HHS Public Access

Author manuscript

Endocr Pract. Author manuscript; available in PMC 2015 August 07.

Published in final edited form as:

Endocr Pract. 2015 August ; 21(8): 903–909. doi:10.4158/EP14553.OR.

PHYSICIANS' SELF-PERCEPTIONS OF CARE FOR EMERGING ADULTS WITH TYPE 1 DIABETES

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Abstract

Objective—Establishing care with adult providers is essential for emerging adults with type 1 diabetes (T1D) transitioning from pediatric care. Although research evaluating the transition from pediatric to adult care has been focused primarily on patients' perceptions, little is known about the adult providers' perspectives. We sought to ascertain adult providers' perspectives of caring for the medical and psychosocial needs of this patient population.

Methods—We developed and mailed a survey to 79 regional adult endocrinologists and 186 primary care physicians (PCPs) identified through 2 regional insurance plans. Questions addressed perceived aptitude in clinical aspects of diabetes management, importance and availability of diabetes team members, and opinions regarding recommended transition methods.

Results—The response rate was 43% for endocrinologists and 13% for PCPs. Endocrinologists reported higher aptitude in insulin management ($P<.01$). PCPs reported greater aptitude in screening and treating depression ($P<0.01$). Although endocrinologists and PCPs did not differ in their views of the importance of care by a comprehensive team, endocrinologists reported better access to diabetes educators and dieticians than PCPs ($P<.01$). Recommended transition methods were described as useful.

Conclusion—These preliminary results suggest that endocrinologists are better prepared to assume diabetes care of emerging adults, whereas PCPs may be better prepared to screen and treat associated depression. Future studies are needed to determine if a medical home model with cooperative management improves care for emerging adults with T1D.

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Parts of this study were presented in abstract form at the American Diabetes Associations' 74th Scientific Sessions on June 15, 2014, in San Francisco, California, and at the 6th Annual Health Care Transition Research Consortium Research Symposium on October 1, 2014, in Houston, Texas.

DISCLOSURE

V.H., S.W., and D.B. have no multiplicity of interest to disclose. S.L. received lecture fees from Lilly USA, LLC. M.K. received grant support from Sanofi and has previously consulted for Sanofi.

INTRODUCTION

Type 1 diabetes (T1D) is one of the most common chronic childhood conditions (1). Approximately 167,000 children and adolescents in the United States live with T1D (2). As these youth become adults, they commonly experience a transfer in medical care from pediatric to adult healthcare systems. The transfer from pediatric to adult diabetes care has been estimated to occur at a median age of 20.1 years, based on data from a cohort in the population-based SEARCH for Diabetes in Youth Study (3).

This transfer often happens during a developmental stage termed emerging adulthood. Emerging adulthood spans from the late teens through the twenties, typically defined as 18 to 25 years (4). The concept of emerging adulthood stems from cultures that allow youth a prolonged period of independence for change and identity exploration while becoming self-sufficient adults (4). Although emerging adults do not view themselves as adolescents, many of them also do not see themselves entirely as adults with adult responsibilities and roles.

Adolescents and emerging adults with T1D represent a vulnerable population with increased risk for poor diabetes-related outcomes (5). According to data from the T1D Exchange Clinical Registry, mean hemoglobin A_{1c} across the lifespan is highest in the adolescents years, followed by the emerging-adulthood years (6). Changes in diabetes self-care often occur during these years, from sharing diabetes management with caregivers in early adolescents to independent self-care in emerging adults (7). Emerging adulthood is also a time of exploration, with some individuals partaking in risky health behaviors, including binge drinking and tobacco use (8).

The transfer from pediatric to adult diabetes care occurs during this time of increased risk for poor diabetes-related outcomes (9). This healthcare transfer has been associated with challenges, including decline in ambulatory diabetes care visits, decreased adherence to recommendations by professional diabetes organizations, and deterioration in glycemic control compared to peers who remain in pediatric diabetes care (3,9,10). To address these challenges, national organizations recommend preparing adolescents and emerging adults with T1D for transition to adult care (11–13). These recommendations include education on how to self-manage a complex chronic illness and proactively navigate the adult healthcare system.

Although recent investigations have focused on patients' perceptions both before and after the transfer of care (14,15), available data about the perspective of the physicians caring for these emerging adults are limited. Inadequate training of healthcare professionals in medical care delivery for emerging adults with T1D is recognized to be a substantial obstacle for ensuring a successful transition (11). To begin to address this obstacle, it is important to first identify the perceptions of healthcare delivery held by the actual adult physicians providing diabetes care to this population. These adult providers include adult endocrinologists and primary care physicians (PCPs) (16). We queried adult endocrinologists and PCPs regarding their perceptions of providing care to emerging adults with T1D through a survey inquiring about specific aspects of diabetes management, importance and availability of diabetes team members, and usefulness of recommended transition strategies.

METHODS

In the absence of an existing questionnaire directed at assessing providers' self-perceptions of care for emerging adult patients with T1D, we created a written survey assessing the expertise and personal experience of local adult and pediatric endocrinologists as well as a review of published studies assessing providers' self-perceptions of care for emerging-adult patients with other chronic childhood conditions (17–19). We focused on a patient age range of 17 to 24 years based on regional overlap of diabetes care by pediatric endocrinologists, adult endocrinologists, general internal medicine physicians, and family medicine physicians for this age range.

The survey contained 85 items evaluating self-assessed clinical aptitude in insulin management, screening for and treating diabetes complications and comorbidities, and managing age-related psychosocial health factors. Opinions regarding the availability and importance of diabetes team members (certified diabetes educators [CDEs], registered dieticians [RDs], and mental health providers) and the availability of transition resources (such as medical summary, personal conversation with referring provider, and option for referral to diabetes-specific young-adult clinic) were solicited. Provider demographic information was collected. The survey responses were anonymous. Response choices, except for demographics, were on a Likert scale. Content validity was determined through a structured literature review and expert consensus of 2 senior pediatric endocrinologists, a senior adult endocrinologist, and a social psychologist.

Using the public websites of 2 large regional insurance health plans, we identified adult endocrinologists, general internal medicine physicians, and family medicine physicians who accepted one or both of these insurance plans. Surveys were mailed to the identified physicians, as email addresses were not consistently available. The survey included an introductory description of the voluntary research study, risks and benefits, and maintenance of confidentiality. Stamped self-addressed return envelopes were provided. Participants did not receive incentives to participate. Approval for this study was obtained from the University of Pittsburgh and Carnegie Mellon University Institutional Review Boards.

Statistical Analysis

Descriptive statistics were summarized as medians with interquartile range (IQR) for continuous data and frequency counts with percentages for categorical data. Mann-Whitney test for continuous data or Fisher's exact test for categorical data were conducted for comparison of responses between physician groups. Significance was set at $P = .05$. We conducted all statistical analyses using IBM SPSS Statistics, version 21.

RESULTS

Respondent Characteristics

The survey was distributed to 265 physicians (79 adult endocrinologists, 94 general internal medicine physicians, and 92 family medicine physicians). Of these, 14 (5%) surveys were undeliverable. Of the remaining surveys, the response rate was 43% (n = 33) for endocrinologists, 10% (n = 9) for general internal medicine physicians, and 16% (n = 13) for

family medicine physicians. One respondent did not identify a specialty of medical practice. As demographic characteristics of age, race, sex, and geographic setting of medical practice were not different between general internal medicine and family medicine respondents, these responses were combined and referred to as PCPs. There were no differences in age, sex, race, or geographic setting of practice between endocrinologists and PCPs (Table 1). A higher proportion of endocrinologists practiced in hospital-based settings ($P = .002$), whereas PCPs reported practicing in community-based group settings ($P = .049$).

Self-assessment of Aptitude in Clinical Aspects of T1D Management

Three main aspects of clinical self-assessed aptitude were considered: (1) managing insulin therapy; (2) screening for and treating diabetes complications and comorbidities; and (3) managing age-related psychosocial health factors. Comfort with insulin management was gauged by 9 questions about insulin therapeutics and education. For all 9 questions, endocrinologists' responses indicated a higher confidence level ($P<.001$; Table 2).

Eight questions were directed toward screening for and treating hypertension, dyslipidemia, nephropathy, and neuropathy. Endocrinologists reported greater self-aptitude in screening for nephropathy ($P = .02$) and treating nephropathy ($P = .05$) than PCPs. Eleven questions inquired about self-confidence in the management of age-related psychosocial health factors, including depression, eating disorders, tobacco, alcohol, reproductive counseling, driving, employment, and diabetes-related medical finances. PCPs reported higher self-aptitude in screening and treating depression than endocrinologists (Table 2). Endocrinologists indicated greater self-confidence to discuss driving issues, employment issues, and medical financial concerns related to diabetes (Table 2).

Importance and Availability of Diabetes Team Members

Endocrinologists and PCPs did not differ in their views of the importance of providing diabetes care through a comprehensive team approach ($P = .7$). Furthermore, there were no differences between endocrinologists and PCPs when asked to rate the importance of regular appointments with CDEs and RDs (Table 2). However, as would be anticipated, endocrinologists reported greater availability of CDEs and RDs in their practice environments (Table 2).

Endocrinologists and PCPs did not differ in their views of the importance of emerging-adult patients to be able to call for insulin dose adjustments between appointments ($P = .5$). However, endocrinologists indicated greater availability of a clinical infrastructure for patient calls between appointments ($P = .044$).

Usefulness of Recommended Transition Methods

Providers were asked to rate the usefulness of various transition methods for the new emerging-adult patients (Table 3). Both endocrinologists and PCPs rated having a concise medical summary as the most helpful of the listed options. Both groups indicated that having family accompanying the emerging-adult patient at the initial clinic visit as the least helpful. The only group difference that emerged was that PCPs rated referral to a young adult diabetes clinic of higher importance than did endocrinologists ($P = .001$).

DISCUSSION

Establishing care with an adult provider is one of the most important components of transitioning patients with chronic medical conditions, such as T1D, from pediatric to adult care. Recommendations and clinical recourses have been put forth by national organizations, including the American Diabetes Association, Endocrine Society, and National Diabetes Education Program, to assist pediatric providers transferring patient and adult providers accepting patients (11–13). These recommendations acknowledge differences in the approach to diabetes care by pediatric and adult providers and endorse early assessment of patient preparedness for transfer to adult care (11). Many teens with T1D and their families have already started thinking about the transition process by 15 to 17 years of age (14). The transfer is a critical event for these youth (11), yet it is accompanied by significant barriers, including not receiving recommended adult providers' names or contact information from pediatric providers (20). Thus, there may be prolonged gaps between leaving pediatric diabetes care and establishing adult diabetes care (20).

Furthermore, additional challenges face the new patient–provider relationship after the establishment of adult care. For emerging adults with T1D, attendance is negatively influenced by the failure to value outpatient appointments and by obstacles, such as work schedules being incompatible with clinic hours (21). From the new-provider perspective, many internists express apprehension in caring for medically complex patients transferring from pediatric care, including insufficient training in childhood-onset conditions and adolescent medicine (17). However, the potential challenges facing physicians providing care to transitioning emerging adults with T1D has not been explored in detail.

To the best of our knowledge, this is the first report describing the self-perceptions of adult physicians related to assumption of care for emerging adults with T1D. Although limited by small numbers, our results suggest relevant differences in comfort levels in specific aspects of care delivery by type of provider. Our finding that endocrinologists report higher aptitude in insulin therapy and education was not surprising, given their additional years of training in diabetes clinical management. The results suggest that PCPs perceive themselves to be more comfortable with screening for and managing depression. As both endocrinologists and PCPs provide diabetes care for emerging adults with T1D, we speculate that additional postgraduate medical training to better prepare PCPs can only ameliorate any identified knowledge deficits.

It was anticipated that endocrinologists would report higher self-perceived aptitude in insulin management and education, given their additional years of training in diabetes clinical management. Endocrinologists also endorsed the importance of regular interactions with CDEs, emphasizing the importance of team involvement in diabetes care. The observation that PCPs gave a high approval ranking to the opportunity for referral to a young-adult specialty diabetes clinic indicates that this group also considers subspecialty team care to be important, despite reduced availability.

Physician responses to managing psychosocial health factors were mixed between physician groups. Although endocrinologists report greater attentiveness to counseling emerging

adults about driving, employment, and financial issues related to diabetes, PCPs report more confidence in screening and treating depression. That endocrinologists felt less well-equipped to identify and treat depression is troubling given demonstrated associations between depression and poor glycemic control in this emerging-adult population (22). Addressing both the severity and content of emotional distress in those with diabetes during routine clinical care is important, as 'depression' in individuals with diabetes may be a continuous dimension of emotional distress that includes diabetes-related distress, depressive symptoms, and major depressive disorder (23). Diabetes-related distress involves the worries and stresses those with diabetes experience due to illness demands and burdens. Defining and measuring depression in individuals with diabetes may be more difficult due to overlap between diabetes distress and depression (23).

These observed variations in reported comfort levels are important, in that they present potential obstacles to achieving desired levels of glycemic control that can ultimately influence risk for diabetes-related complications. Although the intensity of glycemic management achieved by the Diabetes Control and Complications Trial (24) is considered the gold standard of care, questions as to whether this can be provided by generalists in usual practice situations persist (25). However, differences in sociodemographic characteristics observed in patients who go to PCPs rather than diabetes specialists for ongoing care (26) need to be taken into consideration. Racial, socioeconomic, and educational differences have been observed in those leaving pediatric care at a younger age compared to those leaving pediatric care at an older age (10). In a longitudinal study of adolescents with T1D, early age at transfer to adult care (prior to graduation from high school) was associated with lower social status, non-white race, and worse glycemic control (10). In addition, those teens who left pediatric care prior to high school graduation were less likely to be enrolled fulltime in college and more likely to living on their own 1 year after graduation from high school (10). A higher percentage of these teens were seeing PCPs rather than adult endocrinologists when compared to their peers who transitioned to adult diabetes care after graduation from high school (10). The transition process from pediatric to adult care is itself another important facet of healthcare delivery for emerging adults with T1D. A variety of strategies for guiding the transition have been recommended (11–13). These recommended strategies include preparation of a written patient summary. In our survey, both endocrinologists and PCPs rated having a concise medical summary prepared by the referring pediatric physician as being extremely helpful compared to other options (Table 3). In a survey of emerging adults with T1D, 15% reported dissatisfaction with their transition (15). Development of effective strategies that are also acceptable to this group of patients while maintaining high-quality healthcare is essential (9,11,27).

There are several limitations to the findings in the current study. First, our survey instrument is new, was designed specifically for this study, and, therefore requires further validation. Next, the survey was sent to physicians in a geographically selected area, so responses may not be representative of a national population. Although the response rate was comparable to other surveys on medical care of emerging adults (28,29), the overall response rate was low for PCPs in comparison to endocrinologists. The responses by the PCPs should be interpreted with caution. The lack of an incentive to participate may have contributed to the

low response rate. Finally, the survey asked about providers' perceptions of care, which are not the same as the actual care provided.

CONCLUSION

As emerging adults with T1D seek diabetes care from endocrinologists and PCPs (16), we feel that it is important to ascertain the perspective of the physicians caring for this population in order to begin to address challenges associated with the transfer from pediatric care and establishment of adult care. We observed that endocrinologists describe themselves as better prepared to assume the diabetes management of emerging adults with T1D, whereas PCPs feel better prepared to screen and treat depression. The significance of the latter needs to be interpreted with caution, given that depression in diabetes may be a spectrum that includes diabetes-related distress, depressive symptoms, and major depressive disorder (23). Our preliminary results require validation. Nevertheless, our results suggest exploration of a comanagement model between endocrinologists and PCPs and assessment of the impact of such a model on care and outcomes of emerging adults with T1D.

Acknowledgments

We thank the physician respondents for participating in this study. This work was supported by NIDDK grants 2T32DK007729, 5T32DK007052, and R01DK060586.

Abbreviations

T1D	type 1 diabetes
CDE	certified diabetes educator
RD	registered dietitian
PCPs	primary care physicians

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Table 1

Self-reported Demographic Characteristics of Respondents

Characteristic	Endocrinologists (n = 33)	Primary care physicians (n = 22)
Age, median (IQR)	53 (40–61.5)	54 (47–60)
Sex, male (%)	18 (54.5)	10 (45.5)
Race, frequency (%)		
American Indian or Alaska Native	0	1 (4.5)
Asian	10 (30.3)	2 (9.1)
Black or African American	0	1 (4.5)
Native Hawaiian or Other Pacific Islander	0	0
White	22 (66.7)	17 (77.3)
Other	0	1 (4.5)
Prefer not to answer	3 (3.0)	0
Practice geographic setting, frequency (%)		
Urban	20 (60.6)	7 (31.8)
City suburb	7 (21.2)	9 (40.9)
Town	5 (11.9)	5 (22.7)
Rural	1 (3.0)	1 (4.5)
Practice type, frequency (%)[a]		
Solo	3 (9.1)	3 (13.6)
Partner(s)	4 (12.1)	13 (59.1)
Single specialty	13 (39.4)	7 (31.8)
Multispecialty	6 (18.2)	2 (9.1)
Hospital-based	14 (42.4)	1 (4.5)
Community-based	2 (6.1)	6 (27.3)

Abbreviation: IQR = interquartile range.

[a]Percentages do not add up to 100 as instructed to mark all that apply.

Table 2

Perceived Aptitude in Clinical Aspects of Diabetes Management and Importance/Availability of Team Members by Type of Provider

Clinical aspect of diabetes management	Endocrinologists (n = 33) Median response (IQR)	Primary care physicians (n = 22) Median response (IRQ)	*P* value
Insulin management[a]			
Multiple daily injections	7 (7–7)	5 (2.5–5)	<.001
Insulin pumps	7 (7–7)	1 (1–2)	<.001
Results of continuous glucose monitoring	6 (6–7)	1 (1–2)	<.001
Insulin adjustments for medical procedure	7 (6–7)	4.5 (2–5.75)	<.001
Insulin adjustments for illness	7 (6–7)	5 (3–6)	<.001
Insulin education[a]			
Use of insulin vials	7 (5–7)	4 (2–6)	<.001
Use of insulin pens	7 (6–7)	4 (2.5–6.5)	<.001
Use of insulin pumps	6 (5–7)	1 (1–1)	<.001
Carbohydrate counting	6 (5–7)	2 (1–4.5)	<.001
Screening[a]			
Depression	5 (4–5)	7 (6–7)	<.001
Eating disorders	4 (3.5–5)	5 (4–5.5)	.5
Treatment[a]			
Depression	4 (3.25–5)	6 (6–7)	<.001
Eating disorders	3 (2–4)	4 (3–4)	.6
Counseling[a]			
Tobacco	6 (5–7)	6 (5–7)	.1
Alcohol	6 (5–6.5)	6 (6–7)	.1
Contraception	6 (5–7)	6 (4.5–7)	.7
Preconception and conception care	6 (5–7)	5 (4.5–7)	.4
Driving	6 (5.5–7)	5 (4–6)	.016
Employment issues related to diabetes	6 (5–7)	5 (3–6)	.009
Finances related to diabetes	6 (4.5–7)	4 (2.5–5.5)	.005
Importance of regular appointments with CDE[b]	4 (4–5)	4 (4–4)	.08
Importance of regular appointments with RD[b]	4 (4–5)	4 (4–4.5)	.5
Availability of CDE in practice environment[c]	5 (4–5)	4 (3–4.5)	.002
Availability of RD in practice environment[c]	5 (4–5)	3 (3–5)	.006

Abbreviations: CDE = certified diabetes educator; IQR = interquartile range; RD = registered dietician.

[a] On a scale of 1 (not at proficient) to 7 (extremely proficient).

[b] On a scale of 1 (not at all important) to 5 (extremely important).

[c] On a scale of 1 (never available) to 5 (always available).

Table 3

Perceived Usefulness of Transition Methods by Percent Rating as Extremely Helpful

Transition method	Endocrinologists[a] (n = 33)	Primary care physicians[a] (n = 22)	*P* value
Medical records from prior physician	61	71	.6
Concise medical summary	76	81	.7
Personal conversation with prior physician	30	38	.6
Longer appointment time	55	71	.3
Patient's family present at appointment	24	24	1
Opportunities for continuing medical education	46	48	1
Option for referral to young adult diabetes clinic	24	67	.004

[a]Percent rating as extremely helpful on a scale of 1 (not at all helpful) to 5 (extremely helpful).