RESEARCH ARTICLE

Looking forward to transition: perspectives on transition from pediatric to adult diabetes care

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Practice Points

- The majority of pediatric youth with Type 1 diabetes mellitus (T1DM) and their parents have not discussed the need for transition from pediatric to adult diabetes care as a family or with their pediatric providers.
- The lack of planning for transition is concerning and inconsistent with current recommended standards of care for adolescents and young adults with T1DM.
- A significant proportion of adolescents and young adults with T1DM are worried or anxious about the transition process. By working with patients and families prior to the actual transition of care, healthcare providers are in a unique situation to help decrease this worry and anxiety.
- Healthcare providers should begin working collaboratively with patients and families to prepare them for the transition of medical care at least 1 year prior to the actual transition.
- Current approaches are not adequately preparing patients with T1DM for the transition to adult medical care.
- The patient–doctor relationship may be the ideal place to begin addressing the issues surrounding the transition from the pediatric to adult diabetes world.

SUMMARY **Aim:** This study aimed to prospectively investigate transition beliefs, knowledge and needs of pediatric patients with diabetes and their parents. **Patients & methods:** Parallel youth and parent questionnaires evaluating the transition process were distributed over a 6-month time period. Respondents included 123 pediatric patients with diabetes (11–19 years old) and their parents. **Results:** Few families had discussed the transition of diabetes care (~25%). Most had not established a transition plan (~90%). Youth and parents agreed that seeing the doctor alone, discussions about transition and transition itself should occur at 17–18 years of age. **Conclusion:** Youth with diabetes and their parents are not prepared for transition to adult care. Transition discussions should begin at an earlier age. Additional research is needed to learn how and when to begin these discussions.

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The transition process is a major medical issue given that each year approximately 500,000 youth in the USA with complex medical conditions turn 18 years of age and most will require transition from pediatric to adult care [1]. The scientific community has recently begun to examine the challenges faced by young people with Type 1 diabetes mellitus (T1DM) during the transition from pediatric to adult care [2]. A recent analysis completed in patients with T1DM participating in the SEARCH for Diabetes in Youth Study found patients who transitioned to adult diabetes care had a 2.5-times higher risk of poor glycemic control (HbA1c ≥9.0%) when compared with patients continuing to see pediatric providers [3]. Given increased failure to follow-up for routine diabetes care and low rates of medical adherence resulting in poor metabolic control, young people with diabetes who are transitioning from pediatric to adult care are considered a ‘high-risk’ population [1], making the issue of transition from pediatric to adult care a major clinical concern [4].

Moving away from home is often difficult for healthy adolescents and young adults [5], and can be even more challenging for those with chronic health conditions [6]. When transitioning, many patients with chronic medical conditions assume management of certain tasks for the first time in their lives. Until their child leaves home, parents often refill medications, pick up supplies, make follow-up appointments and communicate with the diabetes team. The transition process is further complicated because it typically occurs when young people are encountering some of their most difficult developmental challenges (e.g., leaving home, beginning college, joining the work force and losing medical insurance) [7].

Metabolic control (HbA1c levels) in adolescents and young adults is at its worst at 18 years of age and improves over time [7]. The transition period is also a time when young people fail to follow-up regularly with scheduled medical care, which has been associated with serious and costly medical consequences, such as diabetic ketoacidosis [8,9]. Pacaud *et al.* found that 46% of adolescents with diabetes who had transitioned to adult care reported problems with the transition [10]. They also found that a lapse of more than 6 months occurred between the last pediatric visit and first adult visit in 31% of their population, while 11% was completely lost to follow-up.

Transition is also complicated by the fact that pediatric providers often do not adequately prepare youth for the transition to adult healthcare. Pediatric physicians frequently continue to manage their adolescent patients in the same manner as when they were younger. The Society of Adolescent Medicine produced a position paper to guide the transition of youth with chronic health conditions from pediatric to adult care. They proposed that transition should begin at diagnosis, which does not routinely occur [11]. When pediatric providers do not prepare their patients for transition to adult care, patients and families may not have the time necessary to properly plan for the transition.

Clinic-based transition programs for youth with T1DM have been developed in the USA based on top-down rational processes that have relied primarily on clinical experience with this population. Although this approach may well be adequate, empirical evidence derived from multiple sources is preferable. There is a paucity of literature that has evaluated the needs and knowledge base of pediatric patients and their parents regarding the transition process in the USA. Presently, there are no evidence-supported models that have demonstrated how to successfully engage transitioning patients in medical care systems, help them optimize diabetes management and metabolic control, and assist with the challenges of emerging adulthood [6]. Most existing clinical programs have relied on anecdotal experience to direct transition of care. There is little data derived directly from pediatric patients and their parents regarding preferences and expectations for transition from pediatric to adult diabetes care. The lack of empirical data contributes to the difficultly providers face when deciding what information is preferred by families and how to facilitate the successful transition of young people to adult care.

The goal of the current project was to collect information from youth with diabetes and their parents regarding the transition process. Analogous questionnaires were developed to assess the knowledge, beliefs and needs of patients and their caregivers regarding the transition process. Our overlying hypothesis was that most families had not discussed the transition process and did not have a plan for transition. The approach was unique in that similar information has not previously been collected in the USA.

Patients & methods

Two parallel patient and caregiver versions of transition questionnaires were developed for this project. The questionnaires were developed using five sources of information:

- An exhaustive literature search of published data regarding the transition process for multiple chronic health conditions was completed;
- Questionnaire content was reviewed by an interdisciplinary diabetes provider team that included pediatric and adult diabetes providers, pediatric and adult diabetes educators, pediatric and adult dietitians, a pediatric social worker, and two pediatric psychologists who have a primary focus on diabetes management;
- The transition questionnaires were reviewed by two individuals from other institutions known for their work in the area of diabetes transition;
- Factors well known in the literature to be associated with diabetes management and outcomes were included;
- Focus groups were held in the diabetes center prior to the development of the questionnaires. The focus groups were completed as part of a different research effort, but the purpose was to discuss the transition of care from pediatric to adult medical care. The authors reviewed information collected from the adolescent and young adult patients involved in the focus groups, and this information was used to shape the content of the developed questionnaires.

The resulting questionnaires included 16 items that assessed the family's preparedness for transition, beliefs regarding who is responsible for the process and other related items. Questions regarding the importance of issues that should be addressed during the time of transition (e.g., insurance, sexuality, drug and alcohol use, and driving) were also included. Finally, questions were included to assess the family's beliefs about when youth should begin to see their providers alone, when the transition process should be discussed and when transition should occur (**Supplementary Material**; see online at www.futuremedicine.com/doi/suppl/10.2217/dmt.13.27).

Questionnaires were originally designed to inform the clinic and providers about the patient population's current views regarding the transition of care. The questionnaire's main purpose was to serve as a needs assessment to guide clinical care and future transition interventions.

During a 6-month time period, transition questionnaires were distributed to patients(11–19 years of age) and their parents during their regular scheduled clinic visit to a large tertiary diabetes center in the USA Pacific Northwest. Patients and parents were instructed not to complete the questionnaires together.

Approximately 400 patients were estimated to be eligible for completion of the transition questionnaires. Data were not collected for all eligible patients due to many patients being seen in outreach clinics, questionnaires not being distributed at every clinic, patients not being seen during the data collection period and multiple non-English speaking families who did not have an interpreter available. Of those approached, all English-speaking patients and parents agreed to complete the questionnaires. The current sample represents approximately a third of the eligible patient population (123 collected from potential of ~400 patients). Estimates for the entire eligible patient population are 65% privately insured, 32% federally insured and 3% uninsured. Insurance and overall demographic statistics were similar to the information collected from the 123 patients and parents who completed the questionnaires, thus, we believe our sample to be representative. The data were collected anonymously, so we were unable to compare the population completing the questionnaires to those who did not. Additionally, given that no patients or parents declined to complete the questionnaire, there is no reason to believe the population completing the questionnaire was different from those not completing the questionnaire.

Questionnaires were anonymously completed with no identifying or protected health information collected. Requirements of the associated institutional review board were met prior to implementing clinical data review and analysis for research purposes. Analyses were conducted using SPSS Version 19. Means, frequencies and percentages were calculated for demographic information. Parent and youth responses to yes/no questions were calculated as percentages and compared using the two-sided Fisher's exact test. Analyses of age-related questions were completed with Welch's t-tests to allow for comparison of answers with unequal variance. Age stratification analyses were used to report means, frequencies and standard deviations.

Results

The majority of respondents had T1DM (93.9%). The remaining patients (6.1%) had

Type 2 diabetes. An analysis of descriptive characteristics found a mean patient age of 15.4 years and a mean duration of diabetes of 6 years. The majority of respondents had private insurance (76.5%), 19% indicated they had state-funded Medicaid, 2.5% indicated that they did not have insurance and 1.7% were unsure of their insurance.

Analysis of responses to transition questions found that 75% of patients reported their family had not talked about the eventual need to transition their diabetes care from a pediatric to adult doctor. Parent reports were congruent as 72% of parents reported they had not discussed the need for transition of care **(Figure 1)**. A total of 86% of patients and 92% of parents reported they had not received information from their pediatric clinic regarding transition to adult diabetes care **(Figure 1)**. A large proportion of pediatric patients (90%) and parents (91%) reported they did not have a transition plan **(Figure 1)**. Over 60% of pediatric patients and parents reported they expected adult diabetes care to include a diabetes doctor, diabetes educator, dietitian, social worker and psychologist **(Figure 1)**. Additional results regarding transition knowledge and preparation are included in **Table 1**. An analysis of paired youth and parent responses did not find statistically significant differences **(Table 1)**.

An additional analysis was completed to assess whether discussion of transition was more commonly reported in participants of an older age (11–15 years compared with 16 years or older). When focusing on parent responses, parents of older youth (45.5%) significantly more often reported that their family talked about the transition from pediatric to adult care compared with parents of younger youth (13.2%; x^2 [1, n = 123] = 15.78; $p < 0.001$). When examining youth responses, a similar pattern was seen. Older youth (40.0%) reported discussion about transition of care more frequently compared with younger patients (12.3%; x^2 [1, n = 120] = 12.19; $p < 0.001$). Both older youth (33.3%) and their parents (41.8%) more

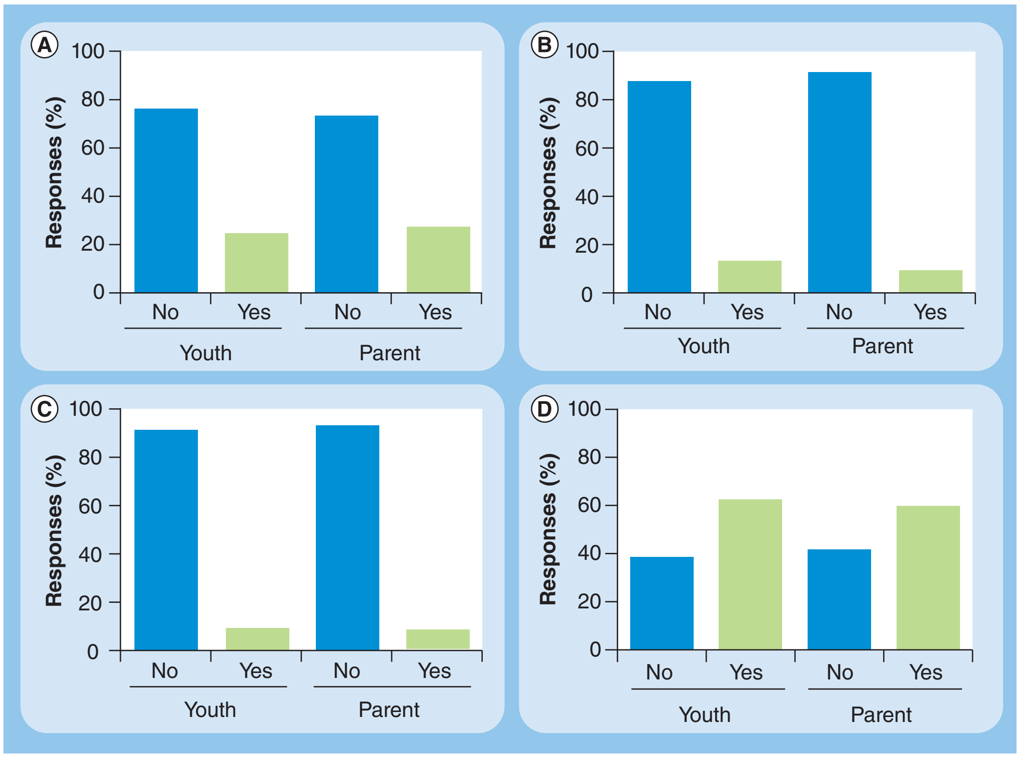

Figure 1. Percentage of 'no' and 'yes' responses from youth and their parents to four questions from the transition questionnaire. The participants answered no or yes to the following: **(A)** family has talked about transition; **(B)** family has information about transition; **(C)** family has a transition plan; and **(D)** adult clinic will have the same support staff as pediatric clinic (medical doctor, certified diabetes educator, social worker and PhD). Paired youth/parent responses were analyzed using the two-sided Fisher's exact test for youth/parent pairs.

Table 1. Youth and parent responses to questions on the transition questionnaire.

Question	Youth (% yes)	Parent (% yes)	p-value
I have brought up the issue of transition of care with our diabetes doctors/nurses	18.0	24.4	0.274
I am anxious and worried about transitioning care from my pediatric diabetes doctors/nurses to adult diabetes doctors/nurses	24.0	34.2	0.090
I have obtained information regarding transition to adult diabetes care services from websites or other sources outside of the clinic	13.0	9.0	0.415
The doctors have brought up the issue of transition from pediatric to adult care with me	26.2	21.0	0.366
It is my family's responsibility to transition care to adult diabetes doctors	54.1	64.0	0.172
It is the adult and pediatric diabetes doctors who are responsible for transitioning care	47.8	54.5	0.351
I expect that if I am in college or continue to live at home after high school that I will be able to continue to see my pediatric doctor	58.6	59.3	1.000

Paired youth/parent responses were analyzed using the two-sided Fisher's exact test.

frequently reported bringing up the issue of transition of care with their diabetes doctors and nurses (youth: x^2 [1, n = 122] = 15.35; p < 0.001; parent: x^2 [1, n = 123] = 16.39; p < .001). Additionally, older youth (21.8%) more frequently reported obtaining transition information from websites or other resources outside of the clinic compared with younger youth (5.9%; x^2 [1, n = 122] = 15.35; p < .001).

When asked who was responsible for the transition process, there was little agreement. Approximately half of the respondents reported that it was the family's responsibility to organize the transition process (54.1% of youth and 64% of parents). An almost equal number reported that it was the physician's responsibility to organize the transition process (47.8% of youth and 54.5% of parents). Pediatric patients and their parents also responded to other specific questions regarding the age and timing of the transition from pediatric to adult medical care. Both youth and their parents felt discussions about transition of care should begin at 16.5–17 years of age. When asked at what age pediatric patients should begin seeing the doctor alone, mean youth and parents answers were similar at approximately 17.5 years. Both youth and their parents felt transition of diabetes care should occur at the age of 18 years.

There were no significant differences identified between youth and parent responses for the age at which transition should occur and the age young people should begin to see providers alone. However, there was a significant difference between parent (mean: 18.03 years; standard deviation: 1.39) and youth (mean: 18.37 years; standard deviation: 1.51) responses regarding the age that youth should be transitioned from pediatric to adult care (t[88] = 2.21; p = 0.03) **(Table 2)**. Although this finding was statistically significant, the difference between responses (0.34 years) would not be considered clinically meaningful by most.

Youth and parent responses were also dichotomized into younger (11–15 years) and older (16 years or older) age groups as a *post hoc* analysis **(Table 2)**.Significant differences were identified between the younger and older youth groups regarding the age at which they believe the diabetes clinic should begin discussing transition with patients (16.44 and 17.50 years, respectively; p < 0.01) and when young people should begin seeing the doctor or nurse alone (16.97 and 18.21 years, respectively; p < 0.01). Younger youth also felt that patients should be transitioned at a younger age compared with the older youth cohort (17.54 vs 18.89 years, respectively; p < 0.01). When focusing on the parents of patients with diabetes, parents with younger patients also believed the discussions of transition should begin at a younger age (16.07 years) compared with parents of older patients (17.26 years; p < 0.01). Parents of younger patients felt that youth should begin seeing the doctor or nurse alone at a younger age compared with parents of older patients (17.07 and 18.35 years, respectively; p < 0.01). Parents of younger patients also reported that patients should transition at a younger age (17.71 years) compared with parents of older patients (19.04 years; p < 0.01).

Table 2. Youth and parent responses to questions regarding the timing of transition were stratified by age (younger: <16 years and older: ≥16 years of age) and analyzed by analysis of variance.

Question	Patient's age (years)	Respondents (n)	Mean	Standard deviation	p-value
Youth					
At what age do you feel the diabetes clinic should begin talking about transition with patients?	11–15	56	16.44	1.78	<0.01
	16 or older	52	17.50	1.36	
At what age do you feel young people should start seeing the doctor/nurse alone?	11–15	53	16.97	1.86	<0.01
	16 or older	45	18.21	1.15	
At what age do you feel young people should be transitioned from pediatric to adult care?	11–15	54	17.54	1.48	<0.01
	16 or older	47	18.89	1.53	
Parent					
At what age do you feel the diabetes clinic should begin talking about transition with patients?	11–15	55	16.07	1.58	<0.01
	16 or older	46	17.26	1.74	
At what age do you feel your child should start seeing the doctor/nurse alone?	11–15	51	17.07	1.80	<0.01
	16 or older	43	18.35	1.15	
At what age do you feel young people should be transitioned from pediatric to adult care?	11–15	55	17.71	1.42	<0.01
	16 or older	46	19.04	1.52	

Youth and parents were also presented a list of potential education topics and were asked to rank the importance of each topic as follows: 0 = not important; 1 = minimally important; 2 = moderately important; and 3 = highly important (Table 3). Both youth and parents ranked college and supplies among the top three educational items. Parents ranked complications as the highest educational item and youth ranked college as the third-highest item.

Discussion

Our findings support our hypothesis that the majority of pediatric youth and parents have not discussed the need for transition from pediatric to adult diabetes care as a family or with their pediatric providers. Our data suggest that neither youth with diabetes nor their parents are well prepared for transition. The results indicate that the majority of families have not received adequate transition information from their pediatric providers and have not sought information from resources outside of the diabetes clinic, such as websites or other information sources. The vast majority of youth and parent respondents reported that they did not have a transition plan. These findings are consistent with studies that have examined transition in adult patients with diabetes [12]. If patients and parents do not establish a transition plan, the inevitable move to adult medical care is likely to include unexpected problems. The lack of planning is concerning

Table 3. Importance of education topics as ranked by youth and parents.

Rank	Youth	Average importance score†	Parent	Average importance score†
1	Supplies	2.47	Complications	2.73
2	College	2.30	College	2.64
3	Insurance	2.29	Supplies	2.61
4	Work/career	2.11	Driving	2.50
5	Complications	2.06	Meal planning	2.45
6	Driving	1.96	Insurance	2.39
7	Meal planning	1.88	Drugs/alcohol	2.27
8	Depression	1.47	Work/career	2.27
9	Drugs/alcohol	1.40	Depression	2.16
10	Pregnancy	1.40	Sexuality	1.84
11	Tobacco use	1.11	Tobacco use	1.74
12	Sexuality	1.04	Pregnancy	1.64

†Average importance score (based on 0–3 scale) is listed to the right of the education topic.

and inconsistent with current recommended standards of care. Previous consensus guidelines have endorsed the early establishment of a transition plan with the transition process occurring over several years [2,11,13,14].

Approximately three-quarters of youth and two-thirds of parents reported that they were not anxious or worried about the transition process. However, extrapolation of these findings suggests that in a clinic of 1000 patients of transition age, approximately 250 patients and 330 parents would be anxious or worried about the transition process. This finding is consistent with those reported by Duke *et al.* who found more than 25% of previously transitioned emerging adults reported feeling worried or apprehensive during the transition to adult care [15]. Providers are in a unique situation to help diffuse this worry and apprehension by engaging in ongoing discussion and planning for the transition of care years in advance. Previously stated recommendations suggest additional education, planning and support during the transition process could decrease the concerns of patients and parents [2,13].

Responses indicate that youth and parents believe the discussion of transition and the actual move to adult care should occur over approximately 1 year. Youth and parents' opinions regarding the transition process do not concur with the recommendations of The Society of Adolescent Medicine. The recently produced position paper proposed that transition should begin at diagnosis [11]. Although we agree this would be ideal, our data suggest that this rarely occurs. The Society of Adolescent Medicine's paper also stated that successful transition to adult care involves young people being more active in their diabetes management, including being seen alone by their medical providers. Youth and parents in our study did not feel this needed to be carried out much earlier than the time of transition.

A recent position statement from the American Diabetes Association recommended that healthcare providers begin working collaboratively with the patient and family to prepare for the transition of medical care at least 1 year prior to the transition of care [13]. The statement also recommended beginning these discussions in early adolescence, which did not occur in our patient and parent sample. Healthcare providers should educate families about the value of early discussion of and planning for transition to adult care.

Providers need to advocate for time alone with youth during clinic visits. However, our anecdotal experience suggests that providers have not routinely requested time alone with adolescent patients, and adolescents have not typically requested to be seen alone. Adolescents and young adults usually continue to see their pediatric providers with their parents until the time they begin seeing an adult provider. This often results in young adults transferring to a new physician at the same time that they begin seeing their diabetes physician alone, which has been found to result in poor medical outcomes and decreased follow-up [16] during a time when patients already have poor continuity of care [12,15,17]. Our findings suggest that families are inadequately prepared for transition, lack an understanding of the importance of the transition process and often experience an abrupt change in their medical care team. These conditions are likely to contribute to less than optimal medical outcomes and decreased follow-up during the transition of medical care.

When examining the timing of transition by dichotomized patient age, younger patients and their parents reported that transition should begin to be discussed at an earlier age and the transition to adult medical care should occur at an earlier age compared with older patients and their parents. Older patients and their parents possibly reported an older age because they had not yet received appropriate information and were not yet prepared or ready for transitioning to adult care. It is possible that simply completing the transition questionnaire heightened their awareness of transition, which influenced younger patients and parents to choose an earlier age. It is important to note that much more than age plays into the discussion and decision to transfer to adult care. A patient's developmental status, maturity, competence completing daily diabetes tasks, access to medical care, insurance and psychosocial situation all play a role when making decisions regarding the transition process [5,13].

Youth and parents reported having similar education needs prior to the transition of medical care. The key issues identified were college, supplies, insurance and complications. Not surprisingly, parents were more concerned about complications than youth. Although college and insurance were listed as important education topics by pediatric patients and their parents, Duke *et al.* found that in a previously transitioned adult population these topics were infrequently discussed prior to transition [15]. In their study, leaving home was discussed with only 45% of previously transitioned adults and insurance was only discussed with 37.5%.

Knowing what issues youth and parents value is important to delivering appropriate care. Previous reports have shown these areas of interest are not being adequately addressed [12,15,18]. Providers may feel pressure to address other issues, but our data suggest that pediatric patients and their families prefer pragmatic information regarding day-to-day issues (e.g., logistics of moving out of the home and how to ensure insurance coverage). There appears to be a disconnect between what providers feel their patients and families need and what patients and families prefer. Our data found that most patients and families lack knowledge about the breadth of services adult care providers typically provide. The differences between pediatric and adult care providers have not been adequately discussed. Future investigations should focus on improving provider communication with families regarding delivering transition information and education.

Additional research focusing on how to best address these educational issues with youth and parents (e.g., together or separately, group settings or alone, or with providers or educators) is needed. Relying on diabetes providers' opinions regarding the ideal method for educating youth and families may not be the most effective approach. It may be that changing provider culture and awareness would be an improved approach. Insufficient transitional care training of healthcare providers is a major challenge to improving the transition of medical care in the USA [13]. Numerous articles have recommended focusing on provider interventions and training as a paramount step in addressing transition issues [2,5,11,13,14].

Conclusion

To our knowledge, these are the first reported data on transition beliefs, behaviors and needs in pediatric patients and their parents from the USA. These data are critical to inform providers regarding the transition of pediatric patients and their families to adult care. To date, transition approaches have largely focused on workshops, classes and seminars to address the transition process in pediatric patients with diabetes. Our data suggest that current approaches may not be adequate for addressing the educational topics patients and parents believe they need.

Future research should focus on applying the information to pediatric populations and their parents who are approaching transition. Further research to identify the most effective approach to addressing the needs of pediatric patients with diabetes and their parents is needed. Future studies should also include investigations into self-management practices in adolescents and young adults, and whether or not these practices can be impacted by transition interventions. Additionally, investigating the ideal time to begin addressing transition issues is needed. Increased discussion between providers and families regarding the transition process is paramount. Based on our findings and recommended consensus guidelines, the foundation of all medical care, the patient–doctor relationship, may be the ideal place to begin addressing the issues surrounding the transition of medical care from the pediatric to the adult world [2,5,11,13,14].

Future perspective

Over the upcoming years, research in youth with T1DM will result in a better understanding of markers of successful transition to adult care. Application of this information to pediatric populations and their parents will allow for identification of the most effective approach to address the needs of pediatric patients with diabetes and their parents. Future studies will include investigation into self-management practices in adolescents and young adults, and whether or not these practices can be impacted by transition interventions. Additional investigations into the ideal time to begin addressing transition issues will also be completed. Furthermore, different clinical care approaches to better prepare youth for transition and address issues with the transition process will also be addressed.

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Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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