

Book Review

The psychology of fatigue in chronic illness: recent studies and new perspectives

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1. Introduction

Many studies have documented that fatigue is a prevalent phenomenon that shows up amongst different populations such as tired housewives, burnt out managers and chronically ill patients. Indeed, recent epidemiological figures reflect the impression that fatigue is a common complaint presenting itself in a variety of different contexts: it may accompany a dull day without interesting activities, follow a day of hard labor as well as signify underlying medical pathology [1–3]. Amongst all these figures, those on fatigue in the healthy population tend to attract media attention since they raise questions about the increase in symptoms of fatigue which are assumed to be due to the hectic and busy lives many of us lead nowadays. Still, it is unclear whether the prevalence of fatigue has really risen or whether we are preoccupied with being tired and tend to interpret signs of discomfort in terms of fatigue [4,5]. Whatever the facts of the matter, if it is true that there is an epidemic of fatigue it certainly is not a typical modern phenomenon which must be interpreted as a sign of massive preoccupation with high aspirations and overloaded agenda's. In fact, the well-documented neurasthenia outburst at the turn of the century may be viewed as the precedent of today's epidemic and parallels the current preoccupation with a fear of overload – while, in our view, in those times people must have lived at a slower pace. Still, even when media attention to fatigue is a case of 'old

wine in new bottles' as Simon Wessely has put it, it may be argued that psychological knowledge or fatigue has not increased much since those days [6]. To be more precise, like in those days psychological studies of fatigue as a health issue tend to be descriptive and rather atheoretical in nature. What is new and may lead to more sophisticated knowledge is the existence of the Chronic Fatigue Syndrome (CFS) in the popular literature also addressed as myalgic encephalomyelitis (ME). The existence of CFS has led to an overwhelming body of research in which biological, psychological and social approaches to fatigue are jointly explored and which may eventually contribute to a better understanding of chronic fatigue. However, also in the case of CFS or perhaps, more accurately, especially in the case of CFS the role of psychological factors in the etiology and perpetuation of CFS is subject to passionate debate.

Recently, two studies in the field of health psychology have been published which focus on fatigue in chronically ill patients: the study of Smets [7] discusses fatigue of cancer patients and that by Vercoulen [8] relates to the Chronic Fatigue Syndrome. Although these studies each address a different population, they share the common perspective of assessing the role of psychological factors in fatigue associated with (chronic) illness. In fact, they also share a very careful and considerate treatment of this issue as if they were afraid to acknowledge the role of psychology in fatigue. Such prudence may

seem appropriate in the case of Smets' book [7] on fatigue in cancer patients undergoing radiotherapy because it cannot be ruled out beforehand that the role of psychology is limited and that fatigue is primarily a physical phenomenon directly related to the ill body and the tiresome therapy. However, one would not expect such reserve in the case of CFS, the topic of Vercoulen's dissertation [8], as the role of psychological factors in CFS has been more elaborated. CFS being the highly intriguing but poorly understood set of symptoms associated with intense and invalidating fatigue without medical explanation, one would assume that psychological factors played a significant role in its explanation – either as etiological factors or as factors determining the way CFS patients cope with their condition. But as Vercoulen and a number of other CFS researchers have experienced, the more ill-defined the complaints the more reluctant patients are to acknowledge the role of psychological factors as if they were anxious their complaints would be considered 'less real' or even that they themselves were to blame for having them [9]. Therefore, the psychological aspects of fatigue in CFS are considered even more controversial than those in cancer, rheumatoid arthritis or any other disease with an unchallenged medical cause.

2. Fatigue and the Chronic Fatigue Syndrome

Very explicitly Vercoulen sets out to limit the focus of his enquiry to research the role of psychological concepts as *perpetuating* factors and repeatedly claims no insight into the role of psychology as a factor in the etiology of CFS. Vercoulen's dissertation is in fact a compilation of articles published earlier in international psychological and medical journals, together with other researchers involved in multidisciplinary CFS research at the Nijmegen University Hospital (The Netherlands), and addresses such diverse topics as fatigue assessment, the natural course of CFS, the role of depression in CFS, the role of physical activity and neuropsychological aspects. Although it was impossible to detect a clear theoretical framework which was used to define and identify a set of psychological

factors, Vercoulen and colleagues have rather systematically explored a number of factors which have repeatedly been highlighted in health psychology and behavioral medicine in the last couple of years. Self-efficacy, attributional style and locus of control are among the most important. The main findings in a sample of almost 300 CFS patients are interesting but not surprising: CFS patients who are self-efficacious and acknowledge their own role in dealing with illness tend to have better prognosis over time than patients who feel less confident about themselves. The study also shows that a strong belief in a viral cause of CFS makes patients vulnerable to a sedentary lifestyle with the number of activities reduced to a minimum which in turn affects their physical condition. Eventually, these patients appear not to be able to escape from the selffulfilling prophecy of avoiding activity and being confirmed in the expectation that they are incapable of effort due to their illness.

Despite these interesting findings, the study is a bit disappointing because of its data-driven character which makes it difficult to appreciate the implications of the results. In contrast, another part of the study is much more appealing. This part deals with a comparison of fatigue data of CFS patients with those of patients suffering from multiple sclerosis (MS), a disease also characterized by intense fatigue. Using data on a fatigue quality of life scale the authors compiled from a number of existing measures they applied linear structural analysis to test the fit of a particular fatigue model on the fatigue data of both patient groups. The findings suggest that different, disease-specific models are required to explain the intense fatigue both patient groups experience. The perpetuation of fatigue in CFS patients appears to be related to low self-efficacy, limited physical effort and a strong focus on physical sensations. The latter two factors appear to be especially important since CFS patients strongly believe that physical effort contributes to the experience of fatigue while in fact the opposite is true: doing nothing makes CFS patients feel tired and enhances their preoccupation with physical sensations. In contrast, MS patients also tend to avoid physical activity but in their case this does not contribute to feelings of fatigue. Even more interesting is the finding that CFS patients have a strong inclination to somatization but not in a way

that they express their emotional distress in terms of physical symptoms: more than MS patients, CFS patients are so focused on physical sensations that they tend to have a biased perception of fatigue symptoms. These results are especially interesting as they may be a link to theories of (biased) symptom perception such as those of Pennebaker [10] and Cioffi [11]. Unfortunately, Vercoulen and colleagues do not discuss their findings in such a way. Nevertheless, it may be important to study the psychological aspects of CFS in a more theory-driven approach in the near future. Both to patients and to physicians, CFS has remained a rather complex and elusive set of symptoms in which bickering over the role of psychological factors has dominated over attempts to clarify that role. The adoption of an explicit and coherent psychological framework may help to initiate a more accurate evaluation of the psychology of CFS.

Another central issue in Vercoulen's book is the part on fatigue assessment. Using items from scales such as the Beck Depression Inventory and the Sickness Impact Profile, combined with a number of items on fatigue, the authors claim to have made a reliable and valid fatigue scale. Apart from the questionable decision to compile well-known and valid scales and factor analyse them into a number of new dimensions, one wonders whether such an approach contributes to an accurate evaluation of the phenomenon of fatigue itself. In fact, the authors have made what may be called a fatigue-specific quality-of-life instrument assessing such aspects as the physical, psychological, emotional, and functional adjustment to CFS. Of course, data obtained with such an instrument are valuable, but by themselves provide no information on the quality and intensity of fatigue experienced by CFS patients. Still, it is true that little information is available about the best way to assess fatigue which may be related to the fact that fatigue defies accurate description. About a century ago the Italian physiologist Mosso acknowledged that there is "... only one term to refer to fatigue. The reason for this is easy to understand... fatigue is *too featureless an internal sensation* to distinguish any varieties..." (Mosso, 1903, p. 119, italics added) [12]. However, there have been several attempts to assess fatigue in a reliable way and a recent attempt is described in

Smets' book on cancer patients undergoing radiotherapy.

3. Fatigue in radiotherapy patients

Like Vercoulen's book, the study of Smets is explorative, addresses a number of related issues on fatigue in a particular patient group (i.e. cancer patients) and consists of a number of articles published earlier in international journals. However, Smets' approach is different from that adopted by Vercoulen in the way that an explicit attempt is made to capture the nature of fatigue experienced by cancer patients. Starting from the literature on fatigue, a multidimensional fatigue scale (the Multidimensional Fatigue Inventory, MFI) was developed, highlighting physical, mental, and general dimensions of fatigue, as well as a dimension of reduced activity and a dimension of reduced motivation. The data obtained with this instrument suggest that fatigue experienced by different populations such as medical students, army recruits, junior physicians and cancer patients is of a similar nature, that is that all five dimensions are present to some extent in these populations and also that the five-dimensional structure was confirmed. Compared with the data on CFS patients and MS patients presented by Vercoulen this is a remarkable finding, especially since the MFI was developed in collaboration with Vercoulen and his colleagues. However, the apparently different findings may be explained by the fact that the results of Vercoulen were obtained by a different instrument highlighting quality-of-life aspects instead of ratings of fatigue 'itself'.

Smets' main findings concern what may be called a bottom-up evaluation of fatigue and its impact on quality of life of cancer patients. Results show that fatigue among 250 cancer patients (miscellaneous diagnoses, including lung cancer, breast cancer, gynecological cancer, hematological malignancies and a number of other cancers) during radiation treatment is a chronic, mostly physical sensation unrelated to foregoing activity and only partly involving the dimensions of lack of motivation and mental fatigue. Fatigue is always present but most intense during radiation therapy. Nine months after completion of the therapy the fatigue experienced by

cancer patients (who were by that time disease-free) is not different in nature and quality from fatigue experienced by a matched control group of healthy subjects, although fatigue experienced by cancer patients was less predictable. At every stage during treatment fatigue causes much distress and affects quality of life of cancer patients, demonstrating once again that the effects of medical treatment cannot be evaluated by medical outcome measures only. Which factors are responsible for the level of fatigue experienced by cancer patients? It appears that physical condition, in terms of functional disability and sleep impairment, is most predictive of the pretreatment level of fatigue which in turn is the best predictor of the level of fatigue during treatment. Nevertheless, according to Smets, psychological aspects are involved during every stage of disease, either as a cause or as a consequence, while personality factors such as optimism play a minor role. Unfortunately, Smets remains unclear about the way psychological processes are involved. In an attempt to pinpoint the role of psychological factors, Smets tried to explain levels of fatigue from a stress-coping perspective considering fatigue as the outcome of a lack of resources (i.e. functional disability) to meet the demands of the situation (i.e. perform daily activities). The hypothesis that a balance between resources and demands would predict fatigue was not confirmed, however, but according to Smets this may be due to the inadequate operationalization of resources and demands in the model. Smets concludes her book by expressing the feeling that many times during the study it was as if the concept of fatigue slipped through her fingers, demonstrating the elusiveness Mosso noted a century ago. Yet, acknowledging that fatigue defies accurate description may open new ways to study its etiology and natural course.

4. Conclusion

The results of Smets' study once again raise the question of how we should understand fatigue and which models we should apply to research it. The stress-coping framework may be an interesting approach and has also been applied in studies on job fatigue. Yet, other approaches may also be valid.

Still, it is remarkable that in health psychology the phenomenon of fatigue raises so much confusion and that so little information is shared with other psychological approaches to fatigue, most importantly those adopted in occupational psychology and psychonomics. Communication of the views developed in occupational psychology, for instance, would teach much about a hot issue in health psychological research on fatigue, that is the relation between activity or effort on the one hand and the sensation of fatigue on the other hand. Occupational studies have demonstrated repeatedly that the amount of effort contributes very little to the explanation of the intensity of fatigue. In fact, in occupational psychology it is common knowledge that fatigue is not so much a matter of 'not being able to' as well as a matter of 'not being prepared to', thereby highlighting the motivational aspects of fatigue Thorndike noted at the turn of the century [13]. It is remarkable that this approach has hardly been explored in health psychological research on fatigue, the only exception that I know of being Salmon's study on post-operative fatigue [14]. His findings and those of others adopting a motivational view of fatigue demonstrate clearly that, except perhaps in cases of total exhaustion, fatigue is always related to 'action readiness' [15]. This is also demonstrated in the work of our own research group. A study on fatigue at a population level performed by de Rijk was originally intended to test a symptom perception approach to fatigue by adopting a 'competition of cues' view (Pennebaker) to fatigue which would explain in which contexts the sensation of fatigue would be most manifest [10,16]. We expected fatigue to be related to either too much activity (contributing to a sense of exhaustion) or too little activity (contributing to the feeling of 'ennui' which is so characteristic for the experience of fatigue), but we found that the level of activity alone (be it understimulation or overstimulation) could not explain satisfactorily why people reported fatigue. Neither too much activity nor too little activity affected the level of action readiness people experienced as long as they felt committed to those activities and were interested in what they felt they needed to do. Also, the role of lay beliefs in the nature and the natural course of fatigue appeared to play an important role in self-regulation of healthy fatigued people and corroborated our

earlier findings on coping and adjustment in CFS patients and patients suffering from Addison's disease (an adrenal insufficiency characterized by intense fatigue) [17]. These studies showed that a belief in the physical nature of fatigue is not a single factor but strongly associated with beliefs on the causes, consequences and controllability of fatigue. Therefore, the way people adjust to fatigue appears to be related to typical ways of thinking about fatigue, consisting of complex sets of different cognitions. It would be an interesting research line to test whether such an approach is also valid for the understanding of fatigue in chronic illness and to determine whether motivation is a key psychological factor in the experience of fatigue associated with being ill.

References

- [1] Bruera E, McDondald RN. Overwhelming fatigue in advanced cancer. *Am J Nurs* 1988;88:99–100.
- [2] Chen MK. The epidemiology of self-perceived fatigue among adults. *Prev Med* 1986;15:74–81.
- [3] Finkelman JM. A large database study of the factors associated with work-induced fatigue. *Hum Factors* 1994;36:232–43.
- [4] David A, Pelosi A, McDonald E, Stephens D, Ledger D, Rathbon R, Mann A. Tired, weak or in need of rest: fatigue among general practice attenders. *Br Med J* 1990;301:1199–202.
- [5] Lewis G, Wessely S. The epidemiology of fatigue: more questions than answers. *J Epidemiol Community Health* 1992;46:92–7.
- [6] Wessely S. Old wine in new bottles: neurasthenia and 'ME'. *Psychol Med* 1990;20:35–53.
- [7] Smets EMA. Fatigue in cancer patients undergoing radiotherapy. Thesis, University of Amsterdam, 1997.
- [8] Vercoulen JHMM. Chronic Fatigue Syndrome: assessment and psychological processes as perpetuating factors. Thesis, University of Nijmegen, 1997.
- [9] McLean G, Wessely S. Professional and popular views of chronic fatigue syndrome. *Br Med J* 1994;308:776–7.
- [10] Pennebaker JW. The psychology of physical symptoms. New York: Springer, 1982.
- [11] Cioffi D. Beyond attentional strategies: a cognitive-perceptual model of somatic interpretation. *Psych Bull* 1991;109:25–41.
- [12] Berrios GE. Feelings of fatigue and psychopathology: a conceptual history. *Compr Psychiatry* 1990;31:140–51.
- [13] Thorndike EL. Mental fatigue. *Psych Rev* 1900;7:466–82.
- [14] Salmon P, Hall GM. A theory of postoperative fatigue: an interaction of biological, psychological, and social processes. *Pharmacol Biochem Behav* 1997;56:623–8.
- [15] Frijda NH. The emotions. Studies in emotion and social interaction. Cambridge: Cambridge University Press, 1986.
- [16] De Rijk A. Similarities in complaints of fatigue: relationship to overload and underload. Paper presented at The Second Dutch Conference on Psychology and Health, 25–27 May 1998, Kerkrade, The Netherlands.
- [17] Heijmans M, De Ridder D. Assessing illness representations of chronic disease: explorations of their disease-specific nature. *J Behav Med* (in press).