

Scientific Study

Diagnosing Contested and Emerging illnesses

“Many currently recognized illnesses were not recognized in the past.”

Science is a slow process, particularly when it comes to diagnosing emerging illnesses. To a great extent, patient suffering occurs in the absence of medical and scientific consensus on the cause of an illness. Without a clear consensus, doctors are led to believe illness is psychological and patients are given useless, and sometimes harmful, psychiatric therapies.

Many currently recognized illnesses were not recognized in the past. These illnesses, including asthma and Mad Hatter’s Syndrome, became accepted as biomedical after first being a source of uncertainty and dispute.

Deborah Swoboda is an Associate Professor of Psychology in the Department of Behavioral Sciences at York College of The City University of New York. She says, “Most emerging illnesses begin as a set of identifiable symptoms whose significance is not understood nor appreciated. A substantial body of work describes how illness legitimization occurs when researchers and health professionals identify a new disease, or when sufferers advocate for recognition of symptoms that cannot be explained in

terms of existing conditions.”

Swoboda suggests that diagnosing physicians advance the legitimacy of controversial illnesses by constructing a means for the diagnosis. She believes that a substantial portion of physicians are thinking beyond current disease models and diagnosing controversial illnesses such as chronic fatigue syndrome (CFS), multiple chemical sensitivity (MCS), and Gulf War syndrome (GWS). This, she says, benefits patients who suffer from these illnesses and advances the legitimacy of these diagnoses.

In 1998, after almost 20 years of debate, the Centers for Disease Control and Prevention (CDC) issued a case definition for CFS that characterized it primarily by the presence of unrelenting fatigue. CFS is now recognized by the Social Security Administration as a disability.

MCS was first discovered around the same time as CFS; however, the CDC has yet to issue a case definition for this syndrome characterized by the multi-system effects of common low-dose chemical exposures. Many governments, organizations, physicians, and researchers recognize MCS, though the illness does not yet enjoy the wider consensus that CFS has attained. MCS is, however, recognized by the Social Security Administration as a disability.



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GWS enjoys the greatest legitimization of the three illnesses. While the symptoms are seen as real, there is still some resistance to legitimizing GWS as a diagnosable condition. Toxic substances, vaccines, and other environmental factors have been linked to GWS. GWS is recognized as a disability by the Social Security Administration.

Swoboda attributes the slow acceptance of these illnesses to several factors:

1. The symptoms are broad and nonspecific,
2. The symptoms differ in kind and severity among individuals,
3. Pathogenic mechanisms have not been identified,
4. Treatment involves competing therapies,
5. They lack conclusive biomedical status, and
6. They are often diagnosed as co-occurring conditions.

"The more knowledge physicians have about an illness," says Swoboda, "the better they are at deciding how to act." However, little information about CFS, MCS, and GWS is provided to physicians during a typical medical school education. Physicians with less information are more likely to focus on psychological symptoms and resist a medical diagnosis, while those with more knowledge of existing diagnostic protocols are more likely to make a medical diagnosis.

Being certain of the cause

of an illness is not required for diagnosis. Doctors don't know with any certainty what causes the majority of even the most well-accepted illnesses. Physicians make many diagnoses based on suspected cause.

Peer-reviewed journal articles are the primary source of new information for physicians, yet the majority of the medical journals are controlled by the pharmaceutical industry, which is in part controlled by the chemical industry. Research which does not support the financial interests of these two industries is routinely denied publication.

"If a study is funded by the industry, it may be closer to advertising than science," says David Ludwig, MD.

A perfect example is presented in the recent study that verified that pharmaceutical companies tend to publish studies which support the drugs they wish to market while burying studies which show the drug either has no effect or has a negative effect. This limits the value of new information received by physicians and interferes with fully informed diagnostic decision making.

In addition, the average time spent with a physician during an office visit has dramatically decreased to only 7 minutes per visit. Administrative time dealing with insurance companies and other paperwork has significantly increased.

Errors are common in diagnosis, particularly in complex multi-system cases such as CFS, MCS, and GWS. Lack of information, inappropriate tests, and failure to consider other causes leads to a quick judgment without all the facts.



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.The overall reduction of time spent with patients has negatively impacted diagnostic certainty, with “best guess” diagnoses being issued after a few moments of inadequate evaluation. Emerging conditions which fit no known disease process, but instead require research and thought, are not given due consideration.

Swoboda hypothesized that:

1. Physicians who diagnose these illnesses are more likely than non-diagnosing physicians to obtain the best available information for evaluating illness legitimacy;
2. Physicians who diagnose these illnesses combine the results of several evaluation tools for determining diagnosis; and
3. Physicians who diagnose these illnesses reject psychological causation for other explanations of illness etiology.

Swoboda mailed surveys to 800 physicians and received a typical physician mailed survey response rate of 59 percent. Both experts and non-experts surveyed returned questionnaires at comparable rates.

The survey results revealed several findings:

1. A significant portion of physicians in the USA are diagnosing CFS, MCS, and GWS.
2. Experts are more likely than non-experts to diagnose, though non-experts are also diagnosing.
3. Physicians diagnosing CFS, MCS,

and GWS use different rational decision-making strategies, mainly reasoned decision making based on informed assessment of all possibilities.

4. Diagnosing physicians believe they are better able to make diagnoses and help patients because they increase their knowledge beyond conventional sources.

5. In the absence of biological markers, diagnosing physicians draw on many of evaluation tools, including empirical testing, psychological evaluation, treatment efficacy, and patient collaboration.

6. Diagnosing physicians seem to be paving the best practices for how to diagnose these illnesses.

7. Diagnosing physicians seem to take the position that diagnosis via standard pattern recognition will not suffice due to the complex nature and varies symptoms.



“To truly improve, patients need physicians with knowledge and understanding who are willing to tolerate uncertainty.”

As such, physicians can lead to diagnostic certainty by simply making diagnoses, expanding their education, gathering information, and doing in depth evaluations.

Swoboda says, “These practices are also associated with greater doctor-patient collaboration, a practice found to increase patient satisfaction and confidence in medical encounters.”

Isn't that what patients want from physicians? Indeed, isn't that what patients pay for? Patients want to get involved in their care and, most important, get better.

A psychiatric diagnosis with a prescription for cognitive behavioral therapy, for example, is, at best, only a cop-

ing mechanism which will not improve or cure the root illness. This type of “care” is nothing more than a placatory band-aid approach... negligence.

To truly improve, patients need physicians with knowledge and understanding who are willing to tolerate uncertainty, think beyond current disease models, research, and increase their knowledge of emerging illnesses.

It is not uncommon for patients to seek out such clinicians.

Reference

Swoboda DA. Negotiating the diagnostic uncertainty of contested illnesses: physician practices and paradigms. Health (London). 2008 Oct;12(4):453-78.

