Author's response to reviews

Title: Parents' reported preference scores for childhood atopic dermatitis disease states

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Author's response to reviews: see over
RE: Revisions to Manuscript 7292816902964883 for BMC Pediatrics

To Whom It May Concern:

We thank the reviewers for their thorough critiques of our manuscript. We have addressed the reviewers’ comments and feel that the manuscript is, as a result, much improved. We are pleased to submit the revised manuscript for your consideration.

On the attached pages, please find our detailed responses to the reviewers’ comments. Please do not hesitate to contact me should you have any questions. We look forward to hearing from you.

Sincerely,

Kevin A. Schulman, MD

Encl.
Responses to Reviewer
Reviewer: (Margaret) Sue Lewis-Jones

1. “Inclusion of other relevant literature in background.”

We agree with the reviewer that the addition of the cited literature would make the background stronger. We have added these citations to the second paragraph of the background section on page 3.

2. “Inclusion of one scenario and a more detailed explanation of health-state preference ratings.”

We agree with the reviewer that the inclusion of a description of the health states would be beneficial. We have included these descriptions in a new Table 1.

3. “Under Methods page 4: Comment -I would have preferred a panel of paediatricians and Paediatric dermatologists to review the scenarios for validity and realism.”

We agree that having a panel of specialists review the scenarios for validity would have been preferable. However, we had limited resources and were only able to rely on expert opinion from one pediatrician and one pediatric dermatologist.

4. “Under Survey Administration page 4: Recruitment of participants over the internet- how was the diagnosis of atopic dermatitis established? Another criticism of the whole survey is selection bias, which the authors do allude to. The participants are from a highly selected, predominately ‘white’ and higher social class group, which limits the use of these health state preferences when applying them to the population as a whole. There was also a financial incentive to complete the forms, which may have acted as a further bias.”

The diagnosis of atopic dermatitis was established through participant self-report. Participants were asked if they had a child between the ages of 3 months and 18 years who had ever been diagnosed by a medical professional with atopic dermatitis.

We agree with the reviewer that the potential for selection bias should be discussed further. Although our sample was predominately white, there were still approximately 350 responses from nonwhite participants, which provided a sufficient number of participants to test for differences by race/ethnicity. We had added more discussion of the selection bias issue in the second paragraph on page 11.

Although there was a financial incentive to complete the survey, the incentive was minimal. Participants were informed that if they participated in the survey they would be entered into a raffle with a chance to win one of five $100 prizes. We feel that this financial incentive played a minor role in the potential for selection bias.

5. “Under Results p 7 I was not clear from the text whether or not the parents’ had rated the eczema severity of their child by using the pictorial scenarios? If not, then labelling
severity according to parents’ beliefs is unlikely to correlate with actual clinical severity in many cases.”

In the revised manuscript, please see the second and third paragraphs on page 7 in the Methods section for a more detailed explanation of how the survey was administered.

6. “Under Table 1: where is the variable labeled ÷÷ with 149 missing responses? I could not find it.”

Please see Table 2 in the revised manuscript (formerly Table 1) for the correction. This was a typographical error and has been removed.

Responses to Reviewer
Reviewer: Petra Warschburger

1. “I find the title of the paper misleading.”

We have renamed the paper to “Parents’ Reported Preference Scores for Childhood Atopic Dermatitis Disease States”

2. “The background of the study is not very clear. The authors report only few empirical studies dealing with the quality of life of parents with a child suffering from atopic dermatitis. What are the specific hypotheses of the study?”

The study was undertaken to measure and estimate preference scores that are necessary to compute quality-adjusted life-years (QALYs) for cost-utility analyses. We did not feel that direct elicitation of preferences using standard gamble or time trade-off methods would be ethical in the context of parents’ participation in such exercises when children were the subjects. We instead relied on an indirect preference assessment in which parents could assign values using a scale that already had preference weights assigned (Lohr KN. Med Care. 2000; 38[9 Suppl]:II194-208). A preference-based measure allows for a combination of factors to be summarized in one number. Thus, our primary objective was to elicit preference weights from parents for health states corresponding to children with various levels of severity of atopic dermatitis. In addition, we evaluated the hypothesis that parents with children who had been diagnosed with atopic dermatitis would assign different preferences to the health state scenarios compared with parents who did not have a child with atopic dermatitis. Please see the third paragraph on page 3 through the first paragraph on page 5 for the revision.

3. “A thorough description of the respondents is missing. How did the authors get information about disease severity? How were the different severity levels defined? Do you have any information about how valid the scorings of the parents are?”

Table 2 (formerly Table 1) provides a detailed description of the respondents, including age,
4. “The description of the methods of the study does not allow a thorough understanding of the used instruments. Why and how did the authors change their scenarios and questionnaire? An example of a scenario would be helpful. What about the pilot test? Is the questionnaire reliable and valid? Why did the authors use five severity levels for AD (how defined: SCORAD? disease status? Necessary medication?), but only one scenario for asthma resp. wearing glasses? What is the rationale behind that procedure?”

We have included a description of the scenarios in a new Table 1.

The pilot test was used to determine whether patients understood what was being asked of them, not to determine its validity and reliability. Moreover, the sample size of the pilot test was too small (n = 20) and not designed to conduct analyses necessary to evaluate its validity and reliability. Please see the revision to the manuscript at the top of page 6.

We developed five levels of severity using a combination of the Investigator Global Assessment and the Eczema Area and Severity Index (Barbier N. Br J Dermatol. 2004; 150(1):96-102). Each scenario included descriptions of erythema, infiltration and/or papulation, excoriation, and lichenification, as well as percent and location of body area affected. We only used one scenario for asthma and glasses, because these health states functioned as comparison states and were not the focus of the study. Please see the Methods section, page 5, paragraph 2, for a more detailed description of the scenarios.

5. “In my opinion, the results were predictable. The authors conclude that the mean value of the preference scores decline with the disease severity of AD. An instrument with discriminant validity should differentiate between groups in that way. Furthermore, the difference between the groups is very small. Taking into account the number of respondents, this difference is statistically, but not clinically relevant.”

We agree that the differences between groups were small in our study. However, differences in preference-based measures are often very small, in part because of the use of a 0-100 scale that is anchored with perfect health and death—as opposed to a scale with anchors corresponding to less extreme differences.
6. “The implications of the study remain unclear. In which way can these results help to evaluate medical therapies? What do we know about parental perceptions of different diseases (there is a bunch of literature available)?”

Given the increasing need to evaluate the value of new medical therapies, reporting preference scores is useful to analysts and decision-makers who rely on these estimates to compute QALYs for use in cost-utility analyses. Please see the first paragraph on page 10.

7. “A main limitation of the study is the use of the Internet. The authors discuss that point, but mainly on the basis of the missing possibility of asking questions or the high socioeconomic status. The response rate of 22% is a major problem because of a possible response bias.”

We have added some additional discussion of selection bias on page 11, paragraph 2. We agree that our response rate was low. However, we are uncertain as to how a higher response rate would have influenced our results, thus we are not certain how the response rate contributed to a response bias, if at all.