

Suicide and ME/CFS -- Lily Chu, MD, MSHS

Everyone in the ME/CFS community, sooner or later, unfortunately has had contact with or hears about patients who have committed suicide. This is an important issue for the community to address yet there is not much research on the topic. Past studies have suggested that [up to 50%](#) of severely affected patients have attempted suicide and that suicide is [one of the top 3](#) causes of death in ME/CFS. However, one [2006 study](#) found that while the suicide risk was much higher for chronically fatigued patients compared to the general population, the risk was not increased for those meeting Fukuda 1994 CFS criteria. These studies all had their limitations though. Consequently, I was encouraged to see this topic explored in [a February 2016 article](#) published in The Lancet by Emmert Roberts et al. from King's College, London, United Kingdom.

Using the ICD-10 diagnostic code for neurasthenia (F48.0) and a bespoke natural language program, Roberts and his colleagues identified 2,147 subjects with chronic fatigue syndrome from a United Kingdom-based medical database. These subjects were followed from 2007 to 2013 or until the time of the death. There were 17 deaths total, with 5 resulting from suicide. Age- and sex-standardized mortality ratios (SMRs) were calculated then by comparing the observed number of deaths to the expected number of death from this group based on mortality rates of the general English and Welsh populations recorded in 2011.

Roberts found that although the SMRs of the subjects did not differ from the general population for all-cause mortality or cancer-related mortality, **subjects with CFS were 6.85 times more likely than the general population to die from suicide. (95% CI, 2.22 – 15.98; p=0.002)** Out of the 5 subjects who committed suicide, 2 had a history of depression while 3 did not. Statistical analysis did not indicate that depression increased the risk of suicide.

Overall, while I found this study to be interesting and relevant to the field, I am not so sure about its conclusions. As the authors relate in the discussion, the number of deaths overall and by suicide were very small, the average age of the cohort (39.1), and those who died were on the younger side (48.3), and no confounders were accounted for. Therefore, results could be occur by chance alone or there could be other explanatory reasons. One of my biggest concerns in ME/CFS research in general is the drawing of conclusions based on studies with small sample sizes and little replication so I am glad that at least the authors (and the [accompanying editorial in the Lancet](#)) acknowledge this limitation.

In addition, I am still not clear how well the authors' efforts succeeded in identifying the right or adequate group of subjects. I wrote Dr. Roberts personally for clarity on subject selection and he assured me that the diagnostic code of "neurasthenia" was for administrative purposes and had no bearing on how the diagnostic process. Nevertheless, it is not clear to me how this translates at the bedside level, i.e. did clinicians diagnose patients with "CFS" or "ME" or "PVFS" and this was coded later, perhaps even by a non-clinician, as "neurasthenia", or did doctors themselves diagnose

patients with “neurasthenia”? The latter case could potentially enroll subjects very different from other subjects in this study and this misclassification and heterogeneity would affect results.

Furthermore, at least for US purposes, for a subsample of 755 patients drawn for examination, only 58% fulfilled US criteria. 88% fulfilled NICE criteria and 68% Oxford criteria. The latter two criteria emphasize fatigue primarily and require less symptoms than Fukuda. So the conclusions might not apply as well to Fukuda-diagnosed subjects. Finally, this study still relies on clinician diagnosis of CFS. We know that CFS is underdiagnosed, definitely in the US, and perhaps still in the UK. If the study underestimated the number of subjects actually affected by CFS, the number of suicides would be incorrect although it is not possible to predict if the percentage of CFS patients committing suicide would be higher or lower.

Another reason I wanted to write about this topic is to encourage professionals and others to **think about reasons for suicide beyond depression and anxiety**. This is especially important for ME/CFS since many mainstream providers still conflate depression or anxiety with ME/CFS or believe that the origins of ME/CFS are psychiatric or psychological. It is also my personal experience, in taking care of elderly people, that thoughts of suicide can occur without depression or other mood disorders being involved.

Symptoms of chronic illness, especially uncontrolled pain, and secondary consequences such as poverty, social isolation, job loss, disability, etc. also play a major role. Surprisingly, there has been very little research examining the effects of chronic illness itself on suicide. Or perhaps not surprising, as suicide is still considered a delicate or taboo subject by many people. Therefore, the UK-based nonpartisan think tank [Demos researched](#) this issue in 2011 by exploring medical databases and interviewing key figures. They concluded that, conservatively, **at least 10% of suicides may be linked to chronic or terminal physical illness; sadly, in the health district they chose to further explore their findings (p. 66-67 of the report), 4 out of 25 health-related suicides were specifically linked to ME.** Furthermore, even if depression and anxiety are involved, it could be argued that these conditions might not have arisen in an individual patient had they not become sick or severely ill with ME/CFS in the first place.

Consequently, **while we should diagnose and treat mood disorders appropriately, I see them as only one stopgap measure in preventing suicide in ME/CFS.** Other stopgap measures include managing symptoms to the best of our ability and addressing the unmet social needs of patients, whether they be concrete, like providing written support for food/ housing benefits, or more abstract, reinforcing the validity of patients’ experiences with their family present or referring them to a support group to decrease social isolation. We can also work on increasing research funding and providing more accurate information to healthcare providers to give patients some degree of hope for a better future. **Ultimately the best way to prevent suicide in ME/CFS will be to find effective disease-modifying treatments or cures for it.**

Some resources:

Risk factors: <http://www.suicidepreventionlifeline.org/learn/riskfactors.aspx>

Warning signs: <http://www.suicidepreventionlifeline.org/learn/warningsigns.aspx>

One list of ME/CFS support groups in the US and internationally:

<http://www.cfsknowledgecenter.com/support-groups.php>

United States National Suicide Prevention Hotline (24 hours, toll-free): 1-800-273- TALK (8255)

International list of hotlines: <http://www.suicide.org/international-suicide-hotlines.html>

Nota bene:

As I was finishing this piece, [an article came out in the New York Times](#) about how the rate of suicide among the general US population (13/ 100,000) and across sex and age categories had risen by an alarming 24% since 1999 and was at a 30-year high. Experts and Time readers speculated that a poor economy coupled with job loss, a frayed safety net, and decreased social/ community engagement might have contributed to higher rates.