Why ME/CFS is not a Psychiatric Disorder

Eleanor Stein MD FRCP(C)

Chronic Fatigue Syndrome, Fibromyalgia, Multiple Chemical Sensitivity & Related Disorders

Phone: (403) 287-9941    Fax: (403) 287-9958
E-mail: espc@shaw.ca
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>
<tr>
<td><strong>Symptom</strong></td>
<td><strong>ME/ CFS</strong></td>
<td><strong>Depression</strong></td>
</tr>
<tr>
<td>------------------------------</td>
<td>-------------</td>
<td>----------------</td>
</tr>
<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.
<table>
<thead>
<tr>
<th>Symptom</th>
<th>ME/ CFS</th>
<th>Anxiety (GAD)</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>NO</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>Symptom</td>
<td>ME/ CFS</td>
<td>Anxiety (GAD)</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------</td>
<td>---------------</td>
</tr>
<tr>
<td>Endocrine (temp control)</td>
<td>✔️</td>
<td>NO</td>
</tr>
<tr>
<td>Autonomic (BP, dizziness etc.)</td>
<td>✔️</td>
<td>NO</td>
</tr>
<tr>
<td>Immune</td>
<td>✔️</td>
<td>NO</td>
</tr>
<tr>
<td>Restlessness</td>
<td>NO</td>
<td>✔️</td>
</tr>
<tr>
<td>Irritability</td>
<td>NO</td>
<td>✔️</td>
</tr>
<tr>
<td>Muscle Tension</td>
<td>±</td>
<td>✔️</td>
</tr>
<tr>
<td>Inappropriate Worry</td>
<td>NO</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.
- GAD requires: inappropriate worry + physical symptoms
- Panic Disorder is situational and each episode is short lived.
Pathophysiologica  l 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

- 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
  
  Lerner AM Virus Adaptation and Treatment 2010; 2: 47-57  
  Hickie I. BMJ 2006; 333(7568): 575  

- **Associations have been found with:** CMV, HHV6, XMRV
  
  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.
- 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.
Referring to the identification and treatment of symptoms associated with inflammation in medically ill patients a recent paper concludes:

“Assuming somatization because of the absence of detectable disease is of little operational value if not misleading”

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.

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”.

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
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.
Stabilization

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

The most effective antidepressant drugs based on head to head comparisons of comparable doses were:

- escitalopram (Lexapro®)
- mirtazapine (Remeron®)
- sertraline (Zoloft®)
- venlafaxine (Effexor®)
Antidepressants

The best tolerated antidepressant drugs based on head to head comparisons of comparable doses were:

- bupropion (Wellbutrin®)
- citalopram (Celexa®)
- escitalopram (Lexapro®)
- sertraline (Zoloft®)
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.
  Lange et al 2005, Flor Henry, Personal communication

- Brain volume is decreased in CFS
  de Lange et al 2005

- Clinically brain function recovers with physical improvement.

- Brain volume may recover with therapy
  de Lange et al 2008
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?
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:
Conclusions

- 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.

IACFS/ME International Conference Sept 22 – 25, 2011 Ottawa Canada see: