

Patients' perspective on the burden of Hyper eosinophilic Syndrome

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Introduction

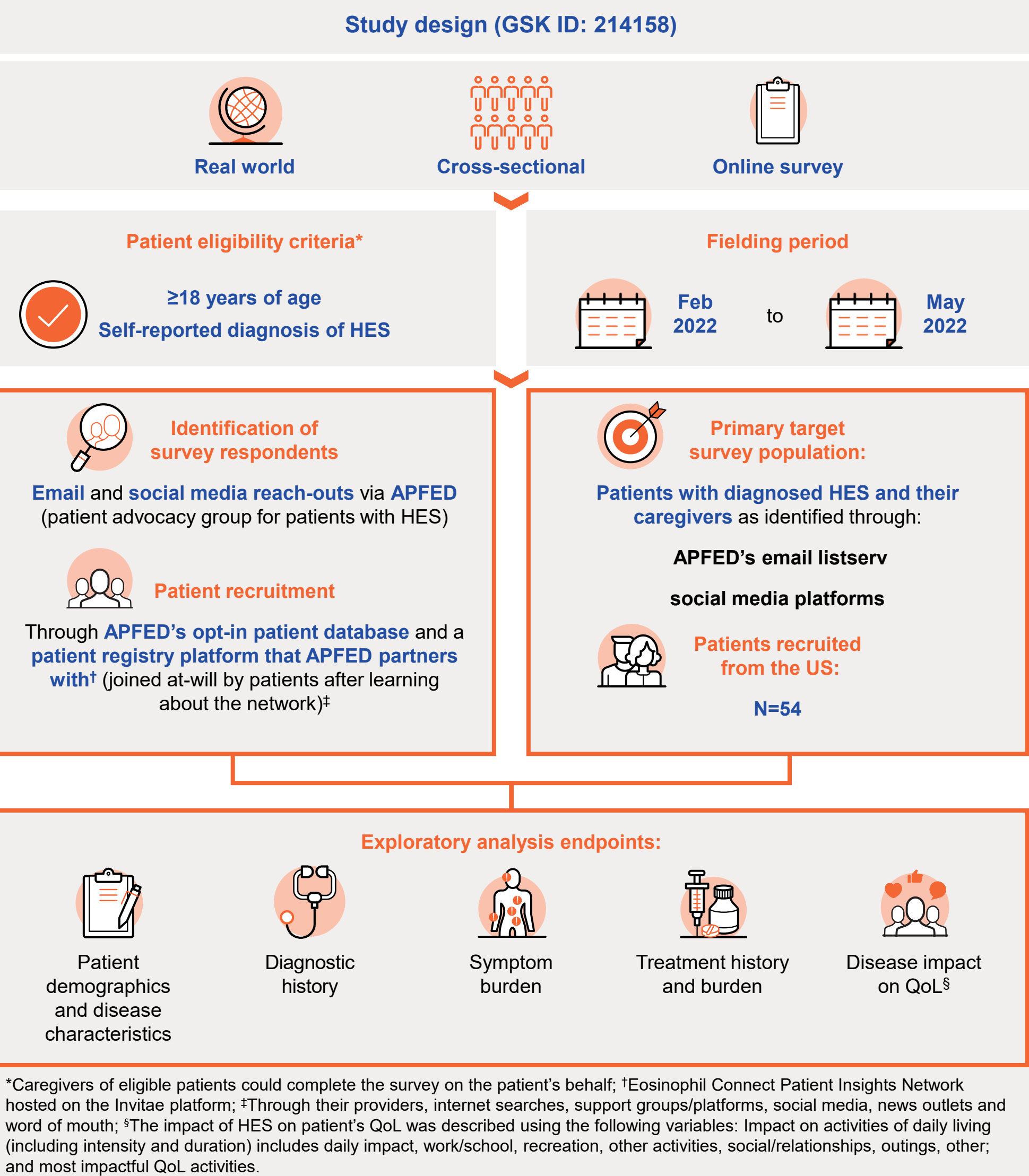
HES is a group of rare hematologic disorders characterized by hyper eosinophilia (typically >1500 cells/ μ L on two or more occasions), eosinophil-driven organ damage and dysfunction, and exclusion of secondary causes of eosinophilia.¹⁻⁵

The identification and diagnosis of HES is challenging owing to the rarity of the disease, the varied clinical presentation, the lack of recognition and overlapping characteristics with other eosinophilic conditions such as EGPA.⁴⁻⁷

The prevalence of HES is relatively low (0.32 to 6.3 cases per 100,000 people in the US), and the patient journey remains poorly understood.⁸ A better understanding of the patient burden associated with HES may facilitate understanding of unmet patient needs in HES and thereby direct improvements in diagnosis and management.

This study aimed to describe the experience of patients with HES, from the patients' own perspective from initial symptoms, through diagnosis, to QoL burdens and treatment experiences and was performed in conjunction with the key patient advocacy group, APFED.

Methods



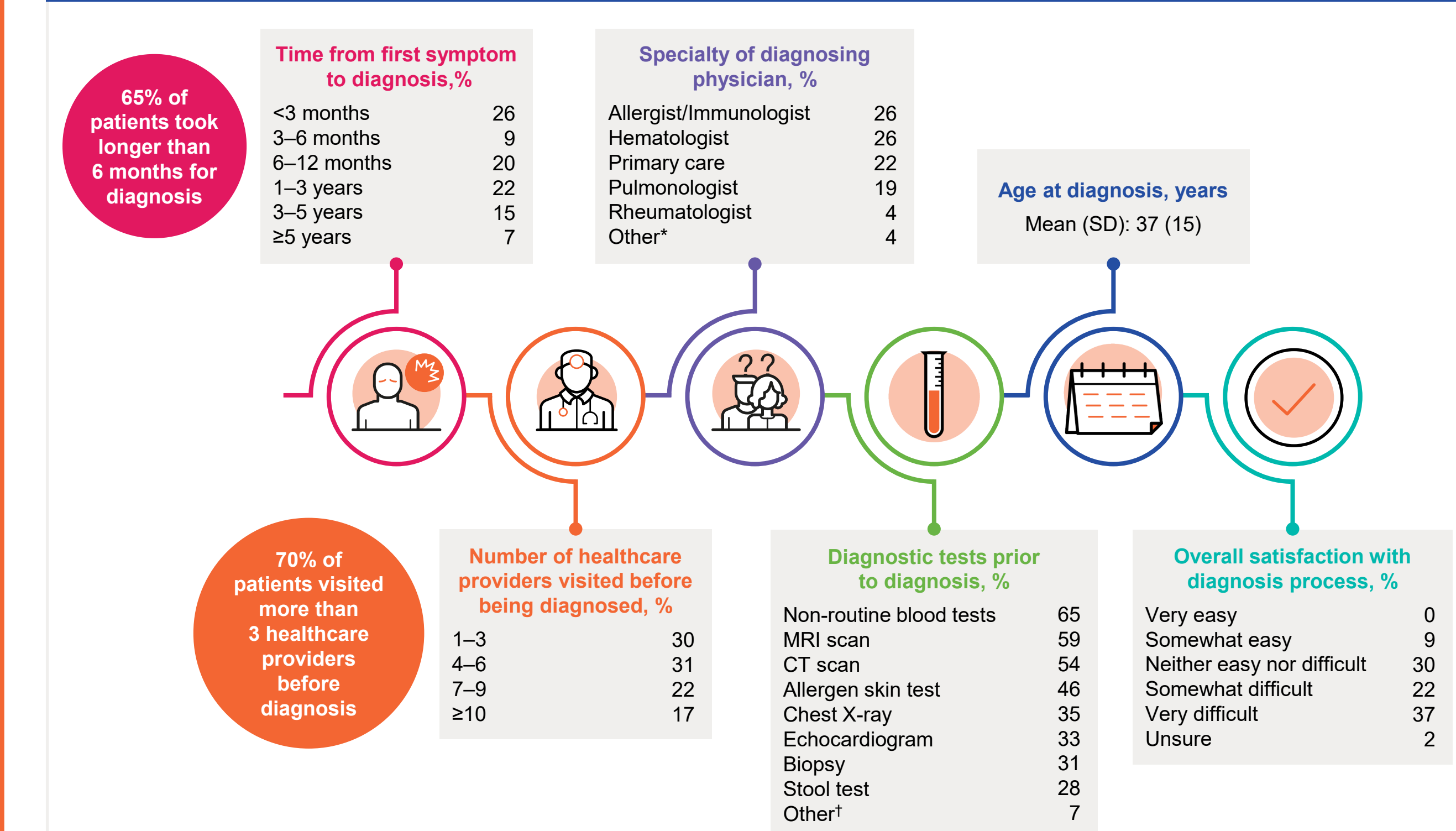
Results

Table 1. The majority of patients had idiopathic HES, and asthma was the most common comorbid or associated condition

	Overall (N=54)		Overall (N=54)
Age, mean (SD), years	43.6 (14.0)	Eosinophilic complications, n (%)	
Male, n (%)	31 (57.4)	Respiratory†	14 (26)
HES subtype, n (%)		Gastrointestinal‡	31 (57)
Idiopathic	32 (59)	Vascular§	7 (13)
Myeloid variant	15 (28)	Five most common treatments taken prior to diagnosis, n (%)	
Lymphocytic variant	3 (6)	Steroids	28 (52)
Other/unsure	5 (9)	Monoclonal antibody injectable medications	15 (28)
Family history of eosinophilic disorders, n (%)	18 (33)	Non-prescription management¶	12 (22)
Most common comorbid or associated conditions, n (%)		Hydroxyurea	9 (17)
Asthma	29 (54)	Vincristine	8 (15)
Anxiety	14 (26)	HES-related HCRU in the past 12 months, n (%)	
Chronic skin disease	13 (24)	Primary care provider	27 (50)
Gastrointestinal disorders*	27 (50)	Urgent care	3 (6)
COPD, emphysema, chronic bronchitis	8 (15)	Emergency room	9 (17)
Chronic sinusitis	7 (13)	Hospital admission	27 (50)
Vasculitis/EGPA	7 (13)	Allergist/immunologist	26 (48)
		Pulmonologist	16 (30)
		Other specialist**	15 (28)

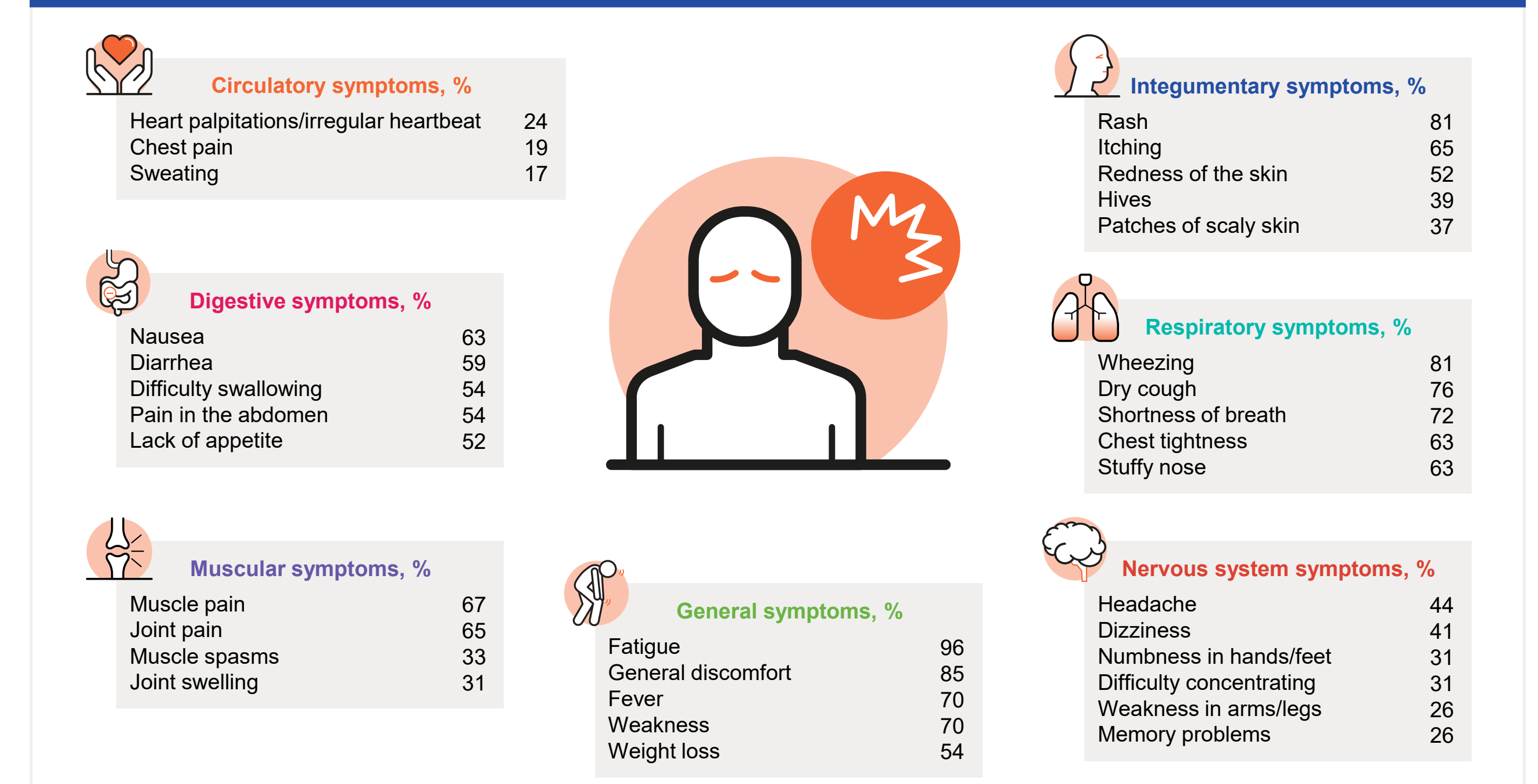
*Includes esophagitis, gastritis, colitis, irritable bowel disease; †Includes COPD, current/former smoker, eosinophilic asthma and eosinophilic pneumonia; ‡Includes eosinophilic gastritis/gastroenteritis, eosinophilic esophagitis, eosinophilic duodenitis and eosinophilic colitis; §Includes EGPA; ¶Includes over-the-counter medications: Tylenol and Flixonase nasal spray; **Includes gastroenterologists, ophthalmologists, hematologists, oncologists, and NIH.

Figure 1. The road to HES diagnosis was reported to be long and complicated



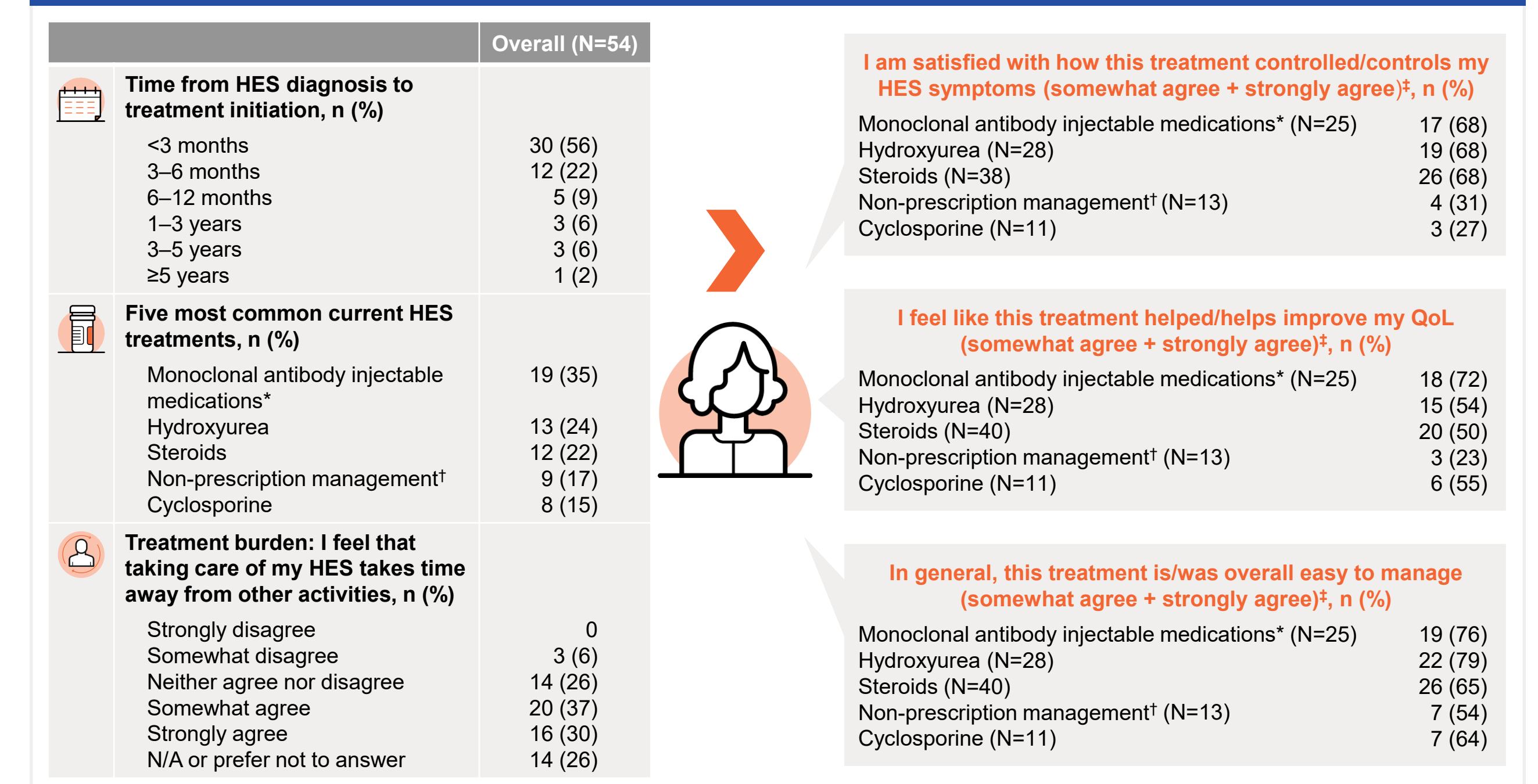
*Includes cardiologist, gastroenterologist and neurologist; †Includes spinal tap, endoscopy, colonoscopy, psychological tests, pulmonary function tests.

Figure 2. Patients with HES experienced a broad range of clinical symptoms*



*Where possible, the five most common symptoms in each category are presented. Symptoms may have been reported in more than one category, for example, shortness of breath and dizziness were also captured under circulatory symptoms (22%).

Figure 3. Patients reported a substantial treatment burden associated with HES, but satisfaction with monoclonal antibody injectable medications was high

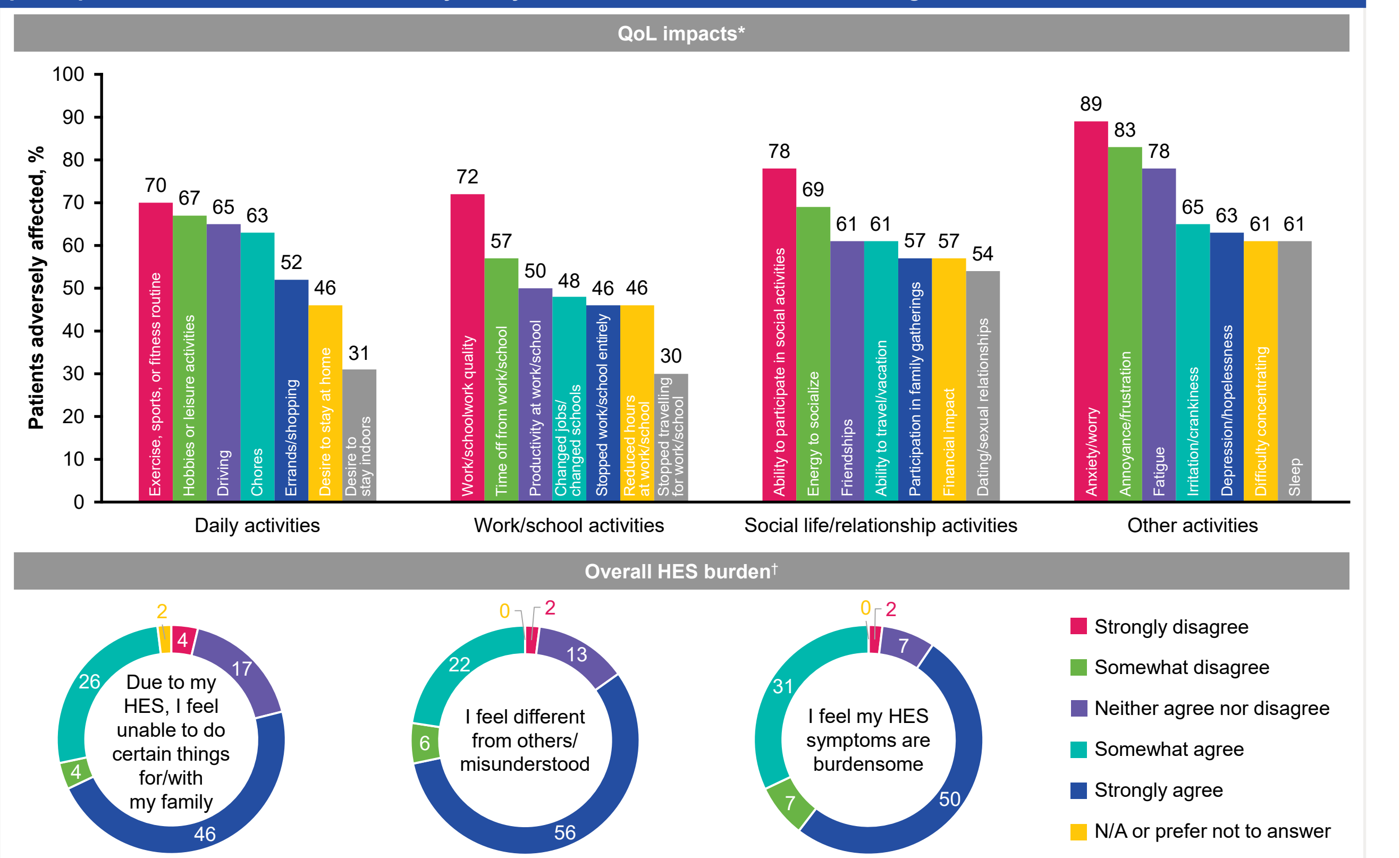


*Includes etoposide 50 mg tablet; †Includes over-the-counter medications: Tylenol and Flixonase nasal spray; ‡Data shown for the five most common current HES treatments.

Conclusions

- This study, using data collected through an exploratory patient survey, demonstrates the heterogeneous clinical presentation of HES and highlights the multifactorial burden associated with this disease.
 - Patients reported that the diagnosis pathway was complex, with several months to years often passing between the first symptoms and diagnosis, and over a third found the diagnostic process very difficult. This likely reflects patients visiting multiple healthcare providers and having extensive diagnostic testing.
 - Idiopathic HES was the most common variant. The rate of myeloid HES was higher and lymphocytic HES lower than previously documented, where incidences were reported between 10% and 20% for both variants.^{5,9-11}
 - The range of symptoms experienced by patients was broad, with the disease affecting multiple organ systems, and the management of which took time away from day-to-day activities; many reported adverse impacts on their QoL.
 - Monoclonal antibody therapy was the most commonly used current HES treatment, and was associated with symptomatic control, and linked closely with improved QoL for these patients.
 - Most patients were satisfied with their steroid treatment, and half felt the steroids helped improve their QoL, but the long-term adverse effects associated with their use were not explored.⁴
- These data highlight the key unmet needs of this population and offer a basis upon which diagnosis, care, and outcomes may be improved.

Figure 4. The most common QoL impacts adversely affecting patients included ability to exercise, work quality, ability to participate in social activities and anxiety/worry, and the overall HES burden was high



*The seven most common QoL impacts in each category are shown; †Percentage of patients in each category depicted.

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Abbreviations

APFED, American Partnership for Eosinophilic Disorders; COPD, chronic obstructive pulmonary disease; CT, computerized tomography; EGPA, eosinophilic granulomatosis with polyangiitis; HCRU, healthcare resource use; HES, hyper eosinophilic syndrome; MRI, magnetic resonance imaging; NIH, National Institute of Health; QoL, quality of life; SD, standard deviation; US, United States.

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