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Concordance of Illness Representations: The Key to Improving Care of Medically Unexplained
Symptoms

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How can effective patient-provider relationships be developed when the underlying cause of the health condition is not well understood and becomes a point of controversy between patient and provider? This problem underlies the difficulty in treating medically unexplained symptoms and syndromes (MUS; e.g., fibromyalgia, chronic fatigue syndrome), which primary care providers consider to be among the most difficult conditions to treat.¹ This difficulty extends to the patient-provider relationship which is characterized by discord over MUS.¹ In this article, we argue that the key to improving the patient provider relationship is for the patient and provider to develop congruent illness perceptions about MUS.

An effective patient-provider relationship is known to be important for all conditions but is considered critical for MUS.² This is because there is no known cure for MUS—rather, patients and providers need to work together to learn the management strategies that improve quality of life for the individual patient.³

Unfortunately, most patients with MUS and their providers feel that they have ineffective relationships. When patients and providers are unable to work effectively together, patients with MUS receive inadequate and even harmful care. Suboptimal treatment/care practices for MUS are common: patients with MUS are subjected to exploratory surgeries, excessive laboratory testing, and inappropriate consultations with specialty providers in the quest to determine a cause. Up to 30% of patients are prescribed opioids,⁴ which is not recommended for MUS.⁵ Improving the patient-provider relationship will not only improve treatment decisions and outcomes, but is what patients want. In fact, a qualitative study found patients with MUS consider improving their relationships with their medical providers as their primary objective, exceeding their desire for functional improvements.⁶

What is not known, however, is which factors most contribute to an effective patient-provider relationship in the context of MUS. Qualitative studies suggest that poor patient-provider relationships are due to discordant beliefs about the cause, consequences, and nature of MUS and the appropriate treatment approach.^{7,8} Patients are more likely to view MUS as primarily a physical condition that requires a medical intervention,^{9,10} whereas providers are more likely to view MUS as primarily a psychological condition related to stress.¹¹ This disagreement can pit patients and providers against each other.

Interventions for MUS that have focused on reducing discordance between patient and provider's beliefs about MUS have been unsuccessful. These include (1) *reassurance*, which involves explaining to the patient that the MUS does not reflect a single medical condition¹² and which leads to patients feeling their concerns are being dismissed¹³ and that the provider is inexperienced or uncaring;¹⁴ (2) *retribution*, which is attributing the cause of MUS to stress/emotions, and which experts have concluded is too simplistic and does not improve health outcomes;¹⁵ and (3) *collusion*, which is appeasing the patient by prescribing unnecessary care/tests and which experts consider iatrogenic.¹⁶

These approaches are ineffective, in part, because they assume patients with MUS only view MUS as a physical condition and that patients pressure their physician to provide medical intervention. Recent studies dispute this. Most patients view their condition as multiply determined.¹⁷ Further, patients' goals often include improving self-care instead of, or in addition to, medical interventions.¹⁸ Within the medical encounter, providers often suggest medical intervention, not the patient with MUS.

Different from these attempts in the literature, we propose that providers need to work with patients to develop concordant beliefs about MUS. *Concordance* results from a process in

which the patient and provider hear each other's beliefs about MUS and negotiate a shared understanding of these beliefs.¹⁹ This approach to improving treatment outcomes requires a scientific understanding of MUS *and* expertise on the individual's experience of MUS, including effective individualized self-management approaches. In other words, both the provider's and patient's perspectives are valid and necessary.

Concordance does not require the provider and patient negotiate until they agree on everything. The authors' and collaborators' clinical and research experience with veterans with severe MUS support this. Care starts with listening to the veteran's beliefs about their MUS. Differences in beliefs between patient and provider are acknowledged and accepted. For example, providers may agree with the veteran that the cause of his/her MUS is combat deployment, but the veteran may be focused on a specific environmental cause while the provider is unsure as to how combat deployment caused the symptoms. This will not disrupt the relationship as long as the veteran's perspective is valued and the provider is knowledgeable. Second, care includes education about illness representations that are inaccurate and will potentially impede treatment, such as assessments or treatment that have little likely benefit and high potential for iatrogenic consequences, such as opioids. Finally, care focuses on negotiating *a shared understanding of aspects of veterans' illness perceptions/beliefs* that are critical to care. For veterans with MUS, this often includes agreeing that MUS is a serious, disabling physical condition and that the goal is to maintain a high quality of life. This focus on developing concordant illness beliefs leads to over 90% of veterans being satisfied with the care provided.²⁰

The negotiated concordant illness perceptions become the foundation for developing an effective treatment plan. In the preceding example, if the provider and veteran agree that the veteran has a debilitating physical condition caused by deployment and the goal is quality of life

improvement, then educated “trial and error” can be used to find treatment approaches that improve this patient’s quality of life (e.g., the patient may keep a food diary, acupuncture or Cognitive Behavioral Therapy). Patients learn their own strategies to improve their MUS, such as being active in the morning and resting in the afternoon (receiving education from the provider regarding how “overdoing it” may exacerbate symptoms). These become part of the treatment plan. With concordant illness perceptions, the patient and provider are united against the MUS, as opposed to trying to change one another’s beliefs about MUS.

There are few empirical studies on concordance of illness representations for MUS. To our knowledge, Phillips and McAndrew²¹ conducted the only study of concordance in MUS illness perceptions and its association with the quality of the patient-provider interaction. They surveyed 243 veterans with MUS and asked if they agreed with their provider about the nature of MUS in general (being primarily medical vs psychological in nature) and also about specific causes (biological, environmental or psychological). Patient’s perceived concordance with their provider about MUS in general or specific causes were related to better satisfaction with care. Evidence among patients with chronic pain also supports the importance of concordance for greater satisfaction,²² better health outcomes,²³ and perceived improvement due to treatment.²⁴ It seems to be particularly important that patient and provider agree that the goal of treatment is long-term management of the symptoms rather than a cure.²⁴

Indirect support for the importance of concordance of illness beliefs can be found in studies conducted in primary care or family medicine settings, where MUS is common. Phillips and colleagues²⁵ found that patients who perceived greater concordance in illness representations with their physicians were more adherent to their physicians’ recommendations in the subsequent

month. Similarly, Kerse and colleagues²⁶ found that patients who reported greater perceived concordance with their physicians were 30% more adherent to medication.

While very preliminary, there is some evidence that it may be possible to develop interventions that succeed in helping patients and provides achieve concordance around MUS. Burton and colleagues²⁷ conducted a pilot project of a “symptom clinic” for patients with medically unexplained symptoms. Patients with MUS saw a primary care provider for a series of consultations. During the consultations the provider first heard out the patient, and then worked with the patient to develop a mutually accepted understanding of the symptoms. This agreed upon explanation was then used to guide cognitive and behavioral actions to improve the symptoms. Results of the pilot study found a clinically significant improvement in patient’s symptoms and quality of life, although the authors recommended replication with a larger, randomized controlled trial.

Summary

Our suggestion of the importance of concordance between patients and providers illness perceptions for improving care of MUS is part of a historical trend of moving from compliance to adherence to concordance.²⁸ While seemingly intuitive, the few published studies of patient-provider relationships in the context of MUS have addressed discordance by seeking to change patients’ beliefs about their MUS. By contrast, our proposed concordance model of patient-provider relationships expands on the Common-Sense Model of Self-Regulation,²⁹ which proposes that patients use their understanding of their health to manage their health. As discussed in this article, improving our understanding of how to develop effective patient-provider relationships in the context of MUS has the potential to improve the medical care of patients with MUS and improve the care of patients with other complex health conditions.

While there is some evidence to support our proposition of the importance of concordant illness representations, there remain many unanswered questions. Most importantly, the extant literature is cross-sectional, qualitative or is based on other medical conditions. There is a need for descriptive and experimental studies with evidence that concordance of illness representations is related to better patient-provider relationships and treatment outcomes among patients with MUS. This work needs to determine how effective providers achieve concordance and the best methods to teach this to other providers in order to improve care for all patients with MUS.

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