

In: Understanding Suicidal Ideation
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Chapter 6

UNDERSTANDING SUICIDAL IDEATION IN PEOPLE WITH CHRONIC INVISIBLE ILLNESS

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ABSTRACT

Recent studies have demonstrated increased suicidal ideation and suicide attempts in the chronic illness community compared with the general population. Suicidal ideation is common in people who have been diagnosed with a variety of chronic invisible illnesses like chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), Ehlers-Danlos syndrome, fibromyalgia, chronic Lyme disease, and postural orthostatic tachycardia syndrome (POTS). Numerous physical and psychosocial factors can contribute to suicidal ideation in this population. Physical factors, like sleep disturbance and pain, are common in chronic illness. Psychosocial issues, such as perceived burdensomeness (feeling like a burden to others), thwarted belongingness (lack of connection to a social group), hopelessness, and depression, may also contribute to an increased suicide risk in people with chronic invisible illness. More research is needed to better understand the underlying risk factors for suicidal ideation in this population. Putting suicide prevention programs in place that will target this under-represented group of physically ill patients is also necessary.

There are a variety of chronic invisible illnesses that significantly decrease quality of life and can ultimately increase the risk of suicide. These include chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), Ehlers-Danlos syndrome, fibromyalgia, chronic Lyme disease, and postural orthostatic tachycardia syndrome (POTS). People with these conditions often have a myriad of significant physical problems, including bodily pain, poor general health, sleep, and physical and social functioning (Pederson & Brook, 2017a; Schmaling & Betterton, 2016).

Despite healthy outward appearances, the level of impairment for many with chronic invisible illnesses significantly decreases their quality of life. Tasks that involve concentration and memory, such as conversing, reading and watching television, are negatively affected by chronic illness, thereby affecting relationships, employability and leisure (Horton et al., 2010). In addition, functional disability is also a concern as most patients report activity limitations due to symptoms, and a significant minority require assistance with the activities of daily living (Pederson & Brook, 2017a). As a result, these chronically ill patients may be stigmatized in the workplace and at home, pressured to downplay their symptoms, and become afraid of triggering a symptom flare from subsequent over-activity (Horton et al., 2010).

Little is known about the etiology of these disorders, leaving many practitioners and loved ones to disregard complaints of fatigue, pain, dizziness, cognitive impairments, headaches and sensitivities to light, sound or smell as being “all in your head.” These symptoms are typically difficult to quantify. Further exacerbating the problem, the vast majority of people with chronic invisible illnesses are women (Arout, Sofuoglu, Bastian, & Rosenheck, 2018; Boris & Bernadzikowski, 2018), who have historically been labeled as hysterical when presenting with psychogenic-type symptoms (Gould, Miller, Goldberg, & Benson, 1986).

Research into the etiology of these disorders is in its infancy. Many chronic invisible illnesses appear to develop following infection (Fedorowski, 2019), human papilloma virus vaccination (Blitshteyn, Brinth, Hendrickson, & Martinez-Lavin, 2018) or concussion (Miranda, Boris, Kouvel, & Stiles, 2018). There is growing evidence that a

significant subset of people with CFS/ME (Loebel et al., 2016), fibromyalgia (Jeong, Kim, Park, Park, & Kim, 2019), chronic Lyme disease (Arvikar, Crowley, Sulka, & Steere, 2017), and POTS (Ruzieh, Batizy, Dasa, Oostra, & Grubb, 2017) may have autoimmune underpinnings that explain their illness. We must fund research on these chronic illnesses in order to understand their etiology and develop better treatment regimens for affected individuals.

ELEVATED RISK: PSYCHOLOGICAL SYMPTOMS

Psychosocial factors can be significant predictors of suicidal ideation. In the general population, depression is an important risk factor for suicide. In the chronic illness community, however, other factors like perceived burdensomeness, hopelessness, and acquired capability for suicide appear to be more important in understanding suicidal ideation and attempts.

Depression

Chronically ill patients are often misdiagnosed with clinical depression and/or anxiety prior to receiving their correct physical diagnosis of CFS/ME, POTS, or another chronic invisible illness (Kavi et al., 2016). There is significant overlap between the physical symptoms of these chronic illnesses and the somatic complaints often attributed to depression and anxiety. Most psychological instruments include questions related to somatic complaints (appetite, sleep disturbance, fatigue, and ability to work) that can be explained by physical illness rather than depression in this population (Pederson, Gorman-Ezell, & Mayer, 2018). In addition, orthostatic symptoms like heart palpitations, lightheadedness, nausea and chest discomfort may be misinterpreted as anxiety (Raj, Opie, & Arnold, 2018). In fact, POTS patients do not have higher current or lifetime prevalence of clinical anxiety or major depressive disorder than the general population (Raj et al., 2018). Furthermore, a study of CFS/ME patients

found that suicidal individuals were not typically depressed, but rather felt trapped by their illness and the lack of viable treatments (Devendorf, McManimen, & Jason, 2019).

That said, nearly half of individuals with chronic illness and/or chronic pain do suffer from depression (Alderson, Foy, & House, 2015; Nicholas, 2011), especially if they have autoimmune disorders or high levels of inflammation (Caneo, Marston, Bellón, & King, 2016). Depression and poor sleep are linked, with one study finding that 85% of patients who met the criteria for major depressive disorder also had clinically significant sleep disturbances (Zimmerman, Ellison, Young, Chelminski, & Dalrymple, 2015). When depression is correctly diagnosed in a chronically ill patient, it must be aggressively treated to improve their quality of life and decrease their risk of suicide.

Perceived Burdensomeness and Thwarted Belongingness

Many chronically ill people require more personal care and have less social interaction than their peers, which may increase suicidal ideation. Their illnesses drastically limit mobility and stamina to the point where teens and young adults require daily assistance for basic personal tasks like bathing and dressing. In addition, they may also require assistive devices (e.g., wheelchair, shower chair, and handicap placard). This can be humiliating and may also lead to a sense of perceived burdensomeness - feeling like a burden to family and friends (Khazem, 2018). Despite their need for assistance and the plethora of symptoms, they often have a healthy outward appearance and patients are often accused of being lazy, anxious or physically deconditioned (Stiles, Cinnamon, & Balan, 2018). Even within their support system, this misunderstanding 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 (You, Van Orden & Conner, 2011). When life experiences vary significantly from the norm, it can be hard to connect with other people in a meaningful way.

The interpersonal theory of suicide – that perceived burdensomeness and thwarted belongingness may increase suicidal ideation (Joiner, 2005) - may be relevant to the chronic illness community. Perceived burdensomeness is elevated in chronic pain populations (Kanzler, Bryan, McGeary, & Morrow, 2012) and can increase the risk of suicide (Wilson et al., 2017). In one study of POTS patients, 30% required assistance for basic personal care (Pederson & Brook, 2017a). This type of functional disability may lead to feelings of perceived burdensomeness and thwarted belongingness that can eventually lead to suicidal ideation. In those with chronic invisible illnesses, perceived burdensomeness is a stronger predictor of suicidal ideation than depression, thwarted belongingness, or loneliness (Pederson & Brookings, 2018).

Acquired Capability for Suicide

The acquired capability for suicide is perhaps one of the most important recent concepts in suicide research (Bauer, Martin, Allan, Fink-Miller, & Capron, 2018) and encompasses a person's diminished fear of pain, injury and death over time (Joiner, 2005). People can habituate to pain tolerance with practice. Therefore, those who self-harm may have a higher pain tolerance which may make transitioning from thinking about suicide to making an attempt more feasible (Koenig, Thayer, & Kaess, 2016). In essence, this theory proposes that the physical and psychological pain that accumulates over time can increase the likelihood of moving from suicidal thoughts to attempts (May & Victor, 2018).

Not all research supports this idea of acquired capability for suicide, however. One study found that neither age nor accumulating painful events have a significant effect on the acquired capability for suicide (Bauer, et al., 2018). Instead, some stages of development (teens and young adults) may be more vulnerable to quickly developing an acquired capability for suicide despite a relatively small number of painful events (Bauer, et al., 2019). Unfortunately, the acquired capability for suicide is not a strong

predictor for differentiating between suicide attempters and non-attempters (Burke, Ammerman, Knorr, Alloy, & McCloskey, 2018).

Hopelessness

Hopelessness is a risk factor for suicidal ideation, attempt and death by suicide (Ribeiro, Huang, Fox, & Franklin, 2018). In the chronic illness community, many have lost hope that their symptom load will improve naturally or that new treatment options will soon be developed (Devendorf, et al., 2019). This hopelessness is often due to their specific circumstances (illness, financial ramifications, etc.), rather than depression (Devendorf, et al., 2019). The duration and intensity of the hopelessness is also important. Patients with longstanding hopelessness have increased suicidality compared with those who felt that their hopelessness was more temporary (Burr, Rahm-Knigge, & Conner, 2018). In young women, a small increase in hopelessness can lead to a significant increase in suicidal ideation (Wolfe, et al., 2019). A positive correlation between hopelessness and lethality of the suicide attempt has also been shown (Jaiswal, Faye, Gore, Shah, & Kamath, 2016).

Hopelessness may directly relate to other psychological factors that increase suicidality. Perhaps hopelessness is the link that can explain why some people with depression consider suicide while others do not (Jaiswal, et al., 2016). In addition, feeling hopeless about perceived burdensomeness and thwarted belongingness may be important in explaining suicidal ideation and suicide risk (Tucker, et al., 2018). Unfortunately, hopelessness is not particularly useful in separating suicide attempters from non-attempters (Qiu, Klonsky, & Klein, 2017).

ELEVATED SUICIDE RISK: POTENTIAL PHYSICAL CAUSES

It is important to recognize that suicidal ideation in this population is not always related to psychological factors alone. There are well-

documented physical challenges that may increase the risk of suicidal ideation or attempt in a chronically ill person. The illness itself, with a high symptom load and functional disability, can increase the risk of suicidal ideation. Chronic pain and sleep disturbances also increase risk. Recognition and aggressive treatment of these symptoms can help to improve quality of life and decrease suicide risk.

Chronic Illness

Suicide is prevalent in many chronic illness communities. Physical illness and functional disability are known risk factors for suicide (Cheung & Sundram, 2017; Pederson, 2018), and those with multiple physical illnesses are at significantly higher risk (Ahmedani, et al., 2017). In a large study of suicide attempters, 50% suffered from a physical illness. Of these, 42% reported that their physical illness played into their decision to attempt suicide (De Leo, et al., 1999). Suicide is the second leading cause of death for those with CFS/ME, with approximately 20% dying by suicide (Jason, Corradi, Gress, Williams, & Torres-Harding, 2006; Smith, Noonan, & Buchwald, 2006). Nearly half of POTS patients are at high risk for suicide, with 15% reporting a previous attempt (Pederson & Brook, 2017a). In those with fibromyalgia, 33% of patients experience suicidal ideation (Triñanes, González-Villar, Gómez-Perretta, & Carrillo-de-la-Peña, 2015), while 4% of people with hypermobile Ehlers-Danlos syndrome had attempted suicide (Cederlöf, et al., 2016). In the United States alone, approximately 1,200 patients with Lyme disease die by suicide each year (Bransfield, 2017). Clearly, suicide is a major concern for the chronic invisible illness community.

Among the physically ill, many who are considering suicide have no mental health diagnosis (Ahmedani, et al., 2017). While 40% of those with CFS/ME report suicidal ideation, nearly half of those did not meet the criteria for clinical depression (McManimen, McClellan, Stoothoff, & Jason, 2018). While suicidal thinking in the general population is often linked with depression, in the chronically ill population suicide can be a

response to suffering from the chronic illness itself or a mechanism to permanently relieve physical and/or emotional distress (Alderson, Foy, Glidewell, McLintock, & House, 2012). Many patients who consider suicide do not want to die, but they do not want to continue living in their current state of illness (Newton-John, 2014).

Chronic Physical Pain

Chronic pain is common among those with chronic invisible illness. This pain can present in a variety of ways – migraine headaches or neuropathic, abdominal, muscular, and/or joint pain – and significantly decrease quality of life (Martín, et al., 2017; Pederson & Brook, 2017a; Schmaling & Betterton, 2016). Fibromyalgia is characterized by widespread pain lasting more than three months (Wolfe, et al., 1990). In CFS/ME patients, pain is pervasive and significantly associated with decreased overall functioning and quality of life (Strand, et al., 2019). People with chronic Lyme disease suffer with generalized musculoskeletal pain (Ranque-Garnier, Eldin, Sault, Raoult, & Donnet, 2019). One small study of people with hypermobile Ehlers-Danlos syndrome found that nearly all reported chronic pain, including joint and neuropathic pain (Bénistan & Martinez, 2019). In POTS, more than half report neuropathic pain, in addition to those with frequent headaches and abdominal pain (Deb, Morgenshtern, Culbertson, Wang, & DePold Hohler, 2015).

Chronic pain has been linked to both increased suicidal ideation and suicide attempts (Legarreta, Bueler, DiMuzio, McGlade, & Yurgelun-Todd, 2018). Pain can interfere with activities of daily living, eventually diminishing the feeling of control over their own lives (Pederson & Brook, 2017a). This can lead to increased perceived burdensomeness, thwarted belongingness, hopelessness, pain catastrophizing, and mental defeat often found in chronic pain patients (Racine, 2017).

People with chronic and/or frequent intermittent pain conditions (i.e., migraine headaches, abdominal pain) are at increased risk for suicide, with 25% of chronic pain patients reporting suicidal thoughts (Racine, 2017). In one study of people with a variety of chronic pain conditions, 19% reported current passive suicidal ideation, and another 13% reported active thoughts of suicide. Of these, 5% currently had a plan for suicide, and 5% had previously made an attempt (Smith, Edwards, Robinson, & Dworkin, 2004). In the CFS/ME community, 21% reported that their overwhelming physical pain increased their suicidal ideation (Devendorf, et al., 2019).

Sleep Disturbance

Sleep disturbances, including non-restorative sleep and insomnia, are typical for many people with chronic illness. Sleep disturbance is a common symptom in people with CFS/ME (Owen-Smith, et al., 2019), Ehlers-Danlos syndrome (Muriello, et al., 2018), fibromyalgia (Calandre, et al., 2015), chronic Lyme disease (Bransfield, 2018), and POTS (Pederson & Brook, 2017b). Nearly all of these patients report poor sleep and excessive fatigue that negatively impact their quality of life (Bagai, et al., 2016).

Sleep disturbance is one of the most important clinical risk factors for suicide prior to making an attempt (Ahmedani, et al., 2017). Sleep disturbance is related to increased suicidal ideation in patients with CFS/ME (Owen-Smith, et al., 2019), fibromyalgia (Calandre, et al., 2015), and POTS (Pederson & Brook, 2017b). Both insomnia and regular nightmares can independently increase suicide risk (Drapeau, et al., 2019). Loss of sleep may negatively impact neurocognitive performance and increase impulsivity the following day. These cognitive changes may result in an unplanned suicide attempt (Porrás-Segovia, et al., 2019). Together, these highlight the need for better diagnosis and more aggressive treatment of sleep disturbances in an effort to improve quality of life and decrease suicide risk (Zullo, et al., 2017).

Quality of Life

Many with chronic invisible illnesses have a severely diminished quality of life as a result of chronic pain, sleep disturbances, fatigue and a myriad of other physical symptoms that impact all facets of their life (Mu, et al., 2019). Functional disability caused by chronic illness can increase isolation, perceived burdensomeness, and depression (Fässberg, et al., 2016). Many feel trapped by their illness and a lack of the personal and medical support that they need to thrive (Devendorf, et al., 2019).

Employment may be difficult for those who suffer from these invisible illnesses. Nearly 60% of fibromyalgia patients report work impairment, including both hours missed and decreased productivity when at work (Bateman, et al., 2016). Many CFS/ME patients and 25% of POTS patients develop such severe symptoms that they are unable to work or attend school and, in some cases, become housebound (Benrud-Larson, et al., 2002; Horton, et al., 2010).

In CFS/ME patients, the quality of life is worse than for people who have schizophrenia, depression, or cancer (Hvidberg, Brinth, Olesen, Petersen, & Ehlers, 2015), while POTS patients had a quality of life similar to those with rheumatoid arthritis, end-stage kidney disease (Bagai, et al., 2011), congestive heart failure, and chronic obstructive pulmonary disease (Benrud-Larson, et al., 2002).

Decreased quality of life is associated with both suicidal ideation and suicide attempt, even in those with well-understood illnesses like cardiovascular disease, kidney failure, and depression (Joshi, Song, & Lee, 2017). Chronically ill people may consider suicide when they experience a loss of independence, dignity and/or pleasure in life (Fässberg, et al., 2016). Poor quality of life is associated with an increased risk of suicidal ideation and attempt in those with POTS (Pederson & Brook, 2017a). In those with multiple physical illnesses, poor quality of life was also linked with increased risk of death by suicide (Wei & Mukamal, 2019).

PREVENTING SUICIDE IN CHRONICALLY ILL POPULATIONS

There are opportunities to identify and help chronically ill patients at high-risk for suicide before they make an attempt. Of those who attempt suicide, 64% visited a healthcare practitioner in the month before the attempt, and 38% visited the week prior (Ahmedani, et al., 2015). Therefore, suicide prevention training for primary care staff is critical in reducing suicide attempts in chronically ill patients (Nakagami, et al., 2018). By practicing compassionate care, screening for suicide risk, and developing a protocol to address suicidal risk and/or behavior when it is discovered, healthcare practitioners can take positive steps toward reducing suicide attempts in this population (Pederson, 2018). Uncovering and more aggressively treating physical symptoms like sleep disturbances (Pederson & Brook, 2017b), pain (Racine, 2017), depression, and fatigue (Dutta, et al., 2017) can decrease suicide risk in chronically ill patients.

Public health policies can reduce suicide risk. Decreasing the stigma associated with suicide, as well as increasing accessibility to suicide prevention resources for families and healthcare practitioners is a good first step (Anestis, et al., 2017). Providing contact information for local counselors and support groups sensitive to the specific vulnerabilities of the chronically ill population, as well as more general, free resources like the National Suicide Prevention Lifeline (1-800-273-TALK) or Hopeline (741741 and text “start”) could be helpful. Additionally, training mental health staff to address issues surrounding perceived burdensomeness, thwarted belongingness and hopelessness experienced by the chronically ill could also decrease suicide risk (Pederson & Brookings, 2018). Furthermore, advocating for proper firearm security, reduction of medication that is potentially lethal in overdose, and managing other important means of suicide can reduce the likelihood of an attempt (Manuel, Crowe, Inder, & Henaghan, 2018). Finally, teaching children strategies that help them to tolerate distress and cope with their emotions

has the potential to protect their mental health and decrease future suicide risk (Anestis, et al., 2017).

Psychological factors associated with suicide risk in chronic illness can be altered by targeted intervention (Racine, et al., 2017), giving practitioners the opportunity to prevent suicide. Mental health practitioners can use a variety of approaches to decrease the psychological aspects of chronic illness related to burdensomeness, hopelessness, and depression, such as cognitive-behavioral therapy and acceptance and commitment therapy. In order to specifically treat suicidal tendencies, dialectical behavior therapy and collaborative assessment and management of suicidality can be helpful (Pederson, Gorman-Ezell, & Hochstetler-Mayer, 2017). If perceived burdensomeness is a major factor, identifying individuals at risk and working with caretakers to make interactions more positive might decrease suicide risk (Pederson, et al., 2017).

Quality social support that nurtures optimism can decrease hopelessness (Beedie & Kennedy, 2002) and reduce the risk of suicide (Chang, et al., 2018). Increasing social connections can decrease suicidal ideation in invisible illness communities (Van Orden & Deming, 2018). Online support groups may provide understanding and companionship as well as increasing social connections and belonging, especially when the patient is home or bedbound (Pederson, et al., 2017). Increasing positive connections with friends and family in an accessible environment is also an important tool in the battle against suicidal ideation. Providing positive life events, such as playing board games, making a favorite snack, or sharing a movie at home, that require minimal energy expenditure and increase social belonging can decrease both perceived burdensomeness and suicide risk (Chang, Muyan, & Hirsch, 2015).

Due to the invisible nature of these illnesses, it is important to believe people when they describe their experience with chronic invisible illness. In recent years, physical anomalies have been detected that authenticate these as “real” illnesses. For example, autoantibodies and other physical markers have been identified for CFS/ME (Loebel, et al., 2016), fibromyalgia (Jeong, et al., 2019), chronic Lyme disease (Arvikar, et al., 2017), and POTS (Ruzieh, et al., 2017). The demonstrated presence of

autoantibodies indicates that these chronic invisible illnesses may actually be part of the autoimmune illness family (Ruzieh, et al., 2017), and not psychosomatic in nature.

In this population, suicidal thinking is sometimes a symptom of depression, often a response to physical suffering, and frequently a practical mechanism to permanently relieve both physical and emotional misery (Alderson, et al., 2012). Taking a longitudinal perspective can be helpful: Chronically ill people perceive themselves as a burden to others, which leads to depression and, ultimately, may increase suicide risk (Pederson & Brookings, 2018). Recognizing and treating the physical and psychological issues in the chronically ill population is critical to decreasing their suicide risk.

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