Why ME is not all in the mind

Doctors get an unfair press when treating chronic fatigue syndrome

SUNDAY'S edition of Frontline (Channel 4) was billed as an indictment of modern medicine. It concerned the illness known to sufferers as myalgic encephalomyelitis (ME), to doctors as chronic fatigue syndrome (CFS), and to journalists as "yuppie flu". It showed an unsympathetic medical establishment, deaf to the pleas of sufferers from (interrible) affliction. To emphasise the point, viewers were told of the awful story of a young boy with ME, unable to speak or move, taken from his family by social workers on medical advice, and subjected to such indignities as being as a swimming pool to see if he would swim. An image of a boy drowning has been used repeatedly with harrowing effect. The stories were convincing, the testimony moving, and the programme fronted by a sympathetic doctor, herself a victim of the same disease. But was it the whole story? There is another version which throws a different and more complex light on these matters. The programme failed to mention that the events surrounding the boy had been subject to an enquiry, summoned by the local government, to investigate the same allegations so graphically described by Channel 4.

The enquiry published a 164-page report a year ago. Conditioned as we are by the litany of medical and social services failures in the past, the conclusions were surprising. The enquiry said that all the professionals involved (including, on one occasion, myself) had acted correctly, indeed, with care and compassion. Doctors and social services were praised, rather than criticised. This should have been the last word. Everyone had acted appropriately and in the best interests of the child. Even better, the story had a happy ending, since the boy recovered. But, as the programme showed, it was not the end, and the passions and anger linger still.

What is at issue is not really the nature of ME at all, the true cause, or causes, of the illness are not yet established. It is far from proven that it is due to a virus, and extremely unlikely to be due to an allergy or vitamin or mineral-deficiency. But ME is not alone in this. The list of medical conditions whose etiology is obscure is a long one. But these illnesses do not attract the media coverage afforded ME.

To find the real issues behind the controversy, one needs look no further than the newspaper coverage which the programme attracted. It shows that in the world of ME, psychiatrists are given to malingers, and that psychiatric and physical disorders are mutually exclusive. Both views are wrong, and indeed offensive to those unlucky enough to suffer psychiatric illness.

Of course patients with ME are not malingerers. Recent papers on the subject go to great lengths to explain the severity and genuineness of disability in ME. According to some studies, 80% of sufferers, general practitioners devote an extraordinary amount of time to their care. It is true that many feel that psychological factors are of considerable importance, but by a surprisingly unanimous research literature. Studies have found that many sufferers show evidence of a psychological disorder, particularly depression. But it is absurd to suggest that this means sufferers are malingerers. It also does not conflict with established physical basis for chronic fatigue syndrome.

Here is the second misunderstanding. Psychiatric disorder and physical illness are not contradictory: they are closely associated. Many of the symptoms of psychiatric disorder in those with physical illness are three times higher than in those without.

An unpublished survey of psychiatrists at my hospital revealed that 50 per cent of them thought ME has an organic basis. This is the real tragedy of ME. It is not unexplained variation in management - in Britain, five clinical trials are in progress, led by psychiatrists (which would hardly be the case if doctors felt the illness was malingered). It is the criticism of medicine frequently called for doctors to be better listeners and better able to empathise with their patients.

These are precisely the skills necessary for a successful psychiatric GP. Neither psychiatrists nor GPs need abnormal tests before they believe that symptoms are real and not people enough. As long as psychiatry remains equated with imagined delusions and psychological grammes such as this will continue to be made.

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