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Individuals Affected by Eosinophilic Gastrointestinal Disorders Have Complex Unmet Needs and Frequently Experience Unique Barriers to Care

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Declarations

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This study (protocol # 161510) was approved by the Institutional Review Board at the Vanderbilt University.

Consent for publication

Not applicable

Availability of data and material

All data generated or analyzed during this study are included in this published article [and its supplementary information files].

Competing interests

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Abstract

Introduction—Eosinophilic gastrointestinal disorders (EGIDs) are a rare but emerging healthcare problem. Patient advocacy groups (PAGs) have an important role in representing the EGID community, and serve as valuable research partners. By leveraging the partnership between medical researchers and PAGs, we examined the unmet needs and barriers to care perceived by individuals affected by EGIDs. Next, we examined if these varied between adult EGID patients and adult caregivers of children with EGID.

Methods—Adult EGID patients and adult caregivers of children (< 18 years) with EGIDs participated in this study. PAGs conducted focus groups comprised of individuals affected by EGIDs to identify domains and questions meaningful to the EGID community and this information was used to develop an online REDCap survey. The survey consisted of 58 questions across medical, healthcare, social, and emotional impact domains. It was distributed via the PAGs' web-based platforms. Demographic data, and responses to questions on a six-point Likert scale were collected and analyzed.

Results—Of the 361 responses analyzed, 90 (25%) were from adult EGID patients and 271 (75%) were from adult caregivers. Of the applicable responses, in the medical domain only 19% of participants indicated that repeated endoscopies to monitor response to treatment was convenient. In the healthcare domain, 67% indicated that lack of insurance coverage for elemental formula was a barrier. In the social domain, only 5% of respondents reported adequate awareness of EGIDs in schools. In the emotional domain, 64% had experienced significant stress due to EGID related out-of-pocket costs. Multivariate logistic regression revealed that some of these responses varied between adult EGID patients and adult caregivers of children with EGID. The respondents indicated highest priority for improvement in the medical domain compared to other domains.

Conclusions—Individuals affected by EGIDs have a constellation of complex unmet needs and perceived barriers across medical, healthcare, social and emotional domains. Addressing unmet

needs in the medical domain is relatively more important for the EGID community. Understanding unmet needs and barriers will likely help design improved patient-centered EGID care paradigms.

Keywords

Rare diseases; Eosinophilic gastrointestinal disorders; Eosinophilic esophagitis; Eosinophilic gastritis; Eosinophilic gastroenteritis; Unmet needs; Survey; Health care barriers; Health services research; Health promotion

INTRODUCTION

Eosinophilic gastrointestinal disorders (EGIDs) are an emerging group of rare disorders.[1] Based on the affected site within the gastrointestinal tract, EGIDs are classified as distinct entities, such as eosinophilic esophagitis (EoE), eosinophilic gastritis (EG), eosinophilic colitis (EC); the term eosinophilic gastroenteritis (EGE) is used when multiple segments of the gastrointestinal tract are involved. EoE is the most prevalent and well-studied EGID.[2,3] Despite significant efforts, the process of detecting, monitoring and managing EGIDs remains expensive, complex and cumbersome.[4] It is conceivable that these factors could result in a constellation of unmet needs and barriers to the EGID community and could impact lives of individuals affected by EGIDs, but this has never been formally studied. Patient advocacy groups (PAGs) such as the American Partnership for Eosinophilic Disorders (APFED), Campaign Urging Research for Eosinophilic Diseases (CURED), and the Eosinophilic Family Coalition (EFC), have emerged as key partners in improving the lives of individuals affected by EGIDs.[5] They are deeply involved in raising awareness regarding EGIDs through educating patients, caregivers, health care providers, government, industry representatives, and the general public.[6] PAGs also have the potential to ensure feasibility and success of research protocols by making valuable contributions to study design, and implementation by connecting medical researchers with large numbers of EGID patients and their caregivers worldwide through a variety of avenues including their web-based platforms.

The 3 aims of this cross-sectional study were to: 1) examine the utility of PAG web-based platforms for reaching the dispersed EGID community with an online survey; 2) identify unmet needs and barriers to care perceived by the EGID community in the domains important and relevant to them; and 3) investigate if the perceived unmet need(s) or barrier(s) differed between adult EGID patients and adult caregivers of children with EGID. We hypothesized that the PAG's web-based platforms would be an effective portal to reach the dispersed EGID community, and that the individuals affected by EGIDs would have complex and varied unmet needs spanning across multiple domains and that the perception of unmet needs and barriers would differ between adult patients and adult caregivers of children with EGIDs.

METHODS

Subjects

Adult EGID patients and adult caregivers of children (<18 years of age) diagnosed with EGID, and enrolled in PAG administered web-based platforms (e.g., email list-serve, social media channel) were invited to participate in this study. Adult caregivers were defined as parent(s) or guardian(s) directly involved in providing care to their children diagnosed with EGID. By limiting participation to adult caregivers as opposed to opening participation to the pediatric population, we were able to minimize potential inconsistencies and irregularities associated with varying cognitive abilities among children and young adolescents, and maintain homogeneity in response quality.

Study Design and Setting

Partnership between medical researchers with expertise in EGIDs and PAGs resulted in development of this study protocol and the survey instrument, as illustrated in Figure 1. This study was approved by the Institutional Review Board at Vanderbilt University (protocol # 161510).

Focus groups—To identify domains most important and relevant to the EGID community and for deeper exploration of the unmet needs and barriers to care perceived by individuals affected by EGIDs, each PAGs conducted focus groups.[7] Each focus group conducted by APFED consisted of 10 participants (3 adult EGID patients, 7 caregivers) recruited from their database. One of the participants was a support group leader for an adult/teen group for EGIDs. Focus groups conducted by CURED consisted of 10 participants (3 adult EGID patients, and 7 caregivers), and EFC focus groups consisted of 5 participants (3 adult EGID patients, and 2 caregivers). Participants included in the CURED and EFC focus groups were recruited through social media and EGID community group outlets. Each of the three PAGs collected feedback via telephone interview and/or online, consolidated and summarized inputs to best represent the needs addressed in the majority of the comments received. None of the participants contributed to more than one focus group.

Developing the survey instrument—Based on the insights from focus groups, a Research Electronic Data Capture (REDCap) survey was developed.[8] The survey underwent multiple iterations of review and refinement by authors who have expertise in the area of EGIDs and survey design (GH, PA, MR, ED),[9,10] and representatives from PAGs (EK, MJS, DM, CR, KS). The purpose of this iterative process was to ensure that precise and simple language was being used in the questionnaire, and the questions were relevant to study aims. The final REDCap survey was comprised of 5 sections and 58 total questions (see supplementary material Appendix 1). The first section collected demographics and disease characteristics, with no personal identifiers. Subsequent sections gathered information over four domains identified to be most important and relevant to the EGID community: (1) medical challenges, (2) healthcare barriers, (3) social aspects, and (4) emotional impact of living with EGIDs. The responses were collected on a 6-point Likert scale ranked as: (1) Totally Disagree, (2) Disagree, (3) Neutral, (4) Agree, (5) Totally Agree, and (6) Not Applicable. Optional comments were collected via a free-text box. At the end of

the survey, respondents were asked to rank each of the domains ranging from greatest need for improvement to least or lowest need for improvement (1: greatest need; 2: some need; 3: little need; 4: lowest or least need). By allowing respondents to rank each of the domains we were able to simultaneously compare relative proportions for each of the domains. The questionnaire was designed to take less than 15 minutes to complete.

Dissemination of the Survey, Reminders and Data collection—Web-based platforms, including electronic mail and social media channels administered by PAGs were used to recruit participants. Electronic reminders were sent every 2 weeks for a total of 4 reminders, resulting in a data collection period of 8 weeks. The data were collected between October 2016 and December 2016. Survey responses were securely stored on the Vanderbilt University Medical Center server until analysis.

Statistical analysis

Data were exported from Stata version 14.0 (StataCorp., College Station, TX) for analysis. Descriptive statistics including counts and percentages for categorical variables, and means and standard deviations for continuous variables were used to characterize respondents. We dichotomized the applicable responses from the participants into “Agree” (Strongly agree + Agree) and “Disagree” (Strongly disagree + Disagree + Neutral) categories to investigate the perceived unmet needs and barriers to care. To compare responses between adult EGID patients and adult caregivers of children with EGIDs, unadjusted logistic regression was used to estimate odds ratios (OR) with 95% confidence intervals (95% CI) for each question in the survey. Multivariate logistic regression was used to adjust for potential independent predictors such as the type of EGID, duration of disease, country of origin, insurance, and disease activity.

RESULTS

Demographics

A total of 414 responses were received. Of these, 53 responses were excluded because 39 were from individuals < 18 years of age and 14 did not specify their age. Of the 361 responses analyzed, 280 (78%) were complete in all aspects. Nearly 18% of participants did not respond to at least one of the questions. The rate of incomplete responses was highest in the emotional impact domain at 18%, and it was lowest for the medical challenges domain at 13%.

Our cohort consisted of 90 (25%) adult EGID patients, and 271 (75%) adult caregivers of children with EGIDs. EoE (88%) was the most common form of EGID reported, and approximately 20% reported overlapping EGIDs (e.g. EGE). Respondents from 9 countries participated in this study, with the top 3 coming from the United States (US; 90%), Australia (5%) and Canada (2%). Within the US, a majority of the participants resided in the southern region (38%). Most participants had private insurance (75%), and only 2% were uninsured. A notable proportion of participants (76%) had been diagnosed with EGIDs within the past 5 years. The characteristics of the EGID patient group and the caregiver group were similar in terms of types of EGIDs, country, region within the US, and insurance coverage status

(Table 1). As expected, significant differences between adult EGID patient group and the caregiver group were noted in age, time since diagnosis of EGID, relationship, and employment status.

Medical challenges

When asked about the medical challenges, 52% of participants indicated that they had to change multiple providers prior to being diagnosed with EGID, and 53% indicated that they had to transfer medical care to a provider knowledgeable in EGID. In all, 78% indicated that their current EGID providers were knowledgeable about EGIDs, and 64% reported that their providers had clearly discussed available treatment options for their EGID. Only a small proportion of participants indicated that repeated endoscopies to assess treatment response were convenient (19%) and affordable (33%). With regards to currently available treatment options, only 31% on dietary elimination, 31% on a combination of swallowed steroids and dietary elimination therapy, 17% on elemental diet, and 21% on immunomodulators (e.g., 6-mercaptopurine) indicated that they were easy to adhere and convenient (Table 2a).

The bivariate and multivariate logistic regression revealed that the perception of unmet needs and potential barriers in the medical domain were similar between adult EGID patients and adult caregivers of children with EGIDs (Table 3a).

Healthcare barriers

In all, 68% of respondents indicated that their insurance covered the cost of endoscopy to monitor EGIDs, and 58% indicated that their insurance covered most of the cost of the swallowed steroids required to treat their EGID. However, only one in three respondents (33%) indicated that insurance covered the cost of their elemental formula. Approximately 64% of respondents indicated that they did not have an easy access to dietitians or nutritionists who they felt understood the challenges faced by EGID patients, and 57% indicated that they had not been evaluated for potential nutritional deficiencies. A majority (68%) of respondents indicated that their medical team sought their inputs while making decisions related to their/their child's care (Table 2b).

There were multiple differences between EGID patients and adult caregivers after bivariate logistic regression, but after multivariate analysis only few persisted. Adult caregivers of children with EGIDs had relatively easier access to dietitians or nutritionists who were familiar with the challenges related to EGIDs compared with adult EGID patients themselves [aOR (95% CI): 1.22 (1.00 – 1.49)], and were more likely to have had their children evaluated by a nutritionist for nutritional deficiencies [1.61 (1.29 – 2.02)]. The adult caregivers also indicated that their medical providers were relatively more knowledgeable about requirements for special accommodations (e.g., school, disability) [1.44 (1.11 – 1.87)], and were more likely to feel that the medical team encouraged their inputs while making EGID care-related decisions [1.67 (1.27 – 2.20)] (Table 3b).

Social aspects

The majority (79%) of respondents indicated that they used social media to connect with peers. Approximately 62% had experienced food-related discrimination due to dietary

restrictions to manage their EGID. In all, 83% reported that they were knowledgeable about preparing allergen-free foods, and 85% knew where to buy specialty foods that were free from ingredients that they were avoiding. Only a small proportion of respondents indicated that there was adequate awareness about EGIDs in schools (5%) and work places (6%), and that teachers or employers were empathetic to their needs (Table 2c).

Multivariate logistic regression revealed that compared to the adult EGID patients, the caregivers of children with EGIDs knew where to buy specialty foods [1.55 (1.13 – 2.12)], and had supportive immediate [1.30 (1.01 – 1.67)] and extended family members [1.44 (1.11 – 1.86)] (Table 3c).

Emotional impact

In all, 70% indicated that they had support through their family and friends. Over half of the respondents (51%) indicated that they felt the need to seek professional help to manage emotional stress related to EGIDs, and 41% had actually sought professional help. Only 17% indicated that they had a local EGID support group in which they could participate. The majority of the participants indicated that their EGID had placed an emotional burden on family members (74%) and caregivers (75%), and 64% indicated that the out-of-pocket costs related to EGID had placed significant stress on them (Table 2d).

Multivariate logistic regression revealed that caregivers of children with EGIDs had actually sought help from a professional therapist to cope with emotional stress related to EGID [1.36 (1.07 – 1.73)], and that the EGID had placed emotional burden on family members [1.62 (1.46 – 2.71)] and on caregivers [1.99 (1.46 – 2.13)] (Table 3d).

Ranking the domains for improvement

As illustrated in the radar plot (Figure 2), 33% indicated that there was greatest need for improvement in the medical domain, followed by the healthcare challenges (32%) and emotional impact of EGIDs domain (20%). The least amount of improvement (33%) was needed in the social challenges domain. The ranking of domains was identical between adult EGID patients and adult caregivers of children with EGIDs.

DISCUSSION

This is the first study to investigate unmet needs and barriers perceived by those affected by the rare group of diseases, EGIDs, in the domains meaningful to them. Our results indicate that individuals affected by EGIDs have complex unmet needs across medical, healthcare, social, and emotional domains, and the perception of some of the unmet needs vary between adult EGID patients and adult caregivers of children with EGIDs.

By leveraging partnership between medical researchers and PAGs, this study achieved participation from a large and diverse group of adult EGID patients and adult caregivers of children with EGIDs. These observations suggest that the internet-based research can be effectively used to complement information generated through traditional healthcare and public health systems, and that the individuals affected by rare diseases including EGIDs can

be highly motivated internet users tapping into online supportive networks, and are receptive to novel web-based research.[11,12]

Unfortunately, more than half of the EGID patients often transition through multiple providers to find a physician knowledgeable in EGIDs and/or experience delays in diagnosis. This is likely related to relatively few centers offering comprehensive and integrated care to EGID patients. While there are multiple therapeutic options to manage EGIDs, [13,14] the decision-making process leading up to the preferred treatment pathway can be complicated. Furthermore, the therapy in itself can be burdensome and expensive, especially if patients lack adequate insurance coverage.[15,16] For many EGID patients, the dietary allergen elimination is an effective therapeutic option, and dietitians play an important role in assuring that EGID patients and their caregivers are informed about the suspected ingredient(s) to avoid and assessing for adequate nutritional status of individuals affected by EGIDs.[17] Our results indicate that limited access to dietitians knowledgeable about EGIDs and not being evaluated for nutritional deficiencies are important unmet needs among those who participated in this study. Our data also highlights the perceived lack of awareness about EGIDs in schools, workplaces, and among family members, as well as the emotional burden EGIDs place on the patients and their caregivers.

This study has limitations. We targeted an online EGID community by leveraging social media platforms administered by three prominent PAGs that serve the EGID population. While this recruitment approach offered us a distinct advantage of reaching out to diverse and dispersed group of individuals affected by EGIDs, it is possible that the same approach also served as a source for introducing potential bias that could limit generalizability of our results. Engaging individuals participating in support groups or advocacy groups could potentially represent those who have ready access to internet, those likely struggling to deal with their condition, and perhaps those more inclined to seek out forums and web-based support. Their responses may not reflect the experiences of a broader EGID community. The use of internet and web-enabled platforms provide an unprecedented opportunity to conduct clinical trials and natural history studies, and educate stakeholders.[18] Moreover, the anonymity of participating in online surveys and self-reporting can be an asset for eliciting information that patients may not feel comfortable discussing with their healthcare providers. However, these methods do not allow us to confirm medical and demographic information provided by the respondents, and do not allow us to reliably calculate a survey response rate. Our study has several strengths. We adapted a community-based participatory research framework wherein the PAGs were actively involved in all aspects of the study.[19] Use of social media outlets to disseminate the survey questionnaire, robust methodology, a large sample size, and rigorous analytical approach further strengthened our study.

In conclusion, EGIDs are receiving more attention due to increased recognition in the healthcare community, improved understanding of the underlying pathophysiology, advances to bring better therapies to market, and greater public awareness. However, individuals affected by EGIDs continue to face a variety of challenges including lack of specialized care, delays in diagnosis, financial burden, negative social consequences, psychosocial ramifications and emotional burden. Our study illustrates a spectrum of complex unmet needs and barriers across multiple domains relevant to the EGID community. Understanding

the constellation of unmet needs and barriers perceived by the EGID community will likely serve as an important step towards further identification and prioritization of their needs, inform evidence-based policy interventions to bridge gaps, and inspire future patient-centered research to complement ongoing biomedical research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

Eosinophilic gastrointestinal disorders (EGID) are group of rare but pose significant burden worldwide

Patient advocacy groups have an important role in representing the EGID community

This is the first study to use online portal to study unmet needs and barriers experienced by individuals affected by EGIDs

Our results reveal that individuals affected by EGIDs have a constellation of complex unmet needs and perceived barriers across medical, healthcare, social and emotional domains

Understanding unmet needs and barriers will likely guide us to design EGID patient-centered approaches to improve their care and clinical outcomes

Figure 1.
Schematic representation of the study protocol

Figure 2.

Radar plot illustrating priority for improvement assigned to each domain by the participants

Table 1

Demographics of individuals affected by EGIDs and participating in the study

	Overall (N=361)	Adult caregiver of children with EGIDs (N=271)	Adult EGID Patient (N=90)	P value
Age (years)				
0–5	77 (21)	77 (28)	0 (0)	<0.01
6–10	90 (33)	90 (33)	0 (0)	
11–19	103 (29)	94 (35)	9 (10)	
20–30	24 (7)	2 (1)	22 (24)	
31–40	30 (8)	3 (1)	27 (30)	
> 40	37 (10)	5 (2)	32 (36)	
EGID				0.85
EoE	319 (88)	239 (88)	80 (89)	
EG	30 (8)	21 (8)	9 (10)	
EGE	45 (12)	30 (11)	15 (17)	
EC	27 (7)	21 (8)	6 (7)	
Overlapping EGIDs	74 (20)	52 (19)	22 (24)	
Country				0.21
United States (US)	295 (90)	225 (92)	70 (85)	
Armenia	2 (1)	2 (1)	0 (0)	
Australia	15 (5)	9 (4)	6 (7)	
Brazil	1 (0.3)	0 (0)	1 (1)	
Canada	7 (2)	5 (2)	2 (2)	
Germany	1 (0.3)	0 (0)	1 (1)	
United Kingdom	3 (1)	1 (0.4)	2 (2)	
Ireland	1 (0.3)	1 (0.4)	0 (0)	
Turkey	1 (0.3)	1 (0.4)	0 (0)	
Region in US Insurance				0.95
Midwest	90 (28)	70 (28)	20 (26)	
Northeast	54 (17)	41 (16)	13 (17)	
South	125 (38)	96 (39)	29 (38)	
West	57 (17)	42 (17)	15 (19)	
Insurance				0.16
Government	102 (28)	84 (31)	18 (20)	
Private	272 (75)	202 (75)	70 (78)	

	Overall (N=361)	Adult caregiver of children with EGIDs (N=271)	Adult EGID Patient (N=90)	P value
Nationalized healthcare system	10 (3)	5 (2)	5 (6)	
Uninsured	8 (2)	3 (1)	5 (6)	
Time since diagnosis of EGID				
0–11 months	71 (20)	53 (20)	18 (20)	<0.01
1–5 years	201 (56)	161 (59)	40 (44)	
6–10 years	59 (16)	40 (15)	19 (21)	
11–15 years	27 (7)	17 (6)	10 (11)	
> 15 years	3 (1)	0 (0)	3 (3)	
EGID activity				
Controlled	199 (56)	151 (56)	48 (54)	0.71
Uncontrolled	161 (45)	120 (44)	41 (46)	
Relationship status				
Single	14 (25 (7)	14 (5)	11 (12)	< 0.01
Married	261 (73)	224 (83)	37 (44)	
Divorced	16 (4)	16 (6)	0 (0)	

Table 2

Challenges and barriers perceived by the participating adult EGID patients and adult caregivers of children with EGID

Medical domain			
Question	Applicable responses		
	Out of a total of 361 responses N (%)	Agree (Strongly agree + Agree) N (%)	Disagree (Strongly Disagree + Disagree + Neutral) N (%)
At the time of diagnosis, my medical providers were knowledgeable about EGIDs	322 (89)	162 (50)	160 (50)
I was referred to a GI doctor fairly quickly for a diagnosis of EGID	313 (87)	116 (37)	197 (61)
I had to change multiple providers prior to being diagnosed with EGID	308 (85)	161 (52)	147 (48)
I had to transfer medical care in order to find a provider knowledgeable in EGID	302 (84)	160 (53)	142 (47)
My current EGID provider is knowledgeable about EGIDs	315 (87)	246 (78)	69 (22)
My team of providers clearly discussed all available treatment options	316 (88)	203 (64)	113 (36)
My team of providers gave me adequate information about the sources of allergens	307 (85)	159 (52)	148 (48)
Getting repeated endoscopies to see if I am responding to treatment is convenient	307 (85)	58 (19)	249 (81)
I can afford repeated endoscopies to see if I am responding to treatment	301 (83)	100 (33)	201 (67)
I am currently on dietary elimination treatment only (such as 4- or 6-food elimination, or allergy test based elimination) and I find this treatment to be easy to adhere to and convenient	241 (67)	75 (31)	166 (69)
I am currently on swallowed steroids (such as Flovent or Budesonide) and I find this treatment to be easy to adhere to and convenient	194 (54)	93 (48)	101 (52)
I am currently on a combination of swallowed steroids and dietary elimination therapy and I find this treatment to be easy to adhere to and convenient	193 (54)	61 (31)	132 (69)
I am currently on a elemental diet and I find this treatment to be easy to adhere to and convenient	169 (47)	28 (17)	141 (83)
I prefer to take steroids over food allergen elimination	254 (70)	78 (31)	176 (69)
I am currently on other medical treatment such as immune modulators (e.g.; 6-mercaptopurine) and not on local steroids or dietary elimination for treatment of my EGID and I find this treatment to be easy to adhere to and convenient	151 (42)	31 (21)	120 (79)
Healthcare barriers			
Question	Applicable responses		
	Out of a total of 361 responses N (%)	Agree (Strongly agree + Agree) N (%)	Disagree (Strongly Disagree + Disagree + Neutral) N (%)
My insurance covers the cost of my endoscopies that are needed to monitor my EGID	292 (81)	199 (68)	93 (32)
My insurance covers most of the cost of the swallowed steroids required to treat my EGID	221 (61)	127 (58)	94 (42)
My insurance covers most of the cost of elemental formula required to treat my EGID	167 (46)	55 (33)	112 (67)
I have easy access to dietitians or nutritionists who understand the challenges of my EGID	290 (80)	104 (36)	186 (64)
I have been evaluated by a nutritionist for nutritional deficiencies	284 (77)	123 (43)	161 (57)

Medical domain			
Question	Applicable responses		
	Out of a total of 361 responses N (%)	Agree (Strongly agree + Agree) N (%)	Disagree (Strongly Disagree + Disagree + Neutral) N (%)
My medical providers are knowledgeable about requirements for special accommodations (e.g., school, disability)	262 (73)	108 (41)	154 (59)
My medical team encourages my input when making decisions about my/my child's care	289 (80)	198 (68)	91 (32)
Social aspects			
Question	Applicable responses		
	Out of a total of 361 responses N (%)	Agree (Strongly agree + Agree) N (%)	Disagree (Strongly Disagree + Disagree + Neutral) N (%)
I often use social media to connect with others who live with EGIDs	296 (82)	232 (79)	64 (21)
I have experienced food-related discrimination due to my dietary restrictions for EGID	286 (79)	179 (62)	107 (38)
I am knowledgeable about preparing allergy-free foods	293 (81)	244 (83)	49 (17)
I know where to buy specialty foods	291 (81)	248 (85)	43 (15)
There is enough awareness in schools about EGIDs and the teachers are empathetic	274 (76)	12 (5)	262 (95)
There is enough awareness in the work-place about EGIDs and the employers are empathetic	238 (66)	14 (6)	224 (94)
My immediate family members (or the people living in my home) understand EGID and are supportive	293 (81)	213 (73)	80 (27)
My extended family members understand EGID and are supportive	293 (81)	111 (38)	182 (62)
Emotional impact			
Question	Applicable responses		
	Out of a total of 361 responses N (%)	Agree (Strongly agree + Agree) N (%)	Disagree (Strongly Disagree + Disagree + Neutral) N (%)
I have emotional support through my family and friends to help with me manage my EGID	293 (81)	205 (70)	88 (30)
I have felt the need to seek help from a professional therapist to manage emotional stress related to my EGID	267 (74)	138 (51)	129 (49)
I have actually sought help from professional therapist to cope with my emotional stress related to EGID	246 (68)	100 (41)	146 (59)
I have ongoing emotional toll related to my EGID	274 (76)	174 (64)	100 (36)
I have a local EGID support group that I participate in	249 (69)	43 (17)	206 (83)
My EGID has placed an emotional burden on my family members	287 (80)	212 (74)	75 (26)
My EGID has placed an emotional burden on my caregivers	257 (71)	193 (75)	64 (25)
The out of pocket cost related to EGID has placed significant stress on me	278 (77)	177 (64)	101 (36)

Table 3

Predictors for positive perception (an agreement) to the survey questions by adult caregivers of children with EGIDs compared to adult EGID patients based on logistic regression analysis.

Medical domain		
Questions	OR (95% CI)	Adjusted OR* (95% CI)
At the time of diagnosis, my medical providers were knowledgeable about EGIDs	1.13 (0.95 – 1.35)	1.05 (0.86 – 1.28)
I was referred to a GI doctor fairly quickly for a diagnosis of EGID	0.90 (0.95 – 1.34)	0.88 (0.73 – 1.07)
I had to change multiple providers prior to being diagnosed with EGID	1.12 (0.85 – 2.43)	1.11 (0.91 – 1.35)
I had to transfer medical care in order to find a provider knowledgeable in EGID	1.02 (0.86 – 1.21)	1.04 (0.86 – 1.26)
My current EGID provider is knowledgeable about EGIDs	1.21 (0.96 – 1.53)	1.20 (0.92 – 1.57)
My team of providers clearly discussed all available treatment options	1.32 (1.08 – 1.61)	1.22 (0.96 – 1.55)
My team of providers gave me adequate information about the sources of allergens	1.38 (1.13 – 1.68)	1.24 (0.99 – 1.56)
Getting repeated endoscopies to see if I am responding to treatment is convenient	0.89 (0.72 – 1.10)	0.88 (0.69 – 1.12)
I can afford repeated endoscopies to see if I am responding to treatment	1.00 (0.83 – 1.21)	0.91 (0.73 – 1.14)
I am currently on dietary elimination treatment only (such as 4- or 6-food elimination, or allergy test based elimination) and I find this treatment to be easy to adhere to and convenient	1.07 (0.87 – 1.31)	1.10 (0.87 – 1.40)
I am currently on swallowed steroids (such as Flovent or Budesonide) and I find this treatment to be easy to adhere to and convenient	1.02 (0.83 – 1.25)	0.99 (0.76 – 1.28)
I am currently on a combination of swallowed steroids and dietary elimination therapy and I find this treatment to be easy to adhere to and convenient	1.01 (0.80 – 1.26)	0.97 (0.84 – 1.12)
I am currently on a elemental diet and I find this treatment to be easy to adhere to and convenient	1.03 (0.77 – 1.40)	0.98 (0.66 – 1.45)
I prefer to take steroids over food allergen elimination	1.06 (0.87 – 1.29)	0.98 (0.79 – 1.22)
I am currently on other medical treatment such as immune modulators (e.g.; 6-mercaptopurine) and not on local steroids or dietary elimination for treatment of my EGID and I find this treatment to be easy to adhere to and convenient	0.90 (0.70 – 1.16)	0.85 (0.61 – 1.19)
Healthcare barriers		
Questions	OR (95% CI)	Adjusted OR* (95% CI)
My insurance covers the cost of my endoscopies that are needed to monitor my EGID	1.09 (0.88 – 1.33)	0.92 (0.72 – 1.19)
My insurance covers most of the cost of the swallowed steroids required to treat my EGID	1.29 (1.02 – 1.62)	1.19 (0.89 – 1.58)
My insurance covers most of the cost of elemental formula required to treat my EGID	1.41 (1.04 – 1.90)	1.21 (0.82 – 1.78)
I have easy access to dietitians or nutritionists who understand the challenges of my EGID	1.37 (1.12 – 1.67)	1.22 (1.00 – 1.49)
I have been evaluated by a nutritionist for nutritional deficiencies	1.54 (1.26 – 1.88)	1.61 (1.29 – 2.02)
My medical providers are knowledgeable about requirements for special accommodations (e.g., school, disability)	1.63 (1.29 – 2.05)	1.44 (1.11 – 1.87)
My medical team encourages my input when making decisions about my/my child's care	1.58 (1.26 – 1.99)	1.67 (1.27 – 2.20)
Social aspects		
Questions	OR (95% CI)	Adjusted OR* (95% CI)
I often use social media to connect with others who live with EGIDs	1.31 (1.05 – 1.64)	1.31 (1.02 – 1.70)
I have experienced food-related discrimination due to my dietary restrictions for EGID	0.98 (0.79 – 1.22)	1.09 (0.85 – 1.40)
I am knowledgeable about preparing allergy-free foods	1.31 (1.01 – 1.70)	1.21 (0.87 – 1.68)
I know where to buy specialty foods	1.48 (1.14 – 1.92)	1.55 (1.13 – 2.12)

Medical domain

Questions	OR (95% CI)	Adjusted OR* (95% CI)
There is enough awareness in schools about EGIDs and the teachers are empathetic	0.90 (0.65 – 1.24)	0.97 (0.65 – 1.45)
There is enough awareness in the work-place about EGIDs and the employers are empathetic	0.88 (0.65 – 1.18)	0.78 (0.55 – 1.10)
My immediate family members (or the people living in my home) understand EGID and are supportive	1.38 (1.11 – 1.71)	1.30 (1.01 – 1.67)
My extended family members understand EGID and are supportive	1.51 (1.20 – 1.90)	1.44 (1.11 – 1.86)

Emotional impact:

Questions	OR (95% CI)	Adjusted OR* (95% CI)
I have emotional support through my family and friends to help with me manage my EGID	1.35 (1.07 – 1.71)	1.29 (0.98 – 1.70)
I have felt the need to seek help from a professional therapist to manage emotional stress related to my EGID	1.26 (1.07 – 1.48)	1.24 (0.97 – 1.58)
I have actually sought help from professional therapist to cope with my emotional stress related to EGID	1.21 (0.98 – 1.48)	1.36 (1.07 – 1.73)
I have ongoing emotional toll related to my EGID	1.18 (0.94 – 1.48)	1.26 (0.96 – 1.64)
I have a local EGID support group that I participate in	1.30 (1.00 – 1.69)	1.33 (0.98 – 1.79)
My EGID has placed an emotional burden on my family members	1.47 (1.17 – 1.86)	1.62 (1.24 – 2.13)
My EGID has placed an emotional burden on my caregivers	1.86 (1.45 – 2.38)	1.99 (1.46 – 2.71)
The out of pocket costs related to EGID has placed significant stress on my family	1.16 (0.93 – 1.44)	1.26 (0.98 – 1.64)

* Adjusted for type of EGID, duration of disease, country of origin, insurance, and disease activity