

Frequency and Predictors of Successful Transition of Care for Young Adults With Childhood Celiac Disease

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See “The Long Road to a Seamless Transition” by Garipey on page 159.

ABSTRACT

Objectives: Transition from pediatric to adult care for individuals with chronic conditions is important to prevent gaps in care, though this has not been well-studied in celiac disease (CD). The aim of this study was to discern rates and predictors of successful transition of care for young adults with childhood-diagnosed CD.

Methods: An anonymous 21-question online survey was sent to individuals on our center’s email contact list seeking responses from those ages 18 to 25 years diagnosed with CD before age 18 years. Information collected included method of diagnosis, demographics, CD-related care, reasons for not seeking care, and symptoms.

Results: Respondents ($n=98$), 70% women, had a median age of 21 years (IQR 19–23 years). The majority were full or part-time students (67%; 95% CI 59%–77%). Only 31% of respondents had successfully transitioned to an adult CD provider. Some 37% (95% CI 29%–48%) were not receiving any CD medical care. An older age at diagnosis was associated with successful transition to adult gastroenterology ($P=0.002$) as well as with greater symptom scores ($P=0.002$). Receiving a referral for ongoing adult CD care predicted successful transition to an adult provider (odds ratio [OR] 3.92, 95% CI 1.58–9.72).

Conclusions: Transition of care for young adults with CD is inconsistent, particularly among asymptomatic patients. Receipt of a referral for an adult provider significantly improves follow-up rates.

Key Words: adolescent, small intestine, sprue, villous atrophy

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What Is Known

- Young adults with chronic diseases are vulnerable to lapses in care and poor disease-related outcomes.
- A planned and organized transition of care for adolescents with celiac disease is recommended, though little data are available regarding factors associated with successful transition.

What Is New

- Receipt of a referral to an adult provider and belief in the importance of ongoing care are associated with improved rates of successful transition of care for young adults with celiac disease.
- Lack of symptoms and younger age at diagnosis predict poor rates of transition to adult care.

Celiac disease (CD), a chronic autoimmune disorder triggered by the consumption of gluten among genetically prone individuals, is treated with a strict gluten-free diet (GFD) (1). Adherence to a GFD can be socially challenging, costly, and difficult because of limited availability of gluten-free foods (2). Adherence to the GFD is the only established means of diminishing disease-related complications associated with persistent villous atrophy, such as malignancy (3), nutritional compromise and bone fragility (4), and disease-related symptoms (5).

Lifelong adherence to a GFD may differ depending upon the age at diagnosis. Individuals with CD diagnosed early in childhood have demonstrated better dietary adherence than individuals diagnosed as older children or adults (6), and those diagnosed in adolescence may be less adherent than their younger and older comparators (7). Transitional periods, such as starting school have been associated with diminished dietary adherence (8). Ensuring a smooth transition from pediatric to adult care is believed to be critical to fostering disease surveillance and treatment adherence, though this can be challenging (9). Transition from pediatric to adult care for patients with chronic disease has been examined for digestive disorders, such as inflammatory bowel disease, demonstrating inferior outcomes for those in whom transition is inadequately supported (10).

Published recommendations regarding transition of care for young adults with chronic gastrointestinal disorders (11) and CD (11,12) have been largely based on expert opinion and evidence from other chronic disorders and lack disease-specific data. The aims of this study were to determine the frequency of successful transition to adult care for a group of young adults with CD; to define the factors responsible for patients’ decisions regarding ongoing care for CD; and to determine whether ongoing symptoms can be predicted by the success of care transition.

MATERIALS AND METHODS

We conducted a cross-sectional study using a survey to gather information regarding young adults with CD. Study participants were identified through our Celiac Disease Center's email contact list. This list includes individuals who had requested to be contacted by our Center though did not exclusively include individuals with CD or patients managed by one of our providers. A link to an anonymized questionnaire created using Qualtrics software (Qualtrics, Provo, UT) was sent electronically to 7785 adults on the contact list seeking individuals specifically ages 18 to 25 years who had received a diagnosis of CD before the age of 18 years and were available to complete the questionnaire on their own behalf.

In addition to basic demographics, participants were asked to give information regarding their method of CD diagnosis (biopsy vs serology alone), education, occupation, current CD-related care, reasons for seeking or not seeking care, and current symptoms.

Celiac Symptoms Index Scale

Current symptoms were determined through the Celiac Symptom Index (CSI) (13), a validated, 16-item questionnaire scored on a 5-point visual analog scale, with items relating to abdominal symptoms, appetite, favorable quality of life (QOL) and GFD adherence. All valid domains retained in the final instrument showed a Cronbach α of >0.70 . Minimum and maximum scores are 16 and 80, respectively, with lower scores indicating a more favorable symptom profile. The instrument authors report a score of ≤ 30 was associated with more favorable QOL and dietary adherence whereas a score of ≥ 45 was associated with poor QOL and adherence (13).

Provider Follow-up and Definition of Successful Transition

Provider follow-up beyond age 18 years was determined by asking participants whether they identified any of the following as the provider managing their CD: adult gastroenterologist, pediatric gastroenterologist, dietitian, generalist, homeopathic provider, no provider, and other. More than 1 selection was permitted. Those selecting "other" were given an opportunity to clarify by free-texting a description in the survey. Respondents were additionally asked about the timing of the most recent medical visit for CD and were offered the choices: last week, last month, 6 months, 1 year, 2 years, $>2-5$ years, $>5-10$ years, or other. Those responding "other" were asked to specify a time-frame.

We defined successful transition to adult care for young adults with childhood CD as those cases where a diagnosis was rendered before age 18 years but an adult gastroenterologist was identified as the current primary CD provider.

Gluten-free Diet Adherence

Participants were asked to gauge their degree of adherence to the GFD by selecting which 1 of 6 categories best described their frequency of knowingly consuming gluten: never, less than once monthly, 1-3 times monthly, once weekly, several times weekly, and daily.

Factors Influencing Care Decisions

Participants were asked to indicate whether any of the following factors influenced their decision of whether to continue

to seek care for CD: health insurance, time constraints, working full time, studying full time, extracurricular activities, receipt of a referral to an adult gastroenterologist, and availability of a knowledgeable CD specialist.

Statistical Analyses

Only fully completed surveys were included in statistical analyses. Respondents who were not currently ages 18-25, or who did not receive a CD diagnosis before age 18, were excluded. Those who were diagnosed with CD without a biopsy were included in data analysis, though separate analyses were performed for these individuals.

Assessment of the probability of successful transition based on factors assessed was performed using multivariate logistic regression. Analyses concerning CSI score predictions were performed using multivariate linear regression. Comparison of non-parametric CSI scores was performed using the Wilcoxon Rank Sum test. The threshold for statistical significance was considered to be 0.05. Statistical analyses were performed using Stata version 13.1 (College Station, TX). This study was approved by the Institutional Review Board of Columbia University Medical Center (protocol number AAAO4953).

RESULTS

Survey Response

Of 7785 surveys sent, 2231 emails (30.4%) were opened, and 108 surveys were completed (4.8% of opened messages; 1.4% of all surveys sent). Two completed surveys were excluded as the respondents indicated they did not have CD. An additional 8 were excluded for respondents less than age 18 years at the time of completion. This left 98 complete responses, which fulfilled our inclusion criteria and were analyzed.

General Respondent Characteristics and Demographics

The median age of respondents was 21 years (interquartile range [IQR] 19-23 years) and 70% were women. Only 8% of patients were diagnosed based on serology alone. The majority was students and nearly equal proportions of respondents lived at home/with relatives as compared with those living with friends/in a dormitory (see Supplemental Table, Supplemental Digital Content, <http://links.lww.com/MPG/B748>).

Transition Frequency and Predictors

Most commonly, respondents reported seeing "no provider" for CD management (37%) with successful transition to an adult gastroenterologist reported in only 31% (Table 1).

Age at Diagnosis

Age at CD diagnosis was a significant predictor of the likelihood of successful transition, with the probability of transition to adult gastroenterology increasing with age at diagnosis (Fig. 1). Those diagnosed at age >13 years of age were significantly more likely to successfully transition to an adult provider by the time of survey completion (odds ratio [OR] 3.7, 95% confidence interval [CI] 1.4-9.8). Those diagnosed at \leq age 13 years were significantly more likely to report "no provider" (OR 3.7, 95% CI 1.5-9.2).

TABLE 1. Celiac disease providers and associated Celiac Symptom Index Scores

Provider [†]	Frequency, %	Median interval since last CD visit (IQR)	Median CSI score (IQR); <i>P</i> value*
Adult gastroenterologist	30 (31%)	6 mo (6 mo to 1 y)	34 (27–42)
Pediatric gastroenterologist	22 (22%)	6 mo (6 mo to 2 y)	25 (20–28); <i>P</i> = 0.002
Generalist	13 (13%)	1 y (6 mo to 2 y)	34.1 (28–40); <i>P</i> = 0.6
Dietitian	6 (6%)	6 mo (6 mo to 1 y)	38.5 (24–47); <i>P</i> = 0.9
Homeopathic provider	3 (3%)	1 wk, 1 y, 5–10 y	43 (26–44); <i>P</i> = 0.9
Other (endocrinologist 1, rheumatologist 1)	2 (2%)	1 y, 5–10 y	34 (25–43); <i>P</i> = 1.0
No provider	37 (36%)	2–5 y (2–5 y to 5–10 y)	30.5 (22–38); <i>P</i> = 0.2

*Analyses comparing median CSI scores to those of respondents seeing an adult gastroenterologist.

[†]Respondents were permitted to select more than 1 provider.

Housing and Education

Living circumstances (living with parent or relative vs living independently) did not impact the likelihood of transition (*P* = 0.3). Similarly, level of education attained, when controlling for age, did not influence follow-up (*P* = 0.2).

Respondent-reported Key Factors

Survey participants reported whether any of several factors influenced their decision regarding providers or whether to seek ongoing care for CD (Table 2). Some 97% of respondents reported

having health insurance. Yet 30.6% of respondents reported that insurance influenced whether to seek ongoing care for CD. When asked “Do you believe you need to see a specialist because you have celiac disease?”, 51% of respondents replied “yes”, and of these, 46% had successfully transitioned to adult care, whereas only 14.6% of those who replied “no” successfully transitioned. There was a significant association between reported belief in the importance of continuing to see a specialist as measured by this question and successful transition (*P* < 0.001), which persisted when controlling for age at diagnosis and CSI score (*P* = 0.005).

Only 34% of those surveyed reported receiving a referral, and receipt of a referral was associated with a greater likelihood of successful transition to adult care (OR 3.92, 95% CI 1.58–9.72). Of those receiving a referral, 50% (17/34) successfully transitioned to an adult provider, compared with only 20% of those not receiving a referral (*P* = 0.002). Among those respondents seeing “no provider”, 29% had received a referral to an adult gastroenterologist compared with 57% of those who did transition to an adult gastroenterologist (*P* = 0.03).

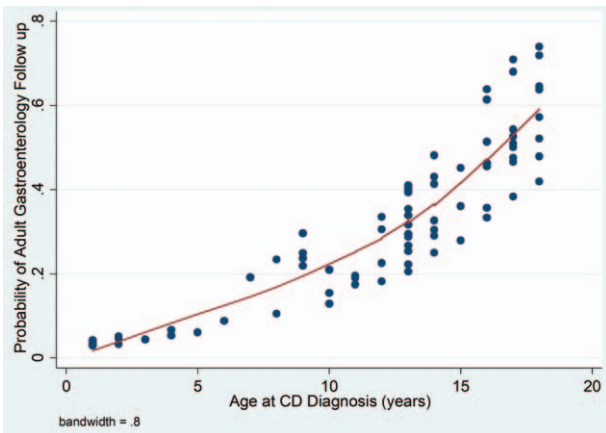


FIGURE 1. Probability of adult gastroenterology follow-up according to age at celiac disease diagnosis. Curve created using logistic regression model with Lowess smoother, controlling for Celiac Symptom Index score.

TABLE 2. Respondent-reported factors influencing ongoing celiac disease care

Factor	Respondents indicating factor influenced care decisions, %
Health insurance	31
Receipt of a referral	35
General time constraints	25
Working full time	9
Studying full time	27
Extracurricular activities	15
Availability of a knowledgeable specialist	51

Celiac Symptom Index Score and Transition of Care

Collectively, the median CSI score of respondents was 29 (range 16–59, IQR 23–38) (Table 1).

CSI score significantly increased unfavorably with age at CD diagnosis (*P* = 0.002), with those diagnosed early in childhood demonstrating the lowest CSI scores (Fig. 2). Although greater CSI score and greater age at diagnosis each predicted successful

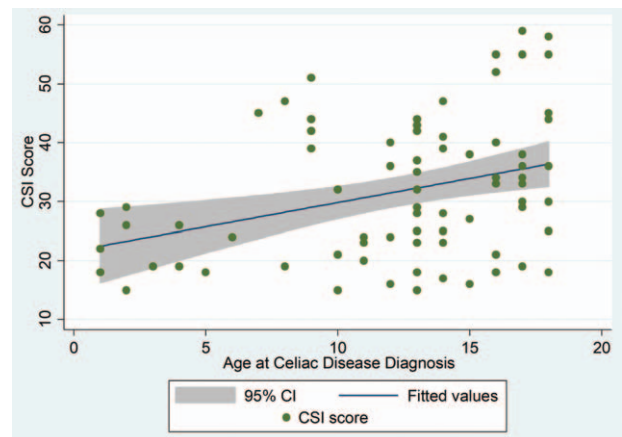


FIGURE 2. Association between Celiac Symptom Index Score and age at diagnosis.

transition in univariate analyses, in a multivariate model incorporating age at diagnosis, only age at CD diagnosis predicted successful transition (OR 1.20, 95% CI 1.04–1.40).

Gluten-free Diet Adherence

Intentional gluten consumption was admitted in 24% of cases (95% CI 17–34%); 2% of respondents reporting gluten consumption several times weekly, 7% 1 to 3 times per month, and 15% less than once monthly. The remaining 76% of respondents denied any intentional gluten consumption. The frequency of gluten consumption was not associated with successful transition to an adult gastroenterologist ($P = 0.2$). Seeing a dietitian was associated with significantly greater frequency of intentional gluten ingestion (67% with intentional gluten ingestion, $P = 0.03$). There was no association between CSI scores and reported frequency of gluten consumption ($P = 0.9$).

Method of Diagnosis

Eight percentage ($n = 8$) of respondents were diagnosed with CD based on serology alone. Patients diagnosed serologically were significantly younger than the group undergoing biopsy ($P = 0.02$). Although only 1 of the 8 serologically diagnosed respondents had successfully transitioned to adult care, there was no significant difference in the likelihood of successful transition to adult care between those biopsied and those diagnosed serologically, when controlling for current age and age at CD diagnosis (OR 2.29, 95% CI 0.22–23.57). Similarly, there was no significant difference in reported gluten consumption between the 2 groups (OR 2.40, 95% CI 0.28–20.59).

DISCUSSION

This study provides new insights in the transition of care of young adults with CD: that a referral is paramount for follow-up; that patients diagnosed young show poorer transition rates; and that those lacking symptoms are less likely to transition to adult care. On the basis of desirable outcomes associated with successful health-care transition of young adults with other chronic disorders (14), we hypothesized that a similar finding would be apparent in the CD population studied. We, however, instead found evidence of a more complex relationship between transition, symptoms, and disease-related education.

It is well-described that symptoms are an unreliable measure of clinical status in CD, given that CD may present in asymptomatic young patients (15) and persistent villous atrophy may be present asymptotically following treatment (16). In this study, those seeing a dietitian had greater symptom scores and a high frequency of intentional gluten ingestion. As it is less likely that patients' greater symptoms are attributable to dietitian consultations, these data imply that symptoms trigger dietitian visits. We showed no association between CSI scores and GFD adherence and those with better adherence were not more likely to transition successfully. Our data have further shown that those diagnosed early in childhood are less likely to report physical symptoms and are less likely to make a successful transition.

Annually over 750,000 children in the United States with special health needs transition to adult care (17), yet the majority of adolescents are not adequately prepared for this measure (18). Young adults with chronic illnesses transitioning care show increased vulnerability, diminished adherence (19–21), and increased use of the emergency department (22). In young adults with inflammatory bowel disease, failed transition of care was associated with increased likelihood of requiring surgery, reduced

growth potential, and medication noncompliance (10). Transferring care in an organized manner has been associated with improved outcomes, such as a greater feeling of preparedness in young patients with chronic illness (23) and improved adherence with medical care (24).

Regarding CD, circumstances surrounding care transition are poorly understood. Irish adolescents with CD graduating pediatric care similarly showed poor subsequent follow-up (25). Children with CD lost to follow-up show poor dietary adherence whereas those followed in primary care alone more frequently show persistently elevated CD serologies (26). Individuals with untreated CD are subject to risks, such as bone fragility (27), fertility complications (28), and malignancy (29). Persistent mucosal damage after treatment has been linked to augmented risk of hip fracture (4) and lymphoproliferative malignancy (3), among other hazards. Yet while expert opinion maintains that regular, annual care for patients with CD is the best (30,31); there are no data that affirm, which care strategy supports good outcomes for young adults with CD.

Recently published recommendations regarding care transfer for young adults with digestive issues (11,32) and specifically regarding CD (12) focus on the importance of patient education. Only half of those surveyed in this study believed in the importance of follow-up care for CD, and holding this view was significantly associated with successful care transition. In addition to education, receiving a referral to an adult gastroenterologist also predicted a greater likelihood of successful transition. Comparing those young adults in our study who had transitioned to an adult gastroenterologist with those who were seeing "no provider," about twice as many of those whose transitions were successful reported receiving a referral (57% vs 29%, $P = 0.03$).

Although this study provides new data regarding transition of care for young adults with CD in the United States, we acknowledge certain limitations. The anonymous method of recruiting and surveying subjects, while enabling us to recruit subjects who were not cared for at our Center, makes it impossible to confirm CD diagnoses and method of survey completion. Further, a complete understanding of causality among the factors examined in this study is not possible, given the cross-sectional design. Future longitudinal studies are indicated to better clarify these relationships. In addition, although the purpose of this study was to discern rates of transition to an adult gastroenterologist, additional important nuances of successful transition of care, such as maturity and transition readiness, were not measurable by our methods. Additionally, our study cohort represents a very small and specific patient population of young adults in the United States: our respondents were mostly college educated or in college, were affiliated with a University-based medical center, and were motivated to respond to our survey. Our results may not have captured the experience of individuals from lower socioeconomic or educational statuses. In this regard, however, our data arguably reflect an inadequate "best-case scenario." Our results additionally were quite similar in several respects to the US National Survey of Children with Special Health Care Needs (NSCSHC), such as with regard to insurance rates (only 3% uninsured in the NSCSHC study as well as ours) as well as frequency of referral to adult care (44% of 12–18-year-olds in the NSCSHC survey, vs in 34% of our respondents) (18). The population of young adults who we studied, however, reported a higher rate of health insurance coverage (97%) than that cited in the 2015 US census data (current at the time of this study) where the coverage rate of 18- to 24-year-olds was noted to be 86.9% (33), which may alter the generalizability of our data. Individuals with higher educational attainment also have more favorable outcomes with respect to persistent lesions of celiac disease (34).

CONCLUSIONS

Young adults with CD have a poor understanding of the importance of follow-up care with an adult gastroenterologist and do not routinely experience purposeful hand-off to adult providers. Although education of the adolescent concerning CD care and a clear and planned transfer of care are indicated, outcomes of young adults with childhood CD remain poorly understood and warrant further study to best understand how to medically care for these patients as they age.

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