

Impact of Patient Engagement and Social Determinants of Health on Care of Eosinophilic Gastrointestinal Disorders Patients

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ABSTRACT

The purpose of this study was to identify factors that influence eosinophilic gastrointestinal disorders (EGID) patients to switch gastroenterologists, assess the prevalence of social determinants of health (SDoH) in EGID patients, and the impact of SDoH on provider switching. 191 patients/caregivers participated in this cross-sectional, online study distributed through Patient Advocacy Groups. The 35-question survey took about 20 minutes to complete and was divided into three sections: demographics; 10 questions about provider switching; and nine-domain SDoH screen. Patients with EGIDs often switch providers, most commonly due to dissatisfaction with engagement in decision making. Additionally, these patients commonly have SDoH, some of which are associated with increased provider switching. Our results highlight the need to mindfully engage patients in decision-making and disease management. Providers also need to look beyond the “clinic space” and into SDoH. These low-cost/high-impact changes in provider behavior can promote continuity of care and patient engagement.

Key Words: eosinophilic gastrointestinal disorders, patient engagement, provider switching, shared decision making, social determinants of health

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Eosinophilic gastrointestinal disorders (EGIDs) are a group of rare, immune-mediated chronic, inflammatory conditions that affect the GI tract (1). Based on which section of a patient’s GI tract is affected, these are termed eosinophilic esophagitis (EoE), eosinophilic gastritis, eosinophilic gastroenteritis, eosinophilic enteritis, and eosinophilic colitis. Of these, the most well studied is EoE with scarce data on the other EGIDs. Although EoE is classified as a rare

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What Is Known

- Management of eosinophilic gastrointestinal disorders (EGID) is complex and patients often switch providers to get the right provider.
- Social determinants of health (SDoH) have significant impact on health outcomes.

What Is New

- More than a third of patients had thought about changing providers—most commonly due to dissatisfaction with engagement in decision-making
- SDoH were prevalent in over half of respondents and some were significantly associated with provider switching.

disease, multiple studies have shown that the incidence of EoE has been rising and is currently between 5–10 new cases per 100,000 persons per year in the United States (2–4). Although non-EoE EGIDs are not as well studied as EoE, these disorders have a reported prevalence of 1.9% in patients with GI symptoms (5).

Despite the increasing incidence of EoE, detecting, monitoring, and managing EoE is complex, cumbersome, and expensive for providers, patients, and the families of patients (6). One study examining the unmet needs in EGID patients found that 52% of respondents changed providers multiple times before even being diagnosed with EGID. After diagnosis, they faced multiple challenges when it came to managing their disease and 53% of respondents indicated they had changed providers to one more knowledgeable in EGIDs (7). This underscores the importance of understanding challenges that patients with EGIDs face and how these affect the patient–provider relationship.

In recent years, increasing emphasis has been placed on understanding social determinants of health (SDoH) and their impact on health outcomes. These SDoH such as access to medical care, education, health literacy, access to nutritious food, stable housing, and neighborhood, occupational, and personal safety and play an important role in determining disease susceptibility risk and disease course. SDoH often drives negative health outcomes (8). With the rising incidence of EoE, understanding how SDoH affect EoE patients will help improve patient-centered care and health outcomes.

The overarching aim of this study is to understand what factors influence adult patients and adult caregivers of pediatric patients with EGIDs to switch gastroenterologists. We hypothesized that SDoH such as transportation, education level, and insurance as

well as the patient perception of their physicians will contribute to a high rate of patient-initiated specialist change.

METHODS

Subjects

We utilized existing partnerships with three Patient Advocacy Groups (PAGs): American Partnership for Eosinophilic Disorders (APFED), Campaign Urging Research for Eosinophilic Diseases (CURED), and the Eosinophilic Family Coalition (EFC) to invite adult patients and adult caregivers of children (<18 years old) diagnosed with EGIDs via their email lists and social media channels. They were invited to participate in our survey. We defined adult caregiver(s) as parent(s) or guardian(s) directly involved in providing care to the children.

Study Design

We conducted a cross-sectional study to collect our data. Our study design was approved by Institutional Review Board at the University of Illinois College of Medicine Peoria. The survey was divided into three sections. For the first section, we collected demographic data about the patient and disease (age, gender, ethnicity, zip code, education status, employment status, insurance, and duration of disease). The second section was a validated SDOH screen developed by the American Academy of Family Physicians (AAFP) The EveryONE Project (9). This is simple, yet comprehensive screen that identifies the existence of multiple domains of SDOH and contains all SDOH domains used by other, longer surveys. The data from this screen was scored using the instruction provided in the screening tool. For the SDOH “concern for personal safety,” the responses to four questions were aggregated to determine the presence of SDOH in a patient per the guidelines outlined in the AAFP screen we are using (9). The third and final section of the survey assessed reasons for specialist switching using a six-point Likert scale. These questions for the third section of the survey were created based on a literature review and consultation with PAGs. These questions assess clinic characteristics (eg, wait times, access to nutritionists), the provider’s availability (eg, retired, pediatric GI physician does not see adults), provider’s personality, provider’s participation in shared decision making, and provider’s knowledge as to how EGIDs impact patient’s lives (7,10–12). Before participants were shown the last section of the survey, they were asked how many times they have switched their primary GI provider in the past. If they had not switched their primary GI provider in the past, they were not shown the third section and exited the survey.

The survey was created and stored in an online, secure Research Electronic Data Capture (REDCap) survey. A REDCap survey link was disseminated using PAG email list serves and social media channels over a 6-week period, with two biweekly reminders. Electronic informed consent was secured before the participant starting the survey. The final survey had 35 questions and took approximately 20 minutes to complete.

Analysis

In this study, means and standard deviations were reported for continuous variables, and percentage values were reported for categorical variables. Chi-square tests or exact chi-square tests were used to check on the associations with categorical variables. To examine the association between the primary outcome (provider switching) and SDOH, the univariate analyses were first performed, and covariates whose *P* value <0.25 were included in the multiple

logistic regression model. The backward model selection with Firth method was performed and the final model was constructed. Whenever necessary, the Firth method was used for the small sample bias correction. *P* < 0.05 was considered as a statistically significant test. All statistical analyses were performed using SAS software version 9.4 (SAS Institute Inc, Cary, NC, USA). All figures were created using R version 4.0.4.

RESULTS

A total of 191 responses were received and all were included in the analysis.

119 of 191 respondents (62.3%) were caregivers of patients and 72 of 191 (37.7%) were patients themselves. The median age of patients was 14, with a mean of 22.1 and a range of 1–63 years. Seventy-six patients (39.8%) had EGID for >5 years (Table 1).

Of the respondents, 69 of 191 (36.1%) had thought of changing their provider and 42 of the 69 who had thought about changing their provider (57.9%) actually changed their provider. Of the 42 respondents who changed their providers, 29 of 42 (69%) did so more than once (Table 2). Of the 10 reasons (Table 2) for changing providers, the most common was dissatisfaction in the care by provider (88.1%), provider not discussing treatment options (69%), and patient not involved in decision-making process (57.1%). Wait times (14.3%) and insurance issues (11.9%) were among the least likely factors that influenced provider switching.

At least one SDOH was present in 110 of 191 respondents (57.6%). Among the SDOH domains surveyed (Table 3 and Table 1, Supplemental Digital Content, <http://links.lww.com/MPG/C536>), the three most prevalent were employment issues (29.3%), financial

TABLE 1. Demographics

Position	
Caregiver/family member of an EGID patient who lives with the EGID patient	119 (62.3)
EGID patient	72 (37.7)
Patient age	
Mean ± SD	22.1 ± 17.1
Median (min – max)	14.0 (1.0–63.0)
Time with EGID	
0–11 mo	37 (19.4)
1–5 y	78 (40.8)
5–10 y	54 (28.3)
More than 10 y	22 (11.5)
Education level of respondent	
College	103 (53.9)
Elementary	2 (1.0)
High school/vocational	15 (7.9)
Post-graduate	71 (37.2)
Employment level of respondent	
Full time student	16 (8.4)
Retired	10 (5.2)
Unemployed	35 (18.3)
Working full-time	88 (46.1)
Working part-time	42 (22.0)
Insurance	
Government (eg, State Medicaid, Medicare, Government Insurance Exchange, Tricare, etc.)	37 (19.4)
Private (eg, Blue cross/Blue shield, Kaiser, Anthem, United Healthcare, etc.)	151 (79.1)
None	3 (1.6)

EGID = eosinophilic gastrointestinal disorder.

TABLE 2. Provider switching

Question	Out of a total of 191 responses, N (%)	Agree	Disagree
I have thought about changing my GI doctor who provides care for my EGID	191 (100)	69 (36.1)	122 (63.9)
How many times have you changed your GI doctor who provides care for your EGID?			
0	149 (78.0)		
1	13 (19.4)		
2	16 (23.9)		
3	9 (13.4)		
4	2 (3.0)		
5	2 (3.0)		
Patients who switched their provider at least once	191 (100)	42 (22.0)	149 (78.0)
Reasons for provider switching			
I changed my GI doctor because my previous doctor retired, relocated, is not available, or is not seeing patients anymore	42	12 (28.6)	30 (71.4)
I changed my GI doctor because my insurance stopped supporting my previous GI doctor	42	5 (11.9)	37 (88.1)
I changed my GI doctor because of personality conflicts	42	19 (45.2)	23 (54.8)
I changed my GI doctor because of unacceptable wait times	42	6 (14.3)	36 (85.7)
I changed my GI doctor because my previous doctor did not discuss all available treatment options with me	42	29 (69.0)	13 (31.0)
I changed my GI doctor because my previous doctor did not involve me in decisions about my treatment as much as I wanted	42	24 (57.1)	18 (42.9)
I changed my GI doctor because my EGID was not being managed to my satisfaction	42	37 (88.1)	5 (11.9)
I changed my GI doctor because I disagreed with the treatment plan	42	22 (52.4)	20 (47.6)
I changed my GI doctor because I did not have access to dietitians or nutritionists who understand the challenges of my EGID	42	18 (42.9)	24 (57.1)
I changed my GI doctor because my previous doctor was not knowledgeable about requirements for special accommodations (e.g., school, disability, etc.)	42	14 (33.3)	28 (66.7)

PGID = eosinophilic gastrointestinal disorder.

TABLE 3. Social determinants of health profile

Social determinant of health	Agree	Disagree
Think about the place you live. Do you have problems with bug infestation?	5 (2.6)	186 (97.4)
Think about the place you live. Do you have problems with mold?	23 (12.0)	168 (88.0)
Think about the place you live. Do you have problems with lead paint or pipes?	3 (1.6)	188 (98.4)
Think about the place you live. Do you have problems with inadequate heat?	0 (0.0)	191 (100.0)
Think about the place you live. Do you have problems with oven or stove not working?	4 (2.1)	187 (97.9)
Think about the place you live. Do you have problems with no or not working smoke detectors?	4 (2.1)	187 (97.9)
Think about the place you live. Do you have problems with water leaks?	16 (8.4)	175 (91.6)
Within the past 12 mo, you worried that your food would run out before you got money to buy more	27 (14.1)	164 (85.9)
Within the past 12 mo, the food you bought just didn't last and you didn't have money to get more	18 (9.4)	173 (90.6)
In the past 12 mo, has lack of transportation kept you from medical appointments, meetings, work, or from getting things needed for daily living?	7 (3.7)	184 (96.3)
In the past 12 mo has the electric, gas, oil, or water company threatened to shut off services in your home?	9 (4.7)	182 (95.3)
Do problems getting child care make it difficult for you to work or study?	31 (16.2)	160 (83.8)
How often does anyone, including family, physically hurt you?*	2 (1.1)	186 (98.9)
How often does anyone, including family, insult or talk down to you?*	83 (43.9)	106 (56.1)
How often does anyone, including family, threaten you with harm?*	9 (4.8)	179 (95.2)
How often does anyone, including family, scream or curse at you?*	55 (29.3)	9 (4.8)
How often does this describe you? "I don't have enough money to pay my bills."	88 (46.1)	103 (53.9)
Do you have a job?	135 (70.7)	56 (29.3)
Do you have a high school diploma?	188 (98.4)	3 (1.6)

AAFP = American Academy of Family Physicians; SDoH = social determinants of health. *These questions reference the SDoH: concern for personal safety SDoH. For the SDoH "concern for personal safety," the responses to four questions were aggregated to determine the presence of SDoH in a patient per the guidelines outlined in the AAFP screen we are using.

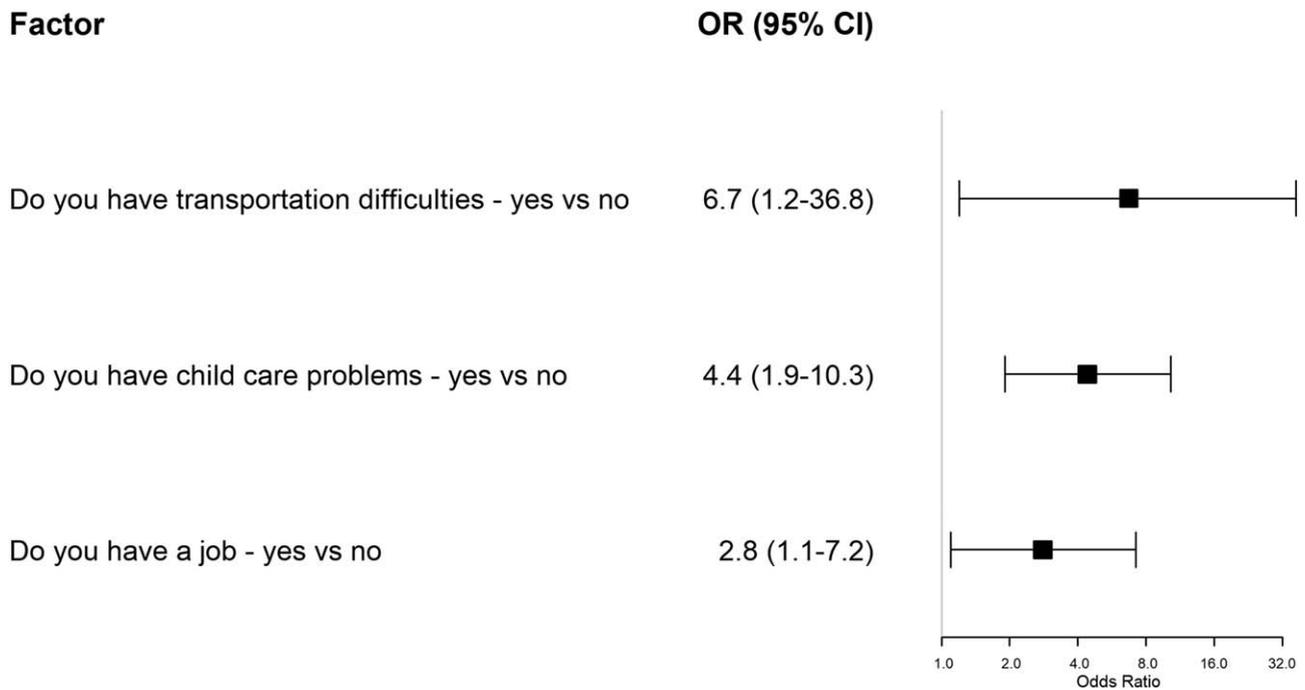


FIGURE 1. Forest plot of the odds ratios with 95% confidence intervals from the multiple logistic regression model for provider switching.

difficulties (25.7%), and housing stability (20.9%). Concern for personal safety (1.57%) and education level (1.57%) were among the least prevalent social determinants of health.

Among the SDoH, patients who had transportation difficulties had a statistically significantly higher rate of provider switching than patients without at 57.1% compared to 20.7% ($P=0.043$). Similar results were seen with difficulties with childcare (48.4% vs 16.9%, $P<0.001$) and employment status (25.9% vs 12.5%, $P=0.041$). Those with issues with transportation or access to childcare had a higher likelihood of provider switching (odds ratio [OR] 6.7, $P=0.029$; OR 4.4, $P<0.001$ respectively, Fig. 1). Respondents who had a job had a higher likelihood of provider switching (OR 2.8, $P=0.034$, Fig. 1).

DISCUSSION

Our study is among the first to look at the rate of provider switching in patients with EGIDs and to investigate the presence of SDoH in EGID patients with the potential impact on patient care. Our results indicate that more than a third of our respondents had thought about switching providers and of these, over 50% had switched providers.

A strong and trusting patient-physician relationship is essential in providing comprehensive and effective care to patients. Multiple studies have shown the benefits of long-term relationships (LTR) between physicians and patients and the preference of LTRs by both patients and physicians alike (10,11,13). This relationship is even more important in patients with rare, chronic diseases such as EGIDs. Because there is no definitive biomarker or easy laboratory test to assess EGID, patients with suspected EGID may need to undergo multiple procedures to confirm the diagnosis. Even after the diagnosis, the treatment is variable, and patients need to have multiple follow-ups for symptomatic, clinical, and endoscopic/histologic assessment (14). A strong physician-patient relationship is essential in ensuring the proper diagnosis and treatment plan for

the patient. Our results indicate that patient involvement in the decision-making process is one of the key factors that influence patients to switch providers. Shared decision making is an important aspect of patient-centered care because it not only leads to increased patient satisfaction but also better treatment adherence. Additionally, shared decision making has also been shown to reduce medical costs and increase provider satisfaction (15,16).

Although provider characteristics are important in determining health outcomes, our study also explored the prevalence of SDoH and their association with provider switching. More than half of our respondents had at least one SDoH present. Multivariate analyses showed that patients with issues with transportation and access to childcare had a statistically significant higher likelihood of provider switching, while those who were employed were more likely to switch providers. Although there are no direct comparisons between SDoH and provider switching, studies have shown that SDoH significantly drives impact on health outcomes. Several studies have estimated that clinical care only accounts for 10–20% of health outcomes (17–19). Accordingly, there has been increased emphasis on clinicians and clinical practices to integrate formal SDoH screening to promote health equity and ultimately better patient care (20). Issues such as financial stability can cause additional stress for parents of EGID patients (21). Our study is one of the first that investigated the presence of SDoH in EGID patients. Our results highlight the importance of these SDoH and the need for providers to take these into account when caring for the patient.

Our study has some limitations. We used a cross-sectional, non-experimental study method using patient self-reported data. We also recruited patients through online PAG registries. These patients might have easy access to the Internet, be more likely struggling to understand their disease, be more inclined to seek online help, or not have a diagnosed EGID at all. Additionally, the patients we want to hear most from—the patients with the most SDoH—might not have internet/computer access or time to engage with PAGs. In fact, the SDoH rates might be even higher than what

we found and further underscores that addressing SDoH is an urgent and unmet need. Although the SDoH instrument we used is validated, there is a lack of a validated questionnaire when asking about provider switching. We used themes identified from previous studies and inputs from PAGs when designing these questions.

However, our present study design was best suited for our research because it gave us a robust platform to reach a large number of patients with this rare disease which would not be as possible using a different study design while maintaining patient anonymity in a single-center clinic-based study. Additionally, our data is consistent with national averages, for example, the percentage of respondents with SDoH was similar to nationally reported averages (17–20).

In conclusion, patients with EGIDs often change providers and their reason for switching providers is likely multifactorial. Our results indicate dissatisfaction with engagement in decision-making plays an important role. Additionally, these patients commonly have SDoH, some of which are associated with increased provider switching. Further research needs to be done to better characterize the SDoH and their true impact on care of EGID patients. Our results highlight the need to mindfully engage patients in decision-making and disease management. Providers also need to look beyond the “clinic space” and into the social determinants of health that might impact patient engagement. These low-cost/high-impact changes in provider behavior can promote better continuity of care and patient engagement.

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