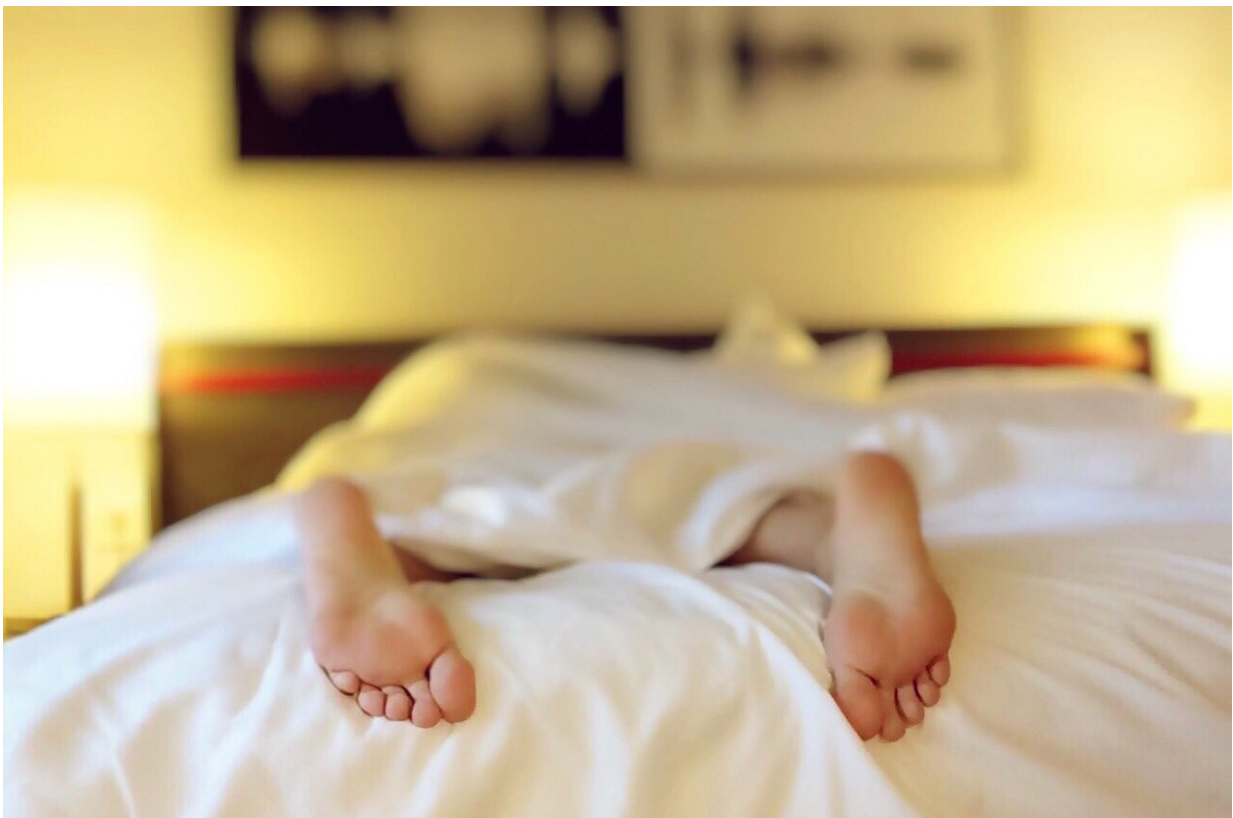


'But you don't look sick': How invisible illnesses like autoimmune disorders impact patient experience

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When your disease is hard to name and doesn't have visible symptoms, it can be hard for others to understand that you are sick. And, when people

don't know much about your disease, it can be hard to explain it to family and friends.

This sentiment is particularly true for the some 50 million people in the United States living with [autoimmune diseases](#), like lupus or multiple sclerosis (MS) —where the condition is chronic but achieving a specific diagnosis may take time, the diagnosis may change, symptoms may not be overtly apparent, and, in many cases, both a cause and a "cure" are unknown.

Patients with autoimmune diseases often have an illness experience riddled with symptom ambiguities and shifting diagnoses. A new Drexel University study found that one way patients and physicians can work through the difficulty and frustration of communicating about these conditions is to use both broad diagnostic terms, like "autoimmune disease," as well as narrow ones, such as "lupus or MS."

Kelly Joyce, Ph.D., a professor in Drexel's College of Arts and Sciences and a member of the Center for Science, Technology & Society, studies the cultural dimensions of medicine. Her research investigates the experiences of people diagnosed with autoimmune illnesses. In analyzing how people live with autoimmune illnesses, Joyce and former Drexel graduate student Melanie Jeske found that the use of a broad category—like autoimmune—provides continuity, certainty and even community for patients who struggle to convey their often-inconsistent illness experiences with clinicians, family and friends.

Drawing on 45 in-depth interviews with people who live with autoimmune illnesses, Joyce's research showed that both broad diagnostic classifications and narrow diagnostic classifications are integral to diagnostic work and illness experiences.

Talking About Illness

Researchers found that participants, regardless of gender, age or specific disease diagnosis, tended to use the broad category "autoimmune" in addition to a specific diagnosis, like Celiac disease or Rheumatoid arthritis, to talk about their health.

Some of the reasons they used the terminology were to describe what's happening in their bodies, and to make it easier to provide continuity, even when there was a change in their specific diagnosis.

"Although friends and families may not understand the precise mechanisms of Lupus or Rheumatoid arthritis, for example, they could understand the general autoimmune process in which the body's immune systems attacks healthy tissue and cells," Joyce said.

The broad term also simplified the process of talking about the disease to friends and family, even as the specific diagnosis might change over time.

"Use of the category 'autoimmune' meant participants did not have to put their lives on hold even as aspects of their specific diagnosis changed from ulcerative colitis to Crohn's disease, from lupus to mixed connective tissue disease (MCT), from one type of MS or lupus to another type of MS or lupus, and from having MS to not having MS to having MS," said Joyce. "Autoimmune, although an umbrella or broad category, is productive for those experiencing illness, lending legitimacy to the symptoms that a person will experience."

It can also help to distinguish their affliction from others that are more stigmatized. One specific example of this was that participants who live with type 1 diabetes—which is an autoimmune disease—who use the broad terminology to distinguish their illness from type 2 diabetes—a chronic condition caused by the body's inability to metabolize sugar—as a way avoiding the stigma and blame often associated with the latter.

Finding Community

Because people can experience the same autoimmune disease differently, participants noted that using "autoimmune" allows them to see similarities between themselves and others— creating a sense of community and shared experience.

"Many participants in our study stressed the heterogeneity of autoimmune illnesses, often saying things like "My MS is not like her MS," or "No two people are alike," Joyce said. "While most participants knew others, who shared their specific diagnosis, it did not mean that their experience of symptoms, their triggers for symptoms, or their responses to particular treatments were similar."

Raising Awareness

Research has shown that people who are ill can benefit from social support when their disease is widely recognized. For example, there is often an outpouring of support during the various cancer and disease awareness months and efforts—both broadly in society and at an individual level. This unifying support can be difficult for illnesses like autoimmune disease that is not as well understood in society.

The researchers suggest that recognizing that autoimmune can be a range of diseases and disorders—similar to the way we think about the autism spectrum—could aid our collective understanding of these diseases and support for those who are suffering from it.

Why Broad Categories are Important

More than 80 illnesses are considered to be autoimmune or autoimmune-related. Though the illnesses under the umbrella vary widely, the

common thread is an immune response that attacks healthy cells, tissue and/or organs. The study suggests that the label autoimmune provides, at minimum, some understanding and a scientific explanation as to what is happening to patients, though an exact diagnosis may be a moving target.

While this research focuses specifically on autoimmune illnesses, it does signal that broad and narrow categories may be important to medicine more generally.

"Within medicine, clinicians and researchers use the language of lumping and splitting to distinguish between two valuable diagnostic classification practices," said Joyce. "The process of lumping creates broad categories and emphasizes connections. In contrast, splitting emphasizes the differences between illnesses—creating categories that tend to be narrow and more specialized, prioritizing difference rather than similarity."

Sociologists study how clinical encounters and medical practice are social practices, that is, practices imbued with values, beliefs, and institutional and policy incentives. Yet, many sociologists who study diagnostic practices have yet to acknowledge the importance of broad categories in diagnostic work, according to Joyce.

"They focus on how clinicians and patients use narrow diagnostic labels, missing the importance of broad categories," she said. "Sociologists who study how people live with illnesses tend to focus on life after a specific diagnosis, so they have also paid little attention to the importance of broad categories in medical practice."

Now That We Know

In light of her findings, Joyce suggests clinicians should consider presenting patients with both broad and narrow disease classifications

when discussing autoimmune diagnoses initially and over time.

The use of the broad category may provide continuity and certainty in doctor-patient communications even as narrow [disease](#) diagnoses change or when symptoms do not map neatly into diagnostic tests or markers.

Some health care organizations are taking the lead and reorganizing the delivery of services in recognition of the changing diagnoses and, at times, unknowable, dimensions of autoimmune illnesses. As an example of this reorganization, West Penn Hospital in Pittsburgh, Pennsylvania opened the first institute dedicated to autoimmune illnesses in February 2018.

In the excitement over precision medicine, Joyce notes this study shows the importance of maintaining the use of broad categories in the experience and treatment of [illness](#) as well as using narrow diagnostic labels.

The full study is available in *Social Science & Medicine*.

More information: Kelly Joyce et al. Using autoimmune strategically: Diagnostic lumping, splitting, and the experience of illness, *Social Science & Medicine* (2020). [DOI: 10.1016/j.socscimed.2020.112785](https://doi.org/10.1016/j.socscimed.2020.112785)

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