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Delving into Uncontrolled or Severe Asthma: Perspectives from Patients and Healthcare Professionals in a Cross-Sectional Study

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Background: Despite the effectiveness of inhalation therapy, uncontrolled or severe asthma remains prevalent challenges in respiratory care Narrative Medicine (NM) offers a linguistic approach to comprehending illness experiences, thereby providing a framework for advancing healthcare.

Aim: The primary aim of this study was to gather narratives from individuals grappling with severe or uncontrolled asthma and their Healthcare Professionals (HCPs), in order to explore the intricate interplay among quality of care, quality of life, psychological and social determinants, and adherence patterns.

Methods: A cross-sectional NM study was conducted in Italy from February to December 2023, encompassing 135 patients with uncontrolled or severe asthma (54.7% male; mean age: 56.7 years) and 47 HCPs (64.9% male; mean age: 54.3 years). A mixed-method approach was adopted to scrutinize themes, language nuances, emotional expressions, and narrative classifications.

Results: Patients with uncontrolled or severe asthma reported an average illness duration of 4.46 years, with exacerbations occurring over the past 20.9 months. Pulmonologists (83% of HCPs) played a predominant role in diagnosing and treating the disease in 96.1% of patients. Additionally, participants with severe asthma reported higher healthcare needs. The most reported emotions were fatigue (25.96%) and a sense of suffocation (11.53%). Upon commencing treatment, while experiencing physical improvement, patients predominantly expressed feelings of "submission/dependence" on medication (28%), followed by "fear" (21%) and "serenity/joy" (21%). HCPs, primarily pulmonologists (83%), emphasized the importance of raising awareness among specialists and General Practitioners (GPs), disseminating information, optimizing prescriptions, implementing phenotyping, tailoring therapy, and considering paediatric needs.

Conclusion: These findings contribute to a deeper understanding of patient perspectives, facilitate personalized interventions, and underscore the factors influencing therapeutic adherence in uncontrolled or severe asthma.

Keywords: uncontrolled asthma, severe asthma, adherence, quality of life, narrative medicine

Introduction

Asthma is a major respiratory global health problem that affects people of all ages.[1,2] Despite the availability of effective and safe treatment options, asthma management remains challenging, with up to 40% of patients experiencing uncontrolled symptoms. Uncontrolled asthma presents significant challenges not only at the individual level but also across families, nations, and globally.[3–5] It contributes to a broad spectrum of health issues and exacerbates the global burden of

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non-communicable diseases (NCDs), with severe consequences, including increased mortality. Moreover, uncontrolled asthma limits physical activity, impacts mental health, and disrupts social interactions, ultimately reducing the Quality of Life (QoL) and productivity of those affected[6] This, in turn, places a substantial burden on healthcare systems and society at large.[7] Prior research has identified significant barriers to optimal asthma management, including patient-related factors such as misbeliefs, physician-related challenges such as limited time and resources, and the inherent complexity of the disease, which often leads to misdiagnosis.[8,9] Qualitative studies, like those by Cheong et al,[10,11] have examined collaborative care models for asthma but have largely centered around Healthcare Professionals (HCPs), highlighting the relevance of involving both patients and different stakeholders to understand the quality of care. More recent studies have begun to explore the personal impacts of both asthma and uncontrolled or severe asthma on life, considering the subjective experience of patients. For instance, individuals frequently describe severe distress during exacerbations, with breathlessness and cough contributing to a "fear of death" due to the sudden onset of symptoms. Severe asthma, which often entails greater comorbidities and polypharmacy, has been linked to poorer adherence to treatment, reduced QoL, and the use of maladaptive coping strategies.[12,13] This body of research underscores how severe asthma undermines patients' functional, social, and emotional well-being, often leading to increased anxiety, depression, and panic disorders. The ongoing experience of uncertainty and vulnerability, exacerbated by severe asthma, highlights the importance of treatment approaches that foster continuity of care and help patients maintain a sense of control and self-efficacy, even during destabilizing events such as the pandemic.[14]

Asthma is classified as severe when it requires maximal, high-intensity treatment to achieve control, or when it remains uncontrolled despite adherence to such treatment.[15,16] On the therapeutic front, however, notable advancements have occurred in recent years, as evidenced by the updates outlined in the Global Initiative for Asthma (GINA) Report.[2] In the 2015 GINA Report, tiotropium, a Long-Acting Muscarinic Antagonist (LAMA), was introduced as a new add-on option for patients aged ≥18 in Steps 4 and.[17,18] Subsequently, the 2016 GINA Report expanded treatment options for Step 5, incorporating the first anti-interleukin (IL)-5 biologic for patients with severe eosinophilic asthma who remain uncontrolled on Step 4 treatment.[19] Further biologics, including anti-IL-4/13 and anti-thymic stromal lymphopoietin, were slated for inclusion in subsequent GINA Reports. The 2019 GINA Report marked a significant shift by no longer recommending short-acting beta-agonist (SABA)-only therapy.[20] Instead, it advocated that all adults and adolescents with asthma receive either symptom-driven (in mild asthma) or daily inhaled corticosteroid (ICS)-containing controller treatment. Notably, the Maintenance and Relief Therapy (MART) approach was designated as "preferred" and strongly recommended due to its efficacy in preventing exacerbations and providing comparable symptom control to regimens incorporating as-needed SABA as a reliever.[21] In the 2021, GINA Report, previous recommendations for adding tiotropium to ICS-LABA (long-acting beta-agonist) were expanded to encompass ICS-LAMA-LABA combinations in a single inhaler, known as Single-Inhaler Triple Therapy (SITT), for use in Steps 4 and 5.[22] It's worth noting that only the medium- and high-dose versions of the extrafine formulation combination of beclometasone dipropionate, formoterol fumarate, and glycopyrronium are commercially available in Italy.

Despite these advances, many patients with severe asthma continue to experience frequent exacerbations, underscoring the need for personalized treatment strategies and improved adherence to clinical guidelines to mitigate the ongoing burden of both uncontrolled and severe asthma.[23,24] Patients with severe asthma typically require maintenance therapy with high-dose Inhaled Corticosteroids (ICS) in combination with other controller medications or systemic corticosteroids to manage the disease and minimize exacerbations.[2,16,25] However, even with access to effective medications, severe exacerbations continue to pose a major health risk. These exacerbations can lead to hospitalization or death, with the likelihood of exacerbations being three times higher in patients with uncontrolled asthma.[16,24] Furthermore, in clinical practice, treatment options continue to vary due to unresolved patient management concerns. For example, there is insufficient data to determine which individuals would benefit more from SITT compared to those who might derive greater benefits from biological drug therapy, despite its significantly higher cost.[26] Moreover, studies examining patients' therapeutic, quality-of-life and/or the subjective and emotional experiences related to the usage of different treatments are noticeably lacking. This knowledge gap extends to understanding healthcare professionals' and patients' pharmacological and therapy preferences, as well as the factors that influence therapeutic adherence. Currently, there is a lack of thorough examination of these elements within a bio-psycho-social framework in the literature.

Narrative Medicine (NM) offers a valuable approach to comprehending the multifaceted experiences of individuals grappling with severe or uncontrolled asthma and its care. It delves into the personal journey through illness, exploring emotions, thoughts, decisions, and societal perceptions.[27–29] This holistic understanding facilitates the development of integrated care pathways that address social, psychological, and clinical dimensions, promoting patient-centered care.[30] In conclusion, NM serves as a powerful tool for comprehensively understanding and addressing the challenges of asthma management. By integrating patient narratives and parallel charts by Healthcare Professionals (HCPs) into clinical practice, HCPs can deliver more personalized and effective care, ultimately improving patient outcomes and enhancing the sustainability of the healthcare ecosystem.

Aims

The *primary aim* of this study was to was to gather narratives from individuals with severe or uncontrolled asthma and their HCPs to explore the intricate interplay among quality of care, quality of life, psychological and social determinants, and adherence patterns. Additionally, a *secondary aim* was pursued to delineate and quantify the dual burdens of disease, both from the perspective of the National Health Service and the individuals affected, through the identification and analysis of direct and indirect costs. These costs encompassed a spectrum of costs, including but not limited to healthcare visits, hospitalization expenses, transportation costs, medication expenditures, lost productivity due to absenteeism, and the opportunity costs associated with forsaken social engagements. Through this comprehensive approach, the project seeks to comprehend the nuanced experience of dealing with severe or uncontrolled asthma. This involves examining therapeutic decisions from both the perspective of HCPs and patients, delving into how these choices are established by the healthcare providers and how they are interpreted and pursued by the patients in their day-to-day management.

Methods

Ethical Issues

The study adhered to the principles outlined in the Declaration of Helsinki and was submitted for acknowledgment to the Institutional Review Board of the "IRCCS Fondazione Don Carlo Gnocchi" del Comitato Etico IRCCS Regione Lombardia (09/12/2020; ID: CE_FdG_09.12.20), as accepted for Narrative Medicine research. Before participation, all individuals provided online written informed consent, having been fully briefed on the project's objectives and the procedures for handling confidential data, in compliance with Italian Law 196/2003 concerning Privacy and the Protection of Sensitive Data, as well as the General Data Protection Regulation (GDPR) of the European Union 2016/679. The participants informed consent included publication of anonymized responses/direct quotes.

Theoretical Framework

As per the insights from Charon[31] and the Guidelines for the Application of Narrative Medicine in Clinical Practice, formulated by the Istituto Superiore di Sanità (Italian Health Institute) during the 2014 Consensus Conference,[32] NM denotes a clinical intervention methodology rooted in a distinct communicative proficiency. Central to NM is the utilization of narrative as a primary instrument through which practitioners gain insight, comprehension, and amalgamation of diverse viewpoints from individuals engaged in the spectrum of a disease and its management. The objective lies in fostering the collaborative development of a bespoke care trajectory, often referred to as a "care story." NM seamlessly integrates with evidence-based medicine, enriching clinical decision-making by offering a multifaceted array of perspectives, thereby rendering care more comprehensive, personalized, efficacious, and apt.

Study Design, Time and Setting

Between February and December 2023, a cross-sectional study utilizing NM was carried out across four hospitals and outpatient clinics managed by Pulmonologists, as well as two patients' associations focusing on pulmonary diseases throughout Italy. Commencing in March 2023, Pulmonologists, and HCPs operating within these facilities and associations voluntarily attended training sessions dedicated to NM, familiarizing themselves with the objectives and methodologies of the project. In order to standardize the recruitment process and enhance the depth of patient-centered

narratives, all healthcare professionals involved in participant recruitment, including pulmonologists, underwent two NM training sessions (1.5 hours each), focusing on empathic communication and active listening techniques.

Subsequently, each trained practitioner extended invitations to both their uncontrolled or severe asthma patients and fellow HCPs, furnishing them with comprehensive information sheets containing the survey link and detailed instructions for participation in the project. An online version was created, accessible through the ISTUD Healthcare and Health Area web portal (https://www.medicinanarrativa.eu/progetti/rinascita). This allowed participants to fill out the online questionnaire, download it to their PCs, save it, and then upload it using the designated button. Alternatively, participants could choose to print the questionnaire and send it directly to ISTUD. Finally, to reach a broad representation of the population, the possibility of filling in the survey and the narrative plots online has been offered, spreading it through the newsletter of the journal Cronache di Sanità e Medicina Narrativa or social networks (ie, Facebook, Instagram, Twitter).

Participants

Adult participants with severe or uncontrolled asthma were consecutively enrolled by General Practitioners (GPs) and Pulmonary Physicians from outpatient clinics of four hospitals across different Italian regions and 2 national associations. Asthma diagnosis and severity classification were based on the 2023 GINA Report criteria[2,33] and verified through medical record reviews during enrollment. All participants had a confirmed asthma diagnosis for at least 3 months and had experienced symptoms or were on medication for uncontrolled or severe asthma within the past 12 months. Severe asthma was defined as requiring high-dose inhaled corticosteroids plus additional controllers or systemic corticosteroids for disease control, or remaining uncontrolled despite adherence to treatment. Uncontrolled asthma was characterized by persistent symptoms or exacerbations in the prior 12 months despite regular treatment. Cognitive impairment, if present, was screened through medical record review to ensure comprehension of the study questions. Informed consent was obtained after a thorough explanation of the study's purpose and providing adequate time for questions. Healthcare professionals (HCPs), primarily Pulmonologists and GPs managing asthma patients, were also eligible for inclusion, though they were not necessarily the treating physicians of the enrolled patients.[2,33]

Data Collection

Two semi-structured questionnaires, one tailored for patients and the other for HCPs, were developed alongside a form designed to gather socio-demographic and lifestyle data.

For *patients*, the quantitative questionnaire aimed to capture:

- *Socio-demographic details* (age, gender, nationality, residence province, marital status, presence of children, educational level, profession, living arrangements).
- *Clinical information regarding asthma* (duration of asthma, initial diagnosis, duration of worsening symptoms, communication of exacerbation, previous healthcare facilities visited, implementation of an asthma treatment plan, specialist availability in the region, therapy changes, exacerbations in the past year, treatment adherence, asthma management costs).

For *HCPs*, the quantitative questionnaire sought:

- *Socio-demographic information* (age, gender, nationality, workplace province, healthcare facility, specialization, years of experience, motivation for specialization).
- *Socio-demographic details of patients with uncontrolled or severe asthma* (age, gender, nationality, residence region, marital status, presence of children, living arrangements, educational background, occupation, duration of asthma, duration of treatment, therapy changes, reasons for therapy changes, existence of a treatment plan, pandemic impact on asthma, lifestyle guidance provided).

Semi-structured questionnaires utilized narrative stimuli to prompt responses, facilitating a chronological account of the uncontrolled or severe asthma experience and its treatment evolution. The patient narrative focused on personal experiences of uncontrolled asthma (including emotions and psychological and social aspects) and perceived quality of life in relation to asthma management. HCPs' narratives centered on their care experiences with patients suffering from uncontrolled or severe asthma, including their observations of emotional and relational aspects impacting quality of life. The completion time for the survey with a narrative component was approximately 25 minutes (Supplementary Material 1).

Following data collection, a webinar was used to communicate preliminary findings to participating centres and associations to facilitate agreement on data interpretation and to ensure informant feedback.[34]

Data and Narrative Analysis

Data analysis consisted of two components: quantitative analysis of sociodemographic variables and qualitative analysis of narrative data. For the *quantitative aspect*, sociodemographic variables were analyzed using *descriptive statistics*, including means, ranges, standard deviations, and frequencies presented as percentages. Jamovi software® (Version 2.3.28) was utilized for this analysis, aiding in comprehending respondent characteristics, and providing context to qualitative responses.

For the *qualitative analysis*, we followed a structured process to ensure rigor and transparency. The narrative plots, originally composed in Italian, underwent independent review by two researchers from Fondazione ISTUD (EV; RT). Findings were then discussed in weekly team meetings to identify overarching themes while adhering to qualitative research principles, such as credibility, transferability, dependability, and confirmability. We utilized NVivo software (Version 12, QSR International®, Melbourne, Australia), for thematic analysis, which facilitated the identification of recurring themes and major semantic clusters within the narratives. This process involved both collective assessment of narratives and individual evaluation to honor their qualitative essence, ensuring that the richness of personal experiences was preserved.

- The *qualitative analysis* emphasized several key components::Identification of recurring themes and narrative structures.

- Language analysis to examine repeated expressions, verbal styles, and metaphors, following Plutchik's wheel of emotions to categorize emotional responses. At this regard, it is important to remember that Robert Plutchik developed the Emotion Wheel to assist people better understand, recognize, and categorize their feelings by organizing complicated emotions.[35]

Thematic analysis based on established frameworks,[36] including Kleinman's classifications of disease-centered, illness-centered, and sickness-centered narratives;[37] Launer's classification of stable, regressive and progressive stories,[38] and Frank's narrative modes of chaos, restitution, and quest.[39] For the sake of accuracy, the cited classifications are briefly explained:

a. *Kleinman's classification*[37] provides insight into how narratives can be categorized, delineating three distinct types:
   - *Disease-centered narratives*: These narratives offer precise and technical descriptions of the illness akin to medical charts. They often lack personal reflections or emotional depth, suggesting a discomfort in discussing one's emotions or a resistance to accepting their condition.
   - *Illness-centered narratives*: Here, individuals delve into their emotional experiences, moral struggles, and psychological reflections, often tracing the roots of their illness to childhood or adolescence. These narratives explore the impact of the illness on various aspects of life, indicating a willingness to share personal experiences and an acceptance of their physical state, albeit with controlled emotions.
   - *Sickness-centered narratives*: This perspective focuses on society's perceptions of illness and the individuals affected by it.
b. *Launer's framework*[38] introduces three narrative archetypes:
   - *Stable stories*: These narratives navigate between past and present experiences, maintaining a sense of stability and continuity.

- *Regressive stories*: Characterized by oscillations between past, present, and future, regressive narratives often lack coping mechanisms to manage the challenges posed by illness.
- *Progressive stories*: These narratives also traverse past, present, and future but are distinguished by the activation of coping strategies, signifying progress, and adaptation in the face of illness.

c. According to *Frank*,[39,40] narratives can be categorized into three distinct modes:
- *Chaos narratives*: These narratives exhibit fragmented storytelling and a lack of coherence, reflecting confusion and disorientation, both emotionally and physically.
- *Restitution narratives*: Here, the focus shifts towards the healing process, treatments, or remedies, often with a passive acceptance of the illness without deeper reflection.
- *Quest narratives*: Representing a journey of self-discovery and enlightenment, quest narratives view illness as an opportunity for personal growth and insight. The individual actively seeks meaning and understanding, placing their subjective experience at the centre of the narrative.

The findings are presented in terms of four main topics: quality of care (encompassing communication, accessibility, and medication therapy), quality of life (considering emotional, physical, and social dimensions), psychological features (focusing on emotions and mental well-being), and social factors (including relationships and support systems).

By integrating quantitative and qualitative analyses, our study aims to provide a comprehensive understanding of the experiences of individuals with severe or uncontrolled asthma and their healthcare professionals.

Results

Socio-Demographic Features

One hundred eighty-two people accessed the online platform, comprising 47 hCPs and 135 patients with uncontrolled or severe asthma (Figure 1). The sociodemographic information of participants is compiled in Table 1, which includes a distinct category for non-responses.

Table 1 illustrates a balanced gender distribution in responses, with a slight predominance of men. The mean age of 56.7 (SD=12.9; range 24–86) for patients and 54.3 (SD=10.9; range 31–70) for HCPs. Notably, responses are more prevalent from southern Italian regions among both groups. To minimize re-identification risk, narrative quotes are coded in the figures and tables with codes differing from participant identifiers.

Quality of Care

The HCPs and the Therapy

Thirty-one participants (65.9%) believe that there is a need for increased specialist awareness of uncontrolled or severe asthma, while 6 participants (12.8%) disagreed. Among supporters, several highlighted the necessity for comprehensive information (21; 44.7%), followed by heightening of attention to prescriptions (1; 3.2%), phenotyping and targeted therapy (1; 2.12%), acknowledgment without underestimation (1; 2.12%), and paediatric considerations (1; 2.12%). Thirty-four participants (72.34%) advocated for greater awareness of uncontrolled or severe asthma among GPs, with 11 participants (23.4%) emphasizing the need for detailed information dissemination. In terms of public awareness, 32 participants (68%) considered it necessary, with 28 (59.5%) emphasizing the importance of providing more information, including suggestions for advertising campaigns.

Additionally, 34 participants (72.3%) supported implementing educational programs for individuals with uncontrolled asthma, while 3 (6.4%) did not see value in such initiatives. Supporters prioritized air pollution initiatives (25; 53.1%) and nutritional education (24; 51%), alongside workplace-related education (19; 40.4%). Further, 1 participant highlighted therapy adherence and 3 underscored the importance of increased patient information.

Regarding treatment plans, HCPs reported that in 33 cases (94.3%) for patients with severe or uncontrolled asthma, there is an established Therapeutic Plan for management, derived from patient records. Of these cases, 17 (57%) had

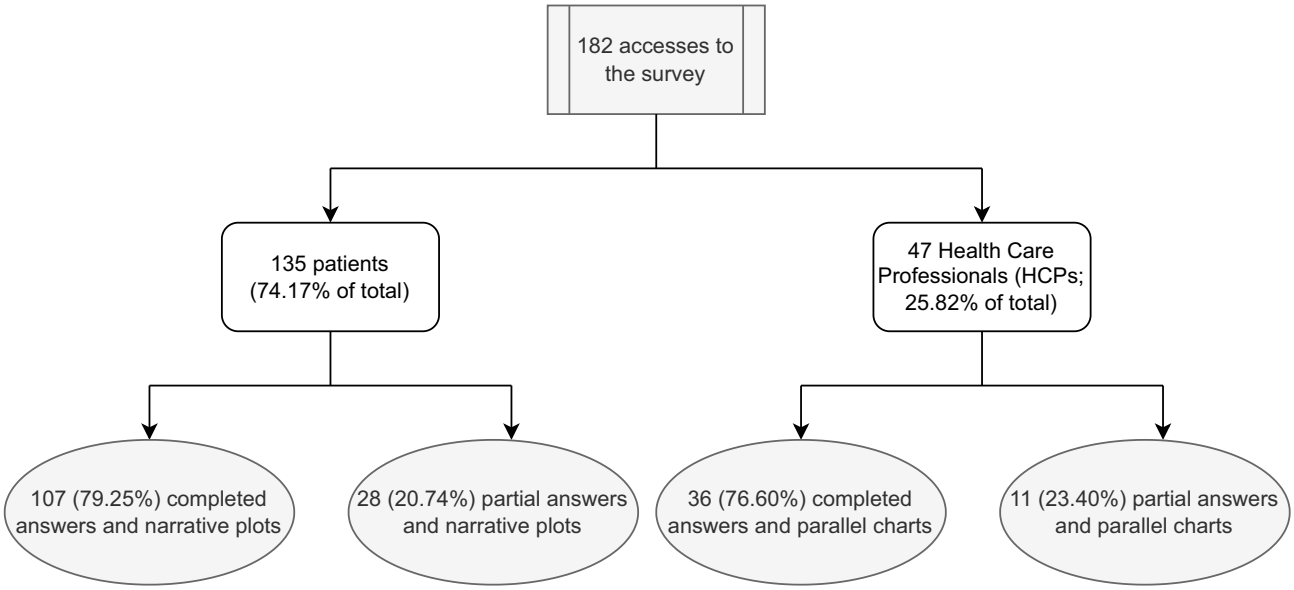

Figure 1 Flow chart of participant selection.

plans structured around asthma worsening. Common reasons for therapy adjustments included drug increase (2; 9.5%) and frequent emergency visits (1; 4.8%). Notably, 21 (61.8%) patients did not have comorbidities.

The Severe or Uncontrolled Asthma Pathway

Eighty-two (60.7%) individuals with uncontrolled or severe asthma reported consulting a Pulmonologist as their initial healthcare provider. This was followed by 18 (13.3%) individuals who sought assistance from a GP, and 2 (1.5%) who consulted an Allergist. Among 98 (72.6%) individuals, a Pulmonologist was solely responsible for diagnosing uncontrolled or severe asthma, while 2 (1.5%) had significant involvement from a GP, and one (0.7%) received a diagnosis from an Allergist. Notably, 14 individuals (10.4%) reported lifelong asthma, typically describing its onset as "allergic

Table 1 Sociodemographic Data

	Patients (n=135)	HCPs (n=47)	Patients About Whom HCPs Narrate (n=35)
Gender (n, %)			
Women	48 (35.5%)	13 (35.1%)	10 (28.6%)
Men	58 (42.9%)	24 (64.9%)	25 (71.4%)
Not declared	29 (21.5%)	10 (21.3%)	–
Average age (Mean in years, SD)	56.7 (12.9)	54.3 (10.9)	55.5 (DS=11.1)
Geographic residence (n, %)			
Northern Italy	3 (2.2%)	3 (6.38%)	3 (8.6%)
Central Italy	4 (3%)	0	0
Southern Italy	99 (73.3%)	32 (68.08%)	32 (91.4%)
Nonresponses	29 (21.5%)	12 (25.53%)	–

(*Continued*)

Table 1 (Continued).

	Patients (n=135)	HCPs (n=47)	Patients About Whom HCPs Narrate (n=35)
Education (n, %)			
Elementary school	1 (0.74%)	–	–
Middle school	9 (6.7%)	–	–
High school	47 (34.8%)	–	11 (31.4%)
Bachelor/Master/PhD	49 (36.3%)	47 (100%)	24 (68.6%)
Nonresponses	29 (21.5%)	–	–
Employment status (n, %)			
Employee	43 (31.8%)	–	8 (22.9%)
Housewives	2 (1.5%)	–	–
Work without a contract	5 (3.7%)	–	–
Not working	8 (5.9%)	–	2 (5.7%)
Retired	23 (17%)	–	5 (14.3%)
Atypical contract workers	2 (1.5%)	–	1 (2.9%)
Freelancers	21 (15.5%)	–	19 (54.3%)
Nonresponses	31 (23%)	–	–
Marital state (n, %)			
Single	21 (15.5%)	–	5 (14.3%)
Married	70 (51.8%)	–	26 (74.3%)
Separated/Divorced	9 (6.6%)	–	3 (8.6%)
Widowers	6 (4.4%)	–	1 (2.9%)
Cohabitant	1(0.74%)	–	–
Nonresponses	28 (20.7%)	–	–
Smoking (n, %)			
Smokers	45 (33.3%)	–	–
Ex-smokers	48 (35.5%)	-	-
Non-smokers	31 (22%)	-	-
Nonresponses	11 (8.14%)	-	-
Years of illness (M, SD)	4.46 (7.97)	-	4.6 (4.77)
Aggravation of symptoms (Mean in months, SD)	20.9 (36.8)	-	24 (1.9)
Facilities visited to obtain a diagnosis (M, SD)	1.5 (1.53)	-	-
Specialisation (n, %)			

(*Continued*)

Table 1 (Continued).

	Patients (n=135)	HCPs (n=47)	Patients About Whom HCPs Narrate (n=35)
Pulmonologist	-	29 (61.7%)	-
Internal Medicine Physician	-	1 (2.1%)	-
Cardiologist	-	4 (8.51%)	-
Psychotherapist	-	1(2.1%)	-
Nonresponses		12 (25.5%)	-
Years of experience (M, SD)	-	28.8 (11.5)	-

Abbreviations: M, Mean; SD, Standard Deviation; n, number; %, percentage.

asthma" or related to "rhinitis", progressing to a clinical picture of "United Airway Disease." Pulmonologists reported symptoms aggravation in 97 patients (71.8%), while GPs and Allergists accounted for 4 (2%) and 1 (0.7%), respectively. Participants reported an average of 1.9 (SD=1.14) flare-ups in the past year (Figure 2). Among them, 91 (67.4%) treated exacerbations at home, 27 (20%) sought hospital treatment, and 2 (1.5%) required emergency care. Additionally, 25 individuals (18.5%) faced comorbidities, with diabetes and hypertension being the most prevalent.

The Role of GP and Pulmonologist from the Patient's Perspective

Ninety-six individuals (71.11%) with uncontrolled or severe asthma reported that their GP has experience in managing uncontrolled or severe asthma. Among these, 16 (11.8%) were referred to specialists. Patients described the specialist's role as "fundamental" (16; 11.8%) and "important/very important" (11; 8.1%). Some characterized the specialist's role as "comforting and reassuring", emphasizing their importance in managing complex respiratory conditions.

Medication Therapy from the Patient's Perspective

One hundred respondents reported changing an average of 3.35 (SD=2.43) therapies for uncontrolled or severe asthma. The Asthma Treatment Plan was established for 102 cases, with 101 (74.8%) adhering to their regimens even during wellness periods. Among 135 patients, 111 provided pharmacotherapy information. Among these 111 patients, 98 are taking ICS (88.3%) (Figure 3). Ten patients were on therapy with a single active ingredient (7 were on therapy with only a corticosteroid [ie, ICS/ Systemic corticosteroids (SCS)], 1 was treated with SCS, 1 was treated only with

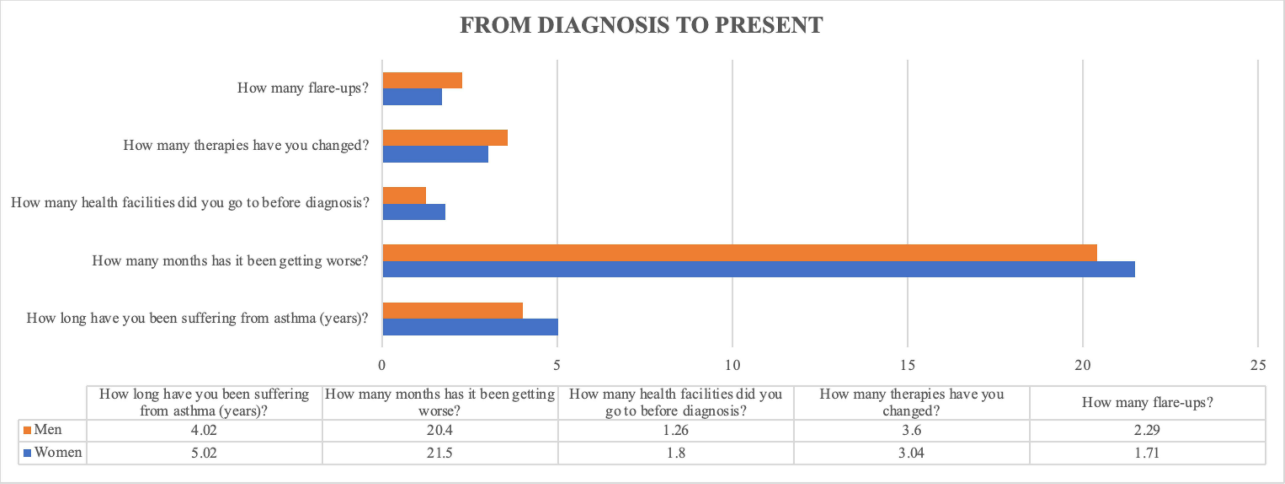

Figure 2 Main information about severe or uncontrolled asthma, reported as Mean, distinguished between female and male respondents.

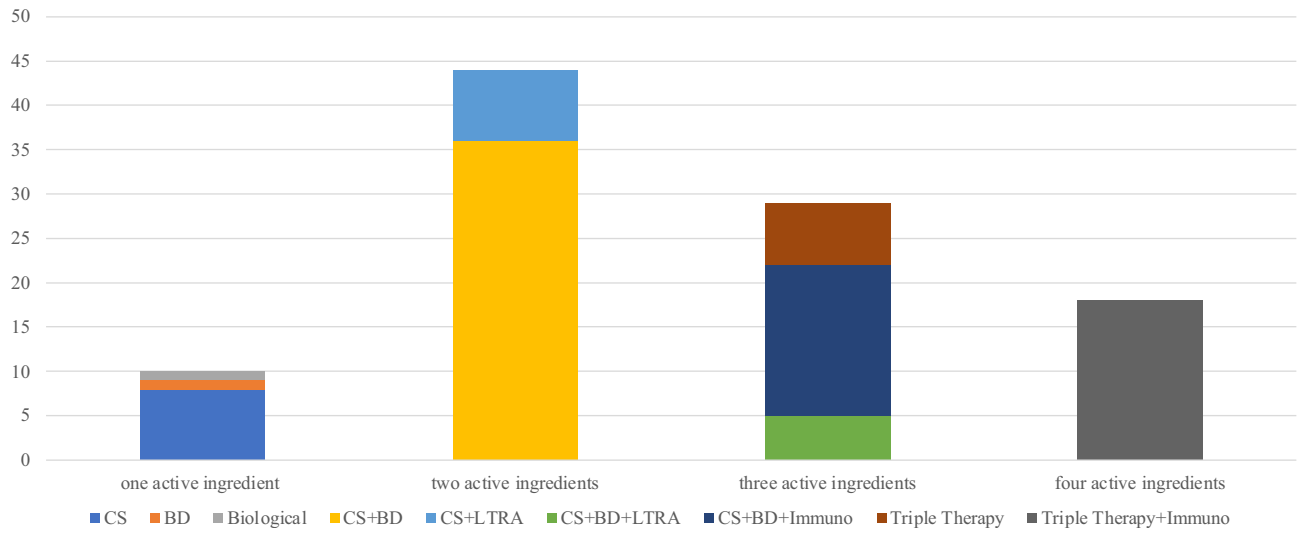

Figure 3 Therapy that participants report has been prescribed.

bronchodilators, and 1 was treated with a biological drug). Forty-four patients were on therapy with two active ingredients (36 and 8 patients were on ICS/SCS therapy combined with either a bronchodilator or an LTRA, respectively). Thirty-nine patients were treated with therapy involving three active ingredients (5 patients were on corticosteroids + bronchodilators + LTRA therapy; 17 patients were on therapy with corticosteroids + bronchodilators + immunotherapy; 7 patients were on triple therapy). Eighteen patients were treated with therapy involving four active ingredients (triple therapy + immunotherapy). A minority of patients are treated with either a single active ingredient or with four active ingredients, while the majority are treated with three or four active ingredients.Moreover, 60 of the people who have been given a Treatment Plan say they are very confident about the therapy and its use, followed by 41 who feel fairly confident and 4 who feel uncertain. Interestingly, among those using corticosteroids, 58 individuals express a strong sense of safety regarding their treatment, followed by 37 who feel moderately safe, and 4 who feel somewhat less secure.Though many patients use inhaled corticosteroids, it was not possible to ascertain the number of those possibly using systemic corticosteroids from narratives. In terms of bronchodilator usage, 38 people report feeling very safe, while 22 feel moderately safe, and 3 feel less secure. When it comes to biologic drugs, 14 individuals perceive a strong sense of safety, although 8 feel moderately safe, and 1 feels slightly less secure. Regarding the use of LAMAs, 20 people feel very safe, 17 feel moderately safe, and 2 feel somewhat unsafe. Finally, concerning the use of Leukotriene Inhibitor drugs, 11 individuals feel very safe, 11 feel moderately safe, and 2 feel unsafe.

Eighty-one (60%) individuals expressed that they received thorough explanations regarding device therapy usage, while 19 (14%) individuals found the instructions to be somewhat adequate, and 2 (1.5%) individuals indicated they received minimal guidance. Eleven individuals expressed a need for assistance in using the devices, whereas 13 (9.6%) individuals stated feeling moderately confident, and 40 (29.6%) individuals admitted to lacking confidence in device management. On the other hand, 39 (28.8%) individuals reported not requiring any support in managing the devices.

Lifestyle Recommendation

Eighty-four individuals (62.2%) reported strict adherence to lifestyle recommendations, viewing them as "very important." Most recommendations included smoking cessation, dietary management, physical activity, and avoiding heavily polluted areas. Regarding routine check-ups, 89 (65.9%) consistently attended, with 10 (7.4%) attending "sufficiently."

The costs of care

Fifty-one individuals (37.7%) noted significant treatment costs associated with their uncontrolled or severe asthma. Simultaneously, 45 (33.3%) individuals reported incurring an additional expense, while 56 (41.5%) do not incur any additional costs. Most of those who incur additional costs say they spend between 1000 and 500 euros/year (Figure 4).

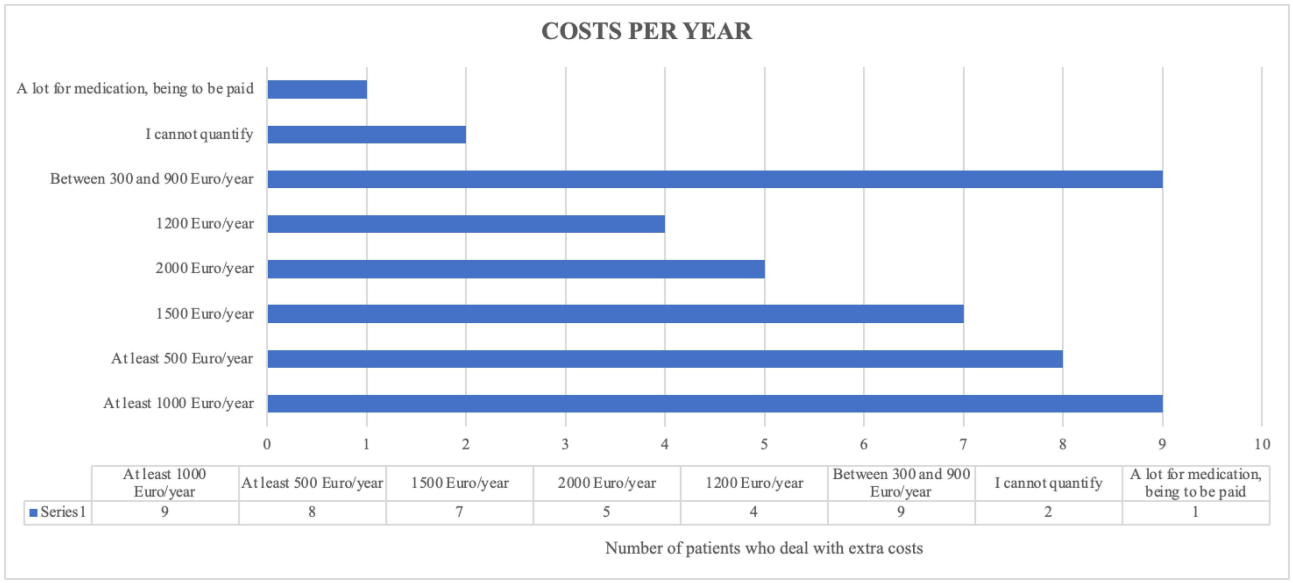

Figure 4 Additional costs reported by participants, incurred annually.

These costs are mostly counted on specialist visits (18; 40%); other visits for other medical conditions (13; 28.8%); physiotherapy (13; 28.8%); other medications (6; 13.3%) and for cleaning, purchase of allergen-free food (1; 2.2%).

Moreover, most respondents claimed to have missed between 20–30 days or 41–50 days or 61–80 days of work due to uncontrolled or severe asthma (Figure 5). Figure 6 shows the main reasons of these missed days.

Quality of Life

Most respondents rated their quality of life as "good" (76; 56.2%), while fewer rated it as "passable" (15; 11.1%) or "poor" (3; 2%). The 100 responses to adherence to therapy and symptoms are displayed in Figure 7.

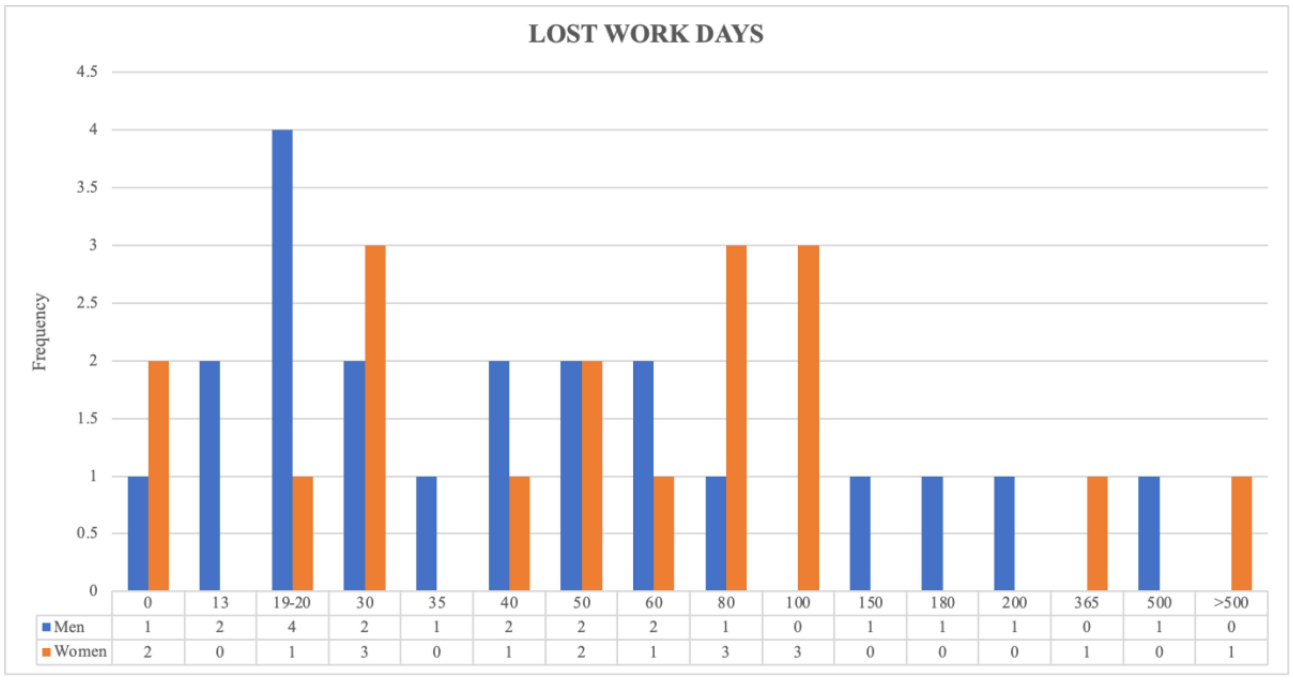

Figure 5 Lost workdays, distinguished by gender.

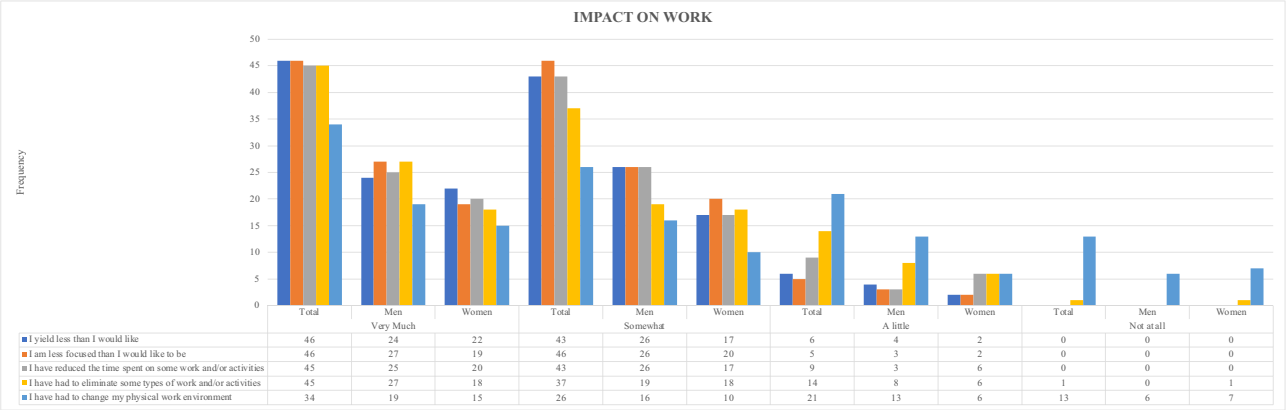

Figure 6 The impact on work and reasons given by participants with severe or uncontrolled asthma, distinguished between the total sample and by gender.

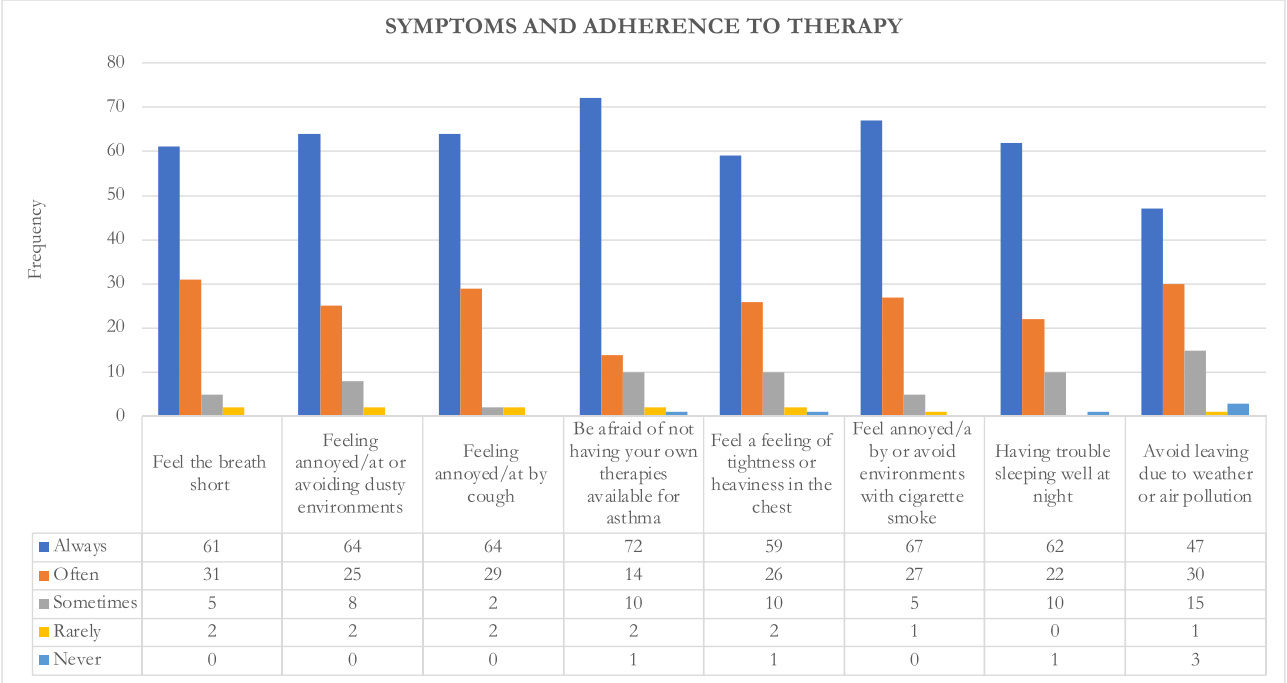

Figure 7 Frequency of symptoms as reported by participants.

Living with Severe or Uncontrolled Asthma in Daily Life

There are 103 people who describe their activities of daily living with uncontrolled or severe asthma. The most frequently used words are "I could" (72; 6.23% weighted coverage); "work" (38; 3.29% weighted coverage); "concentrate" (22; 1.9% weighted coverage); "nothing" (20; 1.73% weighted coverage). One hundred and one participants specified what their ability to move was like in the past. The words most often used to describe abilities are: "exhausting" (30; 6.64% weighted coverage); "difficult" (18; 3.98% weighted coverage); "tiring" (18; 3.98% weighted coverage). On the other hand, one hundred and three people describe their ability to breathe in the past, using words such as "strenuous" (62; 12.18%weighted coverage); "difficult" (38; 6.68% weighted coverage); "difficult" (30; 5.89% weighted coverage) and "impossible" (15; 2.95% weighted coverage), while their current breathing abilities are described by 103 people. The most frequently used terms are "important" (30; 8.24% weighted coverage); "indispensable" (30; 8.24% weighted coverage); "fundamental" (26; 7.14% weighted coverage).

Table 2 shows the distribution of narrative plots with reference to some salient aspects of daily life, as perceived by patients and HCPs in terms of frequency. Sample quotes are also shown. Usually quite telegraphic and brief, the narrations were significant. While some participants seemed to find it difficult to articulate their own experiences, others seemed to give telling their stories simply a token effort.

Psychological Features

Severe or Uncontrolled Asthma Through the Eyes of an HCP

Fourteen metaphors have emerged that describe uncontrolled or severe asthma with professional's eyes. As can be seen from Figure 8, the image that is most frequently used by professionals to describe the uncontrolled or severe asthma of their patients is that of "fish out of water" (9), followed by that of "balloon deflated" (7).

The Emotions of HCPs

There are 35 references to the emotions and feelings of the professional in contact with the patient. 36 times (29.51% weighted percentage) the term "safe " appears. This is followed by words such as "friend" (4; 3.28% weighted percentage), "familiar" (4; 3.28% weighted percentage), "quiet" (4; 3.28% weighted percentage), and "close" (4; 3.28% weighted percentage). There are 33 references (94.28%) to positive emotions. In addition to the importance attached to safety, 7 references (20%) are denoted that are more pertinent to holding a "friend" or "family" role, thus indicating a need for closeness, protection, and reassurance. Only 2 references (5.71%) are more relevant to negative or neutral emotions, mirroring worry and indifference, respectively.

Table 2 Frequency of Some Expressions About Quality of Life's Aspects Broken Down According to Launer's, Frank's and Kleinman's Classifications

			Patients (Ref) n=107	HCPs (Ref) n=36	Examples of Quotes
Movements	**Launer's classification**	**Progressive**	0	5	*≪ I know that every day she goes out with her husband for a walk in a city park≫ (HCP1Z)*
		Stable	0	29	*≪ It is indispensable≫ (HCP1V)*
		Regressive	0	0	
	Kleinman's classification	**Illness**	37	0	*≪ A titanic feat. I felt like I was 80 in the body of a 27-year-old. Trapped inside a body that could not move because of the difficulty of breathing, even if it seemed normal≫ (Patient3A).*
		Disease	3	0	*≪ Possible only after taking cortisone≫ (Patient1Z)*
		Sickness	0	0	
Breath	**Launer's classification**	**Progressive**	5	0	*≪A gift≫ (Patient1A)*
		Stable	93	0	*≪In situations of asthma crisis, there is only lack of air, there is no other≫ (Patient1Y)*
		Regressive	5	0	*≪Simple before.it has become difficult now≫ (Patient3G)*
	Kleinman's classification	**Illness**	147	0	*≪ What is instinctive for everyone is complicated for me, I have to fight to breathe≫ (Patient1G)*
		Disease	56	0	*≪A little easier than before the monoclonal≫ (Patient2J)*
		Sickness	0	0	

(*Continued*)

Table 2 (Continued).

			Patients (Ref) n=107	HCPs (Ref) n=36	Examples of Quotes
The everyday person's wishes	**Launer's classification**	**Progressive**	2	35	*≪ That he could get better. I hope that new ways can be found to guarantee a better quality of life for those suffering from severe or uncontrolled asthma≫ (HCP2F)*
		Stable	64	0	*≪I hoped it was not me who suffered≫ (Patient2K)*
		Regressive	4	0	*≪Being able to start, managing even though I know it is not possible≫(Patient2W)*
	Kleinman's classification	**Illness**	0	0	
		Disease	0	1	*≪…that he returned to the ward to do the rehabilitation and then release her to her daily life≫ (HCP1D)*
		Sickness	0	0	
	Frank's classification	**Restitution**	67	35	*≪Continue to be monitored, from time to time, for fear of* "getting lost"*≫ (HCP1A); ≪I would like to return to the charismatic and charming woman I used to be. To the protective and loving mother who put them and their well-being first. To when twice during the school year I used to pick them up to spend time together alone. To when I organised our little car trips with their favourite songs sung in joy. To when I would spend months creating their Christmas presents. To when I would spend myself searching for the best ingredients to prepare their favourite dishes. When we would go in search of fabrics to create their Halloween costumes. I was a mother of few but firm no's. On education and respect for others, I was very firm and then covered them with caresses and songs in bed before I put them to sleep≫ (Patient3E)*
		Quest	0	0	
		Chaos	1	0	*≪I want…I can…I do?≫ (Patient2H)*

Abbreviation: ref, number of references.

Severe or Uncontrolled Asthma Through the Eyes of a Patient

One hundred and seven project participants describe their uncontrolled or severe asthma. The words most often used to describe it were the following: "disease" (125; 11.25% weighted coverage); "known" (48; 4.40% weighted coverage); "unknown" (43; 3.94% weighted coverage); "severe" (40; 3.66% weighted coverage); "pathology" (34; 3.11% weighted coverage). Included in the classification "Disease", according to Kleinman, are 68 references (68 participants; 63.55%), expressing technical, contingent, and medical language. Here, the most frequently used terms are "disease" (47; 17.94% weighted coverage); "known" (24; 9.16% weighted coverage); "serious" (18; 6.87% weighted coverage); "unknown" (16; 16.11% weighted coverage). There are 49 references (49 participants; 45.79%) that fall under the classification "Illness", according to Kleinman, and 13 (13 participants; 12.14%) metaphors that people with asthma outline to describe uncontrolled or severe asthma (Figure 8).

The Emotions of People with Severe or Uncontrolled Asthma

There is a total of 104 references to the feelings experienced by individuals with uncontrolled or severe asthma before starting treatment. Among these, the most mentioned terms include "tired" (15 mentions; 1.10% weighted coverage), "much worse" (14 mentions; 1.03% weighted coverage), "felt suffocated" (12 mentions; 0.88% weighted coverage), and "felt fatigued" (11 mentions; 0.88% weighted coverage). Of these references, 45 (43.26%) can be classified according to Kleinman's model, with 16 (35.55%) falling under the "Disease" category and 29 (64.44%) under the "Illness" classification. Additionally, 44 references (42.3%) denote the presence of specific emotions, which could be categorized

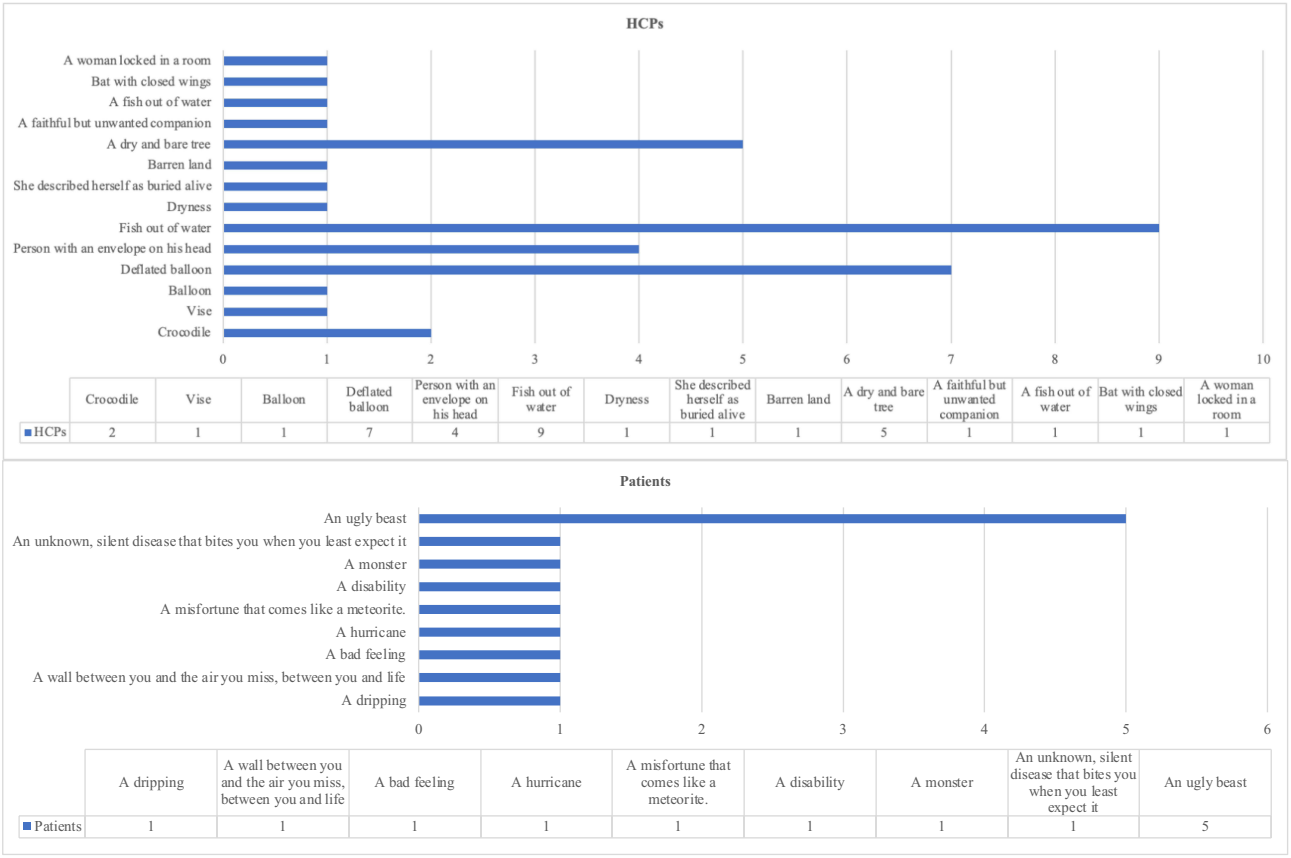

Figure 8 Metaphors used by HealthCare Professionals (HCPs) and patients to describe severe or uncontrolled asthma.

according to Plutchik's Flower model. Specifically, 16 (36.36%) refer to "serenity", 9 (20.45%) to "boredom", 7 (15.9%) to "submission and isolation", 6 (13.63%) to "excitement" and "joy", 3 (6.81%) to "fear", 2 (4.54%) to "annoyance", and 1 (2.27%) to "acceptance".

Furthermore, 104 participants specified their current emotions and feelings after initiating treatment. The most frequently used terms in this context include "better" (111 mentions; 15.57% weighted coverage), "cured" (26 mentions; 3.65% weighted coverage), "followed" (26 mentions; 3.65% weighted coverage), and "anxiety" (10 mentions; 1.40% weighted coverage). According to Plutchik's Flower model, 29 references (27.8%) can be categorized in terms of emotions, with "submission" (8 mentions; 27.58%), "fear" (6 mentions; 20.68%), "joy" (6 mentions; 20.68%), "boredom" (5 mentions; 17.24%), "freedom" (3 mentions; 10.34%), and "ecstasy" (1 mention; 3.44%). Living with severe or uncontrolled asthma can evoke a range of emotions and significantly impact an individual's daily life. Fear and anxiety may arise due to the unpredictability of asthma attacks, while frustration and helplessness can stem from dealing with frequent symptoms despite ongoing treatments.

Social Features

Uncontrolled or severe asthma affected the social relationships to a degree of "much" (28; 20.7%) or "enough" (27; 20%). In general, the narrative plots indicate that individuals may experience social isolation due to the necessity of avoiding triggers and the constraints imposed by asthma symptoms, resulting in feelings of loneliness and a sense of being misunderstood. Nevertheless, the majority describe their loved ones as supportive (53; 39.25%) or well-informed (43; 31.85%), while a minority describe them as apprehensive (5; 3.7%) or lacking understanding (2; 1.48%).

The COVID-19 Impact

The findings revealed that a majority (84; 62.2%) perceived a noticeable effect on their uncontrolled or severe asthma due to the COVID-19 pandemic. Conversely, a minority (13, 9.6%) reported no discernible influence. Several participants reported a worsening of their respiratory conditions, ranging from exacerbated asthma to various unexpected health issues like constipation. Some individuals attributed their deteriorating health to the lingering effects of COVID-19, suggesting that the impact of the virus persisted even after recovery. Interestingly, a subset of respondents linked their health challenges directly to COVID-19 vaccination, expressing concerns about the timing of symptom onset in relation to the vaccination. One respondent recounted a story of hospitalization and intubation following vaccination but expressed gratitude for overcoming the ordeal. These responses collectively highlight the complexity of health outcomes post-COVID-19 vaccination, with some individuals experiencing adverse effects on respiratory health and overall well-being. It is crucial to acknowledge the diversity of individual experiences, underscoring the multifaceted nature of health responses to vaccination.

On the other hand, the reference HCPs believes that COVID-19 has had enough influence in 23 (65.7%) of the people referred to in their parallel charts. Some HCPs believe it has influenced a lot in 8 cases (22.9%), while for others "little" (2; 5.7%) or "not at all" (2; 5.7%). Among those who believe it has affected a lot or enough, the reason is due to poor adherence to therapy (30; 96.7%) and, only in one case (3.2%) to emotional factors.

Discussion

This project engaged 47 HCPs and 135 individuals with uncontrolled or severe asthma, aiming to gain insights into their experiences and perspectives about quality of care, quality of life, psychological factors and social factors. Among HCPs, 76.6% provided complete responses, while the rest gave partial answers. Surprisingly, all operators completed only one parallel chart instead of the expected three. On the other hand, the high participation of individuals with severe or uncontrolled asthma, exceeding expectations by 45, indicated a strong desire to share their stories. The age range of individuals with severe or uncontrolled asthma was wide, spanning from 24 to 86 years, suggesting a diverse representation. Efforts were made to facilitate participation and discourage the selection bias, including online support for those less familiar with technology. The role of hospital clinicians and associations in facilitating participation proved invaluable, encouraging the fact that providing adequate cultural assistance can increase participation.[41]

One key finding was the economic burden associated with severe asthma, with 37.77% of participants reporting significant additional costs. These findings align with existing studies indicating that the treatment and management of severe or uncontrolled asthma entail significantly higher costs compared to those associated with generic asthma cases.[42–44] Our data support this, as participants with severe asthma reported higher healthcare needs, aligning with established research on the economic impact of poorly controlled asthma. Moreover, our study confirm that corticosteroids serve as the cornerstone of traditional asthma management and in our study approximately only one in 10 patients does not take steroid therapy [out of 111 patients, 98 take ICS/SCS (88.3%)]. Only a minority is treated with a single active ingredient or with four active ingredients and the majority is treated with two or three active ingredients. This approach hinges on a continuous cycle of reassessing and evaluating various factors such as patient satisfaction, side effects, comorbidities, risk factors, and symptoms.[15,45,46] Recent studies have demonstrated the safety, effectiveness, and cost-effectiveness of incorporating biological medications alongside conventional therapies for severe asthma. The advent of biologics has enabled the implementation of phenotype-specific treatments, thereby offering the potential for more personalized care.[47,48] However, it's crucial to acknowledge that biologic treatments come with a significantly higher price tag compared to traditional corticosteroid therapies.[49,50] This underscores the importance of accurate diagnosis and the adoption of phenotype-specific treatment strategies.[51] This would also allow for better consideration of the role of preference, perceived safety level and patient satisfaction with drug therapy.[52]

Moreover, the narrative plots revealed emotional challenges, including fear, frustration, and feelings of isolation. It is useful to note how the patient, once therapy is initiated, tends to feel safer and calmer, but at the same time, more submissive, dependent on the therapy itself, with possible consequences on adherence. Addressing these emotions, such as through the identification of personalized strategies, offering educational sessions, monitoring disease progression, and encouraging psychotherapy interventions within a comprehensive care framework, represents just one aspect of the

patient journey.[53] However, its significance grows when we acknowledge that quality of life is shaped by beliefs, expectations, and perceived levels of satisfaction.[14,44,54] It's crucial to recognize that feeling nurtured, supported, and empathized with significantly influences one's sense of belonging.[14,55] Since every narrative reflects an individual's internal state, we measured the movement of narratives using the classifications of Launer, Kleinman, and Frank whenever possible. It is surprising that descriptions of severe or uncontrolled asthma were more focused on the disease for patients than for HCPs. In contrast, there were no stories centered on sickness among the collected narratives, probably due to the perceived limitations during the COVID-19 pandemic period and partly due to the aforementioned lack of sense of belonging.

Considering the points outlined, our study is in line with the United Nations Sustainable Development Goals, particularly Goal 3 (Good health and well-being), Goal 5 (Gender equality), Goal 8 (Decent work and economic growth) and Goal 11 (Sustainable cities and communities), proposing to address health as a multidimensional issue to promote sustainable development.[56]

Strengths and Limitations

One of the main strengths of this study is the high participation rate among healthcare professionals (HCPs) and individuals with severe or uncontrolled asthma, underscoring the significance of gaining insights into their experiences and perspectives. However, the incomplete responses from some participants suggest potential areas for improvement in data collection methods and engagement strategies. While Narrative Medicine is a key strength of this study, as it facilitates a space for both patients and practitioners to share their experiences, we acknowledge that the absence of validated questionnaires may be viewed as a limitation in assessing these experiences. We acknowledge the limitations of this approach and emphasize that narratives are intended to complement standardized assessments, not replace them.

The invaluable role played by hospital clinicians and associations in facilitating participation highlights the importance of collaborative efforts in healthcare initiatives. Nonetheless, a limitation of this study is the challenge in generalizing the data, given that most respondents are from southern Italy. Furthermore, without a larger sample size, it is impossible to determine statistically significant differences between subgroups based on age, socioeconomic position, or geographic area. It may also be important to investigate whether specific types of drugs (eg, biologic drugs) give the patient the feeling of greater safety and whether, compared with other drugs, they have more contraindications. Moreover, while online responses were convenient, they tended to be more succinct and may have lacked depth. Therefore, future research may benefit from integrating online and in-person administration methods to capture more comprehensive subjective views and experiences from participants. Additionally, conducting longitudinal studies and utilizing validated instruments could provide a more accurate understanding of the evolving needs of people with severe or uncontrolled asthma over time. This approach would allow for a deeper exploration of changes in symptoms, treatment adherence, and quality of life, thereby enhancing our ability to tailor interventions and support strategies effectively.

Clinical and Research Implications

Recognizing the perceived importance of specialist involvement underscores the need for effective communication and collaboration between primary care providers and specialists. Developing care pathways that facilitate seamless transitions between primary and specialty care settings could improve patient outcomes. Moreover, one of the key clinical findings of this project is the significant economic burden associated with severe asthma, as reported by a considerable proportion of participants. This underscores the importance of developing strategies to alleviate financial strain on individuals with chronic respiratory conditions and optimize resource allocation within healthcare systems. Moreover, the narratives shared by participants revealed profound emotional challenges, including fear, frustration, and feelings of isolation. Addressing these emotional aspects is crucial for promoting all-inclusive patient centred care and improving overall well-being. This project highlights the need for ongoing research to better understand the multifaceted aspects of severe asthma and develop targeted interventions to improve patient outcomes and enhance the sustainability of healthcare systems. By addressing the economic, emotional, and social dimensions of severe asthma, future research

efforts can contribute to more effective asthma management and ultimately improve the quality of life for individuals living with this condition.

Conclusion

Recognizing and tackling the dimensions of dealing with uncontrolled or severe asthma is paramount. We can see from the study that NM's advantages go beyond the doctor-patient relationship. It enables us to support HCPs and consider their challenges as practitioners in a field beset by loss, in addition to walking with patients as they navigate their disease processes. Furthermore, our findings demonstrate a clear association between severe asthma and increased healthcare costs, emphasizing the need for targeted interventions that enhance multidisciplinary care and address the economic burden faced by patients. HCPs, bolstered by the support of family members and mental health experts, wield considerable influence in assisting individuals to navigate these hurdles and enhance their holistic well-being.

Abbreviations

NCDs, Non-Communicable Diseases; QoL, Quality of Life; GINA, Global Initiative for Asthma; ICS, Inhaled Glucocorticoids; SCS, Systemic corticosteroids; LTRA, Leukotriene Receptor Antagonists; LAMA, Long-Acting Muscarinic Antagonists; LABAs, Long Acting-Adrenoceptor Agonists; SABA, Short-Acting Beta-Agonist; MART, Maintenance and Relief Therapy; SITT, Single Inhaler Triple Therapy; ATS, American Thoracic Society; ERS, European Respiratory Society; NM, Narrative Medicine; HCPs, Healthcare Professionals; GP, General Practitioner.

Data Sharing Statement

All datasets used and analysed during the current research are available in Italian upon reasonable request from the corresponding author.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

Dr Eleonora Volpato reports support for this study from ISTUD. Dr Luca Cavalieri and Dr Mattia Ramaccia are employees of Chiesi Italia S.p.A. and Dr Alessio Piraino is an employee of Chiesi Farmaceutici S.p.A. The other authors report no conflicts of interest in this work.

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