

RESEARCH ARTICLE

Recommendations for transition from pediatric to adult diabetes care: patients' perspectives

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Practice Points

- The reported lapse in care of 1 year or greater by almost a quarter (23.1%) of transitioned young adults is concerning.
- It is important to note that over 25% of transitioned young adults reported that they felt 'worried' or 'apprehensive' about the transition to adult care.
- Although birth control and family planning were reported to have been discussed with 32.5% of patients, a third (33.3%) wished the topic was discussed.
- A diffusion of responsibility often exists across pediatric and adult care providers for providing developmentally appropriate care and guidance.
- It would be an error to assume that these important issues have already been addressed by the patient's family or that responsibility for tackling these issues is not shared with the provider.
- Presuming that emerging adults will independently and appropriately identify an adult provider and make a timely appointment at the time of transition would be misguided.
- A written transition plan should be developed that includes printed information, highlighting common problems and solutions regarding transition.
- Changes in provider culture are needed to meet the needs of emerging adults with diabetes who are transitioning from pediatric to adult care.

SUMMARY **Aims:** This preliminary investigation assessed the experiences of young adults with diabetes to evaluate aspects of the transition process and assess whether developmentally important topics were addressed. **Patients & methods:** Questionnaires were administered to recently transferred patients. Reasons for transition, age, anxiety, lapse in care and how adult providers were selected were examined. Whether 13 developmentally important topics were addressed was also assessed. **Results & conclusion:** Over half (52.5%) of participants did not select their adult provider through pediatric provider

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recommendation. Lapse in care was over 1 year for 22.4% of participants. Important topics were not adequately addressed. Changes in provider culture are needed to meet the needs of emerging adults with diabetes who are transitioning from pediatric to adult care.

Adhering to the recommendations for intensive management of Type 1 diabetes has been established as critical to long-term health [1]. Optimizing adherence is often difficult to accomplish for pediatric patients, with rates of nonadherence to various aspects of diabetes care ranging from 20 to 93% [2]. Implied in the use of the term 'adherence' is that patients have increased autonomy in defining and choosing to follow their medical treatments. This is in contrast to the term 'compliance,' which suggests a restricted medical-centered model of behavior [3]. Herein, we use the term adherence as it better fits the preferred model of modern diabetes care. Modern diabetes care frequently includes multiple daily blood glucose testing and insulin administration, dietary considerations (carbohydrate counting), and exercise recommendations. Managing diabetes is associated with difficulty during childhood. For example, sibling conflict has been shown to be related to increased difficulty with adaptation and adjustment to diabetes [4], and younger patients often believe that having diabetes has negatively affected their relationships with friends [5]. Adherence tends to worsen during adolescence [6,7], and improving diabetes care during the transition from pediatric to adult care has become an important clinical issue and major challenge for healthcare providers in the USA [8,9].

The age range during which transition from pediatric to adult healthcare typically occurs is considered a particularly vulnerable period with regard to managing diabetes [10] due to a host of complex developmental challenges that often impact diabetes management [11–13]. Transition from pediatric to adult-oriented care occurs during the conceptually distinct developmental period of emerging adulthood. Most emerging adults do not yet view themselves as adults or adolescents [14]. Emerging adults may be viewed by pediatric providers as developmentally inappropriate for their service, that is, individuals with a history of risky sexual activity, alcohol use, drug experimentation or other risky behaviors [15]. These behaviors are often outside the expertise of pediatric providers and are a burden to the provider or system resources. By contrast, adult providers may view emerging adults as

developmentally immature and ill-prepared to assume the challenges of independently managing their diabetes as adult care practice often requires. A diffusion of responsibility often exists across pediatric and adult care providers for providing developmentally appropriate care and guidance.

For most emerging adults, the progression from home to educational or workforce settings imposes challenging new schedules and organizational demands. The concurrent management of a chronic health condition significantly increases the difficulty of managing and coping with these challenges [16]. Simultaneously occurring developmental processes include a need to fit in, struggle for independence and a vulnerability to social pressures to engage in risk-taking behaviors. When emerging adults weigh the relative importance of often complex competing demands, managing diabetes is often afforded low priority [15]. An important and well-known clinical problem is that many emerging adults are lost to medical care for extended periods of time during the transition from pediatric to adult care [16]. An increased recognition of these and other difficulties has made improving care during transition a priority for many pediatric and adult care providers [17].

Although guidelines for transition have been established by the American Academy of Pediatrics, the Society of Adolescent Medicine [18,19] and the American Diabetes Association [20], empirically derived information to inform the transition process has been limited [21]. Notably absent has been first-hand information from emerging adults who have recently transferred to adult care in the USA. Limited data are available regarding what young diabetes patients perceive as helpful during transition and what they believe would have improved their transition experience. While several transition models have been tested and implemented outside the USA (e.g., in Canada) [22,23], the application of such models in the USA is limited due to fundamental differences in healthcare delivery and funding systems. Thus far, evidence-driven transition models have not been developed based on US systems of care delivery. Instead, transition recommendations and programs have

been primarily developed and implemented based on top-down rational processes, including anecdotal evidence and expert opinion. Patient-oriented empirical data are uniquely important to inform the development of transition programs, processes and curricula to best serve patient needs.

Questionnaires were developed to assess the clinical experience and the perceived needs of young adults who completed the transfer from pediatric to adult diabetes care. Study goals included assessing the transition experience from the patient's perspective and assessing whether developmentally important topics were discussed during transition.

Patients & methods

Patients who presented to a tertiary diabetes treatment center affiliated with a university-based medical school located in the Pacific Northwest region of the USA were intermittently approached over a period of approximately 6 months to complete questionnaires that assessed quantitative and qualitative aspects of the transition to adult care (**Supplementary Questionnaire**; see online at www.futuremedicine.com/doi/suppl/10.2217/dmt.13.26). We included patients with both Type 1 and 2 diabetes as we believe the transition experience will be similar for both. The adult clinic operates side-by-side with an associated pediatric diabetes clinic. Questionnaires were distributed and completed by participants during their regularly scheduled adult clinic visits as part of clinic efforts to improve transition care. Questionnaires were completed with no identifying or protected health information recorded. The rate of those who declined to complete questionnaires was negligible ($n = 2$), with time constraints endorsed as the limiting factor. Fifty two patients with diabetes aged 19 to 27 years (mean age: 23.2 years) who had recently transferred from pediatric to adult care completed questionnaires. Twelve questionnaires were excluded from final analyses due to significant missing data or age outside of the *a priori* established acceptable range of 19 to 27 years. Forty questionnaires were included in the final analyses. Demographic characteristics of the clinic suggest that patients were predominantly Caucasian (~85%) and that patients were mostly Type 1 diabetic (>95%). Requirements of the associated institutional review board were met prior to analysis of clinical data.

Measures

The questionnaire was developed using four sources of information, including:

- An exhaustive literature search of previously published data regarding transition of patients with diabetes and other chronic illnesses, including cystic fibrosis and renal transplant;
- Review by a panel of interdisciplinary adult and pediatric diabetes care providers, including certified diabetes educators, dietitians, psychologists, nurse practitioners, social workers and endocrinologists;
- Review by two healthcare professionals who are well-known for their work in transition and diabetes;
- The inclusion of factors known to be frequent correlates of glycemic control.

The resulting brief questionnaire included 20 questions about transition.

Questionnaires recorded demographic information, such as age at time of diagnosis and age at time of transfer to adult care. A question asked patients to indicate the time that elapsed between their last pediatric visit and first adult care visit (using the intervals 3–4 months, 4–8 months, 8–12 months, 1–2 years or greater than 2 years). One question asked about the means used to identify an adult diabetes care provider, which included: always seen by an adult provider; went to a transition clinic having both pediatric and adult doctors; pediatric doctor recommended an adult doctor; recommendation from a patient, friend, family member; and other. Questions regarding whether 13 topics considered important during the developmental period of emerging adulthood were addressed by healthcare providers were also included. Participants were asked to indicate whether each topic was discussed during transition and whether discussion would have been helpful. Topics included: prescriptions; grocery shopping, cooking and meal planning; introducing diabetes to others in your life; leaving home or adjusting to new living situations; and birth control and family planning (see **Table 1** for the complete list of items). Specific open-ended questions included reasons for changing to a new care provider and feelings experienced during the change of providers. A broad open-ended question was included that allowed patients to indicate additional topics they felt were important ('is there anything else

Table 1. Topics of discussion during transition.

Topic	Wished it was discussed (%)	It was discussed (%)
Use of diabetes management technology	42.5	42.5
Introducing diabetes to others	40.0	35.0
Advocacy (workplace and academic settings)	37.5	40.0
Birth control and family planning	33.3	32.5
Diet, meal planning and shopping	32.5	47.5
Communicating with the medical team	30.0	42.5
How to get increased social support	30.0	37.5
Leaving home and adjustment	27.5	45.0
Driving	27.5	50.0
Organization and planning skills	22.5	60.0
Alcohol and drugs	20.0	62.5
Insurance issues	12.5	37.5
Prescriptions (e.g., supplies and refills)	12.5	82.5

you would like us to know about changing from pediatric to adult diabetes care?’).

Results

Participant responses to open-ended questions were reviewed and organized into thematic categories according to response similarity. Means, frequencies and percentages were calculated for participant responses using the Statistical Package for the Social Sciences version 19. The mean reported age of participants at time of diagnosis was 9.6 years. Reasons recorded by patients in response to the open-ended question, ‘what was your reason for changing to a new doctor?’ yielded six thematic categories (Table 2). The answer most often given was ‘physician recommended/appropriate age’ (Table 2). The most common method of finding an adult care physician was ‘physician recommended’ (Table 3). Reasons recorded in response to the open-ended question ‘how did you feel about changing doctors at this time?’ yielded the categories: good and fine (57.5%), worried and apprehensive (27.5%), and ambivalent (10.5%). Responses regarding the lapse in care between the last pediatric visit and first adult care visit showed that 7.7% had a lapse in care of

over 1 year, while 15.4% had a lapse in care of over 2 years. Overall, 23.1% reported experiencing a lapse in care of over 1 year (Figure 1).

Age at time of transfer was reported to be 14–16 years by 12.5% of participants, 17–19 years by 52.5%, 20–22 years by 22.5% and older than 22 years by 10%. Analysis of whether a topic was discussed during transition from pediatric to adult care found that healthcare providers discussed ‘prescriptions’ with emerging adults at relatively high rates (82.5%). However, other important topics were less frequently discussed (Table 1).

The three topics patients indicated they wished were discussed most frequently were: the use of technology to improve diabetes management; introducing diabetes to others; and advocacy (Table 1).

Discussion

Although the present study was a small preliminary examination of patient experiences and transition preferences, it is one of the first investigations of this kind conducted in a US diabetes care setting; for an exception see Garvey *et al.* [24]. The present study provides important information we hope can serve as a guide for further scientific inquiry. Given the goal of optimizing adherence and providing developmentally appropriate care during transition, results of this study suggest that improvements are needed in provider policy and procedures to improve the transition of care and to address issues important to this age group. In this section, we offer recommendations related to the findings that may improve the transition of pediatric diabetes patients to adult care settings.

Table 2. Reason cited for changing to an adult provider.

Reason	Respondents (n)	Respondents (%)
Physician recommended/age	14	38.5
Improved care/dissatisfied with pediatric care	9	24.3
Relocated/college	8	21.6
Pregnancy	3	8.1
Insurance	2	5.4
Other	1	2.7
Total (n)	40	100.0

■ **Reason for transition**

Findings regarding reasons for changing to an adult care provider showed that only 38.5% of respondents changed providers because it was recommended by their pediatric provider or because of their age. While most of the reasons cited for transfer of care were physician recommendations and life changes (i.e., relocation, college or pregnancy), almost 25% reported they changed providers because of dissatisfaction with their pediatric provider. Although reasons patients were dissatisfied with their pediatric provider were not specified in this study, it may be partially because pediatric providers are often ill equipped to deal with the developmental issues of late adolescence and emerging adulthood; for example, sexual activity and drug/alcohol use. While 47.5% of the sample reported that they had identified an adult care provider through the recommendation of their pediatrician, the remaining 52.5% did not. This finding suggests that pediatric providers could better meet patient needs by providing specific recommendations for an appropriate adult provider and/or guidance to help emerging adult patients best identify an adult provider appropriate to their needs. Given that pediatric providers often have an established relationship with the patient and are most likely to understand the patient's situation and needs, they are best positioned to make informed recommendations that will be accepted and acted upon.

■ **Selecting an adult provider**

Insurance limitations were cited as the reason for choosing an adult provider by 10.0% of respondents, while the recommendations of family, friends and other patients were cited by 17.5% of respondents. Although these referral sources may lead to acceptable outcomes, they are not ideal as the specific medical needs of the patient may not have been adequately considered. Although only 5% of respondents reported using the internet to identify an adult provider, the unprecedented expansion of communication and internet technologies suggests such resources will probably become more commonplace, increasingly accepted and utilized in the future. Provider websites that include information regarding transition could better prepare emerging adults for the transfer to adult care. Websites developed by adult providers could provide important information and draw emerging and young adults to their practice. Pediatric providers should establish a strong adult referral network. They

Table 3. Means of finding an adult care provider.

Method	Respondents (n)	Respondents (%)
Recommendation of pediatric provider	23	47.5
Recommendation of friends, family or other patients	11	17.5
Insurance referred	4	10.0
Internet search	2	5.0
Unspecified	8	20.0
Total (n)	40	100.0

should draw on their often long-term relationship with the emerging adult patient to guide them to competent adult care providers whose skills, expertise and interpersonal style best match the patient's needs.

■ **Feelings about transition**

Although most emerging adults reported feeling 'good' or 'fine' about the transition process, it is important to note that over 25% reported they felt 'worried' or 'apprehensive' about the transition to adult care. Given that worry may contribute to a lapse in care, this finding has important implications for both pediatric and adult providers. Prior to transfer of care, pediatric providers should provide as much detailed information about adult clinics and specifically recommend adult providers and services if possible. A visit to the adult setting and personal introductions may be possible in some settings, and may be an effective step to facilitating transfer of care and optimizing transition outcomes. An alternative approach would be to develop 'transition' clinic days that allow both pediatric and adult

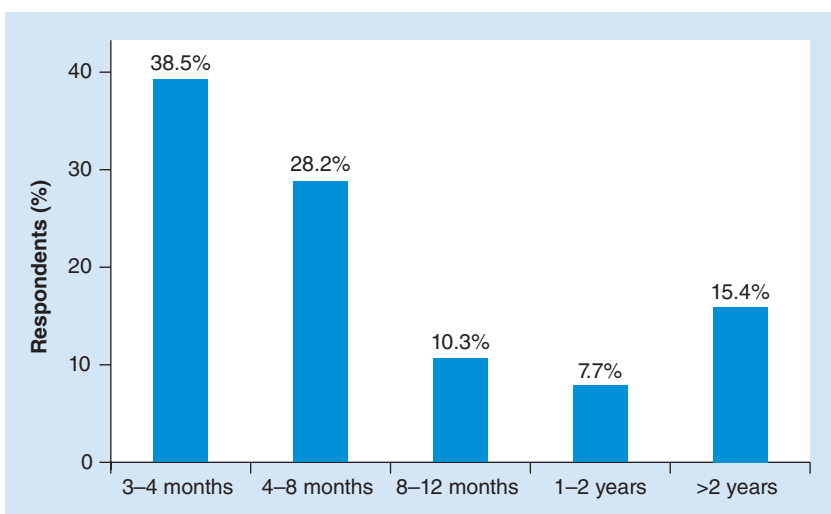


Figure 1. Duration of lapse in care from last pediatric to first adult care visit.

care providers to meet with patients and families [21]. Emerging adults should be provided adequate information to allay any fears, questions should be answered, and confidence instilled regarding adult provider competence, available resources and personal fit. Adult providers should note that approximately a quarter of emerging adults transferring from pediatric settings may be worried and/or apprehensive about the change. Adult providers who establish a personal connection that conveys understanding, warmth and professional competence will help the emerging adult more quickly adjust to a new adult care provider, physical setting and available services. Addressing potential patient concerns will probably reduce dropouts and establish a mutually beneficial, stable and long-term relationship that is ideal for both the provider and the patient.

■ Lapse in care

A reported lapse in care of 1 year or greater by almost a quarter (23.1%) of transitioned young adults is concerning. The competing demands occurring during the developmental period corresponding with transition probably contribute to diabetes management difficulties. Many problems may be patient-centered and not within the scope of the healthcare provider. However, the cumulative results of this study suggest that healthcare professionals can make improvements by providing developmentally appropriate care and guidance during the transition period [15]. Presuming that emerging adults will independently and appropriately identify an adult provider and make a timely appointment at the time of transition would be misguided. The fact that nearly one in four patients struggled to see an adult provider in a timely manner suggests that the information and guidance provided by healthcare professionals has been inadequate. Many emerging adults require specific and concrete recommendations and follow-up to assure that the transfer to an adult provider has occurred. Although informed speculation suggests developmental factors are an important contributing factor, the reasons for the lapse in care are probably multifactorial and were not assessed in this preliminary study.

■ Topics important during the transition period

The list of potential discussion topics that should ideally be addressed during the developmental period corresponding with transition was not exhaustive in this study. However, responses

from recently transferred young adults suggest that important differences exist between what information providers offer and what information patients prefer. Although prescriptions were reported to have been discussed by most patients during transition (82.5%), additional important topics should also be discussed and recommendations provided. Although birth control and family planning were reportedly discussed with 32.5% of patients, a third (33.3%) wished the topic was discussed. Although providers seemed to often address many of the important issues, the percentage of patients who wished important topics were discussed was notable (Table 1). Increased attention to assuring that all emerging adults receive developmentally important information regarding topics such as driving, alcohol use and drug use has the potential to reduce risks and improve health outcomes. It would be an error to assume that these important issues have already been addressed by the patient's family or that responsibility for tackling these issues is not shared with the provider. A checklist of these topics, and others specific to the patient's needs, should be developed and updated by the pediatric provider. Given the potential for a lapse in care, these issues would ideally have been addressed in the pediatric setting. If not, the checklist should transition with the patient's file to the adult provider who could address any remaining issues with the patient.

■ Limitations & recommendations

Our intent in conducting this study was to gauge patient perceptions about their transition from pediatric to adult care to inform the improvement of clinical care. A limitation of the study is that the reduced number of participants may restrict generalization of the findings. However, science is an iterative process and the paucity of similar prior studies lends importance to the present study as a means of guiding further inquiry. Another potential limitation is that the patient-centered approach used makes it impossible to discern the information providers actually delivered. Although our results were limited to patient perception, it may be that this is the more important and relevant viewpoint. Given that this study was a *post hoc* analysis of clinical data and lacked demographic information, future *a priori* studies should include patient information such as gender, time lapse since transfer of care, socioeconomic status and health status (HbA1c). These variables should be examined for

relationships to other demographic characteristics or markers of health status. Collecting this information may yield relationships or patient characteristics that are related to important outcomes. For example, glycemic control (HbA1c) may be associated with lapse in care, socioeconomic status and gender. Although this sample was predominately composed of young adults with Type 1 diabetes, it may be that diabetes type is associated with differences in patient perception of transition. Future research should examine possible differences in the transition experience and outcomes by diabetes type. Changes in transition will only occur in the USA when it can be demonstrated to be financially advantageous. Future research directions should include demonstrating the cost saving benefits of optimizing transition from pediatric to adult care.

Conclusion

There are two related areas of concern regarding transition of care that were assessed as part of this study. One concern is the importance of facilitating the physical transfer of care so that it occurs in a timely and optimal manner. The results of this investigation suggest important changes are needed in provider culture, awareness and systems to best facilitate the transition of care. The second concern is the diffusion of responsibility for delivering developmentally appropriate education and information over the course of transition that is preferred by emerging adults. Results indicate that a gap exists between the information that providers deliver and the information that patients prefer. Improvements are needed to better understand and meet patient needs during the period of transition from pediatric to adult diabetes care. Efforts to improve transition should include means of changing provider culture. The development of a provider-based learning intervention to educate and heighten provider awareness may be an effective and necessary approach to improve transition outcomes.

Transition is widely considered to be a long-term process. As such, the complex issues of transition require ongoing and open collaborative discussion and planning that begins at the initiation of services and is solidified and refined over time. A written transition plan should be developed in cooperation with the patient and family, and should include printed information highlighting common transition problems and solutions that are appropriate to the patient's

developmental status. Our hope is that the present study stimulates open discussion and further promotes individual and institutional commitment to optimize the transition of care for emerging adults with diabetes and other chronic health conditions.

Future perspective

The barriers to optimizing the transition of emerging adults from pediatric to adult care in the USA will be difficult to overcome. The necessary changes are complex and include changes in care providers, institutional systems and insurance reimbursement policies. We expect that positive incremental changes can and will occur, but improving the transition of emerging adults from pediatric to adult care depends on whether care providers have the necessary information, and strongly and persistently advocate for the needed systems changes. The process has begun and changes have been made in some settings, but the current momentum will only lead to gradual change. Awareness and advocacy efforts have not yet created the urgency necessary to fuel rapid change. Future research that demonstrates the monetary value of improved transition should greatly accelerate the process of change.

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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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