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How to deal with medically unknown symptoms

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The term medically unknown symptoms covers various symptoms and diagnoses that change with the advance of medical knowledge.[1] Included in this term are illnesses such as fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, environmental sensitivities, and chemical intolerances (sometimes referred to as multiple chemical sensitivities). Although the acceptability of these symptoms as real depends on the cultural and medical climate in which they are seen, patients will continue to appear in physicians' offices with these types of complaints. Denying that patients have these symptoms will only make their problems worse.

Controversy exists over whether medically unknown symptoms are psychologic, physiologic, or both. Proponents of somatization would place medically unknown symptoms in the realm of psychologic disorders.[1-4]

ENVIRONMENTAL SENSITIVITIES SYNDROME

Environmental sensitivities may best be considered a multisystem, multisymptom syndrome. The most widely used definition suggests that both environmental sensitivities and multiple chemical sensitivities are characterized by recurrent symptoms referable to multiple organ systems and occurring in response to exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. To date, no single widely accepted test of physiologic function has been shown to correlate with symptoms.[5]

Ongoing debate in medical circles over the definition that should be applied to this clustering of medically unexplained symptoms has produced various labels. These range from multiple chemical sensitivities[5-7] to environmental hypersensitivity syndrome,[8,9] total allergy syndrome,[10] environmental illness,[11] idiopathic environmental intolerance,[12] and environmental sensitivities (the last currently in use by the Nova Scotia, Canada, Environmental Health Center), just to name a few. The definitions are either narrow or so nonspecific that almost anyone could be included under their label.

In 1995, the province of Nova Scotia reported that 3% of its population was chronically affected by environmental illness.[13] In a population study, Meggs and coworkers found that 33% of the US population reported chemical sensitivities, with 4% being affected on a daily basis.[14] Recent statistics place the prevalence of environmental illness, diagnosed by a physician, at 6% of the California population. A further 16% report being "allergic or unusually sensitive to everyday chemicals."[15]

Summary points

- The term medically unknown symptoms covers a multisymptom, multisystem, and multifactorial problem that has yet to have a widely accepted definition
- Medical practice traditionally involves making a clear diagnosis before intervening and before healing may occur
- Standard appointment times are not long enough for patients with medically unknown symptoms to tell their story
- Poor communication exacerbates the chronicity of the condition
- Patients respond better if physicians listen with respect, acknowledge their experience, and reassure them

TRADITIONAL WESTERN MEDICINE VERSUS CLINICAL ECOLOGY

Western medicine seeks to practice evidence-based medicine.[16,17] This is not the case for physicians who are clinical ecologists and practice environmental medicine. These physicians advocate the avoidance of a wide range of chemicals and the use of nonvalidated tests and treatments.[18,19] Clinical ecologists think that the symptoms triggered by perfumes or other chemicals are physical and that environmental sensitivities are pathophysiologic.[18] They think that personal observations and experience are all that are necessary to diagnose and treat people with medically unknown symptoms.[18] Their theories and practices have been condemned by most medical societies. Relying on personal experience alone may result in incom-

plete diagnoses, missed diagnoses, and assigning incorrect labels that perpetuate illness as opposed to leading to recovery.

Traditional medicine needs a clear diagnosis that corresponds with a particular disease. When patients have symptoms that fall outside current medical classifications of disease, physicians tend to classify these symptoms as psychological in nature. This can alienate patients, and they will seek opinions (often frequent and multiple) from other specialists. In unpublished data for 1999, the provincial department of health for Nova Scotia found that people with environmental sensitivities used health services 5.5 times more than matched controls.

Relying on a precise diagnosis may be counterproductive for both physicians and their patients. Physicians may find themselves increasingly frustrated by their inability to understand and solve the problem. For patients, the need to have a clear diagnosis for their experience may shift their focus to symptoms to the exclusion of all other aspects of their life. In addition, patients may become isolated from their families by the lack of a label of an illness for their symptoms. This lack of validation by physicians leads many patients to turn to alternative practitioners such as clinical ecologists.

The avoidance of inciting triggers seems a commonsense approach. But avoidance may foster isolation, poor coping skills, and further disability in a person. Furthermore, after undergoing testing methods shown to be unreliable,[19] people are often told that they are sensitive to a wide variety of triggers, making avoidance a difficult, if not challenging, task.[20] At the same time, reliance on a tool that may falsely identify sensitivities limits persons' ability to function, compromising their overall health. Inevitably, everything becomes a possible trigger of symptoms, creating an atmosphere of fear.

THE SYSTEM

The design for appointment visits may not always be adequate for patients, particularly when the patients have symptoms that apparently defy the usual diagnostic criteria (table). Environmental sensitivities are a multifactorial problem that encompasses physical and biologic factors such as pesticides; poor indoor air quality; a genetic predisposition; social issues, such as dynamics in the workplace and financial stress; and psychologic factors that include a variety of personality disorders. Therefore, the standard physician's appointment of 15 minutes may be insufficient for gathering all the facts. Patients frequently express their frustration and anger over feeling rushed to impart information. This may lead to incomplete disclosure, thus compromising a physician's ability to make an accurate diagnosis.

At the Nova Scotia Environmental Health Center, the average duration for an appointment ranges from 34 to 45 minutes. At the same time, 16% of patients at the Center make up 40% of the visits. This suggests a burden of time for physicians that would be difficult to provide in a busy family practice.

Table *Top 10 symptoms reported since start of illness and ranking by sex (N = 381)*

Symptoms	Total, %	Ranking Men	Ranking Women
Fatigue or very tired	95	1	1
Difficulty concentrating	93	2	2
Tiredness not relieved by rest	92	3	3
Forgetful or poor memory	90	5	4
Sneezing or runny or congested nose	90	4	5
Irritability	89	6	7
Other headaches	88	9	6
Itchy eyes	86	10	9
Trouble finding right words	85	19	8
Throat clearing	83	8	12
After exposure			
Sneezing or runny or congested nose	64	1	1
Itchy eyes	61	2	2
Difficulty concentrating	52	3	3
Other headaches	48	8	5
Burning eyes	47	5	6
Hoarseness or loss of voice	46	40	4
Stuffy or full sinuses	45	4	9
Forgetful or poor memory	45	27	7
Tight chest	43	19	8
Usual odors sickening	42	6	13

Further compounding the situation are communication problems in the patient-physician relationship. Communication has been cited as one of the most valuable skills a physician could possess.[21] Despite this, patients often express dissatisfaction with this aspect—77% of patients visiting a physician's office to convey their illness narrative are interrupted, and most of these interruptions occur within the first 20 seconds of the visit.[22]

PATIENT PERCEPTIONS

Ignoring patients' symptoms or labeling them psychologic, by default, forces patients further into a system (socially and medically) whose attitude increases the trauma of not only being ill but also stigmatized.[23] Unable to acquire answers and continuing to experience symptoms that may be frightening because of their indeterminate nature, patients see themselves as more and more disabled and traumatized.[24] Many withdraw from family and friends, unable to cope with the stigma and stereotyping. The fact that symptoms wax and wane makes it difficult for patients to perceive themselves as well. Rather, they begin to see themselves as chronically ill.

SOLUTIONS

Four simple solutions can improve the health outcomes of persons with environmental sensitivities. The most impor-

tant step involves respectfully listening to patients describe their symptoms, without labeling the symptoms prematurely as predominately psychologic. The physician should avoid cutting the patient off in midsentence. Second, every illness has both a psychologic and a physical component, but an accurate assignment of percentage for each may not be possible. Acknowledging the experience for patients increases the likelihood that they will work with you to get better. Third, reassure patients that, although they may continue to have symptoms, their level of functioning will improve. Finally, do a complete assessment, which should include an occupational and environmental history to understand possible triggers. If this health concern is aggressively attended to early, the pitfalls of patients developing chronic illness may be avoided.

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When AIDS became a chronic disease

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"The flu gives you a fever, but your mother puts you to bed."

Folk saying

A basic tenet of medical anthropology is that illness is socially constructed. Agents of disease produce physical symptoms in people, but relatives, friends, and health professionals surrounding a sick person classify and interpret those symptoms to determine if he or she is ill. How a society interprets and classifies symptoms, prescribes treatment, and assigns the sick role vary with many factors, from geographic location to political economy.

In June 1989, Samuel Broder, then head of the National Cancer Institute, declared in a speech at the international AIDS meeting in Montreal, Quebec, that AIDS was a chronic illness and that treatment should follow the model of cancer.[1] This public statement marked a shift in the social definition of AIDS from an acute to a chronic illness, a shift with economic and cultural repercussions for the treatment and understanding of AIDS at the national, local, and individual levels.

CULTURE AND ECONOMY

The relation between political economy and cultural concepts of disease and treatment is illustrated in Fabrega's comparison of contemporary foragers and village societ-