Journal of Psychosomatic Research 116 (2019) 22–24

Contents lists available at ScienceDirect

Journal of Psychosomatic Research

journal homepage: www.elsevier.com/locate/jpsychores

Letter to the Editor

# Improving care for patients with functional disorders in Denmark

Tiredness and dizziness. Headache and difficulties concentrating. Feeling bloated, rumbling in the stomach and frequent bowel movements. Pains, aches, tenderness. They are all common bodily signals that many of us experience on a frequent basis but with great variation. For some, these signals are so loud and so constant that it becomes an almost constant 'state of alert'. When such a 'hurricane' of bodily signals becomes a disorder affecting quality of life and daily functioning, we call it functional disorder.

Functional disorders are frequent, affecting around 10–20% of the adult population. Like other diseases, they have a spectrum of severity ranging from minor, self-remitting conditions to very severe cases affecting around 1–2% of the adult population, where quality of life is severely impaired, daily functioning severely limited, and the patients are in severe distress, bodily as well as socially and mentally.

In the Danish health care system, we fail to provide proper care for patients with functional disorders: they risk prolonged and discontinuous diagnostic workups that rarely lead to sufficient and effective treatment offers and care. Across our country, there are major differences in the content and quality of care. Many people with functional disorders experience stigmatization and suboptimal care in the health care system.

I hear many patients' stories of not feeling welcome, not being respected or taken seriously and of being bounced around between specialists in different hospital departments during clinical odysseys. Many patients are told that 'your illness is something we can't diagnose' or 'it is all between your ears' or similar nonsense. Many patients report that clinicians are neither providing proper information on their condition, nor relevant advice on available treatment and rehabilitation. A number of patients report feeling abandoned by the health care system and loosing hope of ever getting treatment for their disease. We can and must care better for these patients.

In the last couple of years, The Danish Health Authority has had a close dialogue with patients and professionals in the field. In June 2018, we presented a report with a number of recommendations to strengthen the quality of care at all levels by providing a framework with a stepped-care approach to ensure evidence-based care across the nation and to establish specialized multidisciplinary teams for the more severe cases.

With the new set of recommendations, we hope to contribute to greater clarity in an area of controversy, both regarding concepts of disease and approaches to diagnostics, treatment and care. Our objective is to pave the way for a better understanding of the conditions and needs of people with functional disorders, and our hope is that the intensified focus will help improve the quality of care and remove the stigmatization we see in health care as well as in society in general.

When struck by illness, we all have an urge to explain. Why do I have a headache? Why can I not control my legs? Why am I too exhausted to concentrate or to go to school or do my job? People with functional disorders are often in despair, not only because of the lack of effective care but also because they do not receive adequate answers as to the nature of their illness. This frustration easily leads to seeking alternative explanations that often conflict with established medical thinking.

It is important for me to underline that functional disorders are real diseases – it is not something that is imagined by the person reporting bodily symptoms that are not easily substantiated or explained. But functional disorders do share the common trait that they cannot be diagnosed by conventional medical tests such as blood tests, imaging etc. This has led to a number of misconceptions regarding functional disorders, e.g., that they are really just a mental disease or that they are diagnoses of exclusion reached by a process of eliminating well-established diagnoses - a sort of diagnostic 'trash can' or last resort. Both misconceptions are wrong.

First of all, diseases under the umbrella term of 'functional disorders' are all characterized by one or more bodily symptoms affecting daily functioning and qualiy of life and typically presenting in a characteristic pattern. It is this characteristic pattern that is the basis of the clinical diagnosis, and it is therefore a positive and valid diagnosis; not a diagnosis of exclusion or a last resort. As in any other diseases, other conditions - be it somatic or mental or both - that can explain the presenting symptoms must of course be ruled out.

But the diagnostic process should be reasonable and interventions should be relevant. Unnecessarily prolonged and fragmented diagnostic odysseys with the patient being bounced back and forth between specialists risk doing more harm than good: The random finding of anatomical variations, physiological changes or insignificant pathology can cause emotional distress and medicalization, potentially leading to unnecessary and harmful interventions such as surgery or exposure to radiation from repeated CT scans. In addition, diagnostic odysseys can have substantial social consequences affecting the patients' ability to maintain employment, education etc. As diagnostic interventions are potentially harmful, be it harm from overdiagnosis or from the intervention itself, each step in a diagnostic workup should always be offered based on solid professional judgement. This is especially true when caring for patients with a suspected functional disorder, where the condition is not easily substantiated by simple and well-established medical tests such as a blood sample, endoscopy or X-ray.

Second, functional disorders are not mental diseases. Nor can we say that they are purely somatic disease entities, i.e., with purely physical causes and explanations. In reality, functional disorders are best understood and explained by a biopsychosocial multidimensional model of disease: a model incorporating human biology, psyche and social relations as both predisposing, perpetuating and precipitating factors. However, historically and culturally we have a deeply rooted concept of disease relying on a clear distinction of bodily (somatic) and mental (psychiatric) disease. But this concept lacks nuance. In most diseases and conditions such a clear distinction is neither meaningful nor beneficial. Body and mind are inseparable! A dualistic approach also

https://doi.org/10.1016/j.jpsychores.2018.11.003
Received 25 October 2018; Accepted 6 November 2018

neglects the important role of sociocultural factors for the development of disease and concepts of disease. There is a complex interaction of body, psyche, sociality and culture at play in the development and treatment of disease. That is no less true for functional disorders!

Modern health care has greatly contributed to the maintenance of dualism, e.g., through the way we organize our profession and our institutions in specialities and organ systems. The increased centralization and (sub)specialization of health care with clear distinctions between somatic and psychiatric care are major contributors. Our diagnostic hierarchies and manuals, rigidly ordered by specialities and organ systems, also contribute to maintaining biological mechanistic disease models rather than promoting more complex biopsychosocial concepts.

Somatizing diagnoses such as 'interstitial cystitis' or 'myalgic encephalomyelitis', relying on assumptions or hypotheses of pathology, are often consensus-based and poorly defined symptomatic syndromes rather than clear disease entities based on rigorous scientific study and systematic evidence. 'Painful bladder' or 'chronic fatigue' perhaps work better as descriptive terms because they are directly rooted in the symptoms experienced by the patients. And it makes sense for us in the Danish Health Authority to accept the diagnostic umbrella term of 'functional disorders', because we achieve a common language and a common understanding of diseases that exhibit common patterns and where a set of common treatment principles often are effective. While the term 'functional disorders' is not perfect, we lack a better proposal meeting universal consensus, and we feel it will work well under the present circumstances. As a consequence of the widespread misconceptions and the inadequate and fragmented care, patients with functional diseases are often medicalized, misdiagnozed and mistreated.

Some of the central recommendations in our new report focus on the necessity of establishing models of care that ensure a holistic and multidisciplinary approach, while at the same time ensuring a stepped care approach with care delivered at the right level of specialization and competency considering the severity of disease. Care should be organized in a way that ensures that patients are seen by professionals with an understanding of functional disorders, working in teams that can provide a holistic and comprehensive evaluation utilizing specialized competencies and technologies as needed and where the main objective of patient-centered care is to provide the individual with a comprehensive and complete clinical assessment of their condition and treatment options.

In cases of mild to moderate severity, we believe that the general practitioner – the specialist in family medicine – is the central professional to be in charge of care in the Danish system. But the GP needs better resources to better solve that task. It should be much easier for the GP to get professional advice from centers of excellence or specialized departments in major hospitals across the country. Patients with severe cases of functional disorders need specialized and evidence-based treatment and care. Another set of key recommendations in our new report are focused on how the five administrative regions in Denmark organize hospital care for patients with functional disorders. Our proposal is for each region to establish permanent multidisciplinary specialized centers for patients with functional disorders. And we suggest that these centers are primarily based in the somatic hospital system as patients with functional disease experience bodily symptoms. These teams should include a broad scope of disciplines and professions. The treatment options that we know is working in functional disorders are often not pharmacological as the first choice, and they are not surgical. We have evidence to show that graded physical exercise and cognitive therapy are effective in a number of functional disorders. And we are convinced that we can improve the quality of care by establishing permanent multidisciplinary teams including medical professionals from somatic and psychiatric specialities as well as other professions such as pscyhologists, physiotherapists etc.

In our recommendations for the five administrative regions, we propose that these specialized multidisciplinary teams can be established either as permanent centers with dedicated facilities or as more virtual permanent teams across the geographic landscape depending on local preferences. Already today, the five regions have good experience with a number of multidisciplinary diagnostic centers, chronic pain centers etc. that can serve as inspiration or contributors to these new centers. At the same time, it is also important to strengthen knowledge and expertise in the field. The five regions, as well as other institutions and funders, should prioritize research, education and dissemination of knowledge in the field of functional disorders.

The use of the term 'functional disorders' has been critized, also in Denmark. Some patients and some professionals feel that the best way out of stigmatization is to use a new fresh set of concepts and diagnoses. As an example, it has been suggested to use the term 'complex symptoms' as a neutral term to describe this group of patients. I regret that we have not been able to achieve a common terminology across our small country. And I do not feel that 'complex symptoms' is a good term, because in most cases the symptoms are common, such as fatigue, dizziness, headache, pain etc. Unfortunately, the stigmatization and misconceptions around functional disorders can lead to individual health professionals, health care institutions and even authorities such as The Danish Health Authority being exposed to often considerable pressure to recognize and promote certain diagnostic terms and entities, presumed causalities or specific treatment modalities, while at the same time rejecting others such as the term 'functional disorders'. But if we succumb to pressure without a sound basis in well-meaning attempts to counter stigmatization and discrimination of patients, we run the risk of actually sustaining or feeding stigmatization and misconceptions thus causing patients to receive ineffective or potentially harmful treatment or maintaining patients in their illness in spite of the existence of effective and evidence-based treatment.

Health care providers, authorities and society can counter medicalization and overtreatment by being better at recognizing and respecting individuals and individual suffering rather than 'rubber stamping' or 'approving' certain diagnoses, causalities or treatments that are not backed by robust evidence.

A number of diseases that were previously subject to stigmatization has in the modern era been destigmatized. This is the case for a number of sexually transmitted diseases, stress, depression, epilepsy, congenital metabolic diseases or malformations etc. This destigmatization has been achieved through a better understanding of disease mechanisms, development of effective and targeted treatments, information, dialogue with patients and by challenging taboos, silence and doubt. Equally, modern health care can break the stigmatization and misconceptions surrounding patients with functional disorders by meeting them with resepct and empathy, listening to their stories, understanding their symptoms and their suffering and by offering patient-centered and evidence-based treatment and care.

A special kind of stigmatization is connected to mental disorders and/or to treatment and care in those parts of the health care system that are dedicated to patients with mental disorders and using treatment modalities focused on human cognition and emotional processes. This risk of 'mental' stigmatization is very present when caring for patients with functional disorders, where the disease is neither somatic nor psychiatric but in the borderland inbetween these. And where a clear, dualistic concept of disease and care is counterproductive and simply wrong, but where treatment modalities such as cognitive therapy developed in the fields of mental health have proven to be effective. Many patients with functional disorders experience being stigmatized in both the health care system and in their encounter with social services. Some patients report that having a functional disorder apparently leads to not being offered treatment and care or being denied social services that they might be eligible to receive. For that reson, some patients prefer receiving a somatic diagnosis as this improves their chances of receiving the care and help they need. At the same time, many patients report that – even despite receiving 'favorable' diagnoses – they often do not receive effective treatment or

rehabilitation that improve their quality of life. Many patients report a feeling of 'not belonging' in any speciality experiencing neither clinical, scientific nor professional interest in their case or condition. Many patients report an added stigmatization when being subjected to psychiatric care or being cared for by mental health professionals since the patients rarely define themselves as being mentally ill.

We have a long way to go before we have achieved our objectives of improving care for patients with functional disorders in Denmark. With our new report and recommendations, we have taken an important first step. The Danish Health Authority will maintain a strong focus in the coming years.

## Declarations of interest

None.

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