



**HAL**  
open science

## Severe asthma patients' and physicians' perspectives of disease burden: do they match?

Heidi Makrinioti, Angelica Tiotiu, Francisco-Javier Gonzalez-Barcala

### ► To cite this version:

Heidi Makrinioti, Angelica Tiotiu, Francisco-Javier Gonzalez-Barcala. Severe asthma patients' and physicians' perspectives of disease burden: do they match?. ERJ Open Research, 2023, 9 (3), pp.00177-2023. 10.1183/23120541.00177-2023 . hal-04618557

**HAL Id: hal-04618557**

**<https://hal.univ-lorraine.fr/hal-04618557>**

Submitted on 20 Jun 2024

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution - NonCommercial 4.0 International License



# Severe asthma patients' and physicians' perspectives of disease burden: do they match?

Heidi Makrinioti<sup>1</sup>, Angelica Tiotiu<sup>2,3</sup> and Francisco-Javier Gonzalez-Barcala <sup>4,5,6,7,8</sup>

<sup>1</sup>Department of Emergency Medicine, Massachusetts General Hospital, Harvard Medical School, Boston, MA, USA. <sup>2</sup>Department of Pulmonology, University Hospital of Nancy, Nancy, France. <sup>3</sup>Development, Adaptation and Disadvantage, Cardiorespiratory Regulations and Motor Control (EA 3450 DevAH), University of Lorraine, Nancy, France. <sup>4</sup>University of Santiago de Compostela, Galicia, Spain. <sup>5</sup>Translational Research in Airway Diseases Group (TRIAD) – Health Research Institute of Santiago de Compostela (IDIS), Spain. <sup>6</sup>Biomedical Research Centre Network – Respiratory Diseases (CIBERES), Madrid, Spain. <sup>7</sup>Department of Respiratory Medicine, University Hospital of Santiago de Compostela, Santiago de Compostela, Spain. <sup>8</sup>Department of Medicine, University of Santiago de Compostela, Santiago de Compostela, Spain.

Corresponding author: Francisco-Javier Gonzalez-Barcala ([francisco.javier.gonzalez.barcala@sergas.es](mailto:francisco.javier.gonzalez.barcala@sergas.es))



Shareable abstract (@ERSpublications)

A novel open-ended survey revealed contrasting viewpoints and priorities between patients with severe asthma and clinicians. These divergences must be considered when treating individual patients in multidisciplinary treatment teams. <https://bit.ly/40Fsr9o>

Cite this article as: Makrinioti H, Tiotiu A, Gonzalez-Barcala F-J. Severe asthma patients' and physicians' perspectives of disease burden: do they match? *ERJ Open Res* 2023; 9: 00177-2023 [DOI: 10.1183/23120541.00177-2023].

*It is more important to know what sort of person a disease has rather than to know what sort of disease a person has.*

Hippocrates

Copyright ©The authors 2023

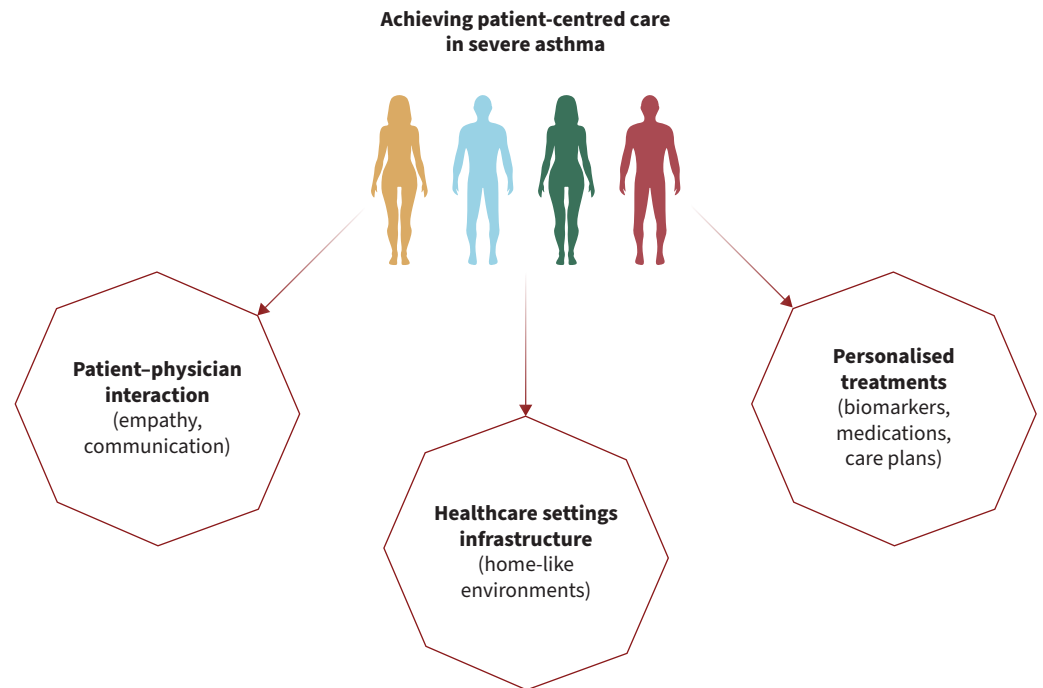
This version is distributed under the terms of the Creative Commons Attribution Non-Commercial Licence 4.0. For commercial reproduction rights and permissions contact [permissions@ersnet.org](mailto:permissions@ersnet.org)

Received: 20 March 2023  
Accepted: 20 March 2023

Significant changes have occurred in the management and treatment of asthma over recent decades. From using anticholinergic alkaloids as first-line treatment to developing adrenergic-based bronchodilators and emerging targeted biologics, advancements in asthma treatment have significantly improved asthma morbidity and mortality [1, 2]. However, the burden of severe asthma (*i.e.* that requires treatment with high-dose inhaled corticosteroids and additional controller medication) remains significant [3]. Severe asthma disease is complex, and impacts patients physically and emotionally [4]. Therefore, in addition to targeted pharmacological treatments, behavioural and lifestyle modifications (*i.e.* regular exercise and stress management techniques) are considered to positively impact outcomes [4]. As described in figure 1, it is becoming more apparent that a comprehensive approach to severe asthma management is strongly recommended. Achieving a comprehensive approach requires, to a large extent, a close collaboration between patients and physicians so that individualised treatment plans addressing individual patients' unique needs and challenges are prioritised. In addition, hospital settings need to be structured in a way that facilitates patient-centred care. Last, but not least, increasing funding needs to be invested in precision medicine research so that we avoid ineffective treatments and adverse effects for patients with severe asthma.

The need for a comprehensive approach in severe asthma management is highlighted in a recently published paired patient–clinician survey. This novel study by AINSWORTH *et al.* [5] used a patient-centred approach to explore whether there are discrepancies between patient and clinician perspectives of the most important aspects of severe asthma (*e.g.* severe asthma barriers) [4]. This study analysed data from a cross-sectional survey that was sent to physicians from severe asthma clinics in seven European countries (the Czech Republic, Denmark, Greece, the Netherlands, Slovenia, Portugal and the UK). The physicians were recruited *via* the European Respiratory Society Severe Heterogeneous Asthma Research collaboration. Physicians completed the first part of the online survey without having access to the patients' identities. The second part of the online survey was completed by eligible patients who did not have access to the physicians' identities. It is of note that the findings from this research study derive merely from severe





**FIGURE 1** How patient-centred care is realised across providers (*i.e.* physicians), healthcare settings and biomedical research (*i.e.* precision medicine). Patient-centred care models focus on trusted patient–physician interactions. In addition, in patient-centred care models, hospital setting infrastructure encourages patient–physician collaboration through a home-like environment that meets patients’ needs. A final but very important example of how patient-centred care is realised is the concept of precision medicine. This new frontier of medicine combining omics and healthcare record data bears the promise of better healthcare outcomes provision in severe asthma.

asthma centres in seven countries. Underserved group representation is missing and this is a limitation discussed by the authors. However, interesting findings from this study support the already described divergence in patients’ and physicians’ perceptions of severe asthma burden [6–8]. The interpretation of some important findings is discussed further below.

When considering differences between patients’ and physicians’ perceptions of severe asthma burden, there are two striking differences described at the study by AINSWORTH *et al.* [5]. The first difference is related to the effort required to self-manage asthma. Physicians reported self-management effort less frequently than patients. It is of note that successful self-management of asthma symptoms has been associated with a reduced number of exacerbations and improved asthma quality of care [9]. Patient education around self-management is crucial and it should be given in a structured way [10]. Understanding clinical symptoms, knowing how to act when symptoms deteriorate and knowing how to best administer medications are the milestones in self-management of severe asthma. It is important that physicians recognise this during their communication with patients and when making joint decisions around management plans.

The second difference between patients’ and physicians’ perceptions of severe asthma burden is related to the identification of stigma as an indirect physical consequence only by the patients. Experience from research in other healthcare conditions has shown that stigma is related to hiding symptoms or illness. Patients who feel their health condition is stigmatizing are less prone to adopting healthy behaviours and seeking healthcare when required [11]. It is important that physicians have conversations with patients that normalise discussions around severe asthma, use empathetic communication strategies and tailor discussions around patients’ preferred understanding around their condition.

An additional finding of the study by AINSWORTH *et al.* [5] is related to the complete lack of recording of indirect physical consequences in patient registries. This is an important omission, as there has been increasing use of registries in clinical research lately. Both observational and interventional studies utilise electronic healthcare records at large and for specific patient registries. Missing important aspects of severe

asthma might be associated with a lack of understanding of the impact of exposures or interventions on patients' outcomes.

Recently, patient-reported outcome (PRO) measures are increasingly used as endpoints in clinical trials. PROs include physical and psychosocial domains of wellbeing and come directly from the patients without further interpretation [12]. Validated PRO tools could be used as endpoints in clinical trials but a careful approach to statistical analysis and interpretation of relevant findings is required [13]. An international, consensus-based, PRO-specific protocol guidance was developed. This guidance included items that should be addressed in clinical trial protocols in which PROs are primary or key secondary outcomes [12]. It is important to emphasise that an improved study design including PROs could ensure that high-quality data inform patient-centred care. For instance, HOLMES *et al.* [14] have shown that coughing, which is included in the theme "direct physical symptoms of asthma" in the study by AINSWORTH *et al.* [5], is the most bothersome symptom for asthma patients.

This novel study reminds us that perception of severe asthma burden differs between patients and physicians, and this has to change. In a medical world where patient-centred care is valued and pursued, educating clinicians to consider outcomes other than physical in the context of patient management is of utmost importance. An equally important parameter is related to the introduction of patient-centred outcomes in clinical research and practice. Adding these parameters to existing patient registries and including these as endpoints in future clinical trials should be prioritised. Then, severe asthma could be more manageable at an individual level and outcomes could improve at a population level.

Provenance: Commissioned article, peer reviewed.

Conflict of interest: H. Makrinioti is on the Early Career Mentoring Programme of this journal. A. Tiotiu has nothing to disclose. F-J. Gonzalez-Barcala has received speaker fees, consulting fees or research grants from ALK, Astra-Zeneca, Bial, Boehringer Ingelheim, Chiesi, Gebro Pharma, GlaxoSmithKline, Laboratorios Esteve, Menarini, Mundipharma, Novartis, Rovi, Roxall, Sanofi, Stallergenes-Greer and Teva; and is an associate editor of this journal.

## References

- 1 Chu EK, Drazen JM. Asthma: one hundred years of treatment and onward. *Am J Respir Crit Care Med* 2005; 171: 1202–1208.
- 2 Brusselle GG, Koppelman GH. Biologic therapies for severe asthma. *N Engl J Med* 2022; 386: 157–171.
- 3 Chastek B, Korner S, Nagar SP, *et al.* Economic burden of illness among patients with severe asthma in a managed care setting. *J Manag Care Spec Pharm* 2016; 22: 848–861.
- 4 Stubbs MA, Clark VL, McDonald VM. Living well with severe asthma. *Breathe (Sheff)* 2019; 15: e40–e49.
- 5 Ainsworth B, Chatburn E, Bansal AT, *et al.* What bothers severe asthma patients most? A paired patient–clinician study across seven European countries. *ERJ Open Res* 2023; 9: 00717–2022.
- 6 Chapman KR, An L, Bosnic-Anticevich S, *et al.* Asthma patients' and physicians' perspectives on the burden and management of asthma. *Respir Med* 2021; 186: 106524.
- 7 Crespo-Lessmann A, Plaza V, González-Barcala FJ, *et al.* Concordance of opinions between patients and physicians and their relationship with symptomatic control and future risk in patients with moderate-severe asthma. *BMJ Open Respir Res* 2017; 4: e000189.
- 8 González Barcala FJ, de la Fuente-Cid R, Alvarez-Gil R, *et al.* Factors associated with asthma control in primary care patients: the CHAS study. *Arch Bronconeumol* 2010; 46: 358–363.
- 9 Osman LM, Abdalla MI, Beattie JA, *et al.* Reducing hospital admission through computer supported education for asthma patients. Grampian Asthma Study of Integrated Care (GRASSIC). *BMJ* 1994; 308: 568–571.
- 10 Liljas B, Lahdensuo A. Is asthma self-management cost-effective? *Patient Educ Couns* 1997; 32: Suppl., S97–S104.
- 11 Ahmad S, Ismail AI, Zim MAM, *et al.* Assessment of self-stigma, self-esteem, and asthma control: a preliminary cross-sectional study among adult asthmatic patients in Selangor, Malaysia. *Front Public Health* 2019; 7: 420.
- 12 Calvert M, Kyte D, Mercieca-Bebber R, *et al.* Guidelines for inclusion of patient-reported outcomes in clinical trial protocols: the SPIRIT-PRO extension. *JAMA* 2018; 319: 483–494.
- 13 Kyte D, Anderson N, Auti R, *et al.* Development of an electronic patient-reported outcome measure (ePROM) system to aid the management of patients with advanced chronic kidney disease. *J Patient Rep Outcomes* 2020; 4: 55.
- 14 Holmes J, O'Neill V, McGarvey LP, *et al.* Adverse perception of cough in patients with severe asthma: a discrete choice experiment. *ERJ Open Res* 2023; 9: 00442–2022.