



## Commentary

# The Importance of Screening for Suicide Risk in Chronic Invisible Illness

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### Abstract

Many people suffering from chronic invisible illnesses like chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), fibromyalgia, Lyme disease, and postural orthostatic tachycardia syndrome (POTS) report increased suicidal ideation and past suicide attempts compared with the general population. A number of factors contribute to suicide risk in chronic illness. Physical factors, like sleep disturbance and pain, as well as psychosocial issues like perceived burdensomeness (feeling like a burden to others), thwarted belongingness (lack of connection to a social group), loneliness, and depression may contribute to an increased suicide risk. Healthcare practitioners are encouraged to actively screen for suicide risk in their chronically ill patients, and have a protocol in place to refer their patients to proper community resources.

**Keywords:** Chronic illness; Invisible illness; Suicide risk; Suicide screening

## Understanding Chronic Invisible Illness

Millions of people around the world suffer from chronic invisible illnesses, in which symptoms tend to be nonspecific and traditional testing often fails to detect abnormalities. These include chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), Ehlers-Danlos syndrome, fibromyalgia, Lyme disease, mast cell activation disorder, and postural orthostatic tachycardia syndrome (POTS), among others. Because little is known about the etiology of these disorders, family, friends, and healthcare practitioners often disregard complaints of fatigue, abdominal pain, muscle or joint pain, dizziness, cognitive impairments, headaches, and sensitivities to light, sound or smell as being “all in your head.” Further exacerbating the problem, the vast majority of people with these chronic invisible illnesses are women [1-4], who have historically been labeled as hysterical when presenting with psychogenic symptoms [5].

Quality of life can be severely diminished in people suffering from chronic invisible illnesses. General health, bodily pain, sleep, and physical and social functioning are all significantly impaired in people with these disorders [6-10]. In particular, various pain conditions - neuropathic pain, migraine headaches, abdominal pain, muscular pain and joint pain - significantly decrease quality of life for many with chronic invisible illness [7,10,11]. Orthostatic intolerance symptoms (e.g. lightheadedness, brain fog, and palpitations) can also lead to both depression and diminished quality of life [12]. Patients often restrict their physical activity due to poor health, and a significant minority of chronically ill people require help for activities of daily living [7,9,10]. In POTS, 25% of these typically young, highly educated women are so disabled that they are unable to work or go to school [6], and a study of fibromyalgia patients found a 58% work impairment, which included both hours missed and decreased productivity while at work [9]. Further, the quality of life for POTS

patients is comparable to those with rheumatoid arthritis, end-stage renal disease [13], congestive heart failure, and chronic obstructive pulmonary disease [6]. This level of impairment significantly decreases quality of life for those with chronic invisible illnesses, despite healthy outward appearances.

Many chronically ill people require more personal care and have less social interaction than most their age, which may increase risk factors for suicide. Often, these illnesses limit mobility and stamina so that even teens and young adults require assistive devices (e.g., wheelchair, shower chair, and handicap placard). Because of their healthy outward appearance and the multitude of hidden symptoms, patients are often accused of being lazy, anxious, or physically deconditioned from lack of exercise [14]. Requiring assistance for daily personal tasks like bathing and dressing can be humiliating and may also lead to a sense of perceived burdensomeness - feeling like a burden to family and friends [15]. Even within their support system, misunderstandings about the level of illness and disability can lead to social isolation and thwarted belongingness, the feeling that one does not fit into a social group [16]. According to the interpersonal theory of suicide, an increased sense of perceived burdensomeness and thwarted belongingness can increase the risk of suicide [17].

Nearly half of people with chronic illness and/or chronic pain are reported to suffer from depression [18,19], especially if they have autoimmune disorders or high levels of inflammation [20]. However, most depression assessments include a significant number of questions related to somatic complaints (appetite, sleep disturbance, fatigue, ability to work) that can be explained by physical illness rather than depression in this population [21]. Chronically ill patients are often misdiagnosed as depressed or anxious prior to receiving the correct physical diagnosis [22]. Items on self-report depression scales should be divided into somatic and affective

symptoms, with depression diagnosed only when there is an elevation in the affective portion of the assessment in a chronically ill patient [21]. Depression can be co-morbid with chronic illness [23-25], and must be taken seriously.

Suicide is a major cause of death in many chronic illness communities. Physical illness and functional disability are known risk factors for suicide [26-28], and having multiple physical illnesses significantly increases suicide risk [29]. In POTS, 50-65% of patients are at high risk for suicide [7,24], whereas in fibromyalgia, 33% of patients experience suicidal ideation [30]. In CFS/ME, the second leading cause of death is suicide, with approximately 20% of patients dying in this way [31,32]. In the United States, there are an estimated 1,200 suicides per year from Lyme disease [33]. Taken together, these data confirm that suicide is a problem for the chronic illness community, and more must be done to understand both why suicidal ideation is increased and to treat the underlying risk factors.

Chronic pain is common among those with chronic invisible illness like CFS/ME, Ehlers-Danlos syndrome, fibromyalgia, Lyme disease, and POTS, and is an important factor in suicide risk [34]. More than half of people with POTS report neuropathic pain [1], and others suffer from frequent headaches and abdominal pain [35]. Pain can interfere with activities of daily living, eventually making the person feel less in control of his/her own life [7]. People with chronic and/or frequent intermittent pain conditions (i.e. migraine headaches, abdominal pain) are at increased risk for suicide [36], with 25% of chronic pain patients reporting suicidal thoughts [36]. Chronic pain has been linked to both increased suicidal ideation and suicide attempts [37] as a result of increased levels of perceived burdensomeness, thwarted belongingness, hopelessness, pain catastrophizing, and mental defeat [36].

Sleep disturbances, including non-restorative sleep and insomnia, are typical for many with chronic illness. Nearly all patients with these chronic invisible illnesses report poor sleep and concomitant high rates of fatigue [3,8,38,39], which significantly diminishes quality of life [40]. Many chronically ill people visited a physician for help prior to attempting suicide, and those at highest risk of making an attempt had sleep disorders, HIV, and/or traumatic brain injury [29]. This highlights the need for better diagnosis and treatment of sleep problems to potentially decrease the likelihood of suicide [41].

Among the physically ill, many who are considering suicide have no mental health diagnosis [29]. While suicidal thinking is often thought to be a result of depression, in chronic illness suicide can be a response to suffering from the chronic illness itself, or a mechanism to permanently relieve physical and emotional distress [42]. Many with chronic invisible illnesses describe life weariness, in which they are tired of living in their current state but do not necessarily want to die [43]. Additionally, negative treatment by healthcare practitioners can increase feelings of hopelessness and suicide risk in the chronically ill [31], further exacerbating the problem. Specifically, such treatment may induce a progression in psychological distress that leads to thoughts of suicide. Lack of social support may develop as weeks of illness turn to months and years. This isolation may lead to feelings of perceived burdensomeness over time, which can

lead to depression and insomnia and, eventually, suicidal ideation [24,41,44,45]. For people with chronic pain, suicide risk may be more related to psychosocial factors such as perceived burdensomeness, thwarted belongingness, and hopelessness than the physical symptoms per se [24,34,36]. Several studies have demonstrated that perceived burdensomeness can be more important than thwarted belongingness [24,41] and loneliness [17] in suicidal ideation. Loss of financial stability and relationships can also increase suicide risk [46].

### **Strategies to prevent suicide in chronic illness populations**

Believing people when they describe their chronic invisible illness is one key to decreasing suicide risk. By definition, the individual looks healthy on the outside, and as a result, it is common for people to doubt the seriousness of their illness. In recent years, physical anomalies have been found that might increase the credibility of these disorders for both healthcare practitioners and the general public. For example, autoantibodies and other physical markers have been identified for CFS/ME [47,48], Lyme disease [49,50], and POTS [51,52]. The demonstrated presence of autoantibodies in some of these disorders indicates that they may be autoimmune [51,53]. However, research on the etiology of chronic invisible illnesses is in its infancy. As a result, many healthcare practitioners still do not believe that these illnesses are physical in nature. The disconnect between what the chronically ill person experiences and the lack of validation from their healthcare practitioners, friends, and family can leave her/him feeling depressed, hopeless, and alone [54]. It is important that healthcare practitioners believe their patients, validate their symptoms, and work with the patient to find treatments that will improve their quality of life.

There are opportunities to identify and help chronically ill patients at high-risk for suicide before they make an attempt. The healthcare community, in particular, could decrease suicide attempts in this population through compassionate care and routine screening for suicide risk. Of those who attempt suicide, 64% visited a healthcare practitioner in the month before the attempt and 38% visit the week prior [55]. Thus, adding a suicide screening to current online questionnaires or topics to discuss during the appointment is appropriate. In addition, healthcare practitioners should develop a protocol to address suicidal risk and/or behavior when it is discovered. This protocol might include gathering contact information for local social workers, counselors, and suicide support groups that understand the specific vulnerabilities of the chronically ill population. Free resources like the National Suicide Prevention Lifeline (1-800-273-TALK) or Hopeline (741741 and text "start") could be included in a packet of information given to patients with increased risk. In larger clinics or hospitals, training mental health staff to address issues surrounding perceived burdensomeness, depression, thwarted belongingness and loneliness experienced by the chronically ill could go a long way to decreasing suicidal risk [24].

A conversation about suicide can be scary for healthcare practitioners who do not routinely deal with mental health issues in their practice. Many practitioners may feel that they do not have time to address suicidal ideation or are concerned

about liability issues, which results in their ignoring signs of suicide risk. Despite these concerns, it is important for healthcare practitioners to take a few minutes during the appointment to ask basic questions about suicide risk. Uncovering and more aggressively treating sleep disturbances [8,56], pain [36,57], depression, and fatigue [58] might help to decrease suicide risk in chronically ill patients. The healthcare practitioner does not have to be responsible for treatment, but rather refer that person to appropriate community resources to get the necessary assistance.

Identifying suicidal ideation and suicide risk during routine medical care also gives time for counselors, family, and friends to intervene. A trained mental health practitioner can utilize mindfulness-based stress reduction, cognitive behavioral therapy, and/or acceptance and commitment therapy to treat aspects of chronic pain, depression, and anxiety that accompany the illness [27,59]. In order to directly address suicidal ideation, mental health practitioners can use the Dialectical Behavior Therapy [60] and/or Collaborative Assessment and Management of Suicidality [61] techniques. If available, group interventions may be especially helpful in reducing the stigma and isolation that can result from the diagnosis of a chronic invisible condition [27]. Mental health practitioners can help caretakers better understand their loved one's needs and work to make interactions more positive [27]. Decreasing feelings of perceived burdensomeness by providing positive life events - such as playing cards, sharing a special meal, or spending time together at home - can increase social interaction without physically taxing the chronically ill individual [24]. Suicide risk can also be decreased by encouraging family and friends to stay in contact via text, phone, or home visits to promote social interaction and foster a sense of belonging [27,62,63].

## Conclusion

People with chronic invisible illnesses are at higher risk of suicide than the general population. This increased risk may be related to physical symptoms such as frequent or chronic pain or sleep disturbance. However, it appears that psychological factors like perceived burdensomeness, hopelessness, and depression may outweigh physical factors. Healthcare practitioners should develop protocols for referring patients with increased suicide risk to qualified mental health practitioners, while also aggressively treating the physical aspects underlying that risk.

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