

"Everybody's Got Asthma" – When Misunderstanding and Public Opinion Become Obstacles to the Care of Patients with Severe Asthma



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Asthma is a heterogeneous condition characterized by airway inflammation that can affect people of all ages. More than 300 million individuals worldwide are estimated to have asthma, and prevalence is projected to increase further.¹ Although asthma is considered a common chronic disease, individuals with severe asthma make up approximately 3% to 10% of patients with asthma and should be considered a special and distinct population of patients who are particularly vulnerable to their disease.² Severe asthma is defined by poor symptom control and ongoing exacerbations despite high medication doses and management of contributory factors, and these patients suffer a disproportionate share of asthma morbidity.³ Recent qualitative evaluation of patients suffering from severe asthma suggest that an overt misunderstanding of disease severity and risk by the patient, the public, and even health care providers creates an undue burden and hindrance in care for the patient living with severe asthma. Although qualitative information about patients can be difficult to obtain, study, and quantify, pervasive themes are becoming clear in the rare literature that currently exists on this important topic, and may be integral in achieving improved success in the care of this challenging illness.

In this issue, Apps et al⁴ qualitatively explored patient perceptions of living with severe asthma and their experience of managing severe asthma by interviewing 29 patients recruited from a specialist Difficult Asthma Service. The authors identified 4 major themes: understanding of severe asthma, emotional impact of living with asthma, public perceptions of asthma, and concerns about medications. Although some of these themes echo previous similar studies on this topic, there are some very

interesting points highlighted in the methodology and results of this research by Apps et al.

First, patients in the Apps et al study noted challenges in understanding the seriousness of the disease, with one respondent describing how "I definitely didn't think asthma could kill people. I mean that's ridiculous." The undercurrent of perceptions that are portrayed by the media and by health care providers, that asthma is easily managed by being responsible and taking appropriate medications, is distilled into patient perceptions and they find themselves shocked by the realization that their condition can in fact be life-threatening. Living with this reality and finding oneself against the tide of general understanding of the disease, patients struggle with a sense of living "alone with asthma" and are burdened with the process of requiring high levels of treatment to simply function, resulting in isolation and at times even more serious mental illness, such as depression. Foster et al⁵ describe this burden of isolation and the worry that other people thought they were exaggerating their symptoms or hospitalizations, with consequent impact on livelihood, earning potential, and personal relationships.⁵ Ironically, the public perception of asthma as generally mild and controllable (which is true for most people with asthma) has been achieved only after many years of painstaking efforts to improve treatment and remove stigma. This contrasts with the 1960s-1970s (before inhaled corticosteroids), when asthma was such a terrible disease that patients were unwilling to admit to having asthma because of the impact on their employability and relationships.

A second important featured discussion in the Apps et al study is the emotional impact of living with severe asthma as a common theme of patient perceptions. A notable undertone was the repetition of concerns of fear or anxiety in completing tasks of daily living. Many patients referred to limitations in activity and choosing to refrain from any activity where their symptoms might present a problem because of statements like, "I'm too scared." In a systematic review of patient experience in living with severe asthma by Eassey et al,⁶ panic and fear are notable concerns for many patients with severe asthma. A subtext that Apps et al present is the distinct fear of hospitalization due to asthma exacerbations, with many patients stating "I hate hospitals."⁴ Multiple prior qualitative evaluations of the patient experience with severe asthma demonstrate that the patient relationship with health care providers is crucial and can have positive and negative impacts on the patient's life and disease process.⁵⁻⁸ A qualitative study by Eassey et al⁷ focusing on patient autonomy in severe asthma highlights the extreme importance of effective health care interactions for patients living with severe asthma. Many patients

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Conflicts of interest: H. Reddel declares that she or her research institute has received honoraria for providing independent medical advice at advisory boards/steering committees/data safety board for AstraZeneca, Boehringer Ingelheim, GlaxoSmithKline, Merck, Novartis, and Sanofi-Genzyme; for consulting for AstraZeneca and GlaxoSmithKline; and for providing independent medical education at symposia funded by AstraZeneca, Boehringer Ingelheim, GlaxoSmithKline, Mundipharma, Novartis, and Teva; her institute has received unrestricted research grants from AstraZeneca Australia, GlaxoSmithKline Australia, and Novartis Australia. S.P. DaVeiga declares no relevant conflicts of interest.

Received for publication June 7, 2019; accepted for publication June 9, 2019.

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J Allergy Clin Immunol Pract 2019;7:2622-3.
2213-2198

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<https://doi.org/10.1016/j.jaip.2019.06.002>

discuss haunting themes of “not being in control of your body, not being able to breathe” and the fear of ultimate loss of personal control and choice. One patient even described a provider suggesting she go into residential care due to her asthma and felt that her perspectives were not considered in her care.⁷ Sally Wenzel included 2 of her patients, Sheila Brillhart and Kristin Nowack, as coauthors in a 2017 editorial describing severe asthma as an “invisible disease.”⁸ This inclusion of the patient perspective is absolutely essential given the damage that has developed over time because, as Wenzel et al state, “by their recipe-like approach, the practitioner can easily believe that every patient will respond as long as they follow the recipe.”

Another important theme in the interviews by Apps et al is patient concerns about the adverse effects of their medications, particularly oral corticosteroids.⁴ These concerns, also emphasized in the study by Foster et al,⁵ are a reality for patients that needs to be taken very seriously by providers. Better guidelines are needed for screening for and managing potential corticosteroid side effects.⁹ Furthermore, in the age of access to biologic therapies, patients with severe asthma should be referred as early as possible to specialists who can prescribe and monitor these agents because they not only reduce exacerbations, but several have also been distinctly steroid sparing.¹⁰

Finally, an extremely important finding in the Apps et al study is that minority patients were underrepresented in the interviews. The authors state that even with efforts made to address this emerging issue, ethnic minority representation remained at only 3% in the study, compared with 18% in the clinic population. This may reflect the overall experience of minority patients with the health care system. The importance of underrepresentation of minority populations in a study such as this cannot be overstated. To date, blacks continue to have disproportionately high health care utilization and death rates from asthma compared with whites, and previous qualitative studies on living with severe asthma lack insight into this population as well.^{6,11}

In conclusion, the findings by Apps et al substantiate some of the previous qualitative work completed in evaluation of the

patient experience of severe asthma and provide some new insights. Wenzel et al,⁸ in their 2017 editorial, advocated for new terminology around severe asthma, and their sentiment resonates with us as well. Perhaps it is time for new terminology and understanding, including, as has been achieved with public messaging about depression, that “There are different types of asthma.” Severe asthma is not simply “slightly worse” asthma, and to present it in this way does a disservice to the patients who need our most vigilant care.

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