

## Perceptions and Attitudes of Health Care Givers and Patients on Medically Unexplained Symptoms: A Narrative Review with a Focus on Cultural Diversity and Migrants

An Mariman<sup>1</sup>, Peter Vermeir<sup>1</sup>, Márta Csabai<sup>2</sup>, Melinda Látos<sup>2</sup>, Anne Weiland<sup>3</sup>, Karen M Stegers-Jager<sup>4</sup>, Marloes L Jacobs<sup>5</sup> and Dirk Vogelaers<sup>1,6</sup>

<sup>1</sup>Ghent University/Ghent University Hospital, Belgium

<sup>2</sup>University of Szeged, Hungary

<sup>3</sup>Erasmus MC University Medical Center, Rotterdam, The Netherlands

<sup>4</sup>Erasmus MC University of Rotterdam, The Netherlands

<sup>5</sup>Erasmus MC University Medical Center, Rotterdam, The Netherlands

<sup>6</sup>AZ Delta, Deltalaan 1, 8800 Roeselare, Belgium

### \*Corresponding author

Peter Vermeir, Ghent University/ Ghent University Hospital, C. Heymanslaan 10, 9000 Ghent Belgium.

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### Abstract

**Background:** Health care providers often struggle with the management of MUS patients, especially with a different ethnic and/or cultural background.

**Objectives:** A review on behaviors and attitudes of health care providers towards MUS patients and of patients themselves, in order to improve healthcare provider-patient interaction.

**Methods:** Screening of PubMed, Web of Science, Cinahl and Cochrane Library on the keywords 'Medical unexplained (physical) symptoms (MUS)', 'Somatoform disorder', 'Functional syndrome', 'Diversity', 'Migrants', 'Ethnicity', 'Care models', 'Medical education', 'Communication skills', 'Health literacy'.

**Results:** MUS patients, especially with a different ethnic background, often feel not-understood, which may provoke medical shopping. Health care providers experience feelings of helplessness. From undergraduate trainees to senior physicians, attitudes and perceptions tend to be negative, impacting on the quality of the patient/health care provider relationship and subsequently on health outcomes, patient satisfaction and therapeutic adherence.

**Conclusion:** This review identified significant room for improvement in both attitudes and behavior of health care providers towards MUS patients, including migrants and patients from cultural diverse backgrounds. These need to be addressed in order to improve outcomes.

**Keywords:** Medically Unexplained Symptoms (MUS), Somatoform Disorder, Functional Syndrome, Diversity, Migrants, Ethnicity, Care models, Medical Education, Communication Skills, Health Literacy.

### Introduction

In MUS patients, providing an acceptable explanatory model remains a challenge, largely because of controversy on pathophysiology. Different theoretical explanatory frameworks are only validated to a limited extent and, in general, integrate

biological, psychological and social factors (e.g. in the biopsychosocial, stress-vulnerability, stress, perceptual-cognitive and neurobiological models and in vicious circles and emotions [2, 7-9, 14, 18]. Given the uncertainty and complexity of MUS, it depends on the quality of communication between health care provider and patient whether their interaction will have a positive

impact on health outcomes, patient satisfaction and therapeutic adherence [1, 11].

Difficulties in communication and lack of appropriate approach are even amplified in patients with a different ethnic background [19-26]. Furthermore, in an increasingly multicultural and diverse society sexual minorities and refugees experience disparities in access to qualitative healthcare [5].

To improve healthcare provider-patient interaction in these domains we performed a narrative review of the literature on the predefined items of perceptions, behaviors and attitudes on the part of patients and healthcare providers in order to define gaps as well as areas for improvement and derive recommendations.

## Methods

A search was conducted on the databases PubMed, Web of Science, Cinahl and The Cochrane Library using the keywords: 'Medically unexplained (physical) symptoms (MUS)', 'Somatoform disorder', 'Functional syndrome', 'Diversity', 'Migrants', 'Ethnicity', 'Care models', 'Communication skills', 'Health literacy'. The keywords were internally validated by the co-authors. In order to qualify articles needed to be 1) published between January 1, 2002 and September 30, 2019, 2) available as full text in English 3) categorizable as original research, reviews, meta-analyses or letters to the editor. Database screening was closed 2nd of October 2019. A structural framework was predefined for the domains of perceptions, behaviors and attitudes of patients and health care providers. Titles and abstracts were reviewed to verify inclusion criteria. If all inclusion criteria were present or if this remained unclear, the articles were fully read. All studies were screened for eligibility by two independent reviewers (PV, AM) who reviewed titles, abstracts and full text. Any disagreements were resolved by discussion and, if necessary, a third reviewer (DV) was consulted. Additional literature was obtained through searching references in the manuscripts.

## Results

Cultural and socioeconomic factors proved powerful predictors of individual somatic symptom perception and healthcare utilization in the domain of functional neurologic syndromes [15, 28]. As an example, 8.2 % of patients, who initially presented with suspected stroke, were ultimately diagnosed with functional disorders, labeled as 'functional stroke mimics'. The percentage of functional stroke mimics varied substantially with patients' nationality, age and gender. According to current models of symptom perception, guided by top-down processes of the central nervous system, cultural beliefs, previous illness experiences and stressful life situations influence patients' expectations, sensory input and finally perception of somatic symptoms [15, 28]. Socioeconomic factors such as health literacy, previous healthcare experiences and socioeconomic status prove strong predictors of healthcare use.

## Patient Coping Characteristics

In primary care, three distinct patterns have been identified among high utilizing MUS patients, who frequently seek medical consultation.

1. 'Coping high utilizers' with psychological insight demonstrated less disability but continued to have high utilization primarily

because of ineffective biomedical approaches.

2. 'Classic high utilizers' without psychological insight displayed more disability and continued to seek care for symptom relief and support.
3. 'Worrying high utilizers' with heightened health anxiety developed anger when confronted with resistance to their expectations and demands from health care providers.

Health anxiety appeared to increase high utilization regardless of patients' degree of insight or ability to cope [12]. Patients with chronic MUS and low psychological insight may benefit from treatment that emphasizes legitimation, support and guidance with self-management and role-negotiation rather than reattribution or symptom explanation. Patients endorsing psychological explanations may have better coping mechanisms and be most open to a strategy of plausible and acceptable explanations. Finally, excessive complaints about access to healthcare may represent a marker for unrecognized and/or unexpressed worry.

Interactions between MUS patients and their physicians are usually perceived as difficult and unsatisfactory by both parties. The term 'difficult' mainly describes healthcare provider experience of diagnosing, explaining, communicating and managing these conditions and their own emotional reactions. Healthcare system deficits and the conceptual basis for MUS were other facets of coining as 'difficult'. This terminology actually masks the complexity of doctor's experiences, which may represent a mechanism of projection. In semi-structured interviews of both medical and surgical senior clinicians, preconceived ideas and attitudes of the use of 'difficult' were challenged. This can help counter the unreflexive perpetuation of negative evaluations stigmatizing MUS patients, encourage greater acknowledgment of physician emotions and contribute to more appropriate conceptualization and management [16].

Conversation and position analysis of recorded consultations between liaison psychotherapists and inpatients with MUS in a tertiary care setting showed that therapists use discursive strategies to influence their patients, with careful and implicit formulations. Three linguistic patterns could be found in which patients subtly refute, drop or undermine the psychosomatic attribution in their reply. Patients positioned themselves as somatically ill or justify their own life situation. Moreover, in this context patients interpreted psychosomatic attributions and even subtle suggestions from the psychotherapists as face-threatening 'other positionings'. Interactional resistance may be a necessary step in the process of the patient's understanding [4].

## The perspective of health care providers: from students to experienced physicians

Medical students in their third year of undergraduate training in the UK reported limited knowledge of CFS/ME and found it difficult to describe symptoms of CFS/ME beyond tiredness or fatigue. They viewed this condition as a diagnosis of exclusion lacking a pathological basis. Some students perceived CFS/ME as caused by biological factors, such as genetics or by a physical disease process such as a viral infection and compromised immune function, while others offered psychiatric explanations or viewed it as a problem caused by personality or hypersensitivity or as simply

'medically unexplained'. In students the legitimacy of CFS/ME patients' symptoms was at times questioned by themselves or by their fellow students. Some reported that without a known physical cause or diagnostic test, they struggled to view the illness as real or the concern of "proper" medicine, with the perception of this condition not fitting the traditional biomedical model commonly endorsed within medicine. This dominance of the biomedical model was further illustrated when students reported that CFS/ME would be a 'difficult', 'frustrating' and 'intimidating' condition to manage due to its 'invisible' nature and perceived complexity [23]. Students felt that CFS/ME was not a serious illness in the absence of a risk of mortality and an associated pathological process. They held both implicitly and explicitly expressed negative attitudes towards these patients. They perceived CFS/ME to be associated with poor coping skills or as related to personality or even 'laziness'. They claimed having encountered these negative attitudes from clinical tutors and that physicians who trained them in clinical settings had been highly influential [23].

Similar findings were found in another report [20]. Medical trainees had received no formal training in MUS, although representing a common disorder [20]. They nevertheless developed views about causes and management and struggled with the concept of 'diagnosis by exclusion'. Attitudes had developed through informal clinical observation and interactions with doctors. This experiential learning from healthcare professionals within clinical placements, or 'hidden curriculum', shifted students towards understanding these conditions as problematic and, in some cases, illegitimate medical presentations. Many had already acquired negative views and felt frustration and hopelessness at the prospect of managing these patients. Training proved a major factor in how open they were to additional learning opportunities.

Junior doctors described patients with unexplained symptoms as challenging, and often 'impossible to help'; some even questioned the legitimacy of such patient's demands on physician time and resources. These patients often appeared to trigger negative feelings such as annoyance, frustration, confusion and anxiety. Uncertainty about MUS seemed linked to a feeling of incompetence, particularly as they were more accustomed to dealing with cases involving clear organic pathology. Some junior doctors indicated avoiding the suggestion of a psychosocial connection to symptoms, fearing this might offend patients or leave them feeling as though they had not been believed or taken seriously [28]. Similar findings emerged from an exploration of how novice and experienced GP's managed MUS patients in Australian GP training practices and how these skills were taught and learned. Negative feelings and a lack of diagnostic language and frameworks may prevent registrars from managing these patients effectively. Some of these negative feelings such as frustration, shame and helplessness, are shared between doctors and patients [24].

GP's experience less satisfaction in treating MUS as compared to medically explained conditions [3]. Across four conditions assessed (depression, anxiety, chronic back pain and fibromyalgia), physicians reported experiencing less satisfaction when treating symptoms that result from choices for which patients are responsible, reflecting the difficulty experienced by caregivers

confronted with patients with low self-efficacy. A deduced skill is the ability of the caregiver to deal with larger ascribed patient self-responsibility and to encourage the patients towards self-efficacy.

Similar themes surfaced in primary care (GP) focus groups in Poland, i.e. negative emotions, insufficient training in the management of patients with MUS and the lack of guidelines [6]. Furthermore, changes in healthcare environment affected the management of MUS patients. This included the GPs' negative image as professionals, barriers to building a continuous doctor-patient relationship, limited resources and limited access to specialists and lack of a multidisciplinary primary care team.

In a questionnaire study of GP's in Northern Italy, 70 % indicated spending much to very much time and energy to MUS patients in daily practice. Providing reassurance and support (73 %) and listening to the patient (69 %) were the most frequent management strategies [21]. Only a third of GP's was well informed about the role of psychologists and 60 % feared neglecting an underlying medical disease. Education on MUS seemed to rely on GP's own initiative through consultation of scientific papers and continuing medical education courses. Younger age and lower length of practice were significantly associated with negative emotional responses.

In an observational cross-sectional study of GP-patient consultations, van der Weijden et al (2003) aimed at gaining insight into test-ordering behavior for patients presenting with unexplained complaints without alarming features [27]. In spite of an existing Dutch College of General Practitioners (DCGP) recommendation of a watchful waiting attitude, there was a positive relation between unexplained complaints and test ordering, with large inter-physician variability; patients' expectations about testing influenced test ordering even more. In spite of frequent patient offering of possible psychosocial background cues in doctor-patient conversations, the initiative for further somatic exploration often originates from the GP [19].

The importance of the interaction between patients and healthcare providers and of active listening was evaluated in a cross-sectional exploration of encoded videotaped intake consultations between clinical nurse specialists and fibromyalgia patients in a third line setting. Patient experiences of pain and emotion were more often expressed in terms of cues than as explicit concerns. Higher evaluation of health was associated with less cues. Both the lack of empathic responding as well as non-specific empathic responses were associated with the expression of an increased number of cues in the consultation [13].

Den Boeft et al (2016) identified four dialogue types between GPs and patients related to explanations in a community-based clinic for MUS [10]. These were, varying to the degree by which the GP controlled the dialogue, a lecture, story-telling, contest and deliberation type of dialogue as framework for interaction. Explanations co-created by patient and GP were most likely to be accepted, a feature of deliberation dialogue, which actually occurred in 40 % of the explanation events assessed. What the effects are of the framework used, requires further study.

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## Discussion and Recommendations

An effective approach to functional disorders requires first of all explanatory models for the pathway from symptom perception to functional syndromes, thereby integrating somatic, psychosocial and mental factors. Dualistic health care systems with separation between somatic and mental health disciplines are not ideally suited. They result in delayed diagnoses (with a mean estimated duration between onset of somatoform disorder and first psychotherapeutic and psychiatric treatment of 25 years) and increase stigma for mental disorders.

Secondly, early recognition and treatment of MUS prevents unnecessary suffering and inappropriate healthcare utilization. Lowe and Gerloff proposed a generic transcultural conceptual model integrating sociocultural factors with symptom perception and healthcare use for the approach of MUS in emergency departments, also applicable in a broader scope of healthcare settings [15]. Consideration of these sociocultural factors should improve care, enhance access to effective treatment, and empower patients through education and early participation in the treatment process. This requires interdisciplinary collaboration among specialists from somatic and mental health disciplines and interdisciplinary training. This may result in increased awareness, required to achieve the goals of early screening and diagnosis of functional disorders and somatic symptom disorders, in a phase more prone to improvement and therefore avoiding chronification, less susceptible to change. The European Network to improve diagnosis, treatment and healthcare in patients with persistent somatic symptoms (<https://www.euronet-soma.eu/>) published recommendations for core outcome domains in the evaluation of interventions. These substantial shifts in the approach of MUS are required, both in society and in the mind-set of patients and healthcare providers and their training, in order to change the deeply entrenched negative perceptions towards MUS.

Thirdly, improvements are necessary in the communication between even trained GPs and their patients. Doctors must help patients to make sense of the complex nature of their problems, reassure that medical attention to psychosocial factors does not preclude vigilance to physical disease, and establish a quality of relationship in which patients do not perceive psychosocial enquiry as inappropriate. This will foster an environment in which physicians can support patient self-management [17]. Training clinicians and patients to recognize and address anxiety and its source will reduce costs. This stresses the need for affirmative and possibly repetitive somatic reassurance throughout longitudinal management. In this process therapists should introduce reattribution in a patient-centered rather than persuasive way and they should openly address patients' fear of stigmatization [4]. This dimension needs to be integrated in the communication skills of caregivers. Reattribution training may contribute to improved uptake of patient cues for psychosocial factors and reduce test ordering in the absence of alarm symptoms by GP's themselves when confronted with MUS [19]. Particular challenges in the management of MUS patients are the frequently found personality traits of neuroticism and alexithymia as well as the dimensions of negative and positive affect. These should be recognized and probed and included in the competency profile of caregivers [9].

Finally, increasing diversity due to migration and the presence of large groups of refugees from crisis areas adds to the complexity of MUS management. These dimensions also have to be addressed, such as taking into account health competencies or health literacy', proper communication in spite of language barriers, the avoidance of misunderstandings due to cultural differences in perceptions of illness/disease concepts and their treatment [25]. These challenges and barriers need to be recognized as well as acknowledged by caregivers and approached in the correct manner in order to guarantee and enhance the delivery of high quality care. This requires specific knowledge, attitudes and skills. Medical teachers agree that this can only be achieved through specific training in the medical curriculum [22]. Cultural competence among health professionals indeed needs to be viewed as a strategy to ensure equal access to healthcare across diverse groups and to ensure that patients receive care in proportion and in accordance with their needs [22].

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