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

<table>
<thead>
<tr>
<th></th>
<th>2012 CCHS</th>
<th>ME/CFS</th>
<th>No unexplained symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>26%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>GAD</td>
<td>19%</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>Any mental disorder</td>
<td>35%</td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>2014 Depression or Anxiety</td>
<td>54%</td>
<td>10%</td>
<td></td>
</tr>
</tbody>
</table>

(Park et al 2017)
Dutch Lifelines Study

- >94,000 people
- 1,166 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.
<table>
<thead>
<tr>
<th>ME/CFS</th>
<th>Major Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical Presentation</strong></td>
<td></td>
</tr>
<tr>
<td>Infectious onset in majority of cases</td>
<td>Rarely follows infectious illness</td>
</tr>
<tr>
<td>Fatigue is necessary for diagnosis</td>
<td>Mood change is necessary for diagnosis</td>
</tr>
<tr>
<td>Muscle and/or joint pain and significant headaches</td>
<td>Not usually associated with pain symptoms</td>
</tr>
<tr>
<td>Afternoon and evening usually the worst time of day</td>
<td>Morning usually the worst time of day</td>
</tr>
<tr>
<td>Orthostatic intolerance, tachycardia, and other autonomic dysfunction are common</td>
<td>No association with autonomic symptoms</td>
</tr>
<tr>
<td>Immune manifestations including tender lymph nodes, sore throat, chemical and food sensitivities</td>
<td>No association with immune symptoms</td>
</tr>
<tr>
<td>Loss of temperature stability and intolerance to extremes of temperature</td>
<td>No association with temperature problems</td>
</tr>
<tr>
<td>Fatigue and other symptoms are worsened by physical or mental exercise</td>
<td>Fatigue and mood improve with exercise</td>
</tr>
<tr>
<td>Decreased positive affect (energy, enthusiasm, happiness)</td>
<td>Increased negative affect (apathy, hopelessness, suicidal ideation, self reproach)</td>
</tr>
<tr>
<td>Children have a better prognosis than adults</td>
<td>Children have a worse prognosis than adults</td>
</tr>
</tbody>
</table>
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

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