

Psychology

Overcoming this is going to be difficult: Suicide risk, stigma, and chronic fatigue syndrome

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Chronic fatigue syndrome is a debilitating illness that affects 1.5 million Americans. Because it is linked with higher risks of suicide, scientists are seeking strategies that may prevent suicide in these patients. In this study, we learned that reducing the surrounding stigma may be one crucial strategy.



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Suicide claims over 800,000 lives per year. Each suicide leaves behind an average of 6 suicide survivors, who often ponder what could have been done to prevent such a tragedy. Many times, conversations about preventing suicide revolve around treating people's mental health. Indeed, while conditions like depression increase one's risk for suicide, not everyone who dies by suicide has a diagnosable mental health condition.

Other factors, like having a chronic illness, may increase suicide-related death. In fact, research finds higher rates of suicide among people with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS), even when considering mental

health conditions. So, what additional factors increase suicide risk among people with ME or CFS?

ME and CFS are debilitating illnesses that are characterized by profound fatigue, unrefreshing sleep, memory difficulties, and feeling worse after mental and physical activities. These symptoms do not only occur during stressful periods, like a college finals week, and then disappear with normal rest. Instead, patients with these illnesses show symptoms for consecutive months, even years, which do not readily subside.

An estimated 1.5 million Americans have ME or CFS, but most people are unaware that these illnesses even exist. As a result, and since the symptoms of

these illnesses are invisible to the naked eye, patients commonly encounter stigma when explaining their illness to others. Many patients report being called “lazy” by family and friends. Furthermore, patients with ME or CFS are less likely to be believed, supported, and provided appropriate treatments by healthcare providers when compared to patients with similar – but more well-known – chronic illnesses.

Given these stigmatizing experiences, coupled with the already challenging nature of ME and CFS, our team at DePaul University wondered if these factors co-occurred with suicidal thoughts among patients. We explored this question by analyzing open-ended text responses from 29 patients with ME or CFS, who reported having suicidal thoughts while but not clinical depression – suggesting that factors other than depression could explain their suicidal ideation. In order to recognize patterns across the data, we classified patients’ responses into themes. For example, we classified the response as “hopelessness,” when a patient wrote, “Overcoming [ME and CFS] is going to be difficult and probably won’t happen in my lifetime.”

Our findings revealed two broad themes in patients’ experiences with ME and CFS and suicidal ideation. The first theme captures how patients felt trapped by their illness. Many patients said they had no access to adequate resources, like a supportive friend or physician, to help them manage their illness. This sentiment was coupled with feeling hopeless about recovering from their disorder. Patients stated that many physicians wrongly think that ME and CFS are mental health conditions – when they are physical illnesses – which leads

physicians to recommend inappropriate treatments like talk therapy. One patient responded:

“It is truly shocking in this day and age to hear that young doctors...learn about ME/CFS through their Psychiatric Disorders lessons....ME/CFS is not a psychological illness.”

The second theme highlights the personal and social tolls of ME and CFS. Patients mourned losing their identities to their illness, often noting how ME and CFS took away their professions, abilities, and sense of self. Patients reflected that when they could not fulfill their usual roles, due to their illness, they were commonly blamed and criticized. As a result, many patients lost their social networks and felt misunderstood. One patient noted:

“When my health improves, I am the person who remembered names, faces and dates. When I relapse [to ME and CFS], I am unable to do this, I have been called unhelpful, stubborn and selfish.”

These findings give clues on ways to help reduce suicide risk in ME and CFS. They suggest that providing patients with social support and an ear interested in learning about their illness can go a long way. Recognizing that ME and CFS are legitimate illnesses – and not something that people can just “snap out of” – can validate patients’ experiences.

The more the public displays support for ME and CFS, through advocacy and having knowledge about these illnesses, the more likely patients will feel heard, supported, and hopeful. These small actions can bear immense, possibly lifesaving outcomes, and may be more important than ever now, because long-haul COVID-19 might increase the risk of developing ME and CFS. [Visit this link to learn more.](#)