Reviewer’s report

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

Version: 1 Date: 8 June 2010

Reviewer: Kristoffer Berlin

Reviewer’s report:

“Assessing Disease Disclosure in Adults with Cystic Fibrosis: The Adult Data for Understanding Lifestyle and Transitions Survey” is a well-written manuscript that addresses an understudied and important topic area. I believe this study will be of interest to the readership of BMC Pulmonary Medicine and has the potential to contribute to the literature and to the care of those with CF. The authors successfully met the objectives of their paper by documenting the rates of disclosing one’s CF and the impact of disclosure on individuals’ relationships. My overall position on this paper is positive. I have no major concerns or compulsory revisions, only a few minor essential revisions, and discretionary revisions detailed below.

Major Compulsory Revisions: None

Minor Essential Revisions:

1) RESULTS (under the “Disclosure by lung function” heading): the authors state “disclosure to others may be influenced by severity of lung disease” and they show significant differences in the extent of disclosure as a function of airway limitation. It appears from the graphs that the extent to which the categories apply (e.g. percent of the “not applicable” category) may account for a large portion of these findings, particularly for the Supervisor/Employer/Teachers and Co-workers categories. This makes sense given that severe airway restriction might influence one’s ability to work. So a remaining, unanswered (yet, closely related) question is: among those to which these categories ARE applicable, do the rates of disclosure vary according to the extent of airway limitation? Running these additional follow-up analyses that exclude those who selected “N/A” may shed some additional light on these findings and control for this potential confound.

2) RESULTS (under the “Challenges discussed with partner” heading). I think these results are interesting in terms of the influence of gender on issues discussed with partner prior to a commitment; however, it is not clear how these analyses relate to the stated objectives of this paper (the impact of disclosure on relationships and/or the “how adults with CF perceived the disclosure process within specific personal and professional relationships”). The authors are encouraged to better link these analyses/results to the disclosure process in the introduction, in terms of the statistical analyses performed (e.g. gender
differences in disclosure) and/or conceptually by making these linkages more explicit. Alternatively, the authors may consider dropping these analyses.

Discretionary Revisions

3) ABSTRACT/BACKGROUND/DISCUSSION: An important finding of this paper was that disclosure appears to vary by the severity of lung disease; however, this is not mentioned in the abstract or as an objective in the background. The authors are encouraged to clarify this point in those sections.

4) RESULTS: The authors are encouraged to consider adding effect sizes to their statistical analyses.

5) DISCUSSION (last paragraph), minor point: The authors state that “preventative disclosure”, as it is termed, may have a positive influence on relationships by increasing awareness and reducing misperception” and rightfully point out that given some potentially negative effects that guidance and suggestions for disclosure may be necessary. It might be helpful to acknowledge that by definition Preventive disclosures include both concealment and disclosure (p. 246 Joachim & Acorn, 2000) for this very reason.

Level of interest: An article whose findings are important to those with closely related research interests

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.