Reviewer’s report

Title: Assessing Disease Disclosure in Adults with Cystic Fibrosis: The Adult Data for Understanding Lifestyle and Transitions Survey

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Reviewer: Monique A.M. Gignac

Reviewer’s report:

This paper provides a descriptive analysis of rates of disease disclosure among adults with cystic fibrosis (CF). The authors note that increased life expectancy and participation in a variety of roles (e.g., higher education, intimate relationships, employment) has meant that individuals with cystic fibrosis must make decisions about whether to disclose their condition to others. The study draws on data from the Adult Data for Understanding Lifestyle and Transitions (ADULT) study that includes questions about demographics, lifestyle and transitions to various roles, as well as questions about disease disclosure. The research addresses an important topic that will become of increased interest across a variety of chronic conditions as new treatments and health interventions enable many individuals with chronic conditions to participate more fully in society. At the same time, the paper and its relevance would be strengthened by situating the findings within a larger body of research on this topic and by more fully discussing the study implications and steps for future research.

Major Compulsory Revisions:

1. There are relatively few studies of disease disclosure in CF. However, there are relevant studies from a number of other chronic conditions. Although different in their etiology, conditions like HIV, arthritis, epilepsy and mental health or mood disorders share some features with CF like being largely invisible to others (i.e., people may not be aware that an individual has a chronic condition), the potential for disability with everyday activities, an uncertain disease course, and periods of wellness interrupted by episodes of impairment or more serious illness flares. These commonalities are relevant to self-disclosure and have been examined in research with other conditions, especially disease disclosure in the workplace. This paper would be strengthened if the introduction and discussion were situated within this larger body of research and the study findings were discussed in terms of the new data they add to the broader research area. Currently, there are only 9 studies referenced in the paper, 4 of which relate to disclosure. In particular, previous studies link disclosure to need (e.g., illness severity), perceived support from others, and concerns about stigma and potential discrimination. Example research to consult includes:


2. Descriptive results are erroneously reported as reflecting a significant causal relationship between variables. However, these relationships weren’t tested. For example, one of the headings in the results section is, “Effect of disclosure on relationship”. This section states that “relationships with relatives or close friends were most likely to be positively affected by disclosure” and “...a negative effect was most likely to be reported for romantic partners…”. The first paragraph of the discussion states, “…this survey is the new insight into patterns of disclosure in adults and its subsequent effects on relationships” and “The decision to disclose CF was shown to be influenced by several factors…, which are most likely linked with self-perceived risk/benefit evaluations of disclosure”. This does not accurately capture the data or the findings. Causal language throughout the results and discussion sections should be changed and replaced with descriptive language and a report of significant associations. For example, rather than “relationships with relatives or close friends were most likely to be positively affected…” the findings should read, “relationships with relatives or close friends often were perceived as being positively affected…”. A “negative effect was most likely to be reported” should be changed to “a negative effect was reported more...
frequently for…”. Stating that “our finding that disclosure has a neutral or positive effect on most relationships…” should be changed to “Our finding that disclosure was often perceived as having no effect or a positive effect on…”

3. As noted earlier, the discussion section would benefit from placing the results within the context of other research on disease self-disclosure to emphasize the complexity of this area and its relevance. For example, the authors note that workplace issues surrounding disclosure may relate to time off for health care utilization and fear of rejection. Elsewhere, they discuss that individuals may be more likely to disclose if they “risk detection”. Other research on self-disclosure highlights that perceived need (e.g., disease severity, need for treatment) and perceiving others as supportive consistently relates to disclosure. Some research has also linked this support to outcomes (e.g., less work stress, more help from others, fewer workplace problems). Putting the findings from this study into this broader context would help develop areas where there is additional research needed in CF. This should be highlighted in the discussion.

4. The tone of the conclusion paragraph should be altered. The authors write, “those with mild lung disease are more likely to conceal their CF diagnosis from supervisors, employers, teachers and co-workers”. This suggests an active attempt to hide one’s disease from others, which may or may not be true. Data from other research suggests that those with mild conditions may feel their condition doesn’t limit or interfere with activities and therefore, there is no need or reason to disclose. Without additional research into the reasons people have for disclosing or not disclosing, a more neutral interpretation or a range of interpretations should be provided. The authors could note that future research should examine in detail reasons for disclosing or not disclosing.

Minor Essential Revisions:

5. The measures section of the paper is incomplete. It should include all measures that are described in the results. This includes demographic information, disease severity questions, and questions related to topics discussed with potential partners.

6. The authors note that responses to medical and screening questions were needed to be included in the final dataset. More information on the response rate would be helpful in understanding the sample and its generalizability (e.g., number of respondents overall; percentage of respondents with complete data).

7. Were questions on education, income, and marital status asked of survey respondents? If so, they would be informative in understanding the current sample and should be included.

8. Figure 2 consists of three separate bar graphs that are difficult to compare. It would be helpful if they were combined into a single graph. The bottom would consist of each comparison group (e.g., relatives) and three bars (mild/moderate/severe airway limitation). This would enable the reader to more easily assess potential differences in disclosure reports.
Discretionary Revisions

9. The last sentence in the first paragraph of the introduction should be clarified. It may be mis-interpreted to mean that over 45% of the population in 2007 had CF and not, among those with CF, 45% were aged 18 years and older.

10. In the Methods section, it would be preferable to change the heading from “Patients” to “Participants” or “Respondents” as this is a community health survey asking about the lives of adults with cystic fibrosis not a clinical study focused on health care treatment or services for patients.

11. The Procedure section of the methods should come before a description of the Measures.

12. What is the n for the section on “Challenges discussed with partner”? This could be noted in the text and Table 2.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests