

52

Diabetes in Adolescence and Transitional Care

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Keypoints

- Adolescence is characterized by significant and complex biological, social and psychologic changes that occur during the teenage years.
- Adolescents with diabetes establish a long-term positive bond with their pediatric health care team. Consequently, the transition to an adult diabetes service provider is a significant event.
- Adolescents are at risk of dropping away from health care professional contact and follow-up during the time of transition, which may be detrimental to their physical and psychologic well-being.
- Adolescents need support to anticipate the issues they may face when preparing to move from children's services and to identify the solutions that may be available to them.
- The transition must be carefully managed so that the adolescent does not need to make an abrupt adaptation in their move from an environment that is very supportive to one where they are expected to be more independent.

Introduction

Adolescence is a life stage characterized by transition and change regardless of health status. Diabetes in adolescence is a life-changing condition requiring diligent and consistent management by a multidisciplinary team of clinicians in addition to comprehensive care and support provided by the family unit. Many young people with diabetes establish a long-term positive bond with their pediatric health care team. Consequently, the transition to an adult diabetes service provider is a significant event. The seamless transfer of adolescents with diabetes from pediatric to adult services can also be a challenge for health services and clinicians. Young people may mourn the loss of the relationships they had with the pediatric health team and can become distressed about learning to trust new staff [1]. There is evidence to suggest that during the time of transfer, adolescents are at risk of dropping away from health care professional contact and follow-up which may be detrimental to their physical and psychologic well-being [2]. As a result, it has been estimated that 10–60% of adolescents do not make the transition successfully from pediatric to adult health services [3,4]. The purpose of this chapter is to enhance understanding of the key issues presenting for adolescents and clinicians, and to consider effective models of care that will facilitate seamless transition from pediatric to adult diabetes care.

Transition

Transition is the reorientation that people experience to a change event [5]. Events that change our lives occur constantly, but they often go unnoticed, unless we are disrupted by them. These are “change events” that produce an end to one's familiar way of living and require the individual to find new ways of being in the world that incorporate those changes. Change is situational, such as a move to a new job, a new city or a new school. Transition is the way people respond to the changes that are occurring in their lives.

Transition involves moving through the change situation and negotiating one's sense of self in an altered world [6]. Transition is the movement people make through a disruptive life event so that they can continue to live with a coherent and continuing sense of self [7]. Understanding transition involves exploring the person's responses to a passage of change. Health care professionals are frequently in the position of supporting people who are in transition because of the changes associated with the impact of illness.

During the last three decades, the concept of transition has evolved in the social sciences and health disciplines, with nurses contributing to more recent understandings of the transition process as it relates to life and health [8–15]. Transitional definitions alter according to the disciplinary focus, but there is broad agreement that transition involves the way people respond to change. Transition occurs over time and entails change and adaptation, for example developmental, personal, relational, situational, societal or environmental change, but not all change

engages transition. Transition is not an event, but rather the inner reorientation and self-redefinition that people go through in order to incorporate changes into their lives [5].

The transition focused on here when discussing adolescent transfer to adult services is when one “chapter” of life is over and the person is unable to go back to the way life was before the change event occurred. The change event under particular focus is the shift to a new and unfamiliar service environment. To enable a “new chapter” to begin these adolescents will need to respond to the changes in their lives, sorting out what can be retained of their former way of living and what has to be released, in order to move forward [15]. This is often the experience of the adolescent moving from child to adult health services. Understanding transition theory will enable health care professionals to assist young people to make this transition during a life stage that is characterized by constant change.

Transition as a process

The terms “transition” and “transfer” have been used interchangeably in the literature when referring to adolescents moving between diabetes services. As a consequence, transition may be interpreted as simply a process of physical transfer to a different service with a failure to acknowledge the psychosocial needs of the adolescent and family members. This oversight may have resulted in a lack of resources to assist the adolescent and parents to make the psychosocial transition between children’s and adult services [1]. A clear distinction between the concepts of transition and transfer is needed.

When people experience transition, they look for ways to move through the unfamiliar to create some order in their lives so they can reorient themselves to the new situation [5]. Transition can involve much trial and error, as people work out ways of living and being in their changing world. When young people are learning to live with a chronic illness such as diabetes they are involved in that transitional process. Over time these people redefine their sense of self, redevelop confidence to make decisions about their lives and to respond to the ongoing disruption that so often accompanies chronic illness. When undertaking the work of reclaiming their sense of self and identity, they come to an understanding of what is changing, or has changed in their lives and how this reality is shifting key values and identity markers.

The transitional process takes time, however, as the adolescent will disengage with what was known and familiar and look toward the altered and new situation that lies ahead. At this point it can be helpful for the person to connect with others they can trust. A familiar health professional, support group, a friend or a family member who is a good listener becomes an important asset in the sense-making process. Without such examination of the change event or events, people’s understanding of what is changing may be limited. This is particularly the case for adolescents who are engaged in major change in all areas of their lives. For many adolescents, leaving the care of their pediatrician and other familiar health care professionals is a passage from security to uncertainty [16]. These young people need time to examine their

perceptions and experiences and to consider the actions that they need or want to take. Adolescents will need support to anticipate the issues they may face when preparing to move from children’s services and to identify the solutions that may be available to them. This is a key point in enabling successful transition for adolescents moving to adult diabetes care.

Adolescence as a time of transition

Adolescence is a transitional stage of human development that occurs between childhood and adulthood. This transition is characterized by significant and complex biologic, social and psychologic changes that occur during the teenage years. During this time the adolescent is developing a sense of self and identity, establishing autonomy and understanding sexuality. Adolescence is a stage of life where control–autonomy–dependence are pertinent issues in the lives of young people [16]. There is often anxiety experienced by the adolescent regarding acceptance by peers which may also impact self-care behaviors.

The events and characteristics that mark the end of adolescence and the beginning of adulthood can vary by culture as well as by function. Countries and cultures differ at what age an individual can be considered to be mature enough to undertake particular tasks and responsibilities such as driving a vehicle, having sexual relations, serving in the armed forces, voting or marrying. Adolescence is usually accompanied by an increase in independence allowed by the parents or legal guardians and generally less supervision in daily life. This is true too of adolescents transferring to an adult care service. The intention is to ensure that the adolescent has the practical and cognitive skills required for diabetes self-care and has developed the capability to interact with others such as health care providers; however, age itself may not be a reliable indicator, as adolescents may have different needs and developmental issues at different stages and mature at different rates. The parents of the adolescent must also be prepared to relinquish some of the responsibility for diabetes care which they may have undertaken with a high degree of vigilance for many years. For some parents, this shift in responsibility can be a time of high anxiety. Fundamental to any successful transition program is the work with parents to help them find a balance between shifting the responsibility to the adolescent and continuing to maintain an appropriate level of interest and family cohesion [4].

Adolescence and diabetes

Type 1 diabetes mellitus (T1DM) is the most common metabolic disease that affects children [17]. It occurs when the pancreas is unable to produce insulin. Treatment consists of at least twice daily insulin injections in order to prevent serious short and long-term complications. In addition, children and their families need to ensure that an appropriate diet and lifestyle is followed and blood glucose levels are closely monitored [17].

For an adolescent with diabetes, the rapid changes in physical, sexual, psychologic, social and cognitive function that occur with adolescence can often lead to a decline in self-care behaviors. Glycemic control during adolescence can be suboptimal [18] because of a number of factors such as the physiologic changes associated with puberty [19], a desire to be perceived the same as peers, poor adherence to insulin regimens and decreased attendance at diabetes care clinics [2]. Irregular attendance at clinics has been associated with poor glycemic control and increased rates of diabetes-associated complications [20].

Adolescents who live with T1DM may experience the transition from the children's to the adult health service as an additional burden over and above the everyday challenges of becoming a young adult because achieving glycemic control may have a significant impact on daily life [21–24]. Clinicians working in both children's and adult services have raised concerns that young people transferring between services often fall through service gaps. Scott *et al.* [4] found that 90% of adolescent survey respondents had felt “lost in the shuffle” when making the transition from pediatric to adult diabetes services.

Adolescence is a time when many young people have not received adequate follow-up until a crisis has forced them back into the system [1,3,21]. Transition in this context was defined by Blum *et al.* [25] as “the purposeful, planned movement of adolescents with chronic physical and medical conditions from child-centred to adult-orientated health care systems.” This definition has been widely applied within a wide spectrum of clinical practice, guidelines and research studies and focuses on the passage between two points within the health care system. The authors contend, however, that a broadening of this definition is needed because the adolescent's transitional process of inner re-orientation also has to be considered in order to provide holistic care.

A systematic review conducted by Fleming *et al.* [21] highlighted the need for collaboration between children and adult services, particularly in light of the well-documented differences between these services [22,26–28]. Some of the differences between services have been identified as decreased parental involvement in adult services and significant differences in clinical practice and culture [29]. While it has been acknowledged that it is necessary for the children's and adult services to have different foci, it is argued that collaboration is needed to help bridge the gap so that transition is experienced by the adolescent as a smoother process [21,22].

Transition in the diabetes care setting

The process of transition in the diabetes care setting involves both the physical transfer of an adolescent from one health care setting to the other (pediatric to adult) as well as the acquisition and practice of self-management skills and the shift of responsibility of care from parent to adolescent. Transition therefore is not only the physical transfer of an individual moving between health

services, but also the environmental, emotional and psychologic factors that are encompassed in this process. Transition is a progressive process that involves patient, health care provider and family or carer and effectively commences, in one dimension or another, once a child is diagnosed with diabetes.

Components of transition

It is useful for the purpose of understanding the complexities of transition to investigate the tasks that are accomplished when transition is successfully achieved. Successful transition involves the accomplishment of a number of tasks, as follows.

1 Acquisition and practice of self-management skills. The pediatric model of care assumes that young people lack the necessary practical and cognitive skills to undertake some of the tasks imperative to daily diabetes management, such as managing food intake, as well as the broader diabetes management tasks such as interacting with relevant health care professionals and keeping up-to-date with current knowledge. The process of transition involves the acquisition and practice of these skills by the patient, independent of parent or carer.

2 Acquisition of skills necessary to maximize utility of the adult health care system. Skills such as self-advocacy, the ability to find and negotiate services and knowledge about general young adult health issues such as substance abuse, mental health, exercise and sexual health prepare the adolescent for self-care [30].

3 Shift of responsibility of care from parent to individual. Responsibility of T1DM management must shift from the parent to the adolescent while maintaining an appropriate degree of parental interest and family cohesion [21,31]. Pediatricians who inappropriately foster persistent parental involvement risk promoting dependency in the patient [32]. It is important to note, however, that a shift of responsibility in diabetes management may be perceived as threatening by parent and patient and may result in feelings of neglect and anxiety. Therefore, both too much parental focus and too early a dismissal of parental responsibility can be disadvantageous to the transition process.

4 Internalization of concept of illness. Prior to transition, it is likely that responsibility of T1DM management belonged to one or both parents of the young person. Transition involves the shift of responsibility of care from parent to individual, and this shift may trigger or complete the process of internalization (consolidating and accepting illness), offsetting the degree of displacement that is implicit when responsibility of care does not belong to the patient themselves. Consequences of internalization can include loss of identity and subsequent reframing of identity at a time when identity is fluid and in the process of development, and loss of control and personal power, which is important for self-esteem. Again, this occurs during a developmental period when the individual may be struggling with self-esteem issues, because of physical changes and changes in peer significance.

5 Integration of T1DM management tasks into emerging lifestyle. In general, the period during which transfer occurs is a time when the adolescent or young adult is adopting a new lifestyle, for

example, leaving secondary school, moving – economically, geographically and emotionally – from the parental home, entering the workforce, attending university or traveling [31]. The adolescent or young adult must learn how to integrate their daily T1DM management tasks into their emerging new lifestyle.

6 Physical transfer to an adult health care system. The physical transfer to adult health care services requires the implementation of a specific set of diabetes management skills and knowledge as well as negotiation and self-advocacy skills that are not assumed in the pediatric health care system.

Adolescent needs during transition

Rarely have young people been asked what their needs are during transition. This is surprising given that the transition between diabetes services often occurs concurrently to the time of significant change in the adolescent's life.

A qualitative study undertaken by Visentin *et al.* [33] found that adolescents focused on the medical transfer of care during transition. The focus on medical care may be because many adolescents had not regularly seen any other health care professional. Adolescents stated they were interested in being introduced to the diabetes nurse educator and dietitian at the adult services [33]. Kipps *et al.* [3] reported a higher rate at attendance of adult services when the adolescent had met a member of the adult team before transfer which signifies the importance of prior contact and collaboration.

The precise needs of adolescents will vary according to culture and circumstances [34] and so research at the service level will be required to ensure services are tailored to need. Flexibility seems to be the key, because young people may be ready to transfer to adult services at different times, dependent on their cognitive and physical development, emotional maturity and general health [34]. The role of health professionals in this process is to tailor advice to young people based on their developmental and cognitive level [29].

During this transitional process, adolescents with diabetes need a shared understanding of their needs from their health care provider. This requires consultation with adolescents themselves [33], planning, ongoing contact and feedback between care providers in the two health care systems, and evaluation of services [35].

Promoting self-care

Promoting better management for adolescents with T1DM by developing their capacity to self-care through healthy choices prior to transition to adult services is an optimal goal. Gradual and early promotion of self-care is particularly important during adolescence when young people may try to act out behaviors in order to demonstrate independence. A cross-sectional multisite study of adolescents was conducted with 130 young people, studying factors that affect blood glucose control, such as how they care for themselves, eating problems, relationships, depression

and health issues [36]. The research found that poor self-care, disturbed eating behavior, depression and peer relations were all associated with poor blood glucose control. Where there were good family relationships and support from parents, girls achieved better control than boys. The researchers suggest that further research should look at the reasons behind these relationships. The authors propose that monitoring of diabetes knowledge and promotion of self-efficacy from late childhood may optimize the transfer of self-care knowledge and behaviors from parents to adolescents [36].

Adolescence and young adulthood is characterized by a number of cognitive, emotional, behavioral and social changes that can present as barriers to effective self-management, including engagement with health care services. Cognitive changes include a shift in thinking from concrete to abstract and the ability to engage in introspection. These new cognitive skills give the ability to reflect on self-identity (self-concept and self-esteem). Adolescence is also a time of experimenting with new behaviors and, in particular, risk-taking behaviors. Socially, the importance of peers significantly increases at this time and concerns with being accepted by peer group are strong.

Successful transition can only be facilitated by provision of appropriate services, programs and resources. Long-term success is heavily dependent on instilling adequate self-care behaviors and self-advocacy skills so that adolescents can deal appropriately with external factors such as home, school and work life which may present as obstacles to effective diabetes management.

Education programs to promote self-care

A powerful predictor of good self-care is self-efficacy. For the purposes of this chapter, self-efficacy can be seen when adolescents have confidence in their capability to make decisions and take actions that demonstrate diabetes self-care. Education programs that enhance self-efficacy by incorporating personal health care goals and social and peer support have been shown to improve health outcomes and facilitate smooth transition in adolescents and young adults with T1DM [30]. Cook *et al.* [37] describe a pilot study demonstrating how the problem-solving behavior of adolescents with T1DM was improved through participation in a workshop style education program. The Choices Program consisted of six small weekly group workshop style sessions where adolescents came together to discuss major diabetes management problems, including psychosocial issues, and work together to identify solutions. This program demonstrated an increase in the practice of diabetes health care behaviors such as blood glucose monitoring and exercise. Cook *et al.* [37] identified three principles that are key to the success of an education program: parental involvement, integration with clinic (e.g. to allow implementation of regimen changes) and six or more sessions plus multiple follow-up and review sessions.

Education programs should be based on current learning and behavior change theories and should be developed with these key principles in mind. Furthermore, education programs should be

part of standard care as well as specific elements in formal transition care programs.

Barriers and facilitators to successful transition

Many authors emphasize the need for collaboration between pediatric and adult diabetes services so as to create a smooth transition for adolescents [1,21,23,28,32]. These authors recommended that transition should be planned and coordinated [21,23,28,32]; however, the reality is that unless there is a transition program in place, adolescents transfer to adult services in an ad hoc manner with little planning, consultation or case management [33]. Hence, the absence of guidelines for the development, implementation and evaluation of transition programs must be viewed as a significant barrier to successful transition. Authors from Australia, the UK and the USA have called for the development of national policies that inform transition for adolescents with chronic conditions [1,21,23,28,32]. More recently, countries such as the UK, Australia and Canada either developed or made progress around developing standards and guidelines for policies in order to improve transition outcomes and experiences. For example, Diabetes Australia – Victoria is undertaking a project to develop a state-wide coordinated transition system for individuals living with T1DM. In addition, some professional organizations have developed best practice guidelines to inform the care of adolescents transferring to adult services. The successful translation of these guidelines into practice, however, remains unclear.

It has been acknowledged that transition to adult services can be difficult for a myriad of reasons. The most reported concern is the notable differences in the approach to care between children's and adult diabetes services. Children's services focus on the whole family and assume the child has little or no knowledge about diabetes and management. The adult sector take a more individual approach and assumes the patient has decision-making capacity and is knowledgeable about diabetes and has the necessary skills to navigate the complex health system [26,28]. In addition, adult services expect a much greater degree of independence from young people and encourage communication without parents being present. It may be difficult for adolescents to adapt to this type of relationship, particularly when they have had a long-standing relationship with their pediatrician [22]. The adolescent may experience significant difficulty if the pediatric health care provider has not recognized the need to up-skill the adolescent in self-care behaviors before transfer to an adult service. A helpful approach to assist adolescents to transition is to focus on the location of the actual aspects that are changing, then to explore how the changes are being experienced by the individual, followed by consideration of how the person is responding or may respond [15].

Adult service staff may make the assumption that the adolescent has the necessary skills and maturity to be able to plan their future and have the insight to understand the consequences if they choose not to undertake diabetes self-care [21,22]. Viner [1] argued that

adolescents are not served well by either model of diabetes care because the children's clinic may not acknowledge their growing independence while the adult clinic may not acknowledge their growth, development and family concerns. It has been recommended that transition be "a family affair" [27] and that transition in health care is acknowledged as only one aspect of a broader life transition that adolescents move through [1].

If the transition process is not meeting the needs of adolescents then they may choose to drop out of the system. While adolescents may continue to access a primary care physician for the prescription of insulin, it is thought that a multidisciplinary approach to diabetes care provides optimal management [38,39]. If diabetes is poorly managed, young adults are at an increased risk of microvascular and macrovascular complications as well as life-threatening acute complications such as diabetic ketoacidosis (DKA) [40].

The demands of diabetes may be experienced as difficult during the adolescent years and it has been documented that glycemic control at this life stage often deteriorates [21,22,41,42]. The deterioration in glycemic control is thought to be related to an increase in insulin resistance that relates to physiologic changes in puberty coupled with the psychosocial pressures associated with this period [41,42]. Of further concern, glycemic control in young people in the 16–25 year age group was found to be poorer than at other times during the lifespan [43].

The health professionals participating in the study of Visentin *et al.* [33] expressed concern about exposing adolescents to older people with type 2 diabetes, particularly if those older patients had obvious complications of diabetes such as amputations. Interestingly, adolescents claimed that such exposure was not an issue for them.

The experiences of adolescents with diabetes living in rural or remote areas have been rarely reported. There appears to be an assumption that adolescents have easy access to services; however, this may not be the case in many counties. In a study by Cameron *et al.* [44], adolescents in rural areas were found to have poorer outcomes than young adults from metropolitan areas, particularly in the areas of mental health, self-esteem and family cohesion. The authors considered a major factor in the differences in these outcomes was a lack of transition programs and other support services. Another factor was that adolescents with diabetes living in rural and remote areas may have less access to peers who also have diabetes, leading to a lack of peer support.

Models of transition care

While the literature has outlined principles for successful transition and made suggestions for model development, there is limited research that provides outcome data to support one model over another [1,3,30]. A study undertaken in the UK compared different models of transfer within one region using data generated through interviews and retrospective casenote review [3]. The models evaluated were:

- 1 Direct transfer to an adult clinic;
- 2 Transfer to a young adult clinic in a different hospital;
- 3 Transfer to a young adult clinic within the same hospital; and
- 4 Transfer to an adolescent clinic that was jointly operated by pediatricians and adult physicians.

The most significant declines in clinic attendance were observed when adolescents were either transferred to a young adult clinic in a different hospital or were transferred directly to an adult service. These adolescents were also the most dissatisfied with their care. Consistent with others studied, those adolescents lost to regular follow-up had higher mean HbA_{1c} levels. Variables such as socioeconomic status and geographic location were not included in the analysis. The authors concluded that transfer to a young adult clinic was preferable to direct transfer to an adult-only clinic and providing the opportunity to meet with staff from the adult service prior to transfer may improve outcomes [3].

Another UK-based study [26] surveyed adolescents who were attending an under 25-year-old-clinic. Interestingly, a high number of adolescents in this study did not report difficulties with transition; however, they did feel it would be helpful to have visited the clinic prior to transfer.

A study undertaken in Australia [45] surveyed adolescents aged between 15 and 18 years. The author concluded that a specific transition clinic can provide an important link and that transition needs to be a gradual process. Another study in Australia reported increased effectiveness when a coordinator worked with adolescents during the transition to adult care [46]. Schidlow and Fiel [27] discussed a transition clinic established in the USA where the pediatrician and adult physician conducted joint clinics in pediatrics as a stepping stone to the adult clinic. Unfortunately, there was no reported evaluation of this service.

There has been little qualitative research that has explored how adolescents experience transition. One recent Australian study researched the experiences of six young adults with cystic fibrosis using in-depth interviews [47]. The aim was to reveal the factors that contributed to the experience of transition and potential outcomes. A number of strategies were outlined that may improve the transition process with this patient group. These included a familiar face at adult clinics, orientation tours and the provision of written and verbal information as part of the transition program.

Table 52.1 provides a summary of the recommended stages of transition and includes specific recommendations for improving outcomes at each stage. Seven out of the eight stages of transition identified in Table 52.1 occur prior to transfer to an adult service and constitute the preparation phase (Phase 1). They focus largely on promoting self-care behaviors through education and practice. The stages are sequential, beginning at diagnosis and followed with a detailed introduction of the concepts of transition, assignment of a transition case manager, an assessment of the patient's diabetes and health knowledge, commencement of an education program, demonstration of learned skills and transfer to an adolescent/young adult transition clinic, where the young

person is given the opportunity to practice learned skills before transfer to an adult service.

Transition case coordinator

There is sufficient evidence to suggest that successful transition can be facilitated by utilizing a transition case coordinator (TCC) and that the cost benefits from reduced hospital admissions otherwise secondary to preventable complications can cover the cost of establishing and running a TCC program [30,46]. TCCs have also been successfully utilized within juvenile idiopathic arthritis transition programs. An evaluation of a transition program delivered to adolescents and young adults with juvenile arthritis revealed that TCCs are highly valued by both patient and parent [30].

TCCs can be any health care professional with a high level of knowledge of T1DM and its complications as well as knowledge and experience in dealing with adolescents. This includes diabetes nurse educators, diabetes educators, primary care physicians or diabetes specialists such as endocrinologists. One of the most important characteristics of a TCC is the ability to communicate effectively with adolescents and young adults, and one might suggest this as a priority over in-depth knowledge of the condition itself. Research has demonstrated that positive results can be obtained through administrative non-medical case management [48].

The fundamental role of the TCC is to support the adolescent or young adult in becoming their own effective lifelong case manager, by ensuring that an increase in the patient's confidence and skills is a priority of the health care system in which the patient resides. In order to improve health outcomes, TCCs need to be clinically sophisticated advocates of evidence-based care. The tasks of the TCC are to coordinate clinic appointments, follow-ups and appointments with allied health professionals and to ensure accurate adequate information is provided to the patient in a timely manner. TCCs are also responsible for facilitating the patient's engagement with relevant community health organizations. It is the role of the TCC to attempt to re-engage "drop-outs" by identifying barriers to engagement and offering to reactivate and facilitate a referral to an appropriate health care professional or diabetes clinic.

A recent 5-year evaluation of a transition care program in a Sydney-based hospital demonstrated that a TCC program can increase clinic attendance and reduce HbA_{1c} and DKA-related hospital admissions [46]. The transition care program consisted of a TCC (a diabetes educator) who followed up bookings and missed appointments and provided an after-hours sick day phone service. The program also involved a primary care physician and a diabetes specialist. The cost savings from reduced hospital admissions covered the costs of the program. Interestingly, the evaluation revealed that the potential to lose contact with adolescents and young adults is greatest in the first few months after referral; 9 out of 10 young adults (mean age 18) lost to follow-up only attended one appointment.

The effectiveness of an administrative-based non-medical TCC has been demonstrated through evaluation of the Maestro Project, an administrative support and systems navigation service

Table 52.1 Recommended stages of transition.

Action	Description	Stage	Age	Practical and psychosocial achievements	Factors that facilitate success
Diagnosis	Introduction of concepts of illness and care to patient and family/carer Mental health support Introduction of concepts of transition (if age-appropriate) Mental health review	1	NA	Patient and family/carer progress effectively through stages of grief Patient and family/carer understand physical and psychosocial effects of illness Patient and family/carer have a broad notion of the concepts of transition	Information provided at diagnosis should be thorough and of immediate relevance Delivery of information should be by a health professional who is contactable for questions at a later time Incorporate a mental health professional into the diabetes management team who can facilitate understanding of psychosocial impact of illness
Introduction	Introduction of concepts of transition Interactive discussion with input from adolescent and parent, and case manager (see below)	2	12*	Dissemination of patient information First draft transition care plan	Transition care plan should consider and address age, gender and cultural issues
Case coordinator	Appoint a transition case coordinator to coordinate aspects of the process and act as key contact	2	12*	Professional relationship with adolescent and parent	Case coordinator should have significant knowledge of mental health and adolescent-specific issues
Knowledge assessment	Assessment of diabetes knowledge and self-management skills Mental health review	3	12–13*	Second draft care plan, incorporating outcomes of assessment, education goals and mental health review Address any mental health concerns	Transition care plan should consider and address age, gender and cultural issues
Education program	Basic diabetes management Skills development	4a	13–15*	Learning	Group education including peers and family/carer
	Advanced diabetes management Adolescent-specific and general health issues Dietary review Solo consultations (in part)	4b	13–15*	Self-efficacy, problem-solving Gaining independence Active participation in care with parents/carer Solo consultations with parent/carer involvement at end of consultation	Parental/peer involvement Integration with clinic Six or more sessions plus multiple follow-up and review sessions

Continued on p. 882

Table 52.1 *Continued.*

Action	Description	Stage	Age	Practical and psychosocial achievements	Factors that facilitate success
Demonstration	Demonstration of learning outcomes	5a	15–17*	Internalization of concept of illness is complete Adolescent is self-managing Adolescent is self-advocating Solo consultations (with parent/carer involvement at end of consultation if deemed necessary) Responsibility of care has shifted from parent to adolescent/young adult	Final diabetes management plan should align health care goals with other life goals
Transfer to adolescent/young adult clinic	Decide on suitable model of transfer, i.e. private vs. public, transition clinic vs. adult clinic Establish adult diabetes management team	5b	15–17*	Third draft care plan incorporating developed skills and health care goals with patient input Professional relationship with adolescent/young adult transition clinic staff, implying multiple visits to transition clinic	Transition clinic staff met prior to transfer First appointment arranged by transition case manager and followed-up Any issues identified addressed immediately
Transfer to adult service	Physical transfer to adolescent/young adult transition clinic to enable patient to practice acquired skills	6	15–25*	Solo consultations Demonstration of acquired skills	Adult staff met prior to transfer First appointment arranged by transition case manager and followed-up Any issues identified addressed immediately
Support, follow-up and evaluation	Physical transfer to chosen adult care provider	7	*	Physical transfer to chosen adult care provider	Adult staff met prior to transfer First appointment arranged by transition case manager and followed-up Any issues identified addressed immediately
	Transition case manager provides support and follows up with adolescent/young adult to discuss transition, concerns, etc.	8	*	Minimum 6-monthly follow-ups (2 per year) for 2 years post-transfer	Use multiple vehicles for follow-up, including formal letters via post, telephone calls and SMS reminders

* Age is indicator only. Progression to subsequent stage should occur when it is deemed appropriate by health professional, patient and family/carer.

available to adolescents and young adults aged 18–35 years with T1DM in the province of Manitoba, Canada [49]. The program, Building Connections: The Maestro Project, commenced in 2002 and consists of biannual telephone and email contact by the Maestro, a non-medical TCC who facilitates connections and appointments with relevant health care professionals and follows up bookings and missed appointments. The program also consists of a website through which program participants can locate local services and other relevant educational materials, an e-newsletter, a casual evening drop-in support group and evening group educational dinner events.

The Maestro Project's 2007 Annual Report reveals that the program has significantly increased engagement with health care services. Of the 101 young adults who were referred to the Maestro Project after they had been transferred to an adult service, medical engagement increased from 59.4% having had one or more visits to an endocrinologist to 73.3% after 1 year in the program. Engagement with a diabetes educator also increased, from 25.7% having had one or more visits, to 41.6%. The program has dramatically reduced drop-out rates in the province, from 40.6% to 10.9% [49]. The Maestro Project is one example of how even basic administrative non-medical transition case management can improve outcomes for adolescents and young adults, in terms of increasing their engagement with the adult health care system.

Successful transition: an adolescent perspective

Many studies have identified factors expressed by adolescents and young adults as important for successful transition. A study by the Royal District Nursing Service Research Unit in South Australia [33] revealed that factors most important to adolescents and young adults include feeling secure, safe and trusting (of health care professionals), gaining independence and being able to access accurate and up-to-date information easily. Additionally, earlier discussions on transition and meeting adult staff prior to transfer are two steps that have been consistently reported by adolescents and young adults, not only in the diabetes health care sector but across many chronic illnesses including cystic fibrosis, juvenile rheumatoid arthritis and sickle cell disease [50]. Studies by Court [45] and Scott *et al.* [4] identified several factors as important to adolescents and young adults progressing through transition (Table 52.2). Furthermore, study participants have identified that endocrinologists, dietitians and primary care physician were the top three most important health professionals to have at a transition clinic [4].

Transition in practice

The most effective approach to the transition process is one that is organized and sensitive to the needs of the individual adolescent and family. There is evidence to suggest that a health worker dedicated to facilitate transition between services can have a positive impact on young people [29]. Adolescents in transition from

Table 52.2 Factors that facilitate transition to adult services.

Preparation process

- Earlier discussions surrounding transition
- Autonomy and self-direction – 71% of study respondents wanted to set goals with their adult health care team [4]
- Important education topics
- Research
- Stress management
- Financial assistance
- Cooking
- Complications (without direct exposure, as occurs in adult clinics)

Consultation and staff issues

- Visits to adult clinic prior to transfer
- Longer initial meetings with adult center staff
- Ability to talk about personal issues
- Continuity of care

Transfer and clinic environment

- Clinics not located in a hospital setting
- Ideal young adult clinic ages 18–30 years and separate from adult clinic
- Evening clinics and opportunities for “drop-in” appointments
- Interaction with peers and peer support

children's to adult diabetes services are involved in a period of critical but forced change. There are variations in the way adolescents engage or fail to engage in transitional processes. For example, adaptation to change often involves undertaking a process of trial and error [10] so that individuals can determine and understand the ways they are responding to change. Sometimes when young people undertake a process of trial and error, health workers may consider that they are engaging in risky behaviors. This may create a problem-orientated approach for adolescents rather than a preventive model of care that may inhibit the promotion of self-care.

Dalton and Gottlieb [51] explored the concept of readiness to embrace change, which they argued was often linked with a person's compliance to a medical regimen. By contrast, previous research revealed that living with long-term illness appears to be about incorporating the consequences of illness into everyday life [10,52]. Dalton and Gottlieb [51] provided an alternative view that conceptualized readiness as a process of *becoming* ready over time. Readiness to change was embedded within a process of learning. Baker and Stern [53] described a process of readiness that involved making the illness a part of life and coming to terms with self-care teaching and having a sense of control. Relationship-building between health care professionals and adolescents, as a means for mapping individual context and identifying shifting values over time, dealing with difference and miscommunication, is perhaps the first step to facilitating this transition.

There have been a number of studies that found that adolescents were keen to receive written and verbal information about transition and that they wanted to be provided with opportunities to meet the new team prior to transition [3,26,45,47]. It is neces-

sary for a transition model to take into account the stakeholders' views (professional, parents and clients). Transition literature from the diabetes and cystic fibrosis fields agree that there is a lack of outcome data that can clearly support one model over another [1,21,32]. Suggestions such as young adult clinics, stepped transition, joint clinics with pediatricians and adult physicians and transition nurses have all been described in the literature.

Health professionals and adolescents in the study by Visentin *et al.* [33] highlighted that transition is frequently focused on the medical transfer of care with the allied health teams having a minor role. Of the four children's services participating in their study, only one had a recall system established to offer adolescents regular education updates at designated intervals. Similarly, only one of the adult services had an established pathway in place to ensure that all of the adolescents were offered dietitian and diabetes nurse educator appointments at the time of the transition. Furthermore, health care professionals reported a poor uptake of these appointments. The ramifications of these findings, which have been replicated in other studies, are that adolescents are not receiving holistic preparation for transition in terms of developing self-management skills required for adaptation to an adult health setting. Adolescents in Visentin *et al.*'s [33] study were keen to be given opportunities to meet staff prior and receive written information. Transition might be easier if adolescents were involved in early planning and informed about what to expect from the adult service and how it may differ to the pediatric service.

Research studies have revealed that transition to adult services is often based on the medical model. Transition needs to be viewed holistically as opposed to focusing solely on the referral from one medical doctor to another. A problem-focused or reactive approach to diabetes care effectively relinquishes the potential for independence and control for the adolescent. If nurses and dietitians are only involved during periods of diabetes instability, then adolescents may not be provided opportunity to learn self-care skills. T1DM is often a family issue with reliance upon parents for information and advice. It is important that diabetes nurses and dietitians become involved in working with adolescents towards self-care as many were diagnosed as children and may never have received first-hand information about diabetes.

The role of diabetes nurse educators in preparation and facilitation of the transition process and follow-up has not been fully realized. Preparation needs to be expanded so that there is a larger focus on developing self-care skills. This approach would assist individuals in taking on the extra responsibilities expected by adult services. Frank [22] stated that a gradual preparation of both youth and parents is an important principle for transition. Blum *et al.* [25] argued that the notion of transition should be discussed as early as diagnosis. One of the transition principles advocated by Rosen *et al.* [32] is to have a designated health professional to coordinate the transition process between children's and adult diabetes services. Diabetes nurse educators are in an excellent position to undertake this role.

Care plans to facilitate a coordinated and planned transition process have been proposed by Weissberg-Benchell *et al.* [31]. The care plans should be developed in consultation with the adolescent and parents, and incorporate all aspects of the transition process such as identifying information regarding specific health services, appointments, and health and education goal planning; however, the effectiveness of the use of care planning as a process to facilitate seamless transition and improve outcomes for adolescents does not appear to have been evaluated.

The optimal goal of transition between services is to provide health care that is uninterrupted, coordinated and developmentally appropriate. The value of early preparation in late childhood from a multidisciplinary team is important for transition. To summarize the evidence, it is proposed that transition programs contain the following elements:

- Early introduction to adolescents of the concept of transition;
- Based on capacity building principles and promotion of confidence and independence and self-advocacy skills;
- Both the pediatric and adult diabetes services have a documented transition program for adolescents;
- Transition care plans incorporating all elements of the transition process;
- Timing of the transition based on maturity and skill rather than age;
- A senior member of the clinical staff from each service is responsible for the successful implementation and maintenance of the transition program;
- A designated professional, who collaborates with the adolescent and family, takes responsibility for the transition of each adolescent;
- The transition program has a multidisciplinary focus with input from consumers, primary care and allied health professionals;
- Adolescents are encouraged to develop a relationship with their primary care physician;
- The transition program should include the details of the process of transition, the expected outcomes and evaluation processes;
- The transition program should promote individualized plans for each adolescent inclusive of expected outcomes and timeframes, opportunity for the adolescent to have a voice in articulating their needs, early involvement with the adult team, opportunity for adolescents and their families to meet with new carers, opportunities to meet with other adolescents who have successfully transitioned to adult services, and access to psychosocial support for adolescents experiencing difficulty in the transition;
- All staff, including clerical and administrative staff as well as clinicians, should be educated in the philosophies and features of the transition program. Parents and children should also have the purpose and principles of structured transition explained and have access to details of the program well before transition commences;
- Include opportunity to address common concerns of adolescents such as growth and development, sexuality, mood and mental health, substance misuse and other high risk behaviors.

Information and communication technology

Modern information and communication technologies such as the Internet and mobile phones have the capacity to provide a unique and effective method of delivering support to adolescents and young adults with chronic illness. Adolescents and young adults are at the developmental age where new technologies are quickly and easily integrated into peer culture and daily life. A study by Rasmussen *et al.* [54] revealed that young women with T1DM use the Internet not only as a means of obtaining information and communicating with others, but also as a means by which to achieve a sense of autonomy and stability.

Text messaging has been recently used in the UK as a way to support young adults with diabetes to achieve goals [55]. The text message provides a weekly reminder of the goal set during clinic, with follow-up messages that reinforce the goal by providing information and reminders. The aim of the program is to optimize self-efficacy and motivate health enhancing behaviors. The program is based on the principles of social cognitive theory and has demonstrated improved metabolic control among participating adolescents [55].

The Internet offers many communication forums that adolescents will be familiar with. Websites, chat forums and various messaging systems are popular and have enormous potential for information sharing and education. For example, Twitter is a free social networking forum that enables users to send and read other users' updates known as "tweets." Tweets are text-based posts and could be used to support self-care and goal achievement for adolescents with diabetes.

There is also major potential for modern technologies such as advanced videoconferencing to provide isolated patients, including those in rural areas, with convenient access to specialist health professionals. The Centre for Online Health commenced a research project in 2000 that aimed to establish and evaluate a telepediatric service in Queensland, Australia [56]. The service operates using a centralized coordination unit, and services regional and remote hospitals. The telepediatric service provides access to specialist pediatric services. A response to the referring clinician is guaranteed within 24 hours. In the first 6 years, more than 4000 consultations were coordinated through the telepediatric service. The consultations have concerned a wide variety of fields including diabetes, endocrinology, burns, cardiology, dermatology, oncology, orthopedics, gastroenterology, neurology and pediatric surgery. A range of communication techniques are used for communicating including email, telephone and videoconferencing. Approximately 90% of referrals result in a consultation via videoconference. The service has demonstrated a significant increase in the number of children accessing specialist services. This type of technology also has significant potential to support adolescents living in rural and remote areas through transition to adult services.

Quality processes

Key performance and clinical indicators developed locally have been identified as being essential for the governance of transition

processes [34]. For example, the Australian Clinical Practice Guidelines: Type 1 Diabetes in Children and Adolescents [57] described three phases of transition: preparation, formal transition and evaluation. The guidelines recommend that the preparation phase commences from 12 years of age; however, it is unclear if such early planning actually takes place because evaluation of transition programs has rarely been reported. The findings from studies such as Visentin *et al.* [33] indicated that the three stages of transition programs are often not being fully implemented in health units.

Evaluation of transition programs may include but not be limited to undertaking a satisfaction survey of adolescent clients and their parents, to determine if they are happy with the service, they were able to adopt the treatment regimen, felt involved in and informed about the transition process and attended follow-up appointments [34]. When auditing, it is recommended to consider the availability and effectiveness of policy detailing transition processes and principles, a multidisciplinary education program, processes to enhance coordination between programs and administration and documentation [34]. In summary, some key evaluation measures include:

- Development and documentation of a structured transition program with established review dates;
- Percent of adolescents transitioning with an individualized plan;
- Adolescent and parental satisfaction; and
- Percent of adolescents attending follow-up after 12 months.

Future research

A body of knowledge has developed that has focused on the transition processes, models and adolescent experiences; however, further research is required to enhance our understanding of how best to serve adolescents with diabetes. For example, several studies have explored how developmental stage and lifestyle impact an adolescents' transition and outcomes but research exploring factors such as ethnicity, socioeconomic status, geographic location (e.g. rural and remote) and gendered experiences have not been reported. Rigorous evaluation of variations in transition programs is also needed to inform future program development that promotes long-term engagement with the health system. The promotion of self-care for adolescents with diabetes is an area that would benefit from focused research. There is currently little understanding of care approaches that increase the effectiveness of self-care strategies in adolescents. In addition, research into how to access and re-engage adolescents who drop out of the health care system is urgently needed.

Further research into how modern technologies, resources and networks can be exploited to provide support to adolescents in transition is also necessary. For example, there is potential for developing and implementing an online transition resource that can be integrated into service coordination tools used by health care providers.

Conclusions

Adolescents in transition from pediatric to adult diabetes services are experiencing forced change. Adolescents with diabetes establish a long-term positive bond with their pediatric health care team, so that the transition to an adult diabetes service provider is a significant event in their lives. Evidence has revealed the major elements of successful transition programs; however, there is a need to evaluate the effectiveness of the various transition models. Promoting better management for adolescents with T1DM by developing their capacity to self-care prior to transition to adult services is an optimal goal. There is significant potential to improve practice and outcomes through establishment of transition programs for adolescents with diabetes.

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