The transition of young adults with type 1 diabetes to adult care

Challenges and approaches

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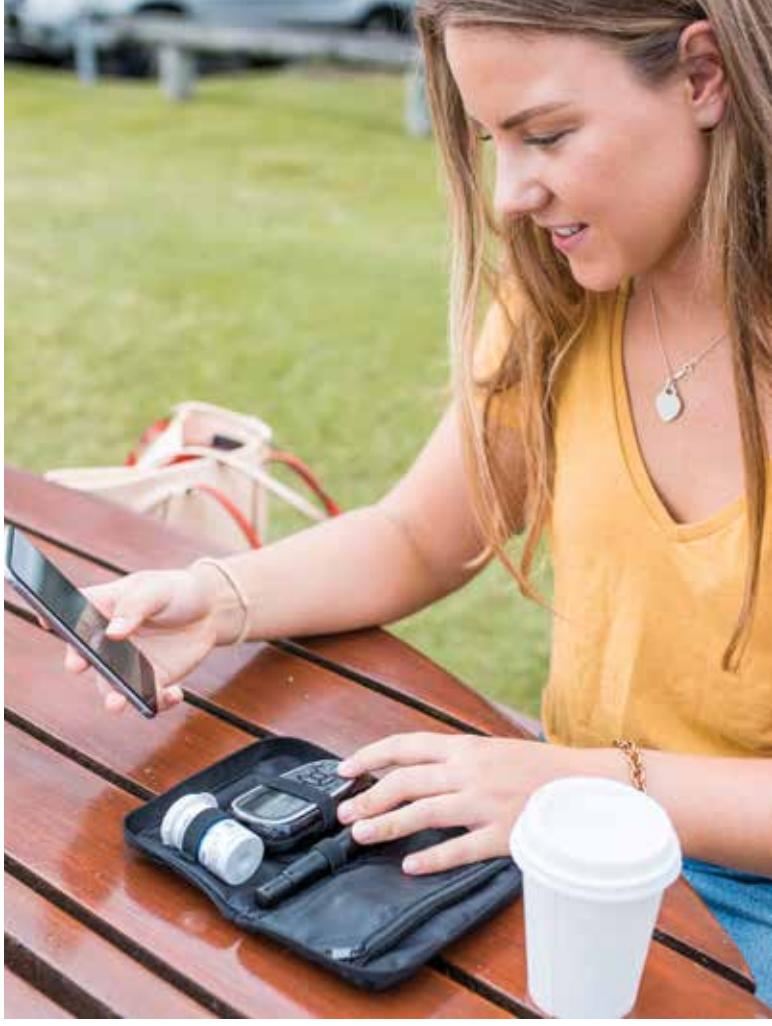
The transition of young adults with type 1 diabetes from paediatric to adult care can be challenging for young adults and their families, especially for those living in rural and remote areas. GPs play an important role in supporting this transition to adult specialist endocrine care.



Transferring young adults with type 1 diabetes to adult care often comes at a time of many other changes in the young adult's life. Leaving school and starting further study, an apprenticeship or work often coincides with this transition. The young person with type 1 diabetes may also be moving away from home, family and friends. Many are forming new relationships and becoming sexually active. Some experiment with smoking and using alcohol and recreational drugs and may not understand the implications of these on health outcomes or their interaction with glucose levels. Parental involvement in diabetes management often declines in adolescence.

The transition period can be associated with deterioration in the health of young people with type 1 diabetes.[1] Diabetes-related hospitalisations have been shown to increase during this period, with previous diabetes-related hospitalisations, lower income and living in areas with reduced physician access being associated with higher admission rates.[1,2] Young adults with a low education level and other comorbidities (e.g. mental health issues, Graves' disease, asthma) are more likely to experience poor diabetes outcomes in the years after transfer to adult care.[3] The frequency of hospitalisation with

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Key points

- **The transition of young adults with type 1 diabetes to adult care comes at a time when many changes are occurring in a young adult's life (e.g. leaving school, further study, moving away from home).**
- **Transition preparation should start at least one year before the planned transfer date, but preferably from diagnosis for older children.**
- **Complications of diabetes should be screened for before and during the transition.**
- **Sexual health and preconception planning are issues that often arise contemporaneously with the transition period.**
- **Specific referrals for adult care should be provided, as well as practical education on the differences between paediatric and adult healthcare services and the logistics of attending an adult clinic. It is helpful to make the first appointment.**
- **Factors identified as disrupting transition to adult care are lack of preparation in the paediatric service, the cost of adult care, difficulty accessing appropriate specialty care and other life stressors.**

both diabetic ketoacidosis and severe hypoglycaemia have been shown to double during the transition.[1] In the first year after transition, diabetes control can deteriorate and HbA_{1c} levels can increase.[1] Microvascular complications also increase, depending on the time between the last visit in paediatric care and the first visit in adult care.[1] Many youth with type 1 diabetes are lost to follow up during this period, only to re-present in diabetic ketoacidosis or other health crises. Attention has focused on more effective transition of patients with type 1 diabetes into adult care, with the hope of improving these outcomes.

Differences in paediatric and adult health care

There are differences between paediatric and adult healthcare systems. Paediatric diabetes care is often family based and parental involvement is encouraged. There is often greater access to an integrated team, including social workers and psychologists, as well as diabetes educators, dieticians and physicians. Adult services may have less availability of social and behavioural health specialists. Adult clinic visits are often shorter, with greater emphasis on objective medical indicators and less input from parents and other support partners.[4] Some youth with type 1 diabetes may find the spectrum of complications seen in a combined type 1 and type 2 diabetes clinic confronting.

A variety of adult healthcare services, including adult endocrinology clinics, primary care and university-based health services, are available. Most adults with type 1 diabetes see endocrinologists for their care, and research suggests that speciality care improves diabetes-related outcomes and provides access to more diabetes-specific services, such as diabetes educators and dietitians with experience in type 1 diabetes.[5] Many specialist centres have established targeted young adult clinics.

Transition preparation

Mental health, sexual health and contraceptive advice

In young adults with type 1 diabetes there is a large interplay of psychosocial disease. Eating disorders are more common compared with their peers without diabetes. Intentionally withholding insulin can be a form of weight control and is reported in up to one-third of young women and one-sixth of young men with type 1 diabetes.[6] Other mental health issues including diabetes distress, anxiety and depression are also common. Substance abuse is at least equally as common among emerging adults with diabetes as without diabetes and has been reported to be associated with poorer diabetes control and more frequent hospital admissions with diabetic ketoacidosis.[7] Although not unique to the transition period, young adults with these issues may require referral to other specialist services if the adult diabetes service does not provide social work or mental health services. GPs can provide Medicare-subsidised mental healthcare plans for referral of patients with type 1 diabetes to psychology and/or psychiatry providers.

Sexual health and preconception planning are also issues that often arise contemporaneously with the transition period. There is poor discussion of contraception by healthcare professionals with teenagers with type 1 diabetes. In a US national survey, less than half of young adults with type 1 diabetes reported discussing reproductive health.[8] Many teenagers are not aware of the need for preconception planning or the adverse effects of poor glycaemic control in pregnancy on the fetus and mother.[9] GPs are experienced in providing contraception advice and can play an important role in sexual health counselling.

Screening of diabetes-related complications

Screening for microvascular and macrovascular diabetes complications should occur before the transition and continue after the time of transition to adult care. A US study has shown that one-third of young adults with type 1 diabetes have at least one early diabetes-related complication, including retinopathy, nephropathy, hypertension or autonomic neuropathy.[10] A UK study of adolescents and young adults showed decreased rates of screening of diabetes-related complications during the transition period.[11]

Referral of young adults with type 1 diabetes to other adult service healthcare professionals, such as optometrists, dietitians and podiatrists, may be enhanced by primary physicians providing Medicare-subsidised healthcare plans to ensure appropriate complication screening and other allied health care.

Timing of transition

The first discussion about the eventual transfer from paediatric to adult health care should occur many years before the actual process of transition. Guidelines recommend the discussion on the eventual transfer to adult health care should begin in preadolescence or at or soon after diagnosis for older children.[12] Transition to adult services is then an anticipated event, rather than a new concept introduced at a developmental stage associated with other major life changes.

In Australia, most people with type 1 diabetes move to adult care between the ages of 16 and 22 years. For young people leaving school earlier, transitioning to a young adult clinic may occur from 16 to 18 years of age. There are conflicting data on the optimal age of transition. Some studies have shown that transition to adult care at a younger age has been associated with poorer glycaemic control, and that older adolescents who remain in paediatric care into early adulthood have better glycaemic control and fewer hospitalisations.[13] However, a more recent review showed stable or even improved control following transfer to adult care.[14] This may reflect a general improvement in glycaemic control in patients in their mid 20s that is seen in large cohort studies.[15] These results are probably multifactorial, including physiological changes (such as a reduction in growth hormone and insulin-like growth factor-1 levels) and in particular a reduction in risk-taking behaviours and an improvement in general psychosocial maturity. Some young patients with type 1 diabetes report satisfaction with increased autonomy in an adult service.[16]

Components of transition

Literature on the outcomes of clinical transition programmes are limited, largely because it is difficult to enrol youth with type 1 diabetes in studies in this area.[17] Many recommendations and position statements are based on expert opinion and consensus statements rather than on trial data. Nevertheless, recent guidelines have been provided (Box 1).

Patient perspectives on healthcare transition

The patients' experience of the transition should be kept in mind. Some young adults feel prepared and ready for the transition to adult care whereas others may struggle to engage in adult-orientated health care. A study found that the lack of a specific adult provider referral name or contact information was the most frequently reported barrier to establishing adult care.[18] Another study found that actually making the first appointment and providing reminders made attendance at the first and subsequent adult specialist appointment more likely.[17] At this point, the intervention of the patient's primary care physician may be especially helpful. It is important that the patient's GP is included in the transition plan and is provided with a copy of this plan. A study in Melbourne found that GPs were only given copies of 60.8% of adult referrals, leaving a significant proportion of primary physicians unaware of the transfer of care and to which centre their patients had been referred. The adult centre was also uncertain of who to contact when patients did not attend.[19] Some area health services have online listings of adult type 1 diabetes services.

Factors identified as disrupting the transition to adult care are lack of preparation in the paediatric service, the cost of adult care, difficulty finding appropriate specialty care and other life stressors. Other factors that can also lead to disruption of transition include dissatisfaction with the adult care, including lack of multidisciplinary diabetes care services, time constraints for appointments, difficulty scheduling appointments and difficulties with continuity of care and communication.[20] Patients and families may not be familiar with navigating the adult healthcare system.

Young adults have reported that the following may help improve the transition process:

- targeted referrals to adult diabetes care providers
- assistance with the logistics of transfer to adult care
- discussion about adolescent issues and specific transition services earlier in paediatric care
- ability to connect with other young adults with type 1 diabetes.

Most young adults also thought parents should continue to be included in the transition as a key part of the patient's support network, rather than being excluded from the process.[21] A survey of young adults with type 1 diabetes showed they especially valued information and opportunities for peer support during transition from web-based platforms (Box 1).[22]

Evidence-based models of transition

Transition that is facilitated via joint appointments with a paediatric and adult healthcare provider has been shown to improve attendance at such a specialist clinic, resulting in reduced diabetes distress.[23] Another model is a dedicated young adult clinic, for example, where only young adults with type 1 diabetes from 16 to 30 years of age are seen, usually with a transition co-ordinator arranging bookings of appointments and providing sick day advice, which has been shown to reduce hospital admission rates with diabetic ketoacidosis.[24]

It may be beneficial to minimise the amount of change during the transition by referring young adults to adult services in the same healthcare system or location as their paediatric care. Patients may prefer to transition to an endocrinologist or public diabetes clinic close to home, and the patient's GP may have knowledge of these local services. These options should be discussed with the patient well before the actual time of transition.

Continuity of care has also been shown to reduce diabetes-related hospitalisations. Meeting an adult care provider before transfer from paediatric care has been associated with increased patient satisfaction.[25] Trapeze is a support service provided through the Sydney Children's Hospital network to help patients transition from paediatric to adult care (Box 1).

Patients and their families have requested more written resources about transition. However, studies have found that use of written resources is low. A study showed that 50% of parents and adolescents used the written information provided and of those only 25% found it very helpful.[26] If written resources are to be provided, they should be reviewed by consumers and written with the health literacy of the patient population taken into account. Targeted resources have been found to improve attendance.

1. Useful resources on transition to adult diabetes care

- Diabetes Australia – www.diabetesaustralia.com.au
- Cameron FJ, Garvey K, Hood K, Acerini C, Codner E. Chapter 17: Diabetes in adolescence. In: Acerini CL, Codner E, Craig ME, Hofer SE, Maahs DM, eds. ISPAD Clinical Practice Consensus Guidelines 2018. Berlin, Germany. Available online at: www.ispad.org/page/ISPADGuidelines2018
- Peters A, Laffel L. Diabetes care for emerging adults: recommendations for transition from paediatric to adult diabetes care systems. Diabetes Care 2011; 34: 2477-2485.
- Marathe PH, Gaoe HX, Close KL. American Diabetes Association Standards of Medical Care in Diabetes. J Diabetes 2017; 9: 320-324.
- Agency for Clinical Innovation transition care resources – www.aci.health.nsw.gov.au
- Trapeze – a support service provided through the Sydney Children's Hospital network – www.trapeze.org.au
- Reality Check – an online forum for patients with type 1 diabetes – www.realitycheck.org.au

2. Recommendations for transition

- Start transition preparation at least one year before the planned transfer date, but preferably this should be incorporated into regular diabetes clinics from diagnosis for older children.
- Provide specific referrals for adult care providers and practical education on the differences between paediatric and adult healthcare services and the logistics of attending adult clinics.
- Ensure that the GP is provided with a copy of the transition referral.
- Provide advanced knowledge surrounding adolescent issues, including smoking, alcohol, recreational drugs, contraception and pregnancy planning.
- Compile medical record documentation in preparation for transfer of care, including history of other illnesses, especially mental health issues and relevant medications.
- Acknowledge developmental and psychosocial challenges that may affect transition.
- Screen for complications of diabetes, as well as for disordered eating, depression and substance misuse before transition.

The role of a transition co-ordinator has been studied in Australia. A randomised, open-label study compared appointment management in which an appointment manager provided telephone and SMS reminders for 12 months compared with usual care. The study showed no increase in attendance at the adult clinic between 0 and 12 months after transition, but did have a positive effect on attendance (2.5 compared with 1.4 clinic visits) during 12 to 24 months after transition.[27]

General recommendations for transition are outlined in Box 2.

Conclusion

The transition of young people with type 1 diabetes from paediatric to adult care can be challenging but is improved by co-ordination of care between paediatric and adult services and the young person's GP. Discussion of transition should begin at least one year before transition and the preferences of the young person with diabetes should be prioritised. Complication screening and addressing psychosocial concerns should occur before the transition. Practical measures, such as providing referrals to adult services, making appointments and providing the young person and the GP with a copy of the transition plan, are essential. **ET**

References

A list of references is included in the online version of this article (www.endocrinologytoday.com.au).

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