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ORIGINAL RESEARCH

Emotional Journey of Patients with Eosinophilic Esophagitis

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ABSTRACT

Introduction: Eosinophilic esophagitis (EoE) is a chronic and progressive disease associated with dysphagia and eosinophilic infiltration of the esophageal mucosa. EoE can have a negative impact on a patient's quality of life (QoL); however, there is very limited data reflecting the emotional journey of patients with EoE or their perceived unmet needs. The aim of this study was to determine the emotional impact of EoE on patients at each stage of the patient journey.

Methods: In this cross-sectional and qualitative research study, adult patients with EoE from eight different countries provided their experiences and feelings across each stage of the patient journey through one-on-one semi-structured interviews.

Results: Twenty-one patients with EoE were enrolled in the study. The results of the one-on-one interviews showed that patients living with EoE go through an exhausting emotional experience during the different stages of the patient journey. In the pre-seeking-care stage, patients feel confused, afraid, frustrated, anxious, lonely, and misunderstood. During the diagnostic process, patients feel highly frustrated and angry because of the long and burdensome process. When EoE is finally diagnosed, patients feel liberated and relieved. When treatment is initiated, patients feel relief and enthusiasm, and, once the treatment starts to be effective and during the monitoring stage, they feel happier, less stressed, more confident, more relaxed, less fearful, and more in control owing to the improvement of their symptoms.

Conclusions: This study pays attention to the different stages of the journey of patients with EoE. There is a lack of awareness by both physicians and patients that negatively affects every stage of the patient journey, but especially the initial phases of pre seeking care and diagnosis. We intend for this article to represent an opportunity to increase EoE awareness and to show the importance of considering the emotional impact on a patient with EoE's journey.

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Key Summary Points

Why carry out this study?

Eosinophilic esophagitis is a chronic and progressive disease that can negatively affect patients' quality of life.

Although there is some evidence on the patient journey, there is still a gap of information regarding the emotions and feelings experienced by patients with EoE, from symptoms onset to treatment and monitoring.

The aim of this research was to determine the emotional impact of EoE through four phases of the patient journey, from pre seeking care through diagnosis and treatment/follow-up and finally monitoring.

What was learned from the study?

Patients with EoE go through a burdensome emotional journey. At the first stages of the patient journey, patients with EoE feel a set of negative emotions such as frustration, fear, anxiety, confusion, and loneliness, while at the final stages of the patient journey, patients feel more positive emotions such as relaxation, relief, happiness, and control.

There is a high unmet need perceived by patients to increase the level of EoE awareness among both patients and physicians.

This study represents an opportunity to increase EoE awareness and to show the importance of considering the emotional impact on a patient with EoE's journey.

INTRODUCTION

Eosinophilic esophagitis (EoE) is a chronic and progressive type 2 inflammatory disease associated with esophageal dysfunction and eosinophilic infiltration [1]. The incidence and prevalence of EoE have increased dramatically over time. EoE has a global presence and a pooled incidence rate of 5.71 cases per 100,000 inhabitants. The pooled prevalence is 30.79 cases per 100,000 inhabitants [2].

EoE can occur at any age, with increasing incidence with age and a peak at 30–50 years of age [3]. EoE clinical presentation is age-related; in adults, the most observed symptoms are dysphagia, food impaction, heartburn, and chest pain while children usually present with reflux-like symptoms, vomiting, abdominal pain, food refusal, and failure to thrive [3, 4]. Consequently, EoE negatively affects the quality of life (QoL) of patients and their families, impairing their social and psychological functioning [3, 5].

The first step in diagnosing EoE is to examine the patient's clinical presentation to see if it is suggestive of EoE and to perform a thorough evaluation for other possible medical conditions. However, to confirm the diagnosis of EoE, an endoscopy with biopsies must be performed [3, 6]. Diagnosis of EoE may be made when the biopsy analysis shows at least 15 eosinophils per high power field and other causes of esophageal eosinophilia have been ruled out [7]. Several studies have reported that the diagnostic process is long, with a mean delay of up to 11.1 years in time from the onset of first symptoms to diagnosis [5, 8, 9]. Patients describe the diagnostic process as burdensome, which contributes in part to the frustration felt by the patients [8]. Early diagnosis of EoE is particularly important as it is a progressive and persistent disease and the duration of the untreated disease directly correlates with more severe outcomes, including the presence of fibrosis, formation of strictures, and esophageal narrowing, resulting in esophageal dysfunction [5, 8, 9].

The standard treatments for EoE include the off-label use of proton pump inhibitors (PPI),

off-label use of oral corticosteroids, and elimination diets; in cases of fibrostenotic strictures, esophageal dilation is used [3, 10]. Dupilumab, a biologic (approved for EoE in 2023), and budesonide orodispersible tablet (approved for EoE in 2018), are the only approved medicines for the treatment of EoE by the European Medicines Agency (EMA) [11, 12]. Whereas in the USA, dupilumab is the only approved medication for EoE and was approved by the Food and Drug Administration (FDA) in 2022 [13].

In addition to the clinical burden, EoE can negatively impact the quality of life of patients and their family members. This burden may begin prior to seeking clinical care for symptoms and continues to worsen as the disease and related symptoms progress, such as dysphagia and food impactions. After treatment has been initiated, burdens often continue; these are related to access to therapies or the practicality of adhering to elimination diets. In the last decade, few studies have been published on the QoL of patients with EoE and shown an association between EoE and permanent QoL impairment in patients and their families. Emotional distress, limiting normal feeding, and restricting social activities were cited as factors contributing to diminished QoL [5, 14–17]. Despite assessing the QoL of patients with EoE, these studies do not reflect how the patient experiences each stage of the patient journey. Knowledge of patient experience related to a disease is essential for the design, implementation, delivery, and evaluation of health services and health technologies [18]. The patient journey represents the time sequence of what happens to the patient, especially during transitions of care. Conversely, the patient is the only person who has a continuously active and first-hand role during their health journey. They alone are in possession of information that characterizes the entire care experience. Every point of the patient journey offers data on health and patient experience outcomes that should be used to guide the improvements of healthcare systems [18]. To the best of our understanding, only one study documenting the journey of patients with EoE has been published [8]. This study provides a deep understanding of the clinical and humanistic burden of patients with EoE and their caregivers from symptom onset to diagnosis and beyond. However, it only included data from US patients and therefore the sample may not be representative of the overall EoE population. Moreover, the research by Pokrzywinski et al. does not reflect the emotional journey nor perceived unmet needs throughout each stage of the journey of a patient with EoE [8].

The aim of this study was to determine the emotional impact of EoE through four phases of the patient journey, from pre seeking care through diagnosis and treatment/follow-up and finally monitoring. At each stage of the patient journey, we sought to (1) describe the care pathway of a patient with EoE; (2) determine the level of EoE awareness of treating physicians; (3) characterize the impact of EoE on patients' QoL; and (4) get a deep understanding of patients' unmet needs.

METHODS

Study Design

This is a cross-sectional, qualitative research study involving one-on-one, semi-structured interviews with adult patients with EoE from eight different countries (USA, France, Canada, Spain, Italy, Germany, the Netherlands, and the UK).

Ethical Approval

As the aim of the study was to determine the patient's emotional perception of their EoE condition, the set of interviews was considered as a Market Research or "patient satisfaction survey." The study was conducted online, and no healthcare practitioners were involved in patient recruitment. The survey falls under the scope of market research and does not fall under the scope of regulations regarding observational studies or research implying human beings. For this reason, submission to an ethical committee was neither required nor sought. The study was

performed in accordance with the Helsinki Declaration of 1964, and its later amendments. Informed consent regarding participation and publication of outcomes were obtained from all individual participants in the study. The participants' privacy and confidentiality were guaranteed following healthcare personal data protection laws and regulations (GDPR, General Data Protection Regulation).

Study Participants

Patient recruitment was carried out by different entities/agencies, including patient associations, the sponsor's affiliate units, and recruitment agencies in each country. Patients were contacted via email or telephone. Once patients had confirmed their interest in participating in the study, a telephone call was arranged to conduct a screening questionnaire. The screening questionnaire consisted of eight questions aimed at understanding the patient's background (age, gender, race, symptom severity, socioeconomic background, and time since diagnosis) and determining eligibility for inclusion in the study. Inclusion criteria for the study were (1) patients must be at least 18 years old; (2) patients must have received a diagnosis of moderate to severe EoE by a specialist at least 3 years prior to this study (Table 1).

Table 1 Characteristics of included patients with EoE

Characteristic	Patients with EoE (N = 21)	
	N or mean	Percentage or range
Age	36 (mean)	20–70
Gender		
Male	12	57%
Female	9	43%
Race		
Caucasian	18	76%
Others	3	14%
Employment status		
Unemployed	2	10%
Student	3	14%
Employed	16	76%
Severity of EoE[a]		
Moderate	10	53%
Severe	9	47%
Symptoms onset and diagnosis, years		
Age at symptoms onset	12 (mean)	0–56
Age at diagnosis	25 (mean)	2–60
Comorbidities[b]		
Asthma	7	33%
Allergies	10	47%
Others	8	38%

[a]Data was not available for two patients
[b]Patients might be affected by more than one comorbidity

Interviews

Researchers spoke to each patient in a one-on-one, semi-structured qualitative interview. Each interview lasted approximately 60 min and was conducted via video conference. All interviews were recorded and were conducted using a guide that had been validated by an EoE specialist clinician.

The interview guide was structured into five sections and included open-ended questions designed to inquire about the patients' profiles, pre-seeking-care, diagnosis, treatment, follow-up, and monitoring journeys. Each of these sections, except the patient profile section, was divided into five different categories: symptomatology, clinical management, awareness and education, impact on QoL, and perceived unmet needs (Table 2). Patient characteristics including, gender, age, race, education level, employment status, symptoms onset and age at diagnosis, the symptoms severity of EoE (using Straumann's dysphagia index instrument, SDI), and comorbidities were determined at the beginning of the interview [19].

Table 2 Sections and categories of the interview guide and description of the open-ended questions asked to the participants

Section/category	Description
Sections	
Pre seeking care	From the time the patient first notices symptoms until they actively sought medical care to understand the root cause of such symptoms
Diagnosis	From the time patients sought care until they received the diagnosis of EoE
Treatment and follow-up	From when patients started treatment until their last treatment
Monitoring	Patient's long-term monitoring with a deep dive into their current situation
Categories	
Symptomatology	Signs, affections, and/or clinical manifestations of the patient experience due to EoE. Additionally, references to consequential emotions and/or impact from such signs can be made
Clinical management	Clinical pathway the patients have followed throughout the specific patient journey phase and their mainly reported remarks on that area
Awareness and education	Level of information of patients regarding EoE, how they get such information, why they want it, and any other similar topic in this area
Impact on QoL	Affection and/or influence the disease has on patients' quality of life. For that, a holistic approach has been taken to consider all aspects of QoL, from emotional to daily life activities
Perceived unmet needs	Main challenges and what would they change from what they had experienced throughout the whole specific patient journey phase, and/or any other general complaint area they have reported

Results Analysis

The qualitative information gathered from the interviews underwent analysis through a content analysis method involving thematic analysis. This technique consists of dissecting qualitative data by perusing a dataset to uncover patterns in its underlying meaning, thereby identifying overarching themes [20]. As for quantitative data, it was analyzed using descriptive statistical measures, such as frequencies, means, and standard deviations, in Microsoft Excel.

RESULTS

Study Participants

A total of 26 patients were screened using a screening questionnaire; four of them were excluded because they did not meet one of the inclusion criteria and one was excluded because of difficulties contacting them (Table 1). Twenty-one patients with EoE were enrolled in one-on-one interviews. Of these patients, seven were from the USA, two from Canada, two from Germany, two from France, two from Italy, two from Spain, two from the Netherlands, and two from the UK.

Pre Seeking Care

Food impaction was the most frequently experienced first acute symptom (70%), followed by vomiting, diarrhea, heartburn, and chest pain (Fig. 1). During these first acute symptoms,

patients reported a variety of reactions, often described as confusion (33%) and fear (27%) (Fig. 2). Patients tend to associate the event with having eaten too quickly, not chewing food properly, or confusing the symptoms with choking (Table 3).

None of the patients had previous knowledge of EoE before visiting a health care provider (HCP) and almost half of them (44%) related their symptoms to other diseases or conditions, such as infections, allergies, and cancer. Almost half of the patients (44%) sought information about the possible causes of their symptoms mainly through the internet. Most of the patients who did not seek information stated that the reason was difficulties finding information at that time as they did not have internet access.

Socialization was the daily life aspect most affected by EoE symptoms before seeking care, affecting 60% of patients participating in social meals (Fig. 3) (Table 3). The reason for that was either the embarrassment experienced from symptoms and their consequences, such as eating slower than others, and/or the stress of having to be prepared to manage an acute event, for example, needing a bathroom nearby to vomit food impactions. A vast majority of patients (85%) stated that at the pre-seeking-care stage, they had already introduced dietary or lifestyle changes to cope with EoE symptoms, such as avoiding certain textures of food or coating their food with sauces to help lubricate it so that it was more easily swallowed, and drinking a lot of liquid. Patients described these lifestyle adaptations as stressful, citing time and energy spent preparing meals, lacking energy due to inadequate nutrition, experiencing limitations surrounding work and social activities, and the inability to travel due to treatment and symptoms burden such as restricted diets and food impactions, respectively. Thirteen percent of the patients stated that their work/school life was the most affected aspect of their daily life, as they had to be absent as a result of their illness. Mealtime, referring to time spent preparing meals, and negative experiences during eating, such as choking, was the most affected aspect of the daily life for 20% of patients. Moreover, EoE symptoms affected the mood and feelings of 89% of the patients, with frustration, anxiety, loneliness, helplessness, and incomprehension being the most reported feelings. The main reasons for these feelings were cited as the uncertainty of not knowing the root cause of the symptoms, as well as the perceived lack of support from those close to them, including their family.

Most of the patients (80%) stated that at this stage of the patient journey they would have liked to have had more information about EoE available and more disease awareness by the medical team, their families, and friends (Table 3).

Diagnosis

Patients' main motivation for seeking care was their symptoms and gradual worsening of them

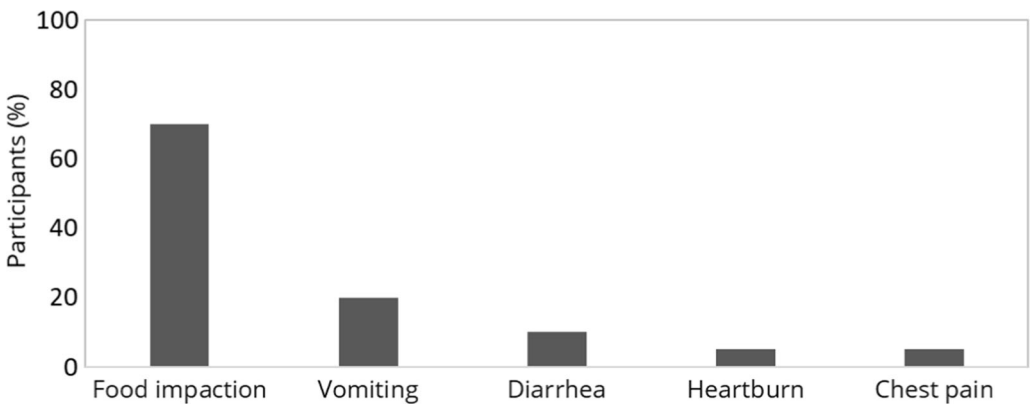

Fig. 1 First symptoms of EoE in the pre-seeking-care stage. More than one symptom could have been selected for each

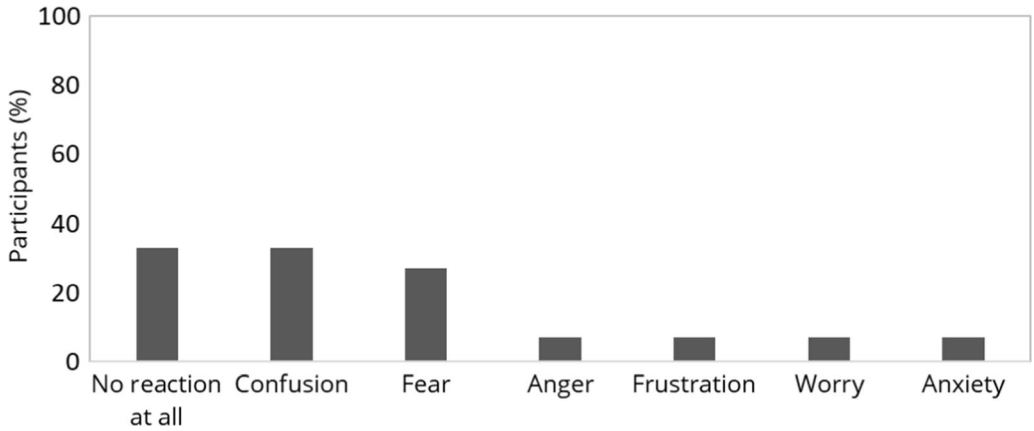

Fig. 2 Emotions experienced by patients with the onset of the first symptoms of EoE. More than one emotion could have been selected for each

(89%). Family pressure was another relevant reason why patients sought medical care (11%).

The main diagnostic pathway mentioned by patients included several types of HCPs, including general practitioners (GP), gastroenterologists (GI), allergologists, endocrinologists, otolaryngologists (ENT), and psychologists. The most frequently mentioned HCP were GPs, allergists, and GIs. The diagnostic process also included multiple visits to different physicians in the same specialty, for example, visiting different GIs to finally reach one who is familiar with EoE and can give a diagnosis to the patient.

The diagnosis of EoE was made by a GI in almost all cases (90%); in one case the diagnosis was made by a GI and an allergologist, and in another case by an endocrinologist. Most patients (86%) claimed to have gone through several referrals before getting to the GI who made the correct diagnosis, further delaying diagnosis. The most frequently reported HCP that was first involved in the process was GP, who then referred patients to ENT, psychologists, allergologists, and GIs. There were three main reasons that patients reported challenges in getting referrals to a specialist; first: the geographic location; patients living in rural areas were less likely to see an HCP who was aware of EoE. Second: the type of specialist referral from the GP; if the GP referred the patient to a GI or to an allergologist, the diagnostic timeline would likely be decreased. In a noticeable number of cases, physicians associated symptoms with psychological reasons, and in some female respondents, physicians attributed symptoms to eating disorders such as anorexia or bulimia. One female patient was referred to a psychiatrist and prescribed antidepressants. Third: patients' EoE awareness made them proactively seek out, or push for, a referral to a GI or to a GI specialized in EoE. During the process of visits to multiple HCPs, patients underwent various tests before being scheduled for confirmatory endoscopy. The most frequent tests were computed tomography (CT) scans, blood tests, allergy tests, colonoscopies, esophageal biopsies, X-rays, and swallowing tests.

The mean time elapsed between a patient's first medical consultation to obtaining a diagnosis of EoE was 7.1 years and ranged from 1 month to 20 years. When considering the age at which patients first experienced symptoms until they obtain a diagnosis of EoE, the median time to receive a diagnosis increases markedly to 12.6 years, with a duration of 30 and 40 years for some cases (n = 3). Average diagnosis time is very dependent upon the country, being the highest in Spain and the lowest in France (Table 4).

During their journey, many patients had to visit the emergency department one or more times before and/or after diagnosis, mostly as a result of food impaction. However, their experience varied greatly between visits that occurred before or after diagnosis. When they occurred after diagnosis, the visits were

Table 3 Examples of patient quotes of each category from the pre-seeking-care stage of the patient journey

Category	Patient quote
Symptomatology	"I was worried and scared because my initial thought was that I was choking, but my sister told me that I wasn't because I was able to breathe. I didn't know what to do at that moment"
Education and awareness	"I thought it was cancer, due to my family medical history"
Impact on QoL	"I told family members that it was difficult to eat, and I was just told that it was all in my head… it was quite scary because at the time I did not know I had any condition, no one was listening to what I was saying… so there was a lot of frustration and worry when I started having symptoms"
Perceived unmet needs	"As a little kid, it was very traumatic, difficult, and intense, knowing that something might be wrong with me and nobody really knew what was going on, plus I missed half of some school years, and people thought it was psychosomatic"

smoother because the patient could inform the physicians about their condition and the medical team could act accordingly.

Once diagnosed, 90% of patients seek more information about EoE. The main areas of interest to patients seeking information were the life experiences of other patients, advice from more experienced patients on how to cope with the disease, the development of new treatments, and the status of academic and clinical research on EoE. Half of the patients with EoE (52%) engaged with patient organizations (POs) after their diagnosis, reporting that POs had been essential for offering unique emotional support and a community of people who have been through the same experience and can show empathy, reassurance, and advice for daily living (Table 5).

Almost half of patients (45%) reported that the impact of the disease and lifestyle adaptations on their QoL did not change from the pre-care-seeking phase. The most recurrent changes in their daily lives would be those related to the implementation of more refined elimination diets, usually proposed by the physicians visited throughout the diagnostic process. While 37% of patients reported no difference in their social life between the pre-care-seeking period and the diagnosis phase, 53% of them stated that their social life was the aspect most affected by EoE symptoms during this stage (Table 5).

Seeking diagnosis affected all patients emotionally. Most patients (75%) reported that

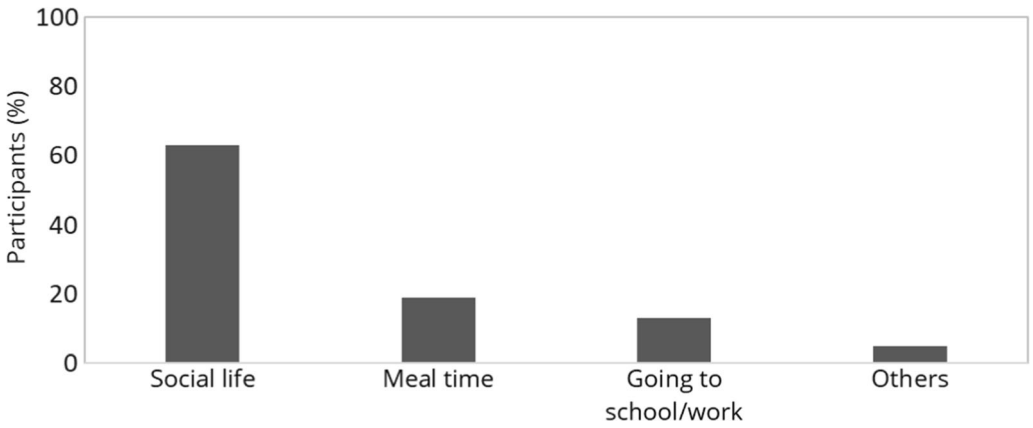

Fig. 3 Aspects of the daily life of patients most affected by EoE symptoms during the pre-seeking-care stage

Table 4 Average time from symptoms to diagnosis per country (years), rounded to the closest integer

Country	USA	Canada	Germany	France	Italy	Spain	Netherlands	UK
Years from first symptoms to diagnosis	16	16	10	< 1	18	19	8	3
Range (min–max)	1–40	10–21	9–11	< 1	15–21	5–33	2–13	3
Years from seeking care to diagnosis	10	7	3	< 1	15	13	5	2
Range (min–max)	< 1–35	5–8	< 1–5	< 1	9–20	5–20	2–7	2

receiving an official diagnosis of EoE was a liberating moment, that they experienced a great sense of relief and validation and felt that their family and friends stopped disregarding their feelings and emotions. It provided general social acceptance and support for their symptom-coping methods. Some patients (25%) reported feeling annoyed and depressed after receiving the diagnosis of EoE or when they began to realize what it meant to live with a confirmed diagnosis of EoE. The main reasons reported were related to the chronic nature of the disease and the enormity of what a diagnosis of EoE means in lifestyle change (Table 5).

All patients reported high levels of frustration due to the long and arduous process of obtaining a confirmed diagnosis. Patients complained about physicians' lack of knowledge about EoE and its symptoms, minimization of the severity and impact of symptoms, as well as physicians' lack of proactivity and empathy in looking for the root cause of symptoms with a holistic perspective (Table 5).

Treatment and Follow-up

All patients reported starting their first EoE-specific treatment immediately or shortly after diagnosis, and this was prescribed and managed by the GI. Elimination diets, PPIs, and corticosteroids were the most prescribed treatments (Fig. 4). In almost all patients (95%), the treatments helped to reduce their symptoms. However, within the different treatments available, there was a notable variation in levels of efficacy reported by patients. Consequently, patients and their physicians must go through their own journey of discovery to assess which treatments work best for them through trial and error. In addition, the efficacy of treatments also sometimes varied over time in the same individual, adding further complexity to symptom management (Table 6).

Most patients (70%) continued to seek information after starting treatment. In addition to talking to their GI physicians, most patients sought information through internet searches, POs, and other communities such as social networks. Patients sought information mainly about their current treatments, existing alternatives, and practical advice (Table 6).

The majority of patients (74%) reported that the efficacy of their treatment for reducing EoE symptoms had a positive impact on their social life. The main areas of improvement were those related to food, such as going out to eat with friends. Consequently, patients' moods and feelings improved; they felt happier, more self-confident, less stressed, and less fearful. In addition, patients reported a greater sense of control, which increased their sense of confidence. However, a considerable number of patients (40%) continued to experience negative feelings while on treatment, such as fear of experiencing an acute event in public, disappointment when a specific treatment was not effective, or fear of the chronicity of the disease. In addition, almost all patients continued to spend more time planning, shopping, and preparing their meals, as well as spending more money on food alternatives. All patients who underwent biological treatments ($n = 4$) expressed high levels of satisfaction, and in some cases described it as a positive life change, in contrast to patients' experiences with other treatments, such as PPIs and corticosteroids, where satisfaction levels varied (Table 6).

Several patients expressed the need for more individualized care, closer support from HCPs,

Table 5 Examples of patient quotes of each category from the diagnosis stage of the patient journey

Category	Patient quote
Symptomatology	"You see food and you see a monster; you don't feel like moving, just imagine, sometimes you can't even swallow your own saliva"
Clinical management	"The GP sent me to the ENT who passed me a probe [to anatomically check her throat] through my nose down to my throat… and he said [her ENT], in your throat, there is enough space for a whole chicken, this problem [referring to her EoE symptoms] is in your mind… he [her ENT] then referred me to the mental health unit, for a suspicion on eating disorders"
	"It was like I knew something was wrong and I was not getting the answers I needed, and it was very frustrating, and it was taking a toll on me"
Education and awareness	"I wanted to know more and more about the disease in general, and mostly to know what process other people had followed [referring to what pushed her to look for POs]"
Impact on QoL	"I cried; I was like, do you see how I was not crazy?! [referring to when she was told she had EoE and could associate her symptoms with a physiological reason]"
	"Relief because I knew what to fight, and I no longer felt guilty. I thought I was the one who could not swallow; I believed I was the problem"
Perceived unmet needs	"I visited six different gastroenterologists and five of them just said that nothing was wrong with me or that I was throwing up to get my parent's attention"
	"10 years ago, when you are already in an emergency room, I would have liked someone to say hey, everything is not psychological, do not swallow a pill and just go home, let's do further testing"

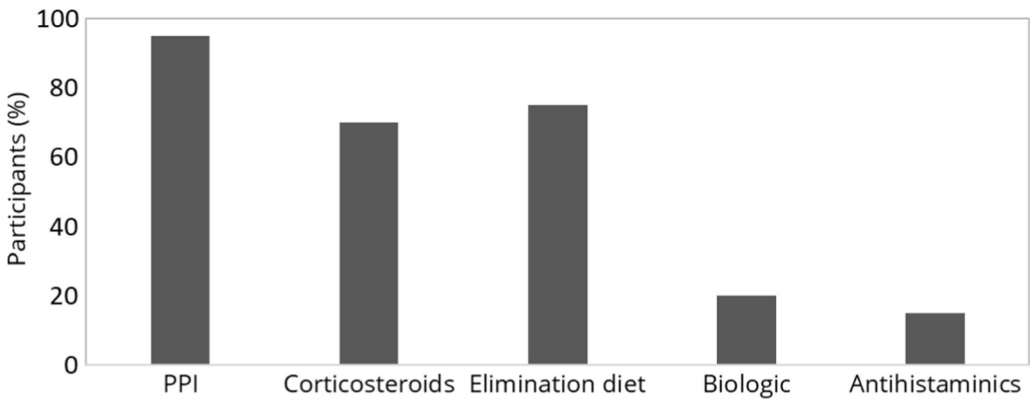

Fig. 4 Percentage of therapies prescribed for the treatment of EoE. More than one therapy could have been selected for each patient

and long-term follow-up. In this regard, patients mentioned several related recommendations, such as that physicians should consider all alternatives when a treatment does not work, take a more holistic view of the patient's evolution when considering treatments, communicate more with patients, be more aware of the chronicity of the disease, and provide/facilitate necessary ongoing support (Table 6).

Table 6 Examples of patient quotes of each category from the treatment and follow-up stage of the patient journey

Category	Patient quote
Symptomatology	"I am not the same. Taking for granted that the food passed all over the esophagus, and now I am aware that you do not notice the food falling into the esophagus, that I don't have to be afraid when I sit down to eat, I enjoy it, and my thoughts are not on the food, but on enjoying the surroundings"
Clinical management	"I remember the doctor mentioning that there were several treatments, without explaining them all, and told me that I would get one treatment and then if it did not work, he would give me another. I am not sure if the doctor mentioned the types of treatments. I would have liked to have a bit more information in order to have a deeper understanding of the treatments and their potential long-term effects"
Education and awareness	"I read a lot of studies and books and sought contact with others, and now it's me telling the doctors what medications I want to test because the doctors offered me treatments, but with no further thought; they just tell me that 'x' drug is being researched and that I could try it"
Impact on QoL	"I was excited to start treatment and see if it could unlock more things for me"
	"I wasn't sad or upset about it because I lived with it for so long, so I've always been pretty practical, but I think I was disappointed that things weren't working out"
	"It has improved drastically, I'm so much more comfortable eating out, and I don't have any more food anxiety or social anxiety when it comes to physically swallowing food"
Perceived unmet needs	"I would have liked to have been taken care of, even when my symptoms were improving, because it's a chronic disease and just because my symptoms are improving doesn't mean it's over"

Monitoring

Almost all patients (95%) reported still being on treatment at the time of the interview; the most frequent were elimination diets, PPI, and corticosteroids. Three patients reported being on biologics. A few patients (10%) mentioned that they took the treatment only when they considered it necessary, while the rest adhered to a consistent treatment regimen. Most patients reported having a check-up appointment every 6 months to 2 years to ensure the disease is controlled. In addition, a few patients mentioned being encouraged to contact their doctor if they feel worse or have questions (Table 7).

When referring to their current stage in their EoE journey, most patients reported a better QoL compared to previous phases. In addition to the improvement resulting from the treatments, some patients mentioned that the experience and knowledge acquired over time, plus the adaptations made to minimize the impact of the disease also contributed positively. However, despite the notable improvements in many patients, the disease still affects them to some extent, with most patients (70%) mentioning that their condition is always on their mind, or they still have some fear of trying new foods or experiencing a food impaction in public. Patients also reported remaining cautious about what they eat, maintaining certain habits they acquired in the past, such as avoiding certain foods, eating slower, or spending more time planning, shopping, or preparing their meals (Table 7).

Regarding disease awareness, most patients expressed an interest in keeping up to date with disease-related information, such as new treatments, including those in development. They usually obtain this information through POs, other patient-centered online resources, and their physicians (Table 7).

Regarding the future of their EoE, 83% of patients expressed the most concern about disease progression and reduced treatment efficacy over time. In addition, patients who have or are planning to have children were concerned that they might inherit the disease. The most reported hopes revolved around new treatments emerging from research. The majority of the

patients were optimistic about biologics and the current path of research.

Emotional Journey

The emotional journey of the patient through all the phases of the disease, from pre seeking care to monitoring, is represented in Fig. 5. Patients with EoE go through an exhausting emotional experience during each stage of their journey. First, during the pre-seeking-care stage, patients reported feeling confused and afraid because of the initial symptoms, which are usually considered by the patient to be punctual events that will not repeat over time. Once the symptoms become recurrent and start requiring lifestyle adaptions, patients feel frustrated, anxious, lonely, and misunderstood. In the diagnosis stage, as patients' QoL worsens, patients reported feeling afraid, worried, and tired of their situation. As a result of the arduous diagnostic process including repeated disregard by the medical team and not getting answers, patients reported feeling highly frustrated and angry. When the diagnosis of EoE was finally confirmed, patients reported feeling liberated, relieved, and with a sense of validation. Patients reported that once they had a diagnosis of EoE, they were immediately offered treatment. At this stage, patients feel relieved and excited to have something that may improve their symptoms, as well as give them some control over EoE. However, during the treatment phase, some treatments were not as effective for all patients or stop working, then the HCP needed to find other therapy options, in turn causing the patients to feel disappointed. Patients on effective treatments described feeling happier, less stressed, more confident, more relaxed, less afraid, and more in control when their symptoms improved. Finally, during the monitoring phase of the patient journey, patients reported feeling the same as in the end phase of the treatment stage, when treatment is finally working. Also at this point, they outlined worries about disease progression and long-term treatment efficacy.

As a result of the high emotional burden of EoE, more than half of the patients (55%) sought help from a psychologist or a related HCP, and half of them considered the experience to have been helpful. The other types of related HCPs cited were food therapists and psychiatrists. Furthermore, most patients (85%) reported that their family members were also affected by EoE in multiple ways. Examples

Table 7 Examples of patient quotes of each category from the monitoring stage of the patient journey

Category	Patient quote
Symptomatology	"Every now and then I feel as if there is a slight pressure in the upper part of the esophagus where there was a stenosis as if it reminded me that I have this disease, but it does not bother me at all"
Clinical management	"At the moment, I take medication only on an as-needed basis, so I'm not taking it regularly; I'm just taking it if I feel like I need it… PPIs and the inhaler as well… I would say more the PPI than the inhaler though"
Education and awareness	"Yes, I think I'm always looking for information, especially on developments in treatments because I have the impression that there are often new things or that they are being developed. It's true that it's not always easy to find information"
Impact on QoL	"The fear of trying new foods and a very, very minor fear of getting an impaction in public. But it really hasn't happened for a pretty long time"
Perceived unmet needs	"I hope to be a mom one day, and I don't want to pass something like this on to my child, but if it happens at least now I know the science to look out for and the things to do, but it's a big worry when it comes to it"

include the need for family members to modify their lifestyle, such as avoiding going out to restaurants and traveling, attending fewer social events, taking time off work, spending more time attending medical appointments and hospitalizations, or providing more caregiving to their family members with EoE. In addition, family members also suffered emotionally by experiencing fear, stress, or frustration.

Regarding the school or work life of patients with EoE, most patients reported having had their school or work life negatively impacted by their disease at some point in their journey. Reduced school/work hours due to doctor's appointments was the most reported reason by patients (50% of patients); 35% of patients missed work or school-related trips as a result of the disease. A few patients (20%) had to change schools or jobs because of the disease. As an example, one patient mentioned having to move to a private school because the public school was overcrowded and could not adequately accommodate the medical needs of the student. A few patients (15%) had to stop working or studying for long periods of time as a result of the disease.

DISCUSSION

EoE has been known as its own entity since 1993 [21]. The knowledge about EoE among clinicians as well as the public has increased in the last 20 years but there is still a need for increased understanding not only to diagnose the disease but also to care for the patients. It is now well known that EoE significantly impacts the QoL of patients, impairing their social and psychological functioning. In the last decade, several studies relating to how EoE affects patients' QoL have been published [5, 9, 22, 23]. However, most of these studies were focused on the QoL of patients at only one phase of the patient journey. Pokrzywinski et al. published a qualitative research study on the journey of patients with EoE; the study has some limitations including limited geographical scope to only US patients, so it may not be representative of the overall EoE population. Furthermore, it does not reflect the patient's entire emotional journey or their perceived unmet needs [8].

In the present study, the patient journey was determined through a sample of 21 adult patients with EoE from eight countries, focusing on the emotions and unmet needs of patients at each phase of the patient's journey.

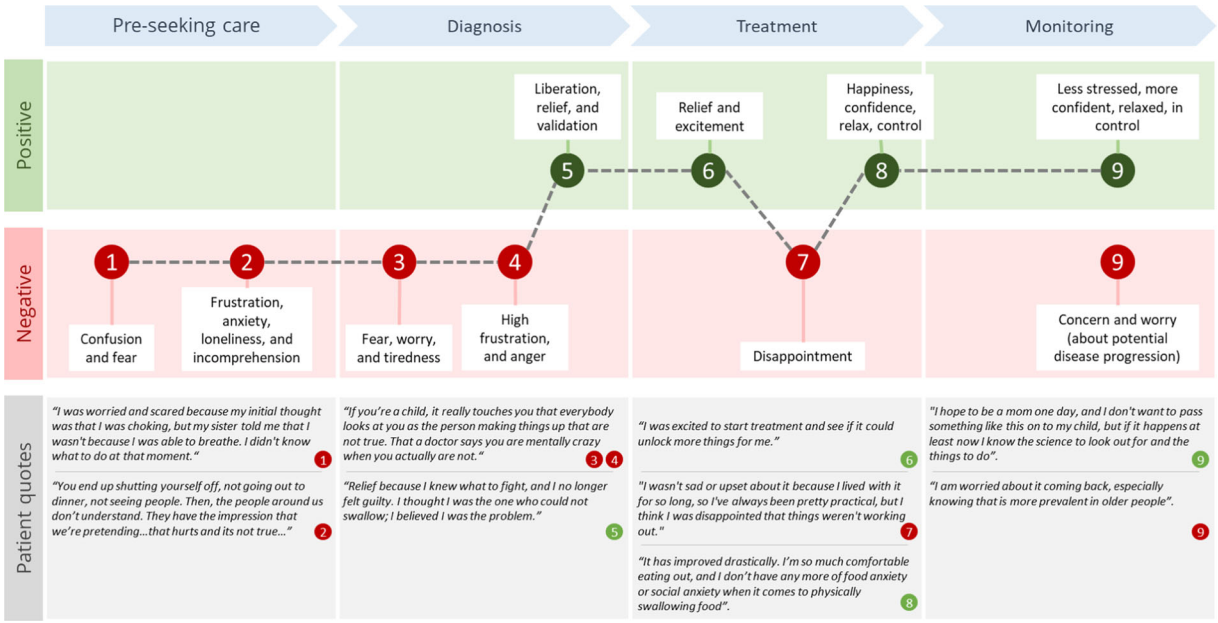

Fig. 5 Emotional journey of patients with EoE

This cross-sectional study showed that when the first EoE symptoms appeared, usually food impactions, (patients typically did not associate them with any specific disease) making them feel confused and/or afraid. This is in line with other studies of QoL and EoE; together with dysphagia, food impactions are the most common symptoms experienced by adults and the symptom that influences most patients' QoL [3, 5, 24]. In this study we show that the diagnosis journey for EoE is long and burdensome; the mean time elapsed between the patient's first medical consultation and obtaining a final diagnosis is 7.3 years, ranging from 1 month to 20 years. This is because the symptoms of EoE are commonly associated with psychological reasons, such as eating disorders and other mental health problems, or with other conditions unrelated to the digestive system, and therefore patients are not initially referred to GIs. This greatly influences the time to diagnosis and increases patient distress during that time. A delay of several years from the onset of symptoms to confirmed diagnosis is common among patients with EoE [9]. However, early diagnosis is particularly important in EoE as it is a progressive disorder that if left untreated progresses to esophageal remodeling, rigidity, and luminal narrowing, further negatively impacting patients' QoL [4, 5]. Evidence suggests that early diagnosis of EoE may help in resolving long-lasting QoL impairments in EoE [5]. The moment when patients receive the diagnosis of EoE is described as a moment of release, relief, and validation by most patients owing to the revelation of the disease-related cause of their symptoms. Shortly after diagnosis patients start receiving treatment with elimination diets, PPIs, and topical corticosteroids being the most commonly prescribed treatments in this cohort. Most patients feel relief and excitement at this stage. Treatment effectiveness improves patients' QoL and, consequently, their mood and feelings, making them feel happier, less stressed, more self-confident, and more in control. However, some patients still feel fear of having an acute event in public and/or disappointment when treatment is not effective. Furthermore, patients highlighted that there is a need for more available treatments for EoE. Elimination diets, PPIs, and orally administered topical corticosteroids, or a combination of these, are the first-line therapies for the treatment of EoE. These treatments may lead to concerns about side effects and how patients continue to function [3, 17] and therefore greater education is needed to inform them about the realities of therapy side effects. Elimination diets have been shown to have a significantly negative emotional impact due to challenges when eating away from home or eating food prepared by others. Additionally, patients express difficulties with adhering to dietary restrictions [5, 17, 23]. Hence, patients claim a need for more available effective therapies for the treatment of EoE. In this regard, biological agents might be an effective treatment alternative, e.g., dupilumab, a monoclonal antibody blocking interleukin-4 and interleukin-13, which has been shown to improve histologic outcomes and alleviate symptoms of the EoE [25, 26]. In our study, all patients who underwent biological treatments (n = 4) expressed high levels of satisfaction, and in some cases described it as a positive life change. It should be noted that at the time of the interviews, dupilumab was only approved in the USA for EoE treatment. Most patients were still on treatment at the time of the interview, and they regularly have check-up appointments once or twice a year. Most patients reported a better QoL in the monitoring phase compared to the previous phases, mostly related to treatments and the experience and knowledge acquired over time.

This research revealed a lack of knowledge of the disease by both physicians and patients. This lack of knowledge, directly or indirectly, has a negative impact on all aspects of the patient's journey at any stage, but especially in the initial phases of pre seeking care and diagnosis (Fig. 5). Furthermore, EoE has a negative impact on all aspects of the patients' life, primarily on social life but also on school and work life, and on the ability to travel. Consequently, more than half of the patients reported in this study have sought help from a psychologist or a related HCP. The disregard of patient-reported symptoms in the initial stages, plus the lack of disease awareness, empathy, and proactivity of

HCPs to look for the root causes contributes to a lengthier time to diagnosis. After diagnosis, patients described needing more individualized treatment plans, closer support, long-term follow-up, and quicker access to their doctors. On the other hand, POs have a key role in all patient journey stages, especially in diagnosis and post-diagnosis stages. Information, awareness, and support-related activities are the main roles of POs. Patients stated that POs provide a unique sense of community, empathy, daily life experience, and practical strategies that cannot be provided by the medical team.

While Pokrzywinski's research provides a more detailed view of the symptoms and overall quality of life at each stage of the patient's journey, the present study focuses on how the patient experiences the disease at each stage of the patient journey [8]. This allowed us to extract the patient's emotional journey, which was the main aim of this research.

This study has some limitations that should be highlighted. First, although the patients selected were intended to be as representative as possible, the sample size was small, which means that the results may not be representative of the general EoE population. This also prevents the study from making valid statements when comparing experiences of participants across countries. Secondly, this is a qualitative study, so the results are descriptive and the quantitative analyses that can be performed are limited, and they need to be used with caution. Third, the inclusion of only patients who received a specialist diagnosis 3 years or more before their involvement in this study serves as an adequate baseline for mapping of a generalized emotional journey. However, more precise and consistent inclusion criteria should be employed for each stage to assess change between stages, such as "time under a specific treatment." These limitations can be addressed in future work, also including a quantitative approach to validate and generalize the emotional journey of patients with EoE through statistical methods and assessing the emotional impact of current innovative treatments.

CONCLUSION

This qualitative study describes the exhausting emotional impact of EoE through the four phases of the patient journey, from pre seeking care through diagnosis and treatment/follow-up and finally monitoring. During the first stages of the patient journey (pre seeking care and diagnosis) patients mainly experience negative emotions such as worry, fear, anxiety, and frustration due to the lack of EoE awareness, the decrease in QoL, and the arduous diagnostic process. Whereas during treatment/follow-up and monitoring stages, patients experience positive emotions such as relief, excitement, happiness, and self-control owing to the effectiveness of the treatment and their knowledge and experience with EoE.

This study highlights that there is a high unmet need for increasing EoE awareness among patients and HCP, as it has been shown that a high level of awareness is key during all stages of the patient journey. We intend for this article to represent an opportunity to increase EoE awareness and to show the importance of considering the emotional impact on a patient with EoE's journey.

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Author Contributions. Helen Larsson, Mary Jo Strobel and Eduardo Perez-Guagnelli have made substantial contributions to the design of

this study and the interpretation of data; drafted the work or revised it critically for important intellectual content; approved the version to be published; and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy of the integrity of any part of the work are appropriately investigated and resolved.

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Data Availability. The datasets generated during and/or analyzed during the current study (except personal data) are available from the corresponding author upon reasonable request.

Declarations

Conflict of Interest. Helen Larsson, Mary Jo Strobel and Eduardo Perez-Guagnelli declare no conflict of interest.

Ethical Approval. The study was conducted online, and no healthcare practitioners were involved in patient recruitment. The survey falls under the scope of market research and does not fall under the scope of regulations regarding observational studies or research implying human beings. For this reason, submission to an ethical committee was neither required nor sought. The study was performed in accordance with the Helsinki Declaration of 1964, and its later amendments. Informed consent regarding participation and publication of outcomes were obtained from all individual participants included in the study. The participants' privacy and confidentiality were guaranteed following healthcare personal data protection laws and regulations (GDPR, General Data Protection Regulation).

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