Transition of Care From Pediatric to Adult Care in Eosinophilic Esophagitis: Insights From a Patient Perspective Survey

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ABSTRACT

Eosinophilic esophagitis (EoE) is a chronic immune-mediated disease. Patients with a childhood diagnosis require ongoing disease management in adulthood; however, knowledge of the patient experience during pediatric to adult healthcare transition is lacking. Here, an online survey captured patient perceptions of the challenges faced by patients with EoE in the United States during transition to adult healthcare, and which resources, if implemented, could better support transition. Of 67 respondents, 91% (n = 61) were under adult care at the time of survey completion. Aspects that respondents struggled with most included meal planning, food shopping, cooking/finding foods that did not exacerbate their condition, and knowledge of insurance coverage. Although most respondents reported confidence in having the knowledge to manage their EoE, almost half of the respondents worried about managing their condition in the future. Resources detailing diet, medication and insurance management strategies could support the transition to adult healthcare for patients with EoE.

Key Words: care coordination, eosinophil, esophagus, gastrointestinal disease, healthcare

What Is Known

- Eosinophilic esophagitis (EoE) is a chronic immune-mediated inflammatory disease with significant unmet needs.
- Transition of care from pediatric to adult healthcare systems can be challenging for patients with chronic conditions.

What Is New

- Considerable gaps in patient knowledge regarding healthcare transition remain.
- Provision of resources detailing disease management strategies could increase knowledge and facilitate a smoother transition to adult healthcare among patients with EoE.
Eosinophilic esophagitis (EoE) is a chronic immune-mediated inflammatory disease, characterized by esophageal eosinophilic infiltration and esophageal dysfunction (1,2). The prevalence of EoE is 50–100 cases per 100,000 persons annually in the United States and is higher in adults than children (1–3).

Healthcare transition is characterized as the planned movement of adolescents/young adults with chronic conditions from child-centered to adult-oriented healthcare systems (4,5). Improved standardization of healthcare transition programs for patients with chronic conditions such as EoE is required. A survey reported that most patients aged ≥13 years with EoE or eosinophilic gastroenteritis (52/75) and their parents (187/245) lacked any prior knowledge of healthcare transition (6). A separate study of four patients with EoE (aged 17–21 years) found that the absence of a defined transition program resulted in disjointed communication between pediatric and adult healthcare professionals, patients lacking knowledge of their condition, and assessments of readiness for transition not being routinely undertaken (7).

Such studies highlight our limited understanding of the transition experience of patients with EoE (7). Our primary objectives here were to better understand the challenges experienced by patients with EoE in the United States as they transition to adult healthcare and to identify best practices to aid a smoother transition and improve self-management from a patient perspective.

METHODS

Study Design and Survey Development

A self-administered, 30-minute, online survey for patients with EoE was developed, with input from four clinical EoE experts, using either a 5- or 7-point Likert rating scale. Interactive cognitive debriefs conducted on four patients (not included in the final cohort) before survey finalization, ensured comprehension of questions as intended and provided feedback on survey content, flow and ease of interpretation. The finalized questionnaire was approved by the Institutional Review Board, University of Mississippi (100 Barr Hall, University, MS 38677, USA) (Document, Supplemental Digital Content 1, the full survey, http://links.lww.com/MPG/C524).

Questions were asked to identify challenges during transition, strategies to support transition, knowledge and resources that participants wished they had before transitioning, and participant attitudes to healthcare and future outlooks on disease management. An example question is detailed below:

For the actions listed below, please indicate how well you feel you handled each action during transition. Please use a scale of 1 to 5, where 1 = “struggled significantly” and 5 = “handled very well”. If an action does not apply to you, select “N/A”.

Participants provided their level of agreement with each statement (1 = lowest; 5 = highest [scale point anchors depended on the question asked]).

Survey Participants

Eligibility criteria were:

- 18–26 years of age, diagnosed with EoE more than 2 years before survey completion and living in the United States,
- receiving healthcare from an adult care physician, or in the process of transitioning from a pediatric to an adult care physician at the time of recruitment,
- completed transition to adult care, managing EoE independently of their parents/caregivers and responsible for managing any medication, communication with medical staff, and food shopping and/or meal planning at the time of recruitment,
- if diagnosed after 18 years of age, must have transitioned to independent management, measured as above, at least 2 years before survey completion.

Participants with EoE were recruited via links and promotions on the American Partnership for Eosinophilic Disorders (APFED) and North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) websites. Owing to the challenges experienced with patient recruitment, additional point-of-care physician referral through a third-party, Toluna USA, Inc (Wilton, CT, USA), was implemented. Consent was obtained for all patients and screening was used to determine participant eligibility. Recruiting physicians and patients enrolled via Web sites received honoraria.

The timeframe between completion of transition and survey completion was not specified as a qualifier for participation.

Statistical Analysis

Data outliers, logical data and survey length were checked. Means, medians and standard deviations (SDs) were provided for continuous variables, and frequencies and percentages were provided for categorical variables. Aggregated respondent-level data were analyzed using t-tests (numeric/continuous variables) and χ²-tests (categorical variables). Data were compared by site of clinical service (academic versus community/private care) using the two-sided χ²-test with Bonferroni correction; statistical significance was determined at a level of 0.05. Data were analyzed using IBM SPSS Statistics, Version 24.0 (IBM Corp., Armonk, NY, USA; 2016).

RESULTS

Participant Demographics

Our study was conducted between March 2019 and May 2019. In total, 120 participants completed screening, 67 of whom met the eligibility criteria and completed the survey in full, and therefore, were included in the final study sample (Supplemental Digital Content 2, http://links.lww.com/MPG/C525).

Overall, 91.0% of study participants had already transitioned to an adult care physician; 9.0% were in the process of transitioning to an adult care physician but had already established future care with an adult physician at survey completion (Table 1). Overall, 49.3% of participants were women. The mean ages (SD) of participants was 18.7 (5.5) years old. The timeframe between completion of transition and survey completion was not specified as a qualifier for participation.

Participant Attitudes and Experiences of Transition of Care

As participants transitioned to adult healthcare, key food-related challenges were identified, such as planning meals, shopping for EoE-friendly foods, as well as cooking/finding foods that did not exacerbate their condition (Fig. 1).

The two most challenging medical aspects of transition were having knowledge of insurance coverage and budgeting for medication costs. Although 82.1% of participants reported confidence in having the knowledge to manage their condition, 47.8% were worried about managing their condition effectively in the future. Additionally, 61.2% and 64.2% of participants noted that knowing which foods were right for them and insurance coverage details, respectively, would have been “very helpful” to learn before transitioning. Learning ways to schedule and adhere to medical appointments, skills for communicating effectively with physicians, and suggestions for adhering to medication schedules would also have been “very
helpful” before transitioning. The ability to handle the stress and emotional impact of EoE was the most frequently reported social skill that participants wished that they had learned before transitioning. Approximately one in five participants (18.0%) considered the support of a transition coordinator potentially helpful.

**Participant Attitudes and Experiences of Transition of Care Stratified According to Care Setting**

Participants under academic care (n = 29) appeared to handle the challenges associated with transition better than those under community/private care (n = 38). A significantly greater proportion of patients under academic care handled the following food-related challenges “very well” compared to patients under community/private care: planning meals; shopping for EoE-friendly foods; and cooking/finding foods that did not exacerbate their condition (academic care: 72.4%, 65.5%, and 69.0%, respectively; community/private care: 10.5%, 5.3% and 2.6%, respectively; P < 0.05). Similarly, a significantly greater proportion of patients under academic care handled the two most challenging medical aspects of transition (having knowledge of insurance coverage and budgeting for medication costs) “very well” relative to patients under community/private care (academic care: 72.4% each; community/private care: 13.2% and 7.9%, respectively; P < 0.05).

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**TABLE 1. Participants’ demographics and disease characteristics**

| Feature                                           | Participants under academic care (n = 29) | Participants under community/private care (n = 38) | Survey participants (N = 67) |
|---------------------------------------------------|------------------------------------------|---------------------------------------------------|------------------------------|
| Age at survey completion, y                       | 23.0 (2.3)                               | 22.4 (2.1)                                        | 22.7 (2.2)                   |
| Age group, y, n (%)                               |                                          |                                                   |                              |
| 18–22                                             | 13 (44.8)                                | 20 (52.6)                                        | 33 (49.3)                    |
| 23–26                                             | 16 (55.2)                                | 18 (47.4)                                        | 34 (50.7)                    |
| Sex, n (%)                                        |                                          |                                                   |                              |
| Male                                              | 16 (55.2)                                | 17 (44.7)                                        | 33 (49.3)                    |
| Female                                            | 12 (41.4)                                | 21 (55.3)                                        | 33 (49.3)                    |
| Transgender male                                  | 1 (3.4)                                  | 0 (0.0)                                          | 1 (1.5)                      |
| Race/ethnic origin, n (%)                         |                                          |                                                   |                              |
| White (non-Hispanic)                              | 10 (34.5)                                | 32 (84.2)                                        | 42 (62.7)                    |
| Black or African American                         | 10 (34.5)                                | 4 (10.5)                                         | 14 (20.9)                    |
| Latino or Hispanic                                | 6 (20.7)                                 | 2 (5.3)                                          | 8 (11.9)                     |
| Asian                                             | 3 (10.3)                                 | 0 (0.0)                                          | 3 (4.5)                      |
| Age at EoE diagnosis, y                           | 19.2 (2.6)                               | 13.3 (4.2)                                       | 15.9 (4.6)                   |
| Age at EoE diagnosis group, y, n (%)              |                                          |                                                   |                              |
| <18                                               | 5 (17.2)                                 | 33 (86.8)                                        | 38 (56.7)                    |
| ≥18                                               | 24 (82.8)                                | 5 (13.2)                                         | 29 (43.3)                    |
| Living situation at survey completion, n (%)      |                                          |                                                   |                              |
| Independently (not in college or with caregiver) | 20 (69.0)                                | 25 (65.8)                                        | 45 (67.2)                    |
| In a college dorm or similar                      | 6 (20.7)                                 | 7 (18.4)                                         | 13 (19.4)                    |
| With caregiver                                    | 3 (10.3)                                 | 6 (15.8)                                         | 9 (13.4)                     |
| Geographical location, n (%)                      |                                          |                                                   |                              |
| Urban                                             | 10 (34.5)                                | 10 (26.3)                                        | 20 (29.9)                    |
| Suburban                                          | 8 (27.6)                                 | 21 (55.3)                                        | 29 (43.3)                    |
| Rural                                             | 11 (37.9)                                | 7 (18.4)                                         | 18 (26.9)                    |
| Highest level of education completed, n (%)       |                                          |                                                   |                              |
| Less than high school                             | 0 (0.0)                                  | 0 (0.0)                                          | 0 (0.0)                      |
| Some high school                                  | 0 (0.0)                                  | 0 (0.0)                                          | 0 (0.0)                      |
| High school or equivalent (eg, GED)               | 5 (17.2)                                 | 8 (21.1)                                         | 13 (19.4)                    |
| Some college but no degree                        | 14 (48.3)                                | 10 (26.3)                                        | 24 (35.8)                    |
| Associate’s degree/technical school               | 7 (24.1)                                 | 2 (5.3)                                          | 9 (13.4)                     |
| College degree (eg, BA, BS)                       | 3 (10.3)                                 | 11 (28.9)                                        | 14 (20.9)                    |
| Some graduate school but no degree                | 0 (0.0)                                  | 2 (5.3)                                          | 2 (3.0)                      |
| Graduate degree (eg, MS, MD, PhD, JD)             | 0 (0.0)                                  | 0 (0.0)                                          | 0 (0.0)                      |
| Currently in college                             | 0 (0.0)                                  | 5 (13.2)                                         | 5 (7.5)                      |
| Healthcare at survey completion, n (%)            |                                          |                                                   |                              |
| Under adult care physician                        | 29 (100.0)                               | 32 (84.2)                                        | 61 (91.0)                    |
| Transitioning from pediatric to adult care physician| 0 (0.0)                                | 6 (15.8)                                         | 6 (9.0)                      |
| Private or commercial health insurance at survey completion, n (%) | 13 (44.8) | 35 (94.6)*                                      | 48 (72.7)*                   |
| Type of specialist managing EoE at survey completion, n (%) | 16 (55.2) | 17 (44.7)                                        | 33 (49.3)                    |
| Gastroenterologist                                | 27 (93.1)                                | 35 (92.1)                                        | 62 (92.5)                    |
| Allergist                                         | 0 (0.0)                                  | 10 (26.3)                                        | 10 (14.9)                    |

Data are mean (SD) unless otherwise stated. BA = Bachelor of Art; BS = Bachelor of Science; EoE = eosinophilic esophagitis; GED = general educational development; JD = Juris Doctor; MD = Doctor of Medicine; MS = Master of Science; PhD = Doctor of Philosophy; SD = standard deviation. n = 37. As reported by the participant. More than one specialist could be managing the same participant.
DISCUSSION

Since the first guidelines on EoE diagnosis and management were published (8), our knowledge of the disease has increased dramatically owing to the growing evidence base; however, our understanding of the patient experience of transition from pediatric to adult healthcare is lacking. To our knowledge, this study is the first comprehensive survey conducted for EoE to better understand the patient experience of transition in the United States.

In this survey, although participants reported confidence in having the knowledge to manage their EoE, almost half the participants reported concern regarding future disease management. Participants thought that acquiring more knowledge regarding foods that did not exacerbate disease, and insurance coverage information would have been helpful before transitioning. Other transitional challenges indirectly highlighted included patients’ fear of the unknown and unfamiliarity with transition and adult healthcare.

Studies have demonstrated transition-associated challenges for patients with chronic conditions (4,5). Interview data from 16 adults with severe asthma identified themes associated with their transition experience, including: “I have to take responsibility”; “a need of being involved”; and “lack of engagement” (9). These patients felt they would benefit from structured preparation, planning and communication throughout transition. Several studies have highlighted the specific barriers to successful healthcare transition for patients with EoE, including a lack of prior knowledge of transition and disjointed communication between pediatric and adult healthcare professionals (6,7).
Such studies highlight the requirement for standardization of transition programs for patients with EoE. The differences in clinical practice between pediatric and adult healthcare should also be considered for transition. An Israeli study found significant differences in EoE treatment preferences between adult and pediatric gastroenterologists and only 54% of adult gastroenterologists were comfortable facilitating transition of patients to their care while they were reintroducing food following dietary elimination. These data identify a need for resources to increase knowledge of EoE and support transition not only among patients and their caregivers but also among adult gastroenterologists. A further complicating factor is the variation in the specialties of healthcare professionals who manage the care of adult patients with EoE, from allergists to gastroenterologists to primary care providers, emphasizing further the need for standardization of transition services. Dedicated transition coordinators may play a crucial role in this standardization, the importance of whom has been emphasized in the literature, which aligns with our data.

Participants under academic care appeared to handle some aspects of disease management better than those in community/private settings. Reasons for this disparity may include variations in access to specialists (eg, dietitians and social workers) or continued medical education between settings. Additional research is warranted to provide further insights into the differences between EoE care settings.

Of 2014 participants who clicked on the first screening question of our survey, most of whom were acquired through Web site links and/or promotions, only 120 completed screening and 67 survey responses were analyzed due to ineligibility and/or incomplete surveys. The large number of patients who failed screening was unsurprising considering the broad recruitment strategy and specific eligibility criteria. One limitation of our study is that 97.0% (n = 65) of the 67 participants were recruited via physician referral, resulting in a highly specific group. Participants in this group were probably still actively engaged with their treating physician and have therefore likely undergone a successful transition, which may explain the overall positive experiences reported. Furthermore, most participants (72.7%) had private medical insurance, and a far higher proportion of study participants were women (49.3%) compared with the observed ratio of 3:4:1 (men:women) in the number of cases of EoE. Additionally, honoraria were provided to participants. These selection biases in the study population may limit the generalizability of the data captured in this study to the broader EoE patient population.

The survey was often completed by participants several years after transition had occurred, which could have affected recall accuracy. Future analyses in which data pertaining to the experience of participants at various stages of transition are collected prospectively, rather than retrospectively as done here, may provide further information regarding the patient perspective of transition. Successful healthcare transition requires input on management considerations from both patients and respective healthcare team(s). Although the aim of this survey was to capture the patient perspective, future studies may provide further insights on the transition process for patients with EoE by addressing the resources available in pediatric and adult healthcare settings.

Despite these limitations, four clinical experts in EoE were involved in the development of the survey, allowing disease-specific challenges to be captured fully. The use of a screening step was of paramount importance, ensuring that only the intended patient population was captured. The comprehensiveness of the survey, which captured information on disease burden on daily life and barriers to transition, was an additional strength. Furthermore, the data were obtained through participant self-reporting rather than caregiver reporting and, therefore, are directly reflective of the patient experience.

In summary, knowledge of specific best practices and provision of resources may facilitate better management of disease and optimize transition to adult healthcare for patients with EoE in the future. Forthcoming studies should aim to identify practical ways to better support transition.

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