The problem of agreeing on a name for the unit then arose, and several were suggested such as psychosomatic or CL psychiatric department, department for somatoform disorders, pain clinic and functional disorders. The name has also since been intensively discussed as people have different preferences. The term functional disorders was chosen as it seemed to best cover the disorders treated in the unit, and also it is a non-stigmatising name for the patients, although especially neurologists find the name stigmatising (Stone *et al.* 2002).

The group decided to establish a research unit as they were afraid that a clinical service would be flooded by patients resulting in fast build-up of long waiting lists, and this scenario would not be politically acceptable. The research unit was instead focus on research and teaching of doctors as to management of these patient groups. The funding was initially a research / development grant from the county and a fixed amount of money for a 5-year period. Besides, the research group received a major 5-year grant from the Danish Medical Research Council. During the process, the administration secretary suggested a gradual build-up of the budget during the 5-year period. Furthermore, he persuaded the group that the financing during the 5-year period be moved from the county's research budget to the operating budget. This meant that the research unit was secured for at least a 5-year period, and since it was made part of the operating budget, no further political decisions or discussions were necessary.

The administration and political system for health care in Aarhus County was split into separate psychiatric and general medicine administrations. Furthermore, the psychiatric hospital and the general hospital in Aarhus are located physically far away from each other, which lead to a discussion on where to place the unit and how to incorporate the unit in the health care administration system. It was agreed to place it at the general hospital (but as a psychiatric speciality), and the head of the unit should refer to a board, including representatives from the university, general hospital, psychiatric hospital, the social sector, primary care, psychology and others. However, in practice it was established as an independent department at the general hospital. At the 5-year evaluation, it was established as a regular department at the general hospital under the Neuro Center with no administrative connection to psychiatry. This decision gave rise to a heated discussion with general psychiatry

that wanted the department located at the psychiatric hospital as part of psychiatry. However, general psychiatry had been little cooperative or helpful during the preceding 5 years (a different professor was in charge at the time), and also it was feared that the patients would be reluctant to attend a psychiatric hospital. Finally a close relationship with non-psychiatric specialties seemed important. It was therefore decided to include the department at the general hospital. At management level, there has been some difficulties in cooperating with general psychiatry, and this has also been the case at university level as the psychiatric professor at the time was quite against the department. For instance, although it is a psychiatric department, it is excluded from receiving local psychiatric research grants. In everyday clinical and research work, there is however an excellent cooperation and close relationship between the department and psychiatry. The development of combined research and clinical fellowships has made a contribution to improving psychiatry's prestige and may have made it easier to recruit psychiatrists.

A problem arises in connection with the planning of specialties. The resource allocation and the planning of future clinical services are often organised according to specialised medical bodies. As the research unit is not part of psychiatry in terms of administration and as the psychiatric professor is against the unit, CL psychiatry and psychosomatics is "forgotten" in the planning of the psychiatric speciality.

At the time of the research unit's establishment, a joint research project with primary care including a study on the effect of training primary care physicians in treatment of MUS was initiated. Through that a very strong relationship with primary care was established, which has also brought a strong support in the administration and political systems. However, this is probably not due to research results but rather to the GPs' indication of having acquired skills that they can apply in daily practice. Also, the GPs feel they have a referral option, although limited. It is the impression that the mouth-to-ear-method has much more impact than research results. The cooperation with primary care made known that it is important to address the GPs needs and put them into practice. Many projects come to nothing because the specialists have not done their homework and hence have unrealistic suggestions for primary care settings.

Important messages

- 1) The area falls in-between general psychiatry and general medicine, which presents unique problems for this subspecialty both organisational /administrative and professionally (academically?).
- 2) Even globally, only few departments work exclusively with MUS / functional disorders, so you are quite alone both clinically and as to research. Most others clinics work with sub-syndromes like CFS and Fibromyalgia or pain in general, so you have to relate to many different subcultures.
- 3) It is important to have strong allies in the administration or political system who know about political decisions on funding etc.
- 4) It is important to have strong alliances with other health professionals / specialties in the area, especially primary care as GPs are very aware of the problem, and they also have problems with the "sub-categorising" of functional somatic syndromes.
- 5) You have to establish a clear profile. This is probably one of the most difficult issues as there is much confusion and disagreement on a name for the disorder or phenomenon. This seems to be one of the greatest problems at present. The clear profile may not be so important in everyday clinical practice. The health professionals quite easily grasp who the target group of patients for such a department is, and they are able to "translate" the description of the target group to make it fit their own

vocabulary or concept. The profile is more important as to the general population, the administration and politicians who will want to more rigidly categorise such a department.

6) General psychiatry is often the biggest problem as they may neglect patients with MUS and believe that money is better spent on the 'real' patients such as schizophrenic and depressive patients.

A more clinical description as well????

Organisation / administration. Psychiatry or general medicine?

It has been intensively discussed whether services for functional disorders / MUS should be organised in psychiatry or in general medicine, and there are pros and cons with both ways of organising them.

General psychiatry has been inclined to neglect somatoform or functional disorders (Bass BJPsych 2001, Creed 2006). As MUS patients are not seen in general psychiatry, it is viewed as a general medical problem rather than a psychiatric one. Therefore, general psychiatry may be directly hostile to new initiatives based on a fear that a service would steal resources from what is believed to be the core groups of psychiatry such as patients with schizophrenia and manic-depressive disorders.

This means that whenever service reductions are implemented, CL psychiatric services are often at stake as psychiatric managers may view this area as less important than those concerned with major psychoses etc. Likewise, if a CL service is only part of another service, for instance a psychiatric emergency service, the priority may well be put on patients with emotional psychiatric disorders, such as depression or schizophrenia, if there is shortage of doctors, whether this is due to vacancies, illness or other reasons. However, the treatment methods, and partly the diagnostic methods used in psychiatry, are also used in the treatment of MUS, and hence it would seem obvious that treatment of MUS belonged under the psychiatric speciality.

However, organising services for MUS etc. under general medicine has the advantage of a close relationship between the psychiatry/psychology specialists and the referring doctors, which also offers potential for teaching activities in the daily clinical work. Additionally, it is more acceptable and logical for the patients to attend a general hospital instead of a psychiatric unit given that their complaints have a physical nature, and they may find it difficult to view themselves as mentally ill. Services for MUS / functional disorders or syndromes and somatoform disorders may in turn compete with more 'hard core' departments like neurology, cardiology, oncology or units such as orthopaedic units which are given funding priority to cut waiting lists, and a lack of understanding for the need for psychological services is likely.

A clear-cut recommendation is that services should have an independent structure and an independent head. Whether organised under psychiatry or general medicine must depend on local circumstances [but departments organised and financed under general medical might have a better chance of survival than departments organised under psychiatry (am I right ???) .]

A more radical solution of the problem of being in-between psychiatry and general medicine would be to establish a completely new speciality for MUS / functional disorders. [What about German psychosomatic medicine?]

b) Improved management in primary care

In primary care a model has been developed that is concerned with getting the patient to see her/his symptom(s) in psychological rather than physical terms – the “re-attribution” model. The studies testing, this have met with limited success. The TERM Model appears to be the most successful (?)..

Described in Appendix B

Lessons to be learned from the primary care/ collaborative care model for depression

Although Randomized Controlled Trials (RCTs) have demonstrated the efficacy and cost-effectiveness of treatment models for major depression in primary care settings, translating these models into enduring changes in routine primary care has proved to be difficult. Guidelines and educational measures alone are not enough.ⁱ The same may be true of services for medically unexplained symptoms.

Various health system and organizational barriers seem to prevent the integration into primary care of the models used in many RCTs. It has been suggested that strategies to improve depression care in medical settings should be based on the chronic care model.^{ii iii} A collaborative care model, such as developed by the IMPACT group^{iv v}, has been proven to be the most effective so far.^{vi}

Adherence to treatment by patients as well as GPs and care managers is of paramount importance for attaining remission of depression^{vii} and collaborative care is the most effective intervention model in terms of enhancing adherence.^{viii} Improved outcomes occur if a collaborative care model includes:

- systematic identification of patients,
- professional background of care managers (CMs),
- method of specialist supervision of CMs and medication compliance.^{ixx}

Systematic identification of patients: A two-stage selective procedure, whereby patients were screened for depressive disorder but only patients scoring above a certain threshold were selected for treatment, was found to be effective.^{xi} Might such a stepwise screening method to identify high risk somatisation patients be effective?

Professional background of care managers The USA model, developed by Katon and colleagues in Seattle involves treatment provided by at least two of following three practitioners: GP, a care manager (CM), and a psychiatrist, who together, establish a treatment plan with the patient and they monitor the treatment following a stepped care procedure with the PHQ9 as indicator for monitoring.

In the Netherlands, this model is adapted and implemented in the primary care setting so most care is delivered by GPs, supported by psychiatric nurses or nurse physicians, with access to Consultation Liaison (CL) Psychiatrists. This sets specific demands on achieving adherence. Once the patients eligible for treatment have been identified and a treatment plan is set up, *treatment integrity and adherence to treatment advice is essential* for attaining remission.^{xii}

The method by which the psychiatrist gives consultation can play an important role in enhancing adherence and treatment integrity in a collaborative care model. (*needs clarification*)

The collaborative care for improving management of depression has several lessons for improving the management of medically unexplained symptoms/ somatisation:

Systematic identification of patients: this is feasible with one of several questionnaires (*has a study of this been performed?*)

Professional background of care managers (CMs),- discussion of GPs, specialist physicians, psychologists, psychiatrists, nurses others??

Method of specialist supervision of Case Managers - and adherence to medication or other compliance (*we need to examine the discipline of therapists in the RCTs*)

Psychiatric consultation has been developed as a way to support PCPs in the treatment of patients with depression.^{xiii,xiv} In the so-called 'patient-centred case consultation' as described by Caplan from the perspective of 'community mental health'^{xv}, the psychiatrist himself/herself sees the patient and provides the PCP with a diagnosis and treatment plan.

This psychiatric consultation can take place at the location of the psychiatric practice, as in the studies of Smith et al.,^{xvi,xvii} or at the Primary Care Centre, where it is mostly done in the presence of the PCP.^{xviii,4} PCPs appreciate this form of support.^{xix}

Psychiatric consultation is often embedded in a larger collaborative relationship in which other disciplines, especially psychiatric nursing, also play a role. Such collaborative models can take a variety of forms, depending on the psychiatric facilities and the target group.^{xx} In the most common form of 'collaborative care' a case-manager, usually a registered psychiatric nurse, treats the patient in the offices of the PCP and follows the course of the mental disorder in accordance with a treatment plan that was drawn up previously in consultation with the psychiatrist, and which is evaluated at regular intervals and adjusted if necessary.¹²

From 2006-2007, the Dutch Multidisciplinary Guideline Workgroup for psychiatric consultation developed a Guideline on psychiatric consultation that was published in 2008.^{xxi,xxii} The guideline presents an overview and recommendations on psychiatric consultation.

Meanwhile, a multidisciplinary guideline workgroup is preparing a guideline on medically unexplained symptoms in the primary care setting as well as other settings. This guideline will probably be ready in 2009.

c) Management by mental health professionals

Many psychiatrists have not received specific training in interviewing patients with marked somatisation in a way which allows a full assessment of the problem. This can best be achieved if the psychiatrist has already discussed with the referring physician the reason for referral and what the patient has been told about it. The medical notes should always be reviewed in detail and independent data obtained from a relative or other informant. During the interview itself the psychiatrist must be prepared to use techniques which deepen rapport with the patient, who may be initially wary or hostile. The psychiatrist should attempt to establish early a treatment alliance. Special aspects of the mental state need to be noted, including the patient's attitude to his/her symptoms and the strength with which somatic beliefs are held. Different approaches may be used according to the nature of the problem and the

therapeutic style of the doctor. An awareness of these interview techniques would greatly reduce the chances of fruitless interviews with a hostile patient who believes the symptoms are being dismissed as being 'all in the mind'.

(Creed , Guthrie 1993)

Who can write about the qualitative studies?

8) MEDICALLY UNEXPLAINED SYMPTOMS IN CHILDREN AND ADOLESCENTS

EACLPP Working Party 2008 Peter Hindley, Charlotte Rask, Emma Weisblatt

Introduction

Medically unexplained symptoms are a common presentation in children and adolescents with estimates varying from 2-10% (Goodman & McGrath 1991; Aro 1987). However MUS in children often do not fit comfortably into ICD or DSM diagnostic categories used in adults. There is an extensive literature but most of it addresses single disorders, such as recurrent abdominal pain or chronic fatigue. Relatively little has so far been written about the area as a whole. Rutter and Taylor's Child and Adolescent Psychiatry Textbook devotes just over a page (of over 1500) specifically to medically unexplained symptoms. This summary document does not attempt fully to review the area (see for example Eminson 2007 for a recent and detailed review) but to summarise current understanding and practice, emphasising similarities and differences from MUS in adult practice, particularly the role of the family and of the paediatric and CAMHS multidisciplinary teams.

Diagnostic categories

As in adult practice, the terminology used to describe MUS is highly inconsistent and varies between countries, between specialties and disciplines, over time and between individuals. This reflects varying concepts of aetiology, physiology and appropriate management and sometimes appears also to reflect the fear of paediatricians that any potentially "mental health" label will frighten the child and family off for good. The diagnostic options in ICD-10 are relatively limited and there are none specific to children and adolescents. In practice they are rarely used by either CAMHS professionals or paediatricians.

Paediatricians use a variety of terms to describe MUS, overlapping with those used in adults, for example: recurrent abdominal pain, non-epileptic seizures, psychogenic pain/vomiting/sensory loss etc, fibromyalgia, irritable bowel syndrome, chronic pain, chronic fatigue, stress-related symptoms. Previously used terms such as "hysteria" and "supratentorial symptoms" are not regularly seen currently and there is controversy about the use of conversion disorder.

Child psychiatrists and other CAMHS practitioners use many of the same terms though rarely go along with the more clearly "medicalising" terminology such as fibromyalgia on a longterm basis.

The psychiatric terms available from ICD-10 are:-

F44 Dissociative disorders – motor, convulsion, sensory loss

F45 Somatoform disorders – somatisation disorder

- undifferentiated somatoform disorder
- hypochondriacal disorder
- somatoform autonomic dysfunction
- persistent somatoform pain disorder

Older textbooks of child psychiatry include asthma and migraine, among others, in “psychosomatic disorders”. This reflects the prominence of psychological factors in determining both response to illness and severity of symptoms, however currently this would be considered as separate from MUS per se.

Two clinical presentations related to, but not identical to, MUS are of significance in children and adolescents:

- 1) As above, abnormal response to illness, or apparently excessive symptoms in the setting of chronic illness. This includes for example, problematic pain or nausea in oncology patients despite what would normally be adequate doses of medication, frequent presentations with shortness of breath in a child with documented asthma or perceived excessive pain in sickle cell disease..
- 2) Factitious illness, particularly that evoked by a parent or carer (sometimes known as Munchausen’s syndrome by proxy): this can present as, for example, recurrent abdominal pain, vomiting, or bleeding PV or PR.

Normal development and age-appropriate coping mechanisms

Abdominal pain or headache are so common in children between the ages of 3 and 11 as to be seen as normal by most parents and clinicians. A prevalence study in a Spanish sample of over 800 children between the ages of 3 to 5 years, for example, found that 56% of the children displayed at least one somatic symptom in the preceding two weeks. 20% of the children had frequent reports of somatic symptoms (Domenech-Llaberia, Jane, Canals, Esparo and Garrald 2004). Only if presented as a problem by school, parents or medical staff do such symptoms become clinically significant and given a label such as RAP (recurrent abdominal pain).

Systemic considerations (family)

There are extensive effects of family factors on expression of emotional distress, illness behavior, attribution of symptoms and consultation behaviour, for children and adolescents of all ages (reviewed by Eminson 2007). Parents with mood disorders and/or physical symptoms consult more frequently for their children as well as themselves and parental beliefs and attitudes strongly affect the amount of time children have off school both for MUS and after surgery or documented medical illness. Two principal groups of family style have been reported, one being chaotic with multiple physical and psychiatric complaints in multiple family members, and the other being high-functioning, outwardly stable families who may have difficulty putting emotional issues into words and strenuously deny any emotional issues. As parents are usually firmly in control of the consulting behaviour of their children, and frequently give all or most of the history even for adolescents, these factors take on primary importance in children and young people.

Wider systemic considerations

The beliefs and behaviours of other health professionals, particularly paediatricians, as well as the structure of paediatric liaison services, are also of great importance. Most children with MUS will present in primary care and maybe managed purely in that setting. A proportion will be referred to paediatricians for further assessment and medical investigations. Paediatricians are thus the primary determinant of referral to or joint work with liaison services. (In the UK many liaison services will not in any case take referrals direct from primary care services). Paediatricians vary widely in their attitudes to MUS and their referral rates to liaison services. There is some consensus among paediatric liaison psychiatrists that joint working, colocated in the paediatric setting, is highly desirable, rather than a model of referring on to CAMHS services once all medical avenues are exhausted. Clinical experience suggests that families are much more likely to engage with a collaborative, “curious” approach with paediatric and mental health services working together, where conversations and terminology can be tailored to the level of understanding of the family and gradual agreement can be reached on an approach to the child’s symptoms.

Intervention

Because services in paediatric liaison evolve locally and vary widely in resources, approaches, relationships with paediatricians, and multidisciplinary mix, there is relatively little evidence for one approach over another. There are RCTs for CBT, and for a variety of interventions in chronic fatigue but overall there remains a paucity of evidence. The list below indicates some of the approaches taken – it is not exhaustive and mapping services and therapeutic approaches across and within countries is a piece of work which this working group hopes to undertake.

- 1) Consultation and liaison to paediatrics: some children are managed by discussion with paediatric and nursing colleagues without direct input. In any case the liaison team has a role in discouraging further investigations and supporting the paediatric team to stick to this decision in the face of pressure from the family for “just one more opinion”. Sharing of the uncertainty with the family, admitting the limitations of knowledge, and avoiding a “diagnosis by exclusion” model are all agreed to be important.
- 2) Solution-focused approach: usually led by psychologists, this approach does not directly explore underlying emotional conflicts but supports the child and family to identify factors that improve the symptoms and build on them. This is generally felt to be more effective if it includes the whole family.
- 3) Psychotherapeutic/family approach: the child engages with a child psychotherapist and other team members work with the mother or other family members, to identify and address underlying emotional issues or family tensions. The authors have seen this approach produce spectacular results in some otherwise difficult-to-engage families although RCTs are lacking.
- 4) Psychoeducation: for families where a single symptom has arisen in the context of an otherwise well-functioning family, a few sessions explaining the links between cognitions, emotions, behaviour and bodily symptoms can be effective.

- 5) Cognitive behaviour therapy, either individual or systemic (CBT in children generally actively involves at least one family member routinely).
- 6) If another psychiatric disorder coexists in child or family member it should be treated accordingly.

It should be noted that for some disorders, particularly chronic fatigue, many families and clinicians prefer to take a completely medical approach and treatment programmes and units run without any mental health professional input. In addition, paediatric psychologists may be part of a paediatric team and work with children with MUS, without involvement from a CAMHS liaison team. This work is carried out using a health psychology model which fosters coping without using psychiatric diagnostic labels.

Some paediatric or adolescent medicine units have well-resourced liaison teams and admit young people with very severe MUS for example chronic pain, pervasive refusal, or unexplained weight loss without clear evidence of anorexia nervosa. In other services these children are admitted to psychiatric inpatient units with paediatric input available.

For many MUS, particularly those severe enough to warrant inpatient paediatric or psychiatric admission, and those where physical sequelae result from eg immobility in bed, the paediatric multidisciplinary team have major roles to play, for example activity coordinators, play specialists, physiotherapists, dietitians and teachers.

The wider system is also critical, including primary care professionals, school teachers, nurses and psychologists, and the community CAMHS team local to the child.

Relationship to adult disorders

There is limited literature on the outcomes of children with severe MUS although retrospective studies of adults with severe MUS report onset in childhood or adolescence in most patients. However, a recent prospective study (Steinhausen & Winkler-Metzke 2007) found that the larger the number of unexplained symptoms in childhood the more likely they were to persist into adulthood. Recurrent abdominal pain in childhood is associated with later anxiety and/or depression and also increased medical consultations. Given the association of parent psychiatry disorder and MUS with MUS in children, there is likely to be a “cycle of MUS” analogous to the cycle of abuse (although there are also likely to be genetic influences).

MUS in children thus present in many ways similarly to those in adults, but family influences on both symptomatology and consulting behaviour are of primary importance in children and adolescents and much of the intervention is negotiated with and aimed at other family members, usually parents. MUS in children can be severe and can disrupt critical developmental stages particularly schooling and interaction with peers, which can have lifelong consequences.

Suggested further work for the working group

- 1) To provide more detailed review of aetiology, prevalence and nosology (Charlotte Rask)
- 2) To provide more detailed review of intervention research (Peter Hindley)
- 3) To map current resources and practice in the UK and other European countries (Emma Weisblatt in liaison with other members of EACLPP)

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Special groups to be considered

Ethnic minorities?

9. CONCLUSIONS AND FURTHER ACTION

Appendix A

Medically Unexplained Symptoms/ Somatisation in different specialities

In Germany, the awareness for the problem of medically unexplained symptoms/ Somatisation in the different specialities comes, as far as I can see, in three stages: They do not necessarily run in parallel with the general acknowledgement of the importance of psychosocial issues in the respective field, as, for instance, the importance of psycho-oncology may be widely acknowledged but the importance of medically unexplained symptoms may be ignored in the same field..

- even in the most medically unexplained symptoms -distant fields of somatic medicine you will find somebody being aware of the problem like, as an example, in urology, you will find the odd urologist (sometimes with an additional training in so-called psychosomatic basic competence or even in psychotherapy) interested in the significance and also management of chronic prostatitis, interstitial cystitis etc. The vast majority of people in the field, however, would not know of the problem at all or would not see them as a “real” clinical problem.
This description is probably true for most surgical disciplines, radiology, nuclear medicine. .
- in some fields, there are larger groups of people specializing in the psychosomatic aspects of their field including medically unexplained symptoms / Somatisation. However, these groups are more or less separate from the main stream of their fields.
This is especially true for gynaecology, where there is a large society for psychosomatic aspects of gynaecology, holding yearly congresses and working on guidelines, organizing some research and organizing guidelines eg for chronic pelvic pain, with surprisingly little effect on mainstream gynaecology. It is also true for dermatology, where there is a smaller psychosomatic society, for the few people working academically in conservative orthopaedics (back pain etc), for people in dental medicine (one professor for psychosomatic aspects of dental medicine in Münster, S. Doering) and for the ENT people specializing in tinnitus.

Gastroenterology: Some medical specialities have made considerable progress in incorporating the problems associated with medically unexplained symptoms in their specialty into guidelines. The Rome committee on the Functional Gastro-intestinal disorders has produced several reports concerned with diagnosis of these disorders but recent editions have included a psychosocial committee because of the importance of psychosocial factors in the management of such common conditions as Irritable Bowel syndrome and functional dyspepsia.

The psychosocial committee:

- reviewed the evidence that psychological factors are important in the onset, persistence and treatment response of functional gastrointestinal disorders
- made recommendations regarding screening for depressive, anxiety, somatisation and other relevant dimensions
- made recommendations for incorporating psychological/psychiatric treatment into the management plan of all patients if relevant. This included the training

of physicians and guidance about referral of patients to mental health specialists.

Neurology

It is well recognised that an important proportion of patients attending neurology clinics have medically unexplained symptoms.

	No. of patients	% MUS		
Carson 2000	300 patient	11% "not at all explained", 19% "somewhat explained" = 30%		
Snidjers 2004		35%		
Jeffereis 2007	197 In-patients	Somatoform disorders = 4.5%		

- In some fields, an (always rather small) part of the main stream researchers deal with problems of medically unexplained symptoms on a scientific and clinical basis. This is true for neurology, where one of the most prestigious chairs of neurology (at the other university in Munich) is mainly dedicated to research on vertigo/ dizziness including the somatoform varieties thereof (Proffs Brandt/ Dieterich). It is also true for gastroenterology where the significance of IBS is increasingly being acknowledged by mainstream gastroenterology. Three further fields for which this is true are
 - academic units for primary care medicine
 - pain treatment and research centers (in Germany mostly run by anaesthetists in collaboration with neurologists, psychologists, sometimes psychosomatic medicine specialists)
 - occupational and environmental medicine

Specialists in psychosomatic medicine in Germany are per definition specialists in dealing with medically unexplained symptoms / Somatisation. Their approach has developed considerably over the last years from a rather general application of psychotherapy under the assumption of psychogenesis to the sub-group of patients with medically unexplained symptoms willing to come to a respective department to a disorder-oriented collaborative multimodal approach where possible in close collaboration with somatic specialists. Similar things can be said for clinical psychologists, although on a Germany wide level they are probably less present and in less contact with somatic medicine.

Psychiatrists in Germany are on the whole not used to deal with the problems of medically unexplained symptoms / Somatisation (with notable exceptions like HP

Kapfhammer, now in Graz, Austria).

Research policies at Medical Faculties in Germany are still dominated by molecular medicine, genetics, neuroscience etc.. Health Services Research is gaining momentum though, in the beginning of 2008 the main funding agency "Deutsche Forschungsgemeinschaft" accepted it as a field for potential funding.

The problem of MUS/ Somatisation has not yet entered the political debate on quality of health care in Germany, on under-, over- and mistreatments etc.

Comment [fh4]: Should we have a separate section for research? We could try and ask the main funding body in each country if they fund research in MUS and see what whether they can give recent examples.

Audiology:- joint working with audiologists – Anders Lundin

The history of treating medically unexplained dizziness is an interesting one and I will present here my personal experience:

When I trained in psychiatry I was already a trained neurologist and I continued seeing neurological patients in a private setting. My increasing psychiatric skills enabled me to see new patterns in the illnesses of neurological patients. One example of that was patients referred for dizziness that gave a clear cut history of panic disorder, BUT the word anxiety or panic had – surprisingly... – been replaced by the words "dizziness" or "unsteadiness". Some of the patients had been going through a benign vestibular affection, some had not. I treated them with Clomipramine – this was before the era of the SSRI:s – and had amazingly good results on symptoms as well as disability. After having discovered and successfully treated a handful of similar cases I provocatively offered my services to the audiology department at the Karolinska – "give me your difficult cases and I will cure them...".

The medically unexplained chronic dizziness patient is a classical heart sinker in audiology as well as in neurology and has traditionally had no treatment or antihistamines or neuroleptics or relaxation therapy with little gain. So we started this as a project with extra money – I saw the patients at the audiology department so there was minimal stigma in being referred to psychiatry – but my service was so successful that it was two years later incorporated into the regular service on a one day a week basis. I don't know about audiologists in the UK but Swedish audiologists are very conservative with a very robust biomedical orientation, maybe even more than neurologists, so bringing a psychiatrist into the service was indeed a unique step. I was soon offered to repeatedly lecture on the annual national postgraduate training courses for audiologists, so many of the new generation of audiologists are now acquainted with these experiences and some of them have adopted enough skills to assess and to treat those patients themselves.

A climax of this development was two years ago at the biggest medical event in Sweden, for all doctors in all specialities (well, Sweden is not so big...), where I was invited to lecture on the topic "Senses (vestibular) and mind in collaboration" together with an audiologist for a huge auditorium of Swedish audiologists, where my point – that dizziness/unsteadiness is sometimes a manifestation of anxiety and could be treated with anti anxiety medication (SSRIs nowadays) – was very well and respectfully taken. The lecturing audiologist, working in another part of Sweden, had

fully adopted my views on the matter and there was no conflict at all in our way of looking at and dealing with these patients.

A couple of years ago the first papers were published, presenting as good results with SSRI treatment as I had in my patients – for references, see below – but to my knowledge there are still no controlled trials for this indication, but there has been some discussions among us to proceed with that. The last years I have, though, been busy in finishing my study on mild head injury so I have not yet taken this further. I have never, which I regret, published any original papers on this, but I have written chapters on medically unexplained dizziness and posttraumatic dizziness in the Swedish standard textbook about dizziness for audiologists. Interestingly a psychiatrist colleague in Gothenburg, Sigyn Zöger, has in later years liaised with the audiology department there for the treatment of tinnitus with an approach similar to mine – medication for comorbid psychiatric illness with good effect on the presenting symptom – and she wrote her thesis on that a year ago. As far as I know her studies has also influenced the way of looking at tinnitus among audiologists and provided new treatment tools.

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So in summary, and referring to the discussion we had in Bologna on the very last session where this topic was brought up, I have some good experiences of having psychiatric knowledge adopted and practised by other specialists, even among those where you would maybe expect it the least.

Anders Lundin

The role of psychiatrists in the treatment of fibromyalgia

Javier Garcia-Campayo

Miguel Servet University Hospital & University of Zaragoza, Spain

Fibromyalgia syndrome (FMS) is a common clinical disorder characterized by widespread pain of at least 3 months' duration and the presence of 11 or more of the 18 specific palpable fibrositic tender points on the body defined for this condition. It is associated with other symptoms such as generalized muscular aches, stiffness, fatigue and non-restorative sleep (1). The Fibromyalgia Multicenter Criteria Committee, working under the auspices of the American College of Rheumatology, developed

criteria that are sufficiently sensitive and specific for use at the bedside, which are generally known as the American College of Rheumatology Classification Criteria for Fibromyalgia (1). These clinical criteria have not been tested in multi-centre trials so that no estimate of their sensitivity or specificity can be made.

Fibromyalgia is a frequent disorder; its prevalence within the community has been established in the range of 2-3% (2), predominantly in women in their third to fifth decade. It is at least twice as common as rheumatoid arthritis and is considered a significant public health problem. The aetiology of FMS is uncertain but the existence of central sensitization is widely accepted (3). The prognosis for symptomatic recovery is generally poor (2) and more than half of patients find it difficult to continue in employment.

Comorbidity with psychiatric disorders is high (4), the most prevalent depressive disorders being anxiety disorders, insomnia, post-traumatic stress disorder and cognitive dysfunction (5). Sexual abuse has also been frequently reported in this group of patients (6). Psychiatric comorbidities are quite significant because they negatively impact on the severity and course of this condition. Fibromyalgia diagnosis is usually performed by rheumatologists or family doctors, but multidisciplinary treatment is recommended. A wide variety of interventions are used in FMS management with only modest efficacy (7). As a consequence, there is no clear consensus on the treatment of choice, and FMS remains relatively refractory to treatment.

The role of psychiatrists seems crucial for the following reasons:

- 1.- Psychiatric comorbidity in fibromyalgia is quite frequent and leads to disability (4).
- 2.- Some antidepressants such as tricyclics or duloxetine are considered first-line treatments for this disorder (8).
- 3.- Cognitive-behaviour therapy has been demonstrated to be one of the most efficacious non-pharmacological treatments (9).
- 4.- Coping seems to be one of the most important prognostic predictors of fibromyalgia and even some subgroup classifications of this disorder are based on coping (10).

In conclusion, new research is necessary on the multidisciplinary treatment of fibromyalgia and on the efficacy of the psychiatric/psychological treatments on these patients.

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Appendix B

Teaching primary care physicians and other non-psychiatrists to diagnose and manage MUS / functional disorders (per Fink)

Teaching in diagnosing and treatment of MUS / functional somatic disorders happens at different levels:

- Pre-graduate training for medical students and other health professional students including psychologists
- Postgraduate teaching of non-psychiatric medical doctors and other health care professionals. There is an important difference between primary care physicians who themselves have treatment responsibility for their patients presenting with MUS and most other medical specialists who do not have responsibility for treating the patients but for diagnosing the disorders and preventing inappropriate treatment. There may also be a particular need for doctors in occupational and social medicine.
- Education of general psychiatrists
- Education of specialists in MUS and functional disorders (and German psychosomatics?)
- Education of non-health professionals, e.g. social workers

General population information?

An example of a programme for postgraduate training.

The TERM model - an educational programme

Background

Patients who consult their GP often present with medically unexplained physical symptoms (i.e. functional somatic symptoms). About 25% of consecutive patients meet the diagnostic criteria for somatoform disorders. These disorders often go undiagnosed and untreated, which results in futile examinations and treatment attempts that may inflict iatrogenic harm on the patient.

The symptom severity spectrum ranges from mild sensations or symptoms that are part of normal life to severe and disabling symptoms. Due to this broad spectrum of severity and the high prevalence of patients presenting with MUS, the major part of the patients must be treated by their GP. This is furthermore important as, at least in countries with a family doctor system, the GP can by early intervention prevent that a disorder develops into a more severe or chronic condition.

In the early eighties, D. Goldberg and L. Gask from Manchester developed the "The Reattribution Model" as a method for teaching GPs in treatment of patients with "somatised depression and anxiety", i.e. patients with depression or anxiety disorder who present with medically unexplained symptom to their GP. The reattribution model has been tested in different studies which indicate that it may improve GPs' communication skills. Several other brief intervention models for different types of problems have been developed for use by GPs in everyday practice (Rollnick *et al.* 1999; Bergethon 1987).

The TERM model was developed for treatment of MUS / functional somatic disorders in primary care. The model is named the TERM treatment model (The Extended

Reattribution and Management Model) because it makes use of the earlier programmes in addition to including knowledge on classification and treatment of MUS / functional disorders. The main aim is to offer GPs an advanced course in assessment and treatment of patients with MUS / functional somatic disorders in a form that is acceptable and practicable to a broad section of primary care physicians. This means that the course caters in particular for the training needs of physicians who are inexperienced in this field, but all participants will be able to profit from the training irrespective of their qualifications.

The aim of the program is to 1) mediate knowledge about (MUS) functional symptoms and disorders, 2) train GPs in general interview techniques and specific treatment techniques for MUS / functional disorders, and 3) mediate a change of attitude towards MUS / functional disorders. The program intends to be acceptable and usable for all GPs in everyday clinical practice, irrespective of prior qualifications.

Due to warranting the clinical usefulness of the program, practical limits were discussed intensively and defined when developing the course. First, most GPs were assumed not to be able to spend more than 2 days on a residential course and 3-4 evening sessions during one month. Second, we presumed that the GPs would be compensated for the loss of earnings due to course participation. Finally, the model was designed to allow its implementation in everyday clinical practice without exceeding the allotted time and the financial constraints.

The programme was developed in a cooperation between The Research Clinic Unit for General Practice, University of Aarhus and The Research Clinic for Functional Disorders, Aarhus University Hospital. The academic contents and the training methods have been protocolised and are thoroughly described in Psychosomatics (Fink *et al.* 2002). All material used during the course as well as teachers' notes are available on http://www.auh.dk/cl_psych/term/TERM-UK.

Mode of delivery

The program consists of a 2-day residential course (2x8 hours) followed by 3 two-hour evening meetings at 1-2 week intervals and a booster meeting after 3 months. The residential course consists of 4 modules of 3 hours in a fixed structure with: 1) A brief introduction to the exercises including a short video demonstration, 2) training with GPs working two and two or with an actor (the session with an actor is video taped), 3) supervision of the recorded videos in groups of 8, and 4) a plenary presentation of a theoretical theme.

The training is based on micro skills training principles and a multifaceted approach to the learning process. The practical training sessions consist of roleplaying (doctor/patient) and feedback. The doctor has 7 minutes for the interview of the patient, and the doctor is restricted to train a specific part of the overall model as well as specific interview techniques in each session. Case stories are given to the patients, and the doctor is provided with written instructions on what to train in each session and examples of how questions can be framed. Every session ends with the patient giving positive feedback to the doctor. During the course, everyone will play both doctor and patient several times and be video recorded with an actor.

A course ideally accommodates 24 GPs. For the weekly evening booster meetings, they meet in groups of 8 with 2 supervisors (a GP and a psychiatrist). The

participants bring video recordings from their consultations with their real patients for supervision.

The teachers have been trained at a 3-day residential course, and a program for training teachers is also protocolised.

Evaluation of effectiveness

Two cluster randomised controlled trials were set up in March 2000 to test the effect of the programme. One was in Vejle County, Denmark, including 38 GPs and 2880 patients, who consulted their GP during the study period. The other study was in Aarhus County and included 38 GPs and 1785 patients. Half of the GPs were trained in the treatment model, the other half was control group. The patients were followed for 1 and 2 years respectively.

Main results:

The trained GPs change attitude towards patients with functional disorders, and they were more confident and felt more comfortable and satisfied with the treatment of MUS patients after the course compared with the non-trained (M Rosendal, Family Practice 2005).

The trained GPs discussed more psychosocial issues with the patients after their training (T Toft, thesis 2005: Managing patients with functional somatic symptoms in general practice) (T Toft et al, A randomised controlled trial of GP training in treatment of functional somatic symptoms (the FIP-study): Effects on health care utilization. Submitted).

The patients were significantly more satisfied if they consulted a trained GP compared with a non-trained (L Frostholm, thesis 2005: Illness perceptions in primary care patients), (L Frostholm, Psychosomatic Medicine 2005).

Patients with somatoform disorders had less physical disability at 2-year follow-up if treated by a trained GP, but in patients with MUS according to their GP, there were no significant improvement (T Toft, thesis 2005: Managing patients with functional somatic symptoms in general practice) (T Toft et al. Training primary care physicians in the treatment of functional somatic symptoms. Effect on patient health in an RCT (the FIP study). Submitted) (Rosendal et al, General Hospital Psychiatry 2007)

Health care use for patients with somatoform disorders during the 2-year follow-up period was 1/3 lower in the intervention group compared with the controls, but the difference was not statistically significant at a 5% level (T Toft, thesis 2005: Managing patients with functional somatic symptoms in general practice) (T Toft A randomised controlled trial of GP training in treatment of functional somatic symptoms (the FIP-study): Effects on health care utilization. Submitted).

The GPs attending the course were in most aspects representative for all GPs in Aarhus county (T Toft, thesis 2005: Managing patients with functional somatic symptoms in general practice) Training primary care physicians in the treatment of functional somatic symptoms. Effect on patient health in an RCT (the FIP study). Submitted)

After the scientific trial period and current status

The TERM model has been implemented successfully after finalising the RCTs, and there has been a considerable demand from GPs and other health professionals for more courses. The demand has not arisen for the reason that the GPs are persuaded

by the scientific evidence but because the word has spread among GPs that the TERM course is excellent.

More than 300 doctors have been trained in the model to date (hereof about 20% of all GPs in Aarhus and Vejle counties). We have continuously tested the doctors' satisfaction with the program, and it has been extremely high.

In 2007, the TERM course was made compulsory for all doctors specializing in general medicine in two out of the five regions in Denmark. Additionally, in one of the regions, all GPs undergo a brief one-day course in the model.

A slightly modified version of the training program has been used in the teaching of other specialised doctors, e.g. rheumatologists and social medicine specialists.

Other parts of the health care system use the TERM model in education on management of MUS patients.

Some of the doctors that have attended the course have requested an extension of the course as they want to acquire skills in treatment of patients with long illness courses and not only treatment of acute problems.

The program is currently being modified, and the update is not yet available in English.

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APPENDIX C

Current national guidelines (Peter Henningsen)

The national guidelines in Germany are mostly organized by the “AWMF” (working group of the scientific medical societies) in collaboration with the German Medical Association. Whereas early guidelines produced in the 1990s mostly were organized and written by one field only (like the guidelines on somatoform disorders by the psychosomatic societies, organized by PH), newer guidelines are considered valid only when they involve all relevant players in the field, i.e. all medical fields plus patient organizations. These guidelines on a so-called S3-Level, the highest level, are based on systematic evidence and on a systematic process of consensus finding. The integration of different fields and perspectives evidently is particularly important for a topic like MUS/ Somatisation. The process of interdisciplinary discussion within the group involved in drawing up the guidelines is of exemplary importance for finding a common language in dealing with these problems.

To my knowledge, four guidelines on S3-level with relevance for the topic of MUS have been completed recently or are under way in Germany:

- S3 guideline on fibromyalgia syndrome, now published. This guideline was organized by the overarching society for pain medicine, it involved rheumatologists, neurologists, orthopedic specialists, psychosomatic specialists, psychiatrists etc., all respective societies accepted the guideline . It succeeded in defining FMS beyond the narrow confines of the ACR criteria (symptom based, without need for tender point counting) and in establishing activating therapies and psychotherapy as the probably most effective therapies. The interdisciplinary guideline on this topic was especially important because views and treatment approaches on FMS differ widely between specialities in Germany. Consensus was literally fought out in intensive discussions and if dissemination is successful it will probably change the attitude especially of the somatic specialists who tried to treat FMS like any other somatic illness.
- S3 guideline on Chronic Pelvic Pain organized by the Psychosomatic society within gynecology, started in 2007. This topic is less controversial, the important question will be how the dissemination of its results will succeed especially within gynecology.
- S3 guideline on Irritable Bowel Syndrome, organized by the German gastroenterologists. The official German society for gastroenterology has finally come round to organize this guideline which has just started. Representatives of psychosomatic medicine are present in all chapters (Classification, diagnosis, treatment).
- S3 guidelines on Patients with organically unexplained medical symptoms, organized by the psychosomatic societies (PH), started in early 2008. This is a new version of the guideline on somatoform disorders, the new name is not only meant to make it more accessible for non-psycho specialists, it also reflects a changed attitude towards the problem of MUS (less psychogenic, more balanced...). The main aim is to increase awareness for the problem of MUS in different somatic specialities. Some of the many societies involved have sent as delegates their “psycho-specialists” which is ambivalent because on the one hand they are knowledgeable of the problem, on the other they may

not be heard within their own society. Others have sent major players of their field. The guideline will try to concentrate on all levels of care and on all management aspects including doctor-patient-communication etc. It collaborates with a guideline started by clinical psychologists on the sub-problem of psychotherapy for somatoform disorders.

Appendix D

Treatment of MUS in the General Hospital (non-systematic review)

Kurt Fritzsche and Astrid Larisch

Treatment

Cognitive Behavioral Therapy (CBT)

In a small case-control study by Ehlerst et al. (1999) of short-term cognitive behavioral therapy (CBT) for hospitalized somatizing patients nearly 15% of the patients met the DSM-III-R criteria for somatoform disorders or showed psychological factors affecting physical conditions. Compared to standard hospital treatment (SHT) patients who had received CBT and SHT (n=21) experienced a significant decrease in their physical complaints on the Freiburg Complaint List (FCL) and a decrease in negative moods as well as a significant outcome in motivation for psychotherapy, e.g. better expectations and attitudes towards psychotherapy.

Follow-up assessments of a non-controlled study (Lupke et al. 1995) regarding the effects of the psychological consultation-liaison-service for patients with somatizing behavior at general hospitals showed that after discharge 48% of patients underwent some sort of psychosomatic treatment (16% were treated exclusively by a psychiatrist, psychotherapist, or in a psychosomatic clinic while 32% chose a combined medical/psychological treatment). Three years later, 37.5% of the patients followed the recommendations regarding psychotherapeutic-psychiatric therapy. However, the percentage of patients with somatoform disorders due to DSM-III criteria within this population was only 17.5%.

In a more recent RCT by Bleichardt et al. (2004) n=191 somatoform patients (as diagnosed by ≥ 8 DSM-IV somatoform symptoms) from a specialized clinic for behavioral medicine have been randomized in three branches: I) standard treatment and "soma" (n=107) II) standard treatment and "relaxation" (n=84) and III) a waiting control group (n=34). Treatment consisted of 8 sessions of 100 min each. In a 1-year follow-up, intervention group patients improved significantly over time in all outcome criteria (number of somatoform symptoms, general psychopathology, anxiety, depression, subjective health status, life satisfaction, and visits to the doctor) while the control group remained unchanged. A significant positive effect for the "soma" group (I) compared to the "relaxation" group (II) was found only by the drop of doctor visits (39% vs. 18%). However, largest time effect sizes were found for the reduction of somatoform symptoms emphasizing that contrary to prior assumptions the number of physical symptoms can change. In summary, this study could demonstrate the success of inpatient treatment.

In a RCT Speckens et al. (1995) compared patients with medically unexplained symptoms receiving an average of 12 CBT sessions (n=39) or optimized medical care (n=40). In a 6-month follow-up, patients of the intervention group had a higher rate of recovery, a lower mean intensity of physical symptoms, and less sleep impairment than the patients from the control group. In a 12-month follow-up, the intervention group still had a significantly lower frequency and mean intensity of the presenting symptoms.

In spite of these patients being outpatients, this study is worth being taken into account; the treatment was delivered in a clinical setting that caused an advantage for the patients not being declassified. As an RCT, the study has a great strength of evidence.

Supportive Psychotherapy

In a RCT by Schweickardt et al. (2007) somatoform patients were randomized into an intervention group (n = 49) and a control group (n = 42). To be a case, patients had to score

positive on the Screening of Somatoform Symptoms (Rief et al. 1997) and had to have at least 2 points on the GHQ. The intervention was based on the reattribution model (Goldberg et al. 1989) and supplemented with cognitive-behavioral techniques and a partner interview if applicable. The short-term treatment consisted of M=4.2 sessions lasting 50 min. each and was delivered by trained psychotherapists. The patients in the control group received psycho-educational reading materials. Results show that patients from the intervention group were significantly more motivated for psychotherapy ($p = 0.001$) than patients from the control group. In the 3-month follow-up, 42% of the patients from the intervention group had contacted a psychotherapist, in comparison to 20% of the patients from the control group ($p = 0.045$). In the 6-month follow-up, however, the ratio of patients having contacted a psychotherapist had changed to 44% and 29% respectively and was no longer significant. There was a reduction of number and intensity of somatoform symptoms at the point of discharge (T1) for both groups but changes were not statistically significant in the GLM over 4 assessment times. Short-term psychotherapeutic interventions for somatizing patients in general hospitals have a moderately better effect on motivation for psychotherapy and contacting a psychotherapist than psycho-educational reading material alone.

In a previous controlled trial ($n=102$) psychological treatment involving psychotherapy, relaxation, and standard medical treatment was compared to standard medical treatment alone (Guthrie et al. 1991). After 3 months, the treatment group showed a significantly larger improvement than the control group on both gastroenterologists' and patients' ratings of diarrhea and abdominal pain, but constipation only changed a little. Good prognostic factors included overt psychiatric symptoms and intermittent pain exacerbated by stress, whereas those with constant abdominal pain realized only little relief through this treatment. This study has demonstrated that psychological treatment is feasible and effective in two thirds of patients with irritable bowel syndrome who do not respond to standard medical treatment.

In a RCT, a brief psychodynamic-interpersonal psychotherapy (PI) for patients with functional dyspepsia (Hamilton et al. 2000) could show significant advantages for the intervention group ($n=37$) on the gastroenterologists' and patients' total symptom score in contrast to the control group ($n=36$) receiving supportive therapy. In the 1-year follow-up, the symptoms scores were similar and both groups showed a similar reduction of psychological symptoms.

At first appearance, studies demonstrate that both CBT and supportive psychotherapy might be feasible and effective treatment approaches for patients with medically unexplained symptoms. But independent from their therapeutic approach, two recent RCTs (Bleichhardt et al., Schweickhardt et al.) have pointed out that somatizing patients benefit from hospitalization. Both the intervention and control group improve their health over time during the hospital stay. This raises considerable problems for these patients. On the one hand, the time at the hospital itself is rewarding for these patients so that the likelihood for the next inpatient stay increases. This could be attributable to several factors, e.g. increased attention, secondary illness gains (visits by significant others, more social contact from the caregivers, nurses and physicians), being in a medical setting, feeling more secure, change of medication, and other factors might contribute to the "success". On the other hand, this effect worsens the outcome in the long run and leads to repeated hospital stays.

For future studies it might be worth changing the outcome parameter. There was already a shift from symptom count to psychotherapy motivation but both seemed to be high targets. A change of symptom management might be the outcome variable most acceptable for the patient and most effective for the researchers.

Appendix E

Problems with terminology and definitions

*Critique of the concept of Somatisation “disorder”, **move to barriers???***

The American *Diagnostic and Statistical Manual of Mental Disorders, Third Edition* (DSM)-IV (American Psychiatric Association 1980) described a diagnosis of “somatisation disorder”. This described people who have a history of many medically unexplained bodily symptoms that started before the age of 30 years and which have led to repeated visits to doctors and/or significant impairment of occupation or social functioning. The WHO ICD-10 has a similar diagnosis. The number of bodily symptoms used in this diagnosis has varied between different editions but currently stands at 8 medically unexplained symptoms across different bodily symptoms.

There are several problems with this definition.

i) It describes a disorder that is very rare in clinical practice (<1% of GP attenders in several studies) whereas the problem of numerous bodily symptoms is common in clinical practice. As a result less restricted definitions have been developed. These include “abridged somatisation” (6 symptoms for women and 4 for men - women have symptoms related to menstruation that have no equivalent in men), “multisomatoform disorder” (3 symptoms) undifferentiated somatisation disorder (a single symptom). Not surprisingly the prevalence of these disorders varies greatly because of the different definitions.

ii) In addition to number of symptoms most definitions require that symptoms have been present for a specific time. Some definitions require symptoms to have lasted many years, others are concerned only with current symptoms. There are problems with these definitions as longitudinal studies have shown that bothersome bodily symptoms wax and wane over time and may not be remembered at subsequent interviews (Leiknes *et al.* 2006b; Simon and Gureje 1999b).

iii) The definition of symptoms as “medically unexplained” is problematic as the unexplained and explained symptom categories are transient and interchanging over time, thus undermining the overall credibility of this distinction (Leiknes *et al.* 2006a). There is evidence that the relationship between number of bodily symptoms and outcome are similar for medically explained and unexplained symptoms (Kisely, Jackson..)

iv) Some authors question the validity of somatisation as a distinct disorder; they argue that it is simply a manifestation of underlying anxiety or depression.

*A perspective from primary care- **move to barriers???***

“Hidden” medically unexplained symptoms in primary care

Despite the high frequency with which patients present medically unexplained symptoms in primary care, most GPs appear to think of labelling only a few of their patients with medically unexplained symptoms. Partly this may arise because GPs regard many of the medically unexplained symptoms as well recognised medical disorders and use functional somatic syndrome diagnosis like “irritable bowel syndrome” (IBS) (and to a more variable degree) Chronic Fatigue Syndrome. Such diagnoses may be regarded as “real” disorders rather than “medically unexplained” and thus belonging within taxonomies of medical illness. Equally, however, it is likely

that psychiatric labels, such as somatisation, are reserved for patients with the most bizarre symptoms or difficult behaviour. This is not just a medical view, much of the narrative work of patients with medically unexplained symptoms is to present themselves as morally strong individuals worthy of normal attention (Werner *et al.* 2004a).

Medically unexplained symptoms in primary care consultations

Understanding of the processes which occur as patients present medically unexplained symptoms has evolved from early models which viewed physical symptoms as a culturally acceptable way of seeking help for mental distress (Bridges and Goldberg 1985) to one in which patients bring multiple possible explanations for their symptoms (Dominice Dao *et al.* 2006a). These explanations may be either adopted or ignored by the practitioner (Salmon *et al.* 2007a). While practitioners commonly normalise symptoms (Dowrick *et al.* 2004a) (a strategy for reducing implicit threat, for instance with phrases such as “I’m sure it will clear up in the next few weeks”) for some patients this appears counter-productive and can lead to contested consultations which both doctor and patient find difficult (Wileman *et al.* 2002a) and as a result lead to unnecessary investigations, referral and treatment (Salmon *et al.* 2006a).

Classification of Medically Unexplained Symptoms – a primary care perspective (Chris Burton October 2008)

Classification schemata need to be adaptable to both the immediate and the long term nature of primary care contacts and be acceptable to both doctors and their patients

MUS prevalence in primary care

Studies of new symptoms presented to general practitioners (GPs) suggest that approximately 25% of these are medically unexplained (Peveler *et al.* 1997a) but in most cases are self limiting and do not lead to repeat consultation. However some patients – around 2% of adults - repeatedly attend their primary care physician with MUS (Verhaak *et al.* 2006) and this repeated attendance is related to a combination of symptom severity and patients’ perceptions of their need for diagnosis or treatment (Mewes *et al.* 2008a).

Epidemiological studies demonstrate that somatoform disorders (defined by the presence of more than a threshold number of physical symptoms) are common, occurring in as many as 35% of GP attenders (Toft *et al.* 2005a) and that these commonly occur alongside, and overlap with, depression and anxiety (Lowe *et al.* 2008). **How do we square this with studies reported above with lower prevalence???**

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Appendix E (contd) Somatoform and dissociative (conversion) disorders in DSM-IV

and ICD-10

DSM-IV Somatoform disorders		ICD-10 Somatoform disorders	
Somatization disorder:	300.81	Somatization disorder:	F45
- a history of many MUSs* before age 30		- at least 2 year history of MUSs*	F45.0
- resulting in treatment sought or psychosocial impairment		- resulting in repeated (3 or more) primary care or specialist consultations	
- a total of 8 or more MUSs in groups I-IV, at least 4 pain, 2 gastrointestinal, 1 sexual, 1 pseudoneurological (33-item MUS list)		- a total of 6 or more MUSs, from at least 2 separate organ groups I-IV (14-item MUS list)	
I Pain (10)		I Gastrointestinal (6)	
II Gastrointestinal (5)		II Cardiovascular (2)	
III Sexual (5)		III Genitourinary (3)	
IV Pseudoneurological (13)		IV Skin and pain (3)	
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
- acute		-	
- chronic		(chronic)	
Pain disorder associated with both psychological factors and a general medical condition	307.89		
- acute			
- chronic			
Pain disorder associated with a general medical condition			
-		Other somatoform disorders	F45.8
Somatoform disorder not otherwise specified	300.82	Somatoform disorder, unspecified	F45.9
-			
-		Somatoform autonomic dysfunction	F45.3
Body dysmorphic disorder	300.7	Hypochondriacal – dysmorphophobia	F45.2
Conversion disorder	300.11	Dissociative [conversion] disorders	F44
		- dissociative amnesia	F44.0
		- dissociative fugue	F44.1
		- dissociative stupor	F44.2
		- trance and possession disorders	F44.3
- with motor symptom or deficit		- dissociative motor disorders	F44.4
- with seizures or convulsions		- dissociative convulsions	F44.5
- with sensory symptom or deficit		- dissociative anaesthesia and sensory loss	F44.6
- with mixed presentation		- mixed dissociative disorders	F44.7
		- other dissociative disorders	F44.8
		- dissociative disorder, unspecified	F44.9
(- Chronic fatigue)		(Neurasteni)	F48.1)

*medically unexplained symptoms (MUSs)

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