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The process of transition from pediatric to adult diabetes care: recommendations for US healthcare systems



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Practice points

- Providers should begin seeing patients alone for portions of the session at approximately 14 years of age, but the course of increasingly independent visits should be based on patient maturity and readiness, not age.
- Pediatric providers should consider the developmental needs of adolescents and emerging adults. Relevant diabetes-related issues include: sex, pregnancy, birth control, family planning, alcohol consumption, drug experimentation, driving, sports involvement, financial issues such as insurance and copays, ordering supplies, independently making healthcare appointments, disclosure of diagnosis (school, employer, roommates, acquaintances, etc.).
- Age alone is not sufficient for deciding when transfer of care should occur. Although typically occurring after high school, the decision should be based primarily on a history of success independently managing diabetes care.
- Family cohesiveness and support are important factors. Identifying need and referring families to services to improve family functioning may be critical to improved diabetes care and the transition process for some families.
- Providers should begin educating families about the transition process earlier rather than later. Clarifying expectations and establishing goals and plans should be an ongoing process that begins at the time of diagnosis.
- Providers should align with families to providing relevant information and education, and to empower family proactivity during the transition process, including the transfer of care.
- Pediatric providers are in the best position to identify an appropriate adult provider for adolescents in their care. Although difficult to accomplish in most settings, covisits or personal introductions would be ideal.
- A transition checklist should accompany all adolescents when transferring to adult care settings. This will allow adult providers to better determine the individual needs of the emerging adult patient.
- Some providers may choose to specialize in providing care for this age group. Specialized training should be undertaken to best understand the developmental issues and complications of patient care during emerging adulthood.
- Current healthcare systems are insufficient to meeting transition needs. Advocacy for improvements in systems and institutions at local, regional, and national levels will ultimately be necessary to facilitate broad changes.
- Joint and Transition Clinics that are comprised of pediatric and adult providers who specialize in emerging adulthood and who work together to transition the patient across systems may be an effective approach.
- Navigators or transition coordinators should be developed within clinics and care centers to facilitate the transition process and address transition issues.
- Participation in professionally led support groups has been associated with improved HbA1c and decreased report of diabetes burden.
- Online support groups have also been useful for providing parent-requested information and online access to professionals throughout the transition process.

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In the USA, transition from pediatric to adult care is a period of increased vulnerability for emerging adults with Type 1 diabetes. During the transition process, youth with Type 1 diabetes experience increased risk of extended lapses in care and associated medical complications. As such, we conducted a review of the transition literature to identify common systemic barriers, interventions designed to improve transition and limitations of current findings. Based on this review, recommendations include ensuring that transition conversations happen earlier in care, that care is appropriately tailored to the developmental level and unique needs of emerging adult patients, and that increased financial and instrumental support is provided to adequately evaluate and provide effective transition services.

KEYWORDS

- adolescent • barrier
- emerging adulthood
- review • transition • Type 1 diabetes

The process of transition from pediatric to adult diabetes care: recommendations for US healthcare systems

For adolescents and young adults with Type 1 diabetes, the process of transitioning from pediatric to adult care occurs during a period of increased vulnerability. This transition, recently defined as a ‘purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults as they grow up learning to live with their lifelong medical condition’ [1], is commonly thought to begin in early adolescence, occur over time and include the adolescent gradually assuming responsibility for independently accomplishing diabetes care. In addition to the psychological aspects of transition (e.g., potential anxiety or sense of loss), the transition process may include directly communicating with diabetes care providers, ordering supplies, resolving issues of insurance and copayments, communicating with employers or educational institutions and making decisions about disclosing relevant personal information to others (e.g., medical or mental health diagnoses). The process of transition often includes youth receiving appropriate information and education about adult-oriented issues related to general health and specific to Type 1 diabetes. Transition-related conversations may provide information or education to inform decision-making such as precautions associated with driving, sex, alcohol consumption, prescription and illicit drugs, roommate interactions, safety at parties and diagnosis disclosure to peers. Additionally, the process of transition for individuals with Type 1 diabetes is complicated by the co-occurrence of normative life events such as moving away from home, managing romantic relationships, navigating education and/or employment responsibilities, assuming financial independence and other life changes associated with achieving independence. The process is difficult even without the additional

burden of doing so while managing Type 1 diabetes. Given the difficulties associated with the transition processes, transitioning youth would benefit from programs specifically designed to facilitate their success.

The need for planned transition from pediatric to adult healthcare services for youth with chronic health conditions has been recognized by numerous well-recognized organizations [2–5]. Ideally, healthcare delivery during the period of transition should be coordinated and seamless, without interruptions that jeopardize health outcomes. Unfortunately, most youth (~60%) report not having participated in recommended discussions regarding healthcare transition with their pediatric providers [6]. In addition, a marked decline in clinic attendance has been observed for youth during the transfer of care [7,8]. Moreover, a relatively high percentage of youth with Type 1 diabetes (24%) have reported a gap of more than 1 year between their last pediatric visit and first adult visit, while over 14% experienced a lapse in care of greater than 2 years [9]. Furthermore, young adults are more likely to have disruptions in the continuity of their care after transfer to an adult setting, with over half switching adult providers at least once [10]. Lapses in care, missed appointments and a revolving door of providers likely increase the risk of poor health outcomes for transitioning youth.

Because of the known difficulties associated with transition, young adults are at heightened risk of suboptimal diabetes management and related complications. Youth with Type 1 diabetes are more likely to display lower rates of adherence during the transition to adult care, placing them at greater risk of adverse outcomes such as suboptimal glycemic control and medical complications [9,11,12]. Indeed, approximately 65% of youth in the transition process indicate they have experienced at least one unfavorable medical outcome due to suboptimal access to medical care [13]. Given that transition to adult

care represents a particularly vulnerable and dangerous period of time for youth with Type 1 diabetes, we conducted a review of the transition literature – with an emphasis on US-based studies – to identify common systemic barriers, interventions designed to improve transition, and limitations of current findings.

Barriers to successful transition

There are multiple barriers to the successful transition of patients with Type 1 diabetes. These barriers can be divided into several categories that include the following: patient factors (e.g., development), family functioning, healthcare provider characteristics (including both pediatric and adult providers) and lastly, healthcare access and delivery systems. These broader categories were identified based on common themes observed during a review of the literature and were organized within a socioecological framework.

• Patient-related barriers

In this section, patient-related barriers refer to normative developmental changes often experienced by adolescents and young adults that are associated with challenges to typical pediatric and adult care. Unfortunately, chronological age is not an adequate indicator of transition readiness, and youth with Type 1 diabetes may face an assortment of developmental challenges that make readiness for transfer of care decisions difficult to determine. Recent advances in neurophysiology [14] indicate that the pace of brain maturation varies, with some aspects of neurological development being more rapid and more dominant until other areas catch up. In the adolescent brain, the prefrontal cortex continues to develop well beyond the age of 18 years, with the maturational process extending to approximately age 25 years for most. Neurological findings correspond nicely with the work of Arnett who has proposed the ages 18–25 years as the distinct developmental period of ‘emerging adulthood’ [15,16]. Thus, it has generally been accepted that young adulthood does not immediately follow adolescence, but begins in the late 20s and even the early 30s. Unfortunately, there are no universal standardized measures of emerging adulthood or transition readiness. Although several promising measures of general transition readiness exist, such as the TRxANSITION [17] and the TRAQ [18], most have various limitations (e.g., burdensome to score, limited in

scope) and are not widely used [19]. Thus, transition-related decisions have typically been based on age or other factors and not developmental status. Also, healthcare providers may not have received the extensive training necessary to best understand developmental processes or conduct developmental assessments, increasing the risk of communication barriers that may hamper the transition process.

There are additional developmental barriers to successful transition that are unique to adolescence. Weissberg-Benchell *et al.* [20] conducted an excellent review of the numerous issues that arise during this developmental period. For example, adolescence is associated with a search for an identity separate from that of family, and by redefining relationships with adults in caregiving roles. The result is increased desire for autonomy which, depending on adult responses, may result in increased conflict with caregivers and decreased compliance with provider recommendations. Other barriers associated with this developmental period may include difficulty obtaining medical insurance, moving away from home and acclimating to the demands of college and/or employment. In addition, adolescence is a period of increased risk-taking (e.g., alcohol and drug experimentation), further increasing the risks of diabetes-related complications [21]. Also, the long-term process of managing a chronic illness places youth with Type 1 diabetes at increased risk of experiencing mild delays in development (e.g., social, psychosexual), resulting in further difficulty successfully assuming adult responsibilities. Symptoms of anxiety and depression are more common during the period of transition, and can interfere with effective diabetes self-management and increase the risk of poor glycemic control [22]. Further complicating matters, short-term poor glycemic control may affect the executive functioning needed to manage diabetes, including planning, organization and memory functions [23], which may diminish the ability of young people to manage their diabetes and understand the consequences of not following the medical regimen [4,14,24,25]. Executive functions are necessary for diabetes care, and the acquisition of executive function abilities is a developmental process that occurs throughout childhood, adolescence and into emerging adulthood [26]. It has been posited that assessing executive functioning may provide valuable information when attempting to determine transition readiness [27].

• **Family-related barriers**

Given the redefinition of roles that occur during adolescence and emerging adulthood, it is not surprising that multiple family factors are relevant to facilitating successful transition to adult care. It has been recognized that adolescents with a higher level of self-efficacy in managing self-care are more ready for transition, but self-efficacy is difficult to achieve without opportunities for independence coupled with support. Family cohesiveness and support are important in promoting the ability of a young person to navigate a new system and assume full responsibility for his/her healthcare [28]. Overinvolvement of parents in diabetes care during childhood may lead to loss of engagement in self-care and difficulties with transition. Conversely, abrupt withdrawal or absence of parental support is often cited as a relevant barrier to transition [28]. Unfortunately, parents often report uncertainty regarding what to expect during the transfer of care and how to best help their child engage in the process of transition to adult care. Given the association between family functioning, adherence and glycemic control [29], neglecting the potentially important role of parents and other family members in facilitating transition would likely increase the risks of poor outcomes.

• **Healthcare provider-related barriers**

Transition research underscores the perception, and the reality, of differences between pediatric and adult care settings and the impact those differences may have on patient transition [28,30]. Pediatric diabetes care settings are most often described as holistic, multidisciplinary and focused on family involvement. In the context of diabetes, adult care settings typically follow guidelines focused on individual responsibility and detection and prevention of long-term complications. The difference between settings has likely contributed to transitioning young adults reporting the adult setting as ‘sterile’ and ‘unfriendly’ [30]. Parents should remain involved in helping their teen manage diabetes as decreased involvement has been strongly associated with worsened adherence [31–33]. Parental involvement in the care of young adults may be discouraged by some adult providers, further adding to the difficulty. However, the difference between settings has not always been associated with negative effects, as some young adults report cherishing the independence gained in the adult healthcare setting and indicate satisfaction

with escaping the ‘paternalistic atmosphere’ encountered in pediatric practice [28].

Based on our review of the literature and anecdotal experiences, we have concluded that there is wide recognition that providers on both sides need to better understand the other’s practice models and the needs of emerging adults. Both pediatric and adult provider teams face the challenge of balancing the time required to facilitate successful transition with the lack of reimbursement for such time. Adult providers face the added burden of needing to determine what diabetes-related education has been accomplished for new patients while attempting to develop rapport with a population that is inherently different than the bulk of their caseload. Unfortunately, adult providers often have scant training on how to effectively build rapport with young or emerging adults and also report a general lack of education and awareness regarding issues relevant to the developmental stage of emerging adulthood.

• **Healthcare systems-related barriers**

The current US healthcare system creates substantial barriers to facilitating successful transition [34–36]. There is a general lack of integrated formal systems and processes needed to successfully transition youth with Type 1 diabetes in an effective and timely manner. The healthcare system and models of managed care currently in place in US systems are often ineffective, inefficient and tend to be rigid and difficult to change. In addition, lack of health insurance has been identified as a major contributor to poor transition outcomes [34]. Fortunately, changes introduced by the Affordable Care Act (ACA) that allow keeping young adults on their parents’ insurance policy until the age of 26 years may significantly improve access to care for some emerging adults. Although the American Academy of Pediatrics, the American Academy of Family Health Physicians, and the American College of Physicians have developed specific practice-level guidelines for the transition of youth with chronic health conditions from pediatric to adult care [35], college-based healthcare has not been included, resulting in a lack of appropriate health resources for transitioning youth pursuing higher education. A recent survey of medical directors from health centers representing US colleges reported that only 51% of those surveyed reported the ability to manage diabetes on campus [35]. In addition,

payment for college-based health services may not be incorporated into health insurance policies [35]. Lack of available adult providers with experience in treating young adults with Type 1 diabetes and a dearth of empirical evidence to support transition protocols are among other system-related barriers often cited in the transition literature [36]. Although there is a clear need to improve access to care and to coordinate the transition process, the current system does not provide adequate payment for the substantial time necessary to facilitate the transition process. Taken together, barriers to transition comprise a complex set of challenges that successful transition programs must address to improve adherence, clinic attendance, glycemic control and overall health outcomes.

• **What works: specific interventions & programs for transition & transfer of care**

Many clinics have developed transition programs that have been initiated based on identified need and anecdotal experiences; however, there has been limited empirical research that has examined programs and models of transition [37–39]. The majority of transition-based studies have utilized observational methods [40], thereby limiting the investigators' ability to draw conclusions regarding causality. Indeed, a recent systemic review by Hanna and Woodward [41] determined that none of the transition studies examined had utilized a well-controlled experimental design. In addition to a lack of high-quality quantitative research, financial costs of programs and restricted reimbursement in the US healthcare system has been a formidable barrier, in spite of research indicating that cost savings would likely offset the cost of a transition program [42,43].

• **General transition guidelines**

The Society for Adolescent Medicine [44] outlined five primary areas of focus in their 'General Principles for Successful Transition' (**Box 1**).

These recommendations are further supported by a consensus statement published by the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians-American Society of Internal Medicine [45] and the American Diabetes Association [4].

Another important aspect of transition is determining the age at which transition processes should begin and when the transfer of care should occur [38,46]. Adolescents and young adults who have transitioned to adult care after completing high school have reduced risk of sub-optimal glycemic control, while adolescents who have transferred to adult care while enrolled in high school have demonstrated higher HbA1c, have been more likely to be lost to follow-up and have evidenced reduced parental involvement and support [38]. Although such findings do not infer causality, it stands to reason that youth transferred between starkly different models of care at an earlier age and without the use of objective readiness measures are more likely to experience negative health outcomes.

Collaboration with all members of the medical and support team are paramount to achieving effective diabetes management. This should include the patient, his or her family and the healthcare system. It is recommended that all parties are involved in creating the transition plan [47]. When individuals with diabetes and their families have reflected on the transition process, they have indicated transition should have occurred over the course of a year, with 23% stating it was an anxiety producing change [39]. However, most recommendations suggest a longer time frame for the process of transition. Patients also indicated their preference for their pediatric provider to plan the transition as they were unable to identify what was needed and how to approach the process [48]. Healthcare systems and medical providers should take the lead in organizing the transition process [48].

Box 1. Transition recommendations of the Society for Adolescent Medicine.

- The transition must be appropriate to the chronological and developmental age of the patient
- The health facility must address common concerns of adolescents in the age group (e.g., growth, development, sexuality, mood, mental health concerns, substance use and other health-promoting and damaging behaviors)
- The transition must also enhance the patient's autonomy, personal responsibility and facilitate self-reliance
- The transfer of care should be individualized to the patient and family
- The transition should include a designated professional, such as a coordinator or advocate, who takes responsibility for the process in collaboration with the patient and family

• **Support groups**

A less commonly studied intervention has been the use of support groups to improve the process of transition between pediatric and adult healthcare. Markowitz and Laffel [49] established a professionally led support group for emerging adults aged 18–30 years. Participation in the group was associated with clinically meaningful changes in HbA1c and a reported increase in diabetes-related self-care behaviors. Additionally, there was a statistically significant decrease in reported diabetes burden.

Another study [50] utilized qualitative methods to evaluate the development of an online support group for parents of youth with Type 1 diabetes. Problems identified by parents included lack of access to credible information and insufficient connection with other parents of youth with Type 1 diabetes. An online format was created allowing access to the following identified themes: access to credible information, parenting resources, transition information and social support [50]. Both studies demonstrated the utility of support groups for young adults and their parents, while the patient is preparing for or is currently transferring care.

• **Navigator or transition coordinator**

Several studies have reviewed the use of a system navigator or transition coordinator to aid transition [25,42,43,51]. In this model, transition-aged individuals are assigned a professional who helps guide the transition process. The duties of the navigator have included scheduling appointments and tracking the patient to ensure follow-up. The navigator also contacted the patient by phone periodically to review the following: medical and education information, presence of chronic complications, hospitalizations related to diabetes and any barriers to accessing care.

Van Welleghem *et al.* [42] reviewed clinic attendance and compared adults who were paired with a navigator after the transfer of care had taken place to patients who were paired prior to the transfer of care. Of the patients that were already enrolled in adult care, only 59.4% attended visits prior to the navigator intervention. Of patients enrolled with the navigator prior to transition, 89.1% attended visits with their adult provider after transferring care.

Holmes-Walker *et al.* [43] reviewed the clinical significance of a transition coordinator with adolescents and emerging adults aged 15–25 years. This study demonstrated a reduction in HbA1c and hospital admission rates for DKA.

Reductions in HbA1c were 0.13% per visit across the first four medical visits. There was a statistically significant reduction in DKA-related hospital admissions; however, there was no significant change in number of readmissions (i.e., repeat DKA admits within 12 months). According to Holmes-Walker *et al.*, the cost of transition coordination was likely offset by the short-term cost savings [43].

Cadario *et al.* [51] reviewed the effectiveness of a structured transition process whereby a provider and a coordinator followed the patient through the transfer of care. The structured transition included preparation for transition a year in advance, written information explaining the process, a joint visit during transition and the pediatrician providing a summative report of diabetes care and management to the patient and adult provider to enhance transition. HbA1c improved in the intervention group at first visit and 1-year follow-up while it remained the same in the control group. Three years following transfer of care, the intervention group continued to attend visits at a significantly higher rate than the control group.

A similar promising intervention has used a structured transition intervention in a multicenter randomized controlled trial to review health outcomes for adolescents and emerging adults aged 17–20 years [25]. Studies such as these are needed to improve the probability of successful transition for adolescents and emerging adults.

• **Joint & transition clinics**

Clinics developed specifically to improve the transition process are another method designed to facilitate successful transition [52–54]. Joint clinics are typically comprised of pediatric and adult healthcare providers working together. Another type of transition clinic is an adult clinic staffed by healthcare providers who specialize in emerging adults. The team that comprises each clinic is somewhat unique and both types of clinics may offer multidisciplinary healthcare providers including physicians, dietitians, diabetes educators, nurses, social workers and psychologists. These clinics may offer evening hours and include after-hours phone support.

Gholap *et al.* [52] retrospectively studied a joint clinic by reviewing clinic attendance, glycemic control, screening for and prevalence of diabetes complications and hypertension. Their review found improved rates of attendance, BP screening and nephropathy and retinopathy screening when

compared with other studies of emerging adults. Logan *et al.* [53] developed a joint clinic followed by an adult clinic as a two-stage transition design. This study reported a relatively high (84%) attendance rate that was facilitated by a nurse who communicated with the patient between visits and tracked cancellations and missed appointments to ensure visits were rescheduled. HbA1c improved significantly across visits, screenings were performed more routinely, and adherence to treatment recommendations also improved. At the first visit 49% were on a basal-bolus regimen, which improved to 74% after 2 years of attending the transition clinic. Eagan *et al.* [54] also evaluated the potential impact of a joint clinic, which incorporated the use of a transition coordinator as well as joint meetings between pediatric diabetes educators, adult nurse practitioners and their patients. Findings indicated that patients involved in the transition clinic evidenced a high rate (100%) of follow-up attendance at both 6- and 12-month appointments but no associated change in HbA1c values.

Another transition program included a therapeutic education program studied by Vidal *et al.* [55]. This program focused on preparing the individual for transition and coordinating the initial visit with the adult clinic to enhance the transfer of care. Follow-up visits also included a professionally led group with other patients with Type 1 diabetes and their relatives. The therapeutic education program included 3–6 months of monthly medical visits, depending on the needs of each individual. Upon discharge from the program, they were scheduled with adult healthcare providers for routine follow-up. The study reported no change in meal plan composition and no differences in total daily insulin dose. However, participants demonstrated increased use of rapid-acting insulin, increased diabetes knowledge and decreased HbA1c.

Taken together, these specific interventions and programs, and others [56] symbolize increased efforts to successfully transition youth with Type 1 diabetes from pediatric to adult care. Although some of these programs have evidenced success, more evaluation is needed before firm conclusions can be drawn.

Discussion

Similar to transition studies in other countries [57] and across disease type [58], there are substantial limitations to the US research on diabetes transition and, thus, less-than-adequate

empirical support to inform transition recommendations and the design of transition programs. Extant studies in this area have seldom utilized randomized controlled designs and have frequently relied on observational approaches and retrospective analyses. In addition, programs that have evidenced improvements in youth health outcomes have demonstrated only small effects. Furthermore, the particular mediators and moderators of effective transition programs remain untested and are thus unclear. For example, which specific components have caused youth behavioral changes and associated health improvements? There is also uncertainty regarding whether it is most efficient to target the behavior of pediatric providers, adult providers or caregivers to improve transition. In addition, transition program outcome research has failed to identify the specific age or development stage at which specific programs are most effective. Another issue with the current state of the literature is that there are few if any longitudinal studies which have examined whether positive outcomes of transition programs may extend into adulthood. Given that these issues remain largely unknown, it is imperative that future studies utilize more sophisticated methodology and follow study participants longitudinally.

• Recommendations

Successful transition programs will likely require changes across all relevant systems (e.g., family, provider, healthcare system) in which youth are embedded. Although extant recommendations remain largely untested, the following recommendations are derived from the available literature, are organized by care system and are consistent with the challenges faced by transitioning youth with Type 1 diabetes. Please reference **Box 2** for a complete list of recommendations.

Patients/families

Patients and families would benefit from recommendations regarding how to best shift increased responsibility for diabetes management from parents to youth over time. For example, it would be useful for youth with diabetes to gain practice in scheduling appointments and ordering medical supplies while still seeing their pediatric provider and under caregiver supervision. Successful transition planning should also involve identifying key players outside of the home (e.g., friends, teachers, coaches and coworkers) who can support youth in becoming

Box 2. Summary of transition recommendations.

Patient/family

- Youth should gain practice scheduling appointments and ordering medical supplies while still in the care of their pediatric provider and under the supervision of caregivers
- Successful transition planning should involve identifying and recruiting key players outside of the home who can provide support, such as friends, teachers, coaches and coworkers
- Some families may require formal coaching and problem-solving related to the transfer of diabetes management responsibility
- Caregiver involvement throughout the transition process will likely be beneficial for most adolescents and emerging adults

Pediatric providers

- Conversations with youth and families about the transition process should begin earlier rather than later
- Families should receive educational information regarding the importance of the transition process. The information should include topics most salient to adolescents and their families (e.g., insurance, college education, access to supplies, increased autonomy)
- Pediatric providers should assume responsibility for facilitating adolescent appointments that include portions of the session alone with the adolescent. A gradual process of increasing adolescent independence will facilitate developing the independent communication patterns needed in adult care settings
- Youth and their families must receive adequate education regarding the importance of planning ahead for the eventual transfer of care
- Youth and their families must receive information regarding transition-related topics salient to the unique needs of the adolescent and family (e.g., insurance, college education, access to supplies, increased autonomy)
- Pediatric providers often have the knowledge and understanding of the patient to best recommend an adult provider to serve the patient's individual needs
- Pediatric providers should directly communicate factors pertinent to the youth's healthcare (e.g., developmental status, mental health, systemic supports, barriers to self-care) with the planned adult provider
- Although not always possible, pediatric providers should facilitate an introductory meeting between adolescents who are transferring care and a suitable adult provider, while the adolescent is in pediatric care
- Pediatric providers should recommend the formal services (e.g., psychology, social work) that may be required for successful transition. Some youth and families may require specialized services
- Conversations with adolescents and families about issues of transition should begin at the onset of the provider/patient relationship and should include ongoing intermittent conversation tailored to the needs of the family and the psychological and developmental needs of the patient
- Pediatric providers may find benefit from using standardized transition checklists to inform and guide needed education and care, and communicate unmet needs to the new adult provider

Adult providers

- Adult provider care can be enhanced by considering the developmental status and unique life circumstances of emerging adults and tailoring recommendations accordingly
- Close collaboration between adult and pediatric providers and/or being housed in the same clinic may also promote successful transition
- To best address the needs of emerging adults, adult providers should consider, extended clinic hours, more time for appointments, increased use of technology and written materials focused on the challenges and issues unique to this age group
- Some adult providers may benefit from additional training to become comfortable addressing the unique needs of young and emerging adults
- Adult clinics may find benefit from using standardized transition checklists to inform and guide needed education and care
- Adult clinics may benefit from establishing a specialized position (e.g., social worker, case manager, care coordination specialist) with time dedicated to following up with emerging adults who have missed appointments

Healthcare systems

- Youth with diabetes, their families and their providers would benefit from increased support for transition efforts by hospitals, payers and overarching healthcare systems
- Evidence suggests financial benefit would result from efforts to change inefficient systems designed for immediate financial benefit without considering the long-term cost benefits of preventative transition-related care. Specifically needed is an investment in up-front costs for systems to facilitate the smooth and timely transition of care, which will improve long-term health outcomes and financial return
- Billing systems should be modified to allow for payment for the provider time necessary to facilitate the timely and efficient transition to adult care
- Hospitals, medical schools and training programs should place increased emphasis on preparing future and current providers to most effectively facilitate transition to adult care

Research

- Further funding of longitudinal randomized controlled clinical trials is needed to determine the most effective means of facilitating the transition process

more independent. For some families providing basic education regarding how to best transfer diabetes management responsibilities to youth will likely be enough. However, other families may require more formal coaching and problem-solving. Regardless, recommendations for caregiver involvement throughout the transition process will likely be beneficial for most adolescents and emerging adults.

Pediatric providers

Youth in transition should be treated like emerging adults, as opposed to children or older adults, and providers should tailor care to the unique needs of each patient, as opposed to a one-size-fits-all model. Given that roughly half of parents reported never having discussed transition with their child's physician [59,60], conversations with families regarding the transition process should occur earlier in the course of care. We posit that provider conversations about issues of transition should be initiated at the onset of the provider/patient relationship and should include ongoing intermittent conversation tailored to the needs of the family and adjusted to address the psychological and developmental status of the patient.

In addition, transition-related discussions should be comprehensive. Over the course of care, youth and their families must receive adequate education regarding the importance of planning for the transfer of care and about transition-related topics salient to patients' and families (e.g., insurance, college education, access to supplies, increased autonomy; [39]). Furthermore, youth need the opportunity to meet individually with their healthcare provider prior to the transfer of care to practice independent communication in preparation for doing so in adult care settings. Pediatric providers should assume responsibility for facilitating appointments that include time independent, private, communication with the adolescent. Given the unique knowledge of the patient acquired through the patient/provider relationship, pediatric providers are in the unique position to best recommend an adult provider who best serves the patients' needs. As concluded by Turner *et al.* [61], patients would likely benefit from pediatric providers identifying appropriate adult-focused providers prior to transition. In addition, pediatric providers should also ensure that they have communicated with future adult providers regarding factors pertinent to the youth's health (e.g., developmental level,

mental health, systemic supports) and should help facilitate older adolescents' and emerging adults' initial meeting with their adult provider while still in pediatric care. Pediatric providers should assess which formal services are necessary to assure successful transition. Some youth and families may require specialized services (e.g., psychology, social work) to prepare for and apply the necessary strategies to ensure effective transition.

Adult providers

Given known differences in models of care found in pediatric and adult care settings, emerging adults would benefit from adult programs tailoring care to better address developmental issues important to the emerging adult. As such, adult providers would ideally provide a different level of care to recently transitioned emerging adults than they may provide to those in middle adulthood. This may require appointments of longer duration to provide the more personalized visit needed to address the developmental needs of this group. Consistent with study findings [62], adult providers may benefit from being mindful of how their recommendations fit with their patient's developmental level and unique life circumstances. In addition, having adult and pediatric providers housed in the same clinic may also promote successful transition [62]. Other suggestions for adult clinics include extended clinic hours, more time allotted for initial appointments, increased use of technology to enhance frequency of communication and written materials focused on the specific challenges unique to the developmental period corresponding with transition. Some adult providers may benefit from additional training to become comfortable addressing the unique needs of young and emerging adults. A practical requirement for adult clinics would be to use standardized transition checklists to inform and guide needed education and care. Adult clinics may also benefit from establishing a specialized position (e.g., social worker, case manager, care coordination specialist) with time dedicated to retaining emerging adults in care by following up with those who have missed appointments.

Healthcare systems

A necessary key to successful implementation of the available recommendations is changing financially driven systems that penalize

healthcare providers for improving the quality of patient care. To conform to the aforementioned recommendations, medical providers need to feel financially and instrumentally supported by the healthcare system in which they are embedded. Youth with diabetes, their families and their providers would benefit greatly from an increased emphasis by hospitals, payers and overarching healthcare systems in support of transition efforts. Evidence suggests financial benefit would result from efforts to change inefficient systems designed for immediate financial benefit without considering the long-term cost benefits of preventative transition-related care. Specifically needed is expenditure in up-front costs for systems to facilitate the smooth and timely transition of care, which will lead to improvements in long-term health outcomes and significant financial return. One form of support would be for payers to establish means for healthcare providers to bill for the time devoted to issues of facilitating transition. Another option would be to require that transition discussions occur for all adolescent appointments (aged 12–20 years), making these conversations as routine as assaying HbA1c or downloading meter readings. In order to most effectively facilitate transition, hospitals, medical schools and training programs should place increased emphasis on training future and current providers on the issues of transition. In the absence of increased funding, one possible means of maximizing service provision while maintaining low costs would be to more frequently support provider technology use (e.g., eHealth, mHealth) to improve diabetes-related outcomes (for a recent review, see [63]). Given the unique difficulties associated with caring for emerging adults, special certifications and associated fee increases for treating emerging adults may be warranted.

Conclusion

Notable limitations of the current system suggest the need for a broad and systemic overhaul. There appears to be a need for a paradigm shift regarding how development is conceptualized and thus a corresponding shift in models of healthcare delivery. The needs of emerging adults require the development of a multifaceted program aimed at addressing the needs of this particularly vulnerable and important population [20]. Given the challenges unique to providers and families, an increased emphasis

on provider-based learning programs and family systems approaches seems warranted. However, changing how providers and parents interact with patients are pieces of the larger puzzle of successful transition. In addition to systemic changes in the provision of care, more funding should be allocated to studying transition and to developing and evaluating transition intervention programs. Such funding would be consistent with the triple aim in healthcare with the purposes of improving the health and care received by youth with Type 1 diabetes during transition and will likely reduce long-term costs associated with poor adherence and inconsistent utilization of preventative care.

Future perspective

Managing diabetes is difficult, and problems are known to increase during the developmental period associated with transition from pediatric to adult care. To effectively address these difficulties, funding of ongoing clinical research to evaluate and identify approaches that are most effective is an imperative. Given the presence of significant financial disincentives within US healthcare systems to implementing transition programs, the future of transition program development is currently dependent on research demonstrating the financial benefits to insurers and other payers. Broad and meaningful system changes will only occur when the necessary efforts can be reimbursed. Fortunately, the process has begun and relevant empirical research and associated literature has been increasing to support the value of addressing transition-related issues. The future holds promise; increased recognition of the difficulties associated with transition, recent changes in US healthcare systems, improved understanding of the unique developmental period of emerging adulthood and increased provider awareness and education have all begun to contribute to meaningful changes in the transition process. Increased efforts are needed by all relevant healthcare professionals with the goal of improving the transition process. The structure and form of future transition programs are dependent on emerging research and efforts to inform progress. The ongoing improvements in transition awareness will translate into a future of improved health outcomes and quality of life for individuals with diabetes who will be transitioning from pediatric to adult healthcare settings.

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