

Study finds 'startling' levels of hidden mental health symptoms among people living with long-term autoimmune diseases

July 25 2023



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More than half of patients with auto-immune conditions experience mental health conditions such as depression or anxiety, yet the majority

are rarely or never asked in clinic about mental health symptoms, according to new research from the University of Cambridge and King's College London.

In a study published today in *Rheumatology*, researchers found that over half of the patients had rarely or never reported their mental health symptoms to a [clinician](#), and that the range of possible mental health and [neurological symptoms](#) is much wider than has been previously reported.

The team surveyed neurological and psychiatric symptoms among 1,853 patients with systemic auto-immune rheumatic diseases (SARDs) such as lupus and rheumatoid arthritis. The researchers also surveyed 289 clinicians, mostly rheumatologists, psychiatrists and neurologists, and conducted 113 interviews with patients and clinicians.

The 30 symptoms that the team asked about included fatigue, hallucinations, anxiety and depression. Among the patients in the study, experience of most of these symptoms was very widespread.

The study found that 55% of SARD patients were experiencing depression, 57% were experiencing anxiety, 89% had experienced severe fatigue and 70% had experienced cognitive dysfunction, for example. The overall prevalence of symptoms was significantly higher than previously thought, and much higher than in a control group of healthy volunteers.

The mental health symptoms described by patients contrasted strongly with clinician estimates. For example, three times as many lupus patients reported experiencing [suicidal thoughts](#) compared to the estimate by clinicians (47% versus 15%). Clinicians were often surprised and concerned by the frequency and wide range of symptoms that patients reported to the researchers.

Some clinicians were much more focused on joint symptoms over mental health symptoms as they held the opinion that SARDs do not commonly affect the brain.

However, other clinicians felt that these symptoms were underestimated because patients were rarely asked about them in clinic. One rheumatology nurse interviewed said, "Doctors don't go looking for it [hallucinations], so if we don't ask we don't think it exists much."

The study found disagreements between clinicians specializing in different aspects of care, but very few hospitals had effective systems where rheumatologists, neurologists and psychiatrists worked together.

Dr. Tom Pollak from the Institute of Psychiatry, Psychology & Neuroscience at King's College London, said the study highlights the importance of all clinicians asking their patients about mental health: "We have known for some time that having a systemic autoimmune disease can negatively affect one's mental health, but this study paints a startling picture of the breadth and impact of these symptoms. Everyone working in health care with these patients should routinely ask about mental well-being, and patients should be supported to speak up without fear of judgment. No patient should suffer in silence."

The study showed that patients were often reticent to report to clinicians [mental health problems](#) they might be having, sometimes feeling that they might be stigmatized. Patients frequently said that even when they did share their mental health symptoms with clinicians, they were often not commented on or not documented accurately or at all.

One patient expressed how this felt: "Feel guilty and useless as well as depressed and very unwell. I don't really feel supported, understood, listened to, hopeful at all. It is awful living like this.... All just feels hopeless."

Dr. Melanie Sloan, from the Department of Public Health and Primary Care at the University of Cambridge, said, "The low level of reporting we identified is a major concern as problems with mental health, fatigue and cognition can be life-changing, and sometimes life-threatening. It's only by fully engaging patients in their health care and by asking them for their views that we will be able to determine the extent of these often hidden symptoms, and help patients get the understanding, support and treatment they need."

The research team suggests that though they found neurological and psychiatric symptoms to be under-elicited in clinic, under-identified in research and under-represented in clinical guidelines, they described almost all clinicians as highly motivated to improve care. Rapidly evolving knowledge—including the behavioral and cognitive impacts of chronic inflammation and a widening range of potential biomarkers—means that there is grounds for optimism.

Sarah Campbell, Chief Executive of the British Society for Rheumatology, commented, "This study highlights the urgent need for improvements in the access patients have to integrated mental health support. Given what the study finds on the prevalence of this issue and the deep impact neurological and [psychiatric symptoms](#) have on patients, it should be of grave concern to [policy makers](#) that only 8% of rheumatology departments in England and Wales have a psychologist embedded in their team. We fully support the study team's conclusion that more inter-disciplinary and patient-clinician collaboration is needed to ensure equity in the care of patients' mental and physical health."

The Rt Hon the Lord Blunkett said, "It's both surprising and deeply concerning that almost half of lupus patients have experienced suicidal thoughts, and that clinicians greatly underestimate the mental health burden of these chronic diseases. This highlights the importance of extra funding for the NHS and the holistic care that is urgently needed for

these patients. I echo the British Society of Rheumatologists' concerns about the poor current provision of [mental health](#) support. Now is the time for the Government to act to give them the support they desperately need."

More information: Sloan, M et al. Prevalence and identification of neuropsychiatric symptoms in systemic autoimmune rheumatic diseases: an international mixed methods study, *Rheumatology* (2023). [DOI: 10.1093/rhe/kead369](#)

Provided by University of Cambridge

Citation: Study finds 'startling' levels of hidden mental health symptoms among people living with long-term autoimmune diseases (2023, July 25) retrieved 27 April 2024 from <https://medicalxpress.com/news/2023-07-startling-hidden-mental-health-symptoms.html>

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