



The Coalition for Diagnostic Rights:
United for Ethical Management of Diagnostic Uncertainty
www.diagnosticrights.org

Diane O'Leary, PhD
10107-3 Windstream Dr.
Columbia, MD 21044
diagnosticrights@gmail.com

Comments to Hearing for Funktionelle Lidelser
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I am a philosopher working in medical ethics, the Executive Director of the Coalition for Diagnostic Rights in the US. We are an organization with an international mission: to end the practice of mistakenly denying medical care to the ill based on reckless diagnosis of any version of "it's all in your head". (That can include all varieties of somatoform disorder, functional disorders, somatic symptom disorder, bodily distress syndrome, bodily distress disorder, pervasive arousal withdrawal syndrome, etc.)

The number of patients and patient groups asking for our assistance is hundreds of times larger than any number we could possibly directly manage – because this problem is an international epidemic. In that context we are gravely concerned about the approach to diagnostic uncertainty currently in force in Denmark. We believe the protocols of Professor Per Fink and The Research Clinic for Functional Disorders and Psychosomatics to be medically reckless to the point of negligence, and we call upon the Danish government to rectify this unethical state of affairs.

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1. There are distinct advantages to any diagnostic approach that can streamline protocols for management of patients with medically unexplained symptoms. These patients absorb roughly 50% of a general practitioner's day and very often lead to large expenditures that yield no diagnostic or treatment insights. Given current financial strains on any national health service, diagnostic innovations that can reduce unnecessary expenditures for such a massive portion of the patient population are very appealing.

The Research Clinic for Functional Disorders works centrally with the concept of "bodily distress syndrome", and that concept is a candidate to replace "somatoform

disorders” in the upcoming edition of the ICD. Aside from its appeal as a Danish innovation, it carries substantial financial appeal for every national health service. BDS competes with “bodily distress disorder”, an approach with considerably less financial pizzazz, but great ease of use.

When considering the merits of a concept like BDS it’s important to keep in mind the context of heated international debate about how to replace the longstanding concept of somatoform disorder. Any psychiatrist who’s developed a genuine contender has a lifetime investment in winning that spot in ICD-11. National investment in the research that makes a new concept like BDS possible is often made in hopes of financial reward as well. These sorts of pressures can make it very difficult for all parties involved to take an objective look at the risks posed by a newly developed approach.

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2. The most important facts about any candidate to replace somatoform disorder are those that clarify the size of the patient population affected by it. Materials on functional disorders in the BDS package focus on the 50% of the GP’s patient roster with “bothersome” unexplained symptoms – and fail to mention immense populations of medical patients whose genuine suffering is systematically ignored by BDS protocols.

- 45% of autoimmune disease patients in the US report having been wrongly denied medical care on the basis of mistaken somatoform diagnosis, according to the American Autoimmune-Related Disease Association. That’s 22 million patients mistakenly denied needed medical care in just that one category. This figure is nearly double the total number who have cancer, according to the CDC.
- Research shows 1/100 US teens suffer from the autonomic disorder known as “POTS”, according to the National Dysautonomia Research Foundation, yet surveys show POTS patients have an 85% likelihood of being refused medical care in error based on mistaken diagnosis of “it’s all in your head”. These kinds of figures are common for poorly understood disorders.
- There are roughly 30 million rare disease patients in the US according to the NIH, and 30 million in Europe, according to Eurodis – rare disease is far from rare. In this US this figure is equivalent to the number swept up in the “epidemic” of diabetes, according to the CDC.
- These figures tell us the average doctor in the US and in Europe sees a bare minimum of 2 patients on every working day with rare diseases whether she knows it or not.
- There are roughly 7000 rare diseases on the current roster according to Eurodis, so those 2 rare disease patients each day are statistically likely to suffer from ailments their doctors have never seen or heard of before.

- Eurodis also reveals that a staggering 41% of rare disease patients in Europe are misdiagnosed at least once.
- There are 290,000 people in Denmark with rare diseases, assuming levels proportionate with population size in Europe. This is roughly equal to the entire population of the city of Aarhus. (Figures from 2009.)
- If you take the unusually large student population in Aarhus and triple it, that number will still fall short of the number of rare disease patients in Denmark who have been misdiagnosed.
- Medical misdiagnosis at least doubles the delay to accurate diagnosis of rare disease according to Eurodis, but psychiatric misdiagnosis – that is, misdiagnosis with something like BDS – will cause much more severe delays to accurate diagnosis and treatment.
- Eurodis studies show that misdiagnosis with something like BDS will take an average 3-month diagnostic journey for Tuberos Sclerosis patients and turn it into a 3-year journey. For patients with Crohn’s Disease unobstructed diagnosis takes 1 year, but misdiagnosis with BDS will transform that into 6 years of untreated suffering and harm. A mistaken diagnosis of BDS for an Ehlers-Danlos Syndrome patient triggers an unspeakable 7 additional years of severe suffering and irreversible harm.

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3. Prof. Fink’s approach to functional disorders at the Aarhus clinic pays little attention to the possibility of diagnostic error – in fact, one 2007 presentation by Professor Fink neglects even to mention it. The patient learns in the clinic’s guidebook that many patients there have received one of more of these diagnoses:

- Fibromyalgia
- Chronic fatigue syndrome (CFS)
- Irritable bowel syndrome (IBS)
- Chronic pain disorder
- Somatisation disorder
- Multiple chemical sensitivity (MCS)
- Whiplash associated disorder (WAD)

with the additions of PMS, tension headache and myalgic encephalomyelitis in other publications. “Most doctors do know the different diagnoses mentioned in the above box”, the guidebook explains, “but they are unaware that they can be viewed as one single illness . . . Today, we regard these as subtypes of BDS”, it reports, as if the world

medical community is in harmony on this point. With the right cocktail of antidepressants, mental health therapy and exercise, apparently all of these problems can be cured.

If this sounds a bit like one of those magical “tonics” sold from covered wagons in the American wild west, it is. Prof. Fink is indeed asserting – as if there simply is no dispute about it – that he has found one magical cure for everything from irritable bowel syndrome to whiplash, from PMS to the disabling suffering of severe ME, and that magical cure is talk therapy, exercise and antidepressants.

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4. A sham of this kind can only be professionalized by expert use of terminology. In this case it's the term “functional” that does all the work. Professor Fink treats the phrase “functional symptoms” as synonymous with “unexplained symptoms” in a 2007 paper, “Symptoms and Syndromes of Bodily Distress”, and he describes them as symptoms “defying the clinical picture of known, verifiable, conventionally defined diseases . . . unbacked by clinical or paraclinical findings”.

Of course the obvious question here is this: what about symptoms of the many disorders on that list that are widely accepted as medical explained? On what basis should any doctor accept the broad conclusion that all of these widely varied medical disorders have psychiatric causes? More specifically, where is the medical research that refutes the enormous numbers of practicing physicians, research centers, medical journals and clinics devoted to understanding and treating, say, fibromyalgia, as a wholly medical condition – in this case one that's made international headlines just this week with robust new medical verification?

On what basis should we conclude that as a psychiatrist Prof. Fink has the expertise to refute claims about irritable bowel syndrome from, say, an esteemed Functional Gastrointestinal Disorders Clinic at University of North Carolina? Their clinic brochure directly contradicts Fink's use of the term “functional” with this unequivocal statement: “It is important to understand that these are not psychiatric disorders”. How would doctors at that UNC clinic – or the thousands like it across the globe – respond to the notion that their devoted work on medical IBS solutions is meaningless because Professor Fink has declared “today we regard [IBS] as a subtype of a psychiatric disorder”?

The field of psychogenic medicine has done a great deal of research on the terminology that makes patients with apparently somatoform symptoms more “compliant”, less likely to angrily insist that their suffering is truly physical. It turns out the term “functional” will pass for “genuinely medical” to the patient who doesn't know any better, and the very wide range of professional interpretations of that term suit the compliance project very well. For the patient who's looking into Fink's insistence that his symptoms are “functional”, a quick Google search reveals countless facilities treating “functional” conditions with medical solutions. “How comforting!” the BDS patient will

exclaim! What he won't see – and this is a cool calculation on the part of BDS proponents – is that at Prof. Fink's clinic the term “functional” actually means “psychiatric”, even if it does mean “medical” elsewhere with greater frequency.

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5. To adequately assess the viability of Prof. Fink's budget-conscious approach you must get to the heart of the matter – research that proves not only that commonly accepted medical disorders like IBS, tension headache, PMS, whiplash and lower back pain are actually psychiatric disorders, but also that they're one and the same psychiatric disorder.

Following that, you must locate proof that none of the “contentious disorders” like fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivity disorder or even something as disabling as ME, could possibly have true medical causes. Keep in mind that researchers announced new evidence this week of fibromyalgia's medical origins, and keep disorders like Lupus in mind too, as serious and quite common diseases once thought to have psychiatric causes.

Next, you must read between the lines to determine what a patient with autoimmune disease endures at the Aarhus clinic, given that she's got a 45% chance of having her medical symptoms mistakenly construed as psychiatric in a standard medical setting. What happens to the 85% of teens with POTS who are routinely forced to suffer untreated by doctors with much broader acceptance of the medically unknown than Prof. Fink can muster? What is an average day at the clinic like for the patient who's been mistakenly diagnosed with BDS when she actually suffers from POTS or lupus?

Finally, and this is the most important of these tasks because it so severely threatens such a massive portion of your population, you must consider the journey of a rare disease patient at the Clinic for Functional Disorders. Remember that there are as many people with rare disease in Denmark as there are people in Aarhus, that 41% of them are misdiagnosed, and that those misdiagnosed with BDS face at least double the delay to accurate diagnosis and treatment – with some, like those with Marfan Syndrome, suffering for an unnecessary 13 additional years.

When these investigations yield startling results ask yourself, “Given the inhumane levels of suffering caused by mistaken diagnosis of BDS, what checks and balances has Prof. Fink built into this system to protect patients who are actually ill from misdiagnosis?”

The individual consequences of improper diagnosis include the worsening in clinical status, psychological damage often related to medical denial of the undiagnosed disease and, in some cases, death.

This is Eurodis clarifying the consequences of diagnostic delay for rare disease patients in Europe.

In addition, families endure other consequences, including lifelong feelings of guilt due to inappropriate behavior toward the affected person prior to diagnosis, or possible birth of additional affected siblings. Without diagnosis a patient's medical or social needs may not receive due attention and the patient may be considered a complainer who, as a result progressively loses confidence in medicine.

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6. There is bad reasoning at the root of Prof. Fink's approach to functional disorders – failure to recognize the distinction between symptoms that “have not been explained” and symptoms that “cannot be explained”. The two might seem quite clearly distinct to the average Joe (certainly if that Joe happens to be a scientist of any kind), but to those in the field of psychogenic medicine this distinction is often elusive. The implication is that a doctor's diagnostic skill is so close to infallible that every symptom a doctor has not readily explained must have causes outside the range of medical expertise – that is, psychiatric causes. Given the extraordinary prevalence of rare disease, and the impossibility of any doctor recognizing even a small portion of the 7000 rare diseases, this is a diagnostic approach that simply cannot be medically defended, no matter how many bold and impressive statistics are built upon it.

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7. The surest sign of uncertainty is secrecy. The practice of medicine is a collaborative endeavor because collaboration works as a filter against reckless and ill-conceived ideas about patient care. On both the conceptual level and the level of clinical practice, open debate is what keeps medicine honest, and patients safe.

If Prof. Fink felt secure that his approach to that list of disorders could withstand medical scrutiny, he would present it not to the patients he treats, but to the doctors whose work he challenges. If he felt he had sufficient grounds for refuting the medical basis of fibromyalgia he would proceed to do so on the level of peer-reviewed medical journals, alongside research supporting the view that fibromyalgia requires medical treatment. As long as there remain doctors, researchers, clinics and publications on the medical origins of any disorder on Prof. Fink's list, that means he has failed to convince the medical community that medical treatment should be withheld – and if he's failed to convince them he certainly should fail to convince the Danish government.

That same indefensible secrecy is evident on the level of patient care in the current epidemic of forced inpatient mental health treatment for disputed disorders. Justina Pelletier was held on a psychiatric ward at Boston Children's Hospital for fourteen months because doctors there insisted the teen's longstanding diagnosis of mitochondrial disorder was mistaken.

Experts in psychosomatic medicine just like Professor Fink were so certain her symptoms had psychiatric causes that they alerted the state to remove the child from her home so that inpatient treatment for somatoform disorder could be possible – the same general treatments provided at Prof. Fink’s clinic. When after a year the girl’s physical condition had clearly deteriorated, the Court was forced to rectify its error with open reversal of its original decision. The Judge ordered the girl to be returned to her original doctors for treatment of the disputed medical disorder. As the family now prepares their lawsuits against the hospital and the state, the girl begins the very long rehabilitation effort that will make it possible for her to walk again, having lost that skill when her medications were recklessly and mistakenly withdrawn.

That atrocity occurred, like so many others across the globe, because doctors in psychosomatic medicine flatly refused to collaborate with doctors currently treating the patient medically. It is difficult to see any way to defend that secretive approach as patient-protective because, again, if a psychosomatic diagnosis is firmly supported it will withstand debate with doctors in favor of a medical approach. Refusal to collaborate can never be a patient-protective choice. Secrecy of that kind is a sign that those standing for psychosomatic diagnosis are afraid their footing will fail when they face a challenge.

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8. In the end of the day, beyond all the statistics, beyond the medical and psychiatric disputes, this is an ethical matter. Failure to recognize a disorder like BDS might result in unnecessary medical tests and treatments, but failure to recognize a medical disorder has consequences so dire that they overturn the very purpose of the practice of medicine. Both the Danish medical system and the Danish government have a duty to recognize that the potential harms of the current approach far outweigh its potential benefits – difficult as that fact may be for the financial bottom line.

Every field has its blind spots, long lapses in vision caused by generations of unconsidered professional habit, lapses no one in the field has ever been called upon to examine or defend. In medicine that blind spot is diagnostic uncertainty. Any outsider can peer in and see there what medical expertise now fails to see: patients with physical suffering have a right to medical treatment until proof exists to support an alternative approach. As things currently stand in Denmark the reverse is true for all the many medical patients whose symptoms happen to pose diagnostic challenges. This state of affairs burdens your population with years of unnecessary suffering.

Any diagnostic protocol that fails to take stock of the risk of error must be rejected, and this one risks inhumane suffering with appalling frequency. When doctors fail to see something like this it is the job of government to make it clear.

Respectfully,

Diane O'Leary, PhD

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