The Cost of Collusion?

Margaret Williams 8th February 2017

In 2003 Professor (now Sir) Simon Wessely published a paper which was particularly disturbing and it remains relevant in 2017.

In his paper, Wessely warned doctors, especially GPs, not to accept that patients presenting with what he deemed to be medically unexplained symptoms might be organically ill (Medically-unexplained symptoms: exacerbating factors in the doctor-patient encounter: JRSM 2003:96:223-227).

Within his label of medically unexplained symptoms (MUS), Wessely included (ME)CFS.

Wessely regards doctors who believe their MUS patients are medically ill as being in danger of causing them iatrogenic harm: he warns doctors not to *"collude"* with their patients, arguing that if GPs take their MUS patients' symptoms seriously, patients would be made worse by the doctor if s/he ordered investigations -- in other words, it would be the <u>doctor</u> who was making the patient worse by believing in their symptoms.

In Wessely's own words:

"This paper proposes that well-intentioned actions by medical practitioners can exacerbate or maintain medically unexplained symptoms (MUS). The term is now used in preference to 'somatisation'".

"The medical specialties employ shorthand descriptions for particular clusters of MUS including... chronic fatigue syndrome".

Whilst mentioning that in (ME)CFS: "Possible precipitating events include chest pain induced by hyperventilation" and that "Additional psychosocial factors may be 'secondary gain', Wessely spelled out the main point of his paper:

"In this paper we focus on the adverse effects of medical interventions at various stages of the doctor-patient encounter....Patients with chronic or multiple MUS are particularly likely to be treated for illnesses that they do not have".

"This paper has identified points within the doctor-patient encounter where MUS may be iatrogenically maintained".

Wessely clearly abhorred the possibility that "the biomedical model may become firmly enshrined for patients and families at the expense of broad-based psychosocial models", stating: "This would matter less if broad-based rehabilitation strategies were not currently the most successful management approaches".

It seems extraordinary conceited for Wessely to suggest that, based on nothing more than his fixed belief about "medically unexplained symptoms", he knew better than the patient's own GP that no investigations were required.

Although Wessely denies working for the insurance industry, he cannot deny his relationship with it.

In 2007, Wessely returned to his theme of doctors' collusion with patients in his article entitled: "Why and When Do Doctors Collude with Patients?" for UNUM's Annual Chief Medical Officer's Report "Mind over Matter: Exploring the Issues of Mental III Health".

This time, however, he was in favour of doctors colluding with patients, especially if it was advantageous to doctors by making their life easier: "No wonder both doctor and patient collude. Euphemisms can be important, if they allow the patient to … engage in appropriate treatment and rehabilitation, but without endangering their self-esteem. Let's hear it for collusion".

However, he then referred disparagingly to some clinicians who "collude" with patients, stating that they: "spout the language of science, but it is a parody of science, mixing 'cod' immunology with... New Age homilies....As soon as one diagnostic fad disappears, it is replaced by another (and...they) provide an explanation that almost invariably avoids any of the self-blame, stigma and guilt of those diagnoses that more conventionally minded doctors use".

He concluded by reverting to support for collusion: "So doctors collude with their patients all the time. It's not such a bad thing after all".

There seem be several points of note regarding "collusion":

(1) Wessely says different things about the same subject depending on his audience at the time

(2) there are inherent dangers in a GP dismissing a patient with multiple symptoms as a somatiser without investigating for underlying disease

(3) Wessely seems to exemplify a particular arrogance in portraying himself as an "expert" who knows better than GPs (who may rightly take exception to being patronised by a psychiatrist without their training and experience).

There is another example of medical "collusion" but it is one that Wessely does not mention: it is between doctors themselves and is not in the best interests of their patients.

The Investigators of the PACE trial (of which Wessely was Director of the Clinical Trial Unit and was in charge of the statisticians) colluded amongst themselves to claim success for CBT and GET, even though independent analysis of the raw data showed that the trial was unsuccessful; in effect, they colluded to deny that the PACE trial failed (as did the FINE trial).

However, the cost-effectiveness of the "evidence-based…rehabilitation strategies" (namely CBT and GET) described by Wessely as "the most successful management approaches" has recently been scrutinised by no less an authority than the House of Commons Public Accounts Committee.

The Countess of Mar recently received a letter from the Chair of the House of Commons Committee of Public Accounts, Meg Hillier MP, who wrote:

"I am particularly concerned by the suggestion that the value for money claimed for NICE-approved NHS treatments may be significantly lower than has been claimed up to this point...taxpayers need to have confidence that approved treatments are good value....NICE... is committed to reviewing the need to update the guidance (on ME/CFS) earlier than the originally anticipated review date...I have therefore asked the National Audit Office to keep a watching brief on the scope and progress of the NICE review" (http://www.margaretwilliams.me/2017/public-accountscommittee.pdf).

There is undoubted relief amongst patients with ME/CFS that – after so many decades -- the assertion by the Wessely School that the interventions they favour (at a cost of well over £5 million in the PACE Trial, £1,147,000 in the FINE trial and £1 million that is to be used in the FITNET trial) are the most successful management approaches for ME/CFS has reached the attention of the National Audit Office who, in conjunction with the Public Accounts Committee, are now maintaining a watching brief as to whether these interventions do offer value for UK taxpayers' money.

To their great personal cost, many in the ME community already know the answer: CBT and GET are neither clinically effective nor cost-effective and it is only the continuing collusion amongst the Wessely School psychiatrists that maintains the illusion of efficacy.

