



An invisible disease: severe asthma is more than just “bad asthma”

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Severe asthma inflicts a tremendous burden on patients with this disease, which is often invisible to others <http://ow.ly/RpGk30cTjIF>

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Severe asthma, although a small portion of all asthma, still impacts millions of patients worldwide. It drives more morbidity, mortality and costs than milder asthma [1, 2]. However, its human toll is much less appreciated. In their timely, moving article, FOSTER *et al.* [3] describe the enormous impact of severe asthma on patient's lives [4]. Interviewing 25 severe asthmatic patients, the authors identified four common themes, including those related to personal interactions, medications, isolation and adaptation of their life. The quotes are simple and pointed. For many reasons, much of this patient perspective has not been appreciated by healthcare providers, the general public, and even by close family members and associates. Thus, this report, detailing the burden that severe asthmatics bear every day, begins to make “visible” a disease that has until now been mostly “invisible”.

As a physician and researcher of severe asthma for over 20 years, many similar and sometimes different stories have emerged. This editorial incorporates these years of impressions, as well as direct input from two patients I have known for over 10 years, S. Brillhart and K. Nowack, two accomplished women, among many, with very severe asthma. Our conversations regarding the extraordinary burden of this disease have contributed to many points incorporated here. These conversations identify a consistent theme, introduced by the article by FOSTER *et al.* [3], and focused around invisibility, the perceived embarrassment and isolation associated with this horrific disease, and the sometimes extraordinary means by which patients will “cover it up”. Other than perhaps mental health disorders, I know of no other “medical” disease in which patients are so reluctant to admit to having their disease. The reasons for this are legion but include biases from: 1) healthcare providers, 2) media and 3) trickle-down biases of the general public.

Biases of healthcare providers

National and international guidelines have had a meaningful impact on asthma care worldwide and almost certainly have contributed to a substantial reduction in asthma deaths. However, by their recipe-like approach, the practitioner can easily believe that every patient will respond as long as they follow the recipe. Until recently, guidelines generally focused on a “one size fits all” approach without recognition of disease heterogeneity and its implications for treatment. Adherence is often pointed to as one of the biggest issues in severe asthma. In some cases it is, but it is becoming increasingly clear that inhaled corticosteroids, with or without a second controller, may not be effective treatments for all patients, with

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adherence having little to do with ongoing severity. Furthermore, “asthma” is one of the most common chronic diseases seen in general practice. This breeds familiarity with the disease and a presumption that the pathobiology of the majority reflects the pathobiology of all. Finally, whether it is residual from a bygone era or diagnostic confusion, healthcare providers can project a nonexistent psychological underpinning to poorly controlled and severe disease that patients often perceive. In fact, a common expressed theme is that the patients themselves are routinely and sometimes continuously “blamed” for their disease by healthcare providers; if they only took their medications more frequently, exercised more and ate better, they would “get better”. It is hard enough to be “sick” but being constantly blamed for the disease adds another twisted dimension.

Media biases

Given the high prevalence of asthma in the developed world, “asthma” is often depicted in film and television, and typically in an unflattering way. We are unaware of any inspiring story of a family that struggled with a child with asthma. In contrast, there are many depictions of anxious and nerdy “asthmatics”, who at the first sign of stress reach for their pacifier, *i.e.* their little blue/red puffer. A review of 66 movies in which an asthmatic character was portrayed found that inhaler use depicted as a stress response was seen in 66% of films, while the asthmatic patient was considered weak or nerdy in 17% [5]. Even the huge success that is *The Big Bang Theory* depicts the inhaler as a pacifier for one of the principal character’s (Leonard) stress response. An asthmatic, even more a severe asthmatic, views these scenes with horror. Thus, a severe asthmatic, whose use of a rescue inhaler is likely substantially more (and more necessary) than that of a milder patient, is going to “adapt” to their disease at an early age by hiding it, never using their rescue inhaler “in public” and thereby never publically admitting how substantially the disease has impacted them.

Trickle-down biases

On a day-to-day basis, the general public (even friends and family) are barraged by messages that asthma is easily controlled, psychological or just “allergies”. In the USA, direct-to-consumer advertising tells patients that if they are prescribed the latest and greatest inhaler, they can live a perfectly normal life. Thus, many nonasthmatics think of asthma as an inconsequential nuisance disease, with no possible perception that asthma could be life changing and life threatening. Any complaining means the patients are whiners or not taking care of themselves, and they just need to try a different inhaler.

These biases have almost certainly contributed to patients “turning inward” or, in their words, becoming invisible or even worse, blaming themselves for their disease. Severe asthma, unlike cancer, heart disease or loss of limb, becomes a disease that no patient wants to talk about or admit to, even among family. Interestingly, until recently, there were no organisations/foundations dedicated specifically to advocating publically for severe asthma, typically because the patients themselves didn’t want anyone to know there was even a problem.

This invisibility and introversion has largely prevented the world from any appreciation of the human toll of severe asthma. We, as healthcare providers, have an opportunity, maybe even a duty, to help them tell their stories, which are often both painful and inspiring. Battling extraordinary odds, both S. Brillhart and K. Nowack have been highly successful, with S. Brillhart being a highly regarded executive chef and K. Nowack obtaining a doctorate in nursing, but both of their careers have been hugely limited by the severity of their illness, need for hospitalisations and high doses of corticosteroids. Their struggles are genuine and legitimate; their fears are real. Both frequently have dreams of ventilators, suffocation and death. Both K. Nowack and S. Brillhart share that people often rush to judgment about their disease. Their “hidden and long-term disability” can lead to being labelled (and shunned) as unreliable, lazy, frail, dishonest or just plain unhealthy. After a short time, personal and professional associates see more liability than asset, fostering internal insecurities that “maybe the outside world is right”. This hidden “disability” leads to prejudices that assume they are “using” their disease to get special treatment, rather than being validated for the greater efforts they put forth to accomplish the tasks at hand. They further worry about the time and effort it takes to deal with an all-consuming illness at the expense of their job and personal life, typically beginning at an early age. They feel enormous embarrassment when colleagues, friends and families utter the dreaded line “you’re sick again?”, presuming again, that it is somehow their fault, so they hide some more. Finally, given the stereotypes described earlier, they feel awkward using their inhaler in public, and not being able to keep up physically in childhood and young adulthood, leading to more frustration and anger, and even more hiding. They would rather put on a mask of “normalcy” than admit to having this poorly understood, debilitating and, as long as they can manage the charade, invisible disease.

Finally, and importantly, long-term systemic corticosteroid use may be worse than the disease itself. These drugs negatively impact sleep and physical appearance, while many experience terrorising psychological reactions further impacting personal relationships and jobs. They are the ultimate Janus, providing lifesaving therapy (and even normalcy) but with terrible side-effects. Thus, the treatment itself further isolates these patients.

Medically and pathologically, it is becoming increasingly clear that severe asthma is a different disease, or diseases, than anything experienced by milder asthma patients [6]. It appears rare for mild asthma to “progress” to severe asthma; they are distinct diseases. Cohorts are increasingly identifying sustained T2 inflammation (despite treatment), co-mingling of other immune processes (granulomas/autoimmune disease) and occasional profound responses to type-2-targeted biologic therapies (on top of high-dose corticosteroids) [7–9]. These findings make it clear that the pathobiology of severe asthma (or asthmas) is not the same as in milder asthma. Unfortunately, for the millions of patients who suffer with severe asthma, it remains categorised as nothing more than a “slightly worse” form of an otherwise eminently treatable disease. It is as though pneumonia is an “infection” in the same way a viral upper respiratory tract infection (URI) is an “infection”. They both are true but the world appreciates that pneumonia is much more severe than a URI. As the term “asthma” has been challenged, it is now time to challenge the term “severe asthma” in order to remove the stigma that these patients suffer by being categorised with the rest of asthma, which contributes to their suffering alone and in silence, rather than being openly supported by an understanding world [10]. New terminology is never easy but professional and patient organisations could work together, perhaps along with the current European Respiratory Society/American Thoracic Society task force and severe asthma networks, to develop terms that highlight the specific biology and separate severe from milder asthma. It is likely patients burdened with this horrible life-changing disease will be both gratified and liberated.

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