Psychiatric Aspects of ME/CFS

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Agenda

- Prevalence of psychiatric diagnoses in ME/CFS
- How to differentiate ME/CFS from depression and anxiety
- Types of emotional symptoms
- How to treat
- Suicide and MAID

Measured prevalence depends on:

- Diagnostic criteria used for ME/CFS

(Jason et al 2004, 2007)

- Ascertainment of psychiatric diagnosis

(Johnson et al 1996)

- Sample size
- Population based / primary care / specialist sample

The CDC Georgia Study

- 57% with CFS had at least one current Axis I psychiatric diagnosis.
- 89% with CFS had at least one lifetime psychiatric diagnosis.
- 29% with CFS had a personality disorder vs 7% of well controls.

(Nater et al 2009)

Canadian Community Health Survey

2012 CCHS	ME/CFS	No unexplained symptoms
Depression	26%	4%
GAD	19%	2%
Any mental disorder	35%	8%
2014 Depression or Anxiety	54%	10%

(Park et al 2017)

Dutch Lifelines Study

- >94,000 people
- 1166 had CFS/ME –1.3% by self report
- Core depression symptoms in CFS/ME - 8.6%
- Any anxiety disorder in CFS/ME – 24%

(Jannsens et al 2015)

Prevalence Summary

- Although many people with ME/CFS have a current or lifetime psychiatric diagnosis **the majority do not**.

- ME/CFS is not a psychological disorder.

(IOM 2015)

ME/CFS vs Psychiatric Conditions

- Depression and Anxiety consist of both emotional and physical symptoms.
- The physical symptoms include: fatigue, unrefreshing sleep, decreased activity and cognitive problems.
- Look for the presence or absence of emotional symptoms to make the dx.

ME/CFS	Major Depression
Clinical Presentation	
Infectious onset in majority of cases	Rarely follows infectious illness
Fatigue is necessary for diagnosis	Mood change is necessary for diagnosis
Muscle and/or joint pain and significant headaches	Not usually associated with pain symptoms
Afternoon and evening usually the worst time of day	Morning usually the worst time of day
Orthostatic intolerance, tachycardia, and other autonomic dysfunction are common	No association with autonomic symptoms
Immune manifestations including tender lymph nodes, sore throat, chemical and food sensitivities	No association with immune symptoms
Loss of temperature stability and intolerance to extremes of temperature	No association with temperature problems
Fatigue and other symptoms are worsened by physical or mental exercise	Fatigue and mood improve with exercise
Decreased positive affect (energy, enthusiasm, happiness)	Increased negative affect (apathy, hopelessness, suicidal ideation, self reproach)
Children have a better prognosis than adults	Children have a worse prognosis than adults

Sometimes Diagnosis is Difficult to Discern

- Patients who are emotionally flat.
- **Is it due to depression or exhaustion?**
- Ask "what would you do if you had the energy?"
- If unsure I suggest a trial of antidepressant.

How to Treat Emotional Symptoms

Type of Symptoms	Timing of Onset	Treatment
Grief or Fear secondary to ME/CFS	Emotional symptoms occur after onset of ME/CFS	Support Counselling Psychotherapy
Comorbid with ME/CFS - emotional symptoms are not parallel to physical symptoms	Emotional symptoms occur before onset of ME/CFS	Psychotherapy and/or medication as per usual
Biological aspect of ME/CFS – emotional symptoms parallel physical symptoms	Emotional symptoms occur at onset of ME/CFS	Management of physical symptoms
Secondary to medication, food, toxins	Unpredictable variability	Avoidance of triggers

Managing Anxiety

- Diagnosis is therapeutic and does NOT reinforce “illness behavior”.
- Listen to patient’s concerns and explain why certain diagnoses may or may not be relevant.
- Undertake appropriate investigation and referral to rule out feared diagnoses.

(Horton et al 2010)

Supporting the Patient
(not just the symptoms)

- Active support of patient obtaining sustainable school/work conditions or leave of absence from school or work, disability insurance, etc.
- Offer to meet with family members to explain the illness and help family renegotiate roles.

When to use Psychotropic Drugs

- Psychotropic medication should be tried if psychiatric symptoms are interfering with sleep or self management.
- Treat co-morbid psychiatric conditions in ME/CFS similarly to similar symptoms in the absence of ME/CFS.
- No antidepressant has been shown to improve the core symptoms of ME/CFS
- Stimulants can be counterproductive.

Start Low and Go Slow

- Patients with ME/CFS are often more sensitive to medications.
- Be willing to titrate and give patient permission to experiment with drug doses within a safe range.
- Consider compounded drug doses.

Ask about Suicidal Ideation

- Suicide is among the top three causes of death in ME/CFS. (Smith *et al*, 2006;Jason *et al*, 2006; Roberts et al 2016)
- Is suicidal ideation a sign of psychiatric illness or an understandable response to having a grievous and irremediable condition for which no treatment or services are available?

Managing Suicidal ideation

- In the absence of depression, patients are often open to shreds of hope.
- Hope can come from being understood, having needed homecare or disability supports in place.
- Assist patient with grief process as you would in any other serious, chronic medical condition.

(Jevne & Miller 1999; Fennell 2012; Taylor 1999)

Medical Assistance in Dying

- Feb 6, 2015 Supreme court ruled law prohibiting physician assisted death was unconstitutional.
- Assisted death became legal on Feb 6, 2016 (by court order only).
- MAID became available in all provinces on June 17, 2016.
- In Alberta, since June 2016, 330 individuals have received MAID.

MAID Eligibility

- Competent adult (18 years of age).
- Have a grievous and irremediable medical condition.
- Advanced state of irreversible decline in capabilities.
- Enduring physical or psychological suffering, caused by the medical condition, that is intolerable to the person.
- The patient's natural death has become reasonably foreseeable (time frame not specified)

ME/CFS and MAID

- Many individuals with severe ME/CFS – house or bedbound meet the medical MAID criteria.
- The sticking point is whether the patient's death can be considered "reasonably foreseeable".
- Defined in Bill C-14 as "on an irreversible path towards death"

Does ME/CFS meet MAID criteria?

- Unless the patient's death is reasonably foreseeable, ME/CFS does not meet current MAID criteria.
- CCA report pending.
- Legal challenges are underway as to whether the current restrictions are constitutional.

Conclusions

- ME/CFS is not a psychiatric disorder but many patients have emotional symptoms.
- ME/CFS can be differentiated from psychiatric conditions.
- Identify nature of emotional symptoms to treat.
- Ask about suicidal ideation and refer for support if present.