Chronic Fatigue Syndrome—Trials and Tribulations

Simon Wessely, MD, MSc, FRCP, FRCPsych, FMedSci

SYSTEMATIC REVIEWS HAVE 2 AIMS. THE FIRST IS TO PRODUCE an unbiased, detailed, and comprehensive synthesis of a particular subject. The second is to permit the emergence of consensus, informing but not mandating clinicians as to which interventions work for which patients. In this issue of THE JOURNAL, Whiting and colleagues[1] report a major systematic qualitative review of the interventions used for treatment of chronic fatigue syndrome (CFS). The results highlight the strengths of the systematic approach, the weakness of the CFS evidence base, and the destructive ideological fault lines that continue to divide the field, to the benefit of no one.

The authors have succeeded in satisfying the first requirement, that of producing a systematic synthesis of the literature on the treatment of CFS. This is no small achievement in a subject for which previous efforts have been notable for the evidence they provide of the deficits of the traditional narrative review.[2] That 2 independent review teams, neither with any CFS axes to grind, have reached similar conclusions that permit a single article is also reassuring.

The combined review comes to 2 firm conclusions. The first is that those treatments that the authors group together as broadly behavioral in nature—namely, either graded exercise therapy (GET) programs or cognitive behavioral therapy (CBT)—are currently the most effective treatments that have been submitted to the test of the clinical trial. The second conclusion is that there is little evidence available for review and that much of what exists is poor quality, made worse by the chaos surrounding case definitions, nonstandardized outcome measurements, and variations in study duration and follow-up.

In response to these findings, members of the CFS research community would, in an ideal world, acknowledge these deficiencies and get together to agree on sounder methodologies, most particularly in the area of valid and reliable outcome measures. However, there is no clearly defined "CFS community." Instead, several different communities exist, each answering to particular constituencies and each united not so much in what they believe, but in what they do not believe, about the nature of CFS and its treatment. Indeed, the conclusions of the report by Whiting et al will be a litmus test for determining to which particular community any individual researcher or advocate owes allegiance.

If treatment for CFS were governed more by evidence and less by passion, several events might be expected to follow publication of this review. For instance, consumer advocacy groups might join forces to lobby for better provision of the 2 interventions—GET and CBT—that have shown promising results, while pointing out that neither approach is commonly provided. Patients might join forces with health service researchers to insist that when these treatments are introduced to the wider world, quality and standards are maintained. Care must be taken to ensure that the cautious GET programs that have shown benefit in randomized trials are not replaced by crude, military style fitness programs. Likewise, the skilled CBT practitioners who delivered the interventions that also have been shown to provide benefit in the clinical trial setting must not be replaced by enthusiastic amateur therapists. Clinical researchers and funding agencies would note that, even though these interventions appear effective, the evidence is based on a small number of studies and neither approach is remotely curative, and would continue their efforts to develop better treatments.

But CFS is a condition for which every possible etiology has several diverse hypotheses.[3] Accordingly, it is regrettable but likely that this review article will not be universally welcomed. Some consumers, and researchers alike, will make it their mission to discredit the authors and their conclusions. At the other end of the spectrum, some patients and clinicians will welcome the findings, and view these approaches as commonsense ways to reduce disability and enhance control over symptoms. Still others may see the findings, especially related to the benefits of CBT, as confirming their prejudices as to the mental instability of patients with

See also p 1360.

Author Affiliation: Department of Psychological Medicine, Guy's King and St Thomas's School of Medicine and Institute of Psychiatry, London, England.
Financial Disclosure: Dr Wessely serves as an advisor for treatment programs and research opportunities for PRISMA, a private company that arranges rehabilitation services. Dr Wessely receives no payment for this position, is not a shareholder, and has no financial interest in the company.
Corresponding Author and Reprints: Simon Wessely, MD, Department of Psychological Medicine, Guy's King and St Thomas' School of Medicine, 103 Denmark Hill, London, England SE5 8AF (e-mail: sphascw@iop.bpmf.ac.uk).

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CFS. Such views are misguided, but undoubtedly still exist in the minds of some health care professionals and employers. Regrettably, the consequences will be to reinforce the fault lines and confirm the hollowness of the term "CFS community".

Consumer or patient activism is a force for change, and can be a force for progress—but the 2 are not synonymous. Many professionals, after a hesitant start, are now welcoming greater consumer involvement in even the previously sacred corridors of research. For instance, in Great Britain, the experience of those who have worked with the Parkinson Society or the Alzheimer Society has revealed what can be achieved when patients, caregivers, and physicians work together. Clinicians have learned to be more aware of patients' needs and agendas, while patients and patient advocacy groups have learned about the difficulties that researchers face and the need to use their newfound power responsibly.

This may still happen with CFS research, but it has not yet. For instance, Internet sites and chat rooms soon will be awash with rumors about the content of the 2 reports that form the substance of the review by Whiting et al, and most likely many will not give much grounds for optimism. However, these types of intolerant views do not represent the wider community of patients. For progress to occur, what is needed is not more polemics, but a rapprochement and increased cooperation between physicians and patient goups. The time has come for clinicians who wish to help their patients with CFS, and for activists who truly represent the interests of patients, to begin by welcoming this review, subject to the caveats concerning quality and service delivery, and determine the direction for coordinating their efforts.

But what will happen if they do not? First, it will hasten the disengagement of some health care professionals who have been active and involved in CFS clinical care and research for many years. There are many who have found themselves increasingly vilified and, as a consequence, have joined the ranks of others who have been abused and intimidated for producing research unpopular to powerful special interests.[4,5]

Second, it will reinforce the fault lines that split CFS researchers and patients alike. Failure to respond positively to the challenges posed by this review will mean that activists and their chosen researchers will continue their own dialogue among themselves, closing their minds to alternative views and approaches, despite supportive evidence. At the same time, it will reinforce the negative stereotypes that already exist among the wider professional and scientific world for whom CFS is not the most pressing issue. Unfortunately, this stereotype only serves to convince the very researchers so desperately needed to investigate CFS (as this review so eloquently confirms) that this is not an area with which to become involved.

Perhaps the most compelling reason for hoping that those who have the best interests of patients at heart will not reject the review by Whiting et al out of hand is that doing so will let down those whose interests they wish to serve—the patients themselves. The interventions that appear to have benefit—at least based on this review—are safe, sensible, and modestly effective. Certainly, these interventions are not the answer to CFS but, based on currently available evidence, seem to be among the best available options. Uncritical rejection of these approaches because of their perceived associations with psychological treatments will be a step backward. And doing so will only add to the confusion and frustration of many patients with CFS who, unburdened by ideology, simply want some help.

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