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

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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>

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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

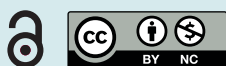
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Significant changes have occurred in the management and treatment of asthma over recent decades. From using anticholinergic alkaloids as first-line treatment to developing adrenergic-based bronchodilators and emerging targeted biologics, advancements 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



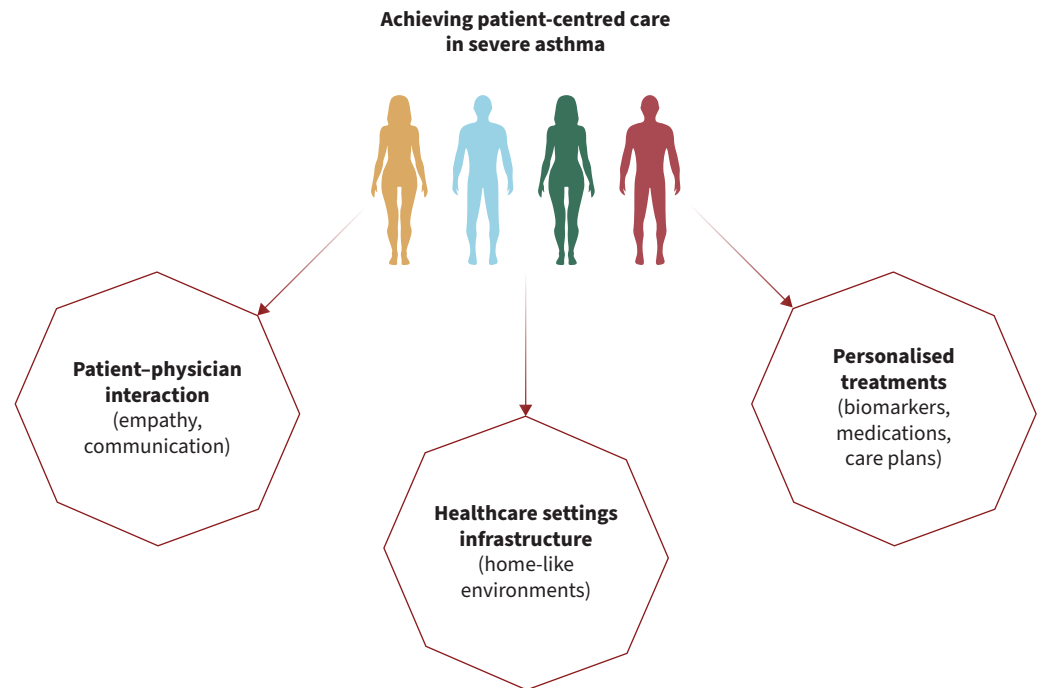


FIGURE 1 How patient-centred care is realised across providers (*i.e.* physicians), healthcare settings and biomedical research (*i.e.* precision medicine). Patient-centred care models focus on trusted patient–physician interactions. In addition, in patient-centred care models, hospital setting infrastructure 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.

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