



A Renewed Charter: Key Principles to Improve Patient Care in Severe Asthma

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ABSTRACT

Asthma is a heterogenous respiratory disease, usually associated with chronic airway inflammation and hyper-responsiveness, which affects an estimated 339 million people worldwide. Severe asthma affects approximately 5–10% of patients with asthma, approximately 17–34

million people globally, more than half of whom have uncontrolled disease. Severe asthma carries a substantial burden of disease, including unpredictable symptoms and potentially life-threatening flare-ups. Furthermore, severe asthma has a substantial burden on health care systems and economies worldwide. In 2018, a group of experts from the clinical

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community, patient support groups, and professional organisations joined together to develop the Severe Asthma Patient Charter, which set out six principles to define what patients should expect for the management of their severe asthma and what should constitute a basic standard of care. Since the publication of that original Charter in 2018, several important changes have occurred, including an improved understanding of asthma and effective asthma management; several new therapies have become available; and finally, the COVID-19 pandemic has placed a spotlight on respiratory conditions, the workforces that treat them, and the fundamental importance of health care system resilience. With those developments in mind, we, representatives of the academic, clinical, and patient advocacy group communities, have updated the Charter to Improve Patient Care in Severe Asthma with a focus on six principles: (1) I deserve a timely, comprehensive assessment of my asthma and its severity; (2) I deserve a timely, straightforward referral to an appropriate specialist for my asthma when it is not well controlled; (3) I deserve to understand what makes my asthma worse; (4) I deserve access to treatment and care that reduces the impact of asthma on my daily life; (5) I deserve not to be reliant on systemic corticosteroids; (6) I deserve to be involved in decisions about my treatment and care.

Keywords: Health care; Patient advocacy; Severe asthma

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Key Summary Points

Severe asthma carries a substantial burden of disease, including unpredictable symptoms and potentially life-threatening flare-ups.

In 2018, a group of experts joined together to develop the Severe Asthma Patient Charter, which set out six principles to define what patients should expect for the management of their severe asthma and what should constitute a basic standard of care.

Since 2018, we have gained a better understanding of asthma and effective asthma management, new therapies have become available, and the COVID-19 pandemic has placed a spotlight on respiratory conditions and the fundamental importance of health care system resilience.

As such, we have developed an updated Charter to Improve Patient Care in Severe Asthma with a focus on six principles.

Patients deserve (1) a timely, comprehensive assessment of their asthma and its severity; (2) a timely, straightforward referral to an appropriate specialist for their asthma when it is not well controlled; (3) to understand what makes their asthma worse; (4) access to treatment and care that reduces the impact of asthma on their daily life; (5) not to be reliant on systemic corticosteroids; and (6) to be involved in decisions about their treatment and care.

INTRODUCTION

Worldwide, asthma affects an estimated 339 million people, making it one of the world's most common chronic diseases [12]. Furthermore, the prevalence of asthma is increasing in

many countries, especially among children [13]. Asthma is a common heterogenous respiratory disease, usually associated with chronic airway inflammation and hyper-responsiveness. Patients with asthma experience respiratory symptoms such as wheezing, shortness of breath, chest tightness, and cough, and these symptoms vary over time and in intensity [11]. Although some countries have seen a decline in hospitalisations and deaths from asthma, it remains a significant public health issue across all countries, regardless of development level and despite the availability of safe and effective treatments [14]. In 2019, 455,000 asthma-related deaths were reported worldwide, which was a 32% increase from 2010 [15–18]. Indeed, evidence suggests many of the asthma-related deaths that occur each year could be prevented with improved patient management, improved implementation of existing best practice recommendations, and increased access to secondary care [14, 18, 19]. It should be noted that the meaning of the term “specialist care” varies between countries and can refer to secondary or tertiary care; in this Charter, we have used the term secondary care to describe care provided by a severe asthma specialist following a referral.

The clinical presentation and severity of asthma can vary widely, including differences in underlying disease processes, types and intensities of symptoms, and differential responses to treatments, among others [20]. Severe asthma affects 5–10% of patients with asthma, representing approximately 17–34 million people globally; furthermore, estimates suggest more than half of those patients also have uncontrolled disease [17, 21–24]. Severe asthma carries a high burden of disease, including symptoms that interfere with day-to-day life, flare-ups that are unpredictable and sometimes life-threatening, and medication side effects that can be associated with substantial short- and long-term adverse effects [11, 25]. Furthermore, severe asthma often interferes with family, social, and working life and can have substantial impacts on a person’s mental health; indeed, everyday life activities can be a challenge and may be overshadowed by a daily struggle to breathe, as well as the risk of

hospital admission, a need for intensive care, and death [26–28].

In many cases, even when treatment for severe asthma has been adequately optimised, medicines are taken appropriately, and other potential causes of symptoms have been ruled out, symptoms do not improve with the usual standard of care (i.e. inhaled corticosteroids [ICS] with or without long-acting β -agonists [LABA]) [18, 21, 29, 30]. In addition to the high patient burden, severe asthma is also associated with a substantial burden on health care systems and economies all around the world [26, 31–33]. Estimates suggest that severe asthma accounts for approximately 60% of all asthma-related costs in some countries, with higher per-patient costs than for a patient with type 2 diabetes or a stroke [34, 35]. Unscheduled health care resource utilisation, as with emergency appointments, hospitalisation, and intensive care, places a particular strain on respiratory care capacity [36].

In addition to health care system and economic burdens, poorly controlled asthma and severe asthma are also associated with substantial environmental impacts. Metered dose inhalers (MDIs) containing hydrofluoroalkanes (HFAs) were introduced in the 1990s to replace MDIs with ozone-depleting chlorofluorocarbon propellants; however, HFAs are greenhouse gasses that contribute to global warming [37]. Some estimates suggest that HFAs contain nearly 300 times the carbon dioxide equivalent per therapeutic equivalent of a comparable dry-powder inhaler (DPI) [38]. Indeed, a recent study found that switching from HFA-containing MDIs to DPI in the UK alone would result in substantial carbon savings [39]. In addition to the carbon footprint of short-acting β -agonist (SABA) overuse and greenhouse gas-containing MDIs, asthma exacerbations are also a substantial source of greenhouse gas emissions, especially in severe asthma [40]. For example, a 2022 study found that while severe and life-threatening exacerbations accounted for just 2% of the total exacerbations in UK adults, they produced a carbon footprint that was more than 1.5 times greater than the carbon footprint of mild and moderate exacerbations combined [40].

The updated American Thoracic Society (ATS)/European Respiratory Society (ERS) 2020 joint guidelines are the most recent clinical guidelines for the diagnosis and management of severe asthma [41]. However, the extent to which guidelines are followed can vary between countries [42]. For instance, Cloutier et al. (2018) found that adherence to guideline recommendations was low amongst both asthma specialists and primary care clinicians for key recommendations, such as written asthma action plans and repeat assessment of inhaler techniques [43]. The ERS and the European Academy of Allergy and Clinical Immunology (EAACI) (2021) have also stated their concern that adherence to guidelines is varied and sub-optimal [44].

The Severe Asthma Patient Charter was first developed in 2018 by a group of representatives from the clinical community, patient support groups, and professional organisations [18]. The Charter set out six principles, which defined what patients should expect for the management of their severe asthma and what should constitute a basic standard of care. Since the publication of that original Charter in 2018, several important changes have occurred. Firstly, understanding of asthma management has continued to improve, with several new therapies deemed effective for the treatment of some types of severe asthma now approved for use. Nevertheless, there remains considerable variation in access to best practice treatment and care, resulting in significant unmet needs for many patients [11]. This may be the case for the approximately 60% of patients with severe asthma who have multiple overlapping endotypes causing inflammation, leaving them underserved or unserved by currently available treatments [45].

Secondly, the COVID-19 pandemic has placed a spotlight on respiratory conditions and the workforces that treat them. Whilst evidence suggests that people with asthma are not at an increased risk of acquiring COVID-19 or at increased risk of COVID-19-related death overall, studies have highlighted an increased risk of COVID-19 death for patients utilising systemic oral corticosteroids (OCS) for the treatment of their asthma—OCS are often used to treat

asthma, and when used frequently or continuously, they are also an indicator of uncontrolled asthma [46–48].

The COVID-19 pandemic has also presented significant challenges in the delivery of health care. Alongside services for other non-communicable diseases, asthma services were disrupted, with patients reporting changes to treatment, the cancellation of routine check-ups, and increased use of telemedicine. This demonstrates the need for new approaches for patients to deliver care that can control their respiratory disease more effectively, reduce the reliance and burden on hospitals, and ultimately decrease pressure on health systems [28]. The pandemic has drawn attention to the importance of health care system resilience. In order to decrease pressure on health care systems, new approaches to the management of patients with severe asthma must be considered. Delivering improvements can relieve the care backlog caused by COVID-19, lessen the future burden of disease, and ultimately unlock more flexible and effective models of care that can withstand the pressures of future shocks.

Considering these developments, we, representatives of the academic and clinical communities, patient support groups, professional organisations, and the industry, have updated the Charter to Improve Patient Care in Severe Asthma, which is in line with the latest science and best practice understanding from existing severe asthma care services, to define the realistic and achievable standard of care patients with severe asthma deserve to receive [18]. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

PRINCIPLE 1: I DESERVE A TIMELY, COMPREHENSIVE ASSESSMENT OF MY ASTHMA AND ITS SEVERITY

An accurate diagnosis is the foundation of effective asthma care, and an initial diagnosis usually occurs in primary care, based on objective testing over time [11, 49]. Asthma severity is not a static feature and may change over

months or years and is assessed retrospectively on the basis of the level of treatment required to control symptoms and exacerbations. Additionally, an initial diagnosis may not consider comorbidities, which could influence the management approach needed to control a patient's asthma [18]. Recommendations from the Global Initiative for Asthma (GINA) suggest that patients with asthma should be reviewed regularly, ideally 1–3 months after starting treatment and then every 3–12 months thereafter [1].

The long-term goals of asthma management are to achieve good symptom control and to minimise future risk of asthma-related mortality, exacerbations, persistent airflow limitations, and side effects of treatment [50]. As a result, patients presenting with symptoms of uncontrolled asthma, in either a primary care or emergency room setting, should be referred for assessment by a specialist to ensure that their symptoms do not remain uncontrolled because of factors other than severe disease, such as treatment [7, 44, 49, 51]. It should first be determined if patients are taking their prescribed medication properly with a good inhaler technique. There is useful guidance for primary care, with acronyms like SIMPLES (Smoking status, Inhaler technique, Monitoring, Pharmacotherapy, Lifestyle, Education, Support) to check all factors that can contribute to impaired

asthma control [52, 53]. The presence of uncontrolled comorbid conditions, which may reduce the effectiveness of asthma medications (e.g. obesity, gastroesophageal reflux disease, and chronic rhinosinusitis) should also be investigated, and modifiable risk factors and triggers (including smoking and environmental and allergen exposures) should be considered [11]. Both patients and health care professionals must have access to a simple, understandable set of criteria for identifying severe asthma based on best practice guidance, such as the recommendations from the ATS/ERS and GINA [11, 41]. However, the guidance does not always include timelines, and there is a general lack of agreement on what is considered acceptable timings within the diagnostic and referral pathway [42, 54].

Measures to improve the accuracy of diagnosis for patients with mild and moderate asthma with persistent symptoms caused by poor medication adherence or triggers other than asthma would also help to ensure the appropriate use of secondary care. In other conditions, such as rheumatoid arthritis and cancer, there are clear referral pathways and established waiting time targets to ensure rapid diagnosis [55, 56]. Establishing similar targets and clear referral pathways for patients with asthma would help patients receive an accurate, early diagnosis and appropriate treatment [7, 51].

Good practice: Referral initiatives

Even with clear referral pathways, challenges still exist in clinical assessments of asthma control due to, for example, lack of awareness of symptoms or of appropriate trigger points for referral. In the UK and the Netherlands, new tools—known as ReferID⁺ and Asthma Optimiser, respectively—are being used, such as screener questionnaires and electronic alerts, which are useful in identifying patients who could benefit from specialist review. These tools can help health care professionals to assess a patient's level of control in an appointment, based on guidance in their country. Tools such as ReferID also provide up-to-date global clinical guidance so that clinicians can make more effective decisions about treatment and care settings [7].

PRINCIPLE 2: I DESERVE A TIMELY, STRAIGHTFORWARD REFERRAL TO AN APPROPRIATE SPECIALIST FOR MY ASTHMA WHEN IT IS NOT WELL CONTROLLED

Internationally recognised recommendations for asthma management state that severe asthma is a complex condition that requires input from experts to confirm the diagnosis and achieve adequate control [1]. It is important that health care professionals communicate clearly to patients what is meant by the word “severe” and follow the appropriate assessment and referral criteria as set out in best practice guidelines. According to recommendations from GINA (2021), severe asthma is asthma that remains “uncontrolled” despite optimised treatment with high-dose ICS-LABA or that requires high-dose ICS-LABA to prevent it from becoming “uncontrolled” [21]. In general, patients experiencing any of the following should be referred to an available expert respiratory physician: oral corticosteroids use for more than 3 months, two or more rounds of OCS treatment in the past 12 months, hospitalisation for asthma in the past 12 months, or impaired lung function despite optimised standard therapy. It is recommended that a diagnosis of severe asthma should be completed by a specialist multidisciplinary team (MDT) with access to the appropriate resources.

However, variability in the clinical consensus on when to refer patients with suspected severe asthma persists, and as such, people with severe asthma often experience several asthma attacks (also known as exacerbations) and admission to emergency departments before they are referred to secondary care [42]. Asthma treatment often has a short-term focus, with priority given to managing exacerbations through, for instance, OCS, rather than treating the underlying cause of the disease and optimising care to prevent further exacerbations [57]. Some patients spend many years experimenting with different treatments and, thus, may continue to suffer from underlying disease progression as well as debilitating adverse effects of treatment before being referred to a respiratory specialist [49, 58]. As such, delaying access to specialist care could lead to permanent loss of lung function and damage from OCS exposure, even after optimal management of severe asthma is achieved [29, 59]. There are significant variations both within and between countries.

Studies have shown that managing patients with asthma in secondary care reduces the risk of being hospitalised for an asthma attack compared with patients managed by a non-specialist [49]. Improving data collection and reporting across all dimensions of severe asthma care is essential to ensure appropriate interventions are designed and implemented to reduce avoidable morbidity and mortality and improve the quality of care.

Good practice: Referral criteria

Education on referral criteria would facilitate rapid referrals, and in countries such as Canada, systems are already in place to automate this process. For instance, introducing “red flags” in systems—which alert clinicians if a person has had multiple courses of OCS over a set period of time—can facilitate a referral to secondary care in accordance with national guidance. Other countries, such as the UK, have created capacity within secondary care to aid quicker referrals by utilising a multi-disciplinary workforce, supported by specialist nurses, to make initial assessments of patients for biologic treatments.

PRINCIPLE 3: I DESERVE TO UNDERSTAND WHAT MAKES MY ASTHMA WORSE

Asthma and its severity are complex, heterogeneous, and change over time. Symptoms, airway inflammation, and airway limitations vary over time and in intensity, and these variations can be triggered by many different factors, including exercise, exposure to allergens and irritants, changes in the weather, and exposure to viral respiratory infections, as well as comorbidities [50].

Asthma is a heterogeneous condition, with different underlying disease processes and recognisable clusters of demographics and clinical and pathophysiological characteristics, including asthma endotypes (distinct mechanistic pathways) and phenotypes (clinical presentations) [60]. The heterogeneity of severe asthma makes management of the disease highly challenging. Up to 60% of patients have multiple drivers of inflammation (such as allergic status and elevated eosinophils), and patients' phenotypes can vary in presentation over time, depending on exposure to triggers [61]. In a study investigating phenotype

stability, around 50% of patients with severe asthma had a different biomarker profile after 1 year of follow-up, with changes potentially influenced by medication changes, adherence to treatment, exacerbations, and exposure to pollution and allergens [33, 62–65].

Supporting patients to understand triggers or modifiable risk factors that increase their risk of exacerbations (e.g. smoking, allergens, air pollution, and exercise) can equip them to manage their condition better and improve their treatment and care. Patients should receive relevant information from their health care professional in a simple and clear format to better understand the available treatment options and the consequences of different management approaches. Recent consensus has called for a “third era” of asthma management, which accounts for the increased recognition of asthma heterogeneity and offers precision management and targeted treatment based on a thorough assessment of the personal characteristics of a patient's disease, drivers, and triggers [66].

Case study: The Carabela project, Spain

The Carabela project, conducted in Spain, works to optimise patient pathways and care in severe asthma through the creation of specialised MDT units with a common framework that was adapted at local and regional levels.

By providing this model of care, health care professionals can appropriately assess and diagnose the pathology of severe asthma patients and treat them in accordance to achieving good control based on the type of asthma that they have. This approach has shortened the time it takes a patient to reach optimal asthma control.

A list of indicators of quality of care for patients with severe asthma care was developed to evaluate the implementation of the MDT joint working, best practice and potential areas for improvements identified, and initiatives proposed to move the project towards an “ideal” asthma unit, which is being rolled out across the country [3-5].

PRINCIPLE 4: I DESERVE ACCESS TO TREATMENT AND CARE THAT REDUCES THE IMPACT OF ASTHMA ON MY DAILY LIFE

Symptoms of severe asthma can affect relationships, careers, parenting, and social lives, sometimes even affecting patients' abilities to undertake the most basic daily tasks [67]. Patients with severe asthma also have more frequent life-threatening asthma attacks, resulting in hospital admission and potentially death [28]. Furthermore, the adverse effects associated with treatments to manage and

prevent such asthma attacks (including OCS, on which patients can become dependent) can also represent a significant burden for people with severe asthma [68]. The goal of asthma management is to achieve disease control and minimise future risk of asthma-related exacerbations, mortality, and the side effects of treatment [18]. The definition of asthma control is based on symptom control and risk reduction—on the basis of the personalised management of a patient's modifiable risk factors for exacerbations, other adverse outcomes, and comorbidities, considering the patient's preferences and goals (Fig. 1) [1].

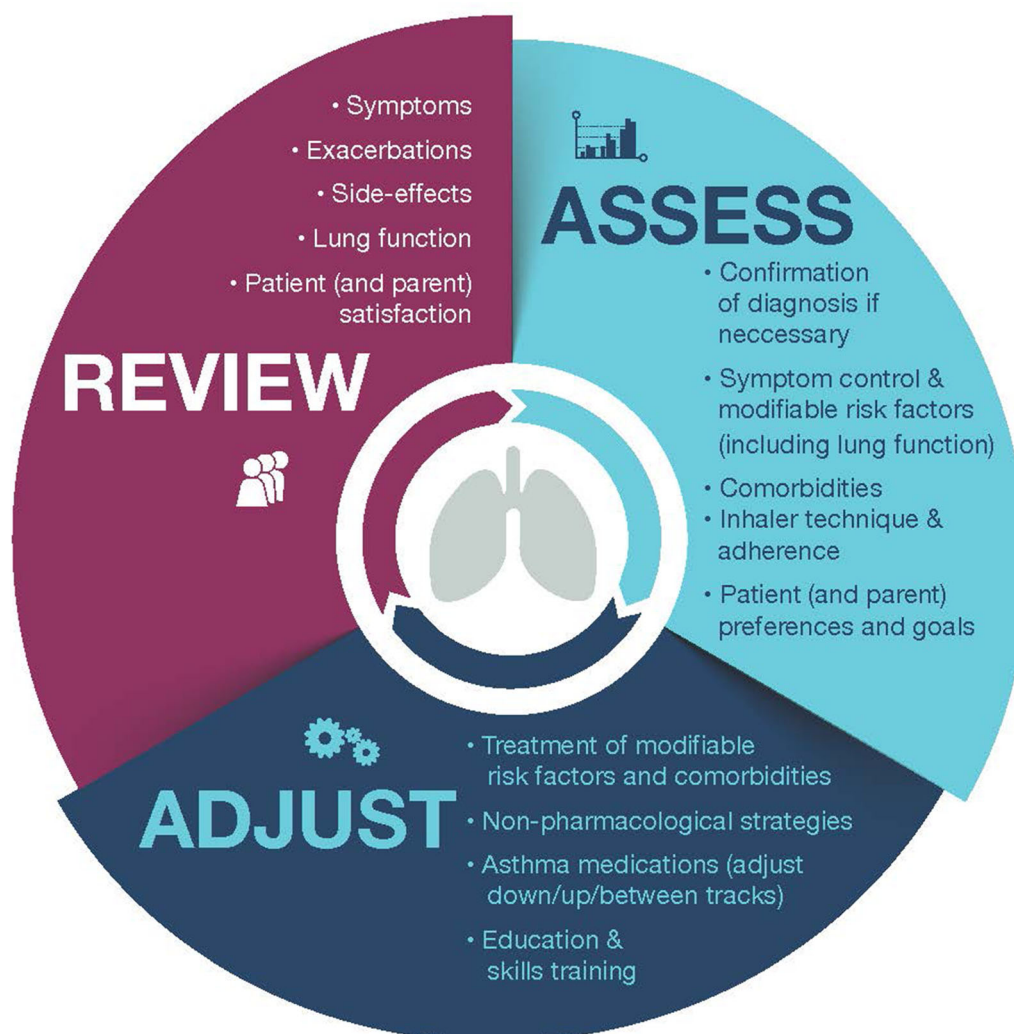


Fig. 1 The disease management cycle for asthma care (adapted from GINA 2021) [1]

The benefits of good asthma control include fewer missed work/school days, a reduced risk of asthma attacks, and reduced health care resource utilisation [69]. Patients with well-managed asthma also have a smaller carbon footprint through reduced SABA use and decreased health care resource utilisation [39, 40, 70]. People with asthma should be reviewed regularly to monitor their symptom control, risk factors, and occurrence of exacerbations, as well as to document the response to any treatment changes. Severe asthma requires input from a specialist team to confirm the diagnosis and determine the best treatment and management approach for individual patients. However, the availability and use of MDTs and specialist asthma nurses for severe asthma varies significantly both between and within countries [42]. Moreover, even after patients have access

Scientific advances have led to the advent of targeted therapies, such as biologics; however, both the availability and use of these therapies vary widely in practice, and there is a dearth of information on both the use and uptake of newer treatments [28, 42]. Indeed, more than 50% of patients with severe asthma have poorly controlled disease despite treatment [65]. Exacerbations leading to hospitalisation occur in between 12% and 27% of patients with severe asthma every year, representing a significant unmet need [23, 71, 72]; however, in comparison, 40–60% of patients who started on biologic therapy continue to experience at least one exacerbation per year [62–65]. There are also significant challenges in access to innovative treatments in low- and middle-income countries, where the cost of treatments, combined with limitations in the asthma management system, limit their widespread availability [73].

Case study: West Midlands Severe Asthma Network, UK

Future innovation of therapies such as biologics to tackle asthma will unlock access to treat more patients. However, without investment in specialist services and system capacity, these patients won't receive the standard of care they deserve.

A Severe Asthma Network has been commissioned in the West Midlands region of the UK, which uses a hub-and-spoke model to centralise and standardise the management of severe asthma [6]. University Hospitals Birmingham acts as the severe asthma centre hub, with several initiating spoke sites.

Severe asthma patients are triaged through MDT meetings and then referred to secondary care centres where optimal therapies can be prescribed. This approach reduces the pathway time from referral to treatment, as well as reducing a patient's travel time to access specialist services and targeted therapies. At a time when health systems look for ways to move care closer to home and away from providers facing a backlog from the pandemic, the West Midlands Severe Asthma Network supports the feasibility and capability of the hub-and-spoke model.

to secondary care, there is also variability in how many appointments they receive [44].

Although national guidelines for the treatment and care of asthma, and in some cases specifically for severe asthma, exist in some

countries, there is limited data infrastructure to assess the performance of health systems [36]. A set of core indicators, best practices, and standards for an improvement in severe asthma care is essential to monitor outcomes and facilitate research and cross-country learning. In order to promote the optimal implementation of best practices, existing global quality standards should be tailored to meet the local or regional requirements of health care systems.

As detailed in principle 1, other conditions such as rheumatoid arthritis and cancer have clear referral pathways and set waiting time targets to ensure rapid diagnosis and treatment. Establishing similar targets and clear referral pathways for patients with asthma would help patients receive an accurate, early diagnosis and appropriate treatment. For example, one of the core pillars of the Carabela project in Spain relates to the systematic measurement of validated indicators, enabling ongoing evaluation of the impact of implemented measures. The indicators were prepared jointly by clinicians, scientific societies, the Spanish Society of Health Directors (SEDISA), and the Spanish Society for Health care Quality (SECA) [3].

There is also a need to educate patients with severe asthma about how to recognise persistent symptoms and know to seek expert treatment to help improve their health-related quality of life. Frequent patient education on correct inhaler techniques is also important to ensure the optimal effect of prescribed treatments. Finally, shared decision-making should be a common practice between patients and their clinicians; this would help ensure that care focuses on limiting the impact of symptoms and the adverse effects of treatment on physical, mental, and emotional health [74]. Each patient will be different, so care should be personalised to address what matters most to them.

PRINCIPLE 5: I DESERVE NOT TO BE RELIANT ON SYSTEMIC CORTICOSTEROIDS

OCS continue to play a vital role in the management of acute asthma exacerbations and in those for whom alternatives are not available

[75]. In an emergency setting, OCS can be crucial and are rightly used to manage acute severe asthma. However, many patients can have treatment optimised to reduce the frequency of these acute severe episodes and result in overall OCS exposure [76]. Repeated use of OCS for recurrent exacerbations should therefore lead to a reassessment of adherence to asthma treatments, particularly baseline ICS therapy, or an adjustment of the ICS dose, as well as an investigation of alternative, OCS-sparing treatments. In some situations, however, there appears to be an acceptance of continuous use of OCS to control symptoms and exacerbations, even though there are often effective alternative treatments available to improve symptoms and exacerbations without the side effects associated with OCS [18, 28].

The significant adverse effects associated with cumulative OCS exposure (beginning at 0.5 g to less than 1 g per year) are well documented [76–78]. Global best practice recommendations now suggest avoiding the use of maintenance OCS if other options are available because of its serious side effects and note that it should be a “last resort” [1, 11]. Cumulative, long-term OCS use is associated with a greater risk of potentially debilitating adverse effects, including immunosuppression, weight gain, impaired glucose tolerance and type 2 diabetes, osteoporosis, glaucoma, skin atrophy, cardiovascular disease (arterial hypertension), pneumonia, and psychiatric disorders [79, 80]. Long-term use of OCS is also associated with increased mortality [81]. Some people also have trouble coping with the psychological effects of OCS, such as anxiety, irritability, depression, and bipolar disorders [82].

Despite the introduction of multiple biologic therapies, uptake remains variable [42]. In parallel, research suggests that 40–60% of people with severe asthma are on, or have experienced, continuous OCS treatment [83, 84]. Perceived costs may be a reason for this; the relatively cheap short-term cost of OCS compared with other medications could be a factor in continued prescribing.

Currently, evidence-based guidelines for OCS use, tapering, and associated comorbidity screening in asthma are lacking [85]. However,

the expert consensus has agreed that tapering should be attempted in all patients receiving maintenance OCS therapy, regardless of comorbidities, although the speed and rhythm of tapering should be individualised [77]. Long-term use is not appropriate in situations where other treatment options are available, but if no alternative treatment options are available, experts consider 5 mg/day or less to be an acceptable dose [77].

A comprehensive and concerted effort is necessary to tackle the issue of overreliance on OCS. As with worldwide efforts to reform the usage of antibiotics through antimicrobial stewardship, changing national and local policy will be crucial to ensure that maintenance OCS treatments become an option of last resort for people with asthma. We have already begun to see this in some countries; for instance, the Japan Asthma Society's Practical Guidelines for Asthma Management (2021) recommend that patients with severe asthma who have exacerbations and need short courses of systemic corticosteroids at least twice a year should be referred to a specialist and considered for biologic treatment [78].

PRINCIPLE 6: I DESERVE TO BE INVOLVED IN DECISIONS ABOUT MY TREATMENT AND CARE

Patients with severe asthma face a huge physical and emotional burden because of their debilitating symptoms (Fig. 2) [18]. Some patients spend many years experimenting with different treatments and suffering from associated debilitating adverse effects before being referred to a respiratory specialist [49, 58]. There are also variations between patients in the amount of time it takes to get to secondary care appointments, which on average include approximately 90 min of travel [42]. In addition to these burdens, many patients with severe asthma have multiple drivers of inflammation, meaning they face further unmet needs, even if treated in secondary care [86].

Four patient journey phases were identified from semi-structured in-depth interviews with a small sample of patients from the Netherlands diagnosed with severe asthma: “looking for a solution,” “recognition and hope,” “given up,” and “accepting the disease.” During this lengthy journey, severe asthma was reported to dominate patients' lives [87]. Additional insights

Takeaways from other asthma initiatives

There are also helpful learnings from initiatives aiming to reduce the reliance on other asthma treatments. For instance, over-reliance on SABA reliever inhalers is associated with poor asthma control and therefore an increased risk of severe exacerbations and mortality from asthma [1, 2]. A SABA-free asthma department was implemented in a hospital in Santa Fe, Argentina [9], and this model is now being expanded to further centres across the country [9]. This evidence-driven solution is supported by protocols like electronic alerts on patient records when SABA is prescribed for clinicians to assess a patient's level of control, and the role of over-the-counter SABA prescribing is also being addressed in collaboration with pharmacists [9-11]. This case presents the importance of engaging the variety of health care professionals that work with patients to improve outcomes, as well as having appropriate alerts to flag uncontrolled asthma.

from a survey of patients with severe asthma reported that one-third of the people surveyed were hospitalised at least once over a 12-month period as a result of their severe asthma [42]. It was also reported that, because of the COVID-19 pandemic, patients with severe asthma experienced cancellations to follow-up care and spirometry [57].

Fig. 2 Patient perspective on severe asthma (adapted from Menzies-Gow et al. 2018) [18]

participate in decisions about their treatment and care and provided with an opportunity to express their concerns.

Case study: Vik Asthma as a digital tool

Telemedicine, which means patients are diagnosed and/or managed remotely, was implemented as a response to disruptions in access to health care (for example, those experienced during the COVID-19 pandemic), offering a potential model for ongoing monitoring of patients with all types of asthma. As people continue to seek health advice online, digital health tools can support patients to engage in the management of their disease. As an example, Vik Asthma, an artificial intelligence-powered chatbot, offers support and resources to empower those with asthma to feel informed and engaged in their care. The app provides curated asthma responses guided by AI to help people monitor their symptoms. This means that patients with asthma can have conversations with their doctor to, for instance, switch their medication, modify their doses or manage side effects, and therefore improve their care [8].

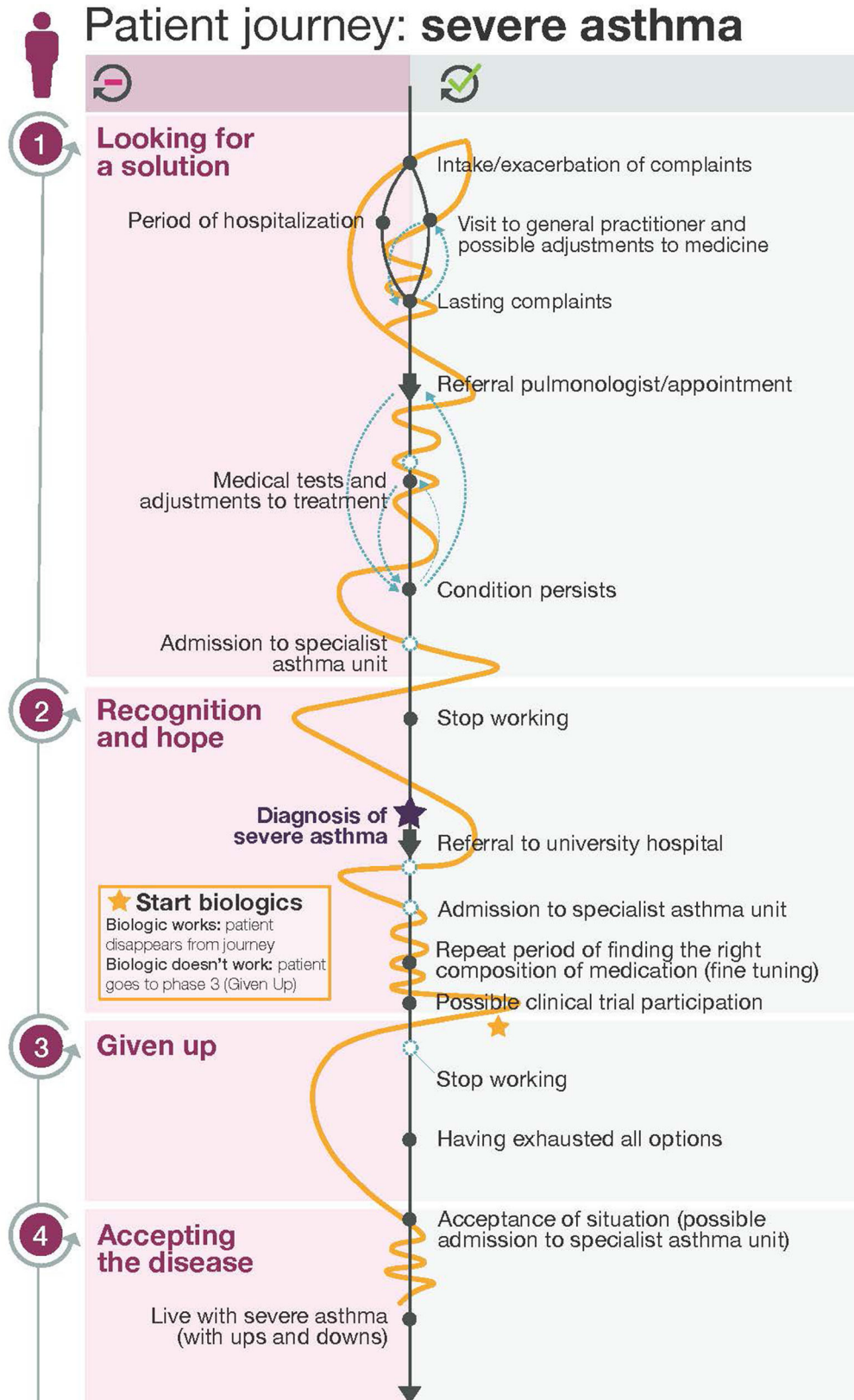
Improving the patient journey is key to improving health-related quality of life for patients with severe asthma. Prompt referral to secondary care is key to reducing hospitalisations and facilitating timely access to biologics [18, 49, 51]; referral can be facilitated by educating clinicians and people with severe asthma to recognise it as a distinct condition with specific symptoms and referral criteria.

People with severe asthma value improved health-related quality of life as an important outcome of treatment [88]. Shared decision-making between people with severe asthma and their clinicians is essential to minimise the impact of adverse effects of treatment on physical, mental, and emotional health and consequently maximise adherence. There is also emerging evidence that shared decision-making is associated with improved asthma outcomes [74, 89–91]. Patients should be encouraged to

There is substantial room for improvements in the accessibility and effective utilisation of educational materials to improve or boost health literacy, asthma management plans, and tools for both patients and physicians across the globe. Well-organised systems to support adequate communication between clinicians and health care professionals involved in severe asthma care are needed, as well as systems to accelerate/automate referral times and procedures.

DISCUSSION

Severe asthma places a significant and growing burden on health systems, the lives of patients, and economies worldwide. Despite existing treatment guidelines, the management of patients with severe asthma in practice all too



often fails to sufficiently achieve outlined goals. As such, there is a need to urgently review the current care provided for patients with asthma and raise expectations regarding diagnosis and treatment. Improvements in the quality of care for patients with asthma fall behind those achieved for other diseases. For example, a patient who experienced a heart attack would not be released from a hospital, without a plan for follow-up and treatment to prevent future events, after the initial attack had been treated. Yet, this is the experience of many patients hospitalised for an asthma attack, even though these patients are very likely to experience another attack that could be potentially fatal.

In the past 20 years, the introduction of biologics for the treatment of rheumatoid arthritis, along with improved care from an MDT, has transformed the experience of patients with this disease. Early diagnosis and effective treatment have resulted in a reduction in the number of hospitalisations required for the management of rheumatic disease, and steroid therapy is less commonly overused [92]. The same revolution is occurring in the treatment of patients with severe asthma, with biologic treatments that have demonstrated effectiveness in reducing future asthma attacks and improving the quality of life for people with severe asthma recently becoming available. However, to achieve these improvements, it is critical to ensure that patients with severe asthma who may benefit from these new treatments are identified and seen by specialists. Early diagnosis is particularly important to facilitate the prescribing of these biologics.

To implement these principles, we recommend the following: people with asthma should receive written asthma treatment action plans from their physician, with specific goals detailed, as a mandatory part of the care they receive; this is especially important for patients with severe asthma. This approach is prompted by patients requesting specific levels of care and is dependent on clinicians being given appropriate training to deliver these action plans and health care systems being able to provide this level of quality management.

Patients should also request that both their physicians and pharmacists provide or make

available training on effective inhaler techniques before they fill new prescriptions. This “double-check” can help avoid errors. In addition, patient organisations should reinforce the need for written action plans and frequent checks of inhaler techniques as part of regular structured asthma reviews. Many patient organisations have programmes to detail what should be in a written action plan, and why it is useful, and often provide instructional recordings demonstrating correct inhaler techniques. Patient organisation representatives should require that participants demonstrate their inhaler techniques, and they should review written action plans to confirm that they understand them correctly.

There should also be a focus on implementing best practice approaches to managing asthma and creating a better future for patients with asthma—one which improves outcomes, reduces mortality, and strengthens global health systems. This should be ingrained in any severe asthma initiative or policy. By moving severe asthma care closer to home and enabling patients to control their condition better, further system capacity would be freed to allow for the recovery of long-term condition management and catch-up of planned elective interventions, as well as possible further waves of COVID-19 or other communicable disease outbreaks in the future [57].

CONCLUSION

The principles we have set out in the Charter to Improve Patient Care in Severe Asthma demonstrate the core elements of quality care that patients with severe asthma should expect to receive. They are based on the latest understanding of the disease and how care should be structured. These principles should be used to benchmark current service provisions. We urge policymakers, those responsible for the delivery of severe asthma care, and advocates for better care to use the principles and action plan set out in this article to prioritise the change required to deliver this quality care. This transformative change will not be achieved without tackling the historic under-prioritisation of asthma and

other chronic respiratory diseases. Governments and policymakers must put in place bold national strategies. These must include investments in new care models; ambitious, incentivised targets; and accountable leadership to build consensus on what severe asthma care should look like in their health system. They should place people with asthma at the centre of care, identify the current gaps and areas for improvement, and implement measures to improve the quality of care and outcomes for people with severe asthma with a view of promoting life with minimal symptoms.

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