Optimising type 1 diabetes care at the transition

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GPs are ideally placed to ensure a smooth transition of young people with type 1 diabetes from paediatric care to the adult healthcare sector. The nature of the doctor–patient relationship will be altered and care should be taken to ensure young patients remain under regular review.

When I have discussed transition with GPs, the question arises 'What transition?' The GP has often been a patient's care provider from birth and continues into adulthood. However, even for the GP, there should be a transition in the nature of the relationship when caring for late adolescents and 'emerging' adults.[1] New ways of engaging with the patient may need to be negotiated, starting to see the young person on their own and assuring them that your discussions during appointments will be kept confidential, except, of course, where the young person is at risk from harm.

Patients with type 1 diabetes are managed comprehensively in the paediatric domain, which also takes responsibility for the timing and frequency of screening for complications. Such resources are frequently not available in the adult healthcare sector. During the transition, young people with type 1 diabetes will potentially have more contact with their GP than they have while under paediatric supervision for their diabetes. Type 1 diabetes has many things in common with type 2 diabetes, including all the components of the diabetes annual cycle of care; however, management of patients with type 1 diabetes has distinct differences. In this article, I will focus on those differences pertinent to the management of young people with type 1 diabetes while also highlighting the similarities with the management of patients with type 2 diabetes that are often neglected.

Terminology

The WHO defines 'adolescence' as between the ages of 10 and 19 years and 'youth' as between the ages of 15 and 24 years, the latter being the age range managed outside of the paediatric field.[2] In Australia, the

Key points

- **The key focus is to keep young people engaged in the process of diabetes care.**
- **Education in adolescents and young adults should be directed towards short-term risks to the young person with diabetes.**
- **Continue to monitor long-term complications in the background including risk for development of associated autoimmune disease.**
- **Closely monitor mental health and wellbeing as these are major factors interfering with the young person's ability to manage their diabetes.**

ENDOCRINOLOGY TODAY 2016; 5(3): 19-23

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1. Case scenario 1: Insulin omission

Mr KB is a 22-year-old man with type 1 diabetes, previously reviewed by a local endocrinologist, who presents to your rooms feeling nauseated but not vomiting. He has not been seen by the specialist for more than two years. He complains that it was getting too expensive to see the specialist and his boss did not like him taking time off his job as a fork lift driver for the appointments. He was not finding the visits very helpful anyway. Mr KB's last glycosylated haemoglobin (HbA_{1c}) measurement at the specialist was 12%.

He tells you he has missed his insulin treatments for the past 24 hours because he has not been eating very much. His usual insulin is 15 units of a rapid-acting insulin aspart with each meal and 40 units of insulin glargine at night. His last dose of insulin glargine was the night before last. He finds he often forgets his insulin glargine because he comes home very tired from work and falls asleep on the couch without taking it. He also does not like taking the rapid-acting insulin aspart to work. He has not had any episodes of hypoglycaemia recently but he states if he takes all the insulin he starts to get hypoglycaemia. He is not doing any testing for his diabetes.

What are the priorities in treatment?

Sick day management is a priority of treatment for Mr KB. He may have developed diabetic ketosis but he is not vomiting, although he may well be dehydrated. He likely will improve just by resuming his usual insulin for 24 hours to 'catch up', particularly as he is usually missing injections each day. Provided he is not vomiting, just resuming insulin will likely resolve the ketosis and he will feel less nauseated.

Simplifying Mr KB's insulin regimen so he is less likely to miss insulin doses is the other priority here. A common regimen used to address this sort of problem is to use rapid-acting biphasic insulin aspart and insulin glargine at breakfast. He could then just take his usual rapid-acting insulin aspart with dinner. He stated that if he took all his insulin he would get hypoglycaemic symptoms. It would be reasonable to reduce his total daily insulin intake to ensure no hypoglycaemia and give him confidence to take all his insulin. A suggestion is to reduce his total daily dose by 10 to 20%, and I would suggest 24 units of rapid-acting biphasic insulin aspart and 30 units of insulin glargine in the morning with 12 units of rapid-acting insulin aspart at night as a first step. Continuing insulin glargine (rather than using rapid-acting biphasic insulin aspart) is helpful as it does reduce the risk of diabetic ketoacidosis in young people who omit insulin.

What investigations should be performed?

Urine or blood testing for ketone levels should be performed. Ketone levels are very likely to be elevated in Mr KB's case due to the insulin omission. They will improve when he resumes taking his insulin. You should indicate to the patient that at any time he starts vomiting he should present immediately to the emergency department, and you could provide him with a letter in case this occurs to indicate the gravity of the situation and the critical importance of resuming insulin. Blood ketone levels less than 1.5 mmol/L can routinely be managed at home. Ketone levels less than 3.0 mmol/L in the absence of vomiting and due to insulin omission, not intercurrent infection, would also reasonably be managed at home provided the young person can continue to monitor ketone levels at home and ensure levels fall with recommencement of insulin. If there is concern about possible ketoacidosis then it is appropriate to refer directly to the emergency department.

A formal glucose blood test should be ordered if glucose readings are not available on a glucometer and HbA_{1c} is unavailable as a benchmark for later improvement. It would be reasonable to also test Mr KB's electrolyte levels. I would expect both glucose and HbA_{1c} levels to be very high but should improve after taking insulin and glucose levels should be monitored by the patient. He could also have all his other annual tests checked at the same time, although it would be advisable to check his fractionated lipid profile once he has started taking his insulin more regularly, because all lipid levels except HDL-cholesterol are increased by insulin omission.

What ongoing monitoring is required?

In the short term, you may suggest that your practice nurse or yourself call Mr KB later in the day to check how things are going. Ask if he has a glucometer and advise him to start testing his blood glucose levels while he is unwell. Ask if he has urine or blood ketone testing strips as well. A patient with a blood ketone level persistently above 3.0 mmol/L despite resuming insulin or above 1.5 mmol/L with vomiting should be referred to the local emergency department; similarly, the persistence of large ketones on urine testing requires referral to the emergency department. Advise repeat testing for ketones at four-hourly intervals until they are cleared.

Longer term the importance of this visit is to engage the young person and encourage them to come back and see you again. Indicate that he needs to have all his annual tests such as eye check, feet check and urine checks and that you will arrange this when he returns.

term 'adolescent and young adult' covers the overlapping age range of 10 to 24 years. The newer terminology of 'emerging adult' refers to the age range of 22 to 26 years.[1]

Re-education of the late adolescent with diabetes

In many ways the timing of transition from paediatric to adult care is difficult. It occurs at a time when the young person is adapting to multiple changes to their routine, usually at the end of schooling, when the brain is still 'under development' with respect to how to manage changing and competing responsibilities. The late adolescent with type 1 diabetes has to learn for themselves the multiple management decisions previously addressed by carers. So, although they may have lived with diabetes since early childhood they require personal re-education in many areas, most of which will be remembered when taught in the context of need and are immediately applicable. Education of the late adolescent has five important areas, as outlined below.

Management of sick days

Ketone levels must be checked when the patient is unwell, with additional insulin being administered if ketones are present. The importance of not omitting insulin when unwell should be stressed to young patients (case scenario 1 in Box 1). Ketoacidosis is much more likely if glycosylated haemoglobin (HbA1c) levels are greater than 11%.[3]

Hypoglycaemia unawareness

Young people should be made aware of the possibility of hypoglycaemia. Severe hypoglycaemia may become a problem when insulin doses are not reduced after completion of adolescent growth. Also, taking on new work roles with a significant increase in physical activity can put them at risk (case scenario 2 in Box 2).[4] Young people should be encouraged to return regularly for review, as their circumstances, and therefore insulin requirements, are changing all the time.

Risk management: driving with diabetes

The importance of testing blood glucose levels before driving and testing every two hours for prolonged periods of driving should be emphasised to young people. This is particularly important if driving is required in their work role. The patient should provide evidence of blood glucose testing in relation to driving and should have had HbA_{1c} levels tested within the past three months when completing fitness to drive assessment forms. Each state and territory has different guidelines for 'fitness to drive' in relation to diabetes managed with insulin, so it is necessary to review the appropriate recommendations. If in the past 12 months a young person has had a severe hypoglycaemic episode (defined as an episode of hypoglycaemia requiring outside help to recognise and/or assistance to treat), the young person should be referred to an endocrinologist to assess their fitness to drive.

Risk management: impact of alcohol on diabetes

There is an increased risk of hypoglycaemia with excess alcohol consumption and ketoacidosis if insulin is omitted after drinking. It is important that the young person ensures they have someone with them who knows about their diabetes and who understands to call for assistance if they are not responding and not presume it is due to alcohol.

Contraception and preconception planning

The GP is well placed to advise the young person about all modalities of contraception. For women with type 1 diabetes, preconception planning is critical to reduce the risk of congenital anomalies by optimising diabetes control before pregnancy and all should be advised to take high-dose folate supplements when they are planning to conceive (5 mg/day as compared with 500 µg/day in normal pregnancy supplements).

Preventing loss of young patients to follow up

Although some hospitals have comprehensive transition programs for the care of young people with type 1 diabetes, this alone is not sufficient to prevent them being lost to follow up. Even when such services are available, up to 50% of patients never transition fully to an adult healthcare environment after leaving paediatric care. The chances of loss to follow up after leaving paediatrics in regional and rural areas is even greater with minimal access to bulk-billing specialists or to specialists at all in some remote areas of Australia.[5] This is important because there is evidence that those young patients lost to follow up have deterioration in diabetes control and higher rates of acute admissions when not under review.[6]

The GP can help to build relationships with the young person who may have become disengaged from hospital-based care. At this stage of development important attributes of a general practice providing care to young adults include the following.

- Acceptance and warmth will help the young person feel comfortable coming for review whether or not things are going 'well' with their diabetes care.
- Clear and consistent advice should be delivered by all members of the team at the practice.
- Changes in diabetes care behaviour should be negotiated with the young patient to achieve an agreed achievable goal.
- Strategies for when the young person is confronted with situations involving risk such as drinking and diabetes should be discussed openly.
- Alternative options should be offered to help the young patient reconnect with a specialist in diabetes care.

2. Case scenario 2: Recurrent hypoglycaemia

Ms TG, 19 years old, presents complaining of hypoglycaemia. She has started working as a hairdresser and is on her feet for prolonged periods and her lunch break is often late or not at all. She is having to try to snack all day while at work. She is worried as her mother had to wake her the other night to give her treatment for a 'hypo'. She has also been waking with readings in the morning of about 2.8 mmol/L and she does not feel that her sugar level is low. She does not usually get time to test her levels at work but the other day one of the other hairdressers had to get her some juice because she thought she would pass out otherwise. She is on 6 units of rapid-acting insulin aspart at breakfast, 4 units at lunch when she eats and 6 units at dinner and 24 units of insulin glargine. She has been on this since her last visit to the specialist six months ago but she has not been back as she is too busy in her new job.

What is the priority?

Ms TG has hypoglycaemic unawareness. The Australian guidelines recommend a 20% reduction in her total daily insulin intake when she becomes hypoglycaemic.[4] The main insulin to reduce is the insulin glargine as the rapid-acting insulin aspart doses are quite small. This would mean reducing insulin glargine to 18 units. She should be referred back to her specialist who should assess suitability to drive, if she is driving, and determine if her insulin doses need to be further reduced.

3. Lipid-lowering treatment in young people with type 1 diabetes[10,11]

- Start treatment if LDL-cholesterol levels >4.1 mmol/L at age >18 years with additional cardiovascular risk factors (excepting women planning pregnancy)
- Treat to standard diabetes criteria from >45 years
- Aim for a target total cholesterol level of <4.0 mmol/L and LDL-cholesterol level of <2.6 mmol/L
- Treat all young people with nephrotic syndrome aged >18 years

Changing goals in the emerging adult with type 1 diabetes

In the period that is now defined as 'emerging adulthood',[1] self-regulation becomes apparent. This means the young person starts to demonstrate the ability to control impulses, think through the consequences of their actions, respond to and learn from rewards and punishments, and resist the influence of their peers. It is at this time that GPs and other healthcare professionals can make the greatest gains to influence the young person's long-term diabetes care behaviours, which will help to prevent both acute and long-term diabetes complications. This is more likely to be achieved if the young person has maintained contact with their health professional during the late-adolescent phase of development.

Patterns of specialist and GP review will be established in this time and carried through into later life. Insulin pump therapy is often initiated in emerging adults, if not taken up earlier, as they review their changing needs and start to develop insight into long-term sequelae of diabetes.

Diabetes-related complications

In patients younger than 30 years of age, the main causes of death are severe nocturnal hypoglycaemia (potentially resulting in 'dead in bed' syndrome or a seizure resulting in aspiration and hypoxia or severe brain injury), severe diabetic ketoacidosis and suicide.[4] In those older than 30 years of age, the main cause of death is cardiovascular causes.

Although complication rates are low in young people, about one in four have diabetic retinopathy and one in five have micro-albuminuria within six years of diagnosis of type 1 diabetes.[7] Diabetes-related complications progress more rapidly across puberty. So if a young person is not in the care of a specialist, it falls to the GP to ensure that the necessary tests are being completed. These include annual spot urine microalbumin testing and biannual optometry eye review if no abnormalities are found and annual review if background diabetic retinopathy is present.

Infrequent specialist clinic attendance after the transition correlates with low rates of complication screening,[5] with less than 10% of young people participating in complication screening as compared with about 50% participating with routine specialist review. This increases up to 90% in specific young adult clinics with on-site complications screening (unpublished audit, DJ Holmes Walker).

Mental health complications in patients with type 1 diabetes

In the recent Australian Diabetes MILES Youth study of mental health and wellbeing in youth with diabetes, 25% of 10 to 19 year olds with type 1 diabetes reported moderate-to-severe depressive symptoms and/or moderate-to-severe anxiety symptoms.[8] Girls reported more diabetes-related distress with the most common concern being that they were 'worrying about their weight'. Girls were more likely than boys (60% *vs* 20%, respectively) to report that it was difficult to manage both their diabetes and their weight. Girls were more likely than boys to report binge eating on more than four days in the past two weeks (25% *vs* 16%). The Diabetes MILES Youth study did not compare the prevalence of mood and eating disorders with age-matched controls without diabetes but other reports suggest the incidence may be higher in youth with diabetes.[9]

The coexistence of a mental health condition is likely to have a significant adverse impact on diabetes control as measured by HbA_{1c} levels. An acute increase in HbA_{1c} level in a previously well-controlled adolescent or young adult may alert the GP to the presence of an intercurrent eating disorder or mental health condition. In this context, the priority is to manage the mental health condition because diabetes control will not improve until this is addressed. A mental health care plan may be required in addition to regular review with the GP to determine if medication or specific psychiatry referral may be required. The young person should also be informed of the option to self-refer to headspace, the national mental health service providing early intervention services for youth aged 15 to 25 years.

Care plans in youth with type 1 diabetes

Although care plans are often prepared for patients with type 2 diabetes, they are not always thought of when caring for young people with type 1 diabetes as a means to increase engagement with podiatrists, diabetes educators, dietitians and exercise physiologists. However, it should be remembered that longer-term engagement of young people with allied health professionals is often limited due to the cost of services not being fully met by the Medicare rebate. So visits to allied health professionals may need to be prioritised; for example, foot care is often neglected and intercurrent issues such as ingrown toe nails and tinea pedis may have more significant consequences in the young person with diabetes in the presence of poor control.

When to commence treatment

Lipid-lowering therapy

Cardiovascular disease is the primary cause of death later in life for people with type 1 diabetes and the optimal age to commence

lipid-lowering therapy remains controversial. Guidelines from the USA indicate that there is a lack of evidence for the treatment of elevated cholesterol levels in young people with type 1 diabetes.[10] However, they recommend treatment with statins for patients with an LDL-cholesterol level greater than 4.1 mmol/L if they are older than 18 years and have more than one cardiovascular risk factor (e.g. hypertension or a family history of young-onset heart disease) in addition to diabetes.[10]

Most data on lipid lowering come from patients with type 2 diabetes and cardiovascular disease; however, the soon-to-be-released Australian Diabetes Society Guidelines[11] recommend statin treatment for patients over the age of 45 years who have had type 1 diabetes for 10 years or more, based on data from a pooled meta-analysis[12] (Box 3). Treatment adherence is likely to be much greater after 25 years of age as the young person generally has greater financial independence and developmentally the young person is able to understand the concept of future risk.

Blood pressure-lowering therapy

About 4 to 6% of youth with type 1 diabetes have elevated blood pressure levels requiring treatment, with a slightly higher prevalence seen in those of Asian Pacific backgrounds.[13] This is similar to the prevalence in youth without diabetes. There is very little evidence regarding the treatment of blood pressure in young people except where nephropathy, as evidenced by microalbuminuria, is present.

There is level 1 evidence to support the treatment of young people with type 1 diabetes and nephropathy with an ACE inhibitor or angiotensin receptor blocker to prevent the progression of diabetic nephropathy.[14] However, one epidemiological study, the Pittsburgh Epidemiology of Diabetes Complications trial, showed that when blood pressure was greater than 120/90 mmHg 10 years earlier, the risk for coronary artery disease was more than doubled.[15]

Guidelines from the National Heart Lung and Blood Institute in the USA suggest the same blood pressure levels for treatment initiation for youth with and without diabetes but lower treatment targets in youth with diabetes once treatment has been commenced.[11] Treatment is recommended for patients with stage 2 hypertension (defined as blood pressure levels above the 99th percentile for age plus 5 mmHg) and in youth with diabetes to achieve a blood pressure level lower than the 90th percentile for age, sex and height.[13] There are online tools to determine blood pressure percentiles for youth.[16] A comprehensive summary of current evidence for treatment of cardiovascular risk factors in youth with type 1 diabetes has been published recently.[13]

Recommended screening for other complications

Young people with type 1 diabetes are at increased risk for other autoimmune diseases, the most frequent being autoimmune thyroid disease (life time risk 25 to 30%), coeliac disease (4 to 6%) and pernicious anaemia (8% of those with autoimmune thyroid disease and diabetes).[10] Annual blood test monitoring should include a fractionated lipid profile but should also screen for other autoimmune diseases and include measurement of levels of thyroid-stimulating hormone (TSH) and vitamin B12, a full blood count, iron studies, urea electrolytes and creatinine, and liver function tests.

4. Autoimmune diseases associated with type 1 diabetes

Common: appropriate to screen annually

- Coeliac disease
- Hyperthyroidism
- Hypothyroidism
- Pernicious anaemia

Less common: not routinely screened

- Rheumatoid arthritis
- Premature ovarian insufficiency
- Vitiligo
- Addison's disease

Coeliac disease may be suggested by the presence of iron deficiency with or without bowel symptoms. The presence of thyroid antibodies and coeliac antibodies are not helpful for diagnosing active disease and do not need to be tested for unless abnormalities on routine screening tests suggest active disease; for example, anaemia or low iron levels (screen for coeliac disease) or abnormal TSH levels (screen for thyroid antibodies). Autoimmune antibodies for coeliac disease and thyroid disease are included in the paediatric annual screening tests because type 1 diabetes and other autoimmune disease often have their onset within a few years of each other in the paediatric age group (Box 4).

Conclusion

There is a dearth of empirical data on the best way to manage the transition process and many social, demographic and mental health issues will influence the likelihood of a young person seeking assistance with their diabetes care. Many doctors have little training in delivering health care to emerging adults.

GPs are more likely to come into contact with those lost to follow up and can play an important role in helping the young person to re-engage with adult healthcare providers and helping them to find the most appropriate specialist based on their more personal knowledge of the young person and local healthcare providers for young people with type 1 diabetes. **ET**

References

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

COMPETING INTERESTS: Associate Professor Holmes-Walker has received personal fees and nonfinancial support from Medtronic Australasia, but this was unrelated to the current manuscript.

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