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HEALTH CARE TRANSITION IN YOUNG ADULTS WITH TYPE 1 DIABETES: BARRIERS TO TIMELY ESTABLISHMENT OF ADULT DIABETES CARE

Katharine C. Garvey, MD, MPH¹, Howard A. Wolpert, MD², Lori M. Laffel, MD, MPH^{1,3}, Erinn T. Rhodes, MD, MPH¹, Joseph I. Wolfsdorf, MB, BCh¹, and Jonathan A. Finkelstein, MD, MPH^{4,5}

¹Division of Endocrinology, Boston Children's Hospital, Boston, Massachusetts.

²Adult Section, Joslin Diabetes Center, Boston, Massachusetts.

³Pediatric, Adolescent and Young Adult Section, Joslin Diabetes Center, Boston, Massachusetts.

⁴Division of General Pediatrics, Boston Children's Hospital, Boston, Massachusetts.

⁵Department of Population Medicine, Harvard Pilgrim Health Care Institute, Boston, Massachusetts.

Abstract

Objective—To examine barriers to health care transition reported by young adults with type 1 diabetes and associations between barriers and prolonged gaps between pediatric and adult diabetes care.

Methods—We surveyed young adults aged 22 to 30 years with type 1 diabetes about their transition experiences, including barriers to timely establishment of adult diabetes care. We evaluated relationships between barriers and gaps in care using multivariate logistic regression.

Results—The response rate was 53% (258 of 484 eligible subjects). Respondents (62% female) were 26.7 ± 2.4 years old and transitioned to adult diabetes care at 19.5 ± 2.9 years. Reported barriers included lack of specific adult provider referral name (47%) or contact information (27%), competing life priorities (43%), difficulty getting an appointment (41%), feeling upset about leaving pediatrics (24%), and insurance problems (10%). In multivariate analysis, barriers most strongly associated with gaps in care >6 months were lack of adult provider name (odds ratio [OR], 6.1; 95% confidence interval [CI], 3.0–12.7) or contact information (OR, 5.3; 95% CI, 2.0–13.9), competing life priorities (OR, 5.2; 95% CI, 2.7–10.3), and insurance problems (OR, 3.5; 95% CI, 1.2–10.3). Overall, respondents reporting 1 moderate/major barrier (48%) had 4.7-fold greater adjusted odds of a gap in care >6 months (95% CI, 2.8–8.7).

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Address correspondence to Dr. Katharine C. Garvey, Division of Endocrinology, Boston Children's Hospital, 300 Longwood Avenue, Boston, MA 02115. katharine.garvey@childrens.harvard.edu.

DISCLOSURE

The authors have no multiplicity of interest to disclose.

Conclusion—Significant barriers to transition, such as a lack of specific adult provider referrals, may be addressed with more robust preparation by pediatric providers and care coordination. Further study is needed to evaluate strategies to improve young adult self-care in the setting of competing life priorities.

INTRODUCTION

The development of evidence-based paradigms for health care transition is critical for both pediatric and adult providers caring for patients with pediatric-onset chronic illness. Health care transition has been defined as “the planned, purposeful movement of young adults from child-centered to adult-oriented health-care systems” (1). A 2002 consensus statement from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians emphasized the importance of a planned and facilitated health care transition for adolescents with special health care needs (2). However, more recent guidelines cited a lack of significant progress in the intervening decade and restated the role of effective health care transition as a basic standard of highquality medical care (3).

The developmental stage from the late teens through the twenties has been defined as “emerging adulthood,” a period characterized by many competing educational, social, and economic priorities (4). In emerging young adults with type 1 diabetes, these competing priorities are compounded by relentless self-care requirements, and the transition to adult medical care adds yet another challenge (5,6). Patients in this population are at risk for loss to follow-up and adverse health outcomes, including poor glycemic control, emergence of chronic diabetes complications, and premature mortality (7–10).

For endocrinologists, type 1 diabetes is an important model for the study of health care transition, given the complex self-management and medical decision making required of patients and the importance of uninterrupted outpatient follow-up in preventing acute and chronic diabetes complications (9,11). Furthermore, given the rising incidence of type 1 diabetes (12–14), increasing numbers of adolescents will need to safely establish adult diabetes care.

The American Diabetes Association recently published expert consensus guidelines on health care transition for emerging adults with diabetes (5), but empirical data remain limited, particularly in the U.S., where there is no mandated transition age. Work in other countries has described gaps between pediatric and adult diabetes care (15–18), decreased posttransition clinic attendance (15,19,20), and patient dissatisfaction with transition (15,19,21), but few studies have systematically examined the specific barriers to transition for patients with type 1 diabetes.

We recently published primary results from our survey of 258 posttransition emerging adults at a U.S. center (22). Although 63% of patients reported feeling mostly or completely prepared for transition, only 49% received the names of specific adult providers and less than 15% had access to any transition intervention programs or written transition materials; a total of 34% experienced a gap >6 months between pediatric and adult care. Patients who felt mostly or completely prepared for transition had a lower likelihood of a gap >6 months

between pediatric and adult care (adjusted odds ratio [OR], 0.47; 95% confidence interval [CI], 0.25–0.88). However, although transition preparation was associated with decreased gaps in care, it was not associated with improved posttransition glycemic control.

To design interventions that will strengthen transition preparation, facilitate the establishment of adult diabetes care, and ultimately improve glycemic control in young adults, it is imperative to better understand young adults' perspectives regarding specific barriers to transition and their relative importance. Therefore, our objectives were to assess the barriers reported by young adults in our transition survey sample (22) and to examine associations between transition barriers and gaps between pediatric and adult care.

METHODS

Data Collection

We assessed transition barriers as part of a survey of emerging adults with type 1 diabetes. The survey also examined transition preparation and satisfaction, gaps in care, current self care, and demographics.

Survey development, recruitment, and fielding are described in detail elsewhere (22). Briefly, survey development was informed by literature review, focus groups consisting of posttransition young adults with diabetes (23), expert review, and cognitive testing with young adult patients with type 1 diabetes.

Eligible subjects included young adults with type 1 diabetes between the ages of 22 and 30 years who were under the care of an adult diabetes specialist at a single tertiary diabetes center. A review of electronic medical records identified patients with the following criteria: encounters classified as International Classification of Disease-Ninth Revision (ICD-9) codes 250.X1 or 250.X3, diabetes diagnosed before the age of 18 years, previous pediatric diabetes care, and a medical visit with hemoglobin A1c (A1c) measured in the adult clinic within 2 years of the study.

We mailed a paper survey to all 484 eligible subjects in three waves. We reminded subjects by telephone and offered a secure electronic Internet option using the Research Data Electronic Capture Survey (REDCap) (24). The institutional committee on human subjects at Joslin Diabetes Center approved this study.

Key Variables

For assessment of barriers, we asked respondents about six specific barriers, each of which reflected the major themes identified in focus groups and provider interviews: (1) "I didn't have a name for an adult provider;" (2) "I didn't know how to contact the new adult provider;" (3) "I couldn't get an appointment with the new adult provider;" (4) "I had other priorities;" (5) "I felt upset about leaving my child/adolescent providers;" and (6) "I didn't have health insurance." For each barrier, the four response options included: not at all a barrier; small barrier; moderate barrier; or major barrier. Patients reported the gap in time between their last pediatric diabetes visit and first adult diabetes visit as 3 months, 4 to 6 months, 7 to 12 months, 13 to 24 months, or >24 months.

All variables were self-reported, except for the most recent adult clinic A1c level (Tosoh, San Francisco, CA), which was measured and obtained from chart review. Self-reported pretransition A1c was assessed with seven survey response options: 7.0%, 7.1 to 8.0%, 8.1 to 9.0%, 9.1 to 10.0%, 10.1 to 12%, >12%, or “don’t know.” The 24 subjects who responded “don’t know” for this item were eliminated from multivariate analyses that included pretransition A1c as a covariate. The other six categories were ordered as continuous variables using the mean for each range and an imputed value of 13% for the >12% option. To validate the self-reported pretransition A1c values, electronically stored measured results from 69 respondents who had previously received their pediatric diabetes care at the same tertiary center were compared with the self-reports. The pretransition A1c values matched the measured values for 72% of these respondents; of the 28% of respondents for whom the values did not agree, two-thirds of the self-reported values were higher than the measured values and one-third were lower.

Statistical Analyses

Analyses were conducted using SAS 9.2 software (SAS Institute, Cary, NC). Descriptive statistics were calculated as means and standard deviations or proportions. For all analyses, $P < .05$ was considered significant.

In multivariate analyses, barriers were dichotomized as not at all/small versus moderate/major in order to sharpen the distinction between those subjects who perceived significant barriers to the establishment of adult care and those who did not. Similarly, we dichotomized gaps at 6 months or >6 months for comparison with other reports (16–18), given the American Diabetes Association recommendation that insulin-treated patients >18 years of age have diabetes visits at least every 6 months (25).

We explored bivariate relationships between specific barriers and gaps in care using chi-square tests. We used logistic regression to assess the odds of a gap >6 months between pediatric and adult care for subjects reporting each of the six moderate/major barriers, adjusting for pretransition A1c, sex, education, and transition age.

Finally, the presence or absence of at least one moderate/major barrier was entered into a logistic regression model with a gap >6 months between pediatric and adult care as the dependent variable, adjusting for the same covariates.

RESULTS

Study Population

We received a total of 258 completed surveys (189 paper and 69 electronic) from 484 eligible subjects (response rate, 53%). Respondents were 26.7 ± 2.4 years of age, with a mean age at diabetes diagnosis of 9.9 ± 4.8 years (diabetes duration, 16.7 ± 5.5 years). Ninety-two percent of respondents were Caucasian, 62% were female, 82% were college educated, and 90% were privately insured.

The mean age at transition was 19.5 ± 2.9 years. The measured A1c most proximal to survey completion was $8.1 \pm 1.3\%$, and these values were highly correlated with the self-reported

pretransition A1c values. Thirty-four percent of respondents reported a gap >6 months between pediatric and adult care, and 13% reported a gap = 1 year.

Survey nonrespondents (n = 226) were not significantly different in age (mean, 26.4 years), race (89% Caucasian), or mean age at diabetes diagnosis (9.8 years), but fewer nonrespondents were female (45%; $P < .0001$) and privately insured (79%; $P = .0005$) and more had higher current A1c values (mean, 8.6%; $P < .0001$).

Pediatric Care Location

In the 12 months prior to transition, 31% of respondents received their pediatric diabetes care at the same tertiary diabetes center and 13% received their pediatric diabetes care at the nearby children's hospital. The remaining 140 respondents (56%) received their pediatric diabetes care from an additional 93 different practices in the United States. There were no significant differences in reports of the six barriers to transition or gaps in care between respondents who received pediatric care at the two Boston institutions and those who received pediatric care elsewhere.

Self-Reported Barriers to Transition

Overall, 78% of subjects reported = 1 barrier of any level (small, moderate, or major) to the establishment of adult diabetes care. Forty-eight percent reported = 1 moderate/ major barrier; of these patients, 52% reported 1 moderate/ major barrier, 27% reported 2 moderate/ major barriers, 14% reported 3 moderate/major barriers, and 7% reported 4 moderate/major barriers.

Figure 1 shows the proportion of respondents reporting each of the six individual barriers. The top three most frequently endorsed barriers were lack of adult diabetes provider name (47%), competing life priorities (43%), and difficulty getting an appointment (41%); in each case, approximately half of the respondents endorsed the barrier as being moderate or major. Lack of adult provider contact information was endorsed as a barrier by 27% of all respondents (11% moderate/major) and 43% of those who felt that lack of an adult provider name was a moderate/ major barrier. Feeling upset about leaving pediatrics (24%) and insurance problems (10%) were less frequently endorsed as barriers to transition.

Relationships between Barriers and Gaps in Care

The respondents endorsed with moderate/major intensity 4 barriers that were significantly associated with a gap in care of >6 months. In other words, compared to subjects without a gap in care, those with a gap >6 months were more likely to report the following as moderate/major transition barriers: lack of an adult provider name (39% vs. 12%; $P < .0001$); lack of adult provider contact information (23% vs. 5%; $P < .0001$); competing life priorities (41% vs. 14%; $P < .0001$); and insurance problems (14% vs. 4%; $P = .003$).

Individual models calculated odds of a gap in care >6 months for each moderate/major barrier, adjusting for pretransition A1c, transition age, sex, and education (Table 1). In these models, the same four barriers were significantly associated with increased odds of gap: lack of adult provider name (OR, 6.1; 95% CI, 3.0–12.7); lack of contact information (OR, 5.3;

95% CI, 2.0–13.9); competing life priorities (OR, 5.2; 95% CI, 2.7–10.3); and insurance problems (OR, 3.5; 95% CI, 1.2–10.3). None of the other nonbarrier covariates was significantly associated with a gap >6 months in these models. In the overall model analyzing moderate/major barriers and gaps in care >6 months, with adjustment for pretransition A1c, transition age, sex, and education ($R^2 = 0.19$; $P < .0001$), respondents reporting 1 moderate/major barrier had 4.7-fold greater adjusted odds of a gap >6 months (95% CI, 2.6–8.7). Report of at least one moderate/major barrier was the only significant predictor in the model. Adjusted ORs for the covariates included the following: pretransition A1c (OR, 1.2; 95% CI, 0.97–1.5), age at transition (OR, 0.95; 95% CI, 0.85–1.1), sex (OR, 0.91; 95% CI, 0.49–1.7), and college education (OR, 1.2; 95% CI, 0.52–2.5).

In a subanalysis examining moderate/major barriers in subjects with a gap in care >12 months (13% of sample), the results were similar; respondents describing 1 moderate/major transition barrier had 7.4-fold greater adjusted odds of a gap >12 months (95% CI, 2.5–22.5). None of the other covariates was significantly associated with a gap in care >12 months.

DISCUSSION

This study details the barriers to establishment of adult diabetes care reported by 258 emerging adults with type 1 diabetes. Other studies have described the general proportion of diabetes patients reporting difficulties or frustrations with establishing adult care (15,17,18), but none have included frequencies of specific barriers or examined associations between these barriers and gaps between pediatric and adult diabetes care. We found that 4 out of 5 young adults reported at least one specific barrier to successful transition and that half described at least one moderate/major barrier. Furthermore, report of barriers was significantly associated with a prolonged gap between pediatric and adult care, and specific and amenable barriers had the strongest associations.

Lack of an adult provider name and contact information were the barriers most strongly associated with a gap in care. These vital systems barriers could be readily improved by enhanced transition coordination. For example, programs featuring lay care coordinators or patient navigators have been shown to decrease posttransition gaps in Canada (18) and to improve posttransition clinic attendance and reduce diabetic ketoacidosis rates in Australia (26). Systems barriers might also be reduced by simpler, less expensive endeavors, such as electronic medical record prompts and continuing medical education programs focused on transition for both pediatric and adult care providers.

Along similar lines, initiatives fostering communication between pediatric and adult diabetes providers—such as local and national directories of adult providers willing to accept young adults with diabetes—may help improve transition referral rates. National directories are particularly important, because many young adults relocate to new geographic areas for school or work. Generalist providers interested in type 1 diabetes care must also be included in such directories, although leadership from adult and pediatric endocrinologists will be critical, given that so many late-teen and young adult patients with type 1 diabetes in the U.S. receive specialty care. For instance, in the multicenter, population-based SEARCH for

Diabetes in Youth Study, 70% of the 363 subjects 18 years old (mean age, 21.2 ± 2.3 years) were seeing a diabetes specialist (25% received care from a pediatric endocrinologist and 45% received care from an adult endocrinologist), whereas only 17% of these subjects were seeing a generalist (27).

In our study, insurance problems were less frequently endorsed but were also significantly linked to a gap in care. Report of this barrier likely underestimates the magnitude of this problem nationally, given the high proportion of insured people in Massachusetts, where health insurance is mandated. The association between health insurance and transition-care delivery warrants systematic study in larger, more heterogeneous U.S. samples.

Competing life priorities were endorsed by 1 out of 4 subjects as a moderate/major barrier and were strongly associated with a gap in care. Innovative paradigms are needed to address this important patient-related barrier. Methods to personalize the approach to transition care and foster greater engagement in self-care (e.g., with the aid of motivational interviewing) may be particularly useful in both pediatric and adult care settings (28–30).

This study has several limitations. The cross-sectional design limits conclusions about causality. The view of patients who have already completed their transition to adult-focused care is important to understand, but recall of the details is subject to potential omission or bias. The provider perspective, which has received little attention in the literature (31), will therefore also help to clarify deficits in the transition process.

Nonresponse bias is also of concern; while our response rate of 53% is robust compared to other survey studies of emerging adults with diabetes (16,17,32), we have no information about whether nonrespondents experienced more or fewer barriers to care. More nonrespondents were male and had public insurance, and these variables warrant examination in future studies. Additionally, the mean A1c was significantly higher in nonrespondents than respondents. Therefore, an analysis of transition barriers in patients with suboptimal glycemic control is also an important priority in future research.

Our study describes a relatively advantaged sample of patients receiving diabetes care at a single specialized center. Nonetheless, even in this sample, the vast majority of subjects endorsed barriers to transition, and more than one-third of patients in this sample had a gap in care >6 months. Our study likely underestimates the degree and impact of various barriers upon the length of the gap between pediatric and adult care. In addition, it is likely that a greater proportion of nonrespondents experienced a gap in care >6 months. Future research should include mechanisms to prospectively track patients as they exit from their pediatric care in order to better capture the true gap in care between pediatric and adult delivery systems. Survey research in patients leaving pediatric clinics will also help elucidate barriers for those who do not successfully establish adult diabetes care. In addition, previous work involving more diverse samples has underscored disparities in the transition process for youth with chronic illnesses (33); future studies should characterize transition barriers in more varied type 1 diabetes populations.

CONCLUSION

In conclusion, improved understanding of the barriers to effective transition should inform optimal design of transition intervention programs. Such intervention programs may serve to decrease gaps in care, prevent deterioration in glycemic control, and reduce the development of diabetes complications in young adults. Organizational barriers, such as lack of referrals to appropriate adult care providers, could be overcome by systems-level interventions promoting more structured transfers and partnerships between adult and pediatric diabetes providers. Finally, to address the formidable barrier of competing life demands, developmentally tailored educational interventions to support and empower young-adult self-care should be empirically tested in both pediatric and adult diabetes clinics.

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Abbreviations

A1c	hemoglobin A1c
CI	confidence interval
ICD-9	International Classification of Diseases, Ninth, Revision
OR	odds ratio

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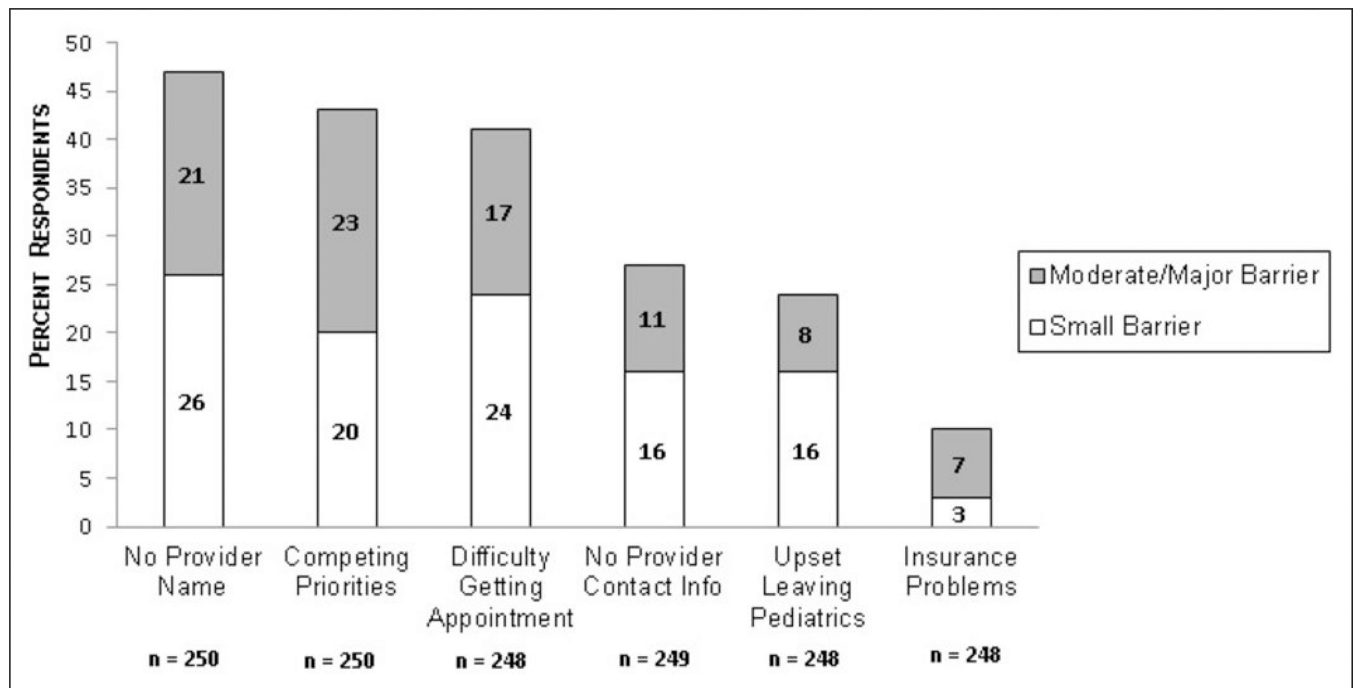


Figure 1.
Graph depicting the proportion of respondents endorsing each of six barriers to the timely establishment of adult diabetes care.

Table 1Individual Barriers Associated With a Gap >6 Months Between Pediatric and Adult Care^a

Variable	Adjusted Odds Ratio [95% CI] for a Gap >6 Months	Subjects in Model	Model <i>R</i> ²	Model <i>P</i> Value (Likelihood Ratio Test)
Lack of adult provider name	6.1 [3.0–12.8]	224	0.13	<i>P</i> <.0001
Lack of adult provider contact information	5.3 [2.0–13.9]	223	0.08	<i>P</i> = .003
Busy/competing life priorities	5.2 [2.7–10.3]	224	0.13	<i>P</i> <.0001
Insurance problems	3.5 [1.2–10.3]	222	0.04	<i>P</i> = .05
Difficulty getting appointment	1.6 [0.76–3.2]	222	0.03	<i>P</i> = .25
Upset leaving pediatrics	0.35 [0.1–1.3]	222	0.05	<i>P</i> = .12

Abbreviation: CI = confidence interval.

^aTable shows results from six different individual multivariate logistic regression models predicting a gap in care >6 months. All models were adjusted for pretransition hemoglobin A1c, sex, level of education, and age at transition.