

A RESPONSE TO RAINE – BRITISH MEDICAL JOURNAL

A Response to Raine, R. Carter, S. Senseky, T. Black, T. " General Practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study" British Medical Journal, <http://bmj.bmjournals.com/cgi/reprint/bmj.38078.503819.EE> 28 May 2004.

By Angela Kennedy

The above article is available as a pdf. file at

<http://press.psprings.co.uk/bmj/may/GPbeliefs.pdf>

This is indeed a very interesting study that allows the reader a glimpse of some of the belief systems in operation within the British Medical Profession around ME/CFS. There are a number of points to make about this particular project, and its relevance to the ways in which clinical guidelines are developed:

1. As with all research that is published in the third person, the reader has to rely on the mediating interpretations, by the researchers, of the responses under study. Even with this in mind, however, it is clear that some of the doctors under study (the response group) exhibited a worrying tendency to confuse Myalgic Encephalomyelitis, for which Chronic Fatigue Syndrome is merely another name, with Chronic Fatigue, a different condition. ME/CFS is classified in the WHO ICD-10 as a neurological disease (G93.3), whereas Chronic Fatigue is classified in ICD-10 as F48 (a mental disorder). It appears from anecdotal evidence that this is a common misapprehension among doctors. This may well be in part due to the misinformation that was promoted by the WHO Collaborating Centre for Research and Training for Mental Health, Institute of Psychiatry, Kings College London, in their publication the 'WHO Guide to Mental Health in Primary Care', and on their website. Some psychiatrists have been (incorrectly) using the two terms interchangeably for some time. This incorrect information had eventually to be clarified (and ultimately corrected) by Lord Warner, at the instigation of the Countess of Mar, earlier this year. **(1)** The lack of knowledge by the respondents about the neurological features of ME/CFS was quite astounding, with one doctor bemoaning the lack of 'precise location' of ME/CFS because it "isn't like a broken leg".

In fact, the authors themselves appear unaware of this major issue, and therefore have been unable to clarify whether they or the responding doctors are actually discussing ME/CFS sufferers, or sufferers of Chronic Fatigue. For the purposes of this discussion, I am assuming that they mean ME/CFS sufferers

2. Some of the response group also exhibited clear tendencies to socially construct ME/CFS sufferers as 'deviant', another worrying development within many in the medical profession in recent years. **(2, 3)** 'Deviant' personality categories were assigned to ME/CFS sufferers. The social and material inequalities experienced by ME/CFS sufferers, because of the social stratification and resulting prejudices arising from such cultural constructions of 'deviance', based on health status, has been enormous, **(4, 5)** and the attitudes and beliefs of the respondents in this study yet another illustration of this.

3. Raine et al describe both the patient' and 'doctor' as violating expected roles in the case of ME/CFS. My concern here is firstly that the socially constructed 'roles' themselves were not critically interrogated at all within this article. Earlier in the article the authors describe ME/CFS sufferers as ignoring the "normal obligation of the 'sick role' to make every effort to get well as possible". Of course, ME/CFS sufferers are not the only people who do not get well easily, if at all. By the rationale inherent in this theme, Doctors would describe many of their patients as 'heartsink', for example: AIDS sufferers, Cancer sufferers, Asthmatics, Congestive Cardiac Failure sufferers, MS or Parkinson's or Alzheimer sufferers, to name but a few. The fact that such a prejudicial term is applied to ME/CFS sufferers, but NOT AIDS or cancer sufferers, for example, is highly significant. Although some of these illnesses have been subject to detrimental cultural construction in the past, work such as Susan Sontag's (6) has changed that. ME sufferers now appear to be suffering from prejudice from certain members of the health professions, that would not now be tolerated against sufferers of these illnesses. (7) Interestingly, Raine et al did not elaborate on how doctors 'violate' their expected roles. A further discussion of this would have allowed deeper levels of understanding as to the decision making process by doctors with regard to CFS, and how this can be improved.

4 An interesting theme that arose was the hostility and resentment expressed by some of the respondents towards ME/CFS self-help and pressure groups. This is of course highly ironic, especially when the British government are currently promoting the concept of the 'expert' patient. As with other highly politicised illnesses (such as AIDS), pressure and self help groups have arisen to advocate for patient's rights and provide support and advice, because of the shortfall of agencies such as the health service and benefits agencies, and the social exclusion suffered by ME/CFS sufferers, some of the very reasons for this uncovered both in this correspondence and in Raine et al's article itself.

5. The authors of this article were uncritical of the 'mental health interventions' that have been promoted by some as a 'treatment' for ME/CFS. They appeared unaware of the intense controversy over these treatments, including the evidence that there is little or benefit to many patients from them, and that these interventions may actually be harmful to patients (**for example see 8, 9, 10,**). What was also of concern was that the doctors themselves appeared, from the article's findings, unaware of these also, although it appears the patients and their advocates may be perfectly aware, hence their tendency of 'non-compliance'.

6. As a qualitative social science researcher myself, I was fascinated by some of the responses, and I would have been very interested to have indulged in some further projects of discourse analysis of the responses, which I believe would have uncovered some of the deeper levels of meaning in the respondents' answers, especially as situated subjects in the production of certain discourses of power. A Foucauldian discourse analysis (11) may well have been pertinent in this project, as well as a semiotic analysis of the thymic categories of euphoric (perceived as 'good') and dysphoric (perceived as 'bad') categories (12, 13) assigned by the doctors to both ME/CFS and IBS sufferers. These may well have provided some clues as to the how certain illnesses, such as ME/CFS for example, are socially constructed within the medical profession and society at large, and why the common experience of ME sufferers (including children) is one of social and material inequality and social

exclusion, and hostility and disbelief from others, including health and social welfare professionals (14).

7. I do question the decision to elucidate comparative responses between ME/CFS and IBS, which, although a painful sometimes moderately disabling illness in which psychological and physiological aetiology is contested, nevertheless has a much better prognosis and much lower rates of disability than ME/CFS. More serious physiological illnesses where the physiological aetiology is NOT contested may have yielded more stark polarisations of doctor's beliefs. On the other hand, the starkness of the polarisations even within this project were highly significant.

8. I agree with the author's conclusions about the deeply held beliefs of doctors mediating their understandings of complex disease mechanisms. In the case of ME/CFS, these have led to many serious problems in the way sufferers are treated, and an improvement in knowledge about this misunderstood illness is vital. This will need to involve the widespread correction of many instances of misinformation being propagated throughout the medical profession, and this is where the issue become highly politicised, which presents major problems for sufferers, the field of medicine and governments. What is clear though, is that patients, in Britain and internationally, are no longer prepared to continue to suffer because of these problems, hence the rise and rise of politically astute patients and advocates.

ANGELA KENNEDY

REFERENCES

1. See for example, Hansard: http://www.publications.parliament.uk/pa/ld199900/ldhansrd/pdvn/lds04/text/40122\ -12.htm#40122-12_unstar0.
2. See "The Doctors Say Psychosomatic, What Do They Mean" http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/When%20Doctors%20Say%20Psychosomatic,%20What%20Do%20They%20Mean.doc
3. See my own BMJ Rapid Response "Re: Your own worst enemy" (Angela Kennedy) at :
<http://bmj.bmjournals.com/cgi/eletters/327/7429/1449#44881>
4. Munson, P. (2000) Stricken: Voices from the Hidden Epidemic of Chronic Fatigue Syndrome, Haworth Press, New York.
5. Hyde, B. Bastien, S. Jain, A. The Clinical and Scientific Basis of ME/CFS (1992) Nightingale Research Foundation, Canada.
6. Sontag, S. (1991) "Illness as Metaphor" and "AIDS and Its Metaphors", Penguin, London.
7. See "The distortion of holistic approaches to health care in ME.doc"

http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/The%20distortion%20of%20holistic%20approaches%20to%20health%20care%20in%20ME.doc

f%20holistic%20approaches%20to%20health%20care%20in%20ME.doc

8. Carruthers et al (2003) “ Myalgic Encephalomyelitis/chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols” Journal of Chronic Fatigue Syndrome, VO. 11 (1) 2003.

9. Van Hoof, E. “Cognitive Behavioural Therapy as Cure-All for CFS” Journal: Journal of Chronic Fatigue Syndrome, Vol. 11(4) 2003, pp. 43-47

10. Van de Sande, M. (2003) “ME/CFS Post-Exertional Malaise / Fatigue and Exercise”

Originally printed in "Quest", the newsletter of the National ME/FM Action Network, 3836 Carling Ave., Nepean ON K2K 2Y6, Canada. Available online at:

<http://www.mefmaction.net/default.aspx?Page=selectedarticlesmedical>

11. Foucault, M. The Archaeology of Knowledge (1985) Routledge, London.

12. Martin, B. Semiotics and Storytelling: an Introduction to Semiotic Analysis (1997) Philomel, Dublin.

13. This method is practised by the Paris School of Semiotics, founded by A.J. Greimas: see Martin, B. Ringham, F. Dictionary of Semiotics (2000) Cassell,

London.

14. TYMES Trust publication, “The Forgotten Children: A Dossier of Shame” available online at: <http://www.tymestrust.org/pdfs/theyforgottenchildren.pdf>