Author’s response to reviews

Title: A survey identifying nutritional needs in a contemporary adult cystic fibrosis cohort

Authors:

Siddhartha Kapnadak (skap@uw.edu)
Kathleen Ramos (ramoskj@uw.edu)
Andrea Lopriore (andrea97@u.washington.edu)
Christopher Goss (goss@uw.edu)
Moira Aitken (moira@u.washington.edu)

Version: 1 Date: 30 Oct 2018

Author’s response to reviews:

Dear Editor:

This letter is in regards to our manuscript ["A survey identifying nutritional needs in a contemporary adult cystic fibrosis cohort" (NUTN-D-18-00054)]. We thank you and the two reviewers for the constructive comments. We believe that we have fully addressed all of the comments and a point-by-point response is included below (and separately attached). We hope that you find our revised version suitable for publication in BMC Nutrition, and again thank you very much for your consideration. Please do not hesitate to contact me should you have any questions. Sincerely,

Siddhartha G. Kapnadak, MD

Point-by-point responses (see bullet points) to reviewer comments:

A) Editor comments: You state in your manuscript that you have obtained a waiver for the requirement of patient consent for the retrospective data review. However, your study also includes prospective data collection of patients medical data. Please provide a clarification whether consent to participate was obtained for the prospective part of the study.

• Patients were given the option to participate in the quality improvement project (including survey). For those who opted to participate, because it began as a quality improvement project, the University’s Institutional Review Board protocol did not require formal patient consent. A
clarification is now provided on page 6, lines 1-4.

B) Reviewer 1: The authors have presented their findings in a well-written manuscript on the topic of patient-centered nutritional support in cystic fibrosis, which they are correct to point out has a paucity of data in the literature. As such, this paper provides some early direction for further study, but is hampered primarily by the small sample size. While they acknowledge this in the discussion section, the differences in responses to some questions seen between the genders and BMI groups, for example, may very well be significant but were not statistically so, due to the study being underpowered to find such differences. I do acknowledge that this was not to be answered with the initial design of this QI project, but feel it warrants specific mention in the discussion, as this could direct future studies. Page 7, line 20: should read "most common mutation" not "most common genotype". In table 1, there is no explanation for why only 65 patients are in some categories. While it is easily imaginable that CFRD status was unknown on a patient due to their not having done appropriate testing, knowing a patient's insurance and whether they have a PEG should be readily knowable.

• As requested, a comment has been added to the Discussion section to further address the sample size limitation (page 16, lines 1-3).

• “Most common genotype” has been changed to “most common mutation” (page 8, line 2).

• A total of 66 patients were approached for the survey and all completed it. However, in one of the 66 patients, certain background clinical data were not prospectively recorded and were thus unavailable at the time of data analysis. Since background clinical data for all other patients were prospectively recorded, we felt that separately reviewing the medical records retrospectively on this one patient could potentially provide biased information, and we thus chose to leave these data out of Table 1. As requested, we have added an explanation for these missing data in Table 1 (footnote in Table 1).

C) Reviewer 2: Kapnadak and co-workers developed a 14-item questionnaire to analyze from a patient-centered perspective the primary nutrition concerns and preferred health-improvement resources of 66 adult CF patients followed-up in a CF outpatient clinic. Traditionally, care of CF patient is centered on the prevention of undernutrition reflected by recommendations of minimal BMI levels in CF patients. The increasing median age of CF patients together with an epidemic of obesity is an explanation for the very interesting results of this study: A large number of CF patients was overweight or obese (28.8% and 9.1% respectively) and consequently "not-gaining further weight" was a chief concern. In parallel to a growing digitalization of our society, preferred health-improvement resources were chosen to be internet-based. In spite of a high prevalence of obesity, a relatively large percentage was physical active (physical activity: 3.6 days/week) and having access to web-bases fitness recommendations was noted by many as a health-improvement resource. The study contributes to a more individualized approach in the follow-up of this patient group with a stronger focus on obesity-related nutritional challenges. The study has limitations which are addressed by the authors (study design, sample size, patient selection). Patients were recruited from March 2016-August 2016. It would be interesting to know how many patients were asked to participate (selection bias?). Ultimately, 66 patients were included. Small sample size represents a limitation to draw conclusions from the socioeconomic analysis generating interesting statistical trends.

• The first paragraph of the Results section was modified to clarify the participation rate for the
As described above pertaining to Reviewer 1’s first comment, as requested we have expanded on this limitation in the Discussion section (page 16, lines 1-3).