Somatopsychic, Psychosomatic or Multisystem Illness

Bursting the Bubble: Challenging the Misconceptions and Misdiagnoses of Neuropsychiatric and Pathogen-Triggered Disorders: AONM

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Disclosure Statement
Robert Bransfield, MD, DLFAPA

- Patients pay me money in return for trying to help them and this is most of my income.
- I have no contract with any insurance company or other payer that might restrict or alter patient care in return for referring patients or providing other benefits.
- I do not have any financial arrangements or affiliations with any commercial entities whose products, research or services may be discussed in these materials.

Outline

- Case presentation
- What Causes Illness and Mental Illness?
- Brain & Body Interaction
- DSM-5 Definitions
- ICD-11
- Making the Diagnosis
- Consequences of Diagnostic Errors
- Discussion & Summary
- Conclusion

Case Presentation

Case Presentation: History

- The patient is an 18 y/o white female with multiple symptoms who had previously been adept at Taekwondo. She had a bulls eye rash, a Bell's palsy, became increasingly debilitated over 4 years, was in a wheel chair and had seizure episodes.
- Prior diagnoses included "wanting attention," fibromyalgia, chronic fatigue, hypoglycemia and pseudoseizures.

Case Presentation: symptoms

- The major symptoms included cognitive impairments (attention, memory, processing speed, concentration/executive functioning), tactile hypersensitivity, sun sensitivity, orthostatic hypertension, weight loss fatigue, non-restorative sleep, pelvic pain, difficulty urinating, headaches peripheral neuropathy, muscle atrophy, cervical radiculopathy, hair loss costochondritis, subluxation of multiple joints and generalized pain.

Case Presentation: Lab

- Lyme IgG Wb: 93 and 41 and IgM 41
- Lyme IgG Wb: 31 IND, 34 IND, 39+, 41+, 56+ IGeneX
- HGE IGM + 1:20
- ANA 1:640, later negative
- EBV VCA IGG AB 1.44 (0.0-0.9), EBV nuclear AB (EBNA) IGG 3.36 (0.0-0.9)
- Parvovirus b19 (IGG) 5.9 (0.0-0.89)
- Brain SPECT: moderate to severe decreased cerebrocortical perfusion, heterogeneous pattern

Case Presentation: Diagnosis?

- A) Somatic symptom disorder
- B) Hysterical conversion reaction
- C) Bodily distress syndrome
- D) Medically unexplained symptoms
- E) Factitious disorder (Munchausen's)
- F) Lyme borreliosis
- G) Other medical condition(s)
- H) Other medical condition(s) and Lyme borreliosis

Case Presentation: Diagnosis?

- A) Somatic symptom disorder
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- F) Lyme borreliosis
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Case Presentation: Diagnosis

- The diagnosis was late stage Lyme borreliosis with multisystemic symptoms, porphyria, Ehlers-Danlos/ALPIM syndrome (Anxiety-Laxity-Pain-Immune-Mood) with seizures caused by increased intracranial pressure from cranio-cervical instability.
- The patient did not have “pseudoseizures.”
- Patient was treated, is physically active, married and leading a productive life.

What Causes Illness and Mental Illness?

Complex & Poorly Defined Diseases

- Poorly understood illnesses are often considered “psychogenic” until the pathophysiology is better understood.
- Complex diseases require complex explanations.
- When dealing with poorly defined conditions, begin by defining it.

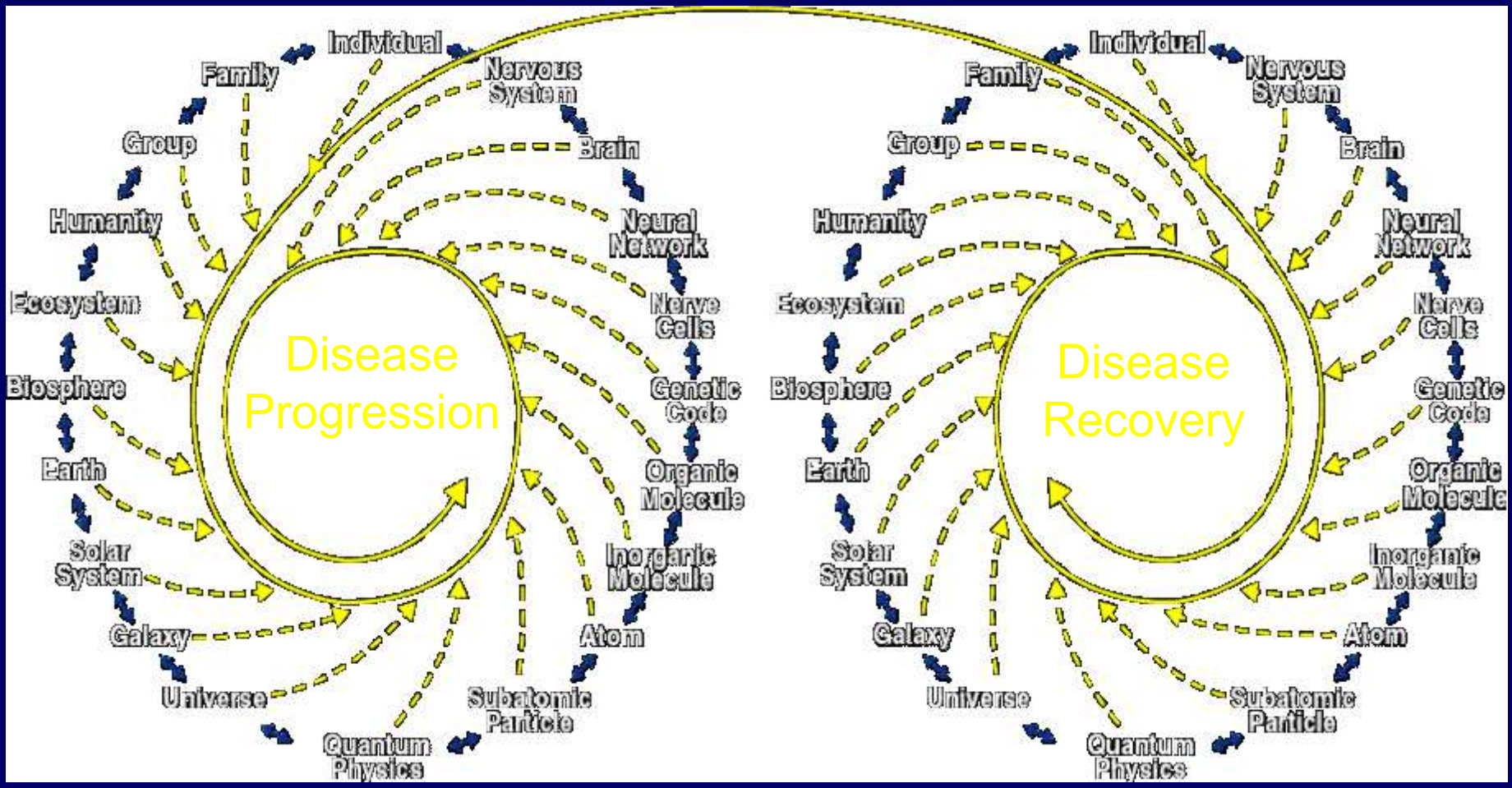
Defining Mental Health

- Mental functioning (cognitive, emotional and vegetative) facilitates adaptive and productive activities, fulfilling relationships and the capacity to enjoy the activities of life; the capacity to contend with adversity and the mental flexibility to adapt to changing life circumstances.

What Causes Illness and Mental Illness?

- Everything is caused by something
- Nothing is caused by nothing.
- Illness is from an interaction of contributors and susceptibilities resulting in a pathophysiological process.
- We can categorize types of mental illness, but we often do not know the cause.
- Mental illness is never a diagnosis by default.

Multi-Systemic Disease Model



Time

- Predisposing & precipitating factors
- Infections
- immune & other reactions
- Pathophysiological processes
- Dysfunction
- Symptoms & Syndromes
- Ineffective Treatment
- Disease Progression

Research & Clinical Observation: Microbes & TBD Cause Mental Illness

- Thousands of peer-reviewed journal articles demonstrate the causal association between infections, somatic illness and mental illness.
- Viral, venereal, vector-borne diseases are associated with persistent infections (Most notably arachnid, tick-borne diseases).
- 400+ peer reviewed scientific articles demonstrate the causal association between tick-borne disease and mental illness.
- Clinical observation by front line physicians also supports this view.

Dysregulated Aversive Emotional States

- Environmental phobias—agoraphobia, claustrophobia, acrophobia, etc.
- Interpersonal—paranoia, social anxiety, body dysmorphic disorder, pathological jealousy
- Body integrity—somatic symptom disorder, illness anxiety disorder
- Traumatic perception—posttraumatic stress
- Alarm—panic disorder
- Doubt—obsessive compulsive disorder
- Futility—depression (often comorbid)

Brain and Body Interaction

Comorbidity: Psychosomatic, Somatopsychic or Multi-systemic?

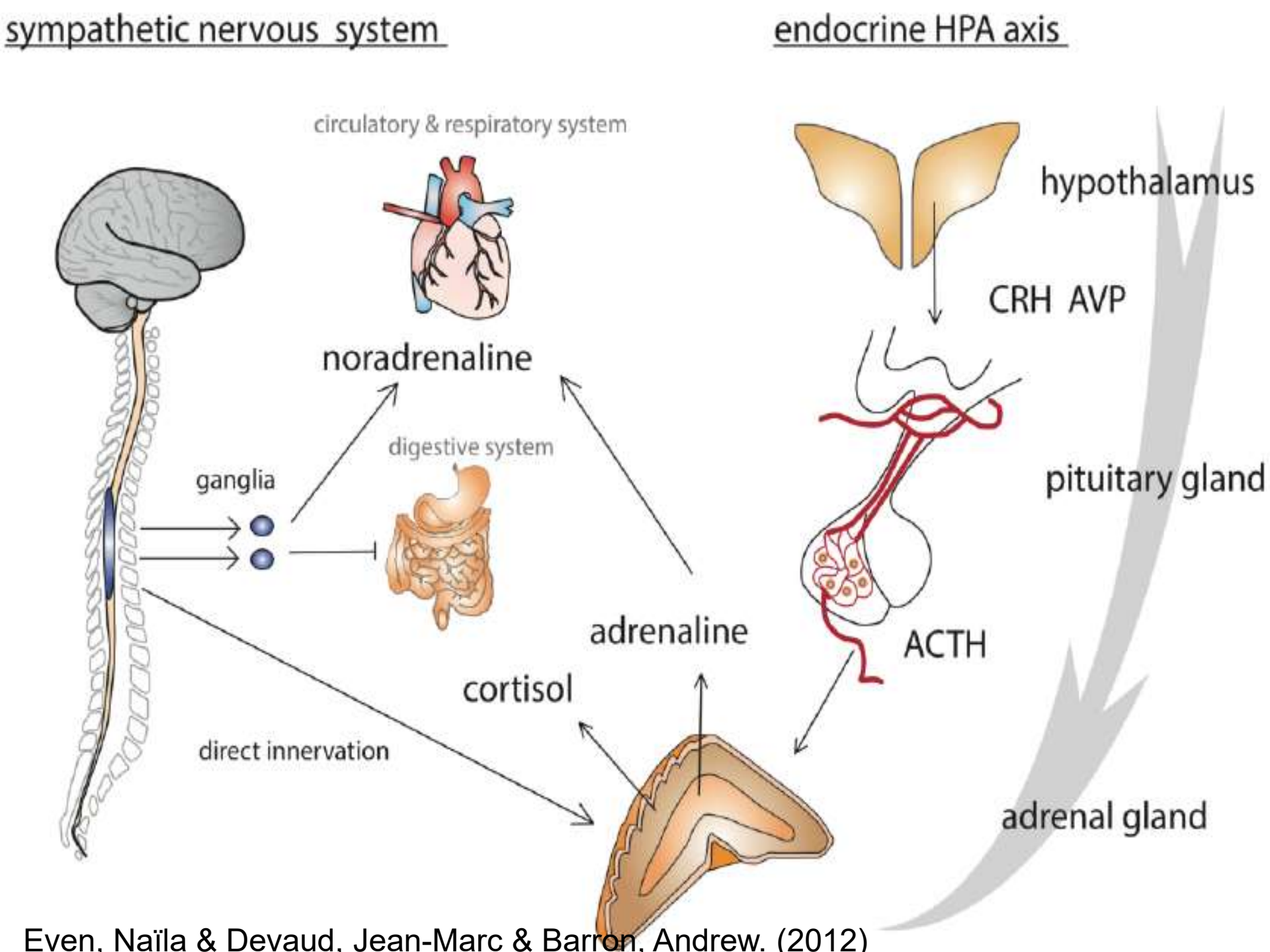
- **Psychosomatic:** Mental distress results in somatic symptoms.
- **Somatopsychic:** Somatic distress results in mental symptoms.
- **Multi-systemic** process adversely affecting the brain and body causing both psychiatric and somatic symptoms.
- Or a combination of the above.

Psychosomatic Disorders

- Somatic illness caused or aggravated by mental distress. High levels of stress &/or high reactivity to stress may contribute.
- Diagnosed by a psychiatric & medical evaluation, not a diagnosis of exclusion from inadequate assessment or diagnose or inability to understand the pathophysiology.
- The term is not included in DSM-5.

Psychosomatic Disorders II

- The list keeps shrinking as scientific knowledge advances. Tuberculosis, hypertension, stomach ulcers were once considered “psychosomatic.” Now it is rare to name a illness that is purely psychosomatic. However many diseases are made worse by stress and anxiety such as psoriasis, eczema, heart disease, irritable gut and skeletal muscle guarding.



Even, Naïla & Devaud, Jean-Marc & Barron, Andrew. (2012)

Stress &/or Stress Reactivity

- Shift: sympathetic-parasympathetic tone, HPA axis
- Increased: blood pressure, heart rate, breathing, blood flow to skeletal muscle, skeletal muscle guarding, blood sugar, inflammation
- Decreased: regenerative activity, blood flow to prefrontal cortex, digestive activity

Psychosomatic: Cardiovascular

- Chronic stress activates the hypothalamic-pituitary-adrenal axis (HPA) and the sympathetic branch of the autonomic nervous system, reduces vagal tone, increases plasma catecholamines, elevates heart rate, causes vasoconstriction, activates platelets and reduces heart rate variability.
- Associated chronic increases in proinflammatory cytokines contribute to endothelial damage, plaque formation, atherosclerosis thrombus formation, vascular occlusion, endothelial damage of the cerebral vasculature and acute coronary syndromes.
- These autonomic and immune system changes, singly and additively, exert adverse effects resulting in high CV morbidity and mortality.

Halaris A. Psychocardiology: Understanding heart brain connection. Psychiatric Times. 9-20-18

Multisystemic vs. Psychosomatic

- A person is reasonably healthy throughout most of their life, and then there is a point in time where a multitude of symptoms progressively appear. The number and complexity of these symptoms may be overwhelming and illness may be labeled hypochondriasis, somatic symptom disorder, or psychosomatic. However, both hypochondriasis and psychosomatic illnesses begin in childhood and are life long conditions which vary in intensity depending upon life stressors. If a complex illness with both mental and physical components begins in adulthood, the likelihood that this is psychosomatic is very remote.

“Functional Disorders”

- Historically a ”functional disorder” (not in DSM) is a medical condition that impairs normal functioning of bodily processes that remains largely undetected under examination, dissection or even under a microscope. At the exterior, there is no appearance of abnormality. This stands in contrast to a structural disorder (in which some part of the body can be seen to be abnormal) or a psychosomatic disorder.
- Generally, the mechanism that causes a “functional disorder” is unknown, poorly understood, or occasionally unimportant for treatment purposes.

“Functional Disorders” II

- Since the development and expansion of brain imaging, neurochemistry, microarray technology and other advances; pathological changes can be identified in psychiatric disorders and “functional disorders” is no longer a valid concept.

“Primary Psychiatric Illness”

- This category of mental disorders includes all those not believed to be associated with a medical condition.
- Like “functional disorders,” it is an outdated and invalid term since medical, physiological changes are associated with psychiatric illnesses.

"Compensation neurosis". An invalid diagnosis.

- “Compensation neurosis:“ Sometimes called by numerous synonyms has been used for many years in discussing the emotional sequelae of accidental injury. The clinical validity of these terms has not come under scrutiny in the literature dealing with issues of diagnosis and classification. An examination of "compensation neurosis" as an illness entity, using standard criteria of diagnostic validity, does not support the view that such a distinct disease exists.

Mendelson G. Med J Aust. 1985 13;142(10):561-4.

Objective vs. Subjective Symptoms

- Symptoms such as fatigue, aches, pain, cognitive impairments, mood dysregulation sensory complaints, etc. are categorized by some as “subjective” and considered to be malingering, factitious and less valid.
- Lab tests, even when poorly standardized, and clinical trials, even when poorly designed, are categorized by some as “objective” and therefore more valid.

Subjective, Non-Specific Symptoms?

- Late Lyme/TBD symptoms are dismissed by some as being subjective and non-specific.
- Two-tiered Lyme testing criteria is highly subjective and non-specific to active infection.
- The only symptoms specific for *Bb* infections are the erythema migrans rash and acrodermatitis chronica atrophicans. The diagnosis is mostly based upon specific pattern recognition.
- Many late stage symptoms are neuropsychiatric and can be demonstrated objectively with mental status evaluations, psychological testing and brain imaging.

Bransfield RC.

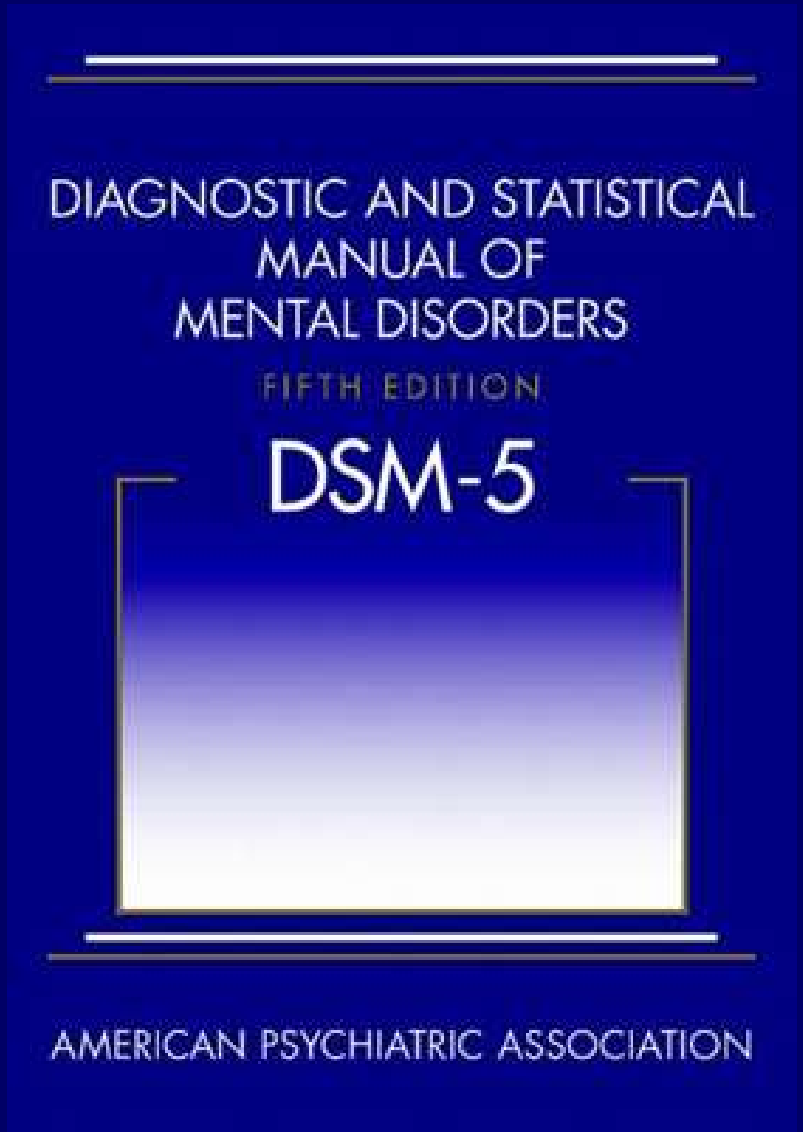
Delusional Parasitosis

- Some patients with peripheral neuropathy from Lyme, Morgellons, diabetes, dental chemicals and drug withdrawal experience formication, which is a crawling sensation under the skin and this is misdiagnosed by some as being delusional parasitosis. Truly delusional patients invariably have more than one delusion.

Defending Flawed Beliefs

- In science and medicine when a finding is incompatible with a hypothesis and diagnosis, then the hypothesis and diagnosis needs to be questioned. The IDSA 2006 Lyme guidelines were defended by instead labelling incompatible findings as “subjective” or “medically unexplained symptoms,” thereby keeping their flawed belief system intact.

DSM-5 Definitions



DSM-5

- The American Psychiatric Association Diagnostic and Statistical Manual (DSM-5)* is the international authoritative source for psychiatric diagnosis.
- DSM-5 & (ICD-10) codes are both shown.

*Diagnostic and Statistical Manual 5, American Psychiatric Association. 2013.

Somatic Symptom Disorder DSM-5 300.82 (ICD-10 F45.1)

- Excessive thoughts feelings or behavior related to somatic symptoms which have been present for at least six months.
- At least one of three criteria: health anxiety, disproportionate and persistent concerns about the medical seriousness of the symptoms, & excessive time & energy devoted to symptoms or health concerns.
- DSM-5 term that improves upon and replaces DSM-IV somatoform disorder.

“Medically Unexplained Symptoms”

- Outdated, not included in DSM-5.
- No medical condition is totally explained or unexplained. Instead, knowledge is on a continuum and all conditions are partially explained to different degrees.
- This label is impacted by the bias and level of knowledge of anyone calling it “unexplained.” These symptoms are often unexamined rather than unexplained.
- Or sometimes medically undiagnosed.*

Diagnostic and Statistical Manual 5, American Psychiatric Association
*Marke J.

Essential Hypertension

- Hypertension was once considered a psychosomatic disorder.
- Hypertension is easily diagnosed but the cause is unexplained, is it therefore a “medically unexplained symptom?”

Infection Load as a Predisposing Factor for Somatoform Disorders: Evidence from a Dutch General Practice Registry

- Results show patients with somatoform disorders have a higher infection load preceding their diagnosis as compared with matched controls, implicating that infection load may indeed predispose for developing functional somatic symptoms. These findings emphasize the importance of further research on immunological mechanisms in functional somatic symptoms.

Lacourt TE et al. Psychosom Med. 2013 Oct;75(8):759-64.

Functional Neurological Symptom Disorder (F44)

- Previously Conversion Disorder: One or more symptoms of altered voluntary motor or sensory function. [APA DSM-5]
- Unconscious repression of intrapsychic conflicts and conversion into physiological symptom, such as hysterical blindness or paralysis. Only rarely seen today in uneducated, unsophisticated patients.
- The last case I saw was 40 years ago in a rural, superstitious, illiterate patient.
- A misdiagnosis of some Lyme paralysis cases.

Diagnostic and Statistical Manual 5, American Psychiatric Association

Factitious Disorder (Munchausen's) 300.9 (F68.10)

- Factitious Disorder Imposed on Self: The falsification of physical or psychological signs or symptoms or induction of injury or disease associated with identified deception.
- Factitious Disorder Imposed on Another: The intentional production of symptoms in another person associated with identified deception (Frequently over diagnosed).

Diagnostic and Statistical Manual 5, American Psychiatric Association

Munchausen's syndrome by proxy and Lyme disease: medical misogyny or diagnostic mystery?

- Physicians unfamiliar with Lyme patients' shifting, seemingly vague, emotional, and/or bizarre-sounding complaints, frequently know little about late-stage spirochetal disease. Consequently, they may accuse mothers of fabricating their children's symptoms--the so-called Munchausen's by proxy (MBP) "diagnoses." Thousands of children, sick from complex diseases, have been forcibly removed from mothers who insist, contrary to customary evaluations, that their children are ill. The charges against these mothers relate to the idea they believe their children sick to satisfy warped internal agendas of their own. "MBP mothers" are then vilified, frequently jailed and publicly shamed for the "sins" of advocating for their children. In actuality, many such cases involve an unrecognized Lyme borreliosis causation that mothers may insist is valid despite negative tests.

Sherr VT. Med Hypotheses. 2005;65(3):440-7.

Body Dysmorphic Disorder DSM-5 300.7 (F45.22)

- An Obsessive Compulsive related disorder with distress and impairment due to a perceived physical anomaly, such as a scar, the shape or size of a body part, or some other personal feature.

Diagnostic and Statistical Manual 5, American Psychiatric Association

Posttraumatic Stress Disorder DSM-5 309.81 (F43.10)

- Exposure to actual or threatened death, serious injury or sexual violation causing clinically significant distress or impairment associated with re-experiencing (intrusive symptoms), avoidance, negative cognitions and mood, and arousal.
- Note: The trauma may be actual or perceived toxic or infectious exposure.

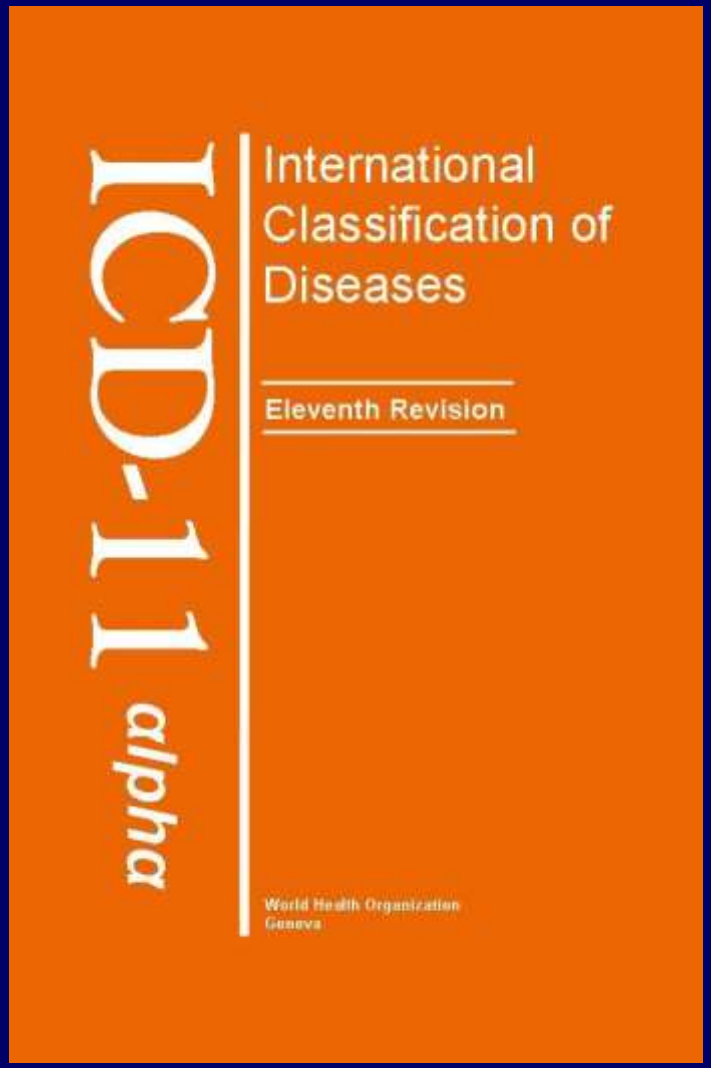
Diagnostic and Statistical Manual 5, American Psychiatric Association

Panic Disorder 300.01 (F41.0)

- There is an abrupt surge of intense fear with a sudden feeling of imminent life threatening alarm accompanied by a high level of physiological arousal.*
- Secondary panic attacks occur following the onset of a physiological event that results in a feeling of loss of control that then leads to a panic attack. (i.e. vertigo, arrhythmias, seizures, POTS, etc.)

*Diagnostic and Statistical Manual 5, American Psychiatric Association

ICD-11


ICD-11 alpha
International Classification of Diseases
Eleventh Revision
World Health Organization
Geneva

ICD11 Lyme Codes (2018)

- **1C1G Lyme borreliosis**
- **1C1G.0 Early cutaneous Lyme borreliosis**
- **1C1G.1 Disseminated Lyme borreliosis**
- **1C1G.10 Lyme Neuroborreliosis**
- **1C1G.11 Lyme Carditis**
- **1C1G.12 Ophthalmic Lyme borreliosis**
- **1C1G.13 Lyme arthritis**
- **1C1G.14 Late cutaneous Lyme borreliosis**
- **1C1G.1Y Other specified disseminated Lyme borreliosis**
- **1C1G.1Z Disseminated Lyme borreliosis, unspecified**
- **1C1G.2 Congenital Lyme borreliosis**
- **1C1GY Other specified Lyme borreliosis**
- **6D85.Y Dementia due to other specified diseases classified elsewhere: Dementia due to Lyme Disease**
- **9C20.1 Infectious panuveitis: Infectious panuveitis in Lyme disease**
- **9B66.1 Infectious intermediate Chorioditis: Infectious intermediate uveitis in Lyme disease**
- **8A45.0Y Other Specified white matter disorders due to infections: Central Nervous System demyelination due to Lyme borreliosis**

Lyme borreliosis (1C1G) additional codes

- Under Lyme borreliosis (1C1G) Lyme borreliosis there are additional code if needed, to identify any associated condition or sequelae. The extension code Cause of late effect' is used in addition to both codes to show the relationship between the causative condition and the resulting sequelae, examples are:
- 1D00.0 Bacterial encephalitis
- 1D01.0 Bacterial meningitis
- 1D01.0Y Other specified bacterial meningitis
- 1D01.0Z Bacterial meningitis, unspecified
- 1D02.0 Bacterial myelitis
- BC42.1 Infectious myocarditis
- 8B88.0 Bell palsy
- 9A10.0 Infections of the lacrimal gland
- 9C20.2 Purulent endophthalmitis

https://www.linkedin.com/pulse/what-lyme-disease-conditions-you-find-revised-icd11-luche-thayer/

Bodily distress disorder in ICD-11

Bodily distress syndrome: the evolution from medically unexplained symptoms

- The investigation and management of those patients who present with long-standing distress and pain of unknown physical aetiology can lead to mutual distress on the part of both the patient and the doctor, as well as costing a lot of money.

Ivbijaro G, Goldberg D. Bodily distress syndrome (BDS): the evolution from medically unexplained symptoms (MUS). Ment Health Fam Med. 2013 Jun;10(2):63-4.

Bodily distress syndrome: the evolution from medically unexplained symptoms II

- Medically unexplained or functional symptoms can capture a range of poorly defined disorders, including chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome, chronic pain syndrome, hyperventilation syndrome, non-cardiac chest pain and somatoform disorder. A possible diagnosis that captures the range of presentations in primary care is that of bodily distress syndrome.

Ivbijaro G, Goldberg D. Bodily distress syndrome (BDS): the evolution from medically unexplained symptoms (MUS). Ment Health Fam Med. 2013 Jun;10(2):63-4.

Bodily distress syndrome: the evolution from medically unexplained symptoms III

- Fink noted that the terminology of bodily distress syndrome captured the disorders of 100% of patients with fibromyalgia, hyperventilation syndrome and chronic fatigue syndrome, 98% of those with irritable bowel syndrome, and 90% of those with non-cardiac chest pain, pain syndrome and other somatoform disorders.

Ivbijaro G, Goldberg D. Bodily distress syndrome (BDS): the evolution from medically unexplained symptoms (MUS). Ment Health Fam Med. 2013 Jun;10(2):63-4.

Bodily distress disorder (6C20)

- Bodily distress disorder is characterized by the presence of bodily symptoms that are distressing to the individual and excessive attention directed toward the symptoms, which may be manifest by repeated contact with health care providers. If another health condition is causing or contributing to the symptoms, the degree of attention is clearly excessive in relation to its nature and progression. Excessive attention is not alleviated by appropriate clinical examination and investigations and appropriate reassurance. Bodily symptoms are persistent, being present on most days for at least several months. Typically, bodily distress disorder involves multiple bodily symptoms that may vary over time. Occasionally there is a single symptom—usually pain or fatigue—that is associated with the other features of the disorder.

Can fatigue be “psychogenic?”

- Fatigue: lack of energy unrestored by rest
- Second most common medical complaint
- Infections, cancer, allergies, injury, etc.-> inflammation->sickness syndrome->fatigue
- Fatigue associated with lack of delta sleep
- Fatigue can cause mental distress
- Depression usually follows fatigue in multi-systemic illnesses & is somatopsychic
- Fatigue can be a symptom of depression
- No evidence ME/CFS is psychogenic

Why is there an investment in “bodily distress syndrome?” Lack of awareness, financial interests?

Bodily distress disorder in ICD-11: problems and prospects

- A central feature of the definition of these disorders, that the symptoms are not due to physical or medical causes, has been criticized for being unreliable and for posing a fundamental nosological problem: defining a disorder on the basis of the absence of a feature rather than the presence of a problem.

Gureje O, Reed GM. Bodily distress disorder in ICD-11: problems and prospects. World Psychiatry. 2016 Oct;15(3):291-292.
Voigt K, Nagel A, Meyer B, Langs G, Braukhaus C, Löwe B. Towards positive diagnostic criteria: a systematic review of somatoform disorder diagnoses and suggestions for future classification. J Psychosom Res. 2010 May;68(5):403-14.

Bodily distress disorder in ICD-11: problems and prospects II

- In both bodily distress disorder and somatic symptom disorder, the most fundamental revision has been the abolition of the distinction between medically explained and medically unexplained somatic complaints.
- The revised classifications specifies features that must be present—distress and excessive thoughts and behaviors

Gureje O, Reed GM. Bodily distress disorder in ICD-11: problems and prospects. World Psychiatry. 2016 Oct;15(3):291-292.

"Excessive" is the critical word"

- Excessive thoughts feelings or behavior related to somatic symptoms which have been present for at least six months. DSM-5
- Bodily symptoms that are distressing to the individual and excessive attention directed toward the symptoms…not alleviated by appropriate clinical examination and investigations and appropriate reassurance…persistent…at least several months…usually pain or fatigue ICD11

Why are those patients excessively distressed by their illness?

Walking around all day with shoes that do not fit would make anyone distressed. Patients with chronic illness have symptoms that are much more distressing.

How is excessive defined?

- If a Lyme patient has paralyzing fatigue and 100 other symptoms, are they excessively concerned?
- The determination of what is excessive is very subjective. Is it impacted by the limits of the examination, the conceptual abilities or the bias of the examining physician and the financial goals of the insurance company or the single payer?

Who's distress are we really trying to relieve?

- If the patient complains about a poor outcome; the flawed belief system, the doctor's ego and conflicting financial interests can be protected by labeling the patient's complaints as subjective and non-specific, the aches and pains of daily living, medically unexplained symptoms, excessive concern, excessive body distress and/or bodily distress syndrome.

Allen Frances, Chair of DSM IV

- "Bodily Distress Disorder"=bad ICD-11 mistake: 1) Will mislabel as mentally ill millions who have normal health worry 2) Allows docs to assume "It's all in your head" 3) Encourages inadequate medical testing/diagnosis 4) Weak research 5) Wide patient opposition 6) Repeats DSM error

Making a Diagnosis

We often form impressions with limited information

Do you see The Creation of Adam, the brain or both?

Assessment and Diagnosis

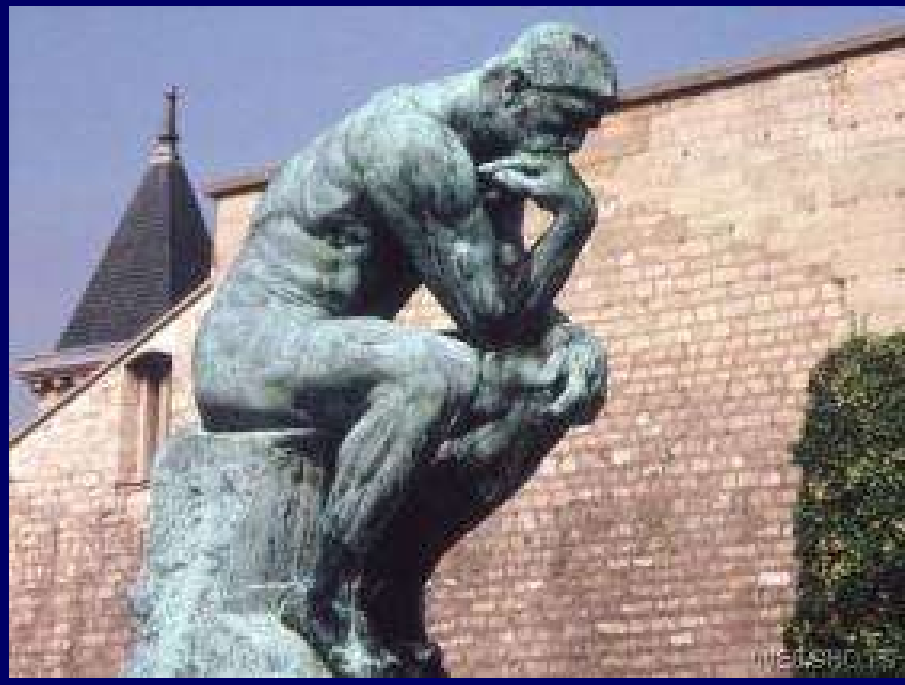
- Sir William Osler:
- There is no more difficult art to acquire than the art of observation.
- If you listen long enough, the patient will give you the diagnosis.
- Yogi Berra:
- You can observe a lot by watching.
- I would have never seen if I didn’t believe it.

Comprehensive Multi-System Assessment

- **Cognitive:** Attention, sensory hypersensitivity, working & short term memory, sequential memory, geographical memory, word finding, speech fluency, neologisms, comprehension, auditory & visual processing, processing speed, writing skills, math skills, dyslexia-like symptoms, imagery, executive functioning, "brain fog."
- **Psychiatric:** Disinhibition, low frustration tolerance, irritability, hypervigilance, exaggerated startle, explosive anger, suicidal, aggressiveness, paranoia, hallucinations, depression, rapid cycling bipolar, panic disorder, obsessive compulsive disorder, intrusive symptoms, posttraumatic stress disorder, social anxiety, generalized anxiety, phobias, depersonalization, self mutilation, psychosis, decreased social & school functioning, accident prone, etc.
- **Vegetative:** Sleep, eating, sexual functioning, thermal dysregulation, fatigue.
- **Neurological:** Headaches (multiple types), cranial nerve neuritis & neuralgia, eye findings, migratory polyneuropathy, spinal cord signs, transverse myelitis, radiculopathy, peripheral neuropathies, motor neuropathies, movement disorders, tics, gait, balance, ataxia, seizures, white matter lesions,
- **Autonomic Nervous System:** POTS, nausea, orthostatic hypotension, anhydrosis, etc.
- **Musculoskeletal:** Migratory arthralgias, arthritis, crepitations, periostitis, fibro, stiffness, neck and back discomfort.
- **GU:** Spastic bladder, testicular pain/pelvic pain, menstrual irregularity, sexual dysfunction, decreased libido.
- **Cardiac/Pulmonary:** Chest pain, shortness of breath, palpitations, heart block, murmur.
- **Gastrointestinal:** GERD, irritable gut, reduced GI motility (gastro-paresis, ileus, etc.).
- **Immune:** Fevers, sweats or chills, lymphadenopathy.

Bransfield RC. Neuropsychiatric Lyme Disease: Pathophysiology, Assessment & Treatment. ILADS European Meeting. Augsburg, Germany. 28 May, 2011.

With Emerging Diseases Think Outside the Box



Science says your doctor doesn't really listen to you

- In 67% of encounters in which clinicians elicited patient concerns, the clinician interrupted the patient after a median of 11 seconds. Uninterrupted patients took a median of 6 seconds to state their concern.

Singh Ospina N, Phillips KA, Rodriguez-Gutierrez R, Castaneda-Guarderas A, Gionfriddo MR, Branda ME, Montori VM. Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters. J Gen Intern Med. 2018 Jul 2.

Adequacy of the Assessment

- Are fatigue, cognitive impairments, pain and depression just subjective?
- No
- They are apparent on a clinical exam.
- The are objectively demonstrated by brain imaging and other testing.
- There are multiple scales that measure fatigue, cognitive impairments, pain and depression.

Adequacy of the Assessment II

- When evaluating or treating physicians have an inadequate knowledge of the illness, take an inadequate history, perform inadequate exams and fail to use adequate clinical judgment; patients often question their clinical impression when they are told there is no physiological basis to their symptoms. Such a failure of reassurance is not bodily distress syndrome.

Why are there such errors?

- Many thought leaders in medical specialties have very little fundamental or updated training in psychiatry, usually consisting of a one month rotation through a public mental hospital 40 years ago.

Is there a perfect storm of ignorance and special interests?

Who prefers less accurate and excessively narrow disease definitions?

- Individuals who can't do weighted decision making
- Some epidemiologists
- Some bench scientists
- Some vaccine researchers and promoters
- Many test kit patent holders
- Individuals lacking clinical assessment skills
- Individuals who's reputations are dependent upon their prior inaccurate beliefs
- Insurance companies
- Managed care delivery systems
- Bureaucrats managing healthcare systems
- Many who just listened to the wrong person

Who prefers more accurate and broader disease definitions?

- Patients
- Advocacy groups
- Individuals who can do weighted decision making
- Clinicians with the long term responsibility of treating these patients.
- Knowledgeable and ethical scientists

Which Facet of the Assessment is Given Greater Significance?

- Complete History
- Environmental Exposure
- Review of Systems
- Psychiatric Assessment
- Thorough Exam
- Time & Symptom Development
- Comorbid Conditions
- Differential Diagnosis
- Pattern Recognition
- Best Evidence Available

- Clinical Judgment
- Disease Progression After Treatment
- Response to Antibiotic Treatment
- Therapeutic Ex Juvantibus

- Lab
- Guidelines

Common Errors

- Lyme disease does not cause mental symptoms
- Symptoms are subjective and subjective symptoms are to be ignored
- Symptoms are non-specific
- Symptoms are self limited
- Immune symptoms are self perpetuating after the infection has cleared
- Psychiatric symptoms don’t have a physiological basis
- Lab tests are more reliable than a thorough clinical assessment

Public Perception of Mental Illness

- 71%: Due to emotional weakness
- 65%: Caused by bad parenting
- 45%: Victim's fault; can will it away
- 43%: Incurable
- 35%: Consequences of sinful behavior
- 10%: Has a biological basis; involves the brain

Stahl S. Essential Psychopharmacology. 1996. Cambridge University Press

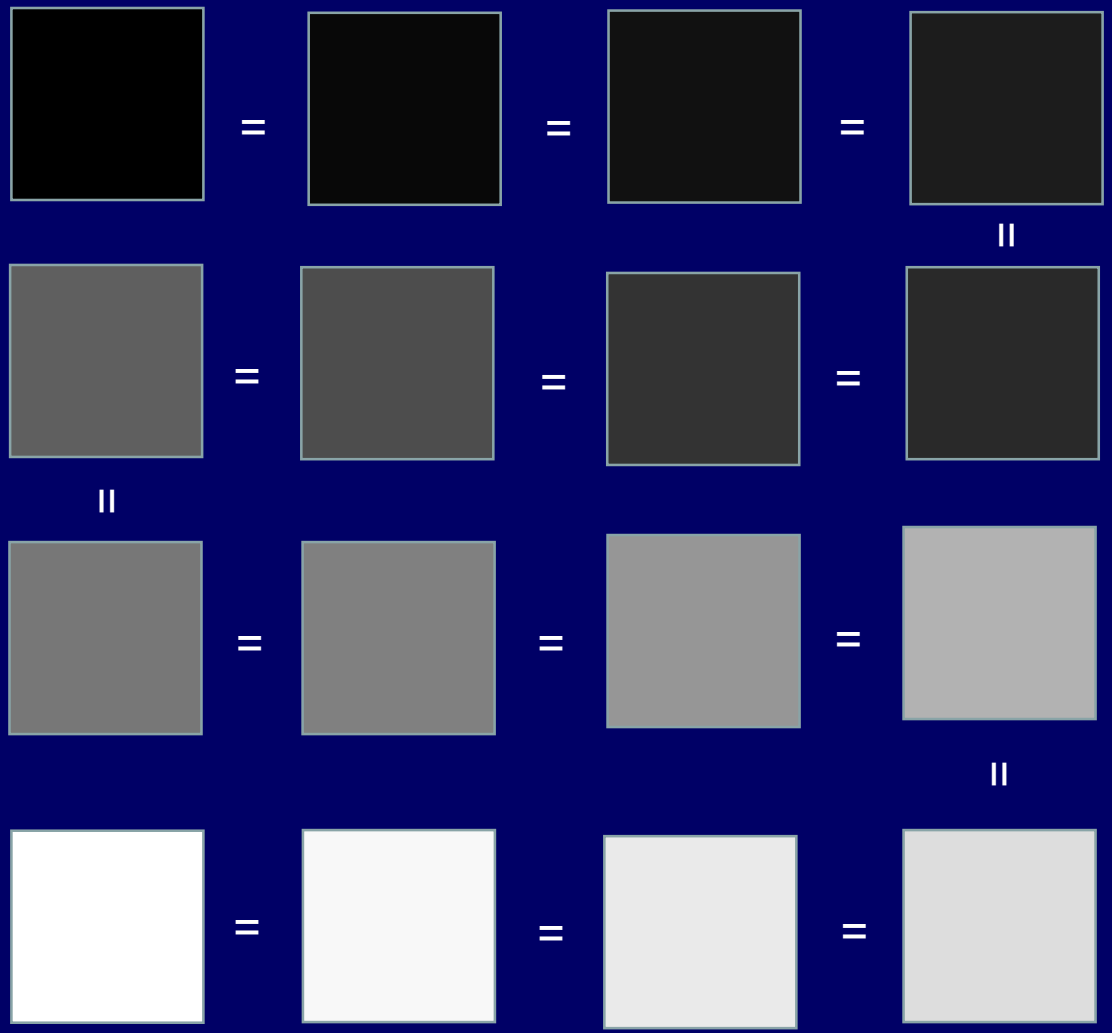
Common advice to patients with illnesses that are difficult to understand

- Get over it!
- Snap out of it!
- It's all in your head!
- Get off the pity pot!
- You're just weak willed!
- I just push myself and so can you!
- Pull yourself up by your bootstraps!

Marginalizing patients & the doctors who treat them

- Patients with complex, chronic and costly diseases can be marginalized.
- One example is mislabeling post inadequate treatment Lyme symptoms as "post treatment Lyme syndrome."
- This is achieved by a series of distortions which added together results in a total 180 degree distortion of the truth.

Squares are about equal: therefore black equals white



Example: twisting the truth

- Surveillance criteria created by epidemiologists is about equal to diagnostic criteria. the IDSA committee can exclude of any findings that did not fit with their belief as "medically unexplained symptoms." Although in Lyme fatigue is comparable to MS fatigue, pain is comparable to post surgical pain & disability is comparable to congestive heart failure; chronic symptoms are subjective, non-specific, excessive & the aches and pains of daily living and can be dismissed as bodily distress symptoms. Even though Klempner excluded PCR patients from his Lyme study, it was sort of a valid study. Even though there were conflicts of interests in the IDSA Lyme guidelines, they are sort of reliable. These guidelines are about equal to standards.
- Therefore doctors who follow traditional medicine with a thorough exam and clinical judgment are quacks.

Consequences of Diagnostic Errors

A case of medical misconduct

- Julia was in a wheelchair from Lyme disease and was blessed by the Pope in Philadelphia. Two psychiatrists independently cleared Julia of any psychological cause. The attending pediatrician refused to accept either report. She told the physical therapist to purposely drop Julia in order to rule out for malingering and the physical therapist purposely dropped Julia on the concrete floor.

https://on-lyme.org/en/sufferers/lyme-stories/item/260-both-blessed-and-cursed-julia-s-story

Multiple Myeloma, Misdiagnosed As Somatic Symptom Disorder: A Case Report

- Here we report on a case of a 57-year-old woman with pain and discomfort in multiple sites of upper body who was diagnosed as somatic symptom disorder after completing a partial examinations of relevant parts which turned out to be negative. She was eventually diagnosed with multiple myeloma after 6-month being misdiagnosed as somatic symptom disorder.

Yao J. Front. Psychiatry, 31 October 2018

Suicide in Chronic Illness

- Suicide is a major cause of death in many chronic illnesses where physical and emotional challenges persist. Physical illness and functional disability are known risk factors for suicide. Increased risk of suicide has also been found in younger persons diagnosed with POTS, CFS/ME, fibromyalgia, and Lyme disease.
- The interpersonal theory of suicide may be relevant to the chronic illness community. This theory proposes that people are at increased risk for suicide if they experience perceived burdensomeness (the perception that they are a liability to those around them) and thwarted belongingness (the perception that they do not belong in a social group). For those who are disabled and unable to work or go to school, loss of social interaction can increase isolation. Loneliness is a known risk factor for suicide.

Pederson CL, Brookings JB. Suicide Risk Linked with Perceived Burdensomeness in Postural Tachycardia Syndrome. Journal of Health Science & Education. 2018

Why are patients with controversial and invisible illnesses suicidal?

- Psychological and social:
  - Isolation and a feeling of abandonment from family, friends, employers, insurance companies and healthcare system
- Physiological:
  - Comorbid depression and other psychiatric illnesses, substance abuse
  - Physiological changes in immune system and neurotransmitters and associated with suicidality

Psychosocial Contributors to Suicide

The psychosocial contributors that collectively can increase suicidal risk include tired of feeling awful; being unheard and told symptoms are imaginary, self inflicted, psychosomatic, etc.; distress dealing with multisystem symptoms; guilt and fears of being a burden; a lack of understanding and negative views of the condition on the part of the family, friends, physicians and others in the healthcare system and losing work, family and friends.

Suicide and Lyme and Associated Diseases (LAD)

- Suicidality seen in LAD contributes to causing a significant number of previously unexplained suicides and is associated with immune-mediated and metabolic changes resulting in psychiatric and other symptoms which are possibly intensified by negative attitudes about LAD from others. Some LAD suicides are associated with being overwhelmed by multiple debilitating symptoms, and others are impulsive, bizarre, and unpredictable.
- Negative attitudes about LAD from family, friends, doctors, and the health care system may also contribute to suicide risk. By indirect calculations, it is estimated there are possibly over 1,200 LAD suicides in the US per year.

Bransfield RC. Neuropsychiatr Dis Treat. 2017 Jun 16;13:1575-1587.

The Death Formula

Lyme & associated diseases infection→

Persistent proinflammatory cytokines→

Dysregulation of tryptophan metabolism→

Quinolinic acid→ NMDA receptor agonism→

Glutamate dysregulation→

Neural circuit dysfunction→

Psychiatric dysfunction→

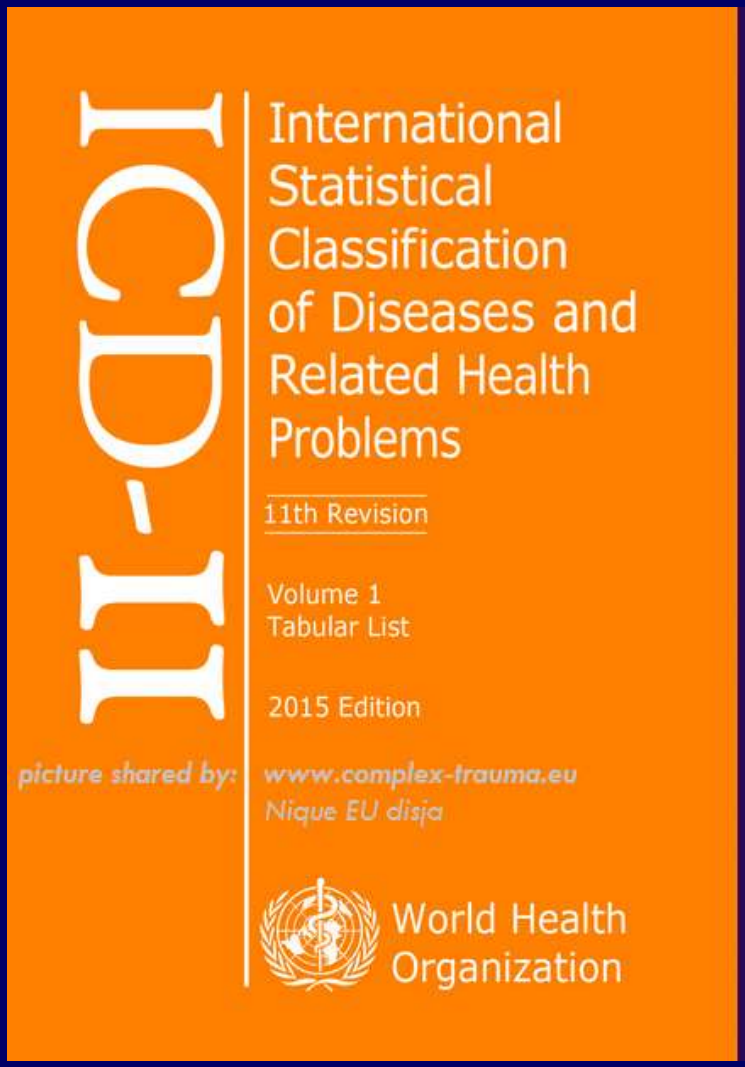
Suicidal, sometimes also homicidal

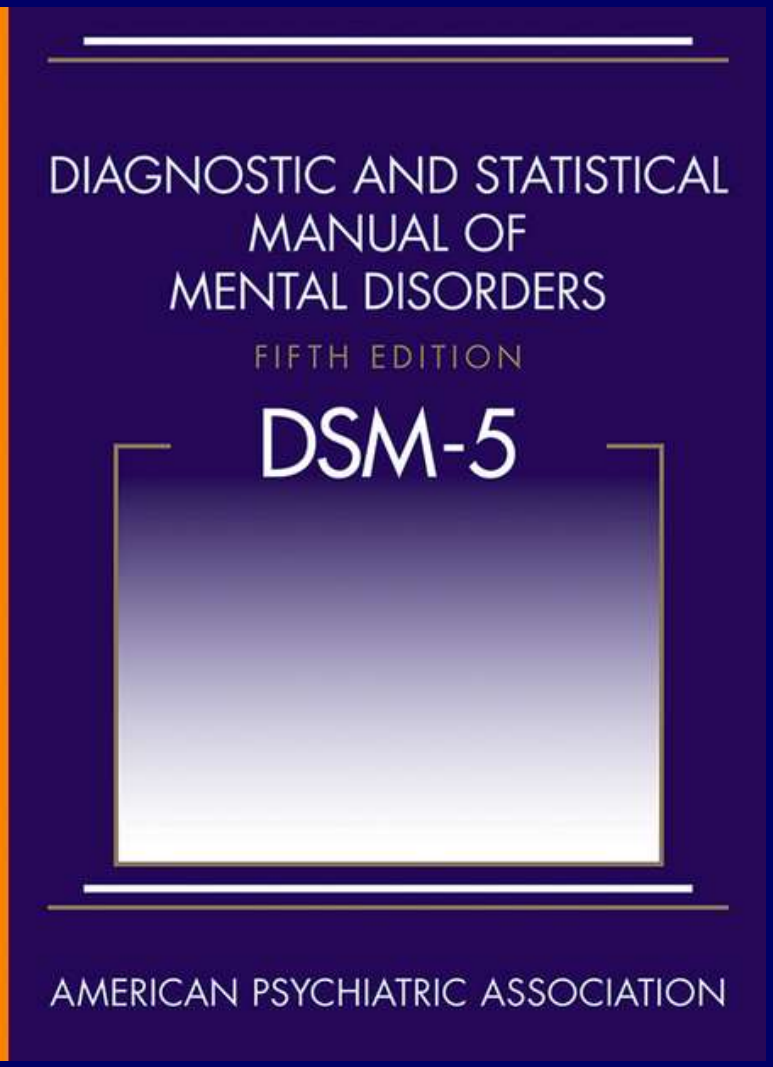
The Importance of Screening for Suicide Risk in Chronic Invisible Illness

- Many people suffering from chronic invisible illnesses like chronic fatigue syndrome/myalgic encephalomyeletis (CFS/ME), fibromyalgia, Lyme disease, and postural orthostatic tachycardia syndrome (POTS) report increased suicidal ideation and past suicide attempts compared with the general population. A number of factors contribute to suicide risk in chronic illness. Physical factors, like sleep disturbance and pain, as well as psychosocial issues like perceived burdensomeness, thwarted belongingness, loneliness, and depression may contribute to an increased suicide risk. Healthcare practitioners are encouraged to actively screen for suicide risk in their chronically ill patients, and have a protocol in place to refer their patients to proper community resources.

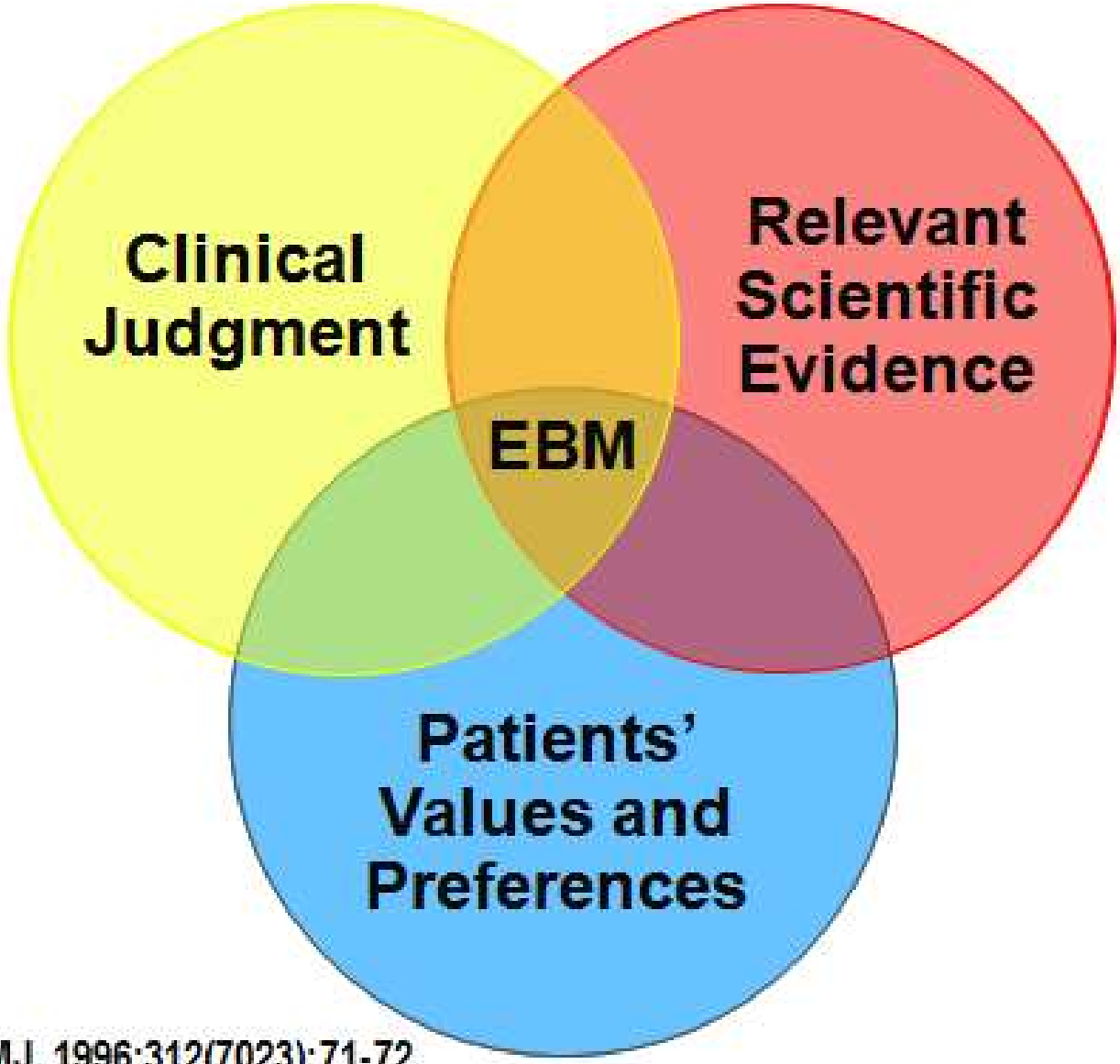
Pederson CL. J Health Sci & Education. 2018; 2(4):1-5.

Discussion and Summary



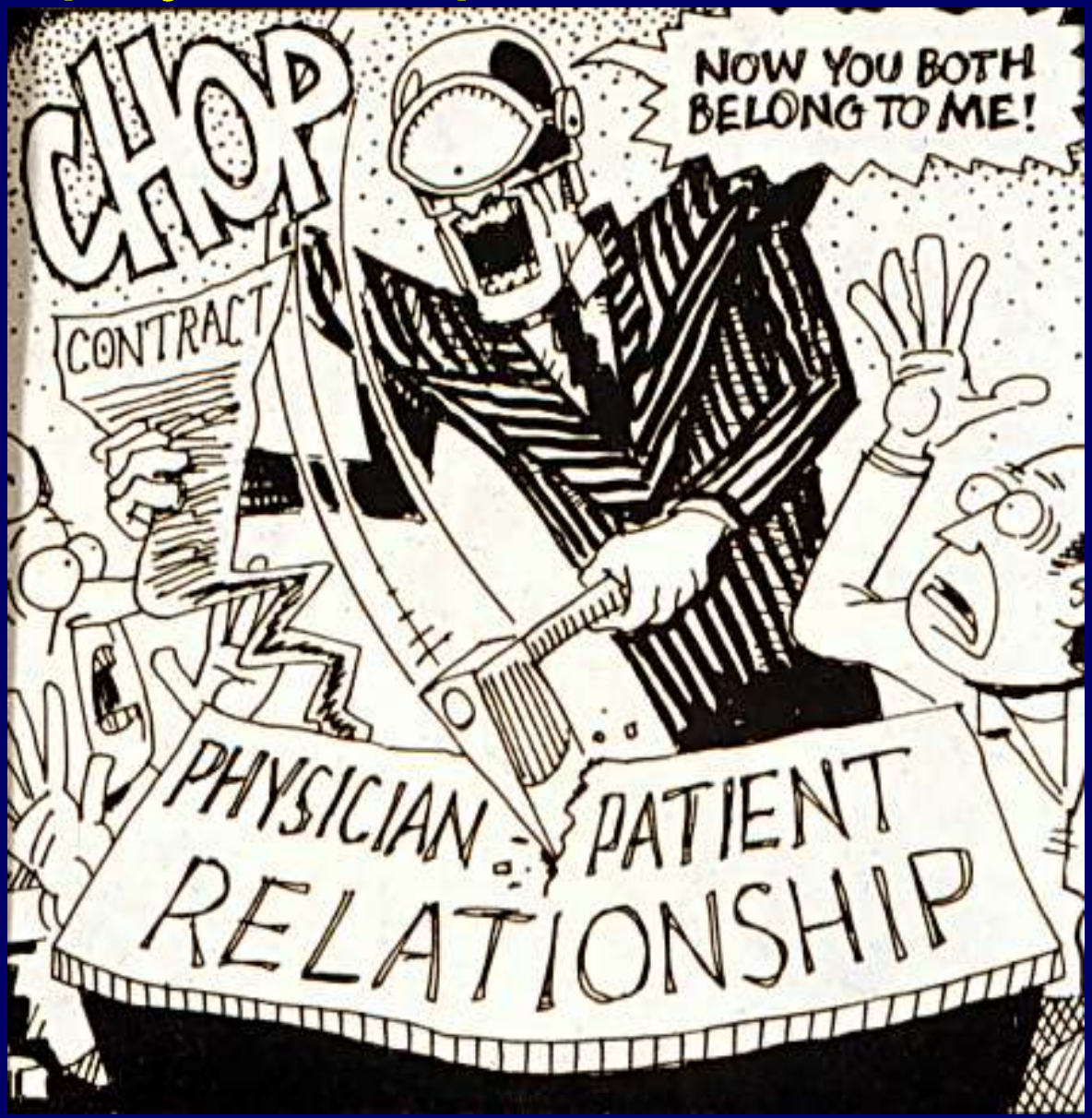


What Is Evidence-Based Medicine?



Sackett DL, et al. BMJ. 1996;312(7023):71-72.

Who has the decision making responsibility in the physician patient relationship?

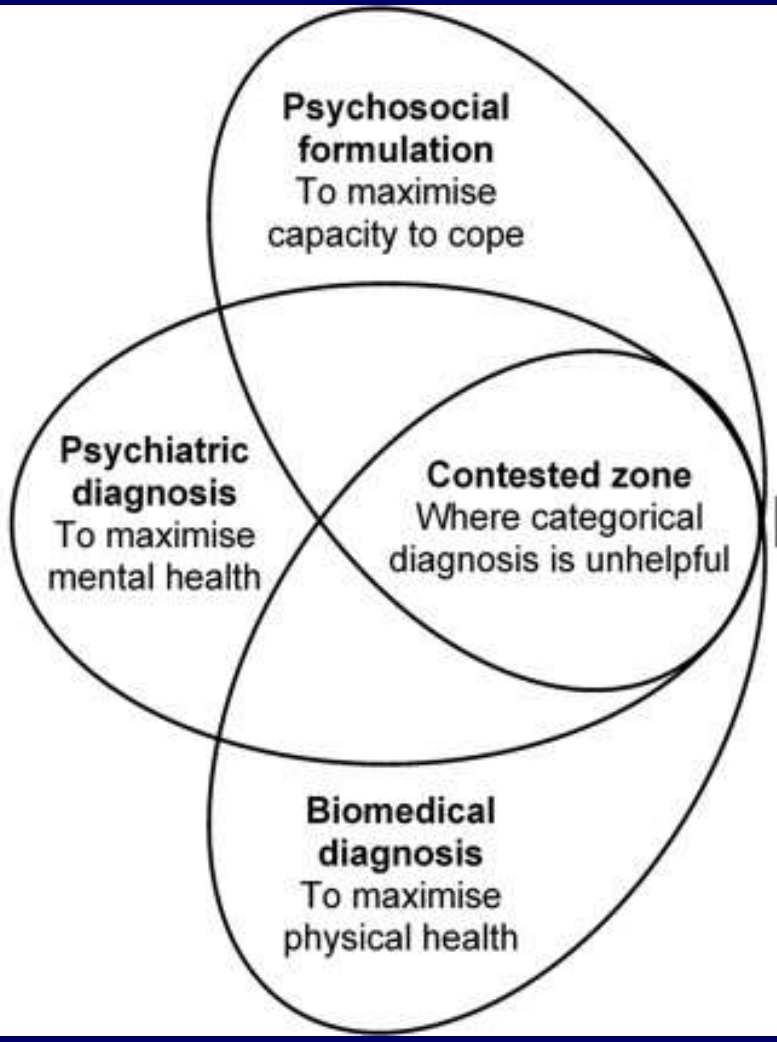


Constructing a helpful explanatory framework for patients with medically unexplained symptoms in general practice

Referral for further diagnostic assessment

Benefit limited by:
- patient choice to engage
- patient capacity to engage
- access to services
- other comorbidities

Potential harm:
- side effects of intervention
- dependence on health personnel or the model of therapy restricting engagement in other helpful treatments



Goals

To construct explanatory frameworks:
- for the patient
- for the doctor
- for other health professionals

That can:
- maximise the patient's power and agency
- minimise stigma
- incorporate a holistic focus to allow treatment in all domains
- validate suffering and provide supportive care

Stone L. Ment Health Fam Med. 2013 Jun; 10(2): 101–111.

The French Tick-borne Disease Working Group Guidelines I

- The French guideline recommendations refute the practice of replacing medical care for biological illness with palliative care for psychosomatic illness.
- *'it is necessary to abstain from the false dichotomy of 'psychosomatic OR biological/organic pathologies."*
- *"A practitioner who does not know how to treat his [Lyme/TBD] patient cannot use therapies for psychosomatic illness instead of treatment for biological/organic illness and infection.*

The French Tick-borne Disease Working Group Guidelines II

- *"However, treatment for the psychological distress caused by such infections, as well as psychiatric conditions arising from neurological damage from the infections, may be used in addition to antimicrobial treatments for the infections and biological illness."*
- "Such psychological or psychiatric therapies may only take place if there is a finding they would be useful and after the patient undergoes a thorough assessment by specialists [psychiatrists and neurologists]."

Approaching Unexplained Symptoms

- Many patients with complex, confusing symptoms and poorly understood diseases are often sent to psychiatrists.
- Psychiatric diagnosis is never a diagnosis of exclusion. A failure to make a diagnosis based upon various so-called “objective tests” is not a basis for a psychiatric diagnosis. The diagnosis of any psychiatric syndrome requires the presence of clearly defined signs and symptoms consistent with each diagnostic category.
- The ethical approach is to continue attempting to explain the symptom.

What Causes Multisystemic Illness?

- We always need to be alert to new and emerging diseases. Not everything has been well understood or categorized.
- Many patients are given a psychiatric diagnosis as a result of an inadequate medical exam.
- The onset of a multisystemic illness is rarely, if ever, associated with a psychogenic etiology. The presence of a psychiatric diagnosis does not eliminate the possibility of a comorbid somatic diagnosis or a comorbid somatic diagnosis causing psychiatric symptoms.

Conclusion

- To properly understand the mind/body connection, a knowledge of general medicine, psychiatry, and the systems which link the soma and the brain are required. No one has a complete knowledge of all fields of medicine. We must have compassion and humility and recognize that not all diseases have been discovered or properly understood and be aware that much remains to be learned about the brain/body interaction.

Conclusion II

- “Bodily distress syndrome, medically unexplained symptoms, somatoform disorder, functional disorders, psychogenic illness, psychogenic pain, primary psychiatric disorders, compensation neurosis,” PTLS, other similar contrived and outdated terms; the misuse of “subjective and nonspecific” and the over diagnosis of conversion disorders, Munchausen by proxy, delusional parasitosis & pseudoseizures distort science, medicine and ethics and harm patients. Strong efforts to oppose such inaccuracies are needed.

Thanks for preventing misperceptions…

Questions?