Guidance is also needed on how to choose from existing asthma-specific quality-of-life measures

To the Editor:

In response to a lack of adequate outcomes standardization for asthma clinical research, National Institutes of Health institutes that support asthma research, together with the Agency for Healthcare Research and Quality in the United States, have agreed to an effort for outcomes standardization. As a preliminary activity, the published documentation relating to asthma-specific quality-of-life (QOL) measures was reviewed. This review identified 11 instruments for adults and 6 for children. The instruments were qualified to be classified as a core instrument because the instruments predominantly measured indicators of asthma control (symptoms, functional status, or both), failed to provide a distinct and reliable score that measured all key dimensions of the intended construct, and/or lacked adequate psychometric data. It was concluded that research is strongly needed to develop and evaluate instruments that provide a distinct and reliable measure of the patient’s perception of the effect of asthma on all of the key dimensions of QOL.

We welcome the effort that has been put into compiling this comprehensive review and fully agree that QOL needs to be conceptualized in a different way, namely as the perceived effect that asthma has on the patient’s QOL. It will take time to develop new QOL measurements for asthma, but unfortunately, the report does not provide any guidance as to how, in the interim, we should choose between the existing suboptimal measures, which are those classified as either supplemental or emerging. Our recently published structured review of QOL measures for asthma gives pragmatic advice for the short-term. We concluded that choosing from existing questionnaires requires a compromise based on the rigor of the development process and the target patient group. We recommend the use of measures that are solely designed for asthma, such as the SYDNEY Asthma QoL Questionnaire or the Living With Asthma Questionnaire. However, for use in multinational studies, it might be convenient or practical to use questionnaires that have been linguistically validated in many different languages, such as the standardized Juniper Asthma Quality of Life Questionnaire or the St George’s Respiratory Questionnaire. Future research on asthma outcomes should go beyond a systematic assessment using review criteria and involve patients in assessing the questionnaires. The de novo development of a questionnaire should be inspired both by theoretic considerations and the patients’ voices/qualitative evidence generated by those whose QOL is actually affected.

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REFERENCES

Reply

To the Editor:

We thank Drs Apfelbacher and Smith for their correspondence concerning the recommendations of the Quality of Life Subcommittee of the 2010 Asthma Outcomes Workshop. Their correspondence and their previously published review of available instruments that aim to assess the effect of asthma on a patient’s quality of life agree with the subcommittee’s conclusion that the available instruments that ostensibly measure “asthma-related quality of life” are actually measuring functional status, asthma symptoms, and, to a lesser extent, emotional/mood states. The writers and workshop recommendations also agree on the urgent need to develop instruments that truly and adequately measure quality of life, specifically the patient’s perception of the effect asthma has on his or her quality of life.

However, the workshop subcommittee went substantially further in concluding that the available instruments are simply not measuring the patient’s perception of the effect of asthma on quality of life. The 1999 analysis of Anderson and Burckhardt came to a similar conclusion with regard to all so-called “disease-specific” quality-of-life measurement instruments.

Notably, the workshop subcommittee concluded that even instruments that focus on measuring functional status, emotional well-being, or both do not adequately measure the intended construct of quality of life. For that reason, the subcommittee purposely eschewed prioritizing existing measures or recommending criteria for selecting among existing instruments as substitutes or placeholders until adequate instruments can be developed. Instead, it provided a table that describes what is actually being measured by the various instruments that purport to measure asthma-related quality of life and the psychometric data that are available to support their use for the purpose of measuring what they actually measure. It is hoped that researchers will find this table helpful for identifying instruments the content of which, as well as the development process, psychometric properties, and other relevant characteristics of which, are appropriate to their research aims and to the population they are studying.
REFERENCES


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