

ME: Organic or Psychiatric --- Decision Time?

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Documenting the progress of medical understanding about the disorder Myalgic Encephalomyelitis (ME), also listed in the International Classification of Diseases as Chronic Fatigue Syndrome (CFS), is likely to prove an interesting challenge for medical historians. There have recently been yet more directly opposing tenets on this condition and it is difficult to accept that both are considering the same disorder.

Of prime significance is the paper from the stable of Professor Stephen Holgate from the MRC Department of Immunopharmacology at the University of Southampton and Dr Jonathan Kerr from the Department of Paediatric Infectious Diseases at Imperial College, London (“Gene expression in peripheral blood mononuclear cells from patients with chronic fatigue syndrome”. N Kaushik, DAJ Tyrell, ST Holgate, JR Kerr et al. *J Clin Pathol* 2005;58:826-832). This long-awaited paper (dedicated to David Tyrell CBE, FRS, former Chairman of the UK 1994 National Task Force Report on CFS/ME/PVFS and a stalwart supporter of those with ME, who died on 2nd May 2005) concludes that patients with ME/ICD-CFS have reproducible alterations in gene regulation and that sixteen genes have an expression profile associated with the disorder that can be grouped according to immune, neuronal, mitochondrial and other functions.

The immunological findings are consistent with work showing that patients with ME/ICD-CFS have evidence of immune activation, such as increased number of activated T cells and cytotoxic T cells, and raised circulating cytokine concentrations.

A neuronal component is identified that is associated with central nervous system hypomyelination and encephalopathy (and in this respect the authors note the association of organophosphates and chemical warfare agents, and that neuronal gene involvement in ME/ICD-CFS has previously been reported by others).

The authors provide evidence of mitochondrial gene upregulation and observe: “The upregulation identified in our present study may represent a common host response to persistent infection with several different viruses”.

The take-home message is clear: “The involvement of genes from several disparate pathways suggests a complex pathogenesis involving T cell activation and abnormalities of neuronal and mitochondrial function and suggests possible molecular bases for the recognised contributions of organophosphate exposure and virus infection, respectively”.

The other viewpoint comes from psychiatrist Professor Michael Sharpe, formerly of Oxford but who currently holds a Personal Chair in Psychology at the University of Edinburgh.

Could it have been by design that it was on National ME Awareness Day, 12th May 2005, that Sharpe gave his inaugural lecture entitled “The Science of the Art of Medicine”, in which his approach might be summarised as “how to treat diseases with

no pathology”, in which he included ME/ICD-CFS (see “Evidence-based Psychiatry” at http://www.meactionuk.org.uk/Evidence-based_Psychiatry.htm).

However, there has been a serious and significant development in relation to Sharpe’s inaugural lecture: in releasing his power-point presentation electronically, Sharpe seems to have revealed his real beliefs and disdain for those with chronic disorders such as ME/ICD-CFS, because submerged within the text of the version he released is material that he had seemingly included in the preparation of his lecture which he may have decided not to use and perhaps thought he had deleted. This material is now in the public domain and includes extracts from a document called “Obviously Post Viral in Oxford”, which may be roughly summarised as containing the belief that “these patients need to change their attitude”, for example:

“It is apparent that the attitude of patients suffering from this chronic state must be changed”

“The knowledge that experience has shown that certain sensations have resulted from certain activities must be replaced by a conviction that these efforts may be made without harm”

“Chronic (postviral) fatigue syndrome --observe beliefs and behaviour”; “fear of symptoms and avoidance”; “hypothesise that they perpetuate the symptoms”; “test if talking treatment helps the patient to change...”; “making symptoms a focus”

“Modern medical descriptions of symptoms without pathology: ‘All in the mind’; ‘Hysterical’; ‘Medically unexplained’; ‘Psychosomatic’ – which diagnosis do patients find most acceptable?”

“ a psychologically sophisticated NHS – Acknowledgments MRC”; “Many modern illnesses are chronic. In this part of the lecture let me use some examples from my own medical experience and some of our research to illustrate the problem. It is a big problem. And does it really matter.... information we collected from patients in this large study shows – it is. (*sic*) How big is this problem? Patients with symptoms that are unexplained by disease.... we have just completed one of the largest observational studies of its kind to find out. This is a survey of 4000 new neurology outpatients in Scotland – a national study”; “The UK PACE Trial for Chronic Fatigue Syndrome”; “to what extent can the patient’s symptoms be explained by organic disease?”

There is nothing new in Sharpe’s views about all this, of course, but what is shocking is that Sharpe included privileged information that has been embedded in his power point presentation, including the names, addresses, age, date of birth, diagnosis and additional details of about 120 patients from a study, all of which can be googled by the public and are accessible via a standard and legitimate programme (Google Desktop). Another programme (Geek) revealed even more of Sharpe’s seemingly unpublished material. The information appears to include Sharpe’s record of patients’ comments on the manner of the consultation and whether or not they were reassured and, disconcertingly, what appear to be Sharpe’s own comments, for example: “Putting it on”; “Can control own symptoms”; “Mad”; “Imagining symptoms” and “Sick leave”.

It seems that even though Sharpe was going into the document and deleting, Word was retaining the information, and the Google search can index text inside documents.

This is a most serious situation and legal advice has already been sought.

In 1996, Dr Louis Appleby reported that the General Medical Council (GMC) takes the subject of patient confidentiality seriously enough to have produced new guidelines. The basis that underpins the doctor-patient relationship is meant to be “trust”, and whatever takes place in the clinic remains confidential. At heart is a single question: do the published details contain enough personal information for the patient to be identifiable? (Observer Life, 11th February 1996).

In the present matter, Professor Sharpe has not only released material from which patients can be identified, but has even included their date of birth and address, thus putting vulnerable patients at risk.

The GMC Guidelines in its Handbook “Professional Conduct and Discipline: Fitness to Practice” are clear: “Doctors have a duty not to disclose to any third party information about an individual that they have learned in their professional capacity. A doctor who decides to disclose confidential information about an individual must be prepared to explain and justify that decision, **whatever the circumstances of the disclosure**”.

The NHS Memorandum of Confidentiality is equally explicit: “Duties of Confidence: All persons involved in the handling of health information have a legal duty, reinforced by their contracts of employment, of confidence and fidelity towards patients. In addition, doctors in particular have an ethical duty of confidence towards their patients”.

Not only does Sharpe apparently dismiss the evidence of serious organic pathology in ME/ICD-CFS, considering it to be no more than an “attitude that must be changed”, he apparently has so little respect for patients that he failed to take basic care to protect what is clearly privileged information.

It will be enlightening to hear what the GMC has to say about this clear breach of patient confidentiality by Professor Sharpe that would seem to amount to serious professional misconduct.