Author's response to reviews

Title: U.S. Healthcare Providers' Knowledge, Attitudes, Beliefs, and Perceptions Concerning Chronic Fatigue Syndrome

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Author's response to reviews: see over
Dear Ms. Pafitis,

Thank you to the editors and reviewers for providing comments on our manuscript “U.S. Healthcare Providers’ Knowledge, Attitudes, and Beliefs Concerning Chronic Fatigue Syndrome.” The comments were insightful, and revisions of the manuscript in response to the comments greatly improved it.

The editors requested that we document within the manuscript the name of the ethics committee, which approved our study, and include a “Competing interests” and “Authors’ Contributions” section.

We did not modify the manuscript to discuss IRB issues. The Docstyles study was reviewed by the Deputy Director of the Division of Health Communication and Marketing, National Center for Health Marketing, at the Centers for Disease Control and Prevention (CDC), acting for the Division Associate Director for Science, and was determined to be exempt research under exemption 2 in 45 CFR 46.101 (b), in that it was research involving survey procedures in which the information is recorded in such a way that respondents cannot be identified. The data are collected for Porter Novelli by a survey research subcontractor and identifying information remains with the subcontractor. The data are national survey data and are property of Porter Novelli. They are licensed to CDC by Porter Novelli for internal use and are released to CDC only with an arbitrary numeric id code for cases that cannot be used to identify the respondent. CDC has licensed these data from Porter Novelli annually since 1995 and has never received information in which respondents can be identified. Over the history of the project, many peer-reviewed articles have been published. One example is the paper by Gust et al.


Similarly, the Conference Healthcare Provider study falls under these exemptions. However, we did obtain permission to distribute USB sticks and collect KAB information by the independent conferences and as industry standards dictate, no identifying information was collected upon data collection. The Conference KAB data was collected by a contractor and the contractor did not collect identifying information. The data was submitted to the CDC by a conference ID only. This information was clarified in the manuscript.

We added the two sections “Competing Interests” and “Authors’ Contributions.”
Reviewer 1
This study tries to investigate the knowledge, attitudes, beliefs and perceptions concerning CFS by healthcare providers in the USA. Although the methodology is impressive and results are interesting, I have some questions about the authors' use of the factor 'perceptions':
-Why isn't this factor mentioned in the title of the manuscript?

The questionnaire was primarily designed to capture knowledge, attitudes, and beliefs. From the results of factor analysis, we observed additional key factor, perceptions. To accommodate this emerged factor, we have included perceptions in the title of the manuscript.

-What are the authors' arguments for considering the statement 'most people with CFS were competitive and driven before they got sick' as indicating 'poor perception of CFS'? I would advise in this respect that the authors would take a closer look at the literature, eg. Harvey et al, Psychosom Med 2008; Van Campen et al, Psychosomatics 2009; Fukuda et al, Compr Psychiatry 2010.

We thank the author for pointing out the potential confusion surrounding this question and for the accompany references, which we found helpful. We did not intend to indicate that the reference statement was “a poor perception” of CFS and have changed the wording. In fact our frequency and factor analysis results show that most respondents were neutral on this statement and that prior history of CFS diagnosis did not impact the response.

Reviewer 2
This is the first substantial attempt to survey the knowledge, attitudes and beliefs (KAB) of U.S. health professionals about chronic fatigue syndrome (CFS). Such a survey is important, because it can give focus to the kind of continuing medical education required to educate clinicians about this important illness. However, the current manuscript contains important methodologic limitations, uses statistical techniques that render the results opaque, and is poorly written.

We thank the reviewer for the helpful feedback and have addressed the methodologic limitations with evidenced based literature, added additional statistics and tables to clarify the results, and improved upon the written quality of the paper.

MAJOR COMPULSORY REVISIONS
1. In the Discussion, the authors recognize the considerable limitations imposed by using a “convenience” non-probability sample of survey respondents. However, they feel the data are worth reporting, despite these limitations. I disagree. It is true that this sample provides information about non-physician health professionals, which the probability sample does not. However, given that it is impossible to know how representative the sample is of the KAB of non-physician health professionals, I don’t think reporting these data is of value.
We thank the reviewer for the comments on convenience samples but respectfully disagree. The evidence-based literature cites many peer-reviewed publications that have utilized convenience samples and convenience samples have been commonly used in clinical studies. While there are disadvantages of convenience samples, probability-based samples also have some limitations such as non-coverage and non-response biases. In our paper, we used the combined probability/convenience sample to enhance the representativeness of the study population.

Singleton et al. state that “while one should be mindful of [these weaknesses] it would be a mistake to rule out nonprobability sampling,” and gives four reasons for using such methodology, one of which is “in the early stages of investigating a problem, when the objective is to become more informed about the problem itself.” Many KAB studies utilize this method as a first step in beginning to understand KAB in the target population. For example, a recent article in BMC Public Health by a Harvard University team led by Zou et al. used a convenient sample to examine religious beliefs on HIV stigma. In 2009, Patel et al. of Vanderbilt School of Medicine used a convenience sample of 1384 healthcare professional (including 970 physicians) to study behaviors and attitudes in intensive care units.

Given the lack of information on CFS and KABs among health care providers in the United States, we believe this study is an appropriate first step to learn more about this issue. We have clarified in the Discussion that further research is needed in terms of CFS and KABs among healthcare providers in the U.S.

References:


2. As I see it, the main results of this study are the range of responses to each question. For example, respondents in the non-probability sample were asked to respond to the statement “CFS is not as big a problem as the media suggests” on a Likert scale ranging from 1-7. The main result that the reader wants to know is what the range of responses was. That is nowhere to be found, for any of the nine questions KAB questions on the non-probability sample survey.

We thank the reviewer for pointing out the confusion. We have added a table (Table 3), which allows the reader to see the range of responses for the convenience sample KAB questions.
3. In contrast, what is found (Table 2) is the result of a principal components analysis (PCA). PCA (and similar statistical techniques) is ideal for empirically determining patterns and groupings in data, for “letting the data speak for themselves”, particularly when there are a large number of data elements. Why is PCA necessary here? The investigators created a small number of questions to pose to survey respondents, and had already grouped them into categories in advance of collecting the data. They didn’t need PCA to create such groupings. If the purpose of PCA is to “assess the reliability and construct validity of the survey” [p. 17], they need to explain in the Methods how PCA does this, and report the result of such validation only after having first reported the main results (Comment 2, above).

The KAB questionnaire was primarily designed to capture knowledge, attitudes, and beliefs and we used PCA to see how the nine KAB questions fell into the KAB categories. We did not a priori assign the questions in categories but instead used factor analysis to look for patterns and grouping. The results of factor analysis revealed an additional key factor, Perceptions, and thus added this to our data analysis and discussion.

We agree with the reviewer on the advantage of PCA in dimensional reduction for a large number of data elements. However, there is no existing validated KAB questionnaire on CFS established in the U.S. population. We sought to use this opportunity to develop dimensional scales and assess their reliability and construct validity of this survey for its application in future studies of small sample size in primary or tertiary care setting. To further examine the item questions in the KAB scales, we have now added chi-square results from associations of item questions with a diagnosis of CFS by healthcare providers.

4. Similarly, ALL the actual results of the respondents in the probability (DocStyles) sample need to be reported in a TABLE—rather than having SOME of them mentioned in the TEXT of the Results. Moreover, tables are needed to highlight interesting examples of how one question was answered by doctors who answered a second question in a different way. For example, 41% of the doctors had made the diagnosis of CFS in at least one patient, and 20% agreed that “CFS is all in a patient’s head”. How many of those who felt “CFS is all in a patient’s head” had (nevertheless) made the diagnosis of CFS in a patient—and how many doctors who did not think CFS was “all in a patient’s head” had given a diagnosis of CFS?

We thank the reviewer for this valuable suggestion and have amended the paper so that the DocStyles results are now included (see Tables 6 and 7). Table 6 lists all data that were described in the Results section. Table 7 shows the chi-square analysis results of making a CFS diagnosis in the context of KAB questions. We also added a third table of chi-square results of the KAB survey with the same CFS diagnosis in the context of KAB question on the KAB questionnaire.

5. It is unclear how various characteristics of doctors in the DocStyle sample were determined. Was this determined by the Epocrates database collectors, or by questions on this survey? How were these characteristics defined? In the Results and Discussion, some of
the descriptors are treated as being mutually exclusive with others. For example, the answers of doctors “in private practice” are distinguished from those in “community settings”: however, most private practices are in community settings. Likewise, the answers of doctors in “hospitals” are distinguished from those in “academic settings”: however, most doctors practicing in “academic settings” do so in a teaching “hospital”. Considerable clarification of these categories is required, for the reporting of the results to be interpretable.

Characteristics of the DocStyles physician samples were drawn from Epocrates Honors Panel and are determined by the Epocrates database collectors. Epocrates randomly selected a sample of eligible physicians from their main database to load into their invitation database. This sample was drawn to match AMA master file proportions for age, gender, and region. Participants in the 2006 and 2007 DocStyles were all asked a variety of health questions including questions on CFS.

In the KAB survey study respondents were asked “Type of setting you practice in” and respondents could select from one or more of the following: hospital, private practice, group practice, academic, community, and other. Out of 1255 responses, 55 persons (4%) selected more than one response. We have clarified the process in the manuscript.

6. The otherwise excellent probability (DocStyles) sample was marred by the fact that data from 15% of the sample was lost due to a data storage error. It is incumbent on the authors to reassure the reader that bias was not introduced as a consequence of this loss. Based on the descriptors of the doctors that were available, were the doctors whose data was lost different in any respect from the doctors whose data remained in the sample?

The lost data was due to an overnight backup data error for data collected during that one day and was not systematically related to specialty of respondent or the content of their responses. The data that were lost were the 205 physicians who took the survey between the time the data was backed up on Thursday and the time the programmer overwrote the data by the backed-up data on Friday. Thus, no particular specialty or demographics were affected, just "one day worth" at the beginning of the field period (we began on the 19th and had 385 completes as of 7/20 and data was lost on 7/21). The original quotas were obtained, and the sample closely matched AMA master file proportions on age, gender, and region as planned for probability sampling. We have updated the manuscript to more accurately reflect the random error.

7. Lastly, the manuscript is replete with grammatical and spelling errors. Particularly since BMC Family Practice does not edit manuscripts, it is the responsibility of the four authors to correct these errors. There also are many unclear statements. For example, at the top of page 7 we find this language: “In exchange for a USB stick….conference attendees were asked to fill out an anonymous, one-page 12-item CFS KAB form….Conference attendees were not required to fill out the KAB form in exchange for a USB stick.” This language appears contradictory, unless the authors mean: “In exchange for a USB
stick….conference attendees were asked, but not required, to fill out an anonymous, one-page 12-item CFS KAB form.”

We thank the reviewer for pointing out the vague statements and have corrected these throughout the manuscript.