

2022-12-30

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Davies, D

<http://hdl.handle.net/10026.1/20149>

10.1183/13993003.02305-2022

European Respiratory Journal

European Respiratory Society (ERS)

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Moving towards patient-centred outcomes: the Severe Asthma Questionnaire.

Authors

Davies D¹, Hyland M E², Lanario J W², Jones R C³ and Masoli M¹.

1. Department of Respiratory Medicine, Royal Devon and Exeter Hospital, University of Exeter, Exeter, UK
2. Faculty of Health, University of Plymouth, Room N10, ITTC Building, Plymouth Science Park, Plymouth, Devon, PL6 8BX, UK
3. Plymouth Marjon University, Plymouth, UK

Corresponding author:

Dr Drew Davies

Department of Respiratory Medicine, Royal Devon and Exeter Hospital, University of Exeter, Exeter, UK

drew.davies@nhs.net

‘Take home’ message: There is a need for more comprehensive measures of quality of life in severe asthma and the Severe asthma Questionnaire provides a validated patient-centred core outcome measure for clinicians.

Available from: <https://doi.org/10.1183/13993003.02305-2022>

Moving towards patient-centred outcomes: the Severe Asthma Questionnaire.

We are pleased with Khaleva et al's [1] recommendation to include a patient-centred approach to core outcome measures in severe asthma. The role of medicine has been described as "to cure sometimes, to heal often and to comfort always" (William Osler) but to do this well requires us to really understand the patient who has the disease rather than the disease the patient has.

The experience of living with severe asthma is very different from mild to moderate asthma with a significant daily burden which impacts on life beyond the individual to the wider family including children [2]. However, the response to biologic treatment can be truly life changing which is missed with traditional asthma outcome measures [3]

Whilst patients consistently prioritise quality of life as one of the most important outcomes they wish to improve it is rarely seen as a primary goal of treatment either in clinical practice, clinical trials or by regulatory authorities [4]. The currently used patient reported outcome measures (PROM) were developed 30 years ago and fail to accurately assess the quality of life deficits experienced by this specific group of patients [5]. We wished to clarify the utility of the Severe Asthma Questionnaire (SAQ) in this regard.

The SAQ was developed to capture key information on asthma specific quality of life (QoL) that is relevant to this patient group including the burden of disease and treatment [6,7].

The SAQ asks how difficult aspects of QoL are in the last 2 weeks because of your asthma or side effects of treatment. The SAQ has 2 parts and provides 2 scores of asthma specific quality of life:

The SAQ has 16 questions which are scored using a 7 point Likert scale ranging from very, very difficult (1) to no problem (7), with responses averaged to form a SAQ score with 3 statistically determined sub-domains (my Life, my Mind and my Body) that are important and relevant to patients.

The Global score was included as patients expressed a desire to provide an overall score for their QoL and uses a scale from 0 to 100, where 0 equates to no quality of life, 100 equates to perfect quality of life. Patients also expressed a desire to record the variation in QoL over time which is represented in the best and worst months of the year.

By focusing on QoL the SAQ has been designed to complement rather than duplicate other symptom focused outcomes such as the asthma control questionnaire to provide a more comprehensive assessment of the experience of living with severe asthma.

The SAQ has been developed using a patient-centred process in accordance with US Food and Drug Administration PROM guidelines and has been validated in UK studies with well described minimal clinically important differences [8]. Currently, the SAQ has undergone validated translation into 16 languages and is freely available for clinical use through the SAQ website (www.saq.org.uk).

During validation studies, the SAQ was found to be sensitive to early change in response to biologic therapy [9]. A recent observational study found that an increase in the aggregated SAQ score of 0.5 in the first 12 weeks of treatment with mepolizumab led to a 6 fold increased prediction of biologic response at 12 months [10].

The SAQ has been adopted into the UK severe asthma mybiologic app and ERS SHARP registry. The SAQ is the primary outcome measure in a large pan-European study investigating the burden of severe asthma on quality of life using a digital tool (the PatientCoach app) which may make collection of patient-centred outcomes easier in the future.

There is a need for more comprehensive measures of quality of life in severe asthma. Asthma PROMs need to be sensitive to change in quality of life to allow clinicians to accurately appraise treatment from the patient's perspective particularly in the new clinical remission/super-responder paradigm.

We welcome what will hopefully be a new focus on the patients experience of living with severe asthma as a core outcome in future research.

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