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Risk factors for suicide in chronic fatigue syndrome

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Abstract

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) includes symptoms such as post-exertional malaise, unrefreshing sleep, and cognitive impairments. Several studies suggest these patients have an increased risk of suicidal ideation and early mortality, although few have published in this area. This study explores risk factors for suicide among 64 individuals with ME/CFS using archival data, 17 of which died from suicide. Results indicated an increased risk of suicide for those for those utilizing the label CFS, for those with limited overall functioning, and for those without comorbid illnesses. Findings suggest that stigma and functional impairments limit access to care and social supports.

Chronic fatigue syndrome (CFS) is a chronic illness that consists of symptoms such as fatigue, post-exertional malaise, neurocognitive and sleep impairments (Carruthers et al., 2011). Some have used the term Myalgic Encephalomyelitis to refer to this illness, or the acronym ME/CFS (which we will use throughout this article). As with many chronic illnesses, these patients are at higher risk for suicide than the general population (McManimen et al., 2016; Roberts et al., 2016). There is also evidence that when suicide does occur due to ME/CFS, it occurs at an earlier age than when it occurs in the general population (Jason et al., 2006). Nonetheless, studies examining specific risk factors of suicide among those with ME/CFS are scarce, and there is a clear need to better understand a range of risk factors.

Several social and cultural factors may place individuals with ME/CFS at risk for suicide, such as unsupportive peer and medical interactions (McManimen et al., 2018). Medical practitioners and family members sometimes consider individuals with ME/CFS malingerers (Dickson et al., 2007). These types of negative attributions may contribute to social isolation and estrangement, which are associated with suicidal ideation in patients (Devendorf et al., 2018).

CFS is the most frequently utilized label for this illness in the United States (Jason, Paavola, et al., 2010). Unfortunately, the term CFS highlights only the symptom of fatigue, which downplays the range and severity of other debilitating symptoms associated with the illness (Terman et al., 2018). One study examining preexisting biases and attitudes surrounding

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terminology revealed that medical trainees were more likely to associate psychological causes if the patient presented with the label CFS, but were more likely to associate biomedical causes if the patient presented with the label ME (Jason et al., 2001). Patients often feel that medical personnel and family members do not believe the patient has a legitimate illness, which may be an effect of having a label that fails to convey the serious nature of the illness (Devendorf et al., 2018). It is possible that the illness label CFS may increase the risk for suicide.

The complexity and range of symptoms experienced often render those with ME/CFS unable to accomplish many daily tasks of living, let alone participate in school or vocational responsibilities. Patients diagnosed with ME/CFS work fewer hours and have significantly less earning power than either healthy controls or patients with multiple sclerosis (Kingdon et al., 2018). Consequently, patients sometimes experience difficulty maintaining connections with friends and family, or holding steady jobs, which can impact their sense of worth. It is likely that functional limitations in tasks of daily living could represent another risk factor for suicide.

In examining risk factors for both lethal and failed suicide attempts, Joiner (2007) identified three primary components necessary for a lethal suicide attempt. These components included thwarted belongingness, perceived burdensomeness, and capability to engage in suicidal behavior. Individuals exposed to all three of these elements are at greatest risk for fatality, as the ability to overcome physical limitations (i.e., the third component) is often the variable that distinguishes those who die from suicide apart from those who merely attempt to or have a desire to commit the act (i.e., through thwarted belongingness and sense of burdensomeness). Therefore, patients with ME/CFS who experience moderate decreases in functionality may be more likely to attempt suicide, as compared to those who are completely limited in their functionality, or those able to complete most if not all of their regularly scheduled activities of daily living.

In addition to social factors and cultural factors, physiological factors may also play a role in the decision to die of suicide. Pain is a commonly identified risk factor for suicide among patients with chronic illnesses (Fishbain, 1999). Individuals who experience chronic pain are twice as likely to die of suicide as those who do not (Tang & Crane, 2006). Many patients with ME/CFS experience discomfort in the form of muscle pain, headaches, and joint pain (Jason et al., 1999). Some patients with ME/CFS have reported that suicide is the only viable option to reduce pain (Devendorf et al., 2018). It is likely that pain symptomatology may be another contributing factor to suicide among patients with ME/CFS.

Another risk factor for suicidal ideation is the absence of diagnosed comorbidities. Although suicide risk is highest for those patients experiencing multiple illnesses due to the compounding effects of pain with additional symptoms (Juurlink et al., 2004), it is possible that for patients with ME/CFS, the presence of a comorbid illness will aid in one’s sense of having a legitimate and socially accepted illness. Having another illness that has fewer barriers to care and resources (e.g., disability benefits) may be a protective factor (Jutel, 2015). At present, there is no identifiable bio-marker for ME/CFS, and a range of controversial case definitions have been used to identify patients. In addition

to the lack of consensus regarding disease etiology, many physicians and scientists align with the belief that there are psychological or lifestyle roots to the illness, as opposed to physiological ones (Jason et al., 2004). Illness labels, and the associations they elicit (e.g., physical vs. psychological), have a direct effect on treatment outcomes (Wojcik et al., 2011). For this reason, it is possible that patients diagnosed with one or more comorbidities that are considered legitimate and authentic are more likely to obtain access to social and medical supports, both of which could alleviate common risk factors for suicide (e.g., social estrangement, unsupportive medical interactions, outcomes associated with lack of disability benefits, etc.).

Although the above social and cultural as well as physiological factors have been explored as risks for suicidal ideation, few studies have examined these factors in patients with ME/CFS who have died. McManimen et al. (2016) examined overall mortality in patients with ME/CFS, and found that they were at an increased risk of all-cause and cardiovascular-related deaths, as well as a lower mean age of death for suicide and cancer when compared to the general U.S. population. In contrast to this previous study, the current study focuses on specific risk factors for suicide within a deceased sample of patients who had ME/CFS. The current study hypothesizes that increased risk for suicide is due to identification with the illness label CFS (as opposed to other utilized labels), decreased functionality, higher endorsement of pain symptom-atology, and lack of comorbid medical conditions.

Method

Participants

Participants included close friends, family members, and caregivers of 64 individuals who died with a ME/CFS diagnosis. The average age of death was 54.8 (SD = 19.7). Of the participants who provided personal information, 52 were women and two chose not to provide their gender. Also, 60 identified as Caucasian, and the average participant's age was 57.7 (SD = 10.5). In regard to the participants' relations to the deceased individuals, 23 were friends, 13 were children, 10 were parents, 7 were domestic partners/spouses, 5 were siblings, 2 were 'other' family members, 2 identified as 'other,' and 2 failed to respond to this question.

Procedure

We collected quantitative and qualitative data, as detailed by McManimen et al. (2016). We sent surveys to participants closely related to the deceased individuals, with questions focusing on various components of the last six months of a patient's life. We recruited survey participants through online convenience sampling with access to a link for survey completion provided electronically using Research Electronic Data Capture (REDCap) software. Specific recruitment methods included social media postings, emails, newsletters, patient advocate news websites, and physician email/word of mouth. We selected social media outlets according to researcher preference and familiarity (i.e., Twitter), and individual contacts (e.g., physicians, patient advocate news websites, etc.) according to relevant professional connections and acquaintances of the DePaul University Center for Community Research located in Chicago, IL.

Recruitment flyers, emails and postings included a breakdown on the intent of the study. Specifically, recruitment materials informed participants of efforts to document the experiences of the patients and family/loved ones so the medical community and relevant government agencies could better understand the illness. Additionally, these recruitment materials noted the lack of existing data on mortality in this population, and provided information regarding the potential of additional literature altering the often negative perception of the disease to the reality of its life-altering disability for those who suffer from it. There was no mention of suicide or other specific means of death in any recruitment material. Each recruitment letter, email, or social media posting indicated an email address that participants could contact if they were interested in participating. Once the participants' emails expressing interest arrived, we sent a consent form in addition to a link to the REDCap survey. We collected only one survey for each deceased individual.

In addition to age of death, cause of death, and type of care the patient required, survey questions focused on the treatment, functional status, and social/emotional experiences of the patient. An additional section of the survey focused on the respondent's relation to the deceased individual, and included questions regarding the experiences of the participant as a caregiver in the patient's life. We classified patients into those who died by suicide versus those who died of other causes (e.g., cancer, stroke, etc.).

Measures

Cause of death—We assessed cause of death using the following multiple-choice question: "What was the immediate cause of death to the best of your understanding?" Participants could then check one or more of the following response options: heart disease; cancer; suicide; B-cell Lymphoma; stroke; chronic lower respiratory disease; diabetes; influenza and pneumonia; nephritis, nephrotic syndrome, and nephrosis; Alzheimer's disease; accidents (unintentional injuries); other, and; unsure or don't know. We then asked for responses to the following two open-ended questions: "Please describe the cause of death" and "Please explain how the patient's death was recorded as being attributable to ME, CFS, CFIDS or a related illness." Of the 64 participants who responded to the question regarding immediate cause of death, 16 attributed the patient's cause of death to suicide.

In reviewing open-ended response items, one participant referenced an autopsy report that suggested a heart attack occurred while the individual was dying due to suicide. According to the participant, the patient was "in the process of attempting to hang himself on [a] tiny 1-inch oak tree limb when he died." Additionally, the participant stated that "Although the rope was around his neck, because his feet were on the ground & all signs pointed to a massive heart attack, the medical personnel in attendance & the examiner believed he suffered an immediate heart attack, which is what the death certificate specifies." For this reason, the death certificate indicated 'heart attack' as the individual's immediate cause of death. However, the heart attack occurred spontaneously and in tandem with a lethal suicide attempt, so his cause of death was coded as 'suicide'—resulting in a final group of 17 patients who died due to suicide.

Although reasoning for his inclusion in the group who died by suicide is limited due to the process of reporting by way of second party (i.e., loved ones), as well as an inability

to directly access autopsy reports, the lethality of this patient's described attempt was severe due to several factors established in the literature, such as intent to die and method of attempt (Kar et al., 2014). Additionally, medical guidelines state that if a non-natural condition (such as injury or poisoning) occurs together with an underlying disease, the manner of death must be considered non-natural and all causal factors reported (i.e., suicide, heart attack, etc.) (Hanzlick, 2006). Therefore, we have classified the cause of death for the patient in question to be suicide, as it was likely self-exacerbated, and it is within best practice to classify it as a fatal, self-inflicted event. We classified the remaining 47 participant responses as non-suicide.

Illness label—To evaluate the illness label that the patient used to describe their illness, we presented participants with the following labels: CFS, ME, ME/CFS, CFIDS, Other, Don't Know. Participants selected any combination of the labels to indicate how the patients described their illness. We omitted participants who responded with 'Other' or 'Don't Know' ($n = 6$) from the analysis. Also omitted were those participants who selected CFS and any other labels ($n = 10$). The aim was to compare patients who described their illness solely as CFS ($n = 16$) to patients who used ME, ME/CFS, CFIDS, or any combination thereof ($n = 32$). The final sample for the analysis of illness label was 48.

Functionality—We measured various components of daily functioning as it pertains to the self (e.g., personal hygiene, cooking, shopping, work, family commitments, etc.) using a single multiple choice question extracted from the DSQ (Jason, Evans, et al., 2010). The survey asked participants which statement "most accurately described him or her at time of death," with response options that included the following: not able to work or do anything, and was bedridden; could walk around the house, but could not do light housework; could do light housework, but could not work part-time; could only work part-time at work or on some family responsibilities; could work full-time, but no energy left for anything else; could work full-time and finish some family responsibilities but no energy left for anything else, and; unsure or don't know. For purposes of analysis, we classified the first response option as 'limited functioning,' the second and third response options as 'moderate functioning,' and the final three as 'high functioning.' Therefore, we coded patient responses into the following categories: bedridden, housebound, or not housebound, all of which captured distinct and observable capacities of functionality. This system of classification was guided by the Energy Envelope Theory (Jason et al., 2013), which describes a unique threshold of available and expended energy that each patient has, with some at very low levels of available and expended energy, and others with more adequate amounts. We placed patients into these categories according to tasks of daily functioning that demonstrated similar energy capacities. We omitted those who responded with 'unsure' or 'don't know' from analyses. The item demonstrated good test-retest reliability among friends and family of the deceased individuals, with a kappa coefficient of 0.68 (Jason et al., 2015).

Pain symptomology—We assessed pain experienced by the deceased individual using 5 pain-based items extracted from the DePaul Symptom Questionnaire (DSQ) (Jason, Evans, et al., 2010). We modified survey items from the original 5-point Likert scale to a 4-point scale (0 = *not a symptom*, 1 = *minor symptom*, 2 = *major symptom, and* 3 = *don't know)*,

as previously established (McManimen et al., 2016). Pain symptoms evaluated included: muscle pain, pain/stiffness in joints, chest pain, stomach/abdomen pain, and headaches.

Comorbidity—Participants recorded the patient's history of comorbid illnesses, if any, as they existed pre- and post-ME/CFS diagnosis by way of the following two open-ended questions: "What illnesses or health conditions did he or she have prior to developing ME or CFS?" and "What illnesses or health conditions was he or she diagnosed with after diagnosis of ME or CFS?" Four participants did not to respond to either question, and among those whose patients died of another cause, nine did not respond to the first question, and five did not respond to the second question. In all, 14 participants who reported on patients who died due to other causes did not respond.

Results

There was a significant relationship between illness label and cause of death χ^2 (1, n = 47) = 4.50, p < .05. Of those patients who only used the label CFS, 43.8% (n = 7/16) died of suicide, whereas 15.6% (n = 5/32) of patients who used the terms ME, ME/CFS, or CFIDS died of suicide. Patients who used the term CFS to describe their illness were 2.81 times more likely to die of suicide, than those who used either ME, ME/CFS, or CFIDS. Of the total sample, respondents were unclear as to the preferred illness label (i.e., ME, ME/CFS, CFIDS, CFS, other, or some combination of these) of 1 patient whose death was attributed to suicide, and 15 patients whose deaths were not attributed to suicide.

We found a significant relationship between range of functionality (i.e., bedridden, housebound, not housebound) and cause of death, χ^2 (2, n = 63) = 9.49, p < .01, with those patients limited to lighter degrees of functionality (i.e., housebound) 3 times more likely to die by suicide than those who were bedridden or those who experienced few overall functional limitations (i.e., not housebound) (Table 1).

We compared individual pain symptoms scores between patient groups (i.e., suicide and non-suicide) using non-parametric independent samples testing. A response of "3" signified missing data and was thus omitted from analyses. There were no significant differences between patient groups on pain symptoms (see Table 2).

We found a significant relationship between existence of comorbid health condition(s) prior to ME/CFS diagnosis, and subsequent cause of death (p = .02, Fisher's exact test). Of those who had a comorbid illness prior to their ME/CFS diagnosis, 11.5% (n = 3) died of suicide, whereas among those who did not have a comorbid illness prior to the ME/CFS diagnosis, 40.0% (n = 10) died of suicide. Patients without a comorbid health condition(s) prior to their ME/CFS diagnosis were 3.48 times more likely to die by suicide than those who had comorbid illnesses. Similarly, there was a significant relationship between those with a comorbid health condition(s) post-ME/CFS diagnosis, and subsequent cause of death, (p = .04, Fisher's exact test). Of those who had a comorbid health condition arise after their ME/CFS diagnosis, 12.9% (n = 4) died by suicide. Of the patients who were not diagnosed with a comorbid illness following their ME/CFS diagnosis, 37.5% (n = 9) died by suicide. Patients without a comorbid health condition(s) following onset of ME/CFS were 2.91 times

more likely to die by suicide than those who had comorbid illnesses. A total 51 participants had knowledge of patient comorbidities pre-ME/CFS diagnosis, and 55 participants had knowledge of patient comorbidities post-ME/CFS diagnosis.

Discussion

Our study identified illness label, level of functionality, and lack of comorbidities as risk factors related to suicide among patients with ME/CFS. We found significantly higher rates of suicide for patients identifying with the illness label CFS, for patients with a moderate overall level of functionality, and for patients without comorbid diagnoses. Pain, however, was not significant as a risk factor between those who died by suicide versus those who died of other causes.

Those who utilized the CFS label were more likely to die of suicide. CFS is a stigmatizing term as this label only focuses on the symptom of 'fatigue' despite the presence of many other debilitating symptoms. Terms with the acronym ME suggest physiological aspects of the illness, as "myalgic" refers to muscle pain, whereas "encephalomyelitis" means inflammation of the brain and spinal cord (Jason, Paavola, et al., 2010). Several studies examining the attitudes associated with various labels found that medical students and college students have a more physiological explanation of this illness when using the term ME as opposed to CFS (Jason et al., 2002, 2004). What individuals associate an illness with, or how it is labeled, has a direct effect on illness treatment and outcomes (Wojcik et al., 2011). Perceptions of illnesses sometimes evolve (i.e., favoring physiological over mental causes), and subsequent biological findings associated with medical advancements contribute to these changes (Wojcik et al., 2011). Unfortunately, our study did not have a direct measure of stigma, but it is highly likely that the term CFS is stigmatizing to many patients with ME/CFS.

We found that patients who were housebound and demonstrated limited overall functioning were at the greatest risk for suicide. Patients who had enough energy and physical functioning to leave their bed, but who did not have the energy for activities outside the house, were at the greatest risk for suicide. This is compatible with Joiner (2007) who found that one's capability to overcome physical limitations and fear associated with self-harm significantly increases one's ability to carry out a lethal suicide attempt. It is possible that those patients who were bedbound and with the lowest level of physical functioning might have also wished to end their lives, but were without the physical energy levels required to accomplish this. In regard to the highest functioning group of patients, it is possible that although they possessed the physical capability to successfully engage in a suicide attempt, their ability to participate in social and vocational commitments, even if limited, served as protective factors for suicidal ideation and suicide (McLean et al., 2008).

In our sample, high levels of pain endorsement were not significantly different from the suicide and non-suicide groups. This suggests that pain may not be a primary factor contributing to one's decision to die of suicide, whereas other factors such as thwarted belongingness, or perceived burdensomeness, may have greater influences on decisions to end life (Wilson et al., 2013). There might also be a threshold factor where above a certain

amount of pain, there are comparable levels of difficulties, and that all the patients had reached this level.

We also found that those without comorbid illnesses, both prior to and following the onset of ME/CFS, were at greater risk of suicide than those patients diagnosed with one or more comorbidities. Findings of this nature are unique in comparison to current literature that has found suicide risk to be greater for patients experiencing multiple illnesses (Druss & Pincus, 2000; Juurlink et al., 2004). However, for an illness such as ME/CFS that is largely misunderstood, it is possible that a second illness may serve as a social buffer. That is, a comorbid illness may allow the patient to present an illness label to others that is more acceptable and has fewer barriers to accessing support and resources (Jutel, 2015).

There were several limitations to the current study. The sample of participants recruited was small, of which only 17 indicated suicide as the cause of death. Still, because there are so few investigations of risk factors for suicide among those with ME/CFS, this preliminary study could provide investigators with ideas for future studies with larger samples. A second limitation is that the study was conducted following the deaths of each patient. Therefore, data were collected from close family members and friends, rather than directly from the deceased individuals. Because information was reported by way of a second party, data obtained might not match the conditions and experiences of the patients themselves. In addition, data were collected through an online survey. Future investigations could attempt to conduct assessments in person with patients who are critically ill and close to death so as to fully apprehend the feelings and experiences of those effected. However, collecting this type of data might be particularly difficult for those experiencing suicidal ideation.

In summary, this study identified label attribution, functional deficits, and the absence of comorbidities as possible risk factors for suicide in patients with ME/CFS. These findings might be due to the debilitating nature of this illness as well as the challenges encountered in regard to accessing care and convincing others of the seriousness of their illness. The findings highlight the importance of health care professionals developing ways to counteract these risk factors when interacting with patients and their family members or friends, particularly through efforts to legitimize their illness and provide needed medical resources, social resources, and support.

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Data availability statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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Table 1.

Endorsement of functionality in suicidal vs. non-suicidal patients.

	Suicide % (*n*)	**Non-suicide % (*n*)**
Bedridden[a]	17.6 (3)	60.9 (28)
Housebound[a]	64.8 (11)	28.3 (13)
Not Housebound	17.6 (3)	10.8 (5)

Note.

[a]Indicates significant difference at $p < .01$. Cases without valid responses or with responses of 'unknown' were not counted as endorsements.

Table 2.

Endorsement of pain symptomatology in suicidal vs. non-suicidal patients.

	Suicide		Non-suicide		
	% (*n*)	Mean (SD)	% (*n*)	Mean (SD)	*U*
Muscle Pain	94.1 (16)	1.88 (0.34)	85.1 (40)	1.75 (0.59)	301.0
Pain/Stiffness in Joints	76.5 (13)	1.69 (0.48)	72.3 (34)	1.71 (0.63)	204.5
Chest Pain	52.9 (9)	1.44 (0.53)	57.4 (27)	1.19 (0.88)	106.0
Stomach/Abdomen Pain	52.9 (9)	1.56 (0.73)	70.2 (33)	1.48 (0.67)	137.5
Headaches	76.5 (13)	1.85 (0.38)	72.3 (34)	1.62 (0.60)	181.5

Note. There were no significant differences for all cases, with $p > .05$.