Why ME/CFS is not a Psychiatric Disorder

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Agenda

- Is ME/CFS a psychiatric disorder and why it matters.
- How to differentiate depression and anxiety from ME/CFS.
- How to manage depression and anxiety plus ME/CFS.
- How to manage “brain fog”.
- Maintaining hope
- Conclusions

Why it matters

- Psychiatric conditions are generally treated with a combination of:
  - psychotherapy ie learning to understand and change thoughts and behavior and
  - psychotropic drugs ie drugs which act on the central nervous system.
- Biomedical conditions are usually treated with drugs that act on some other system eg. inflammatory, immune, heart etc. sometimes with psychotherapy to manage stress and aid self management.
- There is a difference in emphasis between the two approaches.

Why it matters 2

- If ME/CFS is a psychiatric condition then psychiatric treatments should help.
- If ME/CFS is a bio-medical condition then we should keep looking for better treatments for infection, autonomic, endocrine and other systems.
- If ME/CFS is a combination of the two then we need to integrate both approaches.

If we get it wrong

A recent journal debate summarizes difference of opinion in the underlying assumptions about what causes and perpetuates ME/CFS. If we make wrong assumptions treatments will be flawed and people will not get better.

Garbage in ... garbage out

My Opinion

- Although the symptoms of ME/CFS overlap with several common psychiatric disorders AND both the brain and body are involved, the evidence is clear and growing that ME/CFS is not the same as any known psychiatric or biomedical disorder.
The Evidence of Difference

- Looking at large groups of people (epidemiology) shows differences between ME/CFS and psychiatric disorders.
- Looking at individuals (clinical) shows differences.
- Looking at cell and body system function (pathophysiology) shows differences.

The Epidemiological Evidence

- Rates of psychiatric disorder in CFS/ME are similar to rates in other chronic medical conditions (approx 30 - 40%).
- Rates of personality disorder in CFS/ME are not elevated.
- The genetics of depression and ME/CFS are independent.
- Illness severity and not psychological factors predict outcome.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>ME/ CFS</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Unrefreshing Sleep</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Pain</td>
<td>✔</td>
<td>±</td>
</tr>
<tr>
<td>Poor memory and concentration</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Post exertional Malaise</td>
<td>✔</td>
<td>NO</td>
</tr>
<tr>
<td>Autonomic (BP, dizziness etc.)</td>
<td>✔</td>
<td>NO</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Endocrine (temp control)</td>
<td>✔</td>
<td>NO</td>
</tr>
<tr>
<td>Immune</td>
<td>✔</td>
<td>NO</td>
</tr>
<tr>
<td>Low mood</td>
<td>±</td>
<td></td>
</tr>
<tr>
<td>Anhedonia</td>
<td>NO</td>
<td>✔</td>
</tr>
<tr>
<td>Weight change</td>
<td>±</td>
<td></td>
</tr>
<tr>
<td>worthlessness, guilt</td>
<td>NO</td>
<td>✔</td>
</tr>
<tr>
<td>Suicidal thoughts</td>
<td>±</td>
<td>✔</td>
</tr>
<tr>
<td>Change in activity</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>

How to tell the difference

- ME/CFS requires: post exertional malaise and two of autonomic, endocrine and immune symptoms.
- Major Depression requires: low mood and one of anhedonia, feelings of worthlessness or guilt and suicidal ideation.
How to tell the difference

- ME/CFS requires: post exertional malaise and two of autonomic, endocrine and immune symptoms.
- GAD requires: inappropriate worry + physical symptoms
- Panic Disorder is situational and each episode is short lived.

### Pathophysiological Evidence

A review of some of the most replicated research (there is much, much more):
- endocrine function
- autonomic function
- cardiac function
- muscle metabolism
- infectious etiology
- the homeostatic hypothesis

### Endocrine Function

- Major depression, most types of anxiety and Post Traumatic Stress Disorder are associated with increased cortisol levels and decreased receptor sensitivity.
- ME/CFS is associated with decreased cortisol levels and increased receptor sensitivity in most studies (none show increase).
  

### Autonomic Function

- Numerous studies have shown autonomic dysfunction in ME/CFS (especially in younger patients including:
  - increased heart rate at rest and with standing
  - decreased heart rate variability
  - Postural Orthostatic Tachycardia Syndrome
  - Abnormal response on Head up Tilt Table Test
  - Only decreased HRV has been found in psychiatric disorders.


### Cardiac Function

- Cardiac output is decreased in ME/CFS. The decrease correlates with physical but not psychological symptoms.
  
  
  24 hour Holter EKGs are often abnormal with T wave flattening or inversion, tachycardia and premature contractions.
  
  
  Decreased cardiac output may be due to small hearts.
  
Muscle Metabolism

- CFS patients reach exhaustion much more rapidly than normal subjects and have reduced intracellular concentrations of ATP. (Wong R et al. Chest 1992; 102(6): 1716-22.)
- Patients with ME/CFS have abnormalities in recovery of intramuscular pH following standardised exercise. (Jones D et al. Journal of Internal Medicine 2010; 267: 394-401.)
- Cardiac muscle metabolism is impaired (PCr/ATP ratio) in CFS and this impairment correlates with skeletal muscle impairment. (Hollingsworth KG et al. Eur J Clin Invest 2010.)

Infection

- ME/CFS can be triggered by infections including: Enterovirus (especially Parvo B19), EBV, Ross River Virus, Coxiella (Chia J K et al. J Clin Pathol. 0, 1-6. 2007)
- Lerner AM Virus Adaptation and Treatment 2010; 2: 47-57
- Hicke I. BMJ 2006; 333(7568): 575
- Associations have been found with: CMV, HHV6, XMRV (Lombardi V et al. Science 2009; 326(5952): 585-9)
- Lerner AM Virus Adaptation and Treatment 2010; 2: 47-57

Homeostasis

- While no one marker consistently differentiates ME/CFS from control data the homeostatic networks can be reliably differentiated. (Fuite J et al. Genomics 2008; 92(6): 393-9)
- This may explain why it has been so hard to find a single biomarker and why ME/CFS is so stress sensitive.

Why are ME/CFS and psychiatric disorders confused?

- Because if one can't find "objective evidence" of disorder, it's tempting to think it might be "all in the head".
- Many researchers have started out as staunch "bio-medical" advocates only to jump ship when their theories don't pan out.

DSM V

In the "Justification of criteria for Somatic Symptoms" Draft Jan 29, 2010:
- Researchers have abandoned the DSM IV criteria for Somatization disorder – not valid
- Recommends de-emphasis on the term "medically unexplained symptoms".
- This term suggests an invalid dualism between mind and body.

**DSM V**

- New category of Complex Somatic Symptom Disorder is “inappropriate in the presence of only unexplained medical symptoms”
- Category should be used ONLY if a person shows “disproportionate or maladaptive response to somatic symptoms or concerns”
- Still problematic is who judges what is “disproportionate”.


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**Managing Depression and Anxiety if you have ME/CFS**

- The best antidote for depression, anxiety and stress is improved physical health!
- Daily self management is critical
- Symptomatic medical care
- Safe housing and nutritious food... are all prerequisites

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**Finding a therapist/counselor**

- Find someone you trust and who shares enough of a common outlook that you can work together.
- This could be a family physician, non medical psychotherapist, spiritual counselor etc.
- Not mandatory the person know a lot about ME/CFS though it helps.
- Friends and family help a lot but sometimes having a professional who is neutral about your situation is useful.

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**Stabilization**

- First one must stabilize physical and emotional health as much as possible.
- Only then can one start identifying priorities for change.

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**Making Changes**

- Identify beliefs and attitudes that may not be working for you and challenge these.
- Start identifying your priorities and see if any need to be changed.
- This is your chance to make changes.
- Illness can be a wake up call - don't ignore it.

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**Grief Work**

- Identify losses and go through the grief process... even if you get better, you have still lost a lot.
- It is difficult to move forward if you haven't faced up to the reality of your situation.
- Acceptance is the path to the future (it doesn't mean you have given up).
Integration

- You are not the same person you used to be.
- You have learnt a lot.
- After grieving, one can integrate the new learning and new persona with the best of who you used to be.
- You become able to laugh, play and dream again
- You are more than your illness.

Stress Management

- Having a chronic disabling condition is very stressful. Reserve capacity is decreased.
- One cannot use mind over matter when it comes to energy in ME/CFS.
- Perception is everything when it comes to stress.
- Learning to say NO is #1 useful technique.

Psychotropic Medication

- No pharmaceutical has shown effectiveness for core ME/CFS. This includes antidepressants!
- However if you have depression or anxiety, drugs can help.

Antidepressants

- Drugs of choice for both depression and anxiety.
- A recent meta-analysis of all the newer antidepressants shows that ...

wait for it ...
Cognitive Function in ME/CFS

- normal global intellectual functioning
- normal receptive functioning
- normal ability to focus and sustain attention for low effort tasks
- normal ability for verbal and non verbal conceptualization

What is “Brain Fog”

- The cognitive deficit in CFS is not a structural one in any particular part of the brain.
- Primary problems are with working memory and processing speed
- May be a functional disorder of information processing speed and efficiency

Research on “Brain Fog”

- In difficult memory tasks people with CFS activate more parts or different parts of the brain than healthy controls.
- Brain volume is decreased in CFS
- Clinically brain function recovers with physical improvement.
- Brain volume may recover with therapy

Managing “Brain Fog”

- PACING!!
- Give yourself as many breaks during cognitive activity as you need during physical activity (maybe more).
- Switching activities every 15 - 30 minutes.
- Giving yourself more time.
- Using memory aids
- Try not to lose the aids 😊

Brain Games

- In the “Brain that Changes Itself”, Norman Doidge gives much hope that the brain can recover from serious conditions.
- In ME/CFS, mental training such as Brain Fitness® or Wii® have to be tempered with PACING.
- The de Lange research suggests that changing brain activity can help restore volume. There is no research on function.

Maintaining Hope

- A recent interviewee on Tapestries, the CBC radio show on spiritual matters, said “Hope is good, Despair is bad”.
- Hope is essential.
- How does a person with a debilitating, isolating and misunderstood condition maintain hope?
Looking for Hope

- The Hope Foundation of Alberta has a number of inspiring materials, including books and videos. http://www.ualberta.ca/HOPE/
- Finding hope is an active process. One is more likely to find hope if one looks.

Looking for Hope 2

- Examples of useful activities include looking for hope with a camera or through poetry, art or writing.
- It may exist in some cranny one hadn’t thought to look before.
- Spend 10 minutes a day looking for hope and you may be surprised.

Conclusions

- ME/CFS affects the mind AND the body
- It differs from any known psychiatric or bio-medical condition
- ME/CFS is likely a disorder of homeostasis caused by a number of triggers to which the body doesn’t respond optimally.

Conclusions

- One can accurately diagnose psychiatric conditions in people with ME/CFS using the simple material in this presentation.
- Effective treatment of depression and anxiety in ME/CFS includes:
  - self management
  - optimal medical care
  - safe housing, healthy food
  - psychotherapy
  - psychotropic medications
  - stress management
  - maintaining hope

Other Resources

- http://www.mefmaction.net for full text of the Canadian Consensus Guidelines for diagnosing ME/CFS or Fibromyalgia
- “The Chronic Illness Workbook” by Patricia Fennell MSW CSW-R
- “Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia” by Alison Bested and Alan Logan
Upcoming Canadian Conferences

Dr. Daniel Peterson speaking in Calgary April 2/3 2011. MEAO will be sent registration materials.