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Insights from Social Media on the Patient Experience of Living With Rare Eosinophil-Driven Diseases

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Abstract

Eosinophilic granulomatosis with polyangiitis (EGPA) and hypereosinophilic syndrome (HES) are driven by persistently high eosinophil numbers, causing damage to tissues and organs. As rare diseases, they are often underappreciated by healthcare professionals. Using a social listening analysis, we collected patient and caregiver comments relating to EGPA and HES made on online social platforms between 1 January 2019 and 31 May 2020, in English, French, and German. Results were classified into key areas of interest. In total, 746 comments with consent to publish were collected mentioning EGPA, and 39 were identified mentioning HES. The most common theme was sharing of personal experiences (EGPA: 77%; HES: 100%). Diagnosis, including diagnosis delays and misdiagnosis, was mentioned in 33% of comments for EGPA, and 82% for HES. Other common themes included seeking and giving advice, symptoms, and treatments. These insights highlight the views and unmet needs of people living with EGPA and HES. Further work should improve disease awareness and effective communications among healthcare professionals and patients with these conditions.

Keywords

patient education, patient engagement, qualitative methods, social media

Introduction

Eosinophils are white blood cells found in the blood that infiltrate the respiratory tract and other organs.[1] In healthy people, eosinophils work to fight against infections (namely parasites), and are typically associated with allergies.[1] When the number of eosinophils in the body is higher than the normal range for an extended period, they can damage tissues and organs. When activated, eosinophils release substances that are toxic to parasites and damaging to bodily tissues[2]; this can lead to many chronic symptoms and quality-of-life challenges for people living with eosinophil-driven diseases.

Eosinophilic granulomatosis with polyangiitis (EGPA) and hypereosinophilic syndromes (HES) are rare diseases. The Vasculitis Foundation reports the international incidence of EGPA at an estimated 2.5 cases per 100,000 adults per year (25 cases per million).[3] Estimates range from 10.7 to 14 cases per million people in Europe, to 18 cases per million in the United States, and 22.3 cases per million in Australia.[4–8] The World Health Organization estimates that HES are rarer than EGPA, with a yearly incidence of 3 to 4 cases per 10 million people worldwide, although this may be an underestimation due to missed diagnoses.[2]

EGPA is a serious but controllable disease, characterized by continually high eosinophil numbers in the blood, leading

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to tissue and blood vessel inflammation, i.e. vasculitis.[9,10] This can affect major organs, including the lungs and heart.[10] Treatment may control symptoms of the disease but must be maintained long term as this is a chronic illness with no known cure.[9,10] Clinical manifestations and common complications of EGPA include asthma, neuropathy (nerve damage often causing weakness, numbness, and pain), sinus issues, and involvement of other organs, leading to numerous visits to specialists and varied clinical evaluations by healthcare professionals (HCPs).[10] EGPA also has a significant impact on patients' quality of life, including issues related to loss of mobility, disruption to daily activities (such as the ability to work), patients' physical and emotional well-being, and psychosocial effects.[10]

In HES, high numbers of eosinophils are found in the blood and bodily tissues, where they cause damage, over an extended period of time, with no identifiable cause for hypereosinophilia.[11] HES can affect almost any organ in the body, with the skin, lungs, digestive tract, and heart being most frequently affected.[11] Patient symptoms and clinical findings vary significantly based on which tissues and/or organs are affected. The fragmented way in which these symptoms are often evaluated by different physicians can potentially affect the overall diagnosis, which consequently can be mistaken and/or delayed.[12,13] HES are often associated with some degree of disability, which may be severe in some cases, and can be traumatic and financially devastating for the patient and/or their family. HES can be fatal, and for some patients, by the time they receive a diagnosis, there is already substantial and potentially irreversible tissue and/or organ damage.

As rare diseases, there is a lack of information and awareness among HCPs that may lead to delays in diagnosis or misdiagnoses and mistreatments.[14] People with these conditions may feel isolated and uninformed about the disease, and may seek additional information to help understand it and connect with others who have similar experiences. Social media platforms offer patients the opportunity to share their experiences and strategies that have helped them manage chronic medical conditions, and enables them to connect with other patients, caregivers, advocates, and researchers around the globe. Social media is used to share health information and related articles of interest from a variety of online sources, thereby empowering patients through education and supporting discussion and shared decision making with their healthcare providers. Social media is accessed by broad demographics around the globe.[15,16]

Communicating through social forums indeed allows people to share knowledge and experiences, seek or give support, and learn from one another.[15,17] Social listening has been used to study other diseases, including dry-eye disease, multiple myeloma, and COVID-19.[15,17,18] Its strengths have been demonstrated in COVID-19, where a social listening analysis of patient experience has provided novel real-world insights, such as reports of rare and underreported symptoms of particular value to researchers.[17]

In this study, we searched comments on social media (social listening) to explore the patient and caregiver experience of EGPA and HES, including symptoms, diagnosis, and overall journey.

Methodology

This was an exploratory, qualitative analysis of comments and posts made by people with EGPA and HES, and caregivers on social media platforms. Using the Brandwatch Consumer Research platform, in combination with manual searches of sites not covered by this database (eg, Facebook), we developed a search strategy to identify online discussions relating to EGPA and HES between January 1, 2019 and May 31, 2020 (Supplemental Appendix A1). Only online comments from relevant patients and caregivers were included in this analysis and each was manually assessed to confirm and ensure the patient and caregiver experience was captured; online comments were assessed manually to confirm this aspect. Discussions from other individuals, such as HCPs, were excluded. Further information is available in the Supplemental Methods.

Results were analyzed based on key areas of interest and presented descriptively word-for-word, as detailed in the Supplemental Methods. When multiple themes were mentioned in one post, each theme was counted separately. Consent to use the data included in this article was considered implicit via the published terms and conditions of each social media platform, and/or the website privacy agreement with users. Any findings for which consent was not provided were not included in the final analysis. Data used for this publication have been limited to publicly available sources, with consent to use, and data were anonymized to ensure that they did not reveal any personally identifiable information.

Drug-specific information was not included in this report. Any mentions of drug-related adverse events were appropriately reported according to regulations. Patient quotes were reported verbatim.

Themes included: Patient descriptions of their experiences with the disease and quality of life (personal experience); Communication between patients looking for or providing guidance (seeking and giving of advice); Patient word choice relating to symptoms and/or complications (symptoms); Patient experiences with diagnosis, including what patients felt were barriers to optimal care and perceptions of treatments and treatment pathways (diagnosis and treatment); Patient experiences with healthcare services and access to care (experiences with healthcare services); Disease awareness discussions among patients, HCPs, targeted publics (schools, community organizations), or the general public (disease awareness); Any other topics that may be important to patients with EGPA or HES and caregivers (others).

Results

Total Online Mentions

In total, 746 online comments (mentions) relating to EGPA were identified, with consent to use, across at least 14

countries (Table 1), and over 15 social media platforms and websites (Supplemental Table S1). The majority of comments on EGPA were from the United States (386/746), followed by the United Kingdom (150/746), Germany (47/746), France (27/746), and Canada (26/746). A total of 171 comments were excluded due to lack of consent. The key themes are summarized in Table 2.

In total, 916 mentions were identified relating to HES; 877 comments were excluded due to lack of consent, as the comments were on a private page. Only 39 mentions were identified with consent to use from 4 countries and across 8 social media platforms and websites (Supplemental Table S2). Most comments on HES were from the United States (30/39), followed by Germany (2/39), Israel (2/39), and Mexico (1/39). The key themes are summarized in Table 2. Key quotes specific to each area of interest for both EGPA and HES are summarized in Table 3.

Table 1. Comments by Country – EGPA and HES.

Country	EGPA (N = 746)	HES (N = 39)
United States	386	30
United Kingdom	150	0
Germany	47	2
France	27	0
Canada	26	0
Australia	8	0
Colombia	8	0
New Zealand	6	0
Norway	6	0
The Netherlands	2	0
Sweden	2	0
Greece	1	0
St Lucia	1	0
Switzerland	1	0
Israel	0	2
Mexico	0	1
Unconfirmed	75	4

Abbreviations: EGPA, eosinophilic granulomatosis with polyangiitis; HES, hypereosinophilic syndrome.

Personal Experience

Personal experience was the most common issue noted online by patients with EGPA and their caregivers (77%; 577/746). For example, one comment stated, "I've withdrawn from people and seldom go out (unless to the clinic), preferring to talk by text, email and chat. I can't concentrate on work. I feel distant from my husband. I've found it very difficult to talk to friends, they don't quite understand." For patients with HES and caregivers, personal experience was also the most common theme (100%; 39/39), covering topics such as concerns, and sharing experiences with other patients. For both EGPA and HES, patients and caregivers shared the challenges and coping methods in relation to the condition. One patient with HES shared, "Dealing with all this has been hard, I admit. Luckily my family and friends, and my excellent medical team, have been here to help. Often in ways that have surprised and humbled me."

For both EGPA and HES, patients expressed feelings of loss of control, hopelessness, and isolation, as well as frustration with healthcare services. One patient with EGPA noted, "Every time I feel ill, I feel apologetic and ashamed." A patient with HES reported, "There were times I was so angry, bitter, and hopeless I considered suicide."

Patients with HES also shared positive feelings, including supporting others with HES and being able to enjoy aspects of life again once symptoms were under control with medication. One reported, "I wake up in the mornings, looking forward to what the day may bring, and not dreading the pain and tests and constant spiraling downward that had been my life."

Seeking and Giving of Advice

Patients with EGPA sought out advice from others online on how to manage symptoms (38%; 344/746). Their posts were frequently met with advice and encouragement from other patients and caregivers, with one comment offering encouragement: "You will learn to cope with it, but it can be very exhausting at times."

Table 2. Most Frequently Identified Themes – EGPA and HES.

Theme	Number of mentions (EGPA)	Number of mentions (HES)
Personal experience	577	39
Seeking and giving advice	344	18
Symptoms	285	24
Treatments	233	14
Diagnosis	248	32
Feelings of control or lack of control	129	9
Disease awareness (including a lack of)	119	7
Experience with healthcare services	59	6
COVID-19	100	2
Total[a]	746	39

Note: [a]Comments could contain more than one theme.
Abbreviations: COVID-19, coronavirus disease 2019; EGPA, eosinophilic granulomatosis with polyangiitis; HES, hypereosinophilic syndromes.

Table 3. Key Areas of Interest and Selected Verbatim Quotes From Patients and Caregivers With EGPA and HES.

Area of interest	Key quotes – EGPA	Key quotes – HES
Personal experience	• "I've withdrawn from people and seldom go out (unless to the clinic), preferring to talk by text, email and chat. I can't concentrate on work. I feel distant from my husband. I've found it very difficult to talk to friends, they don't quite understand." • "But one thing [my HCP] said has me angry-scared…chances are strong that the pain won't go away completely… My current portfolio of stress coping mechanisms [isn't] working now."	• "Dealing with all this has been hard, I admit. Luckily my family and friends, and my excellent medical team, have been here to help. Often in ways that have surprised and humbled me…" • "I missed so much school – we figured 2-3 days of EVERY week! – that I was lucky to graduate, much less get into university. I spent my entire third-grade year out sick – at home or in hospitals. It was incredibly lonely…"
Seekingand giving advice	• "Just looking for any hints, help or pointers. Anyone else here have this jolly disease?" • "So far her only main side effects have been tiredness, has anyone out there had similar treatment and do they know roughly how long it takes for the tiredness to go, many thanks and good luck all." • "I try to concentrate on what I can do, not what I can't do… I try to play the hand I've been dealt. It's not always easy but doable. Teach everyone about your disease and how it affects your life. We need to raise awareness wherever we can." • "You will learn to cope with it, but it can be very exhausting at times."	• "I saw that you liked a post about eosinophils. I suffer from a rare autoimmune disease called idiopathic hypereosinophilic syndrome. I was just wondering if you also have an eosinophilic disorder or if you are familiar with my disease." • "Hello, I am asking for any help possible in supporting this little boy [with HES] and his family in this very rough time…"
Symptoms	• "Sometimes I am just too tired to play a simple board game." • "I also just got diagnosed with [EGPA]. I've had a recurring cough/wheeze since October." • "I've suffered with a bit of joint pain when I've managed to do any type of exercise (kinda hard to do when most days you get out of breath standing up)." • "I have nerve damage in both thighs, parts of my feet (very minor), and in my left hand. In my hand, my median nerve died which means my palm, thumb, index, middle, and half of my ring finger were numb and immovable (when the nerve dies the muscles it innervates no longer function)."	• "Initially I had itching on my torso, but quickly started to feel tired, breathless, and had heart and lung pain. In what seemed unrelated, I started to feel discomfort in my feet. They were swollen and it was as if they were burning." • "I can't possibly make you understand what it was like to have extremely severe allergies and uncontrolled asthma – when there was virtually NO WAY TO TREAT IT for many years."
Diagnosis	• "It can take months or even years to get a diagnosis" • "My story wasn't unique, it was a case of seeing multiple doctors who weren't speaking to one another and getting multiple tests done and the results of these tests weren't shared between doctors that I was seeing. And the fact that this condition is rare and it just wasn't on the radar for many doctors."	• "It took us almost 20 years, an entire team of specialists (and ultimately NIH) to have the science catch up to what was happening to me – which is atypical [HES]" • "In 2017, I was hit with another major diagnosis: atypical [HES]…Now I think I've had it much, much longer than the past seven years we've documented."
Treatments	• "No side effects…and doing better with all symptoms…awesome stuff… praying for you." • "I have been reduced it (sic) steroid tablets but am concerned about all the side effects from the medications. I have started to get joint [pain] and particularly in the knees and elbow. I am taking several medications to combat steroid side effects. Please can anyone advise how you are coping and any advice on this problem." • "All medicines have done their job and I am back playing tennis 3 or 4 times a week." • "Once treatment started things really improved, and I've never had another flare up."	• "And for the past 10 months I've been on a new medication…that's making a real difference for me. Finally, I can see beyond just barely getting through each day." • "In the hospital, doctors prescribed IV steroids to calm down the pain and to see if that would help with eosinophil count. And it did!" • "I am also on a second biologic for [HES]…which in 20 months has truly been a life-saving miracle for me."

(continued)

Table 3. (continued)

Area of interest	Key quotes – EGPA	Key quotes – HES
Experience with healthcare services	• "I've had numerous [doctors] who have given me the run around and dismissed my concerns over the years." • "Doctors that maybe had one PowerPoint slide introduction to your disease in med school. And, not to show their hand or anything on how out of touch they are, they still call it by its original German name. A lot. And they correct you if you call it by its new name. Like you wouldn't know." • "When I first started seeing my current doctor, I was impressed with his bedside manner, his confidence in getting my illness under control, and seemed hopeful that his plan of attack would bring me something I never expected: remission. I was so excited to see him again." • "My husband has a rare illness EGPA, he has to get infusion treatments… when it gets worse… We have gone [through] our retirement savings paying for medications."	• "After a decade of getting steadily sicker with few doctors taking it seriously, my health was largely wrecked…" • "[After receiving treatment] I wake up in the mornings, looking forward to what the day may bring, and not dreading the pain and tests and constant spiraling downward that had been my life." • "I have another medication that is a biologic…It costs $1000 a month for the co-pay, and I get patient assistance for that. But, if I didn't…or if I lost my insurance…I'd be totally screwed and would be in the hospital more."
Disease awareness	• "The argument that a patient does not have a rare condition because it is rare is infantile." • "I hate when people tell me I'm too young to have all the problems I do. Statistically Churg-Strauss Syndrome is found in adults between 30 to 50 years old, but I've had it since I was 16. Why does my age have to correlate with how sick I am?" • "A sad fact that having a rare disease means we have to be so persistent there just aren't the recognised "pathways" for us. Also, it's presenting so differently this time, I'm under the "wrong" consultant, having fought to get into the respiratory specialism all those years ago." • "People don't think [EGPA] is real…"	• "As supportive as they've all been, none of them, though, not even the doctors, really understand what it's like to try to cope with so many complicated medical problems on top of the severe asthma." • "I have participated in National Eosinophil Awareness Week for two years. I make hot pink ribbons to share with family, friends and all those who ask about the meaning of them. I also wear my special pink bracelet made for this purpose."
COVID-19	• "I have had to explain to a few friends about why I am not panicking although taking this seriously. My short answer now is that I have had to learn how to roll with the unexpected, pick myself back up, get back to my calm positive mindset, and refocus. I think that is our learned superpower!" • "We are concerned that going to hospital may expose her to [COVID-19] (particularly as it is a respiratory nurse that administers it). We are trying to weigh up whether missing the dose is preferable to taking the risk of having it."	• "As a healthy, active 35-year-old I am very concerned about the prospect of widespread infection. I have hypereosinophilic syndrome (read: immune-suppressed) and have been previously hospitalized (ICU) for eosinophilic pneumonia. It's not just the elderly that are at risk."

Abbreviations: COVID-19, coronavirus disease 2019; EGPA, eosinophilic granulomatosis with polyangiitis; HCP, healthcare professional; HES, hypereosinophilic syndromes; ICU, intensive care unit; IV, intravenous; NIH, US National Institutes for Health.

Symptoms

For EGPA, of the patients who mentioned symptoms (38%; 285/746) the most frequently mentioned were asthma, neuropathy, sinus issues, pain, and fatigue. One patient highlighted the earlier symptoms of EGPA, stating, "I also just got diagnosed [with EGPA]. I've had a recurring cough/wheeze." Some posts highlighted the severity of fatigue with EGPA, with one patient noting, "Sometimes I am just too tired to play a simple board game." Other issues mentioned less frequently included skin, digestive, and musculoskeletal (muscle and bone) issues.

Mentions of symptoms from patients with HES (62%; 24/39) included respiratory, gastrointestinal (stomach and intestine), and dermatological (skin) issues.

Diagnosis and Treatments

A total of 248 comments (33%) from patients with EGPA related to diagnosis were identified, including mentions of HCPs overlooking symptoms that ultimately supported clinical diagnosis of EGPA, the length of time taken to gain a diagnosis, and referral to multiple specialists. One patient with EGPA noted, "It can take months or even years to get a diagnosis." Similar topics were explored by patients with HES, with 32 mentions (82%) of those covering diagnosis, including diagnostic delays as long as 20 years: "It took us almost 20 years, an entire team of specialists (and ultimately [the US] National Institutes of Health) to have the science catch up to what was happening to me—which is atypical hypereosinophilic syndrome."

For both EGPA and HES, mentions of drug information covered the efficacy and safety of steroids and biologics. Many patients shared their success stories after receiving treatment for their condition, such as one patient who noted that, "All medicines have done their job and I am back playing tennis 3 or 4 times a week." Another stated, "Once treatment started things really improved, and I've never had another flare up." Some patients also noted the potential negative effects of steroids: "They are not the best for you in the long term as they have a plethora of bad side effects, but you have to see the worth by weighing the good and the bad."

Experience with Healthcare Services

Patients' experiences with HCPs varied between EGPA and HES; however, both the diseases were associated with a high proportion of negative statements made on social media. Negative experiences were expressed in 75% of comments for EGPA and 100% of comments for HES. These included physicians providing an incorrect diagnosis or leaving patients with no diagnosis at all, patients being referred to multiple physicians while feeling a lack of progress toward receiving a diagnosis, and difficulty in accessing treatments due to a lack of diagnosis and affordability. However, 25% of comments for EGPA comprised positive experiences, including receiving treatment to control their symptoms, resulting in gratitude toward their clinician.

In some countries, healthcare services required for the diagnosis and treatment of EGPA and HES can incur significant financial costs. One caregiver of a patient with EGPA in the United States shared, "My husband has a rare illness EGPA, he has to get infusion treatments …We have gone [through] our retirement savings paying for medications." A patient with HES shared, "I also get a biologic drug injection monthly [because] my asthma is eosinophilic, I have an immune system disorder called hyper eosinophilic syndrome; the injection copay is $1000 a month but patient assistance covers it [because] otherwise there's no way."

Disease Awareness

Many comments relating to both EGPA and HES highlighted a lack of knowledge and awareness regarding the conditions, even among HCPs. One patient with EGPA noted, "[The] confusion here is that we are told different things from different doctors." Another said, "[A] sad fact that having a rare disease means we have to be so persistent there just aren't the recognized 'pathways' for us." One patient noted, "[N] one of them, not even the doctors, really understand what it's like to cope with so many complicated medical problems on top of severe asthma."

Other posts mentioned the need for disease awareness in both physicians and local communities, as both EGPA and HES can be misdiagnosed and poorly understood. One patient hopes to raise awareness of EGPA, and commented, "[V]ery little is known about EGPA… I am very lucky to be in remission, but I'm hoping to raise awareness and hoping for a cure." Other patients shared information, including details of awareness days, upcoming conferences, and events for patients with EGPA and their families. Methods for sharing information included patient attendance and discussion at the Vasculitis Foundation conference, and links to publications, podcasts, and videos.

COVID-19

Other comments reflected concern about coronavirus disease 2019 (COVID-19) in relation to EGPA and HES, and isolation. Some mentioned that patients feel vulnerable in the pandemic, but because of the lack of awareness about their illnesses, they often feel invisible. One patient with HES expressed concerns surrounding COVID-19, stating, "As a healthy, active 35-year-old I am very concerned about the prospect of widespread [COVID-19] infection. I have [HES]… and have been previously hospitalized..."

Discussion

We used social listening to explore the patient experience of EGPA and HES. Many comments made by patients and caregivers with EGPA or HES involved sharing of experiences,

seeking or giving of advice, or mutual support. Online discussion threads for both EGPA and HES commonly report many unmet needs, including a lack of information and disease awareness materials for patients, caregivers, and HCPs, highlighting the need for such materials to elevate disease and treatment awareness. Other key issues for patients included delays to diagnosis, symptom severity and associated disability, and available treatments. Patients mostly shared comments in social media groups that were focused on their condition, as well as on general health-focused forums.

Comments collected in this study reflect a broad perspective of patient experience relating to access to care, treatments, and support networks, but exclude discussions in other languages which may complement the findings in future research. Higher numbers of comments from the United States were indeed included in this analysis due to the selection of posts in English, French, and German, and potential cultural differences with respect to the use of social platforms, explaining greater representation of patient experiences from the United States. However, we were unable to explore potential cultural differences between countries due to the smaller number of comments from French and German speaking countries in comparison with the United States and the United Kingdom. Future research should focus on patients globally and include mentions in more languages, which would result in a greater number of mentions and a broader perspective of the patient experience of EGPA and HES.

A common theme discussed by both patients with EGPA and those with HES was the delay to diagnosis or lack of diagnosis. This finding is consistent with other rare diseases. A 2013 survey of patients in the United States and the United Kingdom (representing 466 rare diseases) reported an average of 7.6 years in the United States and 5.6 years in the United Kingdom to reach a diagnosis.[18] Patients reported receiving a diagnosis only after up to 8 physician visits, with 4 primary care physicians and 4 specialists, and following 2 to 3 misdiagnoses.[19] Our research supports this, suggesting that patients have to visit many specialists before receiving an accurate diagnosis.

For patients, describing their feelings and issues beyond disease symptoms may not always be possible in busy clinics. The rarity of their disease can also lead to a lack of disease awareness and understanding, which may lead to frustration and anxiety for patients. Most comments discussed personal experiences of loss of control and isolation, leading to negative impacts on patients' lives. A greater understanding of EGPA and HES and their impact upon the patient's quality of life may help develop a better treatment strategy for the individual patient whose personal experience and priorities may differ from those perceived by their physician. This could be facilitated by patient or HCP education, and tools to explore patient experiences and quality-of-life issues. Questionnaires adapted to these conditions that demonstrate the extent of the impact on patients' lives could support HCP understanding and broaden disease awareness.

There were many patients who mentioned the affordability of diagnosis and treatment that originated from the United States. In some countries, patients may experience financial difficulties and struggle to afford the appointments and tests required for diagnosis and treatment of EGPA or HES. Hence, support programs are required to assist patients with the costs of tests, appointments, and treatments, as well as other costs of living with EGPA and HES. However, such programs are often unavailable.

Limitations

A limitation of this study is that the data collected were constrained by the need for consent in order to use data. This is reflected in the large numbers of comments relating to HES that were excluded from the analysis. Of the 916 mentions collected, consent was obtained for only 39 comments. In comparison, of the 918 comments recorded mentioning EGPA, consent from the platforms was obtained for 746, resulting in a broader range of insights into EGPA than HES. Furthermore, this study was limited to 3 languages: English, German, and French. These languages were initially selected to explore and understand potential differences across cultures and countries in regions of strategic interest to the funder, an endpoint that was not reached due to the overwhelmingly predominant proportions of mentions in English. Although Spanish has more native speakers than English worldwide,[20] it was not included in this initial analysis.

Our study methodology provides holistic access to patient experiences and perspectives of EGPA and HES, highlighting their many unmet needs. However, social listening as a methodology remains challenging due to typographical errors and the use of colloquial language in records, as well as a lack of context for collected data. The use of online social platforms also assumes a bias toward digitally literate patients. That being said, a social listening analysis may provide real benefits to the study of rare diseases, where some symptoms may only appear in a few individuals and might be overlooked using other methods of patient or clinical research, with greater limitations on the number and scope of comments collected.

Conclusions

This social listening analysis has provided personal insights into 2 rare diseases via long-term collection of comments made online by patients and caregivers. Although EGPA and HES manifest differently, patients with these diseases report similar experiences across a range of key areas of interest, including a lack of disease awareness and support from their HCPs, families, and wider communities. These results indicate the need for further research into the experiences of patients with EGPA or HES, as well as their caregivers, and are promising with regard to further insights that could be gained into the experiences of patients with other rare eosinophil-driven diseases.

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Contributors

All authors contributed to the analysis or interpretation of the data. All authors drafted the work or analyzed it critically for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Data Availability Statement

Data are available upon request from GSK authors (lee.x.baylis@gsk.com).

Supplemental Material

Supplemental material for this article is available online.

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