New insights into culture driven disorders

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Rheumatologists frequently encounter patients whose illnesses lack face-value; that is, they lack the typical objective features of pathology that rheumatologists traditionally rely on for diagnosis and developing effective treatment approaches: namely fibromyalgia, chronic fatigue syndrome, Gulf War syndrome, chronic whiplash, chronic low back pain, etc. In this article, we examine this group of illnesses as culture-driven disorders to emphasize the central importance of various societal constraints in the ultimate presentation of patients with these illnesses. We will examine them by first understanding the purpose they serve, the underlying factors that compel societal institutions to sanctify these disorders as diseases, and how research is beginning to examine the behaviour that captures and packages these symptoms to produce their clinical presentation. With this research understanding, rheumatologists may be able to offer patients more useful action plans, but likely changes in societal approaches to the expressions of distress and changes in disability and compensation systems will also be required.

Key words: fibromyalgia; chronic fatigue syndrome; Gulf war syndrome; whiplash; chronic low back pain; silicon implant syndrome; environmental syndromes.
There is no disease that you either have or don’t have—except perhaps sudden death and rabies. All other diseases you either have a little or a lot of.

Geoffrey Rose

Un hombre tiene dolores de cabeza de vez en cuanto; no es agradable, pero hay remedios. Esto pasa a ser algo serio cuando un día supone que detrás se esconde algo, quizá un pequeño tumor. Entonces la preocupación pasajera se convierte en permanente; se convierte en la preocupación principal.

Ernst Jünger

When the heart suffers, the body cries out

Cardinal Lamberto to Don Michael Coleone in the Vatican, Godfather III

Human suffering has no doubt taken on many forms over the millennia. What may be relatively new (centuries rather than millennia), however, is the co-adaptive way in which the medical and social institutions of modern society—in the Western world in particular—have shaped illness behaviour so fundamentally, that these same institutions have lost the capacity to provide meaningful solutions to what may be termed culture-driven disorders. By culture-driven disorders we mean illnesses whose main purpose is to ‘fit in’ to the cultural model of a socially legitimate disease. That is, when patients are suffering from a miserable existence, from stress, and/or from an inability to cope with physical problems in the face of societies’ burdens, there is a social norm that, as we shall see, tends to make them less eligible for the same social support and sympathy from the medical community as patients with rheumatoid arthritis (RA) or diabetes. Culture-driven disorders are illnesses whose presentation is a metamorphosis of the distressed patient’s problem into one that appears more like a ‘disease’ and more legitimate. We believe that fibromyalgia, chronic fatigue syndrome, chronic, disabling neck and low back pain (e.g. whiplash and work-related back pain), Gulf War syndrome, silicon breast implant syndrome, etc. are culture-driven disorders. This is not to say that these patients do not have physical disorders and physiological abnormalities, but rather that these problems in themselves do not explain the behaviour of the patient, which is instead driven by a desire for establishing a legitimacy to their suffering that in large part arises from their life struggles and limited capacity to cope with the pall under which they exist.

Symptoms have little social currency in Western society without personal, medical, and often public interpretation as disease. Whether a symptom should in itself create a sense of urgency to seek medical intervention is largely a learned behaviour; thus a product of societal influences that evolve through media, mimicry, compensation systems that apportion benefits depending on causation, etc. How a symptom or group of symptoms is interpreted by rheumatologists, unless the symptoms are objective, or associate well with some objective measure that specifies a disease, also likely depends on how media, education, mimicry, and pressures operate within a given compensation or social benefit system.

It is not the symptoms or constellation of symptoms themselves which make illnesses like fibromyalgia, chronic fatigue syndrome, etc. controversial. The patients say they are suffering, present in a coherent and relatively homogeneous fashion (i.e. pain
plus fatigue plus numbness in most of these disorders), report lives that have become over-run by their illness, seek out medical care with great frequency, and have many measurable sequelae from their illness (i.e. patients gain weight, lose fitness, have many physiological and immunological measures that are abnormal, etc.). The area of contention flows, instead, from the insistence that these illnesses must be accepted as bona fide diseases even when the type of disease evidence rheumatologists are used to looking for is not apparent. Encounters with these patients is heavily flavoured by behaviour and discussion that impresses the need to support or affirm the patient’s belief that their suffering is driven by pathology, with little capacity for control within themselves, and with no apportion of fault on the part the individual for their illness behaviour—just like a disease. If these criteria are not met, societal support in the form of ongoing medical care, compensation and disability benefits may not be available, because that is how some societies have set up their programs. In this review we consider why this need to present to physicians with a ‘disease’ rather than just suffering exists, how culture-driven disorders result from the expectations of social systems, and how the process from health to a culture-driven disorder evolves. We then consider what approaches we should take to curb this process of fashioning illness behaviour to meet social standards, and where we need to focus research efforts.

LEGITIMACY AND DISEASE

In the predominant biomedical model, disease is considered as a natural category, the physician working to identify the disease, define the precise cause and treat by correcting the disturbance. The biomedical model is dualistic, posing a theoretical separation between mind and body, mental (non-organic) and organic. When a patient is referred with symptoms for which no explanation within the model can be offered the trouble begins; the patient ‘must have something’. This is because it is the diagnostic tag imposed which will define the course of action to follow. Also, subsequent coverage by the health system and/or social support system depends on the diagnosis. In practical terms, a disease for modern medical practice is any condition already medicalized.

This was not the case a few centuries ago, when the main interest of medicine was not in defining a precise mind or body condition provoking the ailment. Initially, physicians were concerned on correcting illness; that is, in alleviating the suffering. The clinical picture was itself the disease. Thus, ‘dropsy’ was a disease in itself until medical progress separated it into cardiac and renal causes among others, and such has been the general history of clinical syndromes being reclassified over time. In time, the definition of disease came to depend on the anatomical changes that could be demonstrated after death and correlated with the symptoms of the living. With this trend came a shift of attention from the individual patient to the afflicted organ. High precision acquired through medical technology has moved diagnostic precision ever forward, nowadays from the damaged organ to the altered molecule. This sustains the difficult connection between basic biomedical science and clinical practice. A similar dichotomy has occurred in clinical encounters: suffering has been less and less the focus in the definition and treatment of disease.

Indeed, diseases are defined often in the absence of symptoms, such as in hypertension, osteoporosis, and hypercholesterolemia. The disease definition here depends on the surrogate marker for eventual demise, and this marker is defined according to the technology available to detect the anomaly; in a sense, technology
invents the disease. Another path to disease diagnosis, however, is medicalization through diagnostic criteria which may be the initial clinical manoeuvre which legitimizes a disease. Whether through correlation of symptoms to pathology, identification of ‘silent’ markers of disease, or diagnostic criteria, this ‘hard data’ of diagnosis is increasingly required by insurance companies and other bodies providing compensation and/or disability support. A hundred years ago, house staff in hospitals received minuscule stipends and attending physicians were salaried by schools of medicine or lived by the ‘Robin Hood’ practice pattern, by fees from private patients. Now, the way medical practice is financed calls for the diagnosis to justify the stipend.

THE HISTORY OF ILLEGITIMATE ILLNESS

Shorter has reviewed historical evidence that the 18th century began with a bias in the medical and among social institutions towards illnesses primarily dependent on life’s stresses, psychological disorder, and/or in the setting of limited personal coping capacity with both physical and psychological burdens. It was not always the case that society viewed depression, anxiety disorder, or ‘madness’ as illegitimate illness, befitting treatments such as shunning, commitment to asylums and certain death, or in more recent times, little social provision for disability support or compensation. Prior to the 17th century, mental illnesses such as hysteria were not particularly segregated from other illnesses. That is, they were still proposed to have a pathophysiology, such as the wandering womb as the basis for hysteria. By the end of the 17th century, even though Descartes had placed some diseases in the body and others in the mind, thus segregating them, Sydenham reflected the prevailing medical opinion that mental illness should be dealt with by physically oriented treatments to purify and fortify the blood, regular exercise, and by the physician taking an interest in the patient’s welfare. By the early 18th century, the chair of medical theory at Collegii della Spaienza in Rome not only advocated exercise, but a change of social circumstances and he encouraged physicians to enquire about the patient’s mental state and to try to instill hope and optimism.

Over time, however, the knowledge of diseases of the body blossomed while diseases of the mind remained poorly understood anatomically. Mental disease did, however, come to be seen as primarily a disease of women, the weaker sex, and of a hereditary nature, while disease of the body was considered acquired. Mental illness therefore, could be a familial weakness, and a social stigmatization was attached to men or women with a family history of illness as they were likely to develop the same or their children would. With few effective treatments and little understanding of mental illness, asylums flourished, and a diagnosis of mental illness not only meant a social stigma, but also commitment to an institution where death was a common result. As Shorter reviews, it is little wonder that in the 19th century, a physician wishing to build his practice would avoid diagnosis of mental illness, but rather would provide patients with fashionable, disease-sounding diagnoses. Psychiatry, if it was to be practised, was to be practised among the poor and in hospitals, not on London’s Harley Street. The medical community failed to provide society with an effective understanding and treatment for mental illness. Society developed instead a strong bias against individuals so afflicted, and in turn the medical community further reinforced this trend by emphasizing ‘legitimate’ disease diagnoses for unexplained symptoms, because that was more palatable.

While Shorter has presented the historical evidence, we do not need to speculate on historical events to confirm this bias is real and has an impact on patients.
As an example Aaron et al.15 examined the disability applications in two cohorts of fibromyalgia patients. One would suppose that two patients, both with the diagnosis of fibromyalgia, with the same symptoms, with the same duration of illness and the same degree of suffering reported, would be given equal opportunity when seeking social benefits for disability. According to the study conducted by Aaron et al.15, however, this is only true if both patients report their illness to have been the result of physical trauma. They found that the fibromyalgia patients who reported their illness to be the result of emotional trauma had to apply four times as often to ultimately receive some disability support. This was the case despite the fact that fibromyalgia after physical trauma is no more verifiable than fibromyalgia after emotional trauma (i.e. the patient’s bring subjective symptoms in each case). Insurance companies commonly have policies that exclude psychiatric and psychological illness as a basis for disability. Chronic low back pain that arises for no apparent reason is not a basis for workers’ compensation even if it affects the worker’s ability, since the back pain is not explicitly determined to have been a ‘work injury’.

Thus, we have here a prime mover of these syndromes, the need for legitimacy of illness. What all these illnesses have in common, beyond their tendency to be associated with subjective symptoms, reports of disability without objective measures of disability, is the insistence that the suffering must be due to what society now calls ‘disease’. The suffering cannot be attributed to a lack of ability to cope with one’s existence, such as overwhelming aches and pains in a dissatisfying job heaped upon a series of troubling stresses. The individuals must be seen as strong (i.e. ‘I have a high pain tolerance’) rather than morally or personally weak, and depression and anxiety, if they are present, are a consequence not a cause. The patients cannot then be blamed for their illness, as we so often do in society with depression and psychological disorders in general, as if character flaws are the basis not only for the onset of illness, but the lack of recovery. Mental illnesses, despite the abundant research on biological factors and the research for biological treatments, still face a stigmatization not shared by RA or lupus.

Since the 19th century, society has deemed the sick person to be one that warrants societal protection against suffering, fiscal demise, calamity and death. Parsons labelled this social construct as ‘the sick role’.16 The sick role is an important identity, as it confers upon the sick relief through secondary gains. Usually, illness brings secondary gain for all of us. Most have experienced the secondary gains of sympathy, freedom from work and social responsibilities, and in some cases financial reward that comes with illness. Where a social support network exists, these are automatic as long as one demonstrates to others that the illness is not one’s fault, and that one is legitimate in one’s presentation—i.e. one has a disease.17 There is a small percentage of the population whose life situation is such that they are suffering, not with inflammation or demyelination or infection, but with life’s miseries. They are, in Hadler’s’18 words ‘living under a pall’, and failing to cope with various burdens. Yet, our social construct is biased against giving these individuals relief. One cannot, in most societies, simply ask others to give a reprieve from all of one’s burdens simply because one is having difficulty in life. This is a personal and psychological failure that is often regarded as socially illegitimate. But when a disease or an injury arises, especially if no self-blame is involved, then one has a socially acceptable reason for failing to cope with one’s life, and all of one’s miseries can then be pinned on that injury or disease.

Psychiatrists and psychologists have explored this aspect for some time. Hirschfeld and Behan19, for example, pointed out that individuals who find themselves stuck in a situation which is personally overwhelming find themselves facing a solution to this
dilemma by becoming the victim of ‘chronic injury’. As explained diagrammatically:

\[
\text{Personal difficulties + Troubled life situation = Unacceptable disability}
\]

but then,

\[
\text{Unacceptable disability + Accident = Acceptable disability}
\]

Hirschfeld and Behan explain that an individual experiencing general dissatisfaction with their life may eventually develop disabling emotional responses. They consider that:

People are often highly motivated by what they feel others think of them. But still more vital is the fact that these opinions are reflected in the person himself and he finds that certain disabilities must be totally rejected by his own conscience, or sense of pride.

The person who has the unacceptable disability finds himself hiding it. He does not wish to share it even with the physician. He does not want to stop work because of it, not only because he will be unpaid, but more significantly because he will think so poorly of himself. The resolution of this problem must therefore await the appearance of an excuse which will make it face-saving to the patient.

For some in society, a collision serves to transform psychological disability into a ‘physical’ disability and therefore an unacceptable disability into an acceptable disability. A collision provides a solution to this dilemma: a socially acceptable form of disability adopted by the patient: as further explained by Ciccone and Grzesiak:

Many patients who go on to develop chronic pain following an acute injury or illness report a premorbid pattern of excessive self-sacrifice, hyperactivity, or overachievement. They often have a history of going to work at an early age, putting in frequent overtime hours, and holding more than one job at a time. They may have permitted or encouraged others to rely upon them excessively and, as a result, were routinely called upon and expected to perform special tasks or favors. These tasks were often burdensome in nature or at least not intrinsically rewarding for the patient. Following the onset of pain, this pattern of unrelenting self-sacrifice and overachievement typically comes to an abrupt halt with the patient becoming the recipient of special care instead of the provider…The onset of physical injury or illness apparently offers these patients an opportunity to relieve themselves of their occupational and social obligations without any need for self-reproach and without any loss of social approval.

**CULTURE-DRIVEN DISORDERS**

We argue here that fibromyalgia, chronic fatigue syndrome and Gulf War syndrome are not very distinct from each other when their social role is understood. They share a great deal in common, namely the argument that focuses on the legitimacy of these disorders as ‘diseases’, common symptomatology, and the vigorous tendency of the patients to point to a causative external agent such as injury, environmental exposure or infection. Increasingly, research is also reflecting that these patients are likely to have
familial and personal histories that place them at high risk for psychological struggle, and
somatization.\textsuperscript{17}

\textbf{Fibromyalgia}

Fibromyalgia is a condition of widespread pain lasting at least 3 months with the
presence of tenderness upon palpation at 11 of 18 established areas of the body.\textsuperscript{21}
These tender points have been shown to be associated with diverse body complaints, not
necessarily pathological. They can be found in subjects without a history of widespread
pain, which renders them as non-specific.\textsuperscript{22} Tender points seem to be a
marker of distress in populations.\textsuperscript{23–25} Somatic symptoms in individual patients are
associated with the level of anxiety, with somatosensory amplification and with
alexithymia\textsuperscript{26}, which is a personality construct characterized by difficulty in identifying
and communicating feelings and externally oriented thinking.\textsuperscript{27} A great majority of
patients improve their function, although pain may not disappear.\textsuperscript{28,29} They seem to
perform better despite their pain by adapting their lives to their new situation.

\textbf{Chronic fatigue syndrome}

The 1994 revision of the US Center for Disease Control and Prevention case definition
required 6 months of persistent fatigue that substantially reduces the person's level of
activity and four of the following conditions: impaired memory or concentration, sore
throat, tender glands, aching or stiff muscles, multijoint pain, new headaches,
unrefreshing sleep and postexertional fatigue. Then a long list of medical conditions
must be discarded.\textsuperscript{30} As with fibromyalgia, relatives of patients with the condition have
higher rates of the disease.\textsuperscript{31,32} Even a 'proxy' chronic fatigue syndrome seems to exist,
where maternal psychological distress is associated with a child's reporting of the
condition.\textsuperscript{33}

\textbf{Gulf war syndrome}

Some veterans of the Persian Gulf War began reporting diverse symptoms after
returning home in 1991. After several studies intended to demonstrate a common
group of symptoms and a possible cause for these ailments, no general consensus has
been achieved, and published evidence shows that the conglomerate of symptoms are
too vague and similar to the conditions so far discussed as to be considered
independent nosologic entities.\textsuperscript{34} The so called Gulf War syndrome has been better
defined by media coverage than by epidemiologic surveys.\textsuperscript{35} It is an example of how
disseminated information can give legitimacy to an illness not otherwise recognized as a
disease. Similar entities have been described after most major wars in which the US
have fought in the last 100 years, receiving different names in each historical period.\textsuperscript{36}

\textbf{Chronic low-back pain}

Chronic low back pain is a syndrome which receives official medical recognition and is a
major cause of disability where compensation systems recognize it. In Western
societies it is the most frequent cause of limited activity in persons under 45 years, and
one of the top three causes of disability payment to workers.\textsuperscript{37} Social environment plays
an important role in symptom severity and prognosis. Studies comparing patients from
the US and from other parts of the world conclude that American low back patients use more medication, experience greater emotional and behavioral disruption and are more dysfunctional.\textsuperscript{38–40} Interventions consisting of minimal physical and at least one of psychological, occupational or social dimensions reduce pain and improve function in these patients.\textsuperscript{41} Changing the beliefs of patients about the consequences of back pain and the management recognized by society improves their clinical outcomes.\textsuperscript{42} Coping inadequacies partially conditioned by previous beliefs and exacerbated by hostile environmental factors and aggravated by legal and compensation issues complicate the therapeutic response and our understanding of the condition.\textsuperscript{43,44} Based on these findings, a population-based strategy of provision of positive messages about back pain has been shown to improve beliefs about back pain and seems to reduce disability and compensation costs.\textsuperscript{45}

The list is not limited to the above-mentioned. Conditions which share these characteristics are chronic hypoglycemia, sick building syndrome, breast implant syndromes, chronic whiplash, and multiple chemical sensitivity, among others.\textsuperscript{46–48} This persistence as officially sanctioned diseases is largely explained by social factors.\textsuperscript{49–51} In fact, these diagnoses can be defined as ‘memes’, giving to the diverse expressions of distress a medically-sanctioned name.\textsuperscript{52} They serve a specific social function in Western societies, which is organizing mental and physical distress into a meaningful narrative, tolerated by the biomedical model.\textsuperscript{53} The continuous emphasis on somatic complaints which are not necessarily pathologic and the insistence on placing a diagnostic tag on these symptoms can make people dependent on the medical apparatus, a process named ‘somatic fixation’.\textsuperscript{54} This process can be initiated by the patient or by anyone in the health care system. Normal results not explaining patient’s complaints lead to further examination and consequent dependence on the system, since ‘they can’t find an explanation for my illness’. What in fact they are after is a reductionist legitimacy based on the existence of an ultimate biopathological cause for their symptoms.\textsuperscript{18}

**POSSIBLE REVISIONS OF NOSOLOGY**

‘Functional somatic syndrome’ refers to those conditions characterized more by symptoms, suffering, and disability than they are by disease-specific, demonstrable abnormalities of structure and function. This common term still has some difficulties. Underlying it, there is the supposition of a disturbed function in the body. Curiously, no uniform consensus has been achieved on which are the altered functions. Since no common dysfunctional organic process has been demonstrated and given the growing evidence that disability is conditioned by the cultural milieu of patients, we suggest the substitution of this term by culturally-driven disorders (CDDs). Some advantages are apparent. Continuing with the line of thought shared by modern medical practice, diagnosis guides treatment and prognostication. Patients with CDDs have an improved prognosis with cognitive behavioral interventions and the acceptance of pain by patients and society in general. They can readapt their function to their new situation, as in most chronic conditions.

We argue that CDDs are an expression of distress in Western societies, but many in Western societies must necessarily contradict that view, since it collapses the purpose of their illness. In some cultures, however, expressions of distress occur in ways different from developing a syndrome based on disease affirmation. In psychiatry, these alternative expressions are recognized as culture bound syndromes (CBSs). All CBSs share two characteristics: they have originally been described within certain cultures
and they cannot easily be placed within the usual psychiatric diagnostic categories.\textsuperscript{55} CBSs keep their specificity as long as the cultural milieu on which they are accepted is conserved in diverse geographic settings. They are socially recognized as 'diseases' and have a natural and expected evolution. They can respond both to culturally sanctioned and regular medical treatments. But CBSs are not diseases as defined by the biomedical model. They are the idiomatic cultural expression of distress, and are the socially-sanctioned 'cause' of the perceived illness.\textsuperscript{56} When they appear in their 'natural' setting everyone around understands these conditions, but on appearance in diverse cultural settings their precise diagnosis requires a 'culturally sensitive' physician. Some examples of CBSs follow (see details in Ref. 55).

\textbf{Amok}

A term originating in Malaysia, Amok refers to an unprovoked episode of violence, with highly destructive and even homicidal behaviour. It comes to a sudden end, occasionally by suicide or with an amnesic episode. Some cases can be provoked by extreme anxiety or hostility.

\textbf{Dhat}

Dhat is characterized by somatic complaints such as fatigue and muscular aching associated with an irrational fear of loss of semen by men and women, happening to occur in cultures where women are believed to segregate semen, too.

\textbf{Koro}

Koro is seen in South Asia, typified by an acute panic reaction associated with the fear of a sudden retraction of the penis into the abdomen in men, and breasts and vulva in women. Victims believe that this will carry serious consequences to their health, possibly death.

\textbf{Latah}

Latah is the excessive response to an acute stressful situation, followed by an involuntary response such as ecolalia, ecopraxia, or a temporal lack of response to stimuli.

\textbf{Nervios}

Nervios consists of somatic complaints such as aching muscles, headache, dizziness, insomnia, and fatigue. These are frequently associated with anxiety or extreme sadness, and the latter are believed to be the initial cause of chronic health problems such as diabetes and hypertension in Latin-American cultures.

CBSs appear in specific cultural milieus in response to acute stressful situations and are a recognized and even expected response to these situations in the context in which they appear. But their etiology is different depending on the viewpoint of the person making the diagnosis. If the diagnosis is made in the biomedical model context they are socially sanctioned expressions of distress. When the diagnosis or recognition is made within a society which gives validation to these conditions no further
explanation is required because each clinical presentation has an implicit etiology; they are self-explanatory. Koro, for example, is due to the possibility that the sufferer will disappear and become a ghost, since everybody in the cultural milieu on which it is expressed knows that ghosts have no genitals.

THE RHEUMATOLOGIST’S APPROACH TO CULTURE-DRIVEN DISORDERS

Appreciate symptoms and symptom amplification

The first approach to patients with CDDs must be to accept, as best one can, the genuineness of the suffering and symptoms. While a number of symptoms may arise from the somatic expression of psychological distress, it is equally likely that these illnesses draw on multiple benign sources of symptoms. That is, we know from numerous epidemiological studies that symptoms of pain, fatigue, cognitive dysfunction, cough, numbness, etc. are common in the general population, and that most often these symptoms are mild and are not brought to medical attention.\(^57\) Since patients with CDDs are just as likely as anyone to experience life’s pool of symptoms, here then is a symptom substrate upon which a culturally-driven process may act to produce the clinical picture. That there is a common symptom pool may explain why CDDs carry different labels but have similar symptom profiles when examined closely.\(^58\) Yet, individuals with CDDs have more than just symptoms, they have severe symptoms and more disabling symptoms than are found in epidemiological surveys of the general population. The bridge to understanding of why is to appreciate the relevance of symptom amplification. Kirmayer et al.\(^59\) have proposed that there may be times in an individual’s life that symptoms arising from numerous physical sources (occupations, recreations, body habits) may capture attention despite efforts to ignore them. Here symptom amplification may take hold.

Studies show how an individual’s symptoms may be modified (amplified) by various factors independent of injury of disease. Some of these factors can be mitigated by physicians, and some, aggravated or even induced by physicians. Barsky\(^60\) has explored in detail how the concept of symptom amplification has wide clinical relevance.

We know from studies that the patient’s emotional state determines how they perceive minor, day-to-day symptoms from life’s activities, including occupational sources. Patients have been shown, for example, to recall symptoms in a way that matches their current emotional state. Thus, if you ask someone who is currently distressed about their headaches, they will state that recently they have had severe headaches, whereas they will recall fewer and less severe symptoms if they are currently in a good mood. Studies further show that the direction of the effect IS NOT that symptoms significantly affect one’s mood, but rather primarily that one’s mood affects symptoms and symptom recall (see Refs. 60-61). Thus, a patient recalls many symptoms during the same period they are emotional or psychologically distressed, and will underreport or have poor recall of symptoms in the more remote past when they were less distressed.\(^61\) Studies show that anxiety and depression facilitate recall of unpleasant past events, negative experiences in general and of illnesses in particular. For example, one study induced a positive or unpleasant mood among a group of subjects who were then asked to recall their prior symptoms in the last 30 days.\(^62\) Those who underwent an unpleasant mood induction recalled more symptoms than individuals who underwent a positive mood induction. Another study, in which otherwise healthy
subjects underwent exposure to a respiratory virus to induce illness, showed that higher psychological stress assessed before the viral challenge was associated with greater symptom scores in response to infection. In considering whiplash symptoms, Michelotti et al. demonstrated that normal subjects, when in states of natural stress, have altered muscle function and tenderness about the jaw, a common problem in whiplash patients. Yet, these normal subjects had suffered no injury and recovered as the psychological/emotional distress levels dropped. Similarly, Castro et al. were, in a laboratory setting, able to reproduce the acute whiplash syndrome in 20% of subjects who were falsely led to believe they had experienced a true motor vehicle collision. Despite the lack of any biomechanical forces to cause injury, the symptoms evoked were seemingly genuine in this setting, and their development was predicted by pre-experiment psychological measures of somatic-focus and tendencies towards anxiety. Mood affects the perception of symptoms and the appraisal of one’s health. A negative mood makes illness-related memories more accessible and induces a poorer assessment of one’s overall state of health.

As Barsky further reveals, what we believe to be the cause of our symptoms affects how severely we perceive those symptoms. Studies show that someone who believes they are injured will underestimate the symptoms in the period before the patient believes they were injured. Thus, it has been shown that patients with whiplash underestimate their pre-injury history of spinal and other symptoms.

Finally, another aspect of symptom amplification is the effect that close attention to symptoms has on producing the syndrome picture. This has been elegantly shown by Kasch et al. who showed that a percentage of patients with ankle sprains, if they are asked to pay close attention to symptoms like headache, neck pain, and back pain through questionnaires and repeated examinations, will become just like whiplash patients in 3 months, with the same symptoms and even restricted range of neck motion, indistinguishable from whiplash patients. Ankle-sprain patients did not start with spinal pain and although their ankle sprains resolved themselves. These subjects are perhaps amplifying the background rate of symptoms that occurs due to life, occupations, stress, etc. and paying more attention to them. Kasch et al showed that by 6 months, there was a 100% recovery from the symptoms of ankle sprain. Their study reaffirmed how good the prognosis for ankle sprain is. It is possible that because the general population has a pre-conceived notion that ankle sprains are painful, but people do not generally become disabled by them in the long term. This may prevent them from having fears or worrying about their outcome. It is clear that people in many societies have heard accounts of whiplash injuries causing chronic pain and disability; such stories about ankle sprains are likely to be rare.

Whatever the sources of symptoms, the phenomenon of symptom amplification is relevant, and thus the evidence suggests that patients with CDD would be affected by being in an environment that increases emotional distress, which creates fears about the seriousness of the symptoms and thus encourages focus on symptoms.

Once the patient presents in distress with amplified symptoms, and anxiety surrounding those symptoms, the response of family members, employers and health care professionals to a person’s illness behaviour may have a strong influence in the subsequent evolution of the condition. Societal attitudes and cultural notions may also contribute to the emergence and persistence of specific syndromes, as has been seen with Gulf War syndrome, diverse conditions associated with breast implants, and similar popular diagnoses that may be promoted by mass media and diverse social and economic interests.
Label, and then move past the label

It seems appropriate to use labels, as they aid communication and seem to be applied in all cultures. A diagnostic label must be helpful for physicians and non-offensive for patients. Any diagnosis which implies a ‘mental’ problem or an unexplained condition is currently much more offensive for patients, since it does not provide the necessary social sanction to be recognized as ‘sick’.70

Health professionals providing the information must acknowledge the beliefs and general aspects of culture of those for whom the information is provided. Education is an interactive process in which there should be a two-way transference in health information. The information provided must help patients to understand their diagnosis and treatment, diverse aspects of prevention and use the new information in their daily experiences. It must also permit patients to take informed decisions about their treatment.71,72 Useful information can be expected to provoke changes in the perception of these conditions in the community. This is important, since developmental experiences of reinforcement and the familial models of health seeking behaviour play an important role in shaping adult illness behaviour. Exaggerated parental concerns with illness, misattribution of normal sensations with consequent medical help seeking may predispose children to develop bodily preoccupation and anxiety as adults.73

Medical practice is not what it used to be a century ago. We are still treating patients with diverse medical conditions, but now these patients must receive, beside their regular care, social sanction of their condition in order to receive economic compensation which will pay for the attention received and for the disability generated by their illness. This is the arena in which struggles and revisions in nosology take place. An illness must be defined as a separate disease to receive compensation and to be included in the list of medical conditions covered by medical insurance. Then, these revisions of nosology are not just of academic importance. After what we have discussed it is self-evident that the conditions so far discussed as CDD could benefit from ‘de-medicalization’.74 Patients with CDD are at permanent risk of iatrogenic illness due to the possible complications of invasive diagnostic procedures and aggressive and frequently unnecessary pharmacological treatments.75 But this de-medicalization will be a difficult process which must receive special attention, since important social and economic interests will be affected.

Which way to Rome?

As an alternative in preventing further dehumanization in patient care, as a consequence of the current practice of medicine, Engel proposed the biopsychosocial model.76 At the bottom, it is the adaptation of Hippocratic medicine to modern times. Dubos, applying a similar approach, mentioned that ‘the humanness of man creates problems not definable in exact scientific terms’.77 Accepting cultural influences on disease definition, evolution and prognosis is a way of operationalizing the concept. Using it, there are several options available to help these patients’ suffering and regaining lost function.

Coping is the effort to adapt to pain, or manage one’s own negative response to pain.78,79 Coping is frequently conceptualized as a set of strategies to control an adverse experience or one’s reactions to it. In CDD we are trying to control an uncontrollable event because most of the situations producing distress, which are finally expressed in the culturally acceptable metaphors of CDD, will not be modified with our intents on
coping. In fact, this has been shown to have a negative impact on adjustment to chronic health problems. 
Acceptance, on contrary, has been associated with less pain, disability, depression, pain related anxiety and better work status in patients with chronic pain. Acceptance of pain is a concept difficult to define. It is not a simple function of distraction or thinking about pain in other terms. It is not the same as ignoring or positive thinking and it is not captured by current conceptualizations of coping with pain. Acceptance is currently defined as a deliberate, realistic, openness to immediate experience—it may be the opposite to catastrophizing. Both perspectives include an acknowledgment that pain will continue; however, catastrophic thinking is a sense of helplessness, whereas in acceptance this acknowledgement is neutrally framed as a willingness to live with pain. 
CDDs are associated with high levels of uncertainty—uncertain diagnosis; uncertain prognosis—at least from the patient’s perspective. In these situations, diverse behavioural approaches are useful in giving the patient our knowledge of what they can do to improve their outlook. Cognitive therapy is a focussed, structured, collaborative, and usually short-term psychological therapy that aims to facilitate problem solving and to modify dysfunctional thinking and behaviour. A useful discussion and description of the techniques employed can be found in the paper by White. 
It can be implemented by primary care physicians using a few simple techniques such as agenda setting, self-monitoring, experimentation, and changing distressing thoughts.

CONCLUSIONS

Illness is the portion of suffering which we have historically chosen to assign to medical practice. The origins of the concept of disease are not in pathology, but in suffering. We should be able to treat conditions even when a specific biologic cause has been defined. Suffering is what must be alleviated. The progress of medicine has sometimes been obstructed by epistemologic traps. We must always keep in mind that the classification of disease is not a reflection of a ‘real’ world beyond our senses, but a practical way of organizing diverse ailments recognized in populations that permit us to learn about the best ways of management. Disease description and classification is a dynamic process; additions and changes in the definitions of disease must be made as new knowledge from different fields is acquired about them. These reflections should provide the bases for the discussion missing from our regular medical curricula. We need a critical understanding of how medical facts are influenced by the cultural milieu when applied in clinics and research settings.

There is a clear dichotomy between what we intend to offer to our patients and what our patients expect from their medical attention. We learn a lot about precise mechanisms of disease but very little about the practice of medicine. Knowledge is not wisdom, and we need more wisdom in the application of scientific discoveries to the lives of suffering people. We must complement the biomedical approach with special attention to the social interactions driving and conditioning the evolution of every illness. The present health care systems were designed to deal with acute diseases and much of the troubles they are facing are consequences of their incapacity to adapt to the changing demands of the populations they cover. With the acute disease model, each health related situation was expected to be resolved, either by death or by complete restoration. In the chronic disease model, we are dealing with reintegration within limits, unfortunately with no possible recovery ad integrum in most cases.
SUMMARY

Fibromyalgia, chronic fatigue syndrome, Gulf War syndrome, chronic low back pain, etc. can be better understood as CDDs: socially sanctioned expressions of distress in Western cultures. They are necessary diagnostic labels to justify social benefits that would otherwise not be forthcoming with less legitimate illness labels. These patients are at great risk from the effects of symptom amplification, over-medicalization, and focussing on sick role behaviour because they are partly driven by the strict expectations of disability and compensation systems for presentation with the traditional appearance of ‘disease’. Ultimately, if the culture drives these disorders by forcing patients to fit a mould to satisfy social systems of compensation and disability support, then we need to move towards systems that do not distinguish fault, blame, or emotional vs. physical trauma, or workplace vs. recreational injury. In the meantime, rheumatologists can give patients a sense that their illness is legitimate, that they have a variety of physical and psychological problems, that we can work within current systems to give them support for the time out they need to seek effective remedies such as exercise and cognitive therapy, and we can mitigate the effects of symptom amplification by having the patient focus less on symptoms, and more on function. We then help our patients avoid having to prove their illness to others by expressing to them our own acceptance that they have legitimate suffering.

Practice points
(modified from Ref. 91)

- remember that adjusting to these disorders is psychologically demanding
- patients adjust in different ways through their own thoughts and interpretations about the world and their illnesses
- in the initial interview, identify psychosocial issues but avoid direct confrontation
- provide unambiguous information about medical findings
- plan time for gradual discussion of psychosocial issues
- work out a problem list and negotiate an agenda with the patient
- set limits for diagnostic investigations

Research agenda

- what do the associated hormonal changes and dysautonomy in CDDs represent? Do they define diverse substrates of patients or are they changes conditioned by the stressful situation provoking the initial illness?
- do primary prevention strategies such as social marketing programmes to alter belief systems in the general population mitigate against the various factors that otherwise drive these disorders?
- do cognitive and behavioural therapies for CDDs have efficacy in the primary care setting?
- how do modifications in insurance and compensation systems contribute to the outcomes of injury?
REFERENCES