COERCION AS CURE?

Eileen Marshall Margaret Williams 21st September 2007

On 15th September 2007 The Times carried an article about cognitive behavioural therapy (CBT) by the newspaper's Science Editor, Mark Henderson. Henderson noted that CBT "*seeks to improve the symptoms of illness by changing patients' attitudes, thoughts and feelings"* and that this had often struck people as being *"flaky"*, even though courses of CBT *"seem to change the way that people approach mental illnesses, allowing them to alter their behaviour in a constructive fashion".*

However, Henderson maintained that the "*flaky"* image of CBT was changing, because CBT "*is showing promise in more unlikely fields. Several studies have shown that it can improve the prognosis for some cancers and this week, Professor Trudie Chalder, of King's College, London, announced that it can help people with type I diabetes. Though her study has not yet been peer-reviewed or published, Professor Chalder described the results as positive".*

No information was provided about the source or authors of the studies of CBT that Henderson claimed had improved the prognosis for cancer.

Henderson stated that studies such as Professor Chalder's are "*feeding a growing consensus that CBT has a lot to offer throughout medicine".* He went on to state that not only in disorders where patients' thought processes are involved, but also in diseases with a clear physical cause, "*compliance with treatment regimes and exercise are often critical to a good prognosis".*

He then referred to chronic fatigue syndrome (CFS), stating that the misleading impression that CBT can only help when the illness is all in the mind *"still inspires hostility towards CBT among people who might benefit greatly (and) CFS is a case in point. The National Institute for Health and Clinical Excellence has recently recommended CBT and graded exercise for the condition, on the back of good randomised clinical trials that indicate a benefit, yet some patient groups have reacted with anger".*

It seems that Henderson may have been misled. Of just seven random controlled trials (RCTs) looking at CBT in "CFS/ME" that exist, three used imprecise entry criteria; two had negative results (meaning that CBT did not work) and one was on adolescents only, leaving just one RCT, and this study used a less aggressive type of CBT from that used by the Wessely School, of which Chalder is a prominent member. None of the seven RCTs included children or patients who were severely affected (see http://www.meactionuk.org.uk/Defiance_of_Science.htm).

Henderson acknowledged that the symptoms of CFS can be real "e*ven if CFS can be at least partially psychosomatic"*.

The article was plainly a vehicle for the promotion of the beliefs of Professor Trudie Chalder, well-known for her passionate adherence to the belief of the Wessely School that "illness" is a "behaviour", not a "disease", and for her personal faith in the power of CBT.

At the Oral Evidence session taken by the Gibson Inquiry into ME/CFS on 7th June 2006 at the House of Commons, Chalder maintained that CBT can reverse the documented HPA axis dysfunction found in "CFS/ME". Gibson Inquiry member Lord Turnberg (the former Professor Sir Leslie Turnberg, President of the Royal College of Physicians and a staunch Wessely School supporter) stated at this same Oral Evidence session that everyone with "CFS" gets better with CBT and that this has been "proven". Lord Turnberg suggested that Dr Jonathan Kerr from the Department of Cellular and Molecular Medicine, St George's University of London (who was also giving evidence) should join forces with Trudie Chalder to look at how the genes of "CFS/ME" patients alter and recover with CBT. It was clear to all who heard this exchange that the Wessely School wanted to get into gene research and that they had got the next stage of their "CFS/ME research" well mapped out.
Chalder's latest claim that CBT helps people with type I diabetes (diabetes mellitus, or DM) is interesting.

Type I DM is thought to result from the selective autoimmune destruction of pancreatic islet b cells occurring in genetically predisposed subjects and possibly triggered or accelerated by environmental agents. One of the environmental risk factors that has been identified by various independent studies is enteroviral infection. Enteroviral RNA has been detected in the blood of more than 50% of type I DM at the time of disease onset and Coxsackie B4 has been isolated from patients with acute onset type I DM (ref: Coxsackie B4 virus infection of cells and natural killer cell insulitis in recent-onset type I diabetic patients. Dotta F et al. PNAS 2007:104:5115-5120).

Enteroviral infection has long been known to be associated with the pathoaetiology of ME/CFS and this is reflected in two current items in the Journal of Clinical Pathology. An Editorial (Enterovirus infection of the stomach in Chronic Fatigue Syndrome/Myalgic Enephalomyelitis. Jonathan R Kerr. J Clin Path 14th September 2007: doi:10.1136/jcp.2007.051342) notes: *"Research studies have identified various features relevant to the pathogenesis of CFS/ME such as viral infection, immune abnormalities and immune activation, exposure to toxins, chemicals and pesticides, stress, hypotension, lymphoctyre abnormalities and neuroendocrine dysfunction. Viruses which have been shown to play a triggering or perpetuating role, or both, in this complex disease include enteroviruses. The role of enteroviruses as a trigger and perpetuating factor in CFS/ME has been recognised for decades. However, the rise of the psychiatric 'biopsychosocial model' of CFS/ME led to a diminished interest in this area. The importance of gastrointestinal symptoms in CFS/ME and the known ability of enteroviruses to cause gastrointestinal infections led John and Andrew Chia to study the role of enterovirus infection in the stomach of CFS/ME patients, demonstrating a detection rate of EV VP1 protein of 82% in CFS/ME patients compared with 20% in normal controls. These intriguing data, for which there is ample supporting data, strongly suggest a hitherto unrecognised disease mechanism in CFS/ME patients. In view of the link between enteroviral infection of skeletal muscle and abnormal lactate response to exercise, it is possible that in an EV infected CFS/ME patient, the extent of the EV infection may determine severity".*

The article by Chia and Chia to which Kerr referred is titled Chronic fatigue syndrome is associated with chronic enterovirus infection of the stomach (J Clin Path 2007:doi:10.1136/jcp.2007.050054). The authors make some key statements: *"Enteroviruses cause acute respiratory and gastrointestinal infections, with well-documented tropism for the central nervous system, heart and muscles. Earlier studies demonstrated circulating antigen*

of enterovirus, raised antibody titres and viral RNA in the blood and muscle biopsy specimens of patients with CFS. Cunningham et al showed a possible defect in control of enteroviral RNA synthesis in the muscle of patients with CFS that might permit persistence of the virus. ***Most patients with CFS have persistent or intermittent upper and/or lower gastrointestinal symptoms****. At the time of oesophagogastroduodenoscopy, a total of 95% biopsy specimens had microscopic evidence of mild chronic inflammation. A total of 82% biopsy specimens stained positive for VP1 within parietal cells.* ***An estimated 80-90% of our 1,400 CFS patients have recurring gastrointestinal symptoms of varying severity, and epigastric and/or lower quadrant tenderness by examination. Finding enterovirus VP1 protein in 82% of stomach biopsy samples seems to correlate with the high percentage of CFS patients with gastrointestinal complaints.*** *Muscle biopsy specimens taken from CFS patients and postmortem examination of brain tissues years after the initial infection also demonstrated the persistence of enteroviral genome.* ***A significant subset of CFS patients may have a chronic, disseminated, non-cytolytic form of enteroviral infection which can lead to diffuse symptomatology****".*

This evidence -- as distinct from psychosocial hypothesis so favoured by the Wessely School -- is diametrically different from the personal belief of Professor Peter White who, in the response from St Bartholomew's Hospital Chronic Fatigue Services to the NICE draft Guideline on "CFS/ME" asserted: "***bowel problems are not part of CFS/ME****"* (Stakeholder Comments on draft chapter 6, page 143). There is a significant literature documenting gastrointestinal problems in this disorder, so it is disturbing that Professor White's Unit seems to be unaware of it.

It is notable that in June 2004, Peter Denton White was awarded an OBE; the citation was: "*For services to medical education"*. Notices circulating at the time proclaimed him as leading the research into "CFS/ME" and said his OBE was a *"well-deserved honour and acknowledgement of his contribution to work on CFS/ME".*

For someone to receive such an honour seems surprising if the person so honoured is apparently ignorant of the established facts pertaining to the subject of his research interest for which he was honoured.

This raises a question that has been asked many times before: at what point will the body of scientific knowledge about ME/CFS be so great that it will be considered serious professional misconduct for self-proclaimed "experts" to pretend that it does not exist?

Wessely School "experts" such as White and Chalder seem curiously detached from and unperturbed by the difference between their own beliefs about ME/CFS and the beliefs of the World Health Assembly about the same disorder. The World Health Assembly, which held its 60th annual meeting in May 2007 in Geneva, is the supreme decision-making body for the World Health Organisation (WHO) and is the forum through which the WHO is governed by its 192 member states, all of which send delegates. The UK is a member state and is therefore bound by the WHO canon. The WHO first classified ME as a neurological disorder in 1969, but White and Chalder (and other Wessely School members) are certain that the WHO is mistaken and that "CFS/ME" is a behavioural disorder.

In his Editorial in the BMJ in which he zealously supported the NICE Guideline's recommendation for "CFS/ME" to be managed by the behaviour-modifying interventions of

CBT and graded exercise (BMJ 1st September 2007:335:411-412), White asserted: "*We remain unsure how to classify (CFS/ME)".*

This is in total disregard of the WHO classification of almost 30 years -- an era, as noted by Douglas Fraser in an eBMJ Rapid Response to that Editorial, when great care was taken over detail and documentation in the identification of a disease entity.

A significant proportion of White's income is known to come from his work for medical insurance companies: from their own internal documents, it is known that it is in the interests of those companies for their medical officers to continue to obfuscate the classification of this expensive disorder.

White's implausible Editorial resulted in Douglas Fraser's cogent comment: "*Fortunately, NICE has made the matter of classification unambiguous and transparent: 'The ICD-10 classification has been used as a basis for the new Institute classification directed at the informed reader'. NICE have placed the Guidance for myalgic encephalomyelitis under 'Central Nervous System', ie. 'Central nervous system>>Completed guidelines>>Chronic fatigue syndrome/Myalgic encephalomyelitis; Multiple sclerosis; Parkinson's Disease'* http://guidance.nice.org.uk/topic/centralnervoussystem ".

On whose proposal was Peter White honoured for his work on "CFS/ME" by the UK establishment when he so clearly and resolutely rejects the WHO canon and is certain that he is right and the WHO (and its 192 member states) are wrong?

There are other equally disturbing matters that seem to involve Professor White.

It is known that the Royal Free (Hampstead) NHS Trust Fatigue Service – a very large Centre -- is coercing "CFS/ME" patients into signing up to participate in CBT and graded exercise on pain of being refused access to a physician unless they do so (ie. patients will have access to a physician for medical advice at the Centre only if they agree to participate in CBT and graded exercise therapy regimes; if patients decline to enter into a contract to participate in such regimes, they will have no access to a physician at the Centre).

In the absence of the part-time Clinical Lead at the Royal Free Fatigue Services Centre, Dr Gabrielle Murphy, the person in overall charge is Professor Peter White.

It is understood that Professor White is recruiting patients attending the Royal Free Fatigue Services Centre to the MRC "CFS/ME" trials (of which he is a Principal Investigator), which raises the possibility that he is recruiting only CBT-compliant patients to his trials, which would decrease the number of trial drop-outs at a stroke. Staff at the Royal Free Fatigue Services Centre (Nathan Butler and Karen Levy, a graded exercise therapist and an occupational therapist respectively) are team members on the MRC PACE trial.

Less than one month after publication of the NICE Guideline on "CFS/ME" on 22nd August 2007, the Royal Free Fatigue Services Centre policy which refuses and denies patients access to a physician unless they agree to be coerced into taking part in a regime that is already known to be harmful in 50% of participants is in blatant breach of that national Guideline.

The NICE Guideline is unambiguous and states in ten places that if a CFS/ME patient refuses CBT and GET, such refusal should not end the treatment contract with the doctor and it

stipulates that patients may not be discharged from medical care -- see the Full Guideline, pp 28, 31, 116, 130, 158, 178, 214, 259, 283 and 298:

Page 28 of 317: "*Healthcare professionals should be aware that – like all people receiving care in the NHS -- people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care".*

Page 31 of 317: "*Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care".*

Page 116 of 317: "*Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care".*

Page 130 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship*".

Page 158 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship".*

Page 178 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship".*

Page 214 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship".*

Page 259 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship".*

Page 283 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship*".

Page 298 of 317: "*All treatments are offered allowing the person with CFS/ME to refuse without compromising the further therapeutic relationship".*

There is no room for doubt about these explicit recommendations. The Guideline Development Group was clear that a patient's right to care should not be limited by the personal treatment preferences of an NHS professional: "*Personal views or beliefs are not allowed to impede any individual's access to care and support"* (page 186). Further, on page 213, the Guideline states: "*The person with CFS/ME and healthcare professionals involved in their care will make decisions in partnership".*

This fundamental principle, enshrined in law and endorsed by NICE, is being actively negated, in letter and in spirit, by NHS practitioners at a leading London CFS/ME Centre.

The NICE Guideline states: "*Objectives of the CBT programme must be agreed with the patient, and they must clearly be willing to take part"*. Indeed so, but some Centres have a way of inducing "consent", and patients who hesitate are threatened with having no access at all to a physician (which, apart from any symptomatic medical care, they need in order to support their claim for state benefits).

Whether in law this amounts to free consent is an issue that will be tested sooner or later. NICE has given clear warning of legal and ethical pitfalls in the care of "CFS/ME" patients, but evidence now exists that some self-styled "experts" think they know better.

That coercion such as that which is occurring at the Royal Free Fatigue Services Centre is not to be sanctioned was confirmed on 28th February 2007 by the Parliamentary Under Secretary of State, Lord McKenzie of Luton: "*There is no requirement for individuals to carry out any specific type of activity or treatment. That cannot be sanctioned"* (Hansard [Lords]: 28th February 2007: GC198).

It has also been established that this same Centre is no longer prepared to support individual patients' applications for Disabled Living Allowance but simply hands patients a pro-forma letter.

This is the same Centre whose poster highlighting a Royal Free initiative to help patients with CFS return to work won first prize at a national conference.

The legacy of expertise and knowledge about ME bequeathed by the late Dr Melvin Ramsay (who was a Consultant at the Royal Free at the time of the 1955 outbreak), particularly his boundless compassion for sufferers, has been eroded by people who seem to have no understanding of such concepts. Dr Ramsay worked tirelessly on behalf of ME patients until his death in 1990 and was immeasurably distressed by the lack of understanding of ME exhibited by the Wessely School.

Such coercion as now exists at the Royal Free brings to mind the words of psychiatrist Thomas Szasz, Professor Emeritus of Psychiatry at the State University of New York in his latest book (Coercion as Cure: A Critical History of Psychiatry published by Transaction, USA, 2007):

"I maintain that it is easy to define psychiatry. I regard psychiatry as the theory and practice of coercion.

"The psychiatrist tends to have contempt for the (patient) and conceals (his) true sentiments behind a façade of caring and compassion. Each meddler believes that he is in possession of the 'truth' and bitterly resents those who dismiss his precious insights and interventions as worthless and harmful.

"Coercive relations – one person authorised by the state to forcibly compel another person to do or abstain from action of his choice – are inherently political in nature and are always morally problematic.

"Psychiatric diagnosis is disguised disdain. Psychiatric treatment is coercion concealed as care.

"Scientific discourse is predicated on intellectual honesty. Psychiatric discourse rests on intellectual dishonesty.

"The history of medicine, no less than the history of psychiatry, abounds in interventions that have harmed rather than helped patients. Nevertheless, physicians have abstained from using state-sponsored force to impose injurious treatments on medically ill people. In contrast, the history of psychiatry is the story of the forcible imposition of injurious interventions (with) terrible injustices committed against (people), rationalised by hollow 'therapeutic' justifications.

"I have, where possible, cited the exact words psychiatrists have used to justify their stubborn insistence that psychiatric coercion is medical care".

It seems that in the case of "CFS/ME" in the UK, coercive psychiatry is alive and well.

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See also:

Corporate Collusion

By Professor Malcolm Hooper, Eileen Marshall and Margaret Williams