Trial By Error: PACE Authors Respond to Monbiot Column with Tired Arguments

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By David Tuller, DrPH

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Last week, Guardian columnist George Monbiot wrote <u>another scathing column</u> about the failure of the UK health care system to address the plight of people diagnosed with ME/CFS. (Monbiot's <u>previous column on the issue</u> appeared in March; our interview about it is <u>here</u>.) The new column was pegged to the case of 27-year-old Maeve Boothby O'Neill, whose death in 2021 from complications of severe disease has received extensive media coverage in the UK (if not, unfortunately, in the US). But Monbiot also described at length the sorry history of London's <u>Science Media Centre</u>, a PR agency masquerading as a purportedly neutral arbiter of research, in disseminating fraudulent research in this domain.

To be clear, I use "fraudulent" in the sense of "deliberately deceptive." I have never claimed that the PACE investigators or their fellow travelers have engaged in the crime of "fraud." I'm not a lawyer, so that's not my area of expertise. Rather, I have argued that their research strategies are designed to generate false reports of success and mislead the medical and patient communities. These studies are the research equivalent of a Potemkin village—constructed to look impressive but, in reality, offering nothing of substance, or less than nothing, behind the glittering façade.

In response to Monbiot's column, the lead PACE investigators (Professors Trudie Chalder, Michael Sharpe, and Peter White) have once again emerged from their cave with <u>a letter</u> defending their honor and promoting their bogus notions. Yet time and science have left these self-important grandees in the dust. They remind me of those ancient Japanese soldiers on obscure islands who didn't know that World War II was over. Like rotten meat, their theories stink, and the investigators themselves passed their sell-by date long ago. If the PACE trial hadn't been so awful and caused so much damage and human suffering, their plight would just be sad and pathetic.

Here's the headline to their letter: "A dualistic view of illness doesn't help those with ME/CFS." In other words, this unholy trinity is regurgitating the same tired accusation they have trotted out over and over again—that anyone who challenges their shoddy work has bought into whatever it is they are calling "dualism."

Their routine bleating about "dualism" is a deflection. Per the descriptions of the interventions—cognitive behavior therapy and graded exercise therapy—the PACE trial was based on the premise that "deconditioning" and "unhelpful beliefs" alone were responsible for perpetuating the devastating physical symptoms characterizing ME/CFS. Refusing to acknowledge that physical symptoms might be caused by pathophysiological dysfunctions sure sounds like dualism to me. Pot, kettle, anyone?

I'm a public health guy, not a biologist or clinician. Early in public health training, students learn about what are called "the social determinants of health." It goes without saying that someone's physical and social environment dramatically impacts their health status. But to extrapolate this self-evident concept and insist that a devastating illness can be attributed solely to "deconditioning" and "unhelpful beliefs" about illness—as the PACE authors have claimed for decades—is absurd.

The three professors dutifully note that Boothby O'Neill's death was "tragic and should have been avoided." But avoided how? Do they think she chose to starve herself to death—even as she was begging for hospital personnel to provide artificial feeding options? Do they believe she would be alive today if only she'd pursued a course of CBT or GET? Do they think these interventions are likely to save the other young women currently suffering at the hands of the National Health Service? They offer no suggestions on what treatment she should have received. Instead, they blame Monbiot for drawing "generalizations" that they claim are "outdated."

Given that post-exertional malaise is a defining characteristic of ME/CFS, pushing people to ramp up their activity level despite a resurgence of symptoms is contra-indicated. Nonetheless, these "experts" refuse to acknowledge the harm their approach has caused to untold numbers of patients over the last 30 years. It must be hard to be told, later in your career, that the science to which you've devoted so many years is not only incompetent but has also made many patients worse. From that perspective, their reluctance to accept reality is understandable. But it is also unconscionable. In any event, their unwillingness to take responsibility for their errors and the indisputable flaws in their research doesn't change the facts.

They write that "no relevant paper has been withdrawn and many systematic reviews and metaanalyses have found the approaches to be beneficial." That statement presumes that the authors of these systematic reviews and editors of the relevant journals are honest brokers conducting honest research. That is not the case. Everyone involved is part of an insular cabal whose members praise and peer-review each others' work and publish in journals with editorial boards populated by their cronies. This body of research is not science. It's propaganda.