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Lack of Knowledge and Low Readiness for Healthcare Transition in Eosinophilic Esophagitis and Eosinophilic Gastroenteritis

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Abstract

Objectives—A growing population of adolescents/young adults with eosinophilic esophagitis (EoE) and eosinophilic gastroenteritis (EGE) will need to transition from pediatric to adult health providers. Measuring healthcare transition (HCT) readiness is critical, but no studies have

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evaluated this process in EoE/EGE. We determined the scope and predictors of HCT knowledge in patients and parents with EoE/EGE and measured HCT readiness in adolescents/young adults.

Methods—We conducted an online survey of patients 13 years and parents of patients with EoE/EGE who were diagnosed when 25 years of age. Parents answered questions regarding their children and their own knowledge of HCT. HCT readiness was assessed in adolescents/young adults aged 13-25 years with the Self-Management and Transition to Adulthood with Rx (STAR_x) Questionnaire (a six domain self-report tool) with a score range of 0-90.

Results—450 participants completed the survey: 205 patients and 245 parents. Included in the analysis (those diagnosed with EoE/EGE at age 25 years) were 75 of 205 patients and children of 245 parent respondents. Overall, 78% (n=52) of the patients and 76% (n=187) of parents had no HCT knowledge. Mean HCT readiness score in adolescents/young adults (n=50) was 30.4±11.3 with higher scores in domains of provider communication and engagement during appointments. Mean parent-reported (n=123) score was 35.6±9.7 with higher scores in medication management and disease knowledge.

Conclusions—There was a significant deficit in HCT knowledge, and HCT readiness scores were lower than other chronic health conditions. HCT preparation and readiness assessments should become a priority for adolescents/young adults with EoE/EGE and their parents.

Keywords

eosinophilic esophagitis; eosinophilic gastroenteritis; healthcare transition readiness

INTRODUCTION

Eosinophilic esophagitis (EoE) and eosinophilic gastroenteritis (EGE) are chronic, immune mediated conditions (1-5) affecting both children and adolescents/young adults (6-9). While the natural history of these diseases is not well understood, there is evidence (10) that children with EoE continue to be symptomatic as they transition to adulthood and require ongoing therapy and chronic disease management. Our clinical experience is that the same is true of EGE.

Healthcare transition (HCT) is the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (11, 12). The key to successful HCT is to accurately measure HCT readiness to determine the most optimal time and mode of transitioning to an adult provider (13). HCT needs in adolescents with chronic conditions has been recognized and studied to facilitate development of needs-based HCT programs (14-18). However, there are certain health conditions such as EoE/EGE in which HCT needs have not been well described (19) or formally assessed in a population with high disease burden.

Therefore, we aimed to assess whether EoE/EGE patients and parents of patients with these conditions had knowledge of HCT, and to determine the scope and predictors of HCT knowledge. The secondary aim was to measure HCT readiness in adolescents/young adults with EoE/EGE using the Self-Management and Transition to Adulthood with Rx (STAR_x) Questionnaire (13, 20) and to correlate it with factors impacting transition readiness.

METHODS

Study Design and Population

This was a cross-sectional survey of patients who were 13 years old with EoE/EGE or parents of EoE/EGE patients of all ages. Of note, these were not parent-child pairs. Using the Qualtrics™ web-based platform, we deployed an online survey through the American Partnership for Eosinophilic Disorders (APFED) and Campaign Urging Research for Eosinophilic Disease (CURED) websites, email lists, social media sites, and other online resources. Two versions of the survey were administered: patient-reported and parent-reported. Patients answered the questions themselves. Parents were requested to answer questions regarding their children and their own familiarity with HCT. The study was approved by the University of North Carolina Institutional Review Board prior to study initiation and informed consent/assent was obtained from all study participants.

STAR_x Healthcare Transition Readiness (HCTR) Assessment

All participants completed a STAR_x Questionnaire (13) to assess readiness to transition from pediatric to adult health care services. Patients completed the survey by answering questions about their own HCT readiness and parents regarding perceived HCT readiness of their children. The STAR_x Questionnaire measures self-reported HCT readiness and self-management for adolescents/young adults with chronic health conditions. The development, reliability, and validity of the tool have been described previously (13, 20). In brief, the STAR_x Questionnaire comprises of 18 questions measured on a 5-point Likert scale and measures HCT readiness in six domains, including medication management, provider communication, engagement during appointments, disease knowledge, adult health responsibilities, and resource utilization. The questionnaire is scored from 0-90, with higher scores indicating higher levels of HCT readiness.

Statistical Analysis

Descriptive statistics were used to summarize characteristics of the study population. Bivariate analyses were used to compare those who did and did not have prior knowledge of HCT in the subset of patients diagnosed with EoE/EGE when 25 years. Student's *t* test and Wilcoxon rank sum were used for continuous variables and Pearson χ^2 test was used for categorical variables. HCT readiness analysis using the STAR_x Questionnaire was restricted to adolescents/young adults aged 13-25 years as it was validated in this age group (13, 20). Analysis of the parent-reported survey was similarly restricted to those who had children with EoE/EGE aged 13-25 years. Mean HCT readiness in each of the six domains and mean total HCT readiness scores were calculated from both the patient and parent surveys. Differences between the parents' perceptions of their children's readiness and patient self-reported readiness were compared using Student's *t* test. Association between HCT readiness scores and patient and provider characteristics were calculated and differences in scores within each domain with increasing age groups were also calculated using analysis of variance. Differences were considered statistically significant at an alpha level <0.05. All analyses were performed using STATA 13 (StataCorp, College Station, TX).

RESULTS

A total of 450 participants completed the survey: 205 patients and 245 parents. We restricted the analysis to those diagnosed with EoE/EGE at age ≥ 25 years, resulting in a sample of 75 patients and all 245 children of parent respondents. A majority in both groups had EoE (Table 1). Among those who took the patient survey, 20% were male compared to the parent survey in which 70% of the children with EoE/EGE were male. In the patient survey, median age (23 ± 7 vs. 12 ± 6) and age of disease onset (16 ± 6 vs. 8 ± 5) was higher, and a larger proportion had active symptoms (92% vs. 77%) compared to the children of parents who took the parent survey. Approximately 80% of the subjects with EoE/EGE in both groups were on active dietary therapy for disease management. A very high proportion from both groups was under the active care of a primary care provider (PCP) (84% vs. 97%), a gastroenterologist (GI) (85% vs. 92%), a nutritionist (69% vs. 71%), and an allergist (84% vs. 89%).

Overall, 78% (n=52) of the patients and 76% (n=187) of parents reported having no prior knowledge of HCT. Factors associated with lack of HCT knowledge among patients were older age (24 vs. 19 years, $p=0.03$), older age at disease diagnosis (17 vs. 12 years, $p<0.01$), and already seeing an adult gastroenterologist (63% vs. 38%, $p<0.05$) (Table 2). Few factors were associated with parental unfamiliarity with HCT other than active steroid use. For example, parents who had children with EoE/EGE and who were on active steroid treatment were less likely to know about HCT (48% vs. 31%, $p=0.03$). Knowledge regarding HCT was not associated with a difference in preferred age to discuss or initiate the transition process. Interestingly, the mean preferred age to initiate HCT was at least 18 in all groups and the highest preferred age of 24 years was in participants taking the patient survey who were familiar with HCT (Table 2).

The proportion of participants who reported knowledge of HCT between the ages of 0-25 years were calculated divided into 5 age groups (Supplementary Figure). Among those who took the patient survey, only about half of those aged between 16 to 20 years were familiar with HCT. The largest percent of parents who were familiar with HCT had children aged 11-15, but this was still under 50%. HCT knowledge was similarly low among parents with children aged 0-10 and 15-25 years.

Healthcare Transition Readiness

Out of 50 subjects aged 13-25 and 123 parents of patients in this age range, mean HCT readiness score was 30.4 ± 11.3 with scores in domains of provider communication, disease knowledge, and engagement during appointments being somewhat higher than other domains (Table 3). Mean parent-reported HCT readiness score was 35.6 ± 9.7 with higher scores in the domains of medication management and disease knowledge and lower scores in the adult health responsibilities and resource utilization domains. Overall, there was a significant difference in parent-reported HCT readiness scores and patient-reported scores across all domains except for disease knowledge and adult health responsibilities. Parent-reported readiness of their children in the domains of provider communication (8.2 vs 5.8, $p<0.01$), engagement during appointments (9.7 vs 5.4, $p<0.01$), and resource utilization (6.3 vs 4.4, $p<0.01$) was significantly lower than patient-reported readiness. For medication

management, patient-reported readiness scores were lower than the parent-reported scores for their children (6.5 vs. 8.8, $p<0.01$).

There was no association between overall HCT readiness score and disease type, age, age at diagnosis, percent of life with disease, active symptoms, active steroid use, dietary therapy, or provider type (Supplementary Table 1). When adolescents/young adults were divided into age groups (13-15, 16-18, 19-21 and 22-25 years of age) based on developmental milestones, there were no significant differences between HCT readiness scores among the different age groups within each domain other than adult health responsibilities and engagement during appointments (Supplementary Table 2). Interestingly, participants taking the patient survey who were 22-25 had lower readiness scores than those in the 13-15 age group in the domain of adult health responsibilities (2.8 vs. 4.7, $p=0.01$). In the parent survey, there was a statistically significant increase in perceived transition readiness of their children with increasing age in the domain of engagement during appointments (7.5 vs 5.0, $p=0.01$).

DISCUSSION

Our study is the only of its kind to assess HCT knowledge and readiness in EoE/EGE. Knowledge of healthcare transition was lacking in more than 75% of the participants, and this lack of HCT knowledge was similar in patients with EoE/EGE and in parents of patients with these conditions. This is a significant deficit in knowledge, particularly as this survey was conducted among a group of subjects connected to patient advocacy groups and support websites, who were likely highly motivated. Among parents, age of the children did not correlate with transition knowledge. In fact, a similar proportion of parents who had children aged 0-10 years reported being familiar with HCT as those who had children aged 15-25. In addition, HCT readiness scores measured with the validated STAR_x Questionnaire were notably low in adolescents/young adults with EoE/EGE. Overall, there was no correlation between overall HCT readiness scores and disease type, markers of disease severity, age, disease duration, or provider type.

When comparing EoE/EGE to other chronic diseases, we were not able to make a valid comparison of the lack of HCT knowledge because HCT knowledge can be assessed in multiple ways. However, the preferred age for HCT of 18 years in both patients and parents reported in our sample is similar to those of other non-GI chronic diseases (21) and inflammatory bowel disease (IBD) (22, 23). Even though pediatric societies recommend ages closer to 12 for HCT initiation (24), the age of 18 is likely seen by patients and parents as a more practical choice as it coincides with a social transition to secondary schooling such as college (25). Another similarity was that the higher readiness scores in domains such as “provider communication” and “engagement during appointments” seen in our EoE/EGE population were also areas of higher mastery in the IBD population (26). One major difference was that the mean scores for HCT readiness were considerably lower in EoE/EGE compared to other chronic disease conditions (13). In a sample comprised primarily of adolescents/young adults with other chronic conditions (chronic kidney disease, IBD, cystic fibrosis, and systemic lupus erythematosus) mean HCT readiness scores measured by the

STAR_x Questionnaire ranged from 43 to 59 with an increase in readiness scores with increasing age of the participants (13).

One of the reasons for lower HCT readiness in EoE/EGE compared to other chronic conditions could be due to lack of HCT knowledge. Three quarters of a highly motivated group of EoE/EGE patients and parents in this study lacked HCT knowledge, and this is markedly higher than has been reported in other conditions (27). There are also provider reported barriers to HCT that have been identified (23) since the process of HCT is a collaborative effort between patients, caretakers, and healthcare providers. Provider perceived barriers to HCT such as lack of infrastructure, disease knowledge, and training in adolescent care (23, 28) have not been assessed in EoE/EGE and would be a valuable perspective to ascertain in future studies.

HCT needs to be prioritized because of the increasing incidence and prevalence of EoE (7). Studies have shown that the prevalence of EoE decreases after age 45 and a majority affected is children and adolescents/young adults (9, 29, 30). For EGE, the overall prevalence is lower compared to EoE, but EGE is most commonly diagnosed in children aged <5 years (4). As a result, there will likely be a large influx of EoE/EGE patients who will need to transition to adult providers without disruption of healthcare. Because of a dearth of literature on this topic in EoE/EGE (19), HCT programs that are tailored to these diseases must be developed and studied. Unlike other chronic diseases, there are certain aspects of healthcare that are specific to patients with EoE/EGE (19). This includes HCT not just from a single pediatric to an adult provider but transitioning to an adult multidisciplinary team including nutritionists and allergists, because patients with EoE/EGE often require a collaborative team for optimal management. In addition to medical and dietary treatment, there is also a need for serial endoscopic assessments with potential need for interventions such as dilations and biopsies that can add to the complexity of HCT.

Our study has multiple strengths and some weaknesses. First, it is the only study to have evaluated HCT knowledge and readiness in a sample of patients with EoE and/or EGE. Second, HCT readiness was measured with the disease-neutral, self-reported STAR_x Questionnaire, which has been shown to be a valid self-report tool with high reliability that can be used to assess transition readiness and self-management skills in adolescents/young adults with a variety of health conditions (20). Third, the study was conducted using an online survey that increases the likelihood of providing a diverse sample of EoE/EGE patients, though there could be selection bias. Those who participated in the study were most likely a highly motivated group of patients and caregivers who have access to an online interface and possibly more social support. However, in this highly selective group of activated health consumers, we would expect a higher proportion with HCT knowledge and larger readiness scores, which we did not find in our study. Therefore, it is possible that our results actually overestimate HCT knowledge in the general EoE/EGE population, highlighting an area that needs significant attention. We also did not obtain information regarding factors that affect HCT such as health insurance, race, access to resources, and education level. Since the survey was distributed through multiple online resources, we were unable to determine the overall survey response rate. In addition, provider perspectives were not collected. Finally, since the study was cross-sectional, we do not have longitudinal

information regarding change in HCT readiness over time or outcomes that correlate with HCT knowledge and readiness.

In summary, approximately three-quarters of patients and parents of children with EoE/EGE who were diagnosed with the disease at 25 years of age were unfamiliar with health-care transition. Given our methodology, this rate of unfamiliarity may be an underestimate. In addition to the significant lack of knowledge of HCT, HCT readiness was also low compared in adolescents/young adults compared to other chronic diseases at baseline without any interventions. Given that a large cohort of EoE/EGE patients will need to transition to adult providers, HCT preparation and readiness assessments should become a priority in these patients and their parents. In addition, barriers for knowledge need to be identified to improve the process of transitioning from pediatric to adult care in the EoE/EGE population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What is known:

- Eosinophilic esophagitis (EoE) and eosinophilic gastroenteritis (EGE) are chronic immune mediated conditions that affect both children and adolescents.
- Healthcare transition (HCT) needs in EoE/EGE have not been well described or formally assessed.

What is new:

- This is the only study to assess HCT knowledge and readiness in EoE/EGE.
- Knowledge of healthcare transition was lacking in more than 75% of patients with EoE/EGE and in parents of patients with these conditions.
- HCT readiness scores measured with the STAR_x Questionnaire in patients aged 13-25 years and parents were notably low compared to other chronic illnesses.

Table 1**Participant Characteristics**

	Patient survey (n=75)	Parent ^e survey (n=245)
Disease Type, n (%)		
EoE ^a	57 (78)	193 (79)
EGE ^b	6 (8)	17 (7)
Both	12 (16)	35 (14)
Male, n (%)	15 (20)	172 (70)
Age, mean yrs $\pm$ SD	23 $\pm$ 7	12 $\pm$ 6
Age at diagnosis, mean yrs $\pm$ SD	16 $\pm$ 6	8 $\pm$ 5
Active symptoms, n (%)	69 (92)	188 (77)
Active steroid use, n (%)	38 (51)	102 (44)
Active dietary elimination, n (%)	63 (84)	193 (82)
Current primary care provider (PCP), n (%)	62 (84)	225 (97)
Type of primary care provider, n (%)		
Pediatrician	16 (26)	154 (68)
Internal medicine	45 (60)	39 (17)
Other health professional	40 (15)	32 (14)
Current GI ^c provider, n (%)	63 (85)	214 (92)
Type of GI provider, n (%)		
Pediatric GI	28 (44)	197 (92)
Adult GI	35 (56)	17 (8)
Nutritionist, n (%)	51 (69)	165 (71)
Allergist, n (%)	62 (84)	207 (89)
Lack of HCT ^d Knowledge, n (%)	52 (78)	187 (76)

^aEosinophilic esophagitis^bEosinophilic gastroenteritis^cGastroenterologist^dHealthcare transition^eParents answered questions regarding their children and their own knowledge of healthcare transition

Table 2

Association of Patient and Provider Characteristics and Familiarity with HCT^a in Patients and Parents of Patients with Eosinophilic Esophagitis and Eosinophilic Gastroenteritis

	Patient survey (n=67)			Parent ^f survey (n=245)		
	Familiar with HCT (n=15)	Unfamiliar with HCT (n=52)	p value	Familiar with HCT (n=58)	Unfamiliar with HCT (n=187)	p value
Disease Type, n (%)			0.09			0.39
EoE ^b	9 (60)	42 (81)		42 (72)	151 (81)	
EGE ^c	3 (20)	2 (4)		5 (9)	12 (6)	
Both	3 (20)	8 (15)		11 (19)	24 (13)	
Male, n (%)	3 (20)	10 (19)	0.95	43 (74)	129 (69)	0.45
Female, n (%)	12 (80)	42 (71)		15 (26)	58 (31)	
Age, mean yrs ± SD	19 ± 4	24 ± 7	0.03	13 ± 5	12 ± 6	0.07
Age at diagnosis, mean yrs ± SD	12 ± 5	17 ± 6	<0.01	8 ± 5	7 ± 5	0.63
Active symptoms, n (%)	14 (93)	47 (90)	0.72	55 (95)	175 (94)	0.73
Active steroid use, n (%)	7 (47)	31 (60)	0.37	18 (31)	84 (48)	0.03
Active dietary elimination, n (%)	14 (93)	43 (83)	0.31	52 (90)	141 (80)	0.10
Percent of life with disease			0.41			0.32
50	3 (2)	6 (12)		27 (47)	73 (39)	
>50	12 (80)	45 (88)		31 (53)	113 (61)	
PCP ^d , n (%)			0.75			0.06
Pediatrician	4 (29)	12 (26)		32 (56)	122 (73)	
Internal medicine	9 (64)	28 (60)		13 (23)	26 (15)	
Other health professional	1 (7)	7 (15)		12 (21)	20 (12)	
GI ^e provider, n (%)			<0.05			0.72
Pediatric GI	10 (67)	18 (38)		50 (91)	147 (92)	
Adult GI	5 (33)	30 (63)		5 (9)	12 (8)	
Preferred age to initiate HCT discussion, mean yrs ± SD	20 ± 8	18 ± 6	0.27	19 ± 7	18 ± 6	0.51
Preferred age to initiate HCT, mean yrs ± SD	24 ± 10	20 ± 4	0.12	21 ± 7	20 ± 6	0.09

^aHealthcare transition

^bEosinophilic esophagitis

^cEosinophilic gastroenteritis

^dPrimary care provider

^eGastroenterologist

^fParents answered questions regarding their children and their own knowledge of healthcare transition

Table 3

Health Care Transition Readiness Scores^a using the STAR_x^b Questionnaire in Adolescents/Young Adults with Eosinophilic Esophagitis and Eosinophilic Gastroenteritis

Domains of STAR _x Questionnaire for Transition Readiness	Patient Survey (n)	Mean Patient Score $\pm$ SD	Parent ^c Survey (n)	Mean Parent Score $\pm$ SD	p value
Medication Management	47	6.5 $\pm$ 2.5	112	8.8 $\pm$ 1.6	<0.01
Provider Communication	40	8.2 $\pm$ 3.1	108	5.8 $\pm$ 3.2	<0.01
Engagement during appointments	50	9.7 $\pm$ 2.6	109	5.4 $\pm$ 2.2	<0.01
Disease Knowledge	44	7.8 $\pm$ 1.5	111	7.6 $\pm$ 1.6	0.48
Adult Health Responsibilities	44	3.7 $\pm$ 1.6	110	4.1 $\pm$ 2.1	0.26
Resource Utilization	50	6.3 $\pm$ 3.0	111	4.4 $\pm$ 3.0	0.01
Total Score	47	30.4 $\pm$ 11.3	112	35.6 $\pm$ 9.7	<0.01

^aScores range from 0 to 90 with 0 indicating lowest health care transition readiness

^bSelf-Management and Transition to Adulthood with Rx

^cParents answered questions regarding their children's perceived healthcare transition readiness