Reviewer's report

Title: Barriers to Healthcare Utilization in Fatiguing Illness: A Population-Based Study in Georgia

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Reviewer: Hyong Jin Cho

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Given the frequent misconceptions and the lack of awareness regarding chronic fatigue syndrome (CFS) among the population and health professionals, the topic addressed in this manuscript is of importance. The population-based study setting and the combination of quantitative and qualitative methods are the strengths, but the manuscript requires an extensive revision due to the problems described below.

- Major Compulsory Revisions

The manuscript is hard to read and the main message is not easy to grasp. As there are too many questions and too many findings described throughout the paper, the readers may get easily distracted and have difficulty to follow the development from the main question to the answer. The authors need to restructure the text. For example, it was hard to locate the results of multivariable analyses, on which the interpretation should be based. Instead, the unadjusted results occupy the majority of the results section and tables/figures, shifting the attention of the readers. Actually, this pattern happens in the abstract as well. Another example is the testing of several questions out of the main theme, which are not stated in the introduction: the likelihood of prior CFS diagnosis according to healthcare utilization, the health outcome of those with or without a prior formal diagnosis of CFS, etc. (This is in addition to various questions that are just vaguely mentioned in the introduction.) Overall, telling a good, convincing, and tight ‘story’ would make the manuscript stronger and appealing to the readers.

The description of the study design should be revised as well. Despite the first impression from the description, it is not a matched case-control study nested in a population-based survey. The primary outcome variable is ‘the occurrence of barriers to healthcare utilization’. Therefore, cases are those who experienced barriers to healthcare utilization. To be a classic matched case-control study, controls should be those who didn’t experience barriers, and the matching should occur regarding these two groups. Even the matching described in the manuscript does not seem adequate for the main question. The matching was done regarding CFS-like vs Well individuals while ideally 4 matched sets should be present: 1) CFS vs Well; 2) comorbid CFS vs Well; 3) ISF vs. Well; and 4) comorbid ISF vs Well. Did the authors conduct a frequency or individual matching? The authors should describe these aspects of the study design and other methods more clearly so that the readers don’t have the problem I had in
understanding the text. These aspects are also important as matched data require matched analysis. If the study did not have a matched design, multivariable adjustment for covariates including ‘matching’ variables should be indeed the main analysis, and the results and the interpretation should be described accordingly.

The main ‘exposure’ variable is the classification of fatigue status consisting of 4 categories. Why did the authors choose this approach? What are the rationale and usefulness of this approach?

Additionally, while the title includes ‘fatiguing illness’ probably indicating 4 categories of the main exposure variable, the abstract and the introduction give an impression that the authors are comparing CFS patients and well controls. All this should be clearly explained.

The authors are recommended to explicitly describe which are exposure, outcome, and confounding variables.

The definition of the main outcome variable is problematic. The authors defined ‘the occurrence of barriers to healthcare utilization’ using the absolute count of ‘how many times a participant has reportedly foregone healthcare’. CFS patients may have much more health problems and symptoms requiring healthcare utilization than well controls. Thus it may not be adequate to compare the ‘ever occurrence’ of ‘unmet needs’ in two groups with disproportionally different ‘needs’. Assuming that CFS patients had much more ‘needs’ during the past year, they may have had more ‘unmet needs’ naturally. The ideal way would be to compare two groups with similar levels of health problems requiring healthcare utilization. According to the authors’ hypothesis, if compared to ideal controls who have a similar level of ‘needs’, CFS patients would forego healthcare seeking more frequently. Alternatively, the authors can control for the number of health problems requiring healthcare utilization (or less optimally for the frequency of healthcare utilization) in the current study design.

Another problem regarding the main outcome variable is the possibility of recall bias. This may be difficult to remedy and very complex to deal with because recall bias may have affected the reporting of symptom occurrence, healthcare utilization and healthcare foregoing. The authors may want to seek more objective data on these variables such as symptom diaries (if these existed at all), report from family members, and clinic records.

Were any ‘chronically unwell not CFS-like’ participants included in the analyses of the present manuscript?

The significance level of 0.01 seems arbitrary. More formal statistical procedures need to be considered.

Was the procedure of qualitative analysis valid enough? Is there any study evidencing the validity of the software used? Was the role of ‘human’ researchers a simple review of the automatically produced results or was there any significant contribution? Was the manual review conducted by a single person or was there
any discussion by a pair or a group of people?

As there were too many questions, much of the discussion section was used to summarize the findings, and again it was hard to grasp the core message. The authors are recommended to write a discussion that is more balanced and adequately supported by the data, taking into account the problems and limitations indicated above.

The abstract should be rewritten. The composition of 780 participants is unclear. The readers may erroneously understand that the sample of CFS patients was larger than the actual size. ‘Classifications’ is an imprecise term. ‘Unexplained unwellness not meeting criteria for CFS’ seems to mean ISF but sounds like ‘chronically unwell not CFS-like’. Overall, the definitions and descriptions of the terms should be more precise and consistent throughout the manuscript.

Tables are complex. For example, it is hard to figure out the odds ratios. The figure needs a legend enabling an easy understanding.

The authors mention that they are unaware of any population-based study of healthcare barriers with patients with fatiguing illness. Are there any primary or tertiary care studies on the topic? The authors could also briefly review the healthcare needs and utilization of patients with fatiguing illness.

Some sentences don’t read smoothly:

“Blacks are also less likely to have health insurance and perceive access to healthcare differently than whites.”

“Not surprisingly this primarily reflected illness…”

“Decreasing the number of people with fatiguing illnesses being misdiagnosed with CFS as well as increasing the number of people under-diagnosed may help to reduce healthcare utilization barriers.”

Despite the volume of my comments, I did not exhaustively list the problems. The authors should thoroughly revise the manuscript for other problems not mentioned here.

- Minor Essential Revisions

In the introduction, the authors are generalizing the data from a few studies to the entire population of CFS patients.

What does ‘insufficient fatigue’ mean in the following sentence?

“ISF status was categorized for participants that did not meet the 1994 international research definition in terms of the number of symptoms or insufficient fatigue.”

- Discretionary Revisions

Although understandable, ‘CFS with exclusionary conditions’ is paradoxical as it is not CFS by definition.
‘Reported duration of fatigue’ is more precise than ‘duration of fatigue’.

**Level of interest:** An article of importance in its field

**Quality of written English:** Needs some language corrections before being published

**Statistical review:** Yes, and I have assessed the statistics in my report.

**Declaration of competing interests:**

I declare that I have no competing interests.