The Epistemic Injustice of the Cognitive Behavioral Model of Chronic Fatigue Syndrome

The cognitive-behavioral model of chronic fatigu syndrome (henceforth referred to as the CBM) is a theoretical framework grounded in cognitive-behavioral psychology for understanding the aetiology of chronic fatigue syndrome (CFS). The model has served as the basis for two treatments aimed at eliminating or alleviating the symptoms of CFS: cognitive behavioral therapy (CBT) and graded exercise therapy (GET). Major healthcare institutions such as the CDC and NHS have recently stopped promoting GET as a treatment option for CFS due to evidence of the physical harm that GET programs have caused to participants.\(^1\) While this acknowledgement of physical harm is a welcome development, I argue that the institutional legitimization of both treatments, and the theoretical model they arise from, has resulted in another form of harm against CFS patients that remains overlooked: epistemic injustice. In order to demonstrate the epistemic harm perpetuated by the CBM, I will first introduce the basic tenets of the model. I will then call into question major scientific research which purportedly validates the claims of the CBM. Next, I will introduce Miranda Fricker’s articulation of epistemic injustice, and apply the concept to the CBM. Finally, I will explore how the CBM intersects with further scholarship on the subject of epistemic injustice.

The Cognitive Behavioral Model

Chronic Fatigue Syndrome (also known as Myalgic Encephalomyelitis) is a chronic illness characterized by persistent fatigue lasting at least several months, intolerance to physical activity, and flu-like symptoms after overexertion. Other symptoms include difficulty

maintaining focus, impaired memory, chronic pain, and sleep disturbances. According to the CDC, between 836,000 and 2.5 million Americans are estimated to suffer from CFS, and an astonishing 90% of individuals with the disease are not formally diagnosed. There is currently no cure for CFS.

The cognitive-behavioral model of CFS stands in opposition to biomedical theories of CFS, which frame CFS as a physical illness grounded in biological abnormalities or systemic dysfunction. In contrast, the CBM argues that the symptoms of CFS are psychological, not biological. In Surawy et al.’s preliminary articulation of the CBM, chronic fatigue syndrome is perpetuated by a “vicious cycle” of dysfunctional cognitions, avoidance of physical activity, and deconditioning. The CFS patient is characterized as overly perfectionistic, believing their self worth to be dependent on the approval of others, and averse to showing weakness. When the CFS patient comes down with an infection or other temporary illness, Surawy et al. claim that the momentary relief from the demands of daily life triggers the patient to continue somatizing symptoms long after the source of the illness has passed. The patient develops a dysfunctional belief that they are still suffering from physical illness, which serves to protect them from the social blame they expect for failing to meet high standards of productivity and perfection. The CFS patient is clinically characterized as being unreliable in their assessments of their own physical and mental state, and defensive to the idea that they might not actually be experiencing physical illness. Several other factors, such as social reinforcement of the “sick role” and

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4 Since doctors and researchers in the 70s-90s struggled to find biological markers that would explain the continuation of certain symptoms after other signs of infection subsided, it was assumed that there simply was no biological explanation to be found.
malingering on symptoms serve to perpetuate the patient’s mistaken belief that they are physically ill.

The justification for intervention via CBT and GET is that cognitive restructuring and behavioral modification interrupt the cycle at two key points: dysfunctional beliefs and avoidance behavior. Once the patient overcomes their misattribution of symptoms to physical illness, and reverses the deconditioning caused by maladaptive avoidance of activity, proponents of the CBM argue that the “vicious cycle” will be halted and CFS patients will be allowed to return to normal functioning.

**Challenges to the CBM**

In response to this formulation of CFS, Geraghty et al. argue that physical illness attribution and avoidance of activity in CFS patients cannot be accurately categorized as “dysfunctional,” since there is a growing body of literature showing that biological abnormalities in CFS patients cannot simply be explained by deconditioning (which, according to the model, is the sole cause of physical weakness in the CFS patient). While the CBM in its current state does not account for the biological abnormalities associated with CFS, it has nonetheless enjoyed considerable staying power due to empirical evidence which has shown CBT to be efficacious in improving fatigue and disability in CFS patients. However, as Geraghty et al. argue, this literature is rife with methodological issues.

The most notable example is the PACE trial—the largest randomized trial of non-pharmacological CFS treatments to date. The PACE trial compared the efficacy of cognitive-behavioral therapy (CBT), graded exercise therapy (GET), adaptive pacing therapy (APT), and specialist medical care (as a control condition). Wilshire et al. heavily critique the

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trial, showing that the adjustment of ‘recovery’ standards prior to data analysis resulted in a
whopping 60% recovery rate for CBT (far outpacing the control condition), while the original
recovery criteria showed minimal and comparable improvement for all conditions. This
readjustment allowed patients whose post-treatment fitness scored below the study’s initial
inclusion requirements to qualify as having “recovered” after treatment. Furthermore, Wilshire et
al. claim that reanalysis of the PACE trial’s data reveals no statistical significance between
treatment groups. This particular claim was contested by Sharpe et al. (2019), who argued that
Wilshire et al. applied unnecessary overcorrection in their recalculation of statistical significance.

However, even if the results of the PACE trial were in fact statistically significant, the
only thing that can be characterized as statistically significant from the trial is the likelihood of
trial participants to rate their fatigue as lower than it was before treatment on the specific
questionnaires used for data collection. On more objective measures of treatment efficacy, such
as various fitness tests and post-treatment employment rate, trial participants did not show
improvement after treatment. Given that the entire premise of CBT is to change the patient’s
assessment and framing of “distressing” situations, it is highly problematic to measure condition
improvement based on self-report questionnaires.

The fatigue rating scale used in the PACE trial asks participants to rate on a 7 point Likert
scale how much they agree with phrases such as “Do you have problems with tiredness?” and
“So you need to rest more?” After this initial self-assessment, subjects in the trial are then
subjected to CBT sessions which frame similarly-worded statements as dysfunctional cognitions.

In the 2004 CBT manual for the PACE trial, for example, the phrase “I feel so tired” is explicitly

7 Carolyn Wilshire et al., “Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of
findings from a recent major trial of graded exercise and CBT.” BMC Psychology, 6(1) (2018),
8 Wilshire et al., “Rethinking the Treatment,” 10.
listed as an “unhelpful thought,” and CFS patients are told that even though they feel that they might need rest, it is unnecessary and detrimental to their nighttime sleep quality. At one point, the CBT manual even primes subjects to doubt any potential negative assessment of the treatment’s efficacy: the phrase “I feel just as tired as I did 3 months ago, there has been no improvement in my illness” is listed as an example of an unhelpful pessimistic thought pattern. Other widely used fatigue-rating questionnaires, such as the Checklist Individual Strength scale (CIS-20), use similar phrasing as the scale used in the PACE trial, which means that these methodological issues may not be unique to the PACE trial.

Furthermore, as Wilshire et al. note, PACE trial participants who were placed in the CBT or GET treatment groups received considerable priming during treatment as to the role of their own commitment in the success of treatment. Both CBT and GET were presented, in patient manuals, as treatments whose efficacy had already been proven, and that recovery from disabling illness was both possible and contingent on adherence to the program. Thus, patients filling out post-treatment questionnaires were already primed with the idea that failure to demonstrate improvement in their condition could be taken as a reflection of their own effort and adherence to their assigned treatment regimen. The PACE trial’s authors, responding to this issue raised in Wilshire et al., claim that a placebo effect is unlikely given the length of time between treatment and follow-up assessments. However, considering the fact that participants were trained to: 1) view negative assessments of the treatment as potentially ‘dysfunctional’ and 2)
view their improvement as reflective of their own effort in therapy, the problems with data validity clearly extend far beyond the definition of placebo effect.

As Wilshire et al. note, the harm lies in the marketing of CBT and GET as effective treatments for CFS, with the promise of potential recovery from a debilitating illness.\textsuperscript{17} Although some patients may experience some improvement in their quality of life after CBT, it is profoundly dishonest to argue that such an improvement validates the cognitive behavioral model of CFS. Not only are such claims questionable in their accuracy, but they also have substantial ramifications for the overall well-being of CFS patients. Studies like the PACE trial have gone on to influence policy recommendations from major health institutions, which in turn influence the healthcare decisions of doctors with CFS patients in their care. Therefore, the cognitive behavioral model must be challenged not only on the basis of its conceptual and methodological failures, but on its potential for harm to disabled patients.

Testimonial and Hermeneutical Injustice against CFS Patients

Miranda Fricker’s articulation of epistemic injustice identifies two ways in which harm is perpetuated against epistemic agents: testimonial and hermeneutical injustice. In testimonial injustice, the credibility of the speaker, and thus the social value assigned to their knowledge, is diminished due to prejudice. In hermeneutical injustice, a lack of shared conceptual frameworks prevents individuals from articulating their experience in ways that are socially valued. In both cases, epistemic injustice serves to prevent marginalized individuals from fully engaging in the vital social processes of accumulating and utilizing knowledge.

The very formation of the CBM can be characterized by testimonial injustice. The foundational model outlined by Surawy et al. (1995) arose from interviews with 100 CFS patients referred to an infectious disease clinic. Interviewers are granted a privileged position of

\textsuperscript{17} Wilshire et al., “Rethinking the Treatment,” 9.
credibility, implied to be more able to discern accurate patterns of behavior and cognitions than the patient themselves. For example, in the section on illness onset, Surawy et al. write: “Onset was usually reported [by the patient] as having occurred in association with the symptoms of a 'viral illness'. Further enquiry, however, typically revealed major psycho-social stressors and difficulties.”

Through this interaction, it is heavily implied that the patient’s assessment of which factors were most relevant in illness onset could not be trusted. The “further enquiry” of the interviewer is framed as a neutral tool to reveal clinically relevant factors, which would otherwise have been obscured by the patient. It is therefore apparent that the foundational principles of the CBM are predicated on interpreting patient testimony through a lens of undue scrutiny—framing the self-knowledge of CFS patients as a potential manifestation of psychopathology, rather than a legitimate source of knowledge in its own right. When contrasted with the presumed rational neutrality of the paper’s authors, it is abundantly clear that the formative conditions of the CBM are representative of Fricker’s definition of testimonial injustice.

Furthermore, since Surawy et al.’s model is meant to serve as the basis for cognitive-behavioral therapy programs, the only way in which a patient might regain any testimonial credibility is through “successful treatment,”—i.e. when the patient demonstrates to a CBT specialist that they have eliminated their “dysfunctional beliefs.” The very statement that challenges the validity of the model—“My illness is physical”—must be disavowed before the patient is considered psychologically sound. Even once the patient is deemed to have regained credibility through successful treatment, their ongoing credibility is dependent on maintaining allegiance with the tenets of the CBM long term, since any future opposition to the model may be framed as a “relapse” into dysfunctional beliefs. As such, the CBM must be understood as

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18 Surawy et al., “Chronic Fatigue Syndrome,” 537.
creating a self-perpetuating testimonial injustice, since the act of identifying and challenging testimonial injustice from the position of the patient only serves to bolster the existing testimonial injustice.

The CBM also serves to bolster existing hermeneutical injustice by creating barriers between CFS patients and knowledge about the illness. Patients receiving CBT treatment may be discouraged from researching their illness, since this behavior could be framed as “malingering” or “reinforcing physical illness attribution.” Therefore, CFS patients subject to CBT may never gain hermeneutical tools that would greatly increase their self-understanding and wellbeing. These patients might, for example, struggle to identify something like difficulty maintaining focus as a symptom of CFS, instead misinterpreting the symptom as fear-based aversion to a challenging activity. Thus, the CBM prevents CFS patients from fully understanding their own illness, and from being able to articulate their experiences using the terminology and frameworks used to discuss physical illness. This latter point is directly taken up in further scholarship on the subject of epistemic injustice.

Beyond Fricker’s Formulation of Epistemic Injustice

Dotson’s concept of contributory injustice articulates the way in which marginalized groups are prevented from contributing their internally developed knowledge and frameworks to the dominant set of hermeneutical resources, often through the dominant group’s dismissal of the worth of the marginalized group’s collective knowledge. As Dotson explains, contributory injustice differs from Fricker’s articulation of hermeneutical injustice in that it does not locate the epistemic harm in a lack of hermeneutical resources. Rather, contributory injustice allows us to see how well-formulated hermeneutic resources may be perceived by the dominant group to

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be inaccurate or frivolous due to situational ignorance about the lived experiences that those hermeneutic resources seek to explain.

The position of CFS patients aligns well with Dotson’s concept of contributory injustice, since existing testimonial injustice works to invalidate the self-knowledge patients may develop over the course of living with their diagnosis. Per Surawy et al.’s formulation of the CBM, any behaviors which reinforce the belief that CFS is a physical illness are motivated by the desire to avoid blame for low performance or functionality. Within this framework, any information that a CFS patient gains through self-monitoring is inherently devalued as observational data, assumed to be biased by the patient’s desire to “prove” that they are ill. As a result, the extensive observational information collected by CFS patients is subject to undue scrutiny, and might not enter into equal consideration when academics and healthcare professionals construct dominant understandings of the disease. This, in turn, may have disastrous consequences for CFS patients, as treatment protocols or funding for research are guided by conceptual understandings of the disease that do not accurately reflect the lived experience of those with the diagnosis.

The collective aspect of contributory injustice is salient in the case of CFS, since the lack of comprehensive research often encourages patients to seek wisdom from others living with the disease. Support groups and online forums are often sites of collective knowledge-building about the diagnosis, and feature information on topics such as the efficacy of various alternative treatments, the prevalence of various symptoms or symptom patterns, and tips for avoiding flare-ups. The CBM preemptively throws suspicion on any knowledge that may be formulated in such a collective manner, since “social reinforcement” is defined as one of the perpetuating factors in the “vicious cycle” of CFS. When the act of coming together to share experiences with

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20 This is not to say that observational information from CFS patients is never biased. Rather, the point is that observational data compiled by CFS patients is inherently assumed to contain more substantial bias than any data collected by able-bodied observers.
the illness is itself pathologized as collective malingering, any knowledge accumulated in that
collaborative space may be preemptively dismissed. Thus, a major source of knowledge is
prevented from contributing to the dominant group’s hermeneutic resources about CFS.

Polhaus’s concept of willful hermeneutical ignorance aligns well with Dotson’s
contributory injustice, characterizing the ways in which the dismissal of hermeneutical resources
from marginalized groups is carried out by members of the dominant group. Willful
hermeneutical ignorance describes how dominant groups, in refusing to attend to the experiences
and explanatory models of marginalized groups, “continue to misunderstand and misinterpret the
world.” Just as in the concept of contributory injustice, willful hermeneutical ignorance
acknowledges that there is not a lack of hermeneutical resources available to either the dominant
or marginalized groups. Rather, the issue is in the degree of attention and validity that the
dominant group ascribes to the knowledge of the marginalized, which results in seriously flawed
or incomplete understandings of the world.

Using Polhaus’s framework, it can be argued that the existence of the CBM is itself an
instance of willful hermeneutical ignorance, in which the dominant group (academics,
researchers, and healthcare professionals) perpetuate distorted understandings of the experience
of a marginalized group (CFS patients) due to their ignorance and dismissal of knowledge from
the marginalized group. Instead of acknowledging that a lack of medical explanations for
patients’ fatigue might be due to a general insufficiency in medical knowledge, the proponents of
the CBM seek to construct hermeneutic resources that assume no medical explanation, applying
existing cognitive-behavioral frameworks to make sense of their incomplete view of the
situation. The CBM then works to perpetuate that same willful hermeneutical ignorance, since

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21 Gaile Polhaus, “Relational Knowing and Epistemic Injustice: Toward a Theory of Willful Hermeneutical
22 Polhaus, Relational Knowing, 716.
any patient testimony which might challenge the validity of the model (i.e. insisting on physical illness as the source of symptoms) is distorted so as to prove the model’s accuracy (i.e. pathologized as “physical illness attribution”) in the eyes of the dominant group. Through the pathologization of patient resistance to the CBM, the proponents of the model perfectly demonstrate the willful aspect of Polhaus’s concept—patient objection to the model is not inaccessible per se to the dominant group, it is instead misinterpreted and distorted due to a failure of the dominant group to acknowledge potential biases and ignorance towards experiences of patients.

Finally, Fairbarn’s concept of inferential injustice seeks to describe instances in which epistemic injustice occurs due to the consistent misinterpretation of the situation by dominant knowers, which prevents the situation from being correctly interpreted within existing frameworks. Fairbarn uses the example of the failure of doctors to correctly diagnose endometriosis, often due to assumptions that excruciating pain during periods is simply normal, or that female patients are exaggerating the extent of their pain. The epistemic injustice occurs when the dominant knower (the doctor in the endometriosis example) fails to recognize his patient’s testimony (complaints of extreme menstrual pain) as applicable to an existing hermeneutical resource (the diagnostic criteria of endometriosis). In doing so, the doctor causes the patient to suffer as she is denied both treatments that might alleviate pain and a conceptual framework which might allow her to understand why the pain is occurring.

The cognitive-behavioral model of CFS perpetuates inferential injustice by preventing the suffering of CFS patients from being recognized as a legitimate physical illness (which cannot be effectively cured by cognitive restructuring.) By casting CFS as a psychological illness

characterized by the mistaken belief of physical illness, the CBM functions to promote certain assumptions about the suffering of patients: that the disability experienced by patients can be overcome through elimination of “avoidance” behavior, that social support for patients only serves to “perpetuate the sick role,” and that recovery from the illness is dependent on the patient’s efforts in therapy. The CFS patient is thus effectively denied the option to have their illness interpreted as anything other than the psychological definition put forward by the CBM. They lose the credibility required for effective self advocacy, and the continued suffering of the patient is blamed on their assumed lack of effort.

Conclusion

I have shown that the cognitive-behavioral model of chronic fatigue syndrome serves to perpetuate epistemic injustice against CFS patients. While graded exercise therapy is now under increased scrutiny due to its history of physical harm to patients, cognitive behavioral therapy continues to be recommended as a potentially efficacious treatment for CFS patients. Even if institutions such as the CDC do not purport that CBT is a curative treatment for CFS, the mere suggestion that CBT might be a worthwhile option in a treatment regimen serves to legitimize the treatment, and its theoretical foundation. It must be noted that the epistemic injustice of the CBM does not require every healthcare practitioner to be an ardent supporter of the model. Simply being exposed to the CBM might be enough to bias how healthcare professionals view their patients and significantly alter how a doctor approaches treatment. Thus, given all the ways in which the CBM perpetuates epistemic harm and the questionable scientific validity of the model itself, I conclude that the failure of the scientific community to properly denounce and delegitimize the cognitive-behavioral model of chronic fatigue syndrome is an act of injustice.

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