

Successful team management of type 1 diabetes in children and young people: Key psychosocial issues

Alan M Delamater

Citation: Delamater AM (2012) Successful team management of type 1 diabetes in children and young people: key psychosocial issues. *Diabetes Care for Children & Young People* 1: 10–6

Article points

1. Studies show that despite advances in medical treatments, most children and young people with diabetes do not meet glycaemic control targets, and regimen adherence problems are common.
2. Key psychosocial issues that increase risk for glycaemic control problems include inadequate blood glucose monitoring and problem-solving, insulin misuse, depression and eating disorders, family conflict and inconsistent contact with the healthcare team.
3. A patient-centred, collaborative model of interdisciplinary team diabetes management that recognises young person and family autonomy and promotes and supports family teamwork is a skillful approach to improving diabetes self-management in children and young people.

Key words

- Behavioural intervention
- Family functioning
- Psychosocial issues
- Regimen adherence

Author

Alan M Delamater, PhD, Professor in Paediatrics and Psychology, Department of Paediatrics, University of Miami Miller School of Medicine, Florida, USA.

Despite advances in medical treatments and technologies, most children and young people with type 1 diabetes do not attain optimal glycaemic control, many are not on intensified insulin regimens and regimen adherence problems are common. A number of controlled studies have demonstrated the efficacy of behavioural interventions to improve regimen adherence and glycaemic control in this group. This article describes an ecological model for understanding glycaemic control difficulties and identifies key psychosocial issues related to diabetes management. High-risk demographics and situations include: ethnic minority and low-income family status; inadequate blood glucose monitoring and problem-solving skills; insulin misuse; depression and eating disorders; family conflict; and inconsistent contact with the healthcare team. The patient-centered chronic care model is described as a skillful approach to increasing the probability of successful team management of diabetes in children and young people. Opportunities for future research are identified.

Type 1 diabetes in children is increasing in incidence worldwide and being diagnosed at earlier ages (Gale, 2002; Patterson et al, 2009). In recent years, there have been many advances in medical treatments for diabetes, including: new fast-acting insulins; efficient and accurate blood glucose (BG) monitoring meters; continuous glucose monitoring systems and smart insulin pumps with capability to download data to computers for the analysis of patterns of BG; basal and bolus administrations; and carbohydrate intake. Despite these technological advances, optimal glycaemic control is attained by relatively few children and young people with diabetes.

It is well known that HbA_{1c} levels near to normal reduce the long-term health complications associated with diabetes, yet the translation of the results of the Diabetes Control and Complications

Trial (DCCT) to routine clinical practice remains a challenge for healthcare teams nearly 20 years after its publication (DCCT Research Group, 1993; 1994). For example, research findings indicate that less than one-third of children and young people have an HbA_{1c} less than recommended targets in the USA (Petitti et al, 2009) and in Europe (de Beaufort et al, 2007; Hanberger et al, 2008), and many have poor glycaemic control (>75 mmol/mol [9%]). Data from the *National Diabetes Audit Paediatric Report 2009–2010* (NHS Information Centre, 2011) showed that in the UK just 14.5% of young people had an HbA_{1c} <58 mmol/mol (7.5%), and over 30% had an HbA_{1c} >80 mmol/mol (9.5%).

This article describes an ecological model for understanding factors associated with glycaemic control in children and young people with type 1 diabetes, reviews research related to key psychosocial

issues, identifies high-risk situations for poor glycaemic control, discusses clinical implications for successful team management of diabetes in children and identifies opportunities for future research.

Ecological model of glycaemic control

It is helpful to use an ecological model to understand factors influencing glycaemic control outcomes in children and young people with diabetes. There are many factors to consider, each of which can be visualised as rings around the centre concept of the young person's glycaemic control (*Figure 1*), which comprise:

- Young person's characteristics.
- Parent, family and social factors.
- Medical system characteristics.

Young person's characteristics

Studies indicate that later age, female gender and longer diabetes duration are associated with higher HbA_{1c} (Petitti et al, 2009). It is also clear that child demographic factors are important to consider, as studies show that children from lower-income, ethnic minority families and children who do not speak the language of the majority culture and have greater difficulty communicating with the healthcare team are at greater risk for glycaemic control problems (Delamater et al, 1999; de Beaufort et al, 2007; Petitti et al, 2009). There is also evidence that more frequent self-monitoring of BG (SMBG) and use of insulin pumps is associated with improved glycaemic control (Paris et al, 2009); however, it is also clear that not all children and young people who check their BG frequently and use insulin pumps attain optimal glycaemic control.

It has been well documented that regimen adherence and glycaemic control declines from childhood to adolescence (Johnson et al, 1992; Helgeson et al, 2010a). Weissberg-Benchell et al (1995) showed that low rates of SMBG were reported by many young people, and 30% admitted to fabricating BG results; only 22% reported never making up a BG result. Wysocki et al (2008) found that even if young people checked their BG, many did not use the results for problem-solving.

Insulin misuse is also common among young people. Research has shown that only 40% of adolescents report never missing an insulin dose (Weissberg-Benchell et al, 1995), up to 30% of

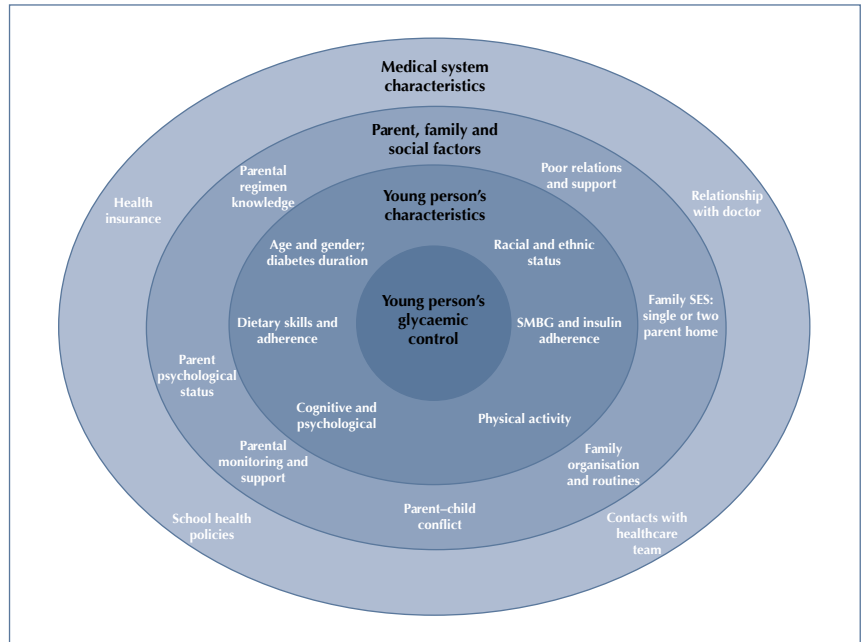


Figure 1. Ecological model of predictors of glycaemic control in children and young people with diabetes. SES=socioeconomic status; SMBG=self-monitoring of blood glucose.

adolescent girls under-dose to control their weight (Neumark-Sztainer et al, 2002) and missed meal boluses are common (Burdick et al, 2004). It is challenging for many young people to understand the composition of the foods they eat in terms of grams of carbohydrate, protein and fat, and then to calculate the optimal insulin bolus to cover the food they are about to consume or have consumed.

Children and young people with diabetes do not differ from those without diabetes, in that they are not getting enough regular physical activity. This is important, not only because physical activity improves cardiovascular and muscular fitness, but also because increased physical activity is associated with improved insulin sensitivity (Schmitz et al, 2002), a factor important to good glycaemic control.

Cognitive and psychological factors are also important considerations when trying to understand adherence and glycaemic control difficulties. Healthcare professionals are concerned with HbA_{1c} results and in helping patients attain targets for optimal glycaemic control. However, Patino-Fernandez et al (2009) examined young people's understanding of the HbA_{1c} test and its implications, and reported that few could accurately define the test and even fewer understood the BG ranges associated with various HbA_{1c} levels. McNally et

Page points

1. Eating disorders and disordered eating are additional psychological factors that have important implications for diabetes management; disordered eating has been associated with insulin omission, higher HbA_{1c} and later increased risk of microvascular complications.
2. Adolescence is often a period of increased stress as young people struggle with normal developmental tasks of self-identity, peer relationships and plans for adulthood; having diabetes makes this already complicated developmental period even more challenging.
3. Many studies have shown that family conflict is associated with decreased regimen adherence and poor glycaemic control, while parental support, clear communication and increased monitoring of regimen behaviour is associated with improved regimen adherence and glycaemic control.

al (2010) showed that executive functioning skills are associated with better regimen adherence and glycaemic control, and that adherence mediates the relationship between executive functioning and glycaemic control. Early studies showed that better adherence and glycaemic control could be predicted by self-efficacy (Grossman et al, 1987), specific health beliefs (Brownlee-Duffeck et al, 1987) and cognitive maturity (Wysocki et al, 1996). These are important factors, but it is helpful to note that many young people underestimate their own risk for diabetes-related complications despite acknowledging others' risks (Patino et al, 2005).

Regarding psychological factors, studies indicate that depression and anxiety are associated with decreased SMBG and higher HbA_{1c} (Hood et al, 2006; Herzer and Hood, 2010; McGrady and Hood, 2010). From the SEARCH study, a multi-site, population-based study of diabetes among young people in the USA (Lawrence et al, 2006), 14% of young people reported mild depression, 8.6% reported moderate to severe depression, with more girls reporting depressive symptoms than boys, and depression was associated with higher HbA_{1c} and increased diabetes-related admissions to accident and emergency departments. Fortenberry et al (2011) showed that perceived control buffered the association between negative affect and poor self-care, indicating that effective cognitive coping abilities may attenuate the adverse effects of negative emotions on diabetes care.

Eating disorders and disordered eating are additional psychological factors that have important implications for diabetes management. Research has shown that at least 10% of teenage girls with diabetes have an eating disorder (Jones et al, 2000), 17% have disordered eating behaviour (Engstrom et al, 1999) and 38% have unhealthy weight-control behaviour (Neumark-Sztainer et al, 2002), a problem that is increasingly being recognised in boys. This is significant because disordered eating has been associated with insulin omission, higher HbA_{1c} and later increased risk of microvascular complications (Rydall et al, 1997). Disordered eating behaviour can be predicted by body image problems and depression (Olmsted et al, 2008), risk factors that healthcare teams should monitor in young people.

Adolescence is often a period of increased stress as young people struggle with normal developmental tasks of self-identity, peer relationships and plans for adulthood; having diabetes makes this already complicated developmental period even more challenging. Increased life stress and maladaptive coping have been documented correlates of decreased self-care behaviour and poor glycaemic control (Delamater, 2009). Berg et al (2009) have shown that coping effectiveness is related to less depression, more self-efficacy and better adherence. In another study (Helgeson et al, 2010b), stressful life events predicted psychological distress, decreased adherence and higher HbA_{1c} over time.

Diabetes also affects the neurocognitive development of children and young people. In a meta-analysis, Naguib et al (2009) found that some children with type 1 diabetes had a variety of mild cognitive impairments and slightly reduced overall intellectual functioning. In a prospective study from Australia, Lin et al (2010) demonstrated that, 12 years after diagnosis, participants with diabetes performed more poorly on working memory; additionally, early onset and a history of significant hypoglycaemia or hyperglycemia were related to poorer attention, learning and mental efficiency. Other work in this area (Patino-Fernandez et al, 2010) has shown that hyperglycaemia is associated with decreased neurocognitive abilities among pre-school-aged children with type 1 diabetes.

Parent, family and social factors

There is a substantial research base documenting the important role of social factors in diabetes management, including parental and family functioning as well as peer relationships and support (Delamater, 2009). For example, family sociodemographic factors such as low income and single parenthood are associated with greater risk for glycaemic control problems (Thompson et al, 2001). Many studies have shown that family conflict is associated with decreased regimen adherence and poor glycaemic control, while parental support, clear communication and increased monitoring of regimen behaviour is associated with improved regimen adherence and glycaemic control (Wysocki, 1993; Miller-Johnson et al, 1994; Anderson et al, 1997; 1999). Family conflict and negative affect related to BG monitoring has also been associated with depression in children (Hood et al, 2006).

Better diabetes outcomes are associated with general functioning in the family, such as more structured family routines, cohesion and authoritative parenting style (Davis et al, 2001; Greening et al, 2006; Shorer et al, 2011). Having a collaborative relationship between the parent and the young person with shared responsibilities for diabetes management is particularly important, and is associated not only with better regimen adherence but also with improved emotional adjustment (Berg et al, 2008; Helgeson et al, 2008). Studies focusing on parental functioning indicate that maternal depression may undermine care-giving effectiveness, and perceived parental burden of diabetes management is associated with poor glycaemic control in children (Cunningham et al, 2011; Wiebe et al, 2011).

Peer relationships are also important in diabetes management, as children and young people may receive considerable emotional support from their friends (La Greca et al, 1995). When young people attribute negative peer reactions to their self-care, they are more likely to have adherence difficulties and increased diabetes stress, which in turn worsen glycaemic control (Hains et al, 2007). On the other hand, when peers are trained about diabetes in the school setting, children with diabetes report a better quality of life (Wagner et al, 2006). Helgeson et al (2009) showed that poor peer relations were related to decreased regimen adherence and worse glycaemic control, while more family support predicted better glycaemic control.

Medical system and community factors

Studies indicate that young people who have inconsistent and infrequent contact with the healthcare team are more likely to have glycaemic control problems (Jacobson et al, 1997; Kaufman et al, 1999). In a prospective study (Helgeson et al, 2010a), poor glycaemic control was predicted by missed clinic visits, peer conflict, negative affect and decreased levels of BG monitoring. There is a large body of literature indicating that the quality of relationship between healthcare provider and patient is an important determinant of regimen adherence in chronic illness care (Delamater, 2006), although few studies have focused on children and young people with diabetes.

In the SEARCH study, Paris et al (2009) found that prescriptions for more intensified insulin regimens including pump therapy were associated with family demographics, including higher socioeconomic status and parental education; additionally, children from ethnic minority groups were less likely to be on insulin pump therapy. Valenzuela et al (2011) also found that children from ethnic minorities were less often prescribed insulin pump therapy, and that the intensity of the insulin regimen was related to the physician's perceptions of family functioning and child competence. However, research demonstrates that young people should not be denied access to regimen intensification based on perceptions of limited competence, as even young people with low self-management competence have been shown to improve with intensive insulin therapy (Wysocki et al, 2003). A report from the Hvidoere Study (Swift et al, 2010) indicated that setting glycaemic targets with young people and their parents was associated with improved glycaemic control.

School policies relating to diabetes management are another factor in the ecological model that may affect diabetes outcomes in children and young people. Some parents report that school policies often restrict optimal diabetes self-care activities; Wagner et al (2006) have shown that training teachers about diabetes management and having flexible policies for diabetes self-care in school is associated with improved glycaemic control.

Clinical implications

Given the significant role of psychosocial factors in the management of type 1 diabetes in children and young people, guidelines issued by international professional organisations such as the International Society for Paediatric and Adolescent Diabetes (Delamater, 2009; ISPAD, 2009) have focused on comprehensive care provided by interdisciplinary healthcare teams. It is recognised that successful team management of diabetes in children requires specialist physicians, nurses and dietitians, as well as professionals with expertise in mental and behavioural health, including psychologists, social workers and psychiatrists (Thompson et al, 2012).

In order to increase the probability of successful team management, the team should strive to maintain consistent contact with patients and families and use other modalities of communication when visits are

Page points

1. When young people attribute negative peer reactions to their self-care, they are more likely to have adherence difficulties and increased diabetes stress, which in turn worsen glycaemic control.
2. School policies related to diabetes management are another factor in the ecological model that may affect diabetes outcomes in children and young people; some parents report that school policies often restrict optimal diabetes self-care activities.
3. In order to increase the probability of successful team management, the team should strive to maintain consistent contact with patients and families and use other modalities of communication when visits are missed, such as telephone, text and email contacts.

“While there may be no substitute for intensive clinical interventions for young people with significant psychosocial disorders and diabetes management problems, electronic health (“e-Health”) interventions show promise for reaching young people that may benefit from increased monitoring and support.”

missed, such as telephone, text and email contacts. The interdisciplinary healthcare team should regularly screen for the presence of several key psychosocial risk factors, such as: depression; eating disorders; other significant emotional, behavioural or body image problems; family conflict or lack of appropriate involvement in diabetes management; inadequate BG monitoring and problem-solving skills; and insulin misuse. Risk factors for poor glycaemic control, such as low family income, ethnic minority status and single parenthood, should prompt careful assessment of diabetes management knowledge, skills and behaviour. In particular, it is recommended that family interaction around diabetes management tasks be routinely assessed.

When parents allow children to have self-care autonomy without cognitive and social maturity, there are more problems with diabetes management (Wysocki et al, 1996). The ISPAD guidelines for psychological care of children and young people with diabetes detail specific strategies for successful diabetes management (Delamater, 2009). These are also consistent with the needs of parents, who are concerned not only with their child’s HbA_{1c} levels, but also with their child’s developmental progress in all areas and their child’s quality of life. Therefore, assessment of quality of life during routine clinic visits may help identify areas of concern. There is evidence that such an approach can improve psychosocial well-being in young people over time (de Wit et al, 2008).

A skilful approach by healthcare professionals is to provide autonomy support to children and young people with diabetes to enhance self-management over time, as they and their parents are essentially in control of diabetes management decision-making on a daily basis. In collaborative team care, consistent with the chronic disease model (Wagner et al, 2001), healthcare providers talk with the young person with diabetes, set mutually agreed upon goals and provide support over time. Cooperation and respect are an essential feature of the relationship between young people and the healthcare team. This empowerment approach to diabetes management has been consistently associated with improved outcomes in adults (Funnell and Anderson, 2004). Successful healthcare team management of diabetes therefore requires a philosophical approach that recognises and supports young people with diabetes and their family autonomy.

The research literature on diabetes in children and young people has provided support for the efficacy of a number of behavioural interventions to promote regimen adherence and improve glycaemic control (Delamater, 2009; Hood et al, 2010). As summarised by Delamater (2009), family-based behavioural interventions – such as goal-setting, increased self-monitoring, social reinforcements, contracts and supportive parental involvement, psychoeducational interventions to improve diabetes problem-solving, coping skills training and interventions to increase motivation – have also been shown to improve regimen adherence and glycaemic control. A key question for healthcare teams is how to deliver these interventions in routine clinical care.

One approach is to integrate preventive interventions in routine clinic visits. For example, there is evidence that an in-clinic intervention designed to promote family teamwork in diabetes management can improve health outcomes in children (Laffel et al, 2003). This seems reasonable for most children and families and can be conceptualised as a team practice to prevent poor diabetes management. However, for children and young people with significant glycaemic control problems, psychological disorders and family dysfunction, it is unlikely that 20-minute interventions delivered in-clinic three to four times per year would be sufficient to have a clinical impact; these young people require far more intensive intervention approaches. Thus a key issue for healthcare teams is how to deliver these interventions outside of the research setting.

While there may be no substitute for intensive clinical interventions for young people with significant psychosocial disorders and diabetes management problems, electronic health (“e-Health”) interventions show promise for reaching young people that may benefit from increased monitoring and support. For example, Mulvaney et al (2010) demonstrated the initial efficacy of an internet-delivered, problem-solving intervention that improved regimen adherence and glycaemic control.

Opportunities for future research

There have been considerable advances in recent years concerning psychosocial factors and interventions to improve health outcomes in children and young people with type 1 diabetes, yet many opportunities

for future research remain. In particular, there is a need for more longitudinal studies that cover key developmental periods, including the transition from childhood to early adolescence and from late adolescence to early adulthood. Study designs will benefit by including larger sample sizes that may require multiple study sites to increase the generalisability of the findings. A key issue is learning more about health disparities, and interventions to reduce these disparities remains a priority.

Intervention research should focus on effectiveness in clinical settings, rather than efficacy in controlled research settings. In particular, there is a need for interventions to: intensify regimens and improve glycaemic control from diabetes onset; increase intrinsic motivation and adopt more intensive regimens in young people with poor glycaemic control; target more effective boluses in young people on the insulin pump; reduce depression and distress; promote effective family teamwork; prevent the expected deterioration of regimen adherence and glycaemic control in early adolescence; and improve the transition of care in late adolescence. More studies are needed to learn how children and young people use new technologies in diabetes care, such as continuous glucose monitoring and sensor-augmented pump therapy. More studies are also needed to increase reach to children and young people through integrated in-clinic psychosocial interventions, as well as through innovative “e-Health” interventions using websites and mobile technology. An important factor for future intervention research designs is the incorporation of health economic measures to demonstrate cost-effectiveness.

Conclusion

Effective management of type 1 diabetes remains a challenge for many children and young people, their families and healthcare teams. Despite advances in medical treatments and technologies, optimal glycaemic control is not attained by most children and young people with diabetes. Regimen adherence problems are common and can be understood through ecological analysis as being related to modifiable factors at personal, family, social and medical system and policy levels. A patient-centred, collaborative model of interdisciplinary team diabetes management that recognises young person and family autonomy and

promotes and supports family teamwork is a skillful approach to improving diabetes self-management in children and young people. Effectiveness trials with health economic measures are needed to improve adoption and translation to clinical settings, and “e-Health” interventions show promise for increasing reach to children and young people with diabetes. Translation of behavioural interventions into routine clinical practice settings remains a priority and a challenge. ■

- Anderson BJ, Ho J, Brackett J et al (1997) Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *J Pediatr* **130**: 257–65
- Anderson BJ, Brackett J, Ho J, Laffel L (1999) An office-based intervention to maintain parent-adolescent teamwork in diabetes management: impact on parent involvement, family conflict and subsequent glycaemic control. *Diabetes Care* **22**: 713–21
- Berg CA, Schindler I, Maharajh S (2008) Adolescents' and mothers' perceptions of the cognitive and relational functions of collaboration and adjustment in dealing with type 1 diabetes. *J Fam Psychol* **22**: 865–74
- Berg CA, Skinner M, Ko K et al (2009) The fit between stress appraisal and dyadic coping in understanding perceived coping effectiveness for adolescents with type 1 diabetes. *J Fam Psychol* **23**: 521–30
- Brownlee-Duffeck M, Peterson L, Simonds, JF et al (1987) The role of health beliefs in the regimen adherence and metabolic control of adolescents and adults with diabetes mellitus. *J Consult Clin Psychol* **55**: 139–44
- Burdick J, Chase HP, Slover RH et al (2004) Missed insulin meal boluses and elevated haemoglobin HbA_{1c} levels in children receiving insulin pump therapy. *Pediatrics* **113**: 221–4
- Cunningham NR, Vesco AT, Dolan L, Hood K (2011) From caregiver psychological distress to adolescent glycaemic control: the mediating role of perceived burden around diabetes management. *J Pediatr Psychol* **36**: 196–205
- Davis CL, Delamater AM, Shaw KH et al (2001) Parenting styles, regimen adherence and glycaemic control in 4–10-year-old children with diabetes. *J Pediatr Psychol* **26**: 123–9
- de Beaufort CE, Swift PGF, Skinner CT et al (2007) Continuing stability of centre differences in paediatric diabetes care: do advances in diabetes treatment improve outcome? The Hvidoere Study Group on Childhood Diabetes. *Diabetes Care* **30**: 2245–50
- Delamater AM (2006) Improving patient adherence. *Clin Diabetes* **24**: 71–7
- Delamater AM (2009) Psychological care of children and adolescents with diabetes. *Pediatr Diabetes* **10**: 175–84
- Delamater AM, Shaw K, Applegate B et al (1999) Risk for metabolic control problems in minority youth with diabetes. *Diabetes Care* **22**: 700–5
- de Wit M, Delemarre-van der Waal HA et al (2008) Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improve psychosocial well-being: a randomised, controlled trial. *Diabetes Care* **31**: 1521–6
- Diabetes Control and Complications Trial (DCCT) Research Group (1993) The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* **329**: 977–86
- Diabetes Control and Complications Trial (DCCT) Research Group (1994) Effect of intensive insulin treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus. *J Pediatr* **125**: 177–88
- Engstrom I, Kroon M, Arvidsson CG et al (1999) Eating disorders in adolescent girls with insulin-dependent diabetes mellitus: a population-based, case-control study. *Acta Paediatr* **88**: 175–80
- Fortenberry KT, Wiebe DJ, Berg CA (2011) Perceptions of treatment control moderate the daily association between negative affect and diabetes problems among adolescents with type 1 diabetes. *Psychol Health*. DOI:10.1080/08870446.2011.561925. Available at: <https://t-mail.com/r/38197/21678164/> (accessed 30.04.12)

Page points

1. There is a need for interventions to: intensify regimens and improve glycaemic control from diabetes onset; increase intrinsic motivation and adopt more intensive regimens in young people with poor glycaemic control; target more effective boluses in young people on the insulin pump; reduce depression and distress; promote effective family teamwork; prevent the expected deterioration of regimen adherence and glycaemic control in early adolescence; and improve the transition of care in late adolescence.
2. More studies are also needed to increase reach to patients through integrated in-clinic psychosocial interventions, as well as through innovative “e-Health” interventions using internet websites and mobile technology.

“A patient-centred, collaborative model of interdisciplinary team diabetes management that recognises young person and family autonomy and promotes and supports family teamwork is a skillful approach to improving diabetes self-management in children and young people.”

- Funnell M, Anderson R (2004) Empowerment and self-management of diabetes. *Clin Diabetes* **22**: 123–7
- Gale E (2002) The rise of childhood type 1 diabetes in the 20th century. *Diabetes* **51**: 335–61
- Greening L, Stoppelbein L, Konishi C et al (2006) Child routines and youths' adherence to treatment for type 1 diabetes. *J Pediatr Psychol* **32**: 437–47
- Grossman HY, Brink S, Hauser ST (1987) Self-efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care* **10**: 324–9
- Hains AA, Berlin KS, Davies WH et al (2007) Attributions of adolescents with type 1 diabetes related to performing diabetes care around friends and peers: the moderating role of friend support. *J Pediatr Psychol* **32**: 561–70
- Hanberger L, Samuelsson U, Lindblad B, Ludvigsson J (2008) HbA_{1c} in children and adolescents with diabetes in relation to certain clinical parameters: the Swedish childhood diabetes registry SWEDIABKIDS. *Diabetes Care* **31**: 927–9
- Helgeson VS, Reynolds KA, Siminerio L et al (2008) Parent and adolescent distribution of responsibility for diabetes self-care: links to health outcomes. *J Pediatr Psychol* **33**: 497–508
- Helgeson VS, Siminerio L, Escobar O, Becker D (2009) Predictors of metabolic control among adolescents with diabetes: a 4-year longitudinal study. *J Pediatr Psychol* **34**: 254–70
- Helgeson VS, Snyder PR, Seltman H et al (2010a) Brief report: trajectories of glycaemic control over early to middle adolescence. *J Pediatr Psychol* **35**: 1161–7
- Helgeson VS, Siminerio L, Escobar O, Becker D (2010b) Relation of stressful life events to metabolic control among adolescents with diabetes: 5-year longitudinal study. *Health Psychol* **29**: 153–9
- Herzer M, Hood KK (2010) Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycaemic control. *J Pediatr Psychol* **35**: 415–25
- Hood KK, Huestis S, Maher A et al (2006) Depressive symptoms in children and adolescents with type 1 diabetes. *Diabetes Care* **29**: 1389
- Hood KK, Rohan J, Peterson C, Drotar D (2010) Interventions with adherence-promoting components in paediatric type 1 diabetes: meta-analysis of their impact on glycaemic control. *Diabetes Care* **33**: 1658–64
- International Society for Paediatric and Adolescent Diabetes (ISPAD) (2009) *ISPAD Clinical Practice Consensus Guidelines 2009*. Available at: <http://www.ispad.org/FileCenter.html?CategoryID=5> (accessed 30.04.12)
- Jacobson AM, Hauser ST, Willett J et al (1997) Consequences of irregular versus continuous medical follow-up in children and adolescents with insulin-dependent diabetes mellitus. *J Pediatr* **131**: 727–33
- Johnson SB, Kelly M, Henretta JC et al (1992) A longitudinal analysis of adherence and health status in childhood diabetes. *J Pediatr Psychol* **17**: 537–53
- Jones JM, Lawson ML, Daneman D et al (2000) Eating disorders in adolescent females with and without type 1 diabetes: cross-sectional study. *BMJ* **20**: 1563–6
- Kaufman FR, Halvorson M, Carpenter S (1999) Association between diabetes control and visits to a multidisciplinary paediatric diabetes clinic. *Pediatrics* **103**: 948–51
- La Greca AM, Auslander WF, Greco P et al (1995) I get by with a little help from my family and friends: adolescents' support for diabetes care. *J Pediatr Psychol* **20**: 449–76
- Laffel L, Vangsness L, Connell A et al (2003) Impact of ambulatory, family-focused teamwork intervention on glycaemic control in youth with type 1 diabetes. *J Pediatr* **142**: 409–16
- Lawrence JM, Standiford DA, Loots B et al (2006) Prevalence and correlates of depressed mood among youth with diabetes: the SEARCH for diabetes in youth study. *Pediatrics* **117**: 1348–58
- Lin A, Northam EA, Rankins D et al (2010) Neuropsychological profiles of young people with type 1 diabetes 12 years after disease onset. *Pediatr Diabetes* **11**: 235–43
- McGrady ME, Hood KK (2010) Depressive symptoms in adolescents with type 1 diabetes: associations with longitudinal outcomes. *Diabetes Res Clin Pract* **88**: 35–7
- McNally K, Rohan J, Shroff Pendley J et al (2010) Executive functioning, treatment adherence and glycaemic control in children with type 1 diabetes. *Diabetes Care* **33**: 1159–62
- Miller-Johnson S, Emery R, Marvin R et al (1994) Parent-child relationships and the management of insulin-dependent diabetes mellitus. *J Consult Clin Psychol* **62**: 603–10
- Mulvaney S, Rothman R, Wallston KA et al (2010) An internet-based program to improve self-management in adolescents with type 1 diabetes. *Diabetes Care* **33**: 602–4
- Naguib JM, Kulinskaya E, Lomax CL, Garralda ME (2009) Neurocognitive performance in children with type 1 diabetes: a meta-analysis. *J Pediatr Psychol* **34**: 271–82
- Neumark-Sztainer D, Patterson J, Mellin A et al (2002) Weight control practices and disordered eating behaviours among adolescent females and males with type 1 diabetes. *Diabetes Care* **25**: 1289–96
- NHS Information Centre (2011) *National Diabetes Audit Paediatric Report 2009–2010*. Available at: www.ic.nhs.uk/diabetesaudits (accessed 26.04.12)
- Olmsted MP, Colton PA, Daneman D et al (2008) Prediction of the onset of disturbed eating behavior in adolescent girls with type 1 diabetes. *Diabetes Care* **31**: 1978–82
- Paris CA, Imperatore G, Klingensmith G et al (2009) Predictors of insulin regimens and impact on outcomes in youth with type 1 diabetes: the SEARCH for diabetes in youth study. *J Pediatr* **155**: 183–9
- Patino-Fernandez AM, Delamater AM, Applegate EB et al (2010) Neurocognitive functioning in preschool-age children with type 1 diabetes mellitus. *Pediatr Diabetes* **11**: 424–30
- Patino-Fernandez AM, Eidson M, Sanchez J, Delamater AM (2009) What do youth with type 1 diabetes know about the HbA_{1c} test? *Child Health Care* **38**: 157–67
- Patino AM, Sanchez J, Eidson M, Delamater AM (2005) Health beliefs and regimen adherence in minority adolescents with type 1 diabetes. *J Pediatr Psychol* **30**: 503–12
- Patterson CC, Dahlquist GG, Gyurus E et al (2009) Incidence trends for childhood type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–2020: a multicentre, prospective registry study. *Lancet* **373**: 2027–33
- Petitti D, Klingensmith G, Bell RA et al (2009) Glycaemic control in youth with diabetes: the SEARCH for diabetes in youth study. *J Pediatr* **155**: 668–72
- Rydall AC, Rodin GM, Olmsted MP et al (1997) Disordered eating behaviour and microvascular complications in young women with insulin-dependent diabetes mellitus. *N Engl J Med* **336**: 1849–54
- Schmitz KH, Jacobs DR, Hong CP et al (2002) Association of physical activity with insulin sensitivity in children. *Int J Obes Rel Met Dis* **26**: 1310–16
- Shorer M, David R, Schoenber-Taz M et al (2011) Role of parenting style in achieving metabolic control in adolescents with type 1 diabetes. *Diabetes Care* **34**: 1735–7
- Swift PGF, Skinner TC, de Beaufort CE et al (2010) Target setting in intensive insulin management is associated with metabolic control: the Hvidoere Childhood Diabetes Study Group centre differences study 2005. *Pediatr Diabetes* **11**: 271–8
- Thompson SJ, Auslander WF, White NH (2001) Comparison of single-mother and two-parent families on metabolic control of children with diabetes. *Diabetes Care* **24**: 234–8
- Thompson R, Delamater AM, Gerbert R, Christie D (2012) Integrated care and multidisciplinary team work: the role of the different professionals. In: Christie D, Martin C, eds. *Psychosocial Aspects of Diabetes: Children, Adolescents and their Families*. Radcliffe Publishing Ltd, London: 101–12
- Valenzuela JM, La Greca AM, Hsin O et al (2011) Prescribed regimen intensity in diverse youth with type 1 diabetes: role of family and provider perceptions. *Pediatr Diabetes* **12**: 696–703
- Wagner EH, Austin BT, Davis C et al (2001) Improving chronic illness care: translating evidence into action. *Health Affairs* **20**: 64–78
- Wagner J, Heapy A, James A, Abbott G (2006) Glycaemic control, quality of life and school experiences among students with diabetes. *J Pediatr Psychol* **31**: 764–9
- Weissberg-Benchell J, Glasgow AM, Tynan WD et al (1995) Adolescent diabetes management and mismanagement. *Diabetes Care* **18**: 77–82
- Wiebe DJ, Gelfand D, Butler JM et al (2011) Longitudinal associations of maternal depressive symptoms, maternal involvement and diabetes management across adolescence. *J Pediatr Psychol* **36**: 837–46
- Wysocki T (1993) Associations among teen-parent relationships, metabolic control and adjustment to diabetes in adolescents. *J Pediatr Psychol* **18**: 441–52
- Wysocki T, Taylor A, Hough B et al (1996) Deviation from developmentally appropriate self-care autonomy: association with diabetes outcomes. *Diabetes Care* **19**: 119–25
- Wysocki T, Harris M, Wilkinson K et al (2003) Self-management competence as a predictor of outcomes of intensive therapy or usual care in youth with type 1 diabetes. *Diabetes Care* **26**: 2043–7
- Wysocki T, Iannotti R, Weissberg-Benchell J et al (2008) Diabetes problem solving by youths with type 1 diabetes and their caregivers: measurement, validation and longitudinal associations with glycaemic control. *J Pediatr Psychol* **33**: 875–84