

S0022-3999(98)00107-X

## EDITORIAL

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# MODERN DISORDERS OF VITALITY: THE STRUGGLE FOR LEGITIMATE INCAPACITY

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### INTRODUCTION

Subjective incapacity and fatigue are common as secondary symptoms in many physical and psychiatric disorders. In the last decade, however, a range of “new” illnesses has emerged in which incapacity and fatigue are the primary and central complaints. Patients with these illnesses may often be difficult to treat on an individual level. In the public domain, they are very vocal, challenging medical expertise.

Patients present with diffuse and unspecific complaints, such as excessive fatigue, muscular aches and pains, and difficulty in concentrating. Embedded in these complaints is a perceived incapacity to perform daily activities in the usual way, so that incapacity becomes an essential and primary characteristic of the illness. As fatigue seems to be the symptom with the closest experiential ties to incapacity, this may be the reason why this symptom figures so prominently in the often excessive lists of complaints of these patients. Although medical examinations reveal no obvious organic explanation, the patients persist in attributing the complaints to a physical cause, either in the body or the environment or both.

The legitimacy of the syndromes invoked in (self-)diagnosis is, to varying degrees, debated in medical science as well as in social security and the law. Examples include multiple chemical sensitivity syndrome (MCS), chronic fatigue syndrome (CFS), silicone breast implant-related toxic syndrome, complaints related to dental amalgam, sick building syndrome (SBS), and fibromyalgia (FM) [1, 2]. They are, as yet, not part of the official classifications of diseases.

In what follows, we present a conceptual perspective intended to strengthen current attempts at avoiding unproductive mind–body splits in dealing with these illnesses. Some of the difficulties in understanding these new illnesses appear to be a consequence of the currently accepted biomedical model of diseases. This model supposes that there are physical or psychiatric illnesses underlying the incapacity, which are identifiable within a human body or person. An alternative conceptualization of incapacity, not as a secondary consequence of another illness, but a pri-

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mary expression of disturbed relations of a person to his or her environment, may be hard to accept because of its overtly vitalistic undertones. However, it may help to understand more clearly some of the phenomena common to the aforementioned new illnesses.

#### “VITALISTIC” ACCOUNTS OF INCAPACITY AND FATIGUE

Since the 19th century, a teleological (or, taken here as broadly synonymous, “vitalistic”) concept of explaining phenomena through a force directed at a certain goal has disappeared from the natural sciences—not least because of its excesses of postulating “ghosts in the machine” like an “*élan vital*.” For a long time, its all-too-easy explanations stood in the way of scientific progress, although recently the necessity for teleological explanations of biological—as opposed to physical—phenomena reappears; for instance, in the form of so-called teleofunctionalism in cognitive science.<sup>1</sup>

Within medicine, all teleological notions have been replaced by the biomedical model, which contains a physicalist concept of explaining phenomena through the mechanistic interaction of causes and effects. This separation of cause and effect is related to a second split that is characteristic of modern biomedical epistemology: the split between psyche and soma. According to this model, incapacity is the effect of a cause that is different from it; that is, there must be a primary illness verifiable by medical examination. The illness can be a physical or a psychiatric one, with symptoms subsequently leading to impairment and incapacity; for example, paralysis (as a sign of a stroke) or formal thought disorder (as a symptom of schizophrenia) may both impair the patient’s capacity to participate in professional and private life. The implication is that treatment of the underlying illness and its primary symptoms will directly diminish or abolish the secondary incapacity.

From the perspective of the biomedical model, incapacity may also occur as part of depressive syndromes. In this case, feeling unable to perform activities in the usual way coexists with a depressed mood, feelings of guilt, bodily complaints, etc. Again, it is assumed that pharmacologic and/or psychotherapeutic treatment directed at the depressive illness as a whole and not primarily at the incapacity will diminish or abolish it.

However, the biomedical model makes it difficult to conceptualize a clinical lack of energy, force, or vitality as the primary problem of a patient, independent of psychological or physical causes inside his or her body.

The psychiatrist and medical anthropologist Kleinman described this particular consequence as follows:

Modern biomedicine is the only major medical system in the world that has banished vitalism; therefore, disorders of fatigue have to be secondary to something else. In every other major system (Chinese medicine, Ayurvedic medicine, most traditional folk healing systems), vitalism is central to the epistemol-

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<sup>1</sup> Strictly speaking, “vitalism” is a term used only for the kind of outdated teleological explanation that postulates “ghosts in the machine” of some sort. Nevertheless, we use the adjective “vitalistic” for the more modern kind of teleological explanations, which, in other contexts, are referred to mainly as “intentional explanations”; that is, an explanation referring to context-dependent intentional states, on a level higher than and not reducible to the usual mechanistic explanations [3].

ogy, and therefore fatigue in itself is not only a legitimate complaint, but a legitimate diagnosis, as a disorder of vitality. [4]

On this abstract level of description, a vitalistic account of “disorders of vitality” would see them as a lack of energy, force, or vitality, which is not secondary to a disturbance primarily located within the person affected by it, but rather primarily due to disturbances in the goal-directed interaction of a person with the particular (social) environment.

We contend that, if it is possible to make sense of this abstract account of incapacity, it may be useful in understanding the new illnesses centered around incapacity, in particular the struggle to legitimate them, and in linking them to the sociopolitical framework in which they occur.

At first, short excerpts from three historic analyses of fatigue and incapacity may help to clarify what a “disturbance in the interactions of a person, her goals and the environment” means in these cases.

Muncie [5] remarked that, when patients with chronic fatigue say “tired,” they mean “tired of it,” and that they themselves mistake this part for the whole. This fact that they do not realize that their tiredness concerns certain objects or goals in their life he calls the “neurotic element of the performance.”

Within German anthropological phenomenology, one finds an historically early awareness of the aim dependency of fatigue and the difficult moral dimension of not being able to perform normally, which leads to the questionable legitimacy of such a complaint.

For cases of organically unexplained exhaustion or fatigue, Von Weizsäcker [6] considered the absence of the usual ability to achieve certain goals at work not as a secondary consequence, but as the primary and central phenomenon. He stated that, in normal circumstances, willingness to do something is dependent on being capable of it. This also means that incapacity usually involves a certain reduction in will. Capability in turn does not only depend on will and other “inner” factors, it must always be judged in relation to a given situation or a goal.

Thirty years later, Von Baeyer [7] expanded on this line of thought: as a starting point, he described the state of being exhausted as psychophysical powerlessness and atonia, which cannot be explained by a lack of physical energy. At this point, Von Baeyer, like Von Weizsäcker, did not conclude that there must be a primary psychiatric illness that causes the exhaustion. He interprets this kind of exhaustion, in a colorful phrase which tries to capture the goal-relatedness of the phenomenon, as “submission under the weight of being there,” with an unwilling–willing capitulation in front of the “too much” of the exigencies of being there—of its senselessness. In other words, the exhaustion of the patient is a form of expressing that his professional or private goals in living are underdeveloped, inappropriate, and/or cannot be realized—whether it is because of one’s own weaknesses or because of the particular social situation in which she or he is living. The moral dilemma facing patients and the doctors judging their illness, Von Baeyer continues, is feeling forced to decide between “being incapable for willed action” versus “being unwilling to be capable.” The former appears as a judgment of legitimate disease, the latter as a judgment of moral failure. However, as Von Baeyer claims, in accordance with Von Weizsäcker, there is no easy distinction here, because “being unwilling to do some-

thing” is an irreducible part in “being incapable to perform”; the incapacity necessarily affects the ability to will. The state of being exhausted in itself does not allow differentiation: it is only the knowledge of the patient’s goals and projects and their possible perils that enables one to make the distinction between an amount of unwillingness that is an acceptable part of exhaustion and the more or less conscious rejection of capability in laziness.

#### USING “VITALISTIC” ACCOUNTS AS AN EXPLANATORY TOOL FOR THE SOCIAL DYNAMICS OF “DISORDERS OF VITALITY”

In contrast to the biomedical approach, vitalistic accounts of incapacity bring in a genuinely interpersonal or social perspective already in the definition of the problem domain “incapacity.” This seems to make them more suitable to explain the typical social phenomena occurring in the new illnesses centering around incapacity.

First, vitalistic accounts make it clear that, for patients, the irreducible connection of incapacity and unwillingness is even more “dangerous” than the “usual” stigma of being psychologically ill. If the context-dependent co-occurrence of disease and moral weakness is viewed under the context-ignorant microscope of biomedicine, the implication of being a malingerer, not ill at all, is raised. This abruptly deprives patients of legitimization of their complaints. Given this dangerous prospect, patients will naturally prefer to identify causes for the incapacity other than the incapacity itself. This tendency they obviously share with the clinician or scientist who adopts the usual biomedical approach. But, patient and clinician often differ on the kind of cause they assume: for patients, symptoms (like fatigue, chemical sensitivities, difficulty concentrating, aches and pains) are assumed to have organic and external causes instead of the more stigmatized psychiatric ones. In contrast, many doctors prefer just these psychiatric explanations (like depression, anxiety, or somatoform disorders) for the symptoms.

Second, vitalistic concepts may also help to understand why the struggle for legitimacy is so fierce in the “disorders of vitality.” Many of these patients argue vigorously for legitimacy via self-help groups, sympathetic doctors and other health practitioners, lawyers, the mass media, and more recently the internet. Increasingly, this campaign bypasses both medicine as a science and medical institutions, not only via alternative medicine, but, more forcefully, via the use of politics or the law for legitimacy, even without scientific acceptance of a certain disorder [8]. Methods employed in the campaign involve not only political lobbying, but also filing lawsuits for alleged scientific malpractice to delay or prevent publications that fail to provide evidence for the organic basis of disorders like MCS [9] (a similar case for Germany has been reported by Altenkirch [10]).

The wish to avoid the stigmatization of a psychiatric diagnosis does not seem sufficient to explain this struggle for legitimacy: other groups of patients—for instance, those with chronic pain—also fear this stigma and suffer a delegitimization of their subjective symptom experiences, but they do not exhibit this kind of behavior. An external, environmental attribution of the perceived causes makes it easier to develop a collective strategy in the struggle for legitimacy, but there are many cases, especially of CFS, FM, and MCS, where the causal attribution primarily concerns

internal factors like viruses, hypersensitivity, etc. As mentioned earlier, the media and persons and groups other than the patients themselves also contribute to the intensity of the struggle—but it seems difficult to imagine that they would be able to do so without a readiness on the side of the patients to “fight for their right.”

Using the vitalistic account, one might mention again that the experiential core of felt incapacity, be it in the disguise of a complaint of fatigue or not, entails a greater amount of “illegitimate” unwillingness than symptoms like pain, dizziness or fear: “I simply cannot” or “I cannot because I am tired” is closer to “I cannot because I do not want to” than “I cannot because I am in pain” or “because I feel dizzy.” From this perspective, the remarkable vigor of the exhausted patient struggling for legitimization seems to be directly related to the goal of persuading not only others but also himself that this illegitimate part of the complaint does not exist. The apparent paradox of somebody who, on the one side, complains primarily of incapacity or fatigue but who, on the other, is capable of actively taking part in the struggle for legitimacy must not be a sign of conscious simulation. It becomes understandable when the goal-relatedness of the incapacity is taken into account; that is, relative to unattainable private or professional goals there may be a “submission under the weight of being there,” but relative to the new goal of reaching legitimate incapacity the same person may show remarkable vigor.

Third, a vitalistic account offers the possibility to link the phenomenon of incapacity more directly to the sociopolitical situations in which it occurs on a macro level. Social transitions, quite literally, which affect the individual’s “work capability” (see ref. 6), professional success, competition, and gender roles inevitably lead to imbalances between the goals of the individual and his felt capability. According to a vitalistic account, this should be related to an increase of vitality disorders—and apart from the general observation that “disorders of vitality” indeed often have an occupational background, there are several reports describing the link to specific sociopolitical situations (see ref. 11 for a study of neurasthenia in a socialist economy and ref. 12 for a study of the influence of changing roles for women in the 1980s on CFS). In this context it may also be possible that, in western societies, postmodernism has led to a change of values and norms. Individual professional success has become a more important determinant of worth as viewed by others and by the persons themselves. Failure to achieve that goal, or just the anticipation of failure, may explain, at least partially, the current vogue in “disorders of vitality”—and if this failure, as it is common now, can be attributed to external causes, it is obviously less damaging to self-esteem. By contrast, how would one have diagnosed chronic fatigue syndrome in the “hippie” generation, when pleasure was arguably more important than professional performance?

A final application of the vitalistic account concerns the role of medicine. Medicine can be seen to bear responsibility for the fierceness of the struggle for legitimacy for two related conceptual reasons: first, its dualistic biomedical model reinforces the patient’s impression that they have either a legitimate disease or an illegitimate moral affliction. Without a “vitalistic” appreciation of context and goals, there is no room for legitimate unwillingness in incapacity. Second, it may be that, as a consequence of its approach to the phenomenon of incapacity, medicine is challenged both epistemologically and socially by patients with “disorders of vitality.” Medicine’s role as a gatekeeper for the legitimization of incapacity is dependent on

the biomedical model of the “human motor” [13]. The rise of neurasthenia at the end of the 19th century challenged this model shortly after it had been established, because of the absence of clear causes for the incapacity in neurasthenia. Ultimately, however, this disorder succumbed to the new view of incapacity and came to be seen as secondary to other, mainly psychiatric illnesses [14]. Proponents of the new “disorders of vitality” again challenge the biomedical model, by proposing new theories incompatible with current toxicology (e.g., toxicant-induced loss of tolerance, or TILT [15]) or by trying to bypass evidence-based medicine completely via the courts. From this perspective, the fierceness of the current struggle could turn out to be not only one from patients for the legitimacy of their incapacity, but also one from medicine against the delegitimization of its privileged role as gatekeeper.

If one is prepared to accept vitalistic accounts of incapacity as valid, they might contribute not only to a better understanding of the behavior of patients, but also help to remind us of the responsibility we have to use adequate concepts for the clinical and scientific interactions with this important group of patients.

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