

The initial impact of a diabetes diagnosis on mental health in young people and families

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A diabetes diagnosis is often accompanied by significant distress in young people and their families. While initial distress around the time of diagnosis is normative, prolonged difficulties adjusting to a diagnosis of diabetes have been associated with adverse long-term health and mental health outcomes in young people. Evidence suggests that screening for behavioural and mental health concerns at diagnosis can identify those young people who are at risk of future difficulties and offer opportunities for early intervention. Behavioural interventions for this population have primarily focused on providing peer-to-peer support for parents around the time of diagnosis. This review highlights recent literature on the psychological impact of a diagnosis of diabetes on young people and their families, and existing interventions promoting psychological adjustment. Clinical implications for diabetes nurse educators working with young people and their families are discussed.

The incidence of diabetes in young people under the age of 20 years is rising. In the US, estimates suggest that nearly 15 000 children are diagnosed with type 1 diabetes and 3700 with type 2 diabetes each year (Liese et al, 2006; Imperatore et al, 2012). An initial diagnosis of diabetes typically includes a brief hospitalisation or emergency department visit paired with comprehensive self-management education on daily diabetes management, nutrition and potential acute and chronic complications (Swift, 2009). This initial diagnosis period can be traumatic and stressful, particularly in the early weeks post-diagnosis, as young people and their families struggle to adapt routines at home and school, and to cope with managing a chronic illness. While psychological distress early in diagnosis is common, persistent psychological dysfunction may contribute to an increased risk of long-term maladjustment in children and families (Northam et al, 2006).

This review highlights recent data examining the impact of a diabetes diagnosis on the mental health of young people and their families. Interventions to promote psychological adjustment and related clinical implications are also discussed.

Initial psychological adjustment to a diagnosis of diabetes

Psychological stressors at diagnosis

At the time of diagnosis of diabetes, young people and parents often report high levels of anxiety, shock, fear and distress. Commonly reported stressors at diagnosis include information overload, the loss of health in the child, fear of concurrent complications (e.g. hypoglycaemia, shortened life expectancy), the realisation of the intense daily management responsibilities and related lifelong management, and worry over the cost of medical care (Landolt et al, 2005; Smaldone and Ritholz, 2011; Rankin et al, 2014). Streisand et al (2008) reported that 61% of

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Article points

1. Many young people and their families have difficulties adjusting to a diagnosis of type 1 diabetes, and these people are more likely to have adverse long-term health and mental health outcomes.
2. Psychological screening for mood and behaviour problems is recommended to occur at diagnosis and at regularly scheduled follow-up visits.
3. Pre-existing difficulties with behaviour or mood, as well as periods such as starting school or moving into adolescence, may require increased support from the mental health team.

Key words

- Children and young people
- Families
- Mental health
- New diagnosis
- Psychosocial adjustment
- Type 1 diabetes
- Type 2 diabetes

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1. Clinically significant symptoms of depression and anxiety are common in the weeks after a diagnosis of type 1 diabetes, both in children and in their parents.
2. Psychological adjustment to the diagnosis is influenced by socioeconomic status, gender, age and illness severity at diagnosis.
3. Children diagnosed with type 2 diabetes are more likely to have mental health difficulties than those with type 1 diabetes; furthermore, some demographic characteristics associated with type 2 diabetes risk are also associated with mental health risk.

parents reported clinically significant depressive symptoms and 59% reported clinically significant anxiety in the initial weeks following their child's diagnosis of type 1 diabetes. Research suggests that children and adolescents also experience psychological distress at the time of diagnosis, including symptoms of depression and social withdrawal (Grey et al, 1995).

Challenges persist during the immediate post-diagnosis period, with many families reporting feelings of isolation upon resuming daily routines, anxiety about returning to school and extracurricular activities, and difficulty telling others about the diagnosis (Smaldone and Ritholz, 2011). In a recent population-based study of young people with type 1 diabetes in Sweden, Butwicka et al (2015) found older children and adolescents were at the highest risk of a mental health diagnosis, including mood disorders, anxiety disorders and substance misuse, during the first 6 months post-diagnosis. The risk of a psychiatric disorder decreased with time, but the overall rates of mental health diagnoses were higher than observed in the general population. Additionally, Wysocki et al (1989) found that in preschool-aged children, adjustment difficulties, such as social withdrawal, difficulty sleeping and depressive symptoms, were reported in the initial period following diagnosis.

Predictors of initial psychological adjustment

Demographic characteristics, such as socioeconomic status, gender and age, influence psychological adjustment following a diabetes diagnosis. For example, families with lower incomes may experience more frequent stress as a result of the added burden of diabetes to the family's limited resources, and mothers tend to experience higher levels of depression and anxiety than fathers (Streisand et al, 2008). Among the children themselves, girls are more likely to be diagnosed with a comorbid psychiatric disorder than boys (Northam et al, 2006), and there is evidence that younger children report more worry at diagnosis than older children (Jönsson et al, 2015). Illness severity at diagnosis also contributes to initial adjustment. For example, young people requiring critical care intervention at diagnosis experience increased trauma and distress (Landolt

et al, 2005). Diabetic ketoacidosis (DKA) at initial presentation of type 1 diabetes may also contribute to difficulties with attention and memory in the months following diagnosis (Cameron et al, 2014). Rankin et al (2014) found that many parents felt guilty for failing to notice their child's symptoms earlier, reporting increased distress when their child presented in DKA at diagnosis.

Psychological adjustment in type 2 diabetes

Despite increasing rates of young people being diagnosed with the condition, there are relatively few studies examining the psychosocial adjustment to new-onset type 2 diabetes in children and adolescents. As many young people diagnosed with type 2 diabetes have at least one relative with the condition (Haines et al, 2007), the diagnosis experience may not be as unexpected or unfamiliar as a diagnosis of type 1 diabetes. However, assessment of diabetes perceptions at diagnosis is important, as there may be misconceptions about diabetes based on family history that can increase distress (Copeland et al, 2013). There is also evidence that young people with type 2 diabetes are at greater risk of mental health difficulties in subsequent years compared to their peers with type 1 diabetes (Hood et al, 2014). The SEARCH for Diabetes in Youth study showed that having type 2 diabetes was associated with depressed mood (Lawrence et al, 2006). Furthermore, some demographic characteristics that are known to be related to depressed mood in young people (e.g. lower family income, single-parent household) were more likely to be present in the paediatric population with type 2 diabetes. In addition to their effects on quality of life, clinically significant depressive symptoms near the time of diagnosis are associated with worse adherence to the diabetes care regimen (Katz et al, 2016).

Promoting positive psychological adjustment

Psychological adjustment over time

Children and parents' adjustment to a diagnosis of diabetes generally improves over time. Kazak's (2006) Pediatric Psychosocial Preventative Health Model can be applied to categorise families'

risk of adjustment difficulties at diagnosis of a chronic illness. Using this model, most families will fall into a low-risk category, functioning relatively well after an initial adjustment period and requiring minimal psychological support to promote positive adjustment.

These findings in children with chronic illness in general are similar to work conducted in children and young people with type 1 diabetes. A psychosocial screener piloted by Schwartz et al (2014) suggested that 74% of families can be classified as low-risk at diagnosis. However, for some families, the risk of significant psychological issues persists well after the initial diagnosis period. For example, Landolt et al (2002) found that 51% of mothers and 42% of fathers exhibited clinically significant symptoms of post-traumatic stress disorder 1 year after diagnosis. Grey et al (1995) observed a fall in psychiatric symptoms in young people with diabetes over the first year post-diagnosis, but symptom scores started to increase again 2 years post-diagnosis. Thus, the medical team's identification of and attention to signs of maladjustment early in the diagnosis period is critical to help young people achieve optimal glycaemic and quality of life outcomes (Cameron et al, 2007).

Predicting psychological adjustment post-diagnosis

Screening for mood and behavioural concerns at diagnosis can identify an at-risk group of young people who may benefit from additional support during the diagnosis period. Schwartz et al (2011) found that newly diagnosed children at high-risk of later medical difficulties, including poor glycaemic control, emergency department use and missed clinic visits, can be identified by sociodemographic risk factors (e.g. low family income, single parent status) and psychological risk factors (e.g. poor coping skills, behaviour problems and anticipated parent-child conflict) at diagnosis. Depressive symptoms were also predictive in this population and were associated with missed diabetes clinic appointments post-diagnosis (Schwartz et al, 2011). Similarly, parental depressive symptoms have been shown to negatively impact children's psychosocial

adjustment (Jaser et al, 2008), emphasising that parent's adjustment post-diagnosis is a useful indicator of future psychosocial needs in children. Other research has shown that elevated child behaviour problem scores at diagnosis are related to difficulties with mood, anxiety and glycaemic control 10 years later (Northam et al, 2005). This suggests that post-diagnosis adjustment issues should be identified as early as possible to buffer against these long-term difficulties.

Interventions to promote psychological adjustment

Supportive programmes for young people and their families at diagnosis may improve psychological adjustment over time. Rearick et al (2011) piloted a parent mentoring programme for parents of children newly diagnosed with type 1 diabetes. The results indicated improved parental psychosocial functioning, including greater perceived social support and lower perceived impact of the child's diagnosis on daily life. A similar parent-to-parent support programme was piloted in the UK, pairing interested parents with peer coaches for a 6-month period within 1–6 months of type 1 diabetes diagnosis (Channon et al, 2016). Although recruitment rates were relatively low, participating coaches (parent mentors) and newly diagnosed families alike reported satisfaction with the programme.

Mackey et al (2016) piloted a more comprehensive parent-focussed intervention involving trained research telephone counsellors plus parent mentors. Findings indicated that the intervention was feasible and well received; furthermore, providing intervention within the first year of diagnosis provided some protection against worsening glycaemic control in children whose mothers had elevated depressive symptoms near diagnosis. However, it is important to note that some studies have suggested that not all parents prefer to work with mentors (Rankin et al, 2014), suggesting that support services should be customised based on parents' needs and preferences.

Perhaps surprisingly, there has been little research into interventions targeting young people at diagnosis to improve psychosocial adjustment. However, screening for psychosocial

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1. Screening models can be used to predict families' risk of adjustment difficulties at diagnosis. Children and families with sociodemographic and/or psychological risk factors are more likely to have poor glycaemic control and less engagement with healthcare professionals in later years.
2. Support programmes conducted shortly after diagnosis, including peer support for parents, can promote psychological adjustment.

Table 1. Sample of online resources addressing psychological adjustment to a diabetes diagnosis.

Provider	Name	Target audience	Resource description	Link
Diabetes UK	Your Child and Diabetes	Parents	Information and resources for parents of children newly diagnosed with type 1 diabetes. Also includes information about the Diabetes UK Careline	www.diabetes.org.uk/Guide-to-diabetes/Your-child-and-diabetes
DiaTribe Foundation	DiaTribe: Making sense of diabetes	Young people, parents, family and friends	Information on diabetes and potential complications. Resources and columns about adjusting to life with diabetes	http://diatribe.org
JDRF	TypeOneNation	Young people, parents, family and friends	Information, resources and social networks for young people newly diagnosed with type 1 diabetes and their families	http://typeonenation.org
Lilly Diabetes and Disney	T1 Everyday Magic	Children and parents	A partnership to provide children and their families with advice and resources about adjusting to a diagnosis of type 1 diabetes	www.t1everydaymagic.com

concerns at diagnosis is recommended and can lead to more efficient connection with behavioural health services for young people and their families (Cameron et al, 2007). Resilience frameworks suggest that early promotion of skills related to better health and diabetes management, including parent–child communication and teamwork, self-efficacy for diabetes care, positive affect and adaptive coping, can start at diagnosis and initiate a healthier trajectory that may persist into adulthood (Hilliard et al, 2012). In addition, a number of excellent clinical resources exist for this population, including the Type 1 Toolkit from JDRF and online forums for discussion of concerns (e.g. TypeOneNation). Examples of these online resources can be found in *Table 1*.

Clinical implications for diabetes nurses

Better psychological adjustment in the initial months post-diagnosis is associated with better long-term glycaemic control and adherence to medical regimens (Northam et al, 2005; Fogel and Weissberg-Benchell, 2010), so it is important to make the diagnosis period as smooth as possible. The time of diagnosis offers an excellent opportunity to provide initial education about mental health in children and adolescents with diabetes and their families. Mental health practitioners should be an integral part of the interdisciplinary healthcare

team for young people with diabetes. Contact with behavioural health team members from diagnosis can normalise the emotional adjustment process for young people and provide additional opportunities for early identification and intervention for mental health concerns (Jönsson et al, 2010). Nurse educators can also highlight the process of adjusting to a diagnosis of diabetes, including the fact that distress is normal and to be expected in early weeks, but that the majority of young people and families adapt with time.

The International Society for Pediatric and Adolescent Diabetes recommends psychosocial screening to occur at diagnosis and during regularly scheduled follow-up visits (Delamater et al, 2014). To be sustainable and successful, screening measures should be brief, sensitive to issues related to stigma and patient burden, clinically and cost-effective, and easy to interpret, and they should result in referral to appropriate behavioural resources within the diabetes team or in the community (Schwartz et al, 2011). Use of clinical interviewing and validated measures of young people’s behaviour and mood at diagnosis can help to identify young people at risk of mental health concerns or early difficulties with daily diabetes management.

Schwartz et al (2014) validated the Risk Index for Poor Glycemic Control, a psychosocial screening tool administered by nurses or other

members of the treatment team, which can be used to identify young people at risk of future difficulties with glycaemic control. Similarly, Kazak et al (2015) developed a Psychosocial Assessment Tool (PAT 2.0) to identify young people and families at risk of adverse outcomes. This tool was initially developed for use in an oncology sample, but has been piloted with a range of chronic illnesses, including diabetes. Domains assessed in the PAT 2.0 include demographic characteristics, diagnosis, family structure, family resources, school information, child/family mental health concerns, family beliefs and stress responses. The PAT 2.0 provides a risk score that can be used to identify families in need of increased psychological monitoring or treatment for severe, escalating or persistent distress.

Pre-existing difficulties with behaviour or mood may require increased support from the mental health team to determine how these difficulties may impact diabetes care and what resources or interventions should be in place to prevent future difficulties. Furthermore, periods of developmental transition, such as starting school or moving into adolescence, may require increased attention to mental health and family functioning (Hilliard et al, 2012; Delamater et al, 2014). A brief review of best practices can be found in *Box 1*.

Future directions

As more young people are being introduced to complex diabetes technology (e.g. continuous glucose monitors) soon after diagnosis, it is increasingly important to attend to their psychological experience. Psychosocial barriers to diabetes technology such as continuous glucose monitoring include increased perceived burden, worry about glycaemic excursions and related impact on quality of life (Phillip et al, 2012). Research has documented the importance of early assessment and intervention to improve coping and adjustment in order to prevent later difficulties with mood and glycaemic control; however, few mental health interventions have targeted the sensitive period immediately post-diagnosis, particularly in children and adolescents. Screening programmes suggest that

Box 1. Practice recommendations for addressing mental health at diagnosis.

- Include behavioural health as part of the interdisciplinary diabetes treatment team.
- Note demographic characteristics that may place the young person and family at risk of difficulties with adjustment.
- Complete psychosocial screening to assess:
 - Child mood.
 - Child behaviour.
 - Family strengths/weaknesses and areas of need.
- Provide resources and support to families at diagnosis to normalise the mental health experience and promote healthy coping.
- Attend to developmental transitions that may require increased support.
- Consider offering peer-to-peer coaching for parents requesting support at diagnosis.

young people and families at high risk of later glycaemic and mental health difficulties can be identified soon after a diagnosis of diabetes; however, it is not yet known whether provision of tailored intervention early in the diagnosis process can reduce these later risks.

Resilience-based frameworks suggest that family-centred diabetes self-management education can work to identify and promote young people and their families' strengths. While temporary distress is common in the initial period after diagnosis, many adapt to a diagnosis of diabetes and will not require more intensive behavioural support. Diabetes nurses play a critical role in helping young people and their families process the diabetes diagnosis and incorporate diabetes care into their daily lives. Early identification and referral of those who may experience persistently elevated distress promotes adjustment and hopefully contributes to a positive trajectory of health and mental health that continues into adulthood. ■

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“Diabetes nurses play a critical role in helping young people and their families process the diabetes diagnosis and incorporate diabetes care into their daily lives. Early identification and referral of those who may experience persistently elevated distress promotes adjustment and hopefully contributes to a positive trajectory of health and mental health that continues into adulthood.”

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