

## REVIEW

# Definitions and aetiology of myalgic encephalomyelitis: how the Canadian consensus clinical definition of myalgic encephalomyelitis works

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A perspective on the various definitions of myalgic encephalomyelitis and the process of discovering its aetiology is presented. The importance of clinical guidelines is emphasised to encourage clinicians to provide clear descriptions of their individual patients required for proper clinical activity; diagnosis, estimation of severity of effect, prognosis, treatment and rehabilitation. This individual knowledge is informed by general and (hopefully) publicly confirmed knowledge resulting from scientific research during the second-person interaction which lies at the core of the clinical encounter. Both types of knowledge are essential.

the basic clinical activities of individual diagnosis, individual prognosis, individual treatment and individual prevention,<sup>4</sup> also including an assessment of its effect on the patient's life (degree of dis-ease and dis-ability or deviation from the state of ease and ability which we call health).

The observational context of clinical activity is thus more complex and begins from the first-person viewpoint generated by the deictic<sup>5 6</sup> coordinates of the individual patient, which then meets the observational and empathic skills of the doctor, as well as the generalised third-person coordinates of established public knowledge backed by various forms of evidence, in the doctor-patient relationship within a second-person interaction. This knowledge then must be reapplied within the deictic coordinates of the individual patient, viewpoints and all. But this is "anecdotal" certainty, and hence irrelevant to science. But, however anecdotal, this clinical work is essential as the patient's unique clinical entity must be identified by being observed accurately and adequately in its proper context. The relevant variables to follow within the entity must be sorted out from the irrelevant ones, and similarly with those in its background. The symptoms and signs expressing this dynamic entity must be observed minutely to see how their qualitative and quantitative changes are developing. Interactions within and without the entity must be observed to find consilient and causal chains to assign symptom priority. The individual effects of treatments must be observed and such effects may trump the statistical results of "evidence-based" treatments in the clinical context.

A primary clinical entity cannot be a static object. It is necessarily subjective in part (as it observes at least itself), and like the primary illness experience that participates in it, is an undivided, in-dividual, as yet unnamed whole, and of the nature of a real process, not to be confused with the set of concepts used to name and describe it (see the problem of realism/nominalism<sup>7</sup>). Notably, all of these clinical practices depend to a large extent on the assumption of the accuracy and adequacy of the patient's experience of illness as it unfolds under the observation of the doctor. If the observational discipline of Western painting is based on the disavowal of deictic reference,<sup>6</sup> then it is no wonder that clinical observation skills are atrophying. But it is the dynamic clinical entity, of necessity both subjective and objective, which orients the field of clinical activity, if clearly and adequately observed.

**D**efinitions of a medical disorder must serve two divergent functions; both necessary, yet mutually exclusive because of their fundamentally different observational contexts—one dealing with groups of patients who can be approached scientifically and the other with individuals in a clinical context.

Research definitions<sup>1-3</sup> provide researchers with (relatively) homogeneous groups of patients to allow meaningfully isolated and controlled observations as they follow various hypotheses in the hope of confirming or refuting them. In the context of research, all knowledge is under review, both what is explicitly in doubt and what is supposed to have been confirmed. Thus, the observational context is one of general uncertainty, but grounded in trust that the scientific method can generate reliable (third-person) knowledge, and we have to start somewhere. As each patient must be viewed as a member of a selected set, methodologically they cannot be viewed as individuals.

At the risk of exhibiting "anecdote", I would like to argue that another context of observation is critical to the clinical endeavour, one that depends on the anecdotal, viewpoint including, first-person experience of a patient. This is not merely consideration of a list of symptoms. It uses what is regarded as established third-person medical knowledge (graded into several categories of certainty or uncertainty), and matches this knowledge with that being provided by the individual patient, in the certainty of her or his experience of illness. These two types of (what is regarded to be) certain knowledge meet in a second-person interchange between the doctor and patient, involving

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If such clarity and adequacy are not achieved, several types of smudging may result. In other words, if the generalisations from the medical model are too generic, they have no chance of adequately meeting the patients' experience of illness and much relevant data may be overlooked or misinterpreted. Thus, the move from a more specific clinical concept such as myalgic encephalomyelitis or fibromyalgia to a more generic concept such as chronic fatigue syndrome or chronic pain syndrome entails missing a lot of the information that makes the syndrome a name match, and an experience. The syndrome as an experience is a coherent entity whose parts run together as a process—as the word syndrome indicates etymologically—and whose causal interactions are sensed directly in the mode of causal efficacy.<sup>8</sup> This entity arises against a background that is treated as a non-entity for the purposes of the observation. Thus, the attempt to organise clinical activity around a non-entity, such as in somatisation disorder and Munchausen syndrome,<sup>9,10</sup> where diagnosis depends on the absence of an entity, may interfere with proper clinical activity by importing a misplaced forensic attitude towards a patient's experience of illness, discounting or distorting its relevance. The move towards ignoring the distinctions between primary and secondary which designate sensed causal directions in a clinical entity, whether applied to depression, anxiety, infection or fibromyalgia, add to the confusion and impede the elucidation of a properly dynamic clinical entity. The widespread use of the holistic biopsychosocial model of disease<sup>11–13</sup> without any distinction between a clinical entity and its background encourages the “drowning” of clinical entities by risk factors, which can proliferate endlessly in a nominalist fury without orientation as to their state of relevance or lack thereof with respect to a real entity.<sup>7</sup>

The Canadian consensus case definition and diagnostic protocol for myalgic encephalomyelitis<sup>14</sup> has been influenced by the clinical method of Sydenham,<sup>15</sup> which is to provide a fuller and richer framework to fit the patient's illness experience into a framework that is specific and complete enough to match the patient's experience, yet consonant with the large body of public and confirmed results that have been obtained by the research activity stimulated by earlier definitions. It tries to be more adequate to the clinical activity that each patient's unique clinical situation demands. It facilitates a precise and adequate observation of the unique clinical entity arising in a patient in contrast with its contextual background. This is necessary to orient clinical activities, to guide the quantification of the events, both syndromal and contextual, which may be of particular relevance, as well as sorting out their causal direction and priority. It tries to remain close enough to be adequate to the illness experience of the patient, and thus invariant to the changes in interpretation of this experience as science evolves over the years.<sup>15</sup> Unless a disease entity is “eliminated” by better understanding and better technology, it will continue to require clinical attention, whatever we hypothesise its “natural kind” to be.

To improve clinical observation, the Canadian definition and diagnostic protocol lays out several regions of pathophysiological dysfunction, as necessary components of the syndrome of myalgic encephalomyelitis, but the particular expression of symptoms within each region is contingent between individuals, and their specific pattern is left open to be decided by clinical observation of the individual and later diagnostic classification. These component regions include fatigue, which must be severe and prolonged and of a certain dynamic pattern (delayed and prolonged reactive) and marked dysfunction must be observed in the following realms—sleep, pain, neurological or cognitive, and at least one of the following three realms—autonomic nervous system, neuroendocrine and immune

system. This approach facilitates identification of the patient's individual clinical entity or syndrome, how its parts fit together and interact, as well as its effect on the patient's life—seen as dis-ability and dis-ease—and leading to a more accurate and adequate diagnosis. It allows estimates of the clinical course and prognosis, decisions on treatment, estimation of the treatment effects and search for successful preventive and rehabilitative strategies. With its flexible combination of necessary and optional features, the definition allows the diagnosis to fit the patient rather than the other way around (as with Procrustes, an innkeeper from Greek mythology who stretched the guests to fit his bed!).

The possible aetiology of myalgic encephalomyelitis is under scientific observation. This is done by experiment and by controlled observation. Many observers are following various lines of investigation and observation as to the aetiology of myalgic encephalomyelitis, which we are all following with interest.

There are some problems. A hypothesis is a cognitive structure necessary to organise our experimental efforts. When rigorously tested independently and often enough, our hypothesis can be regarded as tentatively confirmed. But in the context of research, we should work to disprove our hypothesis. As noted by Sydenham,<sup>15</sup> to arrange reality to save it can cause much error. I quote:

In writing the history of a disease, every philosophical hypothesis whatsoever, that has previously occupied the mind of the author, should lie in abeyance. This being done, the clear and natural phenomena of the disease should be noted—these and these only. They should be noted accurately, and in all their minuteness; ... No man can state the errors that have been occasioned by these physiological hypotheses. Writers, whose minds have taken a false colour under their influence, have saddled diseases with phenomena which existed in their own brains only; but which would have been clear and visible to the whole world had the assumed hypotheses been true.

The opposite problem of importing a context of doubt into the clinical arena, which is heavily dependent on deictic certainties, can result in the disruption of the second-person clinical observation structure and subsequent clinical practices, as observed with the “smudge” diagnoses mentioned earlier.

The problem of cultivating a holistic view without adequately structuring the field with a proper clinical entity can lead to great confusions of relevance, where contextual and syndromal features are confounded, with no way of clinically quantifying their relative effects. Choose the right kind of entity or you may end up only considering background factors with no clinical entity left that they are the background of—see the fate of the Cheshire cat in *Alice in Wonderland*, where the cat fades, leaving only the smile!<sup>16</sup>

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