CHRONIC FATIGUE SYNDROME: A TRUE ILLNESS

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SETTING THE SCENE

Chronic fatigue syndrome (CFS), whatever it may be, is nothing new, and neither is the observation that it provokes disputes between patient and doctor, and between doctors themselves. In this pair of linked papers, Professor Showalter and myself address some of these disputes. It will be clear that there is much about which we agree -the importance of social and cultural pressures in determining health and illness, and in the shared assumption that regardless of the nature of their malaise, those who currently present to doctors under the label of CFS and its variants are indeed ill, and deserve respect and sympathy; we also hope to illuminate some of the honest differences that emerge from the perspectives of on the one hand the practising clinician, and on the other the social historian.

In this paper I shall argue that CFS is both a valid nosological entity, and also a concept that can be useful to both doctor and patient alike. Of course, as Professor Showalter shows, CFS is not without its difficulties and limitations. However, I submit that these are not unique to clinical medicine, and that the advantages of accepting the diagnostic category outweighs the disadvantages. Before outlining why I argue that CFS is a useful and valid entity, it is worth considering these limitations in more details.

1: There is no diagnostic test for CFS.

True enough, and the literature is scattered with discredited claims for such tests. However, this deficiency in not enough to undermine CFS as a distinct illness, as medicine embraces many entities that lack a truly diagnostic test or that can be be diagnosed on clinical grounds alone even if all investigations prove negative: well known examples include migraine, irritable bowel syndrome and epilepsy..

2; CFS is not a disease.

Critics of CFS point to the absence of any clear cut pathological process underlying the experience of CFS, and hence that it cannot be considered a valid disease. Again, perfectly true,

and far from unique in clinical medicine. Instead, and using the important framework proposed by commentators such as Eisenberg, Mechanic and Kleinman, CFS is not a disease (since there is as yet no clear pathological abnormality), but an illness, in which the person is clearly distressed, symptomatic and unable to continue to perform in a normal fashion. In many settings, notably primary care, I would contend that doctors treat illnesses, and not diseases.

3: It is part of normal experience to feel very tired.

At first sight this seems to be an unfair criticism, since anyone with direct experience of running a CFS clinic, as this author does, will have been exposed to such distress and disability that is well outside normal human experience. All of us have indeed experienced fatigue, but few of us have experienced such intensity of symptoms after minimal activity such that most normal activities of daily living become impossible. However, on closer inspection there is indeed a case to answer. It is true that fatigue as a symptom, like most symptoms, is normally distributed in the community¹, and that there exists no clear cut boundary between that sensation and the fatigue experienced in CFS. The patients I encounter in the clinic are clearly well beyond the normal range, but what about those with lesser degrees of distress and disability that are common in primary care²? These merge into normal experience. Not just fatigue, but all the symptoms held to comprise the concept of CFS are dimensional, and not categorical, entities. Overall there is indeed no simple cut off or point of rarity that distinguishes between CFS, chronic fatigue and normality. However, this in no way invalidates the concept of CFS as an illness. A good analogy is with hypertension. If one excludes the occasional case of renal artery stenosis or adrenal tumour, for the vast majority of cases hypertension has no specific cause. Likewise, there is no particular cut off at which blood pressure ceases to be normal and suddenly becomes abnormal. Instead there is a continuous distribution of risk and damage - the higher the blood pressure, the greater the risk of complications and the greater the need for treatment. I would argue that is exactly the case of CFS, and that the absence of a clear cut and specific boundary between normal experience and illness no more invalidates the concept of CFS than it does that of hypertension.

4. CFS is a damaging diagnosis.

Psychiatrists, perhaps more that any other branch of medicine have traditionally being sensitive to the dangers of labelling - that when some one is given a label such as schizophrenia they then start to conform to the expectations and stereotypes expected by that role. That this can happen with CFS is beyond dispute. Once someone becomes convinced that they are in the grip of an invisible virus, malevolently destroying their immune system, and for which the only treatment is bed rest and hoping for the medical breakthrough, then indeed the chances of recovery reduce. All of these have been part of the concept CFS in the media and popular literature ³, although fortunately the situation has improved in recent years.

The clearest evidence that the diagnosis of CFS can be damaging for your health comes from the paediatric literature. We, and many others, are seeing more and more children appearing with the label of CFS. If this is felt to imply the child is suffering from some mysterious, progressive viral or immunological disorder, then eyes can be closed to other sources of distress, and attempts to rehabilitate the child in the context of family and school ignored. One can still encounter statements such as "ME in children lasts an average of 4 and a half years". This can become a self fulfilling prophecy. If that had only happened once, it would be a source of concern, but the impression amongst the paediatric community and the literature is that this is not an infrequent occurrence, and that entrenched attitudes can conspire against recovery. American paediatricians recently wrote that dangers exist labelling children with a disease which "has profound implications for their level of functioning in society, especially when the disease is not well defined in childhood and when there are no irrefutable laboratory markers for it" ⁴ yet is all too often seen as persistent or even incurable. Indeed Plioplys - a committed champion of CFS in adults - has recently suggested the diagnosis should never be made in children ⁵. He argues that in all the patients he has seen, there was an alternative, and by implication more accurate and more appropriate, diagnosis available.

All the above is grist to Professor Showalter's mill. However, the fault lies not with the concept of CFS, but with the connotations it conveys in certain circles ⁶. Similar assaults were made on the concept of schizophrenia in the past, but such attacks did not lead to the abandonment of the diagnosis. Instead it did lead to an awareness that it is important that the diagnosis does not imply certain outcomes or behaviours that cannot be justified. The advantage of the label of CFS, and one that is not possessed by its close companions "myalgic encephalomyelitis", or "chronic fatigue and immune deficiency syndrome" is that it is aetiologically neutral. The three Royal Colleges who recently produced a consensus report on the subject concluded that myalgic encephalomyelitis (ME) was indeed inappropriate, because it endorsed the existence of a pathological process that is not present⁷. But at the same time they gave a strong endorsement to the use of the term CFS, which did not have the same automatic implications. Of course, there are numerous examples when the label is used inappropriately, and does lead to therapeutic nihilism and despair, but the fault lies with the "extras" conveyed by those making or writing about the condition, and not with the label itself. I shall argue in the second part of this essay that the label of CFS can be a very constructive and helpful part of the medical consultation.

5. All those with CFS have known psychiatric disorders

Another criticism of CFS is that it is already more than covered by existing classification systems, and in particular that all of those who fulfil criteria can more parsimoniously be considered as suffering from discrete and well known psychiatric conditions, namely depression, anxiety and somatisation.

In a contentious subject, no statement is more certain to infuriate supporters of the CFS concept. No statement is as regularly attacked, assaulted and ridiculed. Despite all that opprobrium, the feeling that CFS is but a synonym for better known psychiatric disorders refuses to go away, because it is partly true.

Note I say partly. Study after study confirms the association between CFS and psychiatric disorder, regardless of definition, setting or methodology. The association is too close to be explained as a reaction to physical disability - no fewer than seven studies that directly compare CFS and chronic physical illnesses find that the relative risk of psychiatric disorder in CFS is too high to be considered simply the consequence of illness. Prospective studies likewise confirm that previous psychiatric disorder is a risk factor for subsequent CFS. The association persists in primary care, and is not solely a result of selection bias. But no study has ever shown complete congruence between CFS and psychiatric disorders - in all a substantial proportion of subjects remain who fulfil criteria for CFS and nothing else. Furthermore, there are differences between

the known neurobiology of the major psychiatric disorders such as depression and those observed in CFS, principally in the function of the hypothalamic-pituitary adrenal axis, and the presumed activity of the serotonin input to that system. Whereas classic depression is associated with high cortisol and underactivity of the serotonin system, in those subjects with CFS and no comorbid depression, the reverse has been observed⁸⁹. The significance of such observations remains unclear, and it remains plausible that this is simply an epiphenomenon of differences in the sleep/wake cycle between classic depression and CFS¹⁰, but it does mean that the assertion that CFS is no more than masked or somatised depression cannot be sustained in all cases.

An appropriate analogy is with post traumatic stress disorder (PTSD) - not because of the intriguing overlaps between the neuro endocrinology of PTSD and CFS, but because of the similar relationship each have with the formal categories of psychiatric disorder. Most cases of PTSD also fulfil criteria for depression and/or anxiety, and many of the risk factors for PTSD are shared with those of psychiatric disorder as well. However, there are certainly many subjects who develop PTSD and do not at the same time fulfil criteria for depression or anxiety. More importantly, losing the concept of PTSD, or insisting that all cases be labelled solely as depressed or anxious, will remove vital aetiological, phenomenological and clinical information. Depression is itself a broad church, operationally and not aetiologically defined. We need improved classification systems for both depression and CFS, and simply assuming that all CFS can be subsumed within the category of depression is inaccurate.

WHY DIAGNOSE CFS - THE RESEARCH VIEW

What is the scientific evidence for the validity of the concept of CFS? Perhaps the most important comes from recent epidemiological surveys, which confirm that those fulfilling the criteria for CFS are not uncommon ^{11 12}. In many cases, perhaps even the majority, such subjects also fulfil criteria for recognised psychiatric disorders (vide supra). However, all studies in whatever setting always find that a proportion of those who fulfil criteria for CFS do not fulfil those for psychiatric disorders - the exact proportion depending on sample and criteria.

It is true that this group almost invariably fulfil criteria for neurasthenia ¹³. Neurasthenia nowadays is seen by most as another variant on the theme of neurosis, and thus another psychiatric disorder, but this is a gross simplification ^{14 12}. Whereas most now accept the resemblances between the concepts of neurasthenia and CFS - one person's neurasthenia is another person's CFS ¹⁵, few are aware of the historical origins of neurasthenia, which was first conceived as a physical, neuromuscular disorder, often arising out of a combination of overwork, stress and infection, leading to exhaustion of the body's supplies of energy, and for which the solution was rest. It is only in the first half of this century that neurasthenia became accepted as a psychiatric diagnosis, a change that also paved the way for its eclipse. However, new epidemiological studies that have confirmed the existence of a syndrome charactised by easy fatigability, and that, whilst closely associated with both depression and anxiety, is still distinct from both ^{16 17}. It seems that there is room for a fatigue syndrome, whether we call it CFS or neurasthenia, in our classifications of illness.

Recent surveys have also confirmed another finding known to Victorian medicine -that neurasthenia/CFS is a major source of morbidity, albeit not mortality. Whilst to a certain extent

this is tautologous, since the criteria themselves specify functional impairment, nevertheless, that there exists considerable numbers of sufferers who are markedly incapacitated in many aspects of their lives is clear ^{18 19 20}.

WHY DIAGNOSIS CFS - THE EMPIRICAL VIEW

Let us for a moment accept Professor Showalter's analysis, namely that there is no such entity as CFS, the sooner it is abandoned the better, and instead it is the duty of the doctor to not only firmly refute the label, but also to point out the real source of the patient's symptoms, namely their psychiatric disorder.

Many of the new wave of satirical news quizzes, such as "Have I Got News for You" or "They Think it's All Over" have sections called "What happened next?". I have often wondered about replaying videos of standard consultations between consultants and patients with ME and asking a similar question. Does anyone seriously consider that the consultant who (and I add, just like in the quizzes, the phrase allegedly, since no one knows what was actually said) told a medical conference that ME doesn't exist ²¹ expected his patients to immediately abandon their symptoms and return to work when he shared that information with them? The opposite is more likely.

Let us continue to watch the consultation between our sceptical consultant and the patient who believes he or she has CFS. "So it is all in my mind, is it doctor?" says the patient threateningly. The correct answer from our consultant if he or she remained true to form would be "yes", perhaps followed by a plaintive "but psychiatric disorders really are genuine illnesses", but by that time the doctor will be addressing an empty room, since the patient may well have left in disgust. Whereas Professor Showalter and most readers of this volume consider depression to be a legitimate diagnosis without moral overtones, this view is not shared by some of those who attribute their symptoms to ME³. A recent survey of members of an ME support group showed they did not distinguish between malingering and psychiatric illness, concluding that "it was assumed that anyone with depression *wanted* to be ill and taken care of by others"²². Hence the consequences of introducing any psychiatric label are much the same as calling a person hysterical or work shy. I possess several large box files of cuttings from the media and self help literature in which such scenarios are recounted, followed by passionate denunciations of the doctor for his or her ignorance, cruelty, stupidity or all of the above. Of course the assertion that psychiatric diagnoses are a refuge for the inadequate or work shy is outrageous and wildly inaccurate, but no one who reads the popular literature can be in doubt that such views exist.

Norton Hadler has outlined the dilemma ²³ - to get well in these circumstances is to abandon veracity. Patients will be more inclined to get better when they are provided with satisfactory explanations for their problems ²⁴. By satisfactory I mean from the patient's point of view - not satisfactory in a narrow scientific sense, but in a symbolic or even metaphorical perspective ²⁵. Explanations that are not acceptable are not simply discarded - the patient may embark on a mission to actively prove them false.

Does this matter? If the aim of the doctor is the simple one of ensuring that he or she does not have to see the patient again, then such an interchange in which CFS/ME is given short

shrift will have achieved the desired effect. However, one trusts that is not the intention. Unfortunately, because patients rarely return to a doctor who they feel is denigrating or discrediting their illness experience, whether intentional or not, that will be the result. This does matter. An essential opportunity for engaging the patient in treatment is lost. A disillusioned patient may now turn to the alternative therapists, where the patient can be guaranteed an explanation in keeping with their own views of illness, but always at a price. That price also rarely covers any treatment of proven efficacy. The patient will conclude that conventional doctors don't understand, and an ever present polarisation between doctor and patient will be re inforced. Also re inforced will be simplistic notions of body and mind - the patient's view that they have a disease solely of the former will now be held with even more conviction, whilst the doctor's suspicion of the key role of the latter may also be confirmed by the vehemence of the patient's response. David Mant has pointed out this Catch 22 - the more the patient denies psychosocial causation, the more the doctor suspects it is present ²⁶.

PATIENTS MUST HAVE A DIAGNOSIS

Several studies that concentrate on the views of sufferers confirm that the act of diagnosis is central to the experience of CFS^{27 28}. Without it the patient feels stigmatized, overlooked and ignored. With the diagnosis comes relief, credibility and acceptance. Some quotes from media articles capture the paradox : "The day Nomi Antelman learned she had an incurable disease, she rejoiced" ²⁹. Another sufferer was first told she had a virus that would go away. Later this optimistic prognosis was altered, as she learnt she had ME which would, in her own words, take away her independence, regress her to a being a baby and in which progress would be minimal. She "felt fantastic" ³⁰. For another, even if the prognosis was uncertain "the mental relief was phenomenal" ³¹.

Any management strategy that wishes to actual help patients must therefore take account of this. Even in general practice we know that patients given a firm diagnosis for non specific symptoms have a better outcome that those patients randomly allocated to consultations in which uncertainty was expressed ³². Patients must leave the consultation with a firm diagnosis - otherwise they will be unable to organise their dealings with family, friend and work, let alone consider how to get better, If you don't give them a diagnosis, someone else will. It is also, however, the duty of the specialist to avoid the "contest of diagnosis" ²³ from which neither side will emerge the winner.

PATIENTS WHO SAY THEY HAVE CFS MAY BE RIGHT.

Diagnosis must be acceptable to both doctor and patient. One that satisfies the former but not the latter may please the consultant, but it won't be effective. I have outlined all the reasons why telling a patient who presents already convinced of the nature of their problem, in this case that they have ME or CFS, that they are wrong is only acceptable in one situation - when there is a clear cut alternative, unambiguous diagnosis that requires treatment. Most physicians who are interested in this subject can recount stories of patients with recognised physical disorders which were mislabelled as CFS. The list of possible medical causes of CFS is long, but in practice excluding alternative diagnoses is relatively straightforward ³³.

In all other circumstances telling the patient that not only are they wrong, but that the

alternative label is one that is totally unacceptable to them, a psychological problem, is ruinous to the doctor patient relationship. So why do it? Instead it seems to this author that the ethical, truthful and sensible option is to agree. CFS is an operational diagnosis, and if someone fulfils the appropriate criteria, then that is what they have.

After all, how valid are the alternatives? Psychiatric diagnoses have a similar status to CFS - both are operational criteria and both lack external validation. As Tony Komaroff expresses it - "One problem is that CFS is defined by a group of symptoms, without any objective abnormalities on physical examination or laboratory testing that readily establish the diagnosis. Another problem is that the same is true of depression and somatization disorder" ³⁴. Attempting to replace a solely physical model with an equally monolithic psychogenic explanation is not only doomed to failure, it is also misguided, and unnecessary.

It is indefensible to give a patient a label that implies a chronic incurable condition or a non existent pathological process ("encephalomyelitis") whose cure must await a medical "breakthrough" always promised and never forthcoming Instead I propose that diagnosis is the beginning, and not the end, of the process. Indeed, this author frequently begins the consultation with the diagnosis - "I agree, you have CFS - now what do we do about it?" in order to bypass the difficulties that diagnosis involves. A positive diagnosis of CFS has a firm place in clinical practice, providing that it is used in a constructive fashion. At present like that of fibromyalgia or irritable bowel syndrome, CFS can be of use in clinical practice as a structure for patient understanding and a model for treatment ³⁵.

This is not the chapter to outline what should happen next. In practice this involves broadening the assessment to take account of all the factors that come together in the final common illness presentation that is CFS - physical, cognitive, emotional, behavioural and so on. This multi dimensional approach has been outlined elsewhere ^{33 36} and has empirical support as a basis for treatment ^{37 38}. To improve, patients do not need to, and indeed do not, alter their views that either their problem is ME/CFS or that it began as a physical illness. Instead, improvement only requires a shift in the patient's view on the relative merits of rest and exercise ³⁹. Patients with CFS usually believe that rest is the best way of controlling activity, and that other than that they are helpless about altering the course of the illness ⁴⁰. Disability is related to the presence of catastrophic beliefs about the disastrous effect of activity ⁴¹ Effective management involves a collaborative approach to testing these assumptions, but not the physical origin of illness, and not the nosological status of CFS ^{37 38}.

CONCLUSION

I therefore conclude that CFS is a valid diagnostic entity, and a useful addition to clinical practice. Granted there are drawbacks in real life, but these come from misinformation and misunderstanding about the meaning and implications of the label, and are not central to the concept itself. The subject is still replete with ambiguity and uncertainty. However, it is still a valid and useful concept. CFS is a diagnostic entity that we can, without committing scientific fraud or perjury, call CFS and use in our clinical dealing with often very disabled patients.

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