Persistent physical symptoms: Descriptive or etiologically-oriented classification? Implications for treatment

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Thanks to mentors, co-workers, and patients:

Michael Sharpe  
*Developed Somatic Symptom Disorder (DSM-5)*

Emma Rehfeld  
*The first to treat Bodily distress syndrome (ICD-11 PHC)*

Per Fink  
*Developed Bodily distress syndrome (ICD-11 PHC)*

Winfried Rief  
*Developed Chronic primary pain (ICD-11)*

Torben Jørgensen  
*Unravels the causes of Functional Somatic Syndromes*

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**COI:**
None.
How do persistent physical symptoms present to health care professionals?

Somatization disorder

Irritable bowel syndrome

Medically unexplained symptoms

Fibromyalgia
How do people, who suffer from persistent physical symptoms, look like?
What are persistent physical symptoms? Definition according to a recent article:

Persistent Physical Symptoms as Perceptual Dysregulation: A Neuropsychobehavioral Model and Its Clinical Implications

Peter Henningsen, MD, Harald Gündel, MD, Willem J. Kop, PhD, Bernd Löwe, MD, Alexandra Martin, PhD, Winfried Rief, PhD, Judith G.M. Rosmalen, PhD, Andreas Schröder, MD, PhD, Christina van der Feltz-Cornelis, MD, and Omer Van den Bergh, PhD, on behalf of the EURONET-SOMA Group

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### Table 1
Differences and similarities in criteria and concepts between different diagnostic constructs.

<table>
<thead>
<tr>
<th>Bodily distress syndrome (BDS)</th>
<th>Somatic symptom disorder (DSM-5)</th>
<th>Somatoform disorder (ICD-10)</th>
<th>Functional somatic syndromes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Defined by physical symptom pattern</td>
<td>Defined by emotional and behavioural symptoms/characteristic</td>
<td>Defined by physical symptom pattern including emotional and behavioural symptoms/characteristics and exclusion of organic basis</td>
<td>Defined by a primary symptom, or a symptom pattern or/and assumed attribution (depending on the FSS)</td>
</tr>
<tr>
<td>Organic (CNS) based bodily symptoms</td>
<td>Bodily symptoms of any aetiology</td>
<td>Symptoms without organic basis (medically unexplained)</td>
<td>Organic based (CNS or peripheral)</td>
</tr>
<tr>
<td>Emotional or behavioural symptoms not necessary for the diagnosis but are prevalent and may be important for the treatment</td>
<td>Emotional or behavioural symptoms are crucial for the diagnosis</td>
<td>Includes worrying and preoccupation with physical health and bodily sensations</td>
<td></td>
</tr>
<tr>
<td>Medical and psychiatric differential diagnoses have to be excluded</td>
<td>No requirement of exclusion of a medical diagnosis, but of psychiatric differential diagnosis</td>
<td>Organic explanations and other mental disorders have to be excluded</td>
<td>Fibromyalgia (FMS)</td>
</tr>
<tr>
<td>Suffering from symptoms of BDS</td>
<td>Suffering from emotional and behavioural trouble related to bodily symptoms or sensations</td>
<td>Suffering from medical unexplained symptoms and emotional/behavioural trouble</td>
<td>Irritable bowel syndrome (IBS)</td>
</tr>
<tr>
<td>Cause unknown but emotional or physical stress and dysfunction in the CNS likely to be involved</td>
<td>Health anxiety and misinterpretation of bodily symptoms</td>
<td>Stress, emotional conflicts etc.</td>
<td>Chronic fatigue syndrome (CFS)</td>
</tr>
<tr>
<td>Challenge the mental/physical dichotomy thinking of medicine</td>
<td>A mental disorder</td>
<td>A mental disorder</td>
<td>Multiple chemical sensitivity (MCS)</td>
</tr>
<tr>
<td>Based on empirical studies</td>
<td>Consensus driven</td>
<td>Consensus driven, poor empiric basis with a few exceptions</td>
<td>Electric hypersensitivity (EHS)</td>
</tr>
</tbody>
</table>

P. Fink

*Journal of Psychosomatic Research 97 (2017) 127–130*
Why is it so difficult to give people, who suffer from persistent physical symptoms, a meaningful diagnosis?
A clinical diagnosis is a powerful tool

Provides a label and gives meaning to a person’s symptoms

Legitimates the “sick role”

Serves for communication issues between healthcare professionals

Is a pragmatic tool to guide treatment
Fibromyalgia is a bitterly controversial condition. It pits patients, pharmaceutical companies, some specialty physicians, professional organizations, and governmental agencies – groups with substantial political and economic power who benefit from the acceptance of FM – against the large majority of physicians, sociologists, and medical historians in what we call the “fibromyalgia wars”.
Persistent physical symptoms:

Do you prefer a descriptive or an etiologically-oriented classification?

Do you prefer a mental or a physical diagnosis?
Mental disorder

- Defined by cause and/or illness mechanism
- Postpartum depression
  - Unhelpful illness-related cognitions and behaviors
  - Intra-psychic conflicts

Emotional symptoms
- Panic disorder

Descriptive
- Defined by symptoms and/or clinical signs
- Low back pain

Physical symptoms
- Diabetes
  - Pathophysiological mechanisms
  - Organ defect

Physical disease

Etiologically-based
- Defined by cause and/or illness mechanism

Originates from the brain and/or the mind:
- Unhelpful illness-related cognitions and behaviors
- Intra-psychic conflicts

Originates from the body:
- Pathophysiological mechanisms
- Organ defect
Systemic exertion intolerance disease (SEID)

Defined by cause and/or illness mechanism

SSD (DSM-5)

Etiologically-based

Originates from the brain and/or the mind

Myalgic encephalomyelitis

Descriptive

Symptoms and signs

Chronic fatigue syndrome (CFS)

Originates from the body

Whiplash associated disorder

Multiple chemical sensitivity

Medically unexplained symptoms

Fibromyalgia (FMS)

Physical symptoms

Systemic exertion intolerance disease (SEID)

Emotional symptoms

Originates from the brain and/or the mind

SSD (DSM-5)

Mental disorder

Physical disease

Myalgic encephalomyelitis

Chronic fatigue syndrome (CFS)

Fibromyalgia (FMS)

Medically unexplained symptoms
Mental disorder

Descriptive
Symptoms and signs

SSD (DSM-5)

Emotional symptoms

SSD (DSM-5)

Etiologically-based
Defined by cause and/or illness mechanism

Primary Pain
(IASP, adopted by WHA for ICD-11)

Fibromyalgia (FMS)

Originates from the brain and/or the mind

Multiple chemical sensitivity

Originates from the body

Bodily distress syndrome (BDS)

Medically unexplained symptoms

Physical symptoms

Physical disease
Persistent physical symptoms:

“Our study also has important implications for clinical management: The knowledge about etiological factors that is gained from our review has to be translated into explanatory models for single patients. For each individual case the contribution of biological, psychosocial and healthcare factors has to be weighted, acknowledged, and discussed with the patient.”

Schröder A. Kleinstäuber M. et al. submitted

“A biopsychosocial model of interacting biological and psychosocial factors in the predisposition, onset and maintenance of FMS symptoms is more appropriate than the dichotomy between a somatic disease and a mental (somatoform) disorder.”

Why the Bodily distress syndrome diagnosis (in my opinion) solves many of the classification problems
Diagnostic criteria for BDS

1) ≥ 3 symptoms from at least one of the groups or ≥ 4 overall
2) Moderate to severe impairment
3) Relevant differential diagnoses ruled out
4) Duration ≥ 4 weeks? 6 months? 12 months?

Cardiopulmonary / autonomic symptoms
1. Palpitation / heart pounding
2. Precordial discomfort
3. Breathlessness without exertion
4. Hyperventilation
5. Hot or cold sweats
6. Dry mouth

Musculoskeletal symptoms
1. Pains in arms or legs
2. Muscular aches or pains
3. Pains in the joints
4. Feeling of paresis or localized weakness
5. Back ache
6. Pain moving from one place to another
7. Unpleasant numbness or tingling sensation

Gastrointestinal symptoms
1. Abdominal pains
2. Frequent loose bowel movements
3. Diarrhea
4. Feeling bloated/full of gas/distended
5. Nausea
6. Regurgitations
7. Burning sensation in chest or epigastrium

General symptoms
1. Concentration difficulties
2. Excessive fatigue
3. Headache
4. Impairment of memory
5. Dizziness

Fink P & Schröder A. J Psychosom Res 2010;68: 415-426
1. The BDS diagnosis solves (some of) the FSS overlap, and teaches symptom pattern recognition

DanFunD - Danish Study of Functional Disorders (www.danfund.org)
- The DanFunD cohort: N=9,656
  - 53.9 % (n=5203) females
  - Mean age: 52.5 (SD: 13.2)

Scientific symposium 20, Friday 10:30-12:00, Leeuwen Room I & II
T. Jørgensen et al.
Impaired lipid- and glucose metabolism in persons with various FSS points towards a common genesis

2. The BDS diagnosis takes the best from both the lumpers and the splitters

Bodily distress:
Pathophysiological responses to prolonged or severe mental and/or physical stress in genetically susceptible individuals.


3. The BDS diagnosis resists the question, whether it should be understood as a mental disorder or a physical disease. While descriptive in its approach, the diagnosis is conceptually focussed on the interplay of biological and psychosocial factors.
4. The BDS works well in both the clinic as well as in clinical research

- Easy to teach GPs and somatic specialists
- Have been used in four randomised clinical trials and one prospective clinical cohort study during the last 14 years
- Point of departure for patient education, for a new, common understanding of the persistent physical symptoms, and for further treatment.
Organisational model

STreSS-1 trial: Group CBT vs. EUC
for people with multiple FSS / multi-organ Bodily Distress Syndrome

Clinic for people with Functional Somatic Syndromes

STreSS = Specialised Treatment for Severe Bodily Distress Syndromes

(-/ multidisciplinary clinics)

CL-psychiatry

Gen. medicine

Gastroenterology
IBS

Rheumatology
Fibromyalgia

Neurology
Headache

Anaesthesiology
Pain

Others

Gen. psychiatry

General psychiatry
Somatoform and related disorder

The Research Clinic for Functional Disorders and Psychosomatics
Type of FSS had no differential effect on outcome (but illness severity important)

Schröder et al. Lancet Psychiatry 2015
Difference in slope
STreSS vs EUC:
- 3514 € / year
(p=0.006)

Difference in level STreSS vs EUC (indirect and healthcare costs):
- 7,184 €
(p<0.001)
Pharmacological treatment

STreSS-3 trial: Imipramine, compared with pill placebo, improves patients“overall health”

if supported by regular contacts with clinicians

Agger JL., Schröder A. et al. Lancet Psychiatry 2017
“Understand your illness and your needs”: Assessment-informed patient education for people with multiple functional somatic syndromes

H. Frølund Pedersen\textsuperscript{a,*}, A. Holsting\textsuperscript{a}, L. Frosthølm\textsuperscript{a}, C. Rask\textsuperscript{b}, J.S. Jensen\textsuperscript{a}, M.D. Høeg\textsuperscript{a}, A. Schröder\textsuperscript{a}

\textsuperscript{a} Research Clinic for Functional Disorders and Psychosomatics, Aarhus University Hospital, Nørrebrogade 44, 8000 Aarhus C, Denmark
\textsuperscript{b} Centre for Child and Adolescent Psychiatry, Aarhus University Hospital, Palle Juul-Jensens Boulevard 175, Entrance K, 8200 Aarhus N, Denmark
Element 1: Clinical assessment, 3-6 hours
1. Life-time interview (social events, on-set of symptoms, contacts to health care system)
2. Schedules for Clinical Assessment in Neuropsychiatry (SCAN interview)
3. Feedback: Diagnosis and information on treatment options at the clinic
4. Shared decision making on treatment plan

Element 2: BDS school, 3 hours
1. Introduction and patient interview
   - Why are you here? 
   - What is BDS? Diagnosis? 
   - How do you explain? 
2. How to manage BDS? 
   - Illness behavior and illness perceptions 
   - Homework: Graded exercise, sleep, or diet (patients choose one theme as homework) 
   - Lunch break (1 hour) 
3. How to cooperate with social authorities 
   - Further treatment options: Module 2

Element 3: Follow-up consultation, 1.5 hours
1. Evaluation of treatment outcome, homework, and further need for treatment at the clinic
2. Shared decision making on treatment plan
3. If referred to own GP: Written suggestions for further treatment are send to the GP

ACT
6 x 3 hours
8-10 patients

MBSR
9 x 3 hours
15-20 patients

General practitioner

Individual consultation: Treatment response?

Questionnaire

The Research Clinic for Functional Disorders and Psychosomatics
### Evaluation of the BDS school (n=144)

<table>
<thead>
<tr>
<th>What do you think of the BDS school?</th>
<th>True %</th>
<th>Partly true %</th>
<th>Not true %</th>
<th>Don’t know %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was treated well by the therapists who were responsible for the BDS school</td>
<td>95.1</td>
<td>4.2</td>
<td>-</td>
<td>0.7</td>
</tr>
<tr>
<td>2. My opinions and worries were taken seriously</td>
<td>87.5</td>
<td>9.0</td>
<td>-</td>
<td>3.5</td>
</tr>
<tr>
<td>3. I feel that the therapists know how they can help me</td>
<td>58.3</td>
<td>36.1</td>
<td>0.7</td>
<td>4.9</td>
</tr>
<tr>
<td>4. I learned something new and valuable at the BDS school</td>
<td>52.8</td>
<td>34.0</td>
<td>8.3</td>
<td>4.9</td>
</tr>
<tr>
<td>5. I want to work with the things I have learned</td>
<td>82.6</td>
<td>13.2</td>
<td>1.4</td>
<td>2.8</td>
</tr>
</tbody>
</table>
Individual statements about the BDS school

Themes:
- Being taken seriously by the health care system
- New understanding of own illness

"A fantastic experience coming at your department. Seems very professional and completely different than anything else I have experienced on my long journey through different departments (…)"

"I gained an insight into my life that I had not been aware of – or I wasn’t aware that I should look into that direction."

"I did not at all feel that the website’s description [of BDS sufferers] was identical with what was wrong with me. But when the doctor described it, it made much more sense."
”Understand your illness and your needs” -
A pragmatic approach to the classification of Functional somatic disorders

(while we all wait for the final classification solution...)
“Our study also has important implications for clinical management: The knowledge about etiological factors that is gained from our review has to be translated into explanatory models for single patients. For each individual case, the contribution of biological, psychosocial and healthcare factors has to be weighted, acknowledged, and discussed with the patient.”
CARINA’S CASE FORMULATION

Vulnerability

Early life adversity, grown up too early
Difficulties to be in contact with own emotions and desires
Very ambitious, busy life

Triggering event

Recurrent sinusitis

Perpetuates and worsens

Continues her busy life
Boom and bust behaviour
Sleep problems
Health care system (lots of diagnostic work up without a clear result)
Frustration, anxiety
VIDEO
Perpetuates and worsens Thoughts….  
Behaviour….  
Carried out by physiotherapists and occupational worker
Long-term effect of an interdisciplinairy early behavioural intervention (Get going after concussion, GAIN\textsuperscript{1}) on persistent post-concussion symptoms

- **Relative Risk** of having high symptom level at primary endpoint (3 months after treatment):
  - 0.6 (95% CI 0.4 – 0.9, p=0.008) in favour of GAIN

Scientific symposium 25, Friday
15:30-17:00, Mees Auditorium
Thastum MM et al.
Early intervention for persistent post-concussion symptoms: Results from a randomised trial

Median months after concussion

Thastum MM et al. under review
Key principles in the management of Functional Somatic Disorders

Conclusions:
Implications for treatment

At assessment and at the beginning of the treatment:
• Increase motivation and boost expectations for improvement / recovery:
  o make a (non-harmful) diagnosis
  o provide a clear illness model
  o ensure to understand your patient’s / client’s illness model(s)
Key principles in the management of Functional Somatic Disorders

During treatment:

• Build a strong collaborative (conscious) working alliance (If you are trained within psychodynamic therapy, build a strong unconscious alliance as well)
• Enhance awareness and acceptance of bodily sensations and emotions; Facilitate transition from implicit to explicit emotional processing (Richard Lane)
• Reduce pressure from outside (but do not join your patient’s wars)
• Reduce uncertainty, lack of control, symptom catastrophizing
• Reduce fear avoidance beliefs and related behaviours
• Reduce dysfunctional interpersonal responses (helplessness, dependent on others, blame others, etc. - if you are trained, work in the transference relationship)
Web-Ressources

www.functionaldisorders.dk

www.neurosymptoms.org

https://www.awmf.org/leitlinien/detail/ll/051-001.html

www.recoverynorway.org

Thank you for your attention!