Health Care Transition in Type 1 Diabetes

Perspectives of Diabetes Care and Education Specialists Caring for Young Adults

Eveline R. Goethals, PhD

Rebecca O. La Banca, PhD, RN, MSN

Peter W. Forbes

Gabriela H. Telo, MD, PhD

Lori M. Laffel, MD, MPH

Katharine C. Garvey, MD, MPH

From Pediatric, Adolescent, and Young Adult Section, Joslin Diabetes Center, Harvard Medical School, Boston, Massachusetts (Dr Goethals); KULeuven, Leuven, Belgium (Dr Goethals); Pediatric, Adolescent, and Young Adult Section, Joslin Diabetes Center, Harvard Medical School, Boston, Massachusetts (Dr O. La Banca, Dr Telo); Institutional Centers for Clinical and Translational Research, Boston Children's Hospital, Boston, Massachusetts (Mr Forbes); Pediatric, Adolescent, and Young Adult Section, Joslin Diabetes Center, Harvard Medical School, Boston, Massachusetts and Division of Endocrinology, Boston Children's Hospital, Boston, Massachusetts (Dr Laffel); and Division of Endocrinology, Boston Children's Hospital, Boston, Massachusetts (Dr Garvey).

Correspondence to Katharine C. Garvey, MD, MPH, Division of Endocrinology, Boston Children's Hospital, 300 Longwood Avenue, Boston, MA 02115, USA (katharine.garvey@childrens.harvard.edu).

Author Contributions: E.R.G. and R.O.L. made equal contributions as co-first authors. E.R.G researched data and wrote initial manuscript draft; R.O.L. researched data and wrote initial manuscript draft; P.W.F. analyzed data and reviewed/edited manuscript; G.H.T. analyzed data and reviewed/edited manuscript; L.M.L. designed the study, researched data, and reviewed/edited manuscript; and K.C.G. designed the study, researched data, and reviewed/edited manuscript.

Purpose

The purpose of the study was to describe experiences reported by diabetes care and education specialists caring for young adults with type 1 diabetes and to assess perceived deficiencies in clinical resources and barriers to care delivery.

Methods

A 60-item electronic survey was fielded through email to members of the Association of Diabetes Care and Education Specialists (ADCES). Respondents completed a survey consisting of: (1) clinical practice characteristics

Acknowledgments: Dr Goethals' work was funded by the Belgian American Educational Foundation (BAEF) and in part by a Mary K. Iacocca Research Fellowship provided by the Iacocca Family Foundation. Dr Laffel's work is supported by the National Institute for Diabetes and Digestive and Kidney Diseases (K12DK094721 and P30DK036836), Eleanor Chesterman Beatson Fund, Maria Griffin Drury Pediatric Fund, and Katherine Adler Astrove Youth Education Fund. Dr Garvey's work on this project was supported by the National Institute for Diabetes and Digestive and Kidney Diseases (K12DK094721, K23DK102655) and the William Randolph Hearst Foundation.

Conflict of Interests: The authors have no conflict of interests to disclose.

Guarantor Statement: Dr Katharine Garvey is the guarantor for this manuscript and, as such, had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

DOI: 10.1177/0145721720918815

and respondents' demographics; (2) health care transition components (eg, referrals) and their perceived importance; (3) framework of current clinical diabetes care delivery and perceived need for additional support; and (4) perceived barriers regarding clinical care delivery. Statistical analyses included descriptive statistics, chi-square tests, and logistic regression.

Results

Respondents (N = 531, 96% female, median years in practice = 13; interquartile range = 7-20) represented 49 states plus the District of Columbia. Although 88% of respondents reported reviewing pediatric records as important/very important, only 22% often/always reviewed them. Although 58% of respondents noted easy access to mental health care providers for young adults, 50% stated a need for additional resources. Furthermore, diabetes care and education specialists without easy access to mental health professionals were significantly more likely to report barriers to diabetes management for young adults with depression, substance abuse, eating disorders, and developmental disabilities.

Conclusion

Study findings highlight modifiable factors that may improve diabetes care coordination for transitioning young adults. Uniform approaches and increased access to trained mental health professionals may help support diabetes care and education specialists in their care of young adults with type 1 diabetes.

Young adults with type 1 diabetes must balance diabetes self-management and health maintenance with competing life demands, including education and job decisions and moving out of the parental home.[1,2] During this vulnerable life stage, declining treatment adherence, deteriorating glycemic control, and risk for acute and chronic diabetes complications and early mortality are documented.[3-5] Currently in the US, only 17% of youth and 21% of adults with type 1 diabetes achieve the A1C goal of <58 mmol/mol (<7.5%) for youth and of <53 mmol/mol (<7%) for adults, respectively.[6]

Importantly, lack of effective health care transition may contribute to fragmentation in care delivery and increased risk of adverse health and psychosocial outcomes.[7-9] Expert consensus statements by the American Diabetes Association, International Society for Pediatric and Adolescent Diabetes, and the American Academy of Pediatrics underscore the importance of a well-coordinated transition, yet substantial gaps remain between expert recommendation and implementation in practice.[8,10,11] Previous research has documented gaps between pediatric and adult care, suboptimal transition preparation and care coordination practices, and increased acute care utilization around time of transfer.[12-16]

To improve the transition process, it is essential to understand the experiences and perspectives of multidisciplinary providers. Whereas previous work has described the perspectives of adult and pediatric endocrinologist on transition care,[17-19] the experiences of diabetes care and education specialists remain understudied. Diabetes care and education specialists are key members of the multidisciplinary diabetes team, responsible for diabetes education and patient care across the lifespan.[20,21] Consequently, understanding their unique perspectives may help guide the development and implementation of effective interventions to improve type 1 diabetes transition care.

The objectives of the study were to: (1) describe experiences reported by a national sample of diabetes care and education specialists caring for young adults with type 1 diabetes and (2) assess the available clinical resources and perceived barriers to care for young adults with type 1 diabetes.

Methods

Research Design

The survey for the current study was adapted from one previously used to assess perspectives of a national sample of adult endocrinologists[17]; content was shaped to the diabetes care and education specialist's experience with multidisciplinary stakeholder input. The final survey consisted of 4 domains and 60 items, utilizing multiple-choice options and open responses. The 4 domains covered: (1) clinical practice characteristics and respondents' demographics such as age, sex, and ethnicity; (2) health care transition components (eg, referrals) and their perceived importance; (3) framework of current clinical diabetes care delivery (ie, easy access to multidisciplinary resources, such as endocrinologists, mental health providers, or care coordination) and perceived need for additional support in these areas; and (4) perceived barriers with regard to clinical care. The secure electronic survey was created using the Research Electronic Data Capture, or REDCap.[22] Respondents self-administered the questionnaire via an online link.

At the end of the survey, participants had the opportunity to provide free text comments about their experiences. Survey completion took 10 to 15 minutes. The study was approved by the local Institutional Review Board, and no study procedures were performed until approval.

Sample/Setting

A third party, Medical Marketing Services, Inc., provided email addresses for registered members of the Association of Diabetes Care and Education Specialists (ADCES). The survey was fielded to diabetes care and education specialists with valid email addresses, and the sample was refined with preliminary survey screening questions. Inclusion criteria assessed in the survey screening questions included diabetes care and education specialists who cared for at least 5 young adults aged 18 to 30 years old with type 1diabetes. Educators who worked mainly in a pediatric setting were excluded. The survey was emailed in 4 waves between June and August 2013. Responses were anonymous. For inclusion in the analyses, all items on transition care components needed to be complete. Respondents selected an option of a $10 donation to the ADCES or JDRF.

Statistical Analysis

Survey data were summarized using mean, standard deviation for continuous variables, and proportions for categorical variables. Chi-square tests provided associations of practice setting (academic, yes/no) with reported components of transition and clinical resources as well as associations of experience in diabetes education (>10 years of experience, yes/no) with the same 2 components. Given the recognition that mental health services were often lacking for adult endocrinologists,[17] additional analyses explored associations of deficient mental health services with various challenging clinical scenarios (eg, depression, eating disorders, substance abuse, etc.).

For the clinical scenarios created to assess barriers, logistic regression provided the odds of endorsing any barrier for each specific scenario (eg, depression) according to reported lack of mental health resources. Statistical analyses were conducted using SAS Version 9.2. (SAS Institute Inc, Cary, NC). Because of the number of survey questions and comparisons, a P-value of <.01 was used as the threshold for statistical significance.

Open-Ended Response Analysis

Three members of the research team (K.C.G., G.H.T., and L.M.L.) performed thematic analysis of open-ended question responses. Team members independently read the free-text comments to identify initial codes. Subsequently, team members resolved discrepancies and reached consensus on each comment, resulting in a list of second-cycle codes. The revised coding framework was applied to all free-text comments, and the researchers met to agree on final themes.

Results

Survey Response

In total, 4,510 surveys were electronically delivered. There were 1,116 surveys received (24% response rate). Of these, 703 respondents fully completed the survey, 329 surveys were incomplete, and 84 diabetes care and education specialists caring for young adults with type 1 diabetes were deemed ineligible (eg, retired). Of the 703 fully completed surveys, 172 respondents did not care for at least 5 young adults with diabetes. Therefore, 531 surveys were analyzed.

Sample Characteristics

Table 1 summarizes respondent and practice characteristics. Most respondents were female (96%), Caucasian (86%), and >45 years old (80%). The majority (87%) had nursing degrees, and 78% were certified diabetes care and education specialists. A small minority were dietitians (8%) or other professionals (eg, physician assistants).

With respect to practice locale, 76% of respondents worked in urban or suburban settings, and the majority worked in hospitals—38% in community hospitals and 21% in academic medical centers. By US Census region, 20% of respondents practiced in the Northeast, 36% in the South, 28% in the Midwest, and 16% in the West. In sum, 49 states plus the District of Columbia were represented in the sample.

Transition Referral Practices

When asked about common methods of patient entry into adult practice, educators endorsed "often/always"

Table 1

Sample Characteristics (N = 531)[a]

Characteristic	%
Female	96%
White/Caucasian	86%
Age	
<35 y	7%
36-45 y	13%
46-55 y	40%
>55 y	40%
In practice >10 y	56%
US Census region of practice	
Northeast	21%
South	36%
Midwest	27%
West	16%
Professional status	
Registered nurse	68%
Advanced practice nurse	19%
Dietician	8%
Other	5%
CDE certification	78%
Primary practice	
Adult provider	61%
Pediatric and adult provider	28%
Pediatric provider	11%
Practice setting	
Urban	39%
Suburban	38%
Rural	23%
Practice type	
Community hospital	37%
Academic practice	21%
Large group practice	16%
Small group practice	15%
Other	11%
No. of patients with type 1 diabetes 18-30 y of age in provider panel	
5-10	37%
11-25	30%
26-50	17%
>50	16%
Diabetes care return visit duration >20 min	91%

[a] Percentage based on number of respondents per item.

receiving referrals via pediatric providers (29%), family member/friends (29%), self-referrals (20%), or health insurance plan (5%). In addition, 25% endorsed "other," the majority of which were referrals following inpatient/emergency department admission to an adult hospital or from adult primary care provider/endocrinologist.

Components of Transition Care

Figure 1a displays the proportion of educators who endorse as important or very important 6 specific guideline-recommended transition components recommended in clinical guidelines. The figure also shows proportions reporting that these components often or always occur when transitioning young adults entered their practices. Although the majority (62% to 88%) endorsed 5 of these components as important/very important, components were actually occurring at low frequencies. For example, 35% reported communicating with referring pediatric providers, 22% reported reviewing pediatric records, and only 7% reported reviewing a patient summary. Chi-square tests showed no significant differences in the reported occurrence of transition care components by educator experience or practice setting.

Clinical Resources for Young Adult Diabetes Care

Figure 1b presents the clinical resources easily accessible to adult educators (in-house or by referral) for young adults with type 1 diabetes and resources for which educators needed additional access. The overwhelming majority reported easy access to dietitians (93%), endocrinologists (81%), interpreters (74%), and mental health providers (58%), with fewer reporting easy access to care coordinators (31%) and exercise physiology (22%). Approximately half required additional access to mental health, care coordination, and exercise physiology, compared with ≤30% for all other resources.

Barriers to Clinical Management of Young Adults With Type 1 Diabetes

The survey asked educators to consider 9 clinical scenarios regarding a 22-year-old patient with type 1 diabetes, encompassing both medical and psychosocial issues. Barrier options included lack of clinical expertise, inadequate clinical resources, additional time required, and other barriers. Figure 2 depicts the proportion of educators endorsing lack of expertise or inadequate resources

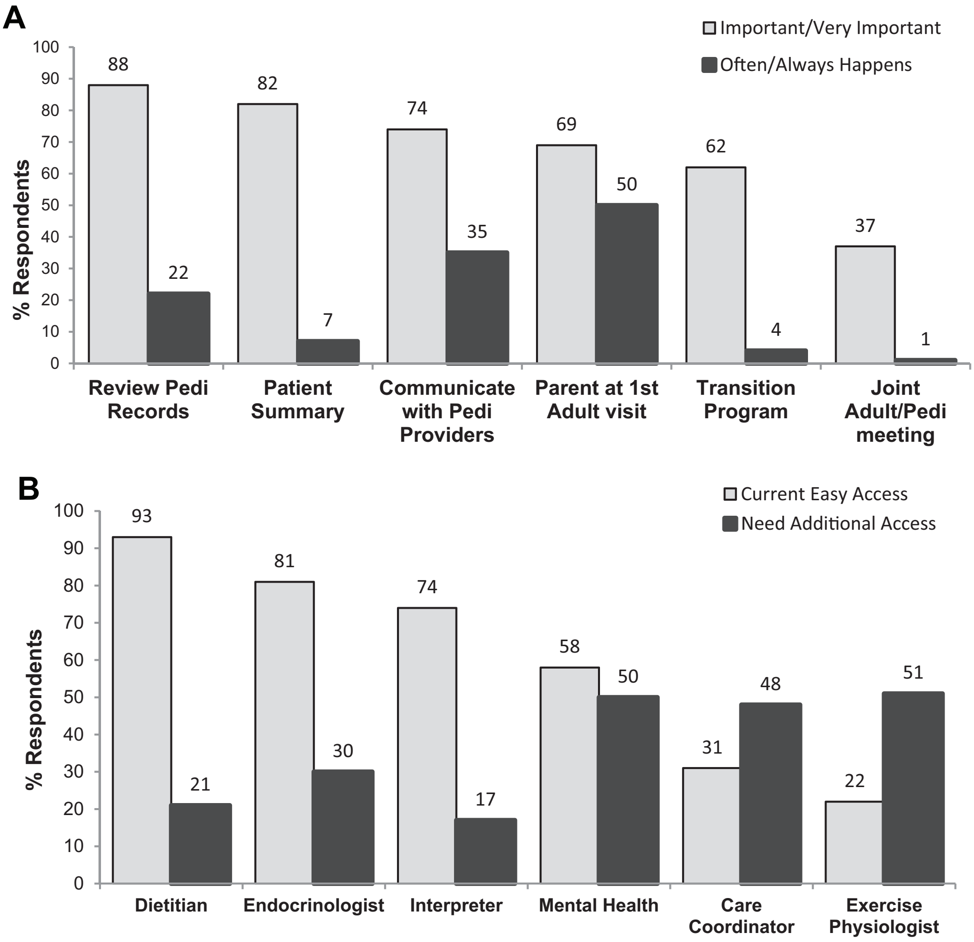

Figure 1. (a) Health care transition components: reported occurrence in practice and perceived importance. (b) Clinical resources for young adult type 1 diabetes care: reported availability and recognition of need.

as barriers for each scenario. Overall, inadequate time was minimally endorsed (≤12%) across all scenarios. The barrier of inadequate clinical resources was most highly endorsed for scenarios involving substance abuse (45%), depression (38%), eating disorder (37%), and developmental disability (32%). For all other scenarios, inadequate resources were endorsed ≤21%. Lack of expertise was most commonly endorsed for scenarios involving substance abuse (41%), eating disorder (36%), elite athlete (33%), depression (25%), and developmental disability (25%), while a smaller minority (3-17%) endorsed resource barriers for medical scenarios.

Diabetes care and education specialists were far more likely to report any barrier to diabetes management with suboptimal mental health services for the scenarios involving depression (odds ratio [OR] = 6.2; 95% CI, 4.0-9.5), substance abuse (OR = 3.4; 95% CI, 2.1-5.3), eating disorders (OR = 1.9; 95% CI, 1.3-2.7), and developmental disabilities (OR = 1.9; 95% CI, 1.3-2.7). No other clinical scenarios yielded significantly increased barriers.

Overall Perceptions and Suggestions for Improvement in Young Adult Diabetes Care

Most diabetes care and education specialists (84%) enjoyed seeing young adults with type 1 diabetes and even reported they would like to see more of them (71%). Half felt that treating young adults with type 1 diabetes is time-consuming, and 45% reported that treatment of young adults requires more practice resources.

To achieve optimal care for young adults with type 1 diabetes, diabetes care and education specialists endorsed specialized online practice resources (90%), continuing medical education about adolescent and young adult

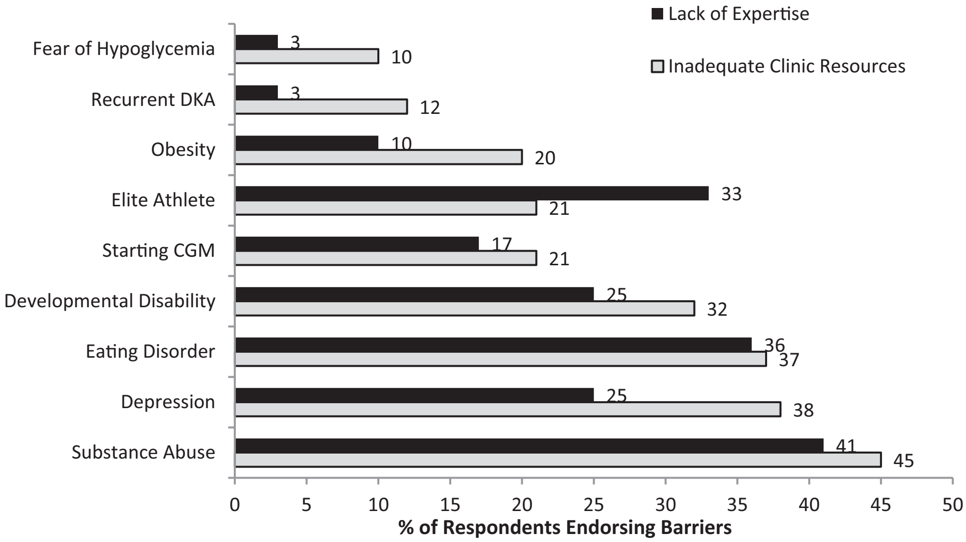

Figure 2. Common clinical challenges facing diabetes care and education specialists caring for young adults with type 1 diabetes: perceived lack of expertise and need for more resources.

behaviors (90%), improved rates for reimbursement (84%), young adult support groups (83%), more time to spend with this population (81%), and additional administrative support (62%).

Open-Ended Response Analysis Results

Over one-third (n = 196) of respondents provided free-text responses to the open-ended question asking for additional input. In thematic analysis, researchers agreed on a total of 7 final themes, of which 3 main themes accounted for the clear majority (77%) of comments. These main themes included: (1) challenges with nonadherence and competing demands of young adults (33%), (2) intensive time and care coordination requirements caring for young adults (29%), and (3) positive and personal experiences caring for young adults (15%).

Regarding challenges with nonadherence and competing demands, diabetes care and education specialists caring for young adults with diabetes tended to describe these challenges in relation to specific attributes of young adulthood, such as the feeling of invincibility. Educators also perceived tension between diabetes self-care and other life demands, such as starting a career, having a family, and so on. Furthermore, respondents noted how family and societal factors may impede adherence to self-care, for example, family conflict, absence of family support, or loss of health insurance coverage.

Regarding intensive time and care coordination requirements, educators desired more time to devote to this vulnerable population as well as dedicated transition programs and additional referral resources, including mental health providers.

For positive and personal experiences, educators expressed joy and hope in the work they do with young adults. Educators also shared personal involvement with diabetes such as having diabetes themselves or having a child or family member with diabetes.

Table 2 displays key representative quotations from the top 3 themes. The remaining 4 themes included young adult need for financial and insurance resources (12%), value of family and social support (4%), divergent approaches to care from pediatric versus adult diabetes providers (4%), and other/miscellaneous comments (3%).

Discussion

Diabetes care and education specialists are important for education and coordination of care in persons with type 1 diabetes,[8,10,11,20] but their role in supporting transition from pediatric to adult diabetes care remains understudied. To our knowledge, this is the largest study analyzing the perspectives of diabetes care and education specialists who care for young adults with type 1 diabetes transferring from pediatric to adult diabetes care in the United States. Our study encompasses perspectives from

Table 2

Representative Quotations From Thematic Analysis of Narrative Comments

Theme	Representative Quotations
Challenges with nonadherence and competing demands	• "Diabetes is in addition to what all emerging adults face. Getting patients to come to programs is difficult with their busy schedules. They don't see the importance of being proactive. They 'wing it.'" • "They need a lot of support, coaching, follow up—not always education needs, but behavior and lifestyle support. They want to take care of themselves but life and fun can get in the way. . . . It takes a complication scare to sometimes change things."
Intensive time and care coordination requirements	• "Management wants the visits to be between 15-18 minutes regardless of language of choice, level of education, disability. Funding for psych would help, also increased funding for education, nutrition counseling." • "Phone volumes require nurse/CDE attention (family problems along with large volume of insurance mandated information/authorization) require staff primarily on phones rather than in clinic setting addressing young adolescent patient needs."
Positive and personal experiences	• "Working with persons with diabetes is a true passion of mine because I am a type 1 for 57 years" • "It is so rewarding in watching an individual understand how to manage their daily lives with reasonable blood glucose control or tight control. . . . I am always learning from the people I see." • "I really love what I do. So rewarding to try to help patients understand the why's of the disease to help them achieve success in their management."

531 diabetes care and education specialists across 49 states and diverse practice settings. Our results highlight a number of gaps and challenges in transition practice and clinical care delivery for young adults with type 1 diabetes who often find themselves "lost in transition."[23]

Although transition guidelines (first published years prior to this survey fielding) affirm the importance of transition planning and communication between pediatric and adult health care teams,[8,10,11] based on our survey data, the implementation of these recommendations is suboptimal. Furthermore, several disconnects surfaced between what diabetes care and education specialists reported as important aspects of transition care and what they integrated in their clinical practice. For example, 74% of diabetes care and education specialists felt that direct communication with pediatric providers was important/very important, yet only 35% often/always did this in clinical practice. A similar disconnect emerged between perceived importance of pediatric record review and the actual reported review of records. Notably, a majority of respondents endorsed the presence of a transition program as important; however, few diabetes care and education specialists reported that the young adults in their clinical practices had participated in such programs. Hence, adult educators may be ideal to create and/or lead transition program initiatives, especially to welcome and orient young adults into the adult diabetes care setting. Indeed, diabetes care and education specialists may also support care coordination and the continuity of communication between pediatric and adult teams.

Regarding clinical resources, relatively few diabetes care and education specialists reported a need for additional access to endocrinologists, dieticians, and interpreter services. However, respondents did note a need for additional access to exercise physiologists and care coordinators. Furthermore, inadequate clinical resources and lack of expertise were most highly endorsed as barriers to clinical management for scenarios involving mental health issues such as substance abuse, depression, eating disorders, and developmental disability.

The need for additional access to trained mental health care providers' expertise and availability, as endorsed by our survey respondents, is also recognized by the American Diabetes Association.[24] The shortage of mental health care resources has previously been documented as a serious concern in the US.[25,26] Combined with the high prevalence of mental health problems such as depression, anxiety, and disturbed eating behaviors in ~10-35% of young adults with type 1 diabetes,[27,28] this shortage constitutes an obstacle for clinical care in this vulnerable age group. There is a need to address this gap in care to make mental health care more accessible and available. In the interim, one might consider additional education and training of diabetes care and education specialists on mental health issues. For example, continuing education in this area might help educators to triage and identify those young adults in greatest need of specialized mental health care.

Analysis of free-text comments from this sample highlighted the particular need for dedicated time and care coordination in order to help young adults adapt to the combined demands of diabetes self-management and competing life events. Transition interventions such as inclusion of a dedicated care coordinator can help address these challenges and warrants further study. Moreover, transition programs, which are typically developed on the pediatric side of transition, might benefit from including an adult diabetes care and education specialist.[29] Furthermore, nurse-led groups might offer additional support for transitioning young adults with type 1 diabetes.[19] Finally, there was an optimistic tone in many of the free-text comments when the diabetes care and education specialists expressed their sense of joy and hopefulness in their caring for young persons in this age group.

Survey findings of diabetes care and education specialists mirrored our previous publication on adult endocrinologists caring for young adults with type 1 diabetes.[17] We observed some similarities as well as some differences between their perspectives. First, about half of both groups endorsed the need for additional mental health resources. This is like a survey in which 92% of Canadian adult endocrinologists endorsed the challenges of access to mental health services and in which access to pediatric health records was suboptimal.[29] Next, there were observed different perspectives between the adult diabetes care and education specialists and the adult endocrinologists with respect to the importance of direct communication with pediatric providers at the time of transfer. Most educators (74%) deemed this important compared with a third of adult endocrinologists (36%). Finally, while the diabetes care and education specialists reported substantial joy and pleasure in their work with young adults, adult endocrinologists tended to find the care for this age group time-consuming and considered these young adults with type 1 diabetes ill prepared for self-care and adulthood.

Our study has some limitations. The response rate of 24% raises the potential for nonresponse bias and may impact generalizability. However, our response rate compares favorably to other published studies,[17,18] and this survey reached a large and diverse national sample. Also, there was no information on nonrespondents, so it was not possible to compare respondent with nonrespondent characteristics. Furthermore, research involving surveys may also yield potential for recall bias. Finally, the authors acknowledge that this survey was fielded about 5 to 6 years ago, yet recent publications[12,29] have underscored the uniformity and persistence of challenges in the care transitions of young adults with type 1 diabetes today. Additionally, a very recent North American conference on caring for young adults with diabetes in the adult care setting[30] confirmed similar challenges and deficiencies facing this population, highlighting the value of our observations.

Implications

Survey findings affirm previous observations of challenges in the delivery of care to young adults with type 1 diabetes. Several of the reported care barriers may be modifiable, for example, related to care coordination, communication, and access to mental health services. Our results remain highly relevant, and diabetes care and education specialists may offer an opportunity to overcome these barriers by playing a critical role in communication between pediatric and adult health care teams while assisting in care coordination and triaging those in need of mental health support. Indeed, diabetes care and education specialists might be in an ideal position to bridge the gap between pediatric and adult care systems, referred to as two different "subcultures,"[17] especially if they have sufficient clinical time. Given that transitioning young adults are often surprised by the unexpected differences between pediatric and adult health care,[31] enhanced pediatric transition counseling, greater pediatric preparation, and support from diabetes care and education specialists could all improve the transition process.

ORCID iD

Rebecca O. La Banca https://orcid.org/0000-0001-6084-3657

References

1. Goethals ER, Oris L, Soenens B, et al. Parenting and treatment adherence in type 1 diabetes throughout adolescence and emerging adulthood. *J Pediatr Psychol*. 2017;42(9):922-932.

2. Weissberg-Benchell J, Wolpert H, Anderson BJ. Transitioning from pediatric to adult care: a new approach to the post-adolescent young person with type 1 diabetes. *Diabetes Care*. 2007;30(10):2441-2446.
3. Lotstein DS, Seid M, Klingensmith G, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. *Pediatrics*. 2013;131(4):e1062-e1070.
4. Bryden KS, Dunger DB, Mayou RA, Peveler RC, Neil HA. Poor prognosis of young adults with type 1 diabetes: a longitudinal study. *Diabetes Care*. 2003;26(4):1052-1057.
5. Wills CJ, Scott A, Swift PG, Davies MJ, Mackie AD, Mansell P. Retrospective review of care and outcomes in young adults with type 1 diabetes. *BMJ*. 2003;327(7409):260-261.
6. Foster NC, Beck RW, Miller KM, et al. State of type 1 diabetes management and outcomes from the T1D exchange in 2016-2018. *Diabetes Technol Ther*. 2019;21(2):66-72.
7. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14(7):570-576.
8. Peters A, Laffel L; The American Diabetes Association Transitions Working Group. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems. *Diabetes Care*. 2011;34(11):2477-2485.
9. Lyons SK, Becker DJ, Helgeson VS. Transfer from pediatric to adult health care: effects on diabetes outcomes. *Pediatr Diabetes*. 2014;15(1):10-17.
10. Cameron FJ, Garvey K, Hood KK, Acerini CL, Codner E. ISPAD clinical practice consensus guidelines 2018: diabetes in adolescence. *Pediatr Diabetes*. 2018;19(suppl 27):250-261.
11. White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.
12. Garvey KC, Foster NC, Agarwal S, et al. Health care transition preparation and experiences in a U.S. national sample of young adults with type 1 diabetes. *Diabetes Care*. 2017;40(3):317-324.
13. Garvey KC, Wolpert HA, Rhodes ET, et al. Health care transition in patients with type 1 diabetes: young adult experiences and relationship to glycemic control. *Diabetes Care*. 2012;35(8):1716-1722.
14. Pacaud D, Yale JF. Exploring a black hole: transition from paediatric to adult care services for youth with diabetes. *Paediatr Child Health*. 2005;10(1):31-34.
15. Nakhla M, Daneman D, To T, Paradis G, Guttmann A. Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System. *Pediatrics*. 2009;124(6):e1134-e1141.
16. Nakhla M, Bell LE, Wafa S, Dasgupta K. Improving the transition from pediatric to adult diabetes care: the pediatric care provider's perspective in Quebec, Canada. *BMJ Open Diabetes Res Care*. 2017;5(1):e000390.
17. Garvey KC, Telo GH, Needleman JS, Forbes P, Finkelstein JA, Laffel LM. Health care transition in young adults with type 1 diabetes: perspectives of adult endocrinologists in the U.S. *Diabetes Care*. 2016;39(2):190-197.
18. de Beaufort C, Jarosz-Chobot P, Frank M, de Bart J, Deja G. Transition from pediatric to adult diabetes care: smooth or slippery? *Pediatr Diabetes*. 2010;11(1):24-27.
19. Agarwal S, Raymond JK, Schutta MH, Cardillo S, Miller VA, Long JA. An adult health care-based pediatric to adult transition program for emerging adults with type 1 diabetes. *Diabetes Educ*. 2017;43(1):87-96.
20. Rinker J, Dickinson JK, Litchman ML, et al. The 2017 diabetes educator and the diabetes self-management education national practice survey. *Diabetes Educ*. 2018;44(3):260-268.
21. Beck J, Greenwood DA, Blanton L, et al. 2017 national standards for diabetes self-management education and support. *Diabetes Educ*. 2017;43(5):449-464.
22. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381.
23. Laffel L. Lost in transition: finding a path forward for young adults with type 1 diabetes. *Diabet Med*. 2018;35(8):1061-1062.
24. Young-Hyman D, de Groot M, Hill-Briggs F, Gonzalez JS, Hood K, Peyrot M. Psychosocial care for people with diabetes: a position statement of the American Diabetes Association. *Diabetes Care*. 2016;39(12):2126-2140.
25. Peyrot M, Rubin RR, Lauritzen T, Snoek FJ, Matthews DR, Skovlund SE. Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabet Med*. 2005;22(10):1379-1385.
26. Ducat L, Rubenstein A, Philipson LH, Anderson BJ. A review of the mental health issues of diabetes conference. *Diabetes Care.* 2015;38(2):333-338.
27. Bernstein CM, Stockwell MS, Gallagher MP, Rosenthal SL, Soren K. Mental health issues in adolescents and young adults with type 1 diabetes: prevalence and impact on glycemic control. *Clin Pediatr (Phila)*. 2013;52(1):10-15.
28. Luyckx K, Verschueren M, Palmeroni N, Goethals ER, Weets I, Claes L. Disturbed eating behaviors in adolescents and emerging adults with type 1 diabetes: a one-year prospective study. *Diabetes Care*. 2019;42(9):1637-1644.
29. Michaud S, Dasgupta K, Bell L, et al. Adult care providers' perspectives on the transition to adult care for emerging adults with type 1 diabetes: a cross-sectional survey. *Diabet Med*. 2018;35(7):846-854.
30. Joslin Diabetes Center. Caring for Young Adults with Diabetes Conference. Accessed December 12, 2019. https://www.joslin.org/about/news-media/caring-young-adults-diabetes-conference
31. Garvey KC, Beste MG, Luff D, Atakov-Castillo A, Wolpert HA, Ritholz MD. Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolesc Health Med Ther*. 2014;5:191-198.