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# Transition experiences and health care utilization among young adults with type 1 diabetes

Katharine C Garvey<sup>1</sup>  
Jonathan A Finkelstein<sup>2,3</sup>  
Lori M Laffel<sup>1,4</sup>  
Victoria Ochoa<sup>1</sup>  
Joseph I Wolfsdorf<sup>1</sup>  
Erinn T Rhodes<sup>1</sup>

<sup>1</sup>Division of Endocrinology, Boston Children's Hospital, <sup>2</sup>Division of General Pediatrics, Boston Children's Hospital, <sup>3</sup>Department of Population Medicine, Harvard Pilgrim Health Care Institute, <sup>4</sup>Pediatric, Adolescent and Young Adult Section, Joslin Diabetes Center, Boston, MA, USA

**Background:** The purpose of this study was to describe the current status of adult diabetes care in young adults with type 1 diabetes and examine associations between health care transition experiences and care utilization.

**Methods:** We developed a survey to assess transition characteristics and current care in young adults with type 1 diabetes. We mailed the survey to the last known address of young adults who had previously received diabetes care at a tertiary pediatric center.

**Results:** Of 291 surveys sent, 83 (29%) were undeliverable and three (1%) were ineligible. Of 205 surveys delivered, 65 were returned (response rate 32%). Respondents (mean age  $26.6 \pm 3.0$  years, 54% male, 91% Caucasian) transitioned to adult diabetes care at a mean age of  $19.2 \pm 2.8$  years. Although 71% felt mostly/completely prepared for transition, only half received recommendations for a specific adult provider. Twenty-six percent reported gaps exceeding six months between pediatric and adult diabetes care. Respondents who made fewer than three diabetes visits in the year prior to transition (odds ratio [OR] 4.5, 95% confidence interval [CI] 1.2–16.5) or cited moving/relocation as the most important reason for transition (OR 6.3, 95% CI 1.3–31.5) were more likely to report gaps in care exceeding six months. Patients receiving current care from an adult endocrinologist (79%) were more likely to report at least two diabetes visits in the past year (OR 6.0, 95% CI 1.5–24.0) compared with those receiving diabetes care from a general internist/adult primary care doctor (17%). Two-thirds (66%) reported receiving all recommended diabetes screening tests in the previous year, with no difference according to provider type.

**Conclusion:** In this sample, transition preparation was variable and one quarter reported gaps in obtaining adult diabetes care. Nevertheless, the majority endorsed currently receiving regular diabetes care, although visit frequency differed by provider type. Because locating patients after transition was incomplete, our findings suggest the need for standardized methods to track transitioning patients.

**Keywords:** type 1 diabetes mellitus, health care delivery, young adults, transition to adult care

## Introduction

Health care transition has been defined as “the planned, purposeful movement of young adults from child-centered to adult-oriented health-care systems”.<sup>1</sup> In 2002, a consensus statement from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians underscored the importance of a planned and facilitated health care transition for adolescents with special health care needs.<sup>2</sup> Unfortunately, updated guidelines in 2011 described inadequate implementation of transition care over the intervening years and reiterated the importance of transition coordination as a basic standard of high-quality care.<sup>3</sup>

Correspondence: Katharine C Garvey  
Division of Endocrinology, Boston Children's Hospital, 300 Longwood Avenue, Boston, MA 02115, USA  
Tel +1 617 919 3045  
Email [katharine.garvey@childrens.harvard.edu](mailto:katharine.garvey@childrens.harvard.edu)

Type 1 diabetes is a chronic disease that requires complex daily self-management and medical decision-making and is an important model for the study of health care transition. The developmental period of emerging adulthood is rife with competing educational, social, and emotional priorities.<sup>4</sup> In young adults with type 1 diabetes, as in young adults with many other chronic health conditions, such developmental priorities are compounded by intensive self-care requirements. The transition to a new adult care system adds still further challenges.<sup>5,6</sup> Young adults with type 1 diabetes are at risk for gaps in medical follow-up and adverse diabetes-related outcomes, including poor glycemic control, acute complications, emergence of chronic diabetes complications, and early mortality.<sup>7–12</sup>

The American Diabetes Association recently published expert consensus guidelines on health care transition for emerging adults with diabetes,<sup>5</sup> but empiric data remain limited. Previous research has demonstrated difficulties in the transition process, including delays in care,<sup>13–17</sup> increased post-transition diabetes-related hospitalizations,<sup>18</sup> and patient dissatisfaction with transition.<sup>13–17</sup>

To design interventions to improve transition outcomes, it is necessary to understand the transition experiences from the perspective of young adults who have been through the process. Previous work has examined perceptions of health care transition in young adults who have successfully established care at specialty adult diabetes centers.<sup>14</sup> However, little information is available about the transition experiences, disposition, and current medical care from the perspective of patients who have transferred from pediatric diabetes clinics.

Therefore, our objectives were: to describe the current status of care (type of medical provider, frequency of visits) and quality of care (receipt of recommended screening tests) in post-transition young adults with type 1 diabetes who had previously received pediatric diabetes care at a single tertiary pediatric center; to evaluate associations between health care transition characteristics (eg, gaps between pediatric and adult care, transition preparation) and the current status of care; and to evaluate associations between current diabetes care and health-related quality of life.

## Materials and methods

### Subjects

Eligible subjects included emerging adults with type 1 diabetes, who had been previously followed in the pediatric diabetes clinic at Boston Children's Hospital. Criteria for eligibility included: at least one diabetes clinic encounter

with International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes 250.X1 or 250.X3 (where X = 0 through 9) between June 2000 and May 2010; age at least 15 years at the last diabetes clinic visit; and not seen in the 18 months prior to May 2010. To exclude cystic fibrosis-related diabetes, subjects with coexisting ICD-9-CM code 277.0X (cystic fibrosis) were excluded. The study was approved by the institutional review board at Boston Children's Hospital.

### Survey instrument

We developed a survey to assess the transition experiences of patients with type 1 diabetes. Initial survey development was based upon review of the academic health care transition literature in type 1 diabetes and other pediatric chronic illnesses, as well as an Internet search for resources on health care transition. We also utilized qualitative data obtained from focus groups of young adults with type 1 diabetes.<sup>19</sup> Experts in pediatric and adult diabetes care and health care transition reviewed the instrument for content validity. Pretesting of the final version was performed using six young adults with type 1 diabetes.

The survey was divided into six sections: medical history; attributes of current diabetes care (eg, type of adult medical providers seen and visit frequency); health care transition (eg, reasons for transition, transition preparation and satisfaction, gaps in care); current diabetes self-care practices and social support; health-related quality of life; and demographics. A secure electronic version of the survey was created using a Research Electronic Data Capture (REDCap) survey<sup>20</sup> hosted by Boston Children's Hospital. The complete survey is available upon reader request.

This survey was developed concurrently with a second survey fielded in a different population of post-transition young adults with diabetes who were known to be receiving care at a single adult diabetes clinic.<sup>14</sup> There was no overlap in subjects between the two studies. Because subjects in this study had left their pediatric center and current adult care status was unknown, this survey included unique items related to location, type, and quality of current medical care.

For transition preparation, we asked yes/no questions about receipt of eight key preparation elements as well as a summary preparation question (response options: completely unprepared, mostly unprepared, neutral, mostly prepared, and completely prepared). We also included a parallel summary question about satisfaction with transition. We examined self-reported gap between last pediatric diabetes appointment and first adult diabetes appointment

(response options:  $\leq 3$  months, 4–6 months, 7–12 months, 13–24 months, or  $> 24$  months).

To understand current care patterns, we asked, “Have you ever seen any of the following types of adult medical care providers for your diabetes?”, listing endocrinologist, diabetes educator, internist/primary care physician, dietitian, or other; and how many times the subject had seen each of these providers in the past 12 months. We then asked subjects to specify the person they identified as the primary provider of their diabetes care.

The survey asked for self-reporting of most recent glycosylated hemoglobin ( $HbA_{1c}$ ) levels, with seven response categories, ie,  $\leq 7.0\%$ , 7.1%–8.0%, 8.1%–9.0%, 9.1%–10.0%, 10.1%–12%,  $> 12\%$ , or “don’t know”. We asked subjects to report their most recent diabetes screening tests, including separate items for each of the following: blood tests to measure cholesterol and thyroid function; urine tests (microalbumin) to assess kidney status; and an eye examination to check for effects of diabetes on the retina. Response categories for the screening tests included  $< 12$  months ago, 1–2 years ago,  $> 2$  years ago, never, or “don’t know”.

Health-related quality of life was measured using the Duke Health Profile (DUKE),<sup>21</sup> a 17-item instrument containing six health measures (physical, mental, social, general, perceived health, and self-esteem), for which acceptable levels of reliability and validity have been demonstrated for adults as well as adolescents.<sup>22</sup>

## Survey administration

We mailed the survey in three waves from October to December 2010 to the last known address in the Boston Children’s Hospital records. The first mailing included a small gift (sticky notes) and respondents were entered into a raffle to win an Apple iPad 2®. After completing the three mail waves, we offered the remaining eligible subjects (69% of sample) a final opportunity to complete an abbreviated survey electronically that omitted the health-related quality of life module. Because email addresses for subjects were not available, we mailed a letter with a web link for the abbreviated electronic version of the survey and included a \$2 bill. To maximize the response rate, the survey was anonymous and no self-identifying information was collected. Subjects returned a separate identifier postcard to report survey completion for the raffle.

## Statistical analysis

All statistical analyses were conducted using SAS version 9.2 (SAS Institute Inc, Cary, NC, USA). An alpha

of 0.05 (two-tailed) was used for statistical significance. Descriptive statistics were calculated as means and standard deviations or proportions. We used Fisher’s exact test or bivariate logistic regression to evaluate associations between transition characteristics and current diabetes care patterns, where appropriate. Due to the small sample size, we did not perform multivariable analyses.

Questions about overall transition preparation and satisfaction as well as current perceived success in diabetes management were analyzed as dichotomous variables (combining “mostly” and “completely”) to distinguish subjects reporting positive experiences.

Gaps between pediatric and adult diabetes care were also analyzed as a dichotomous variable of up to six months or more than six months. This dichotomization was selected a priori, to allow comparison with other reports,<sup>14,16,17,23</sup> and given the American Diabetes Association recommendation that insulin-treated patients older than 18 years have diabetes visits at least every six months.<sup>24</sup>

In bivariate analyses, responses for adult clinic visit frequency were analyzed for at least two visits in the past year, and “receipt of all recommended screening tests” was defined as report of blood tests for cholesterol and thyroid, urine tests for microalbumin, and retinal examination in the previous year.

For health-related quality of life, we examined the physical health, mental health, social health, and general health scales on the DUKE (0 = poorest and 100 = best health status). We used Wilcoxon rank-sum tests to explore associations between scale scores and current diabetes care patterns (visit frequency, self-reported  $HbA_{1c}$ , and perceived success in diabetes management).

## Results

We mailed surveys to the last known mailing address of 291 former patients based on the above criteria. Eighty-three surveys (29%) were returned to sender. Three subjects were found to be ineligible (one deceased, two miscoded as having type 1 diabetes). From 205 eligible subjects, 65 surveys were returned (56 paper surveys from waves 1–3 and nine electronic surveys from the final wave 4). The overall response rate was 32% (65/205).

## Sample characteristics

Table 1 displays subject characteristics. The mean age of the respondents was  $26.6 \pm 3.0$  years and the mean age at onset of diabetes was  $9.7 \pm 3.2$  years. The majority were male (54%), Caucasian (91%), college-educated (64%), employed

**Table 1** Demographic and clinical characteristics of respondents

Characteristic	Observed Sample Size (n)	Mean $\pm$ SD or %
Current age	65	26.6 $\pm$ 3.0 years
Male	65	54%
Race	65	
White/Caucasian		91%
Black/African-American		5%
Asian/Pacific Islander		4%
Highest level of education	63	
High school or equivalent		11%
Some college		25%
Four-year college degree		32%
Some graduate school		8%
Graduate degree		24%
Health insurance	64	
Private insurance		77%
Public insurance		23%
<b>Diabetes history</b>		
Age at diabetes diagnosis	59	9.7 $\pm$ 3.2 years
Most recent HbA <sub>1c</sub> (self-reported)	62	
$\leq 7.0\%$		25%
7.1%–8.0%		34%
8.1%–9.0%		31%
9.1%–10.0%		3%
10.1%–12.0%		6%
$> 12.0\%$		0%
Don't know		1%
Comorbidities	65	
Diabetic retinopathy		3%
Hypercholesterolemia		8%
Hypertension		6%
Depression		11%
Anxiety		11%
<b>Health care delivery</b>		
Age at transition to adult diabetes care	60	19.2 $\pm$ 2.8 years
Gap between last pediatric diabetes visit and first adult visit	61	
$\leq 3$ months		28%
4–6 months		46%
7–12 months		20%
$> 12$ months		6%
Current main diabetes care provider	61	
Adult endocrinologist		79%
Internist/primary care		17%
Nurse practitioner/diabetes educator		2%
Other		2%
Receipt of all recommended diabetes screening tests in past year	62	66%

**Abbreviations:** SD, standard deviation; HbA<sub>1c</sub>, glycosylated hemoglobin.

full-time (56%), and had private insurance (77%). Twenty-nine percent were living with their parents and a third of respondents described their parents as moderately or very involved in their diabetes care. Overall, 69% felt mostly or completely successful in diabetes self-management.

Twenty-five percent of subjects reported a most recent HbA<sub>1c</sub> level in the American Diabetes Association target range ( $\leq 7.0\%$ ) while 40% reported HbA<sub>1c</sub> levels  $> 8.0\%$ .

Those who did not respond to the survey (including undeliverable surveys as well as nonrespondents) were 59% male ( $P = 0.55$  for comparison with respondents) and had a mean age of  $25.9 \pm 3.8$  years ( $P = 0.19$ ). No other data were available for comparison between respondents and nonrespondents.

## Transition characteristics

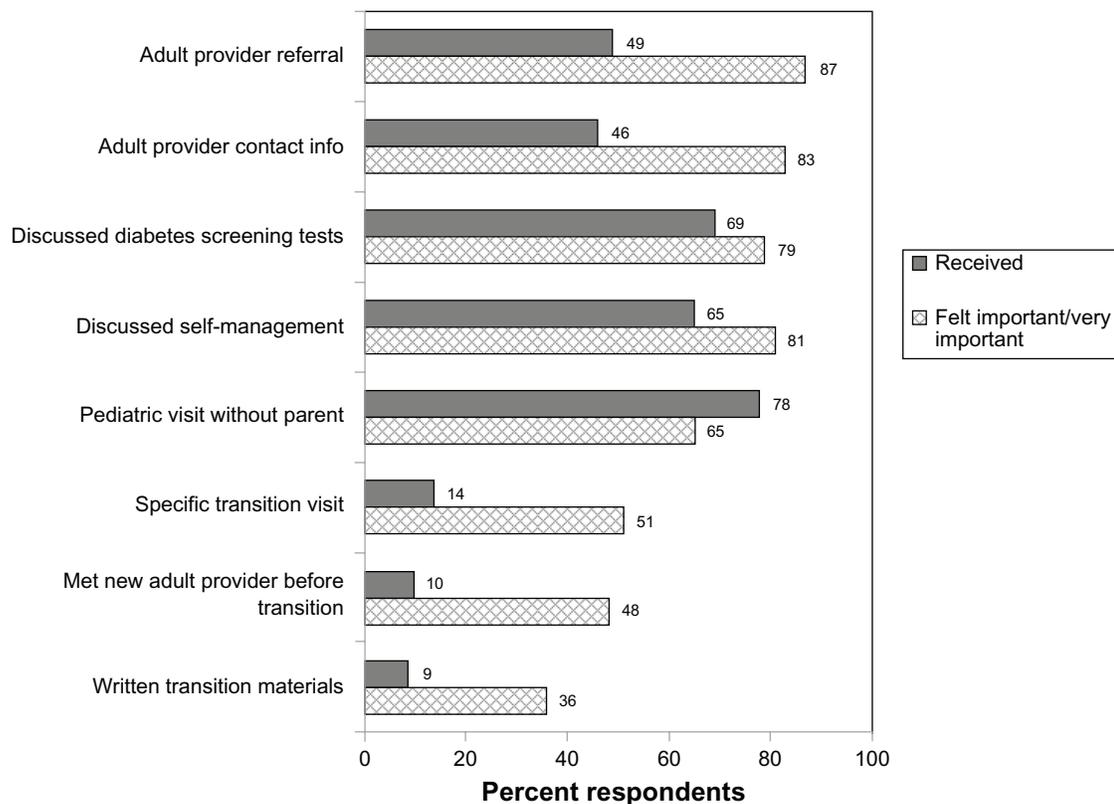
The mean age at transition was  $19.2 \pm 2.8$  years. The top three reasons for transition endorsed as “most important” included pediatric provider suggestion (29%), feeling “too old” for pediatrics (25%), and moving (15%). Overall, 71% felt mostly or completely prepared for transition, and 68% felt mostly or completely satisfied with their transition experience. Perception of overall preparation and satisfaction were highly associated ( $P < 0.0001$ ).

Figure 1 shows the report of eight specific pediatric transition preparation activities as well as the perceived importance of each one in facilitating a successful transition. More than 50% of respondents reported receiving three of these items (having a pediatric diabetes visit without a parent/guardian in the room, discussing annual diabetes screening tests, and discussing independent diabetes self-management). Approximately one half of respondents received a specific recommendation for an adult provider or clinic, while more than 80% felt that these recommendations were important. Less than 15% had a specific transition visit, received written transition materials, or met the new adult provider before transition, while 36%–51% felt that these items were important.

Twenty-six percent of respondents reported a gap of more than six months between the last pediatric diabetes visit and the first adult visit, and 6% reported a gap of more than 12 months (Table 1). In bivariate logistic models, respondents (46%) who had fewer than three pediatric diabetes visits in the year prior to transition (odds ratio [OR] 4.5, 95% confidence interval [CI] 1.2–16.5) and those who cited moving/relocation as the most important reason for transition (OR 6.3, 95% CI 1.3–31.5) were significantly more likely to report gaps between pediatric and adult care of more than six months. Twenty-three percent of those who felt mostly/completely prepared for transition reported gaps in care, while 35% of those who felt neutral or unprepared reported gaps in care; this difference did not reach statistical significance (OR 0.5, 95% CI 0.2–1.8).

## Delivery of adult care

Overall, 80% of subjects had seen their main adult diabetes doctor at least twice in the previous year. The frequency of



**Figure 1** Solid bars represent proportions of respondents who reported receiving specific transition preparation items. Cross-hatched bars represent proportions of respondents who felt that receipt of each item was important or very important in the transition process.

adult diabetes visits in the previous year was not significantly lower in subjects who felt unprepared for transition (OR for at least two adult diabetes visits in the past year 0.5, 95% CI 0.1–1.8) or who reported gaps in care of more than six months (OR 0.4, 95% CI 0.1–1.8).

Seventy-nine percent of respondents identified an adult endocrinologist as the current main diabetes provider, while 17% identified an adult primary care doctor or internist, 2% reported a nurse practitioner, and 2% reported another provider (Table 1). Eighty-eight percent of those identifying an endocrinologist as the main diabetes provider reported at least two diabetes visits in the past year, compared with 54% of those identifying an internist or other types of diabetes providers. Compared with the rest of the sample, those identifying an adult endocrinologist as the main diabetes provider were six times more likely to report more than two diabetes visits in the past year (OR 6.0, 95% CI 1.5–24.0). Self-reported glycemic control and satisfaction with current adult diabetes care did not differ by visit frequency or type of main diabetes provider.

Regarding annual screening for diabetes complications, 66% of respondents reported receiving all of the recommended tests in the preceding year; 84% of all respondents had received an eye examination for retinopathy. Less than

3% reported “don’t know” for each screening test frequency, except for thyroid function testing (9%). Report of screening tests in the previous year did not differ by visit frequency or type of main diabetes provider.

## Health-related quality of life

Health-related quality of life data were available for 53 subjects. Overall, mean DUKE scores for physical, mental, social, and general health were high ( $82.1 \pm 17.2$ ,  $79.2 \pm 19.4$ ,  $78.5 \pm 19.9$ , and  $79.9 \pm 14.3$ , respectively), comparable with or higher than scores reported in a general population of adolescents and young adults.<sup>22</sup> General health scores did not differ significantly by gender, type of primary diabetes provider, visit frequency, self-reported HbA<sub>1c</sub>, or perceived success in diabetes self-management.

## Discussion

This study offers a paradigm for assessment of the health care transition experience and post-transition health care of young adults with type 1 diabetes. Our study complements prior studies elucidating key challenges in type 1 diabetes transition. We contribute the perspective of patients previously cared for at a pediatric diabetes clinic in a US tertiary pediatric center.

In this sample, post-transition health care delivery reports were promising in that the vast majority of respondents were receiving regular adult diabetes care, with 75% reporting at least two diabetes visits in the previous year. These rates of follow-up are significantly higher than those published in observational studies in Europe,<sup>15,25</sup> but analogous post-transition data for comparison are limited in the US.

Interestingly, the high rates of follow-up reported in this sample occurred despite lower reports of transition preparation. For instance, less than half of patients received specific adult provider referral names or contact information, and yet the vast majority of respondents (>80%) felt that these were important aspects of transition. Our findings are consistent with other reports of nonpurposeful transitions in type 1 diabetes.<sup>13–15,26</sup> More broadly, deficits in preparation for transition have been described in large national surveys of young adults with a mix of chronic health conditions,<sup>27,28</sup> as well as in patients with single diagnoses associated with intensive daily self-management requirements, such as cystic fibrosis<sup>29</sup> and complex health screening recommendations, such as Turner syndrome.<sup>30</sup>

Gaps between pediatric and adult diabetes care may be detrimental to long-term diabetes outcomes, especially given the known associations between infrequent clinic follow-up and the occurrence of acute and chronic diabetes complications in youth with type 1 diabetes.<sup>9,31</sup> One quarter of our respondents reported a gap of more than six months between pediatric and adult care, a figure consistent with several other studies.<sup>14,16,17,32</sup> Respondents with fewer than three pediatric visits in the year prior to transition and those who cited relocation/moving as the main impetus for transition were more likely to report gaps in care. Transition coordination programs in Canada and Australia have shown reduced care gaps for patients with type 1 diabetes.<sup>23,33</sup> Our findings suggest a possible role for targeted transition care referrals and tracking for those patients who are relocating. In particular, our high survey nonresponse underscores the potential important role of tracking programs to ensure follow-up of patients once they leave their pediatric care.

A priori, we had planned to examine relationships between transition characteristics (preparation, gaps between pediatric and adult care) and current adult care patterns (in particular visit frequency). However, because the majority of respondents in our sample were receiving regular diabetes care with at least two visits in the past year as per American Diabetes Association guidelines, we did not have sufficient numbers of respondents to explore this question fully. We found that patients identifying an adult endocrinologist as

their main diabetes provider were significantly more likely to report regular diabetes clinic visits compared with those identifying general internists or others as the main diabetes provider. This finding did not translate into differences in screening test patterns or reported glycemic control, although small numbers may have limited our ability to detect differences in these outcomes.

Our findings regarding provider characteristics are consistent with the multicenter, population-based SEARCH for Diabetes in Youth Study, which showed that 70% of 363 subjects  $\geq 18$  years of age (mean age  $21.2 \pm 2.3$  years) were seeing a diabetes specialist (25% reported a pediatric endocrinologist and 45% an adult endocrinologist) while 17% were seeing a generalist. Subjects seeing a generalist were significantly less likely to report receipt of recommended diabetes screening tests compared with those seeing an endocrinologist.<sup>34</sup> Variation in the nature and quality of diabetes care from different types of adult providers requires further study, and transition preparation may need to be tailored to the type of adult provider a patient will be seeing following transfer. Additionally, continuing medical education about young adult diabetes care should be targeted to general internists and family physicians as well as adult endocrinologists.

Several limitations of this study must be noted. The cross-sectional design prevents assertions about causality. The survey instrument was new, which could impact the validity of responses, although we developed the items based on literature review, qualitative data from focus groups, and expert input. There is evidence in the literature of concordance between self-reported survey data and medical record data for outpatient diabetes care,<sup>35,36</sup> but our self-reported survey data are nonetheless potentially subject to recall and social desirability biases. Further, the study design could not include any validation of respondent data from pediatric or adult medical records.

Nonresponse bias is also a concern; the response rate was suboptimal, although comparable at 32% with other post-transition diabetes studies.<sup>16,37</sup> While the age and gender distribution of the nonrespondents and respondents was similar, no other data were available for nonrespondents. The respondent sample was further impacted by the use of the last known mailing address in recruitment, which may have biased the sample towards people still connected with medical care near their childhood homes. Finally, the small sample size limited our ability to conduct multivariable analyses and to control for confounders such as socioeconomic status. Despite these limitations, our findings are consistent

with previous publications and provide contemporary information from emerging young adults who transferred from pediatric care solely within a children's facility to adult care providers.

Our respondent sample was, on average, a highly educated, relatively advantaged group of patients, most of whom were currently receiving regular diabetes care. As in other studies of youth with type 1 diabetes, health-related quality of life was generally high.<sup>38,39</sup> Many of our observations are encouraging regarding the follow-up care of youth with type 1 diabetes following their transfer to adult providers, but given the relatively low response rate, our findings may represent a "best-case" scenario. All of the respondents had some type of health insurance, due to extremely high rates of health insurance in Massachusetts that are not representative of the current landscape throughout the US. Therefore, we were not able to evaluate associations between health insurance and transition care utilization. Previous research has pointed to disparities in the transition process for youth with childhood-onset chronic illness from more diverse patient samples, including the underinsured.<sup>40</sup> The challenges in transition identified in this study would likely be magnified in more diverse young adult populations, and this remains a key area for future research.

Finally, 28% of our surveys were returned to sender, which represents an important finding. It is difficult to track young adults in a mobile society after they leave a pediatric center, and, as other studies have found, this difficulty increases with each passing year after transition.<sup>37</sup> This is not diabetes-specific, and is an area of concern for the care of emerging adults. The US health care transition consortium "Got Transition" has put forth six core practice elements ([www.gottransition.org](http://www.gottransition.org)) based on expert consensus, one of which is clinic-based registries to follow transitioning youth. Our results support the need to create patient registries to track the follow-up of transitioning patients as well as the utility of prospective research to facilitate understanding of transition outcomes.<sup>41</sup>

## Conclusion

Our findings highlight the importance of operationalizing the transition process to improve patient satisfaction and health outcomes among emerging adults with type 1 diabetes. This study utilized a survey instrument that other investigators and programs may use to evaluate transition characteristics and adult care patterns in their patients with type 1 diabetes and which can be adapted to the study of other chronic pediatric illnesses. Systematic prospective assessment of transition

and post-transition variables will be important in studying the impact of future interventions aimed at making transition preparation more purposeful.

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## Author contributions

KG designed the study, developed the survey, collected data, analyzed data, and wrote and reviewed/edited the manuscript. JF participated in the study design and survey development, contributed to discussion, and reviewed/edited the manuscript. LL participated in data analysis, contributed to the discussion, and reviewed/edited the manuscript. VO participated in data collection, contributed to discussion, and reviewed/edited the manuscript. JW participated in the study design and survey development, contributed to discussion, and reviewed/edited the manuscript. ER designed the study, participated in survey development, participated in data collection and analysis, and reviewed/edited the manuscript. All authors read and approved the final manuscript.

## Disclosure

None of the authors have any competing interests relevant to this study to report.

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