

Perspectives From Before and After the Pediatric to Adult Care Transition: A Mixed-Methods Study in Type 1 Diabetes

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OBJECTIVE

Among the many milestones of adolescence and young adulthood, transferring from pediatric to adult care is a significant transition for those with type 1 diabetes. The aim of this study was to understand the concerns, expectations, preferences, and experiences of pretransition adolescents and parents and posttransition young adults.

RESEARCH DESIGN AND METHODS

Participants completed questionnaires and responded to open-ended qualitative questions regarding self-management, self-efficacy, and their expectations and experiences with pediatric and adult care providers across the transition process.

RESULTS

At a mean age of 16.1 years, most pretransition adolescents had not yet discussed transferring care with their parents or doctors. Although many posttransition young adults reported positive, supportive interactions, several described challenges locating or establishing a relationship with an adult diabetes care provider. Qualitative themes emerged related to the anticipated timing of transfer, early preparation for transition, the desire for developmentally appropriate interactions with providers, the maintenance of family and social support, and strategies for coordinating care between pediatric and adult care providers.

CONCLUSIONS

Standardizing transition preparation programs in pediatric care and introducing transition-oriented clinics for late adolescents and young adults prior to adult care may help address patients' preferences and common transfer-related challenges.

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The transition from adolescence to young adulthood, often referred to as “emerging adulthood,” is a vulnerable period marked by changes in physical, emotional, and social domains (1). Changes in health self-management put emerging adults at risk for poor health later (2). For youth with type 1 diabetes and other chronic conditions, the transfer from a pediatric to adult health care setting is particularly significant (3,4). Challenges can include reluctance to end a trusting relationship with the pediatric team, worries about “starting over” with a new care provider, and

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discomfort with the unfamiliar adult medical setting (e.g., shorter visits, less emphasis on multidisciplinary care) (5–7). Thus, it is not surprising that clinic attendance decreases and many young people with type 1 diabetes are lost to follow-up between leaving pediatric care and initiating adult care (6,8–10). Suboptimal self-management (10), out-of-range glycemic control (11–13), and more frequent complications and hospitalizations (14,15) are of substantial concern during the transition years.

To address markedly elevated risks during and after the transition to adult care, the American Diabetes Association and others have published transition guidelines (7,16). Recommendations include initiating conversation about the transition process at least 1 to 2 years prior to the planned transfer to adult care; gradually shifting self-management responsibilities to the adolescent; discussing how adult health care differs from pediatric care; educating adolescents about insurance and other logistics of obtaining health care; and providing a written medical summary to the patient, family, and adult diabetes care provider. Existing transition programs show modest yet promising results (17–20), although, unfortunately, poor outcomes remain a substantial concern in patients in this age range (21).

To guide the ongoing development, implementation, and refinement of transition programs, the experiences of youth and their families are invaluable. Previous qualitative research has reported that many youth feel confused about how to establish an adult care provider (22) or face challenges with access (23). Some youth report positive, supportive interactions with adult care providers, and others feel put off by briefer visits, more directive communication styles, and a lack of consistency in providers or clinic staff (23). Youth want adult diabetes care providers to understand how other aspects of young adult life, such as school, work, and social demands, impact diabetes management and control (24,25). Qualitative work has also emphasized the importance of social and family support. Although

parents' roles change continuously as youths become more independent, their support is frequently identified as an important component of successful diabetes management and control throughout emerging adulthood (22,23). However, some emerging adults also report wanting to establish independence, which can detract from parents' ability to be supportive during the transition (23). Previous research has mainly focused on reflective posttransition interviews, and less is known about younger adolescents and their families as they approach the transition.

The purpose of this study was to describe the concerns, expectations, preferences, and experiences of youth and their parents before and after transitioning from pediatric to adult care. To highlight the most critical issues, one goal was to identify themes that emerge across the transition planning process. Guided by the diabetes transition framework of Hanna (26), we used a mixed-method approach to assess transition events (e.g., changes in doctors), personal characteristics (e.g., self-efficacy), and environmental features (e.g., parent-child relationships) and to characterize the experiences of youth and their families surrounding the process of transitioning and ultimately transferring care.

RESEARCH DESIGN AND METHODS

Two samples of young people with type 1 diabetes were recruited for this study: one was composed of adolescents prior to transferring from pediatric to adult care ("Transitions Expectations" group), and one was composed of young adults after the transfer ("Posttransition" group).

For the Transitions Expectations group, adolescents aged 15–17 years with type 1 diabetes were recruited during diabetes clinic visits at a pediatric tertiary medical center in the Mid-Atlantic region of the United States. Each adolescent and accompanying parents were approached before the visit to describe the study, determine eligibility, and obtain written informed consent (from a parent) and assent (from the adolescent). Inclusion criteria included current treatment with insulin,

diabetes duration of at least 1 year, and English language fluency. After consenting, participants completed a semistructured interview with the clinic's nurse educator and a brief survey. Youth received \$10 and parents \$5 in appreciation of their participation. In the Transitions Expectations group, 20 diabetes clinic patients were approached about the study, and 100% of patients provided informed consent and complete data. All adolescent participants had at least one parent present (12 mothers, 9 fathers), and two interviews included two parents.

For the Posttransition group, the diabetes educator from each of three participating pediatric diabetes clinics contacted young adults aged 18–22 years who were previously treated at their clinic to introduce the study and obtain informed consent. Eligibility criteria included previous treatment with insulin for type 1 diabetes at one of the three participating centers and English language fluency. Each participant was provided a unique username and password to log onto a secure online system to access the survey, and participants reviewed and completed the informed consent online. Paper surveys were available to participants without computer access. Participants received \$25 for study participation. For the Posttransition group, 59 of the 70 former patients (84%) who were contacted provided informed consent and complete data.

Measurement Methods

A mixed-methods approach was used to assess participants' experiences either before or after the transfer from pediatric to adult diabetes care. Participants in both groups completed quantitative questionnaires and provided qualitative responses to open-ended questions. All participants provided demographic and clinical information, including age, ethnic/racial background, diabetes duration, and method of insulin administration (i.e., continuous subcutaneous insulin infusion or multiple daily injections). A1C values, an indicator of overall glycemic control, were collected as part of routine clinical care during the clinic visit and were documented by study

staff for the Transitions Expectations group. For the Posttransition group, A1C was assessed via A1CNow from Metrika for 50 participants. The remainder self-reported values from their most recent clinic visit. The institutional review boards at all participating institutions approved study procedures.

Transitions Expectations Measures

Adolescent participants in the Transitions Expectations group completed the Self-Efficacy for Diabetes Self-Management measure (27).

Respondents rated their degree of certainty in their ability to correctly execute 10 diabetes management tasks (e.g., adjust insulin when eating more/less than usual) on a 10-point Likert scale ranging from “not sure at all” to “completely sure.” The Self-Efficacy for Diabetes Self-Management measure has demonstrated good psychometric properties and associations with diabetes management and control (27). Parent-reported transition preparation behaviors were assessed via the following questions: 1) how often do you go with your child to the regular diabetes clinic appointments? (5-point Likert scale from “never” to “all the time”), 2) have you talked with your child about what will happen when he/she leaves the pediatric diabetes clinic? (yes/no), and 3) have you talked with your child’s doctor about what will happen when he/she leaves the pediatric diabetes clinic? (yes/no).

Adolescents and parents participated in semistructured interviews with their pediatric diabetes educator. Open-ended questions prompted discussion about expectations for the transition to adult diabetes care, including anticipated timing, type of care to be received (e.g., preferred characteristics of the adult care provider and how the visits would transpire), and potential shifts in youths’ and parents’ roles in diabetes management.

Posttransition Measures

Young adults in the Posttransition group completed a questionnaire assessing feelings and experiences with their adult diabetes care providers. The questionnaire included the Physician/Health Care Team subscale of the Chronic Illness Resources Survey (28),

composed of three items assessing supportive patient-provider interactions (e.g., good communication, shared decision making). This scale has demonstrated good reliability (28). Twelve additional items, adapted from the Chronic Illness Resources Survey, assessed interactions with the adult diabetes care team. All items are rated on a 5-point Likert scale ranging from “not at all” to “a great deal.”

Participants in the Posttransition group answered the following four open-ended questions regarding their experiences prior to and since transferring to adult care: 1) what was most difficult during the transition from pediatric diabetes care to adult care; 2) what would they change about pediatric diabetes care that could have made the transition easier; 3) what would they change about pediatric care that could have improved care before the transition; and 4) what would they change about adult care that could improve the care they receive now.

Data Analysis

Descriptive analyses of the quantitative data were conducted using SAS software (Version 9.3). Data gathered from transcriptions of qualitative responses were analyzed using Atlas.ti software (Version 7.0). Three psychologists (one clinical, two developmental) and two research assistants reviewed a subset of the transcripts to identify themes and develop a coding scheme (Table 1). Two reviewers independently coded each transcript. The resulting coded text was reviewed by the research group (including all authors), and discrepancies were resolved through consensus. In addition to brief in-text quotes to illustrate key themes, longer participant quotes are provided in Table 2.

RESULTS

Clinical and Transition Characteristics

In the Transitions Expectations group, the mean participant age was 16.1 ± 0.6 years, participants were 60% female, and all self-identified as Caucasian. The mean A1C level was $8.7 \pm 1.5\%$. The mean age at diagnosis was 4.7 ± 3.1 years. From the survey, the mean diabetes self-management self-efficacy

score was 85.4 ± 10.1 (range 64–100), representing relatively higher self-efficacy compared with younger adolescents (27). One hundred percent of parents endorsed attending all diabetes clinic visits, and most parents reported that they had not yet discussed the transition with their adolescent (65%) or the diabetes care team (60%).

In the Posttransition group, the mean participant age was 21.1 ± 1.4 years and 47.5% were female. Most participants (83.1%) self-identified as Caucasian, and 16.9% as black or African American. The mean A1C level was $8.5 \pm 1.7\%$. Most participants received a diagnosis before 12 years of age (83.1%). Approximately one-half of participants (49.2%) received insulin via continuous subcutaneous insulin infusion, and the remainder via multiple daily injections. During the previous year, nearly one-third of participants (29.8%) reported attending at least one diabetes visit with a pediatric care provider, and 81.0% reported attending at least one diabetes visit with an adult care provider. Thus, a subset of the Posttransition group was in the process of transitioning to adult care. The majority (91.4%) were enrolled as part-time or full-time students, and of those, 90.2% reported not seeing a different physician for diabetes care away from home. Two-thirds of the group (67.8%) worked part-time. Mean scores for items regarding supportive interactions with diabetes care providers are summarized in Table 3 and indicate generally high ratings of supportive interactions with current adult diabetes care providers and low-to-moderate negative feelings about the transition.

Transition Themes

Timing of Transfer

In the qualitative interviews with the Transitions Expectations group, most adolescents and families anticipated transferring to adult diabetes care between the ages of 17 and 19 years. Many linked this to some chronological milestone of adulthood, such as graduating high school or starting college. Several parents expressed a desire for delayed transfer or sadness about ending their relationship with the

Table 1—Coding scheme for qualitative data

Topic	Examples	
	Transitions Expectations group	Posttransition group
Self-management	Changes in self-management of diabetes tasks (e.g., blood glucose checks, insulin administration) Youth responsibility, skills, autonomy Involvement of parents, friends, other supports	Challenges with adherence Difficulty meeting stricter A1C goals Personal responsibility Changes in parent involvement
Logistical issues	Obtaining/managing supplies Making medical appointments Transportation to clinic	Selecting new provider, with/without help from pediatric team Meet adult care provider before transfer Making and keeping medical appointments Access to adult care provider
Characteristics of appointments with adult care provider	Independent interactions with provider (no parent) Knowing what to ask Similarities/differences compared with pediatric visits	Team size and membership (e.g., diabetes educator, psychologist) Fewer, less frequent visits Shorter visits
Relationship with and characteristics of adult care provider	Sex match Communication/listening style Open-minded, nonjudgmental Personality “click”	Like/dislike adult care provider Time to build relationship, trust, rapport Level/type of communication with provider Less personal, perceptions of disinterest in patient Teach new provider personal medical history
Preparation for transfer	Discussed or not discussed transition with adolescent, family, diabetes care team	Structure pediatric visits more like adult visits as transfer approaches Treat like adult, do not “dumb things down”
Timing of transfer	Age (e.g., 18 years) End of high school/start of college Emotional statements related to anticipated transfer	Delay transition until after college Delay transition indefinitely

Coding themes and example items were developed from qualitative transcripts.

pediatric team (Table 2, Quote 1). Some families had not yet thought about a plan for transferring care or were unsure about when to transfer care (Table 2, Quote 2).

Early Transition Preparation

Participants in both groups emphasized the importance of early preparation for the transition process to adult diabetes care. In addition to highlighting the importance of simply “talk[ing] about it sooner” (18-year-old male), participants mentioned various behavioral strategies to prepare for transition during the mid-adolescent years. For example, several pretransfer adolescents and families discussed gradually shifting responsibility for specific diabetes management tasks from parents to adolescents, typically in the context of preparation for leaving home for college or to live independently (Table 2, Quotes 3 and 4). Others noted the value in practicing self-management skills such as interacting with the medical

team independently without parents present, making medical appointments, monitoring supplies, and refilling prescriptions (Table 2, Quotes 5 and 6).

Developmentally Appropriate Interactions

Wanting to be treated in a developmentally appropriate manner was a resounding theme from adolescents, young adults, and parents. Several participants expressed their desire to be talked to like an adult rather than like a child (Table 2, Quotes 7 and 8), suggesting a wish to engage in meaningful conversations about diabetes care in both pediatric and adult settings. Many wanted their adult diabetes care team to be aware of the unique challenges of the transition period, and to tailor their interaction style and expectations accordingly (Table 2, Quotes 9–11).

Social/Family Support and Building a “Safety Net”

Many adolescents and parents in the Transitions Expectations group discussed parents’ roles shifting between adolescence and early adulthood, from directly completing diabetes management tasks to a role of monitoring and providing backup support (Table 2, Quote 12). Although one 15-year-old female described her mother’s involvement as “extremely helpful,” she envisioned changes as she becomes a young adult (Table 2, Quote 13). Many participants described parents as acting as a “safety net” (mother, 16-year-old female), a “safeguard” (father, 16-year-old male), or “they’re there to . . . remind me if I forget” (16-year-old female). One challenge noted by young adults in the Posttransition group was bearing the immense responsibility of diabetes management without easy access to this “backup” or hands-on support, and several pretransition parents expressed

Table 2—Participant quotes illustrating cross-cutting qualitative themes

Quote no.	Respondent	Youth age (years), sex	Quotes
Timing of transfer			
1	Mother	16, male	"He can stay here [in pediatric care] forever. For my money, he doesn't have to go anywhere. I'd like to see him be a bit older."
2	Mother	15, female	"I haven't thought about it. . . . It occurred to me as we passed into your quarters this morning, like, 'gulp!'"
Early transition preparation			
3	Father	16, female	"Well, she's mentioned how when she goes away to college, how is she going to keep track of her numbers at night, and how is she going to manage that. So, she's already anticipating that, which I think is great."
4	Youth	16, male	"Everything will be on my shoulders. There will be no her [mom] keeping records, her reminding me to check, her reminding me to take the Lantus shot. It's all up to me, which I'm trying to work on that. I'm just trying to get it so I'm doing all of it so it won't be a new thing when I go off to college. It will be the same routine in a different place."
5	Youth	19, female	"[Preparation for transition could have been improved if I]. . . could have slowly been doing things on my own, that way I would already be used to going to the doctors by myself and telling him what was going on."
6	Youth	15, female	"I tend to be a little less responsible in regards to my supplies and what I have, I tend to just rely on the fact that there's a mass amount of stuff in our house, so I guess that's something that I should pay more attention to."
Developmentally appropriate interactions			
7	Youth	20, male	"I was finally being treated like the adult I should have been. At the age of 17 I feel I was too independent to have [my diabetes center] 'holding' my hand through diabetes care. I think once a human matures they no longer need their doctors to treat them like they are 10 years old."
8	Youth	21, male	"I feel the doctors can more fully explain things, because I feel they sometimes 'dumb things down.'"
9	Youth	15, male	"Not acting like you're six. . . and explain absolutely everything to you as if you haven't heard it a million times."
10	Youth	15, female	"Well, most importantly would be understanding that this is really difficult to deal with, that I do have other things going on in my life, and I can't devote every second to diabetes."
11	Youth	22, female	"They need to understand how you don't all of a sudden become an 'adult' when you turn 18. You still need extra support, especially in college learning how to take care of yourself and put yourself first."
Parents' roles/safety nets			
12	Father	16, female	"I'm hoping by the time she makes that change [to young adulthood], that she's to the point where she doesn't have to depend on me as much."
13	Youth	15, female	"My mom doing a lot less. . . not telling me to check my blood sugar, not packing stuff, not really doing anything. Hopefully, she won't follow me around like she does right now, but pretty much 99% me and 1% her, instead of, like, my mom is, like, 75% right now."
14	Youth	21, female	"I lost the constant support and attention from my parents that I had always had. I still had support from my parents, friends, and doctor, but overall I had to learn to handle my diabetes independently and take more responsibility for myself and my health, and that was very difficult."
15	Mother	16, female	"I think the challenge at college is just going to be not having the safety net and the transition with mom and dad, and not having the friends that she has known and her friends who know her diabetes. . . . Mom and dad aren't going to be there every day saying, 'What's your blood sugar? What's your bolus?' And I just think it's going to be a huge, huge, huge shift in responsibility when she realizes."
16	Mother	16, female	"[I hope my daughter is comfortable]. . . sharing the fact that she has diabetes and educating people about what a 'hypo' looks like and what they would need to do in the event she needs help."
17	Mother	16, male	"I need him to have a best friend that's his shadow that would replace me, that would monitor his blood sugars or be on him or know what to do if he passes out or has a reaction of some kind."

Continued on p. 351

Table 2—Continued

Quote no.	Respondent	Youth age (years), sex	Quotes
18	Mother	15, female	"I do know a family that when their son went off to college, the mom actually met the roommates and trained the roommates as well, so there'd be somebody there to recognize the symptoms."
Suggestions for coordinating care			
19	Youth	21, male	"Having appointments where both the pediatric and adult care professionals would be there to meet and discuss my treatment."
20	Youth	19, female	"[Adult care provider] review my diabetes records before I went to the appointment instead of having to explain everything that my pediatric unit had prescribed."
21	Youth	19, male	"[Patient and pediatric care provider] meet together with the adult doctor . . . for the first two visits so it does not feel awkward, and then gradually [the pediatric care provider would] back out."
22	Youth	21, female	"Meet once with the adult clinic while still seeing the pediatric care team . . . then be able to ask the pediatric team my questions and concerns."

worries about their child losing this support as a young adult (Table 2, Quotes 14 and 15). Several parents shared hopes and ideas to establish a safety net away from home (Table 2, Quotes 16–18).

Coordinating Care

Participants in both groups had ideas about coordinating care between the two systems. One theme was for the pediatric care provider to offer more logistical help in transferring to a high-quality adult diabetes care provider. A number of young adults reported difficulties selecting an adult doctor who was accessible (e.g., geographically, capable of making a prompt appointment) or who they personally liked, including at least two who reported they had not yet transferred to an adult care provider. Complaints about adult care teams included the physician 1) being "not as personal" and 2) "does not wish to have a relationship with me" (18-year-old female) and that "the amount of time was decreased, I did not feel that I was a patient but just a number that day" (22-year-old female). In addition, various ideas for overlapping visits with the pediatric team and a specific adult diabetes care provider were proposed. Seamless information sharing was one commonly noted purpose for coordination between pediatric and adult care providers (Table 2, Quotes 19 and 20). Others discussed the pediatric team's role in providing support or comfort during the transfer process (Table 2, Quotes 21 and 22).

CONCLUSIONS

The purpose of this study was to describe the experiences of youth with type 1 diabetes and their families before and after the transfer from pediatric to adult care. The mixed-methods design integrated quantitative assessment of participants' diabetes management beliefs and behaviors with qualitative data capturing their unique experiences and perspectives. Participants' expectations and wishes for the transition process aligned with American Diabetes Association recommendations (16). Transition experiences were generally positive, as evidenced by adolescents endorsing relatively high diabetes self-care self-efficacy, young adults reporting positive interactions with adult care providers, and many respondents indicating they would change nothing about their diabetes care experiences. Cross-cutting themes emerged related to the desire for early preparation for the transition and ultimate transfer of care, to developmentally appropriate interactions with providers, and to concrete support in connecting with high-quality adult care providers. There was an apparent disconnect between youth and family preferences for more comprehensive transition services and infrequent engagement in some transition preparation behaviors. Together, results call for continued development and refinement of effective patient-centered transition programs to reduce loss to follow-up,

and to promote optimal diabetes management and control before and during emerging adulthood.

Early Transition Preparation

In some areas, the qualitative and quantitative data contrasted with one another. For example, while many youth and families discussed the importance of early preparation for the transition, the quantitative data indicated that various transition preparation behaviors had not yet begun by 16 years of age. As in other chronic conditions, a minority of adolescents in this sample had discussed transition with their families or diabetes care teams (9,29), and participants unanimously reported that parents always participated in adolescents' medical visits. Findings from this study confirm previous conclusions that young people with chronic conditions would prefer programs that provide needed structure to the transition process (30,31). On the other hand, several families described current or planned transition preparations in the context of daily diabetes management tasks, such as beginning to shift responsibility to adolescents for daily management tasks and involving friends in supporting diabetes self-management away from home (32).

The difference between these findings may reflect the salience of autonomy in daily self-management tasks compared with quarterly diabetes clinic visits. That is, youth and families may anticipate and prepare for increasing autonomy in

daily tasks, but they have less frequent opportunities to consider when, whether, and how to prepare for the transfer of medical care. In addition, families may rely on the doctor to initiate transition preparation activities that occur in the context of a medical visit. Although it is recommended that medical teams introduce transition planning at least 1–2 years before the anticipated transfer (7,16), there may be barriers to providers' adherence to these recommendations, such as competing priorities during increasingly brief visits or limited awareness of transition preparation guidelines.

Developmentally Appropriate Interactions

Consistent with themes from other domains (e.g., occupational, social) in the emerging adulthood literature, adolescents and young adults with type 1 diabetes desire to be treated not like children or like older adults, but rather like the emerging adults that they are (33). This complements previous findings of young adults expressing discomfort or feeling out of place in adult-oriented diabetes clinics in which the other patients were older and more visibly disabled by complications of their (often type 2) diabetes (24). Consistent with the unique experiences characteristic of emerging adulthood (1), many adolescents and young adults in this study did not feel satisfied with interaction styles in either pediatric or adult care settings. Although they wanted more independence, autonomy, and respect as they moved through the transition to adulthood, they also resoundingly expressed their desire to receive continued support from their family, friends, and medical providers.

Indeed, themes related to social support were commonly voiced by both youth and their parents, similar to other qualitative findings (22). To explain this phenomenon, Allen and Gregory (5) discuss young adult independence as a myth: despite increasing self-management skills and a growing desire for autonomy, emerging adults often continue to rely on family and friends. Thus, parents, friends, and romantic partners may play critical roles in diabetes self-management across emerging adulthood and should not be

ignored during the transition process. This may, in part, explain parents' active involvement in diabetes management in middle to late adolescence. Transition preparation programs may benefit not only from addressing the logistics of changing care providers, but also from introducing practical strategies for seeking and optimally using available social supports.

Connecting With Adult Care Providers

Many pretransition participants discussed wanting to find adult care providers with similar characteristics to their pediatric care providers, possibly reflecting attachment to the pediatric care team and worries about not connecting as well with adult care providers. As in other samples of emerging adults with diabetes (22,25), the participants in this study emphasized the importance of a good fit with an adult care provider and expressed worries about having negative interactions. Despite these concerns, young adults in the Posttransition group largely reported positive experiences, suggesting that many adult care providers adequately address young adult issues in their practice. Although details of participants' suggestions for coordination between pediatric and adult care providers varied, many hoped to have their first encounter with an adult provider while still under the care

of their pediatric team. One remaining question is who holds the responsibility for facilitating pediatric-adult coordination and introducing patients to an adult care provider: the pediatric team, patient/family, or adult health-care system.

This use of mixed-methods research extends the existing literature related to type 1 diabetes management in emerging adulthood. Combining quantitative and qualitative data allows researchers and clinicians to integrate individuals' beliefs, behaviors, and characteristics with their unique narratives and perspectives to more fully understand their experiences during important events related to diabetes management (34,35), such as the transition from pediatric to adult care. This study assessed adolescents, parents, and young adults at various points along the transition process, thus providing a broad range of perspectives on important diabetes care issues during a vulnerable period.

Sample limitations include the relatively small sample size and potentially biased recruitment of adolescent participants with involved parents. The respondents' ethnic homogeneity is consistent with the composition of the participating clinics. Studies exploring transition experiences of emerging adults with type 1 diabetes from diverse social, economic, and ethnic backgrounds (22)

Table 3—Posttransition group experiences since transferring from pediatric care (n = 59)

Item	Mean	SD
In the past 6 months. . .		
Doctor involved you as equal in illness management decisions	3.9	1.1
Doctor listened carefully	4.0	1.0
Doctor thoroughly explained laboratory results	3.8	1.0
Doctor in tune with your current lifestyle	3.6	1.1
Doctor sensitive to your educational and employment situation	3.9	1.1
In the time since leaving pediatric diabetes clinic. . .		
New provider earned confidence	3.8	1.2
Felt stressed by change in diabetes team	2.4	1.4
Felt upset by change in diabetes regimen	2.2	1.4
Felt upset by exclusion of family members from treatment	1.5	1.0
Felt unprepared to take over diabetes care	2.0	1.3
Felt too little time with physician in adult clinic visits	2.0	1.4
Felt adult clinic supportive of diabetes management efforts	3.8	1.1
Felt abandoned from long-term relationship with pediatric team	2.1	1.4
Felt family members supportive of diabetes management efforts	3.9	1.1
Felt friends supportive of your diabetes management efforts	3.5	1.2

All items were rated on a 5-point Likert scale ranging from 1 (not at all) to 5 (a great deal).

are needed. Similarly, transition issues will become increasingly relevant as type 2 diabetes becomes more prevalent in pediatrics. The lower age limit for the Transitions Expectations group was older than the age at which guidelines recommend initiating self-management preparation (i.e., age 12–13 years); thus, we did not explore these early transition preparation experiences. In contrast, our sample focuses on transition preparation experiences among older adolescents for whom transition is a proximal concern. Additionally, not including parents in the Posttransition group limits our understanding of parents' retrospective reflections of the transition process.

Study design limitations include nonparallel measurement tools across the two groups and the inability to track individuals from pediatric to adult care, making it difficult to draw conclusions about longitudinal processes. Several questionnaires developed for adolescents were adapted to be appropriate for the transition period, potentially limiting their psychometric properties. In the Transitions Expectations group, the interviewer was a familiar member of the diabetes care team. This may have promoted rapport and open responses from participants, but it is also possible that respondents inhibited negative responses. Because youth and parents in this group were interviewed together, responses may have been less candid than if separate interviews had been conducted. Finally, insurance coverage was mentioned by a number of participants and may impact related issues (e.g., choice of adult doctor, ease of obtaining supplies); however, a comprehensive discussion of this topic was beyond the scope of the current report.

The results of this study reinforce the need for transition-oriented diabetes care clinics with providers who understand the unique developmental experiences of emerging adults. Such clinics may help adolescents, young adults, and their families' progress from pediatric to adult care by continuing to offer multidisciplinary team care, albeit with teams that are perhaps smaller or more specifically targeted to the needs

of emerging adults. Previous findings indicate that patients prefer to be seen by familiar providers (24,35), and the ideas shared by this study's participants suggest that introducing pediatric patients to the transition clinic providers prior to transfer may ease the transfer and potentially reduce gaps in care. Others have noted that the first few years of emerging adulthood may not be the optimal time for a significant change in care, given other developmental milestones during this time (32,36). Thus, transition-oriented clinics may be ideally suited for the first stage of emerging adulthood, with a later transfer to adult care once the individual has cemented his/her independent self-management skills and has become more established in their adult routines.

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