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

Harvey & Wessely BMC Med 2009; 7: 58.
Maes & Twisk BMC Med 2010; 8 (1): 35.

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.

Symptom	ME/CFS	Depression
Fatigue	✔	✔
Unrefreshing Sleep	✔	✔
Pain	✔	±
Poor memory and concentration	✔	✔
Post exertional Malaise	✔	NO
Autonomic (BP, dizziness etc.)	✔	NO

Symptom	ME/CFS	Depression
Endocrine (temp control)	✔	NO
Immune	✔	NO
Low mood	±	✔
Anhedonia	NO	✔
Weight change	±	✔
worthlessness, guilt	NO	✔
Suicidal thoughts	±	✔
Change in activity	✔	✔

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.

Symptom	ME/CFS	Anxiety (GAD)
Fatigue	✔	✔
Unrefreshing Sleep	✔	✔
Pain	✔	NO
Poor memory and concentration	✔	✔
Post exertional Malaise	✔	NO

Symptom	ME/CFS	Anxiety (GAD)
Endocrine (temp control)	✔	NO
Autonomic (BP, dizziness etc.)	✔	NO
Immune	✔	NO
Restlessness	NO	✔
Irritability	NO	✔
Muscle Tension	±	✔
Inappropriate Worry	NO	✔

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).

see Cleare AJ. Trends Endocrinol Metab 2004; 15(2): 55-9. for a review of the topic.

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.

Boneva RS et al. Auton Neurosci 2007; 137(1-2): 94-101
Stewart JM et al. Pediatrics 1999; 103(1): 116-21.
Hoad AM. QJ 2008; 101(12): 961-5.

Cardiac Function

- Cardiac output is decreased in ME/CFS. The decrease correlates with physical but not psychological symptoms.

  Peckerman A et al. Am J Med Sci 2003; 326(2): 55-60.
- 24 hour Holter EKGs are often abnormal with T wave flattening or inversion, tachycardia and premature contractions.

  Lerner AM et al. Virus Adaptation and Treatment 2010; 2: 47-57.
- Decreased cardiac output may be due to small hearts.

  Miwa K et al. Intern Med 2009; 48(21): 1849-54.

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.
- Impaired metabolism may be due to mitochondrial dysfunction. Myhill S et al. Int J Clin Exp Med 2009; 2(1): 16.

Infection

- ME/CFS can be triggered by infections including: Enterovirus (especially Parvo B19), EBV, Ross River Virus, Coxiella
  Chia JK et al. J Clin Pathol. 0, 1-6. 2007
  Lerner AM Virus Adaptation and Treatment 2010; 2: 47-57
  Hickie I. BMJ 2006; 333(7568): 575
  Kerr, J. J Gen Virol 2010; 91(Pt 4): 893-7.
- 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.
  Broderick G et al. Brain Behav Immun 2010 epub ahead of press.
- 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"
  Dimsdale JE et al Psychosomatics 2007; 48(3): 247-52.

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.

http://www.dsm5.org/Documents/Somatic/APA%20DSM%20Validity%20Propositions%201-29-2010.pdf

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".

http://www.dsm5.org/Documents/Somatic/APA%20DSM%20Validity%20Propositions%201-29-2010.pdf

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®
- mirtazepine (Remeron®)
- sertraline (Zoloft®)
- venlafaxine (Effexor®)

Antidepressants

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

- buproprion (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?

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:

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:

http://www.iacfsme.org/Home/tabid/36/Default.aspx