

---

## Medical constructions of long-term exhaustion, past and present

Olaug S. Lian<sup>1</sup> and Hilde Bondevik<sup>2</sup>

<sup>1</sup>*Department of Community Medicine, University of Tromsø - The Arctic University of Norway, Norway*

<sup>2</sup>*Institute of Health and Society, University of Oslo, Norway*

---

**Abstract** Culture and history affect the ways in which medical knowledge is shaped, sustained and changed. The less knowledge we have, the larger the space for the cultural imprint becomes. Based on these assumptions, we ask: how have medical constructions of long-term exhaustion changed over time, and how are changing constructions related to societal change? To discuss these questions we conducted a comparative study of medical texts from two historical periods: 1860–1930 and 1970–2013. Our data are limited to two diagnoses: neurasthenia and encephalomyelitis. After comparing the two periods by identifying diverging and converging aspects, we interpreted observed continuities and interruptions in relation to historical developments. We found that in the medical literature, long-term exhaustion became transformed from a somatic ailment bred by modern civilisation to a self-inflicted psychiatric ailment. At the same time, it changed from being a male-connoted high-status condition to a female-connoted low-status condition. We interpret these changes as contingent upon culturally available modes of interpretations. Medical knowledge thereby becomes infused with cultural norms and values which give them a distinct cultural bias. The historical controversies surrounding this medically contested condition neatly display the socially contingent factors that govern the social construction of medical knowledge.

---

**Keywords:** chronic fatigue syndrome, chronic illness, long-term illness, medical knowledge, sociology of scientific knowledge

### Introduction

It is impossible to understand how health and illness is constructed without discussing when and where and by whom it is constructed. This historical and cultural contingency also applies to the medical knowledge of diseases (Brown 1995, Freidson 1970, Jutel 2011, Rosenberg and Golden 1992, Wright and Treacher 1982). To increase our understanding of how culture and history influence the ways in which medical knowledge is shaped, sustained and changed, we need to study how human problems are medically named and explained in relation to a specific sociocultural context.

In this article we employ a historical sociological approach (Abrams 1982) to study the social transition of medical knowledge related to long-term exhaustion (a severe form of

tiredness). Our aim is to uncover the ways in which cultural norms and values become absorbed into what is presented as medical knowledge about this condition, and we ask: how is medically unexplained long-term exhaustion understood in contemporary Western medicine, compared to earlier times, and how are changing constructions related to cultural and societal conditions? We approach these questions via a comparison of historical and contemporary medical texts discussing two diagnoses: neurasthenia, as used in the period from 1860 to 1930, and myalgic encephalomyelitis (ME), as used from 1970 to present day. Our purpose is not to say anything about what these bodily afflictions are but how they have been named, defined, explained and responded to by medicine in two historical periods. Apart from the introductory sections, our presentation has three parts. Firstly, we present a thematic description of each time period separately. Secondly, we present a comparative analysis of the two periods. Thirdly, we discuss our main findings in relation to some of their theoretical and political implications.

We chose long-term exhaustion as a case for our study because it is a chronic and medically contested condition that is difficult to identify, localise, explain and cure with the aid of modern biomedical knowledge and technology, and therefore leaves ample room for cultural influence. The modern biomedical cosmology is a way of knowing based on collecting, delimiting and classifying symptoms (signs of disease) and by locating them in a place in the body (if possible). Technologically generated findings play an important role in this process. When findings are missing and nothing can be 'seen' in the body, symptoms are often interpreted as 'manifestations of the mind' (Nettleton *et al.* 2004: 63). These conditions score low in the social 'hierarchy of diseases' (Canguilhem 1989: 39, Album and Westin 2008), and their reality is often questioned: 'less physical, less real' (Jutel 2011: 13). Long-term exhaustion is a typical example of a somatic symptom that lacks observable biomarkers to verify organic disease. The condition has been disputed ever since it became medicalised in the 19<sup>th</sup> century (Aronowitz 1998). Whether the exhaustion is psychogenic (caused by the mind) or somatic (caused by the physical body), or a blend of both, is now a question heavily debated not only in medical journals but also in virtual communities on the Internet (Lian and Nettleton 2014), in the public media (de Wolfe 2009) and in consultation rooms (Banks and Prior 2001). An implicit, yet fundamental theme in this debate is to what degree people themselves are to be held responsible for their illnesses.

Our analysis is founded on the assumption that medical knowledge is socially constructed by human beings and therefore infused with cultural norms and values (Canguilhem 1989, Freidson 1970). This implies that we perceive medical knowledge as socially conditioned, and contingent upon (but not reducible to) a specific cultural and historical context. These constructions may or may not have a foundation in a biological reality but in line with Freidson (1970: 212) we perceive this question to be 'beside the point' because they always have a foundation in a social reality, which is where our interest lies. Studying the social construction of medical knowledge means exploring 'the origins of professional beliefs' (Brown 1995: 37). In line with this perspective, our aim is to explore how the broader social context impinges on these constructions. Emphasising the cultural sensitivity of medical knowledge means accommodating health and illness as meaningful phenomena that transcend what they represent with regard to underlying biological pathology.

## **Sociology of medical knowledge**

The social construction of medical knowledge has previously been explored through a wide range of empirical and theoretical studies. Relevant here is the work of Arksey (1994), who

examined the medical knowledge of repetitive strain injury (RSI), a disease characterised by pain, stiffness or numbness in upper limbs. While rheumatologists explained RSI as a physical condition caused by repetitive movements and overuse, orthopaedics argued that it was psychogenic because it had no 'objective' observable signs. Arksey interpreted these 'incommensurable thought-styles' (p. 462) as being related to different treatment options: as opposed to holistically oriented rheumatologists, orthopaedics found their surgical skills to be of no use for these patients. In a study of aetiological debates about multiple sclerosis, Nicolson and McLaughlin (1988) found that competing theories (autoimmune and vascular theories) were filtered by different skills and modes of interpreting research results by immunologists and neurologists and by the unequal power balance between the specialities.

Another example is the work of Aronowitz (1998), who studied how various chronic conditions became medically named and explained through social processes of negotiation. Ulcerative colitis, for instance, became redefined from a psychosomatic to an autoimmune condition after more effective treatment options were found. Lyme disease became constructed as a new disease, different from its similar antecedents, because of individual characteristics of researchers (nationality, disciplinary background, methodological approach, interpretation of biological evidence, and attitudes to medical research results). Finally, he described how long-term exhaustion became named with two different diagnoses: ME and chronic fatigue syndrome (CFS), and how this split reflected an underlying issue of patients seeking legitimacy for having an actually existing somatic disease. This is in line with the work of Shorter (1992), who argues that neurasthenia was a fashionable disease in the 19<sup>th</sup> century because it was defined as an organic disease. Its popularity disappeared, however, when psychiatry parted from neurology and defined neurasthenia as a psychiatric disease.

Medical knowledge is also influenced by societal changes in employment, education and family structures, and by historically contingent notions of women (Annandale 2009, Bordo 1992, Moscucci 1990, Moss and Dyck 2002). Based on a discussion of three typically female diagnoses at different times (hysteria, agoraphobia and anorexia), Bordo (1992: 5) describes the female body as a place where 'the politics of gender are inscribed with special clarity'.

The use of medical knowledge in clinical encounters has also been explored. While observing meetings in a cardiology outpatient clinic, Hughes and Griffiths (1996) found that, although clinical decisions were presented as purely technical judgements devoid of normative content, they were often affected by the patient's social status (class, gender and ethnicity), and perceptions of individual deservingness. These considerations were often hidden in accounts for actions in terms of medical benefit. In other words, there is a space for doctors 'to act according to their perceptions of deservingness, while accounting for their actions in terms of medical benefit' (p. 193). Similarly, Berg (1992: 158) showed how biomedical knowledge and information from clinical investigations were (re)constructed after being blended with social considerations like 'rarely visits physician' and 'intelligent patient'.

## Study design

To explore the relation between medical knowledge and the societal context in which it occurs, we have conducted a qualitative case study (QCS) with a comparative design. Our methodology is informed by Robert E. Stake's (2005) interpretative and constructivist approach to the QCS. Although our main aim is to gain detailed, in-depth information about two unique cases (medical constructions of long-term exhaustion in two historical periods), this methodology enables us 'to learn from the case about some class of things' (Stake 2005:

447). From our cases, we learned something about the social construction of medical knowledge more generally. Because we assume that historical change is best seen as a chain of disruptions (a Foucauldian perspective), as opposed to a linear development with an underlying continuity, our empirical data consists of medical texts discussing long-term exhaustion from two historical periods 40 years apart. All work related to our study was conducted by the authors of this article.

#### *Data collection*

Our data consist of a purposive selected sample of medical books and journal articles discussing neurasthenia (in the period between 1860 and 1930) and ME (in the period between 1970 and 2013). We chose neurasthenia because it was the first precise medical diagnosis for long-term exhaustion, and ME because it is currently preferred by patients. The ME diagnosis is used interchangeably with CFS, and our findings would probably have been similar had we focused on CFS. Neurasthenia was used as a diagnosis mainly between 1860 and 1930, and contemporary understandings of ME dates back to the 1970s – hence the chosen time periods.

In the first stage of our data collection we identified available medical literature using scholar.google.com. Our search terms were ‘neurasthenia’ (published between 1860 and 1930) and ‘myalgic encephalomyelitis’ (published between 1970 and 2013), combined with ‘(a)etiolog\*’ (truncated search). Initially, the two cases consisted of about 11 000 and 6 000 hits, respectively (including many duplicates). Based on a set of pre-defined criteria (Table 1) we then selected about 50 texts for each of the two diagnoses for a more thorough qualitative in-depth analysis. Both authors suggested relevant texts before an ultimate decision was agreed on.

Our selection of texts might be biased, and other selections could have given different results. We find the main weakness of our sample to be that we downplay national differences and minority views. Our presentation must therefore not be understood as a true and complete picture, but as our interpretation of some interesting systematic patterns.

#### *Data analysis*

In the first stage of our analysis we conducted an inductive qualitative thematic analysis of each of the two cases. This analysis involved searching for, identifying, analysing and reporting patterns (themes) that stretched across the data material (Braun and Clarke 2006). We limited our final analysis to three themes, formulated as questions: how are diagnostic criteria described; which casual factors are emphasised in aetiological explanations; and how is the typical patient described. After reading the selected texts, we identified and grouped extracts from all texts containing information related to our three themes (for each case separately). We then compared the two cases by identifying patterns of divergence and convergence. Finally, we searched for possible explanations of change and stability by interpreting observed

Table 1 *Selection criteria*

- 
- Original (not secondary) texts from Anglo-American sources
  - Texts discussing aetiological theories
  - Internationally cited texts
  - Clinically influential texts
  - Texts written by authors who became decisive in setting the scene of their time, for neurasthenia:
  - Beard and Mitchell in the US and Ballet, Freud and Kraepelin in Europe, for ME: Straus in the US and McEvedy, Beard and Wessely in Europe
-

continuities and interruptions against the backdrop of cultural and historical developments. During this process we formulated and reformulated our hypotheses several times through an exploratory and case-led approach, and we rechecked our reading and our interpretations several times. Through this grounded theory strategy (Charmaz 2014, Glaser and Strauss 1967) we constructed theories from the data itself. To maintain rigour we interpreted the data first individually and then both of us together.

### **Long-term exhaustion in the age of nervousness (1860–1930)**

In the second part of the 19<sup>th</sup> century, long-term exhaustion became medicalised and redefined from a troublesome situation to a medical diagnosis: neurasthenia. For a period of 50 years (1880–1930), this was one of the most commonly used diagnoses in Western countries (Shorter 1992).

#### *Neurasthenia: an overview*

By far the most influential writings about neurasthenia came from the American neurologist George Beard (1839–1883). Beard (1881: 5–6) described neurasthenia as an organic ‘lack of nerve-force’ expressed through severe exhaustion, accompanied by symptoms such as headache, insomnia, fever sensations, sensitisation of the sensory organs, weak limbs, emotional instability and anxiety (the list contained 80 symptoms). In Europe, the French neurologist and professor Gilbert Ballet (1853–1916) was among the leading interpreters. Ballet (1908) conceptualised the condition much in the same way as Beard.

The class and gender distribution of neurasthenia varied between countries (Gijswijt-Hofstra and Porter 2001). In France, Germany, The Netherlands and the USA (not so much so in Britain), the distribution pointed to upper-class men. In Germany in the 1890s, von Hösslin (1893: 66) counted 604 men of a total of 828 cases. In American sources, the typical neurasthenic was portrayed as a hard-working upper-class brain-worker who was ‘civilized, refined, and educated’ (Beard 1881: 26). Pritchard (1905: 12) also designated neurasthenia as ‘a disease of bright intellects, its victims are leaders and masters of men’. In France, Ballet (1908: 11) claimed that neurasthenia had an ‘almost exclusive limitation to the cultivated classes’. In short: neurasthenia was a high-status diagnosis usually given to people from the upper classes, including world-famous authors (Marcel Proust, Virginia Woolf and Charlotte Perkins Gilman), health professionals (Sigmund Freud and Florence Nightingale) and a sociologist (Max Weber, who was diagnosed with ‘neurasthenia due to years of overwork’ (Radkau 2011: 145) by Emil Kraepelin in 1898).

#### *Aetiology*

According to Beard (1881), neurasthenia was an organic lack of nerve-force originating in – and located in – the nerves, and caused by strain on the brain. Ballet (1908: 17) also explained neurasthenia as caused by the ‘exaggerated action of the brain’ through intellectual work. This strain caused pathological changes in the ‘chemical structure’ of the central nervous system (Beard 1869: 218). This theory built on a common assumption at that time: that disease was divisible in sthenia (excess of stimulation) and asthenia (incapacity to react to stimulus). Compared with Beard, Ballet expressed his theories with more uncertainty: ‘nervous energy is known to us only by its manifestations; we are almost totally ignorant of its fundamental causative conditions’ (Ballet 1908: 136). Both Beard and Ballet explicitly defined neurasthenia as not a psychiatric disease: it was ‘a physical not a mental state’ (Beard 1881: 17) and ‘a somatic disease of the nervous system, and may be contrasted to

hysteria, which is a psychiatric disease' (Ballet 1908: 3). This definition, including the organic-sounding name, obstructed any notion that the condition might be imaginary (Shorter 1992).

Neurasthenia was described as a by-product of 'the progress of civilisation' (Ballet 1908: viii) and the rapid upheavals and changing social structures it entailed (urbanisation, industrialisation, capitalism, new technology for communication and transport and women's entrance into the labour force). Modernity was contrasted with nostalgic descriptions of the past: 'In bygone days the world was a peaceful place' (Briggs 1921: 19). Both Beard and Ballet claimed that modern civilisation created new ways of living that damaged people's health. The centre of their attention was the fast pace of urban life, sometimes symbolised by the invention of watches: 'The perfection of clocks and the invention of watches have something to do with modern nervousness, since they compel us to be on time' (Beard 1881: 103). Those who fell ill were perceived as unfortunate victims of an increasingly busy and demanding society. Both Ballet and Beard described heredity as a predisposing factor, often seen in people with 'fine, soft hair, delicate skin, nicely chiselled features, small bones... superior intellect, and with a strong and active emotional nature' (Beard 1881: 26).

To explain the damaging effects of modern civilisation on the nervous system, Beard (1881: 98) used the electrical generator as an analogy: the generator is designed for a limited amount of energy. If the consumption exceeds this limit, the generator shuts down. In a similar way, neurasthenia terminated an overload. As such, it was a sign of a body that was functional rather than weak. Ballet agreed: 'intense or too prolonged intellectual work may give rise even in an energetic and well-balanced man to symptoms of a neurasthenic nature' (Ballet 1908: 17–18).

In the beginning of the 1900s somatic explanations were gradually replaced by more psychogenic ones, particularly among German physicians such as Emil Kraepelin, Alfred Hoche and Karl Jaspers. After the German professor of psychiatry Georg Stertz (1928) explicitly defined neurasthenia as a mental illness in a psychiatric diagnostic manual, the use of the diagnosis declined significantly (Shorter 1992).

Aetiological discussions about neurasthenia were often gendered and class-related. The arguments referred to both biological and social factors, often the different roles played by men and women in society. Isaac G. Briggs (1921: 19) assumed that neurasthenia was more common in men than in women 'because of the more active part played by them in the struggle for existence'. According to Ballet (1908: 23), young boys seldom acquired neurasthenia because they 'simply stop work when they are tired'. Those affected became ill because of 'the evil discipline of boarding schools' (p. 25), and the living conditions there (poor hygiene, long working days, masturbation and lack of sleep and physical activity). For girls and women, he had other explanations:

Those who go out much, and especially women, have their whole day taken up by duties that the vain care of their reputation impose on them: visits, dinners, balls and evening parties make their life one of continual constraint, and of obligations without respite. (Ballet 1908: 27)

Robert Jones (1911), a physician in London, linked neurasthenia in girls to modern schools (the tight timetables and the athletic games they were forced to engage in). This, he claimed, made them 'mentally numb and cold from a lack of resourcefulness and self-confidence. Such states of mind and body carve the way for the worst type of 'nerves' or neurasthenia' (Jones 1911: 329). Emil Kraepelin built his gendered explanations on a mix of social and biological factors:

Of the men, naturally those who are more talented, better educated, and more active, are the individuals who most often suffer from this disease . . . Women, because their weaker powers of resistance and greater emotional irritability, are more susceptible than men. (translation from Diefendorf 1918: 147)

In biological explanations, assumed differences between the mental capacities of women and men were important. The American neurologist Silas Weir Mitchell (1829–1914) described gender differences as biologically determined to such an extent that it could not be compensated for by giving women more education: ‘nor do I think any educational change in generations of women will ever set her . . . as an equal beside the man’ (Mitchell 1901: 37).

Neurasthenia was sometimes related to sexual energy, and referred to as sexual neurasthenia. Freud (1985), who thought that ‘every neurasthenia is sexual’, described it as ‘a frequent consequence of an abnormal sexual life’ (pp. 39–40). These theories were also gendered: neurasthenia could be caused by too much (men) or too little (women) use of libido (Freud 1985). For men, ‘self-abuse or sexual excesses’ could undermine their nerve strength (Briggs 1921: 22). For women, such disturbances were related to sexual frustration.

Class-specific and gender-specific aetiological descriptions were also visible in statistical data. In a study of 167 cases of neurasthenia in the USA between 1885 and 1910 (Gosling and Ray 1986), overwork was attributed to 69 per cent of middle-class men, but only to seven per cent of middle-class women (Table 2). Given that overwork was perceived less stigmatising than substance abuse and sexual excess, middle-class men received the most sympathetic explanations, and lower class women and men the least sympathetic ones (Gosling and Ray 1986).

### Long-term exhaustion in the age of tiredness (1970–2013)

Today, long-term exhaustion touches on a perceived cultural characteristic of our age, epitomised by the book title *The Age of Tiredness* (Lilleaas and Widerberg 2001). The condition is referred to by medical diagnoses such as ME, CFS, burn-out, somatic symptom disorder or other generic names. The debate on nomenclature is central because the label is not merely a name: whereas chronic fatigue describes a symptom, ME points to a localised somatic organic

Table 2 *Percentage of indicated causes of neurasthenia 1885–1910, by gender and social class (N = 167)*

Cause of illness	Women		Men	
	Lower class (%)	Middle-class (%)	Lower class (%)	Middle-class (%)
Overwork	26	7	26	69
‘Female trouble’	40	49	–	–
Sexual excess	0	0	41	20
Substance abuse	14	14	29	10
Heredity	12	23	0	10
Other	12	14	9	6
Sum*	104	107	105	115

\*Percentages exceed 100 because in some cases several causes are indicated (Gosling and Ray 1986).

pathology ('myalgia' means muscle pains, 'encephalomyelitis' means brain damage). The debate is rooted in two questions: should the condition be understood primarily as psychogenic or somatic, and should it be understood as an illness in its own right or a symptom that occurs in various illnesses, the same way as fever?

### *ME: an overview*

The term ME was first used in the 1950s in connection with epidemic outbreaks of an unknown, polio-like assumed infectious disease in Los Angeles (1934), Iceland (1955) and London (1955) (Anonymous 1956). In the ICD-10, the World Health Organization (WHO) classifies ME as a neurological condition of the brain (code G93.3) (WHO 2010).

ME is defined as long-term debilitating physical exhaustion that cannot be directly associated with a well-defined illness. Post-exertional malaise that does not disappear after resting is a key component (Morris *et al.* 2013), accompanied by symptoms such as malaise, headaches, bowel problems, sleep disturbances, difficulties with concentration and muscle pain (National Institute for Health and Care Excellence [NICE] 2013). An international expert group defines ME as a profound dysregulation of the central nervous system that results in an impaired ability to produce sufficient energy, accompanied by neurological, immunological, endocrinological, metabolic and cognitive symptoms (Carruthers *et al.* 2011). Diagnosis is primarily based on symptom descriptions and case histories. The absence of technologically generated findings, medical explanations and curative treatments makes ME a controversial diagnosis with low status and low legitimacy in modern medicine (Aronowitz 1998).

ME is a rare illness: using strict diagnostic criteria, the estimated prevalence is 1–2 per thousand (Fluge *et al.* 2011). The proportion of women suffering from this illness is thought to be somewhere between 70 and 85 per cent (Capelli *et al.* 2010). The typical patient is often portrayed with a 'female touch' and stereotyped as a well-educated and previously successful middle-class woman with an ambitious and perfectionist personality (Hart and Grace 2000). As far as we know, there are no available statistics that support these views. In an epidemiological study about CFS, the researchers found no empirical support for 'the social class stereotype of higher social status among individuals with CFS' (Jason *et al.* 1999: 2136).

### *Aetiology*

The aetiology of ME is unknown but possible aetiologies include neurological, endocrine, immunological, genetic, psychogenic and infectious factors (NICE 2013). The main aetiological divide goes between somatic and psychogenic explanations.

In the somatic model, a dominant theory is that ME is an autoimmune disease that involves alterations in immunological functions (concurrent pathological findings in these patients indicate a persistent immunological response). Viral and bacterial infections are assumed to be important triggering and maintaining factors (Morris *et al.* 2013). A recent review article supports the neuro-immune explanation of ME (Morris *et al.* 2013). One of the studies in this review (a Norwegian randomised controlled trial that received international attention in 2011) showed that ME patients benefited from being treated with rituximab, a drug used for treating leukaemia and several autoimmune diseases (Fluge *et al.* 2011). An international consensus panel also concludes that recent studies (in addition to clinical experience) 'strongly point to widespread inflammation and multisystem neuropathology' (Carruthers *et al.* 2011: 327).

Despite these research results, the dominating explanation of ME is currently based on a psychogenic model in which psychological casual factors are foregrounded. This understanding of ME appeared after two physicians in 1970 explained the outbreak of the polio-like disease in London in 1955 as a characteristic case of mass hysteria that 'occurs in populations of segregated females – in girls' schools, convents, and among female factory hands' (McEvedy and

Beard 1970: 9). Their core argument rested on the high proportion of women affected. In a much debated article from 1988 the American physician Stephen E. Straus and his colleagues added age and ethnicity to the list of risk factors, and defined ‘educated adult white women’ with ‘unachievable ambition’ and ‘poor coping skills’ as being particularly susceptible (Straus *et al.* 1988: 791). Later, ‘epidemic hysteria’ became changed to ‘culturally induced’, with clear hints that to an imaginary status (its very existence is questioned): ‘there is no specific disease and, therefore, no specific treatment’ (Mouterde 2001: 562).

Today, the theory of sustained arousal dominates aetiological descriptions. According to this theory, ME is the result of a long-lasting stress response caused by somatisation of stress. Bodily responses to stress are often functional, but they can become harmful by an inability to cope with stress: ‘The arousal response is gradually turned off when successful (‘coping’). If not, the arousal may be sustained’ (Wyller *et al.* 2009: 2). This assumption rests on complex non-verified hypotheses that builds on a simple monocausal explanatory model in which mental factors are ascribed a causal effect (although it all happens in the physical body). The theory of causation is deduced from various studies of statistical associations, such as an experiment showing that when ME patients are exposed to a small amount of strain, such as hypothermia or an upright position, their sympathetic nervous system (the part of our autonomic nervous system that is beyond our conscious control) mobilises the body’s reactions to stress in a way that is different from that in healthy people:

The body is therefore permanently in ‘a state of alert’; the sympathetic nervous system behaves as though the person is fleeing from a lion, when in reality they are at rest. (Wyller 2008: 12, our translation)

This stress response is described as being caused by a vicious circle that involves both precipitating factors (an infection, acute stress or long-term stress) and predisposing factors (genetic disposition or personality). Personality characteristics and lifestyle are presumed to influence people’s vulnerability. Ambitious, conscientious perfectionists are seen as being particularly susceptible (Prins, van der Meer, and Bleijenberg 2006, Wessely 1994, Wyller 2008, Wyller, Eriksen, and Malterud 2009):

At the same time, it has been scientifically substantiated that certain personality traits, such as being conscientious and a perfectionist, represent a risk in children and young people. This also harmonises well with clinical experience; the patients generally appear as ambitious and resourceful. (Wyller 2008: 9, our translation)

### **Continuity and interruption**

In our selected texts, certain aspects continue and others remain the same. By comparing the two periods and linking converging and diverging aspects to societal factors, the historical and cultural contingency of medical constructions of long-term exhaustion become visible.

#### *The aetiological U-turn*

One of the most striking historical interruptions is the transition from structural to individual explanations. In neurasthenia’s heyday, medicine primarily used societal explanations, while portraying neurasthenic patients as unfortunate victims of societal change. Today, medicine seeks explanations in individual peoples’ personalities and coping skills, and the illness is no

longer regarded as an expected and socially legitimate result of being exposed to strain. This aetiological U-turn also involves a shift from somatic to psychogenic explanations. The exhaustion relates to the nervous system in both periods, but the causal arrow is reversed: a somatic illness causing mental afflictions became a somatic symptom (persistent fatigue) caused by personality traits.

### *Cultural availability*

Neurasthenia became established as a diagnosis at a time when heritage, degeneration and bacteriological factors were emphasised. Yet prevailing societal conditions became the main explanatory factor. When contextualising the medical system – seeing it as embedded in its cultural surroundings – this becomes understandable. The diagnosis evolved against the backdrop of the second industrial revolution. This was a symbolic important time (the turn of a century) with rapid societal change and growing cultural pessimism (expressed by, among others, Ferdinand Tönnies in *Gemeinschaft und Gesellschaft* in 1887, and Georg Simmel in *Die Großstädte und das Geistesleben* in 1903). It was also a time of widespread epidemics of infectious diseases such as cholera (diseases linked to poor living conditions), and a time when new ideas emerged about a socio-political role of medicine in creating more egalitarian societies (in Europe, most of all represented by Rudolph Virchow). Eventually, these ideas led to a new medical speciality (social medicine) with a strong emphasis on the social determinants of health (Porter 2006). Medical constructions of neurasthenia absorbed these surroundings.

In a similar way, the current psychogenic understanding of ME has absorbed a hallmark of modernity in Western societies: the individualistic notion of disembedded individuals acting on the basis of a free will. The individualistic ‘triumph of the will’ (Brown and Baker 2012: 32) has substituted societal factors with individual choices (unhealthy lifestyles) in medical explanations of diseases. The behavioural argument constitutes the core of a modern biomedical system in which individual freedom and responsibility are emphasised (Porter 2006).

Culturally available modes of medical constructions can also be explored through literary constructions (Bondevik and Stene-Johansen 2011). In the second part of the 19<sup>th</sup> century exhausted women appeared in several novels written by authors such as Flaubert, Dumas, Tolstoj and Gilman. In Flaubert’s *Madame Bovary*, the main character of the novel bearing her name was bedridden with long-term exhaustion in several periods of her short life. In her least well periods ‘she said nothing, heard nothing, and even seemed to be in no pain – as if body and soul both were resting from all they had suffered’ (Flaubert 2011: 184). She tried to compensate for her ailment in various extramarital relationships and by spending money on material goods, but her efforts were in vain. At less than 30 years old, she ended her life by taking poison. Nevertheless, Flaubert presents this woman and her ailment in a morally neutral manner without judging or condemning her in any way. Quite to the contrary, he demonstrates the ways in which the cultural circumstances of bourgeois society (as opposed to individual free will) determined the position of women at that time. In contemporary literature, such as in Sue Townsend’s (2012) novel *The Woman Who Went to Bed for a Year*, this perspective is absent. When Eva – a married mother of two – decides to stay in bed for one year, she is morally condemned:

Her mother said it straight out: ‘Look at her now! Lolling about in bed like the Queen of Sheba ... I didn’t bring her up to be a lazy cow’ (pp. 101–2).

This switch from cultural circumstances and social recognition to individual blame and disbelief is similar to the shift we see in medical constructions.

Contemporary psychogenic explanations of ME are linked to cultural views of tiredness in our culture. These norms tell us who has permission to be tired and when, where and how we are allowed to show it. Today, tiredness is a sign of weakness that must be fought and hidden (Widerberg 2005). In this cultural context, psychogenic explanations of long-term exhaustion run the risk of stigmatising the sufferer.

### *Gendered and class-related explanations*

Medical constructions of long-term exhaustion mirror cultural conceptions of gender and social class. Cultural views of women were particularly visible in diagnostic descriptions from the heyday of neurasthenia: while women were described as overloaded by emotional and social pressures, men were described as being overloaded through intellectual work. This relates to presumed gender differences at that time: women were associated with the irrational body and men with the rational mind (Annandale 2009, Moscucci 1990). These theories were given a scientific gloss through assumedly value-neutral evolutionistic biological models that explained an assumed inherent constitutional weakness of women. Biological descriptions bore a class dimension: the weak, delicate and sickly upper-class woman was portrayed differently from the strong, dangerous and infectious lower-class woman (Annandale 2009).

Explanations of neurasthenia were founded on neurological theories that focused on nervous energy. The reserves of this energy were assumed to be finite (Porter 2001). At that time, neurology had a central position in medicine: the role of the nerve fibres in connecting body and brain gave neuroanatomy 'a prima facie prominence in the elucidation of maladies of mood and behaviour' (Porter 2001: 31). According to these theories, the woman was a passive energy-building being with an especially sensitised and delicate nervous system, and because she consumed most of her energy in the reproductive process she had to live a life of reduced activity (Moscucci 1990). If her delicate organism became overloaded she was punished with weakness and sickliness.

Biological portraits of the female body as more fragile and less capable than the male body were formulated in a time when women's rights arguments were beginning to be developed (Annandale 2009, Bordo 1992, Moscucci 1990). This challenged the doctrine of separate spheres (men as breadwinners, women as mothers and homemakers). The emancipated woman who took on new social roles outside her domestic life may have encouraged societies to regulate women in new ways. Physicians 'were among the most important groups influencing gender ideology in the Victorian period' (Gosling and Ray 1986: 251). The role of the medical profession in this undertaking is visible, for instance, in discussions about neurasthenia in relation to the development of girls' schools. A physician in London argued that the girls' schools must be changed if 'the present mental lukewarmness of girls towards the principles of house-keeping, the care of infants, the true instincts of motherhood, and civic duties is to be changed' (Jones 1911: 329). Explaining neurasthenia as a result of societal change could serve to support arguments against the new roles women were taking on in society.

Aetiological theories of neurasthenia were related to basic social structures at that time. Married middle-class women could not have neurasthenia linked to working for a wage because they did not do so. When the role of women in society changed in the 1970s and 1980s a new theory emerged: wage-earning women have poorer coping skills than men, and ME is a self-inflicted creation of educated wage-earning women who have become too ambitious and perfectionist. Today, the dominating aetiological description of ME is based on gender-neutral but class-related psychological explanations. Although explicitly gendered arguments are rarely seen in the early 1990s, probably as a result of changing norms about what is culturally legitimate to say about women, the typical patient is still portrayed as a well-educated woman unable to cope with stress and pressure which arise when she does not respect the limits of

her capacity. This is the energy theory of the 1800s, dressed in modern individualist clothing that gives it a stigmatising effect. The silhouette of the upper-class woman of the 1800s, who failed to cope with stress and pressure in expending her energy both in and out of her home, is visible in the background here. The female-connoted ME diagnosis therefore still carries with it a view of women that has deep historical roots.

### *From heroes to losers?*

The theory of overexertion has survived as a main theory, but it is adapted to a new age. Originally, it served to justify long-term exhaustion by explaining that the overload is a result of increasing societal demands. Today, the deciding factor is the individual's ability to cope. This change expresses an individualistic ideology that we all are responsible for preserving our own health, and when we fail to do so by choosing unhealthy lifestyles, we are the ones to be blamed (Brown and Baker 2012).

The aetiological U-turn has therefore changed our view of the sufferers. In the 18<sup>th</sup> and 19<sup>th</sup> century, nervous conditions were 'a badge of honour' and 'a mark of superior sensibility' (Porter 2001: 32). The pale, tender, sensitive, nervous and passive neurasthenic woman resting on a chaise longue was more than socially acceptable; she was a symbol of a sophisticated class-conscious vulnerability that was admired and looked up to as a normative ideal, almost the pure incarnation of all that was feminine (Bordo 1992). The neurasthenic man was also portrayed heroically, as a cultivated leader of shining intellect. The absence of condemning undertones in medical descriptions (also seen in Flaubert's novel) expresses something of the *Zeitgeist* of that time. When the admiration of the heroic disappeared, ME patients became portrayed in moralistic ways as ambitious perfectionists without the ability to live up to their own ambitions. From depictions of individual women making (misguided) lifestyle choices it is a fairly short step to the conclusion that women are liable for their own downfall (Annandale 2009).

Medical diagnosis has the power to remove or enforce stigma and blame. When we transfer causal factors from society to individuals we also transfer blame and responsibility. In our culture, the ability to cope with life is an important social value. Any illness caused by a lack of coping is interpreted as self-inflicted and related to weakness: a character defect. Psychogenic explanations may therefore have a stigmatising effect and make patients feel burdened by guilt and shame. According to a review of 34 qualitative studies, ME patients often report that their doctors question their moral character and throw doubt on the reality of their symptoms (Anderson *et al.* 2012). Several studies also show that doctors feel negatively towards ME patients, holding the belief that they often exaggerate the severity of their symptoms (Anderson *et al.* 2012).

Shifting blame and responsibility from society to the individual has more consequences than stigmatisation; it can also undermine people's rights to receive social security benefits and healthcare services, as currently seen even in the most comprehensive welfare states: the Scandinavian countries (Michailakis and Schirmer 2010).

## **Medicine's cultural bias**

The comparison of the two historical periods illustrates how medical constructions of long-term exhaustion is not merely revealed or discovered, it is also interpreted within a particular sociocultural context. Through this interpretation, medical knowledge becomes infused with cultural norms and values which colour medical constructions and give them a distinct cultural bias. Medical and cultural aspects are so closely entwined that they become difficult to

separate, especially in the present time because the cultural blindness that comes from culture is something we often take for granted. Through the use of historical data, we have tried to overcome some of this blindness.

Our main finding is that medical diagnoses for long-term exhaustion have been redefined from a somatic condition bred by modern civilisation to a self-inflicted psychological condition. We also find that when the somatic foundation was removed, long-term exhaustion changed from a male-connoted, high-status illness (neurasthenia) to a female-connoted, low-status illness (ME). The condition changed from being constructed as a legitimate result of heroic effort by intelligent 'leaders and masters of men', to being constructed in a stigmatising way, as a result of women's insufficient abilities to cope with their lives. We explain this transformation by changes in societal structures and the changing cultural conceptions of gender and social class. As our discussion indicates, we interpret these factors in an intersectionality perspective, as integrated factors that interact with and modify each other in a complex interplay (Iyer *et al.* 2008).

Modern medicine and healthcare systems are increasingly challenged by bodily ailments for which they have no cure. Medical constructions of these conditions are based on normative judgments presented as value-neutral knowledge, free from cultural influences. By overlooking the historical, cultural and normative dimensions of medical knowledge, we fail to see how medical constructions can enforce stigma and blame. By recognising and elucidating their cultural imprint through empirical research we can identify, question and challenge the implicit normative messages that increase the conflicts that often arise in relation to medically unexplained conditions. Unveiling these messages facilitates political action, as well as theoretical developments. Technologically invisible and medically unexplained conditions are sociologically interesting because they offer ample room for cultural influence, and because they neatly display the socially contingent factors that govern the social construction of medical knowledge.

*Address for correspondence: Olaug S. Lian, Department of Community Medicine, Faculty of Health Sciences, University of Tromsø- The Arctic University of Norway, N-9037 Tromsø, Norway. E-mail: olaug.lian@uit.no*

## Acknowledgements

The work on this article (first author) is financed by The Norwegian Research Council, Research Program of Health and Care Services (grant no. 212987/H10). We would like to thank the anonymous referees for helpful comments to this article.

## References

- Abrams, P. (1982) *Historical Sociology*. New York: Cornell University Press.
- Album, D. and Westin, S. (2008) Do diseases have a prestige hierarchy? A survey among physicians and medical students, *Social Science & Medicine*, 66, 1, 182–8.
- Anderson, V.R., Jason, L.A., Hlavaty, L.E., Porter, N. *et al.* (2012) A review and meta-synthesis of qualitative studies on myalgic encephalomyelitis/chronic fatigue syndrome, *Patient Education and Counseling*, 86, 2, 147–55.
- Annandale, E. (2009) *Women's Health and Social Change*. London: Routledge.
- Anonymous (1956) A new clinical entity?, *Lancet*, 267, 789–90.

- Arksey, H. (1994) Expert and lay participation in the construction of medical knowledge, *Sociology of Health & Illness*, 16, 4, 448–68.
- Aronowitz, R.A. (1998) *Making Sense of Illness. Science, Society, and Disease*. Cambridge: Cambridge University Press.
- Ballet, G. (1908) *Neurasthenia*, 3rd edn. London: Henry Kimpton.
- Banks, J. and Prior, L. (2001) Doing things with illness. The micro politics of the CFS clinic, *Social Science & Medicine*, 52, 1, 11–23.
- Beard, G.M. (1869) Neurasthenia, or nervous exhaustion, *Boston Medical and Surgical Journal*, 3, 13, 217–21.
- Beard, G.M. (1881) *American Nervousness: Its Causes and Consequences*. New York: Putnam's Sons.
- Berg, M. (1992) The construction of medical disposals. Medical sociology and medical problem solving in clinical practice, *Sociology of Health & Illness*, 14, 2, 151–80.
- Bondevik, H. and Stene-Johansen, K. (2011) Sykdom som litteratur. 13 utvalgte diagnoser (Illness as literature. 13 selected diagnoses). Oslo: Unipub.
- Bordo, S. (1992) The body and the reproduction of femininity: a feminist appropriation of Foucault. In Jagger, A. and Bordo, S. (eds) *Gender/Body/Knowledge*. New Brunswick: Rutgers University Press.
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3, 2, 77–101.
- Briggs, I.G. (1921) *Epilepsy, Hysteria and Neurasthenia: Their Causes, Symptoms and Treatment*. London: Methuen.
- Brown, B.J. and Baker, S. (eds) (2012) *Responsible Citizens: Individuals, Health and Policy under Neoliberalism*. London: Anthem Press.
- Brown, P. (1995) Naming and framing: the social construction of diagnosis and illness, *Journal of Health and Social Behavior*, 36, (extra issue): 34–52.
- Canguilhem, G. (1989) *The Normal and the Pathological*. New York: Zone books.
- Capelli, E., Zola, R., Lorusso, L. et al. (2010) Chronic fatigue syndrome/myalgic encephalomyelitis: an update, *International Journal of Immunopathology and Pharmacology*, 23, 4, 981–89.
- Carruthers, B.M., van de Sande, M.I., De Meirleir, K.L. et al. (2011) Myalgic encephalomyelitis: international consensus criteria, *Journal of Internal Medicine*, 270, 4, 327–38.
- Charmaz, K. (2014) *Constructing Grounded Theory*, 2nd edn. Los Angeles: Sage.
- de Wolfe, P. (2009) ME: the rise and fall of media sensation, *Medical Sociology Online*, 4, 1, 2–13.
- Diefendorf, A.R. (1918) *Clinical Psychiatry. a Textbook for Students and Physicians, Abstracted and Adapted from the Seventh German edition of Kraepelin's 'Lehrbuch der Psychiatrie'*. New York: Macmillan.
- Flaubert, G. (2011 [1857]) *Madame Bovary*. London: Penguin.
- Fluge, Ø., Bruland, O., Risa, K. et al. (2011) Benefit from B-lymphocyte depletion using the anti-CD20 antibody rituximab in chronic fatigue syndrome, A double-blind and placebo-controlled study, *PLoS ONE*, 6, 10. doi:10.1371/journal.pone.0026358.
- Freidson, E. (1970) *Profession of Medicine*. Chicago: University of Chicago Press.
- Freud, S. (1985) *The Complete Letters of Sigmund Freud to Wilhelm Fliess 1887–1904*. Cambridge: Harvard University Press.
- Gijswijt-Hofstra, M. and Porter, R. (2001) *Cultures of Neurasthenia. From Beard to the First World War*. Amsterdam: Rodopi.
- Glaser, B.G. and Strauss, A.L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter.
- Gosling, F.G. and Ray, J.M. (1986) The right to be sick. American physicians and nervous patients, 1885–1910, *Journal of Social History*, 20, 2, 251–67.
- Hart, B. and Grace, V.M. (2000) Fatigue in chronic fatigue syndrome: a discourse analysis of women's experiential narratives, *Health Care Women International*, 21, 3, 187–201.
- Hughes, D. and Griffiths, L. (1996) 'But if you look at the coronary anatomy: risk and rationing in cardiac surgery, *Sociology of Health & Illness*, 18, 2, 172–97.
- Iyer, A., Sen, G. and Ostlin, P. (2008) The intersections of gender and class in health status and health care, *Global Public Health*, 3, S1, 13–24.

- Jason, L.A., Richman, J.A., Rademaker, A.W. *et al.* (1999) A community-based study of chronic fatigue syndrome, *JAMA Internal Medicine*, 159, 18, 2129–37.
- Jones, R. (1911) Girls' schools, games, and neurasthenia, *The Lancet*, 177, 4562, 329.
- Jutel, A.D. (2011) *Putting a Name to It. Diagnoses in Contemporary Society*. Baltimore: Johns Hopkins University Press.
- Lian, O.S. and Nettleton, S. (2014) 'United we stand': framing myalgic encephalomyelitis in a virtual symbolic community, *Qualitative Health Research*, doi:10.1177/1049732314562893.
- Lilleaas, U.-B. and Widerberg, K. (2001) *Trøtthetens tid [The age of tiredness]*. Oslo: Pax.
- McEvedy, C.P. and Beard, A.W. (1970) Royal free epidemic of 1955: a reconsideration, *British Medical Journal*, 5687, 1, 7–11.
- Michailakis, D. and Schirmer, W. (2010) Agents of their health? How the Swedish welfare state introduces expectations of individual responsibility, *Sociology of Health & Illness*, 32, 6, 930–47.
- Mitchell, S.W. (1901) *Doctor and Patient*, 3rd edn. Philadelphia: J.B. Lippincott.
- Morris, G., Berk, M., Galecki, P. and Maes, M. (2013) The emerging role of autoimmunity in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), *Molecular Neurobiology*, 48, 2, 1–16.
- Moscucci, O. (1990) *The Science of Woman. Gynaecology and Gender in England 1800–1929*. Cambridge: Cambridge University Press.
- Moss, P. and Dyck, I. (2002) *Women, Body, Illness. Space and Identity in Everyday Lives of Women with Chronic Illness*. Lanham: Rowman & Littlefield.
- Mouterde, O. (2001) Myalgic encephalomyelitis in children, *Lancet*, 357, 9255, 562.
- Nettleton, S., O'Malley, L., Watt, I. and Duffey, P. (2004) Enigmatic illness: narratives of patients who live with medically unexplained symptoms, *Social Theory & Health*, 2, 1, 47–66.
- National Institute for Health and Care Excellence (NICE) (2013) Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME in adolescents and children. National Institute for Health and Care Excellence. Available at <http://www.nice.org.uk/guidance/cg53> (accessed 21 January 2014).
- Nicolson, M. and McLaughlin, C. (1988) Social constructionism and medical sociology: a study of the vascular theory of multiple sclerosis, *Sociology of Health & Illness*, 10, 3, 234–61.
- Porter, D. (2006) How did social medicine evolve, and where is it heading?, *PLoS Medicine*, 3, 10, 1667–72.
- Porter, R. (2001) Nervousness, eighteenth and nineteenth century style: from luxury to labour. In Gijswijt-Hofstra, M. and Porter, R. (eds) *Cultures of Neurasthenia. From Beard to the First World War*. Amsterdam: Rodopi.
- Prins, J.B., van der Meer, J.W.M. and Bleijenberg, G. (2006) Chronic fatigue syndrome, *Lancet*, 367, 9507, 346–55.
- Pritchard, W.B. (1905) The American disease: an interpretation, *Canadian Journal of Medical Surgery*, 18, 10–22.
- Radkau, J. (2011) *Max Weber. A Biography*. Cambridge: Polity.
- Rosenberg, C.E. and Golden, J. (eds) (1992) *Framing Disease. Studies in Cultural History*. New Brunswick: Rutgers University Press.
- Shorter, E. (1992) *From Paralysis to Fatigue: a History of Psychosomatic Illness in the Modern Era*. New York: Free Press.
- Stake, R.E. (2005) Qualitative case studies. In Denzin, N.K. and Lincoln, Y.S. (eds) *The Sage Handbook of Qualitative Research*. Thousand Oaks: Sage.
- Stertz, G. (1928) Die neurasthenische reaktion. In Bumke, O. (ed) *Handbuch der geisteskrankheiten*, Vol. 5. Berlin: Springer.
- Straus, S.E., Dale, J.K., Wright, R. and Metcalfe, D.D. (1988) Allergy and the chronic fatigue syndrome, *Journal of Allergy and Clinical Immunology*, 81, 5, 791–5.
- Townsend, S. (2012) *The Woman Who Went to Bed for a Year*. London: Penguin.
- von Hösslin, R. (1893) Aetiologie. In Müller, F.C. (ed) *Handbuch der Neurasthenie*. Leipzig: Verlag von F.C.W. Vogel.
- Wessely, S. (1994) Neurasthenia and chronic fatigue: theory and practice in Britain and America, *Trans-cultural Psychiatric Research Review*, 31, 2, 173–209.

- World Health Organization (WHO) (2010) International Classification of Diseases (ICD-10). <http://www.who.int/classifications/icd/en/> (accessed 5 November 2013).
- Widerberg, K. (2005) Embodied gender talks – the gendered discourse of tiredness. In Morgan, D., Brandth, B. and Kvande, E. (eds) *Gender, Bodies and Work*. Hampshire: Ashgate.
- Wright, P. and Treacher, A. (1982) Introduction. In Wright, P. and Treacher, A. (eds) *The Problem of Medical Knowledge. Examining the Social Construction of Medicine*. Edinburgh: Edinburgh University Press.
- Wyller, V.B. (2008) *Kronisk utmattelsessyndrom hos barn og ungdommer. Myalgisk encefalopati [CFS/ME]*. (Chronic fatigue syndrome in children and adolescents. Myalgic encephalomyelitis [CFS/ME]) Oslo: Paediatric Clinic, National Hospital.
- Wyller, V.B., Eriksen, H.R. and Malterud, K. (2009) Can sustained arousal explain the chronic fatigue syndrome?, *Behavioral and Brain Functions*, 10, 5. doi:10.1186/1744-9081-5-10.