

Additional Support Needed for Successful Transition of Care from Pediatric to Adult Providers for the Management of Eosinophilic Gastrointestinal Diseases

Gary W. Falk¹, Lauren T. Gehman², Bhupinder Singh², Mary Jo Strobel³

¹University of Pennsylvania Perelman School of Medicine, Philadelphia, PA; ²Allakos, Inc., Redwood City, CA; ³American Partnership for Eosinophilic Disorders, Atlanta, GA

BACKGROUND

- Eosinophilic gastrointestinal diseases (EGIDs), including eosinophilic esophagitis (EoE), eosinophilic gastritis (EG), and eosinophilic gastroenteritis (EGE), are chronic conditions characterized by eosinophil infiltration into the gastrointestinal mucosa^{1,2}
- Children and adolescents with EGIDs typically continue to experience symptoms into adulthood, thereby requiring lifelong disease management³; transition to adulthood necessitates a transition from pediatric to adult healthcare providers
- Transition of care (TOC) from pediatric to adult providers maximizes long-term outcomes; while timing should be specific to each person, ideally it should occur between the ages of 18 and 21 years⁴

AIM

- To better understand the challenges, unmet needs, and utility of resources to aid in successful TOC for patients with EGIDs

METHODS

- An online survey of adolescents and young adults with EGIDs, ages 15-26 years, or their parents/caregivers, was conducted from 12/18-1/19; participants were recruited through the online platforms of the American Partnership for Eosinophilic Disorders (APFED)
- The survey consisted of 19 multiple choice questions related to patient characteristics, degree of patient independence, challenges transitioning from pediatric to adult providers, and need for resources to support TOC; there were no statistical analyses, as this study was intended to be descriptive only
- Forty-one participants completed the survey; their characteristics are shown in Table 1

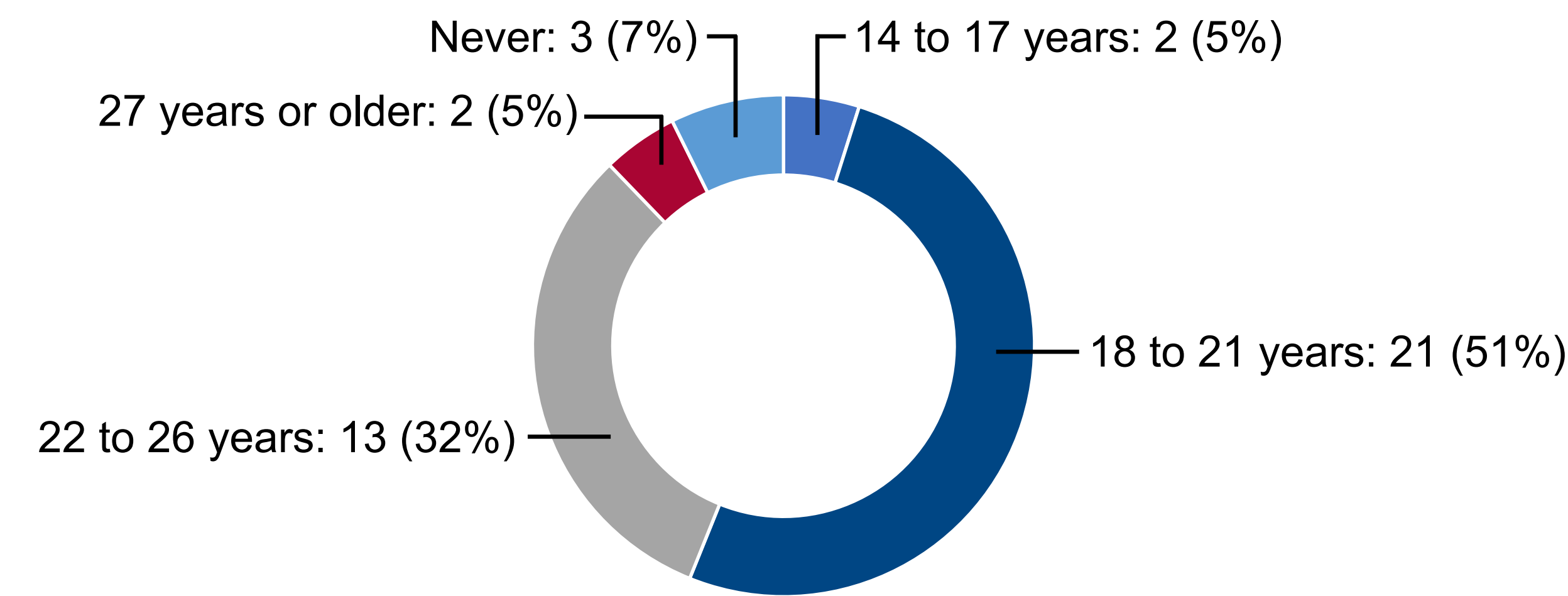
Table 1. Patient characteristics

	Survey respondents (n=41)
Respondent type, n (%)	
Adolescent or young adult patient	7 (17%)
Parent or caregiver	34 (83%)
EGID diagnosis, n (%)	
Eosinophilic esophagitis (EoE) only	33 (81%)
Eosinophilic gastritis, enteritis, gastroenteritis, or colitis (EG, EE, EGE, EC) only	1 (2%)
EoE and EG, EE, EGE or EC	7 (17%)
Patient age, n (%)	
15 to 17 years	16 (39%)
18 to 21 years	18 (44%)
22 to 26 years	7 (17%)
Patient age at diagnosis, n (%)	
0 to 5 years	18 (44%)
6 to 10 years	11 (27%)
11 to 14 years	6 (15%)
15 years or older	6 (14%)
Diagnosing provider specialty, n (%)	
Pediatric gastroenterologist	39 (95%)
Allergist	2 (5%)
Current primary EGID provider, n (%)	
Pediatric gastroenterologist	24 (59%)
Adult gastroenterologist	10 (24%)
Allergist	3 (7%)
No provider	4 (10%)
Insurance coverage, n (%)	
Private/commercial	35 (85%)
Medicaid	5 (12%)
Self-pay/uninsured	1 (2%)

RESULTS

Nearly all patients plan to transition to an adult provider at some point

Figure 1. Age at transition, planned or actual

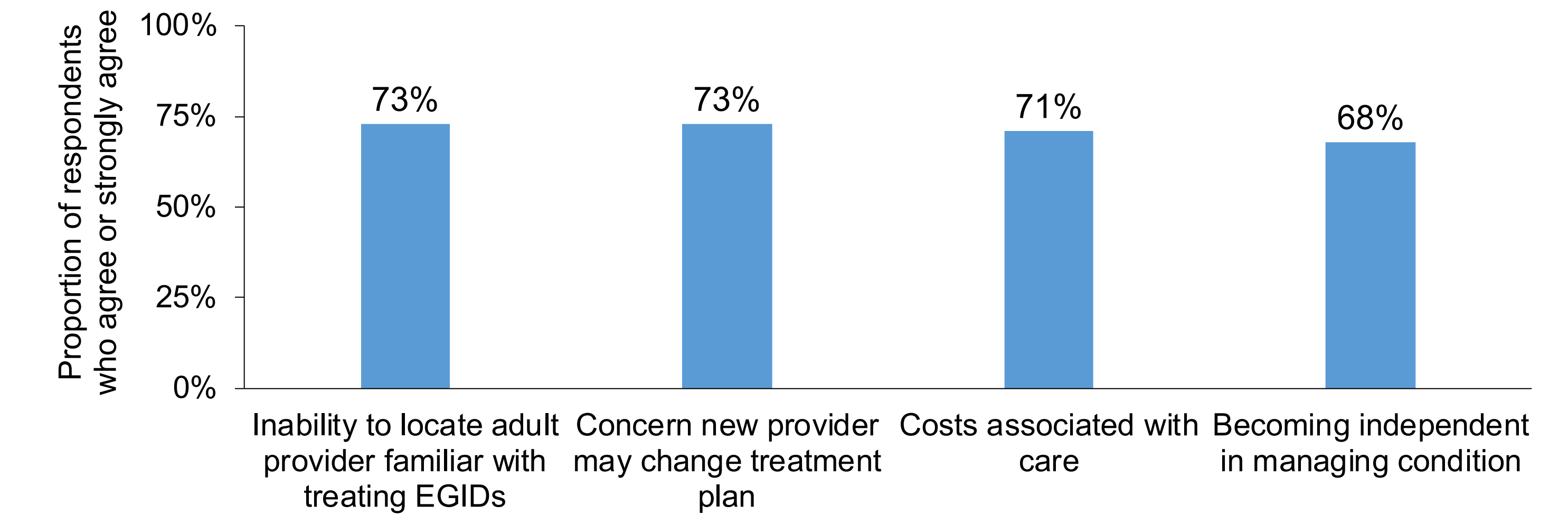


- Twelve respondents (29%) indicated that the patient had already transitioned to an adult provider, while the remaining patients have yet to transition
- While nearly all patients (95%) plan to transition to an adult provider at some point, 15 patients (37%) plan to wait to transition until age 22 or older (Figure 1)
- A few patients stated they do not intend to ever transition and instead plan to remain with their pediatric gastroenterologist indefinitely (Figure 1)
- Twenty-six (63%) and 21 (51%) patients have discussed TOC with their family and with their healthcare provider, respectively

RESULTS

All respondents identified challenges associated with transitioning from pediatric to adult care

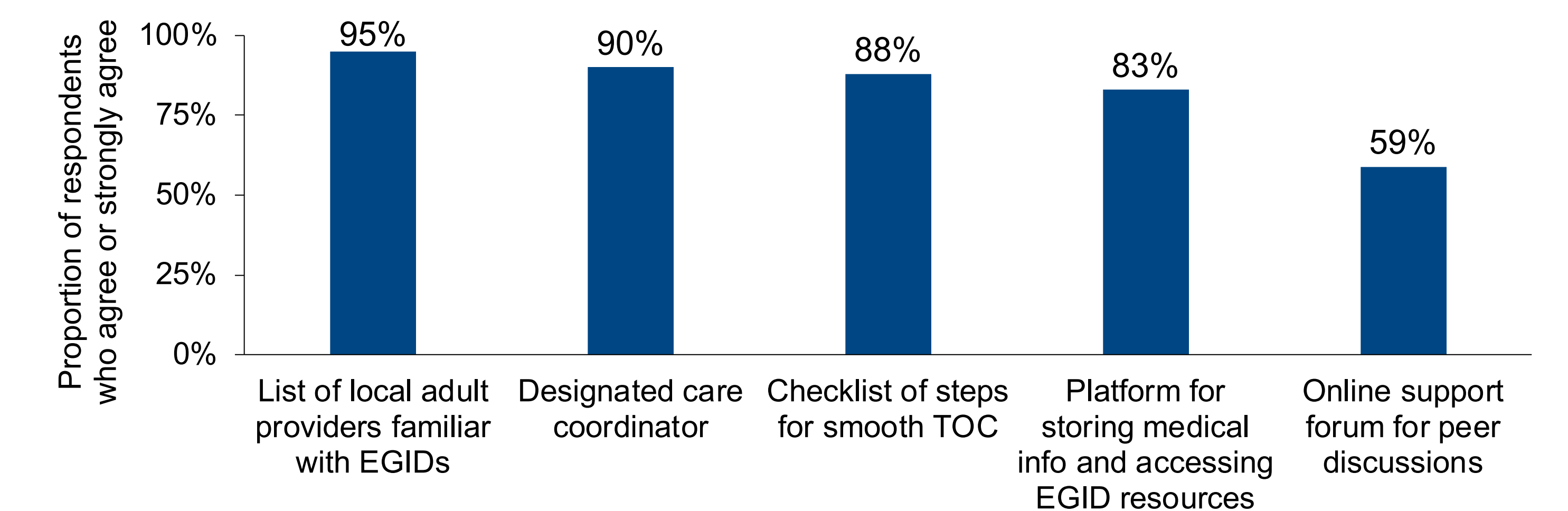
Figure 3. Challenges an adolescent/young adult may face as they transition



RESULTS

All respondents perceive value in additional resources to support successful transition

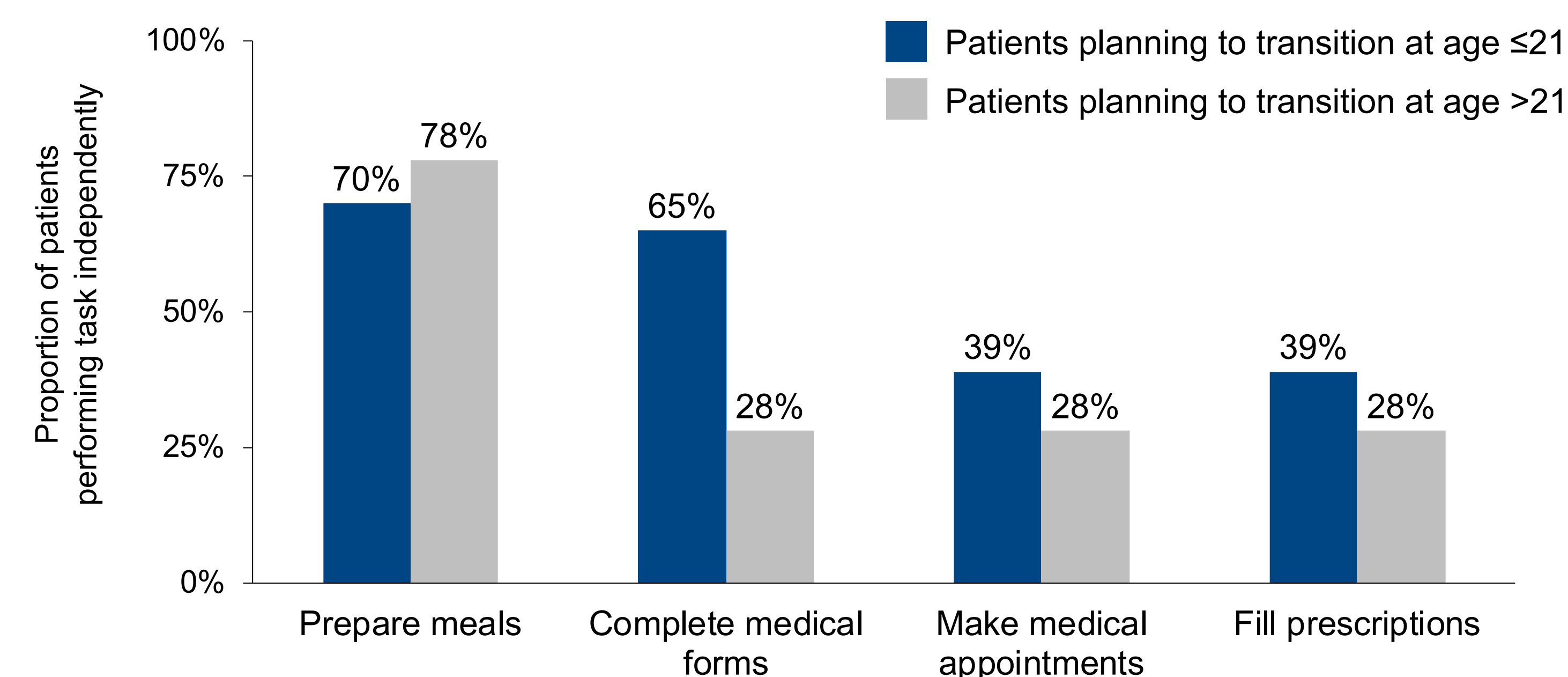
Figure 4. Resources that may help facilitate TOC



RESULTS

Planned age of transition may be related to the patient's current ability to perform tasks associated with their medical care

Figure 2. Patient ability to independently perform tasks, based on planned age at transition



- The majority of EGID patients can prepare meals for themselves, but fewer patients are comfortable performing tasks related to their medical care (Figure 2)
- A greater proportion of patients who plan to transition at a younger age (≤21 years) state they are currently able to complete tasks related to their medical care compared with patients planning to transition at an older age (Figure 2)

CONCLUSIONS

- This study identified several potential barriers to successful TOC and highlights the need for additional resources to ensure a smooth transition from pediatric to adult providers for the management of EGIDs
- Increased EGID disease awareness and education among adult providers may address the challenge patients face trying to locate an adult provider
- Implementation of tools that enable efficient transfer of relevant medical history and current management plan may help optimize continuity of care as patients transition into adulthood
- Additional resources to assist patients with EGIDs to become more knowledgeable about and independent in the management of their condition may also improve patient experience and support successful TOC

References:

- Reed CC, Dellon ES. (2019). Eosinophilic Esophagitis. Med Clin North Am. 103(1):29-42.
- Gonsalves N, Furuta GT, Atkins D. (2016). Eosinophilic gastrointestinal disorders affect more than just the esophagus. J Pediatr Gastroenterol Nutr. 62(1):1-2.
- Collins C, Palmquist J, Proudfoot JA, Qian A, Wangberg H, Khosh-Hemmat E, Dohil R, Aceves SS. (2019). Evaluation of Long-term Course in Children with Eosinophilic Esophagitis Reveals Distinct Histologic Patterns and Clinical Characteristics. J Allergy Clin Immunol. S0091-6749(19)30826-7.
- Castillo C, Kitsos E. (2017). Transitions from Pediatric to Adult Care. Glob Pediatr Health. 4:2333794X17744946.