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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### Questioning Biomedicine's Privileging of Disease and Measurability

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##### Abstract

Within biomedicine, the diagnosis of disease is often privileged over a patient's experience of illness. Yet up to 30% of primary care visits might be attributable to persistent illness without a diagnosed disease, including functional somatic syndromes like fibromyalgia and chronic fatigue syndrome. When clinicians are unable to diagnose disease or correlate symptoms with measurable changes in biomarkers, patients experiencing such an illness are at increased risk for suspicion, misplaced questioning, or having their motives misinterpreted through damaging social and cultural narratives about gender, race, ethnicity, socioeconomic status, or disability. Adhering strictly to a biomedical model of thinking about disease and diagnosis can prevent clinicians from empathically engaging with patients and helping them navigate their illness experiences.

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##### Biomedicalization

Traditional biomedical approaches often assume that physiological changes in bodies generate predictable, measurable effects. In this model of thinking, a patient's subjective experience of *illness* is validated mainly by empirical verification of the presence of *disease*. In contrasting disease with illness, I will be adhering to the distinction that psychiatrist and medical anthropologist Arthur Kleinman has made.<sup>1</sup> Practitioners of biomedicine focus on what they consider to be a distinct disease entity, with the patient's symptoms reliably correlating with an identifiable lesion or a change in biomarkers, such as fluctuations in vital signs or lab values. Illness, however, refers to the experiences and meaning making of both the individual with symptoms and his or her family and social network.<sup>1</sup> Within the **biomedical model**, illness with disease (such as the sore throat that is found to be caused by strep infection) and disease without illness (such as the often-asymptomatic conditions of diabetes or hypertension) are given greater epistemic authority than illness without disease. Accordingly, without a diagnosis of disease, a patient's pain might be questioned and interpreted through

damaging cultural narratives, such as those about gender, race, ethnicity, socioeconomic status, or disability.

### Illness Without Disease

Individuals who experience illness without disease may be told that their illness is less real or even be accused of malingering.<sup>2</sup> Functional somatic syndromes, a group of chronic illnesses without disease that includes **chronic fatigue syndrome**, fibromyalgia, irritable bowel syndrome, chronic pelvic pain, and multiple chemical sensitivity, to name only a few, thus exist at the margins of biomedicine. These illnesses do not fit neatly into the biomedical model, and those who have them continue to suffer even when reassured by practitioners of biomedicine that they have no disease.<sup>3,4</sup> Functional somatic syndromes are persistent and painful, lack organ pathology and abnormal lab results, and have symptoms that do not correspond to a “conventionally defined medical disease” diagnosis.<sup>5</sup> In some estimates, up to 30% of primary care visits are attributable to patients with functional somatic syndromes, making this a significant yet often unacknowledged part of general medical practice.<sup>6</sup>

The chronic and intractable nature of these illnesses is what makes many practitioners feel at a loss when attempting to treat them.<sup>7</sup> The initial specialist to whom the patients are referred often dictates their diagnostic path: “A gastroenterologist will probably diagnose IBS [irritable bowel syndrome], a rheumatologist ... fibromyalgia, and a gynecologist ... chronic pelvic pain syndrome.”<sup>4</sup> Thus, many diagnostic names exist for the patient’s ultimately irreducible experience. The individual insists that something is corporeally wrong, and the practitioner of biomedicine attempts to reassure that individual that he or she is able to read the body better than the patient.<sup>8</sup> The physician’s belief that the patient’s body is fine might result in a referral to psychiatry because of the sharp divide biomedicine maintains between mind and body.<sup>9,10,11</sup>

It is important to remember that the medical gaze’s privileging of disease over illness was not the inevitable march of scientific progress. The **medical gaze** ascended to its current place of power in the 19th century in part due to the professionalization of medicine and its institutionalization in the clinic and in hospitals, as care stopped being delivered in the patient’s home.<sup>12</sup> The rise of biomedicine meant that patients and their healers no longer shared the conception of the body as a system interacting with its environment.<sup>13</sup> Therapeutics became increasingly invisible, and patients were no longer able to witness them working, instead relying on the physician’s safeguarded knowledge. As visits more often occurred in the physician’s own domain rather than in the patient’s home, patients became further removed from their own care. In this new model, only the medical gaze could penetrate the opaque body to see whether disease was actually lurking and, if so, verify the patient’s illness.<sup>12</sup>

When physicians are unable to find the biomarkers of disease, they must inevitably rely on their own assumptions. In such cases, a diagnosis might be affected by the physician’s own implicit biases and his or her ideas about how sickness should appear.<sup>14</sup> Clinical medicine is much less of a lab science and more of a hermeneutical endeavor than many admit.<sup>15</sup> In the absence of a disease diagnosis, patients must appear sick enough to be taken seriously, but not so sick as to be suspected of exaggerating. For instance, a study published in the *Annals of Internal Medicine* explains to its readers—presumably, internal medicine physicians—that individuals with functional somatic syndromes often demonstrate “disability out of proportion to physical exam findings.”<sup>3</sup> These subjective criteria encourage physicians to decide what are acceptable

levels of pain and functional impairment for certain conditions. For illness without a disease diagnosis, any pain may be questioned.

Physicians are taught to watch for the risk factors of functional somatic syndromes: female gender, low socioeconomic status, lack of education, a history of trauma (particularly sexual abuse as a child), actively seeking disability benefits, and comorbid medical and psychiatric conditions.<sup>5,16,17,18</sup> As with all chronic illness, risk factors prime the physician's interpretation of the patient's illness.<sup>19</sup> Once a patient has received a functional somatic syndrome diagnosis, he or she is likely marked for all future encounters. As psychiatrist P.D. White notes: "Probably the most replicated risk marker for a functional somatic syndrome (FSS) is that having one is strongly associated with having another."<sup>20</sup> We cannot know whether this stacking of functional somatic syndrome diagnoses is due to the specialization of medicine, physicians' biases and positionality, or a yet-to-be-identified underlying disease. However, that gender, socioeconomic status, and other culturally charged classifications are accepted risk factors for functional somatic syndromes empowers physicians to make potentially problematic judgments about how different types of people, such as women and those seeking disability benefits, should "normally" present, both inside and outside of the clinic.

### **Gender and Functional Somatic Syndromes**

Although functional somatic syndromes vary in their gender distribution, women predominate in each condition, with the female to male ratio ranging from 2:1 to 6.8:1.<sup>7</sup> Women's increased incidence of illness without disease cannot be explained away by biological differences or by an increased likelihood to present for medical examination and subsequent medicalization.<sup>21</sup> Instead, a more phenomenological perspective must be considered that does not reduce a woman to her body's hormonal differences and ability to reproduce or to her allegedly fragile psyche. Negative life experiences, which women might be more likely to endure, cause invisible wounds and physical pain that is just as real as that caused by an organic lesion.<sup>21</sup>

The patient-physician relationship is inherently unequal. Furthermore, Western narratives often gender doctoring as male, so when the patient is female, the preexisting power imbalance is only augmented as gender inequalities come into play.<sup>22</sup> Female patients' complaints are more often taken less seriously or dismissed as psychosomatic or hysterical.<sup>7,14,22,23,24</sup> Women's pain is often read through moralizing cultural narratives that see women as less rational than men and more likely to be hypochondriacs.<sup>23</sup> Although women may experience illness without disease more often than men due to negative life experiences, they might also be more frequently given a functional somatic syndrome diagnosis because of the gendered cultural narratives they encounter.

### **Future Directions**

How might physicians care for individuals with functional somatic syndromes? Many of these patients refuse cognitive behavioral therapy, antidepressants, or other psychological treatments because they worry that opening the door to a mental source of their symptoms might permanently close the door to finding a somatic cause.<sup>2</sup> Even if these therapies might help, as they often do in treating pain for patients with cancer, they must be rejected because, unlike individuals with cancer, those with functional somatic syndromes have not had their pain validated by the presence of disease.<sup>2</sup>

Some individuals with functional somatic syndromes seek acknowledgment of their suffering, something that the field of medical humanities has increasingly made possible by introducing narrative ethics into medical school education. These patients wish to partake in “joint storytelling”<sup>25</sup> with the physician, asking not necessarily to be given a traditional biomedical diagnosis but to have the physician help them make meaning out of their illness experience, empathically witness their pain, and acknowledge that biomedicine may not have all of the answers.<sup>1,24</sup> Anthropologist Megan Crowley-Matoka advocates for cultural competency training that focuses not just on teaching physicians about patients’ cultures but also on a closer examination of the culture of biomedicine and physicians’ own assumptions.<sup>11</sup> Unfortunately, with the increasing bureaucratization of medicine and physicians’ often expected patient quotas, a renewed focus on and empathic attention to patients’ **illness narratives** may not always be possible. Functional somatic syndromes serve as an important reminder that physicians’ ability to care is often just as important as their capacity to cure.

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