Psychosocial risk screening for children and adolescents at diabetes onset

Anna Lindholm Olinder, Janeth Leksell

Person-centred care highlights the importance of knowing the person behind the patient in order to engage that person as an active partner in his/her care and treatment. When a child gets diabetes the whole family needs to be involved and the parents are often the primary caregivers. We therefore suggest that the concept of family-centred care is more suitable in this context. Taking care of diabetes – for example, self-management of diabetes – in children and adolescents is an active and proactive process that involves activities and goals, and is continuously ongoing. It involves shared but shifting responsibility for diabetes care and decision making between the child and their parents, and it is a process that also involves health care staff.

To be able to plan the treatment and care together with the parents and the child, it is necessary to know/collect data regarding the family’s abilities and needs.

The incidence of type 1 diabetes among children and adolescents is increasing. Unfortunately, several children and adolescents have poor glycaemic control, and only 30% reach the recommended HbA1c target. The Diabetes Control and Complications Trial and follow-up data clearly indicate that poor glycaemic control increases the risk of severe complications, such as nephropathy and retinopathy later in life. The importance of good glycaemic control from onset of diabetes is shown in a recently published study. High HbA1c levels during the first three to 15 months after diagnosis in children is related to glycaemic control and complications in early adulthood.

The reasons for poor glycaemic control are often unknown, and there are no or few strategies to support these children. The root of the problem is probably both biological and psychosocial and/or a mix of these factors. We know from clinical practice as well as anecdotes and research that self-management of diabetes can be burdensome. Great demands are placed on achieving a functioning self-management at home, which can be difficult in families with unsolved psychosocial problems. For each meal a dose of insulin is needed; which dose to be administered is dependent on several factors and frequent blood glucose monitoring is therefore of utmost importance. It is well known that a healthy lifestyle with good diet and regular exercise is an important part of the treatment in order to achieve good glycaemic control. Factors such as mental illness contribute to an unsatisfactory level of glycaemic control. For diabetes teams this highlights the importance of person-centred/family-centred care.

Screening of psychosocial risk factors can be useful in order to be able to give each family the required care, education and support. Psychosocial screening in diabetes care has been recommended by both the American Diabetes Association and the International Society for Pediatric and Adolescent Diabetes (ISPAD). A lack of a simple, brief screening tool has been a hindrance until now.

However, in a recently published article, Schwartz et al. describe the development and validation of the ‘Risk Index for Poor Glycaemic Control’ (RI-PGC). RI-PGC was used in connection with the onset of diabetes in 196 children, aged 3–18 years, and their families. Glycaemic control was evaluated one to four years post diagnosis. Higher scores on the RI-PGC predicted poor glycaemic control, diabetes-related emergency visits and diabetic ketoacidosis. The screening tool can be used by physicians and diabetes nurses, and does not require a psychologist’s input.

Psychosocial risk factors for poor glycaemic control

RI-PGC screens for nine risk factors: Medicaid insurance, caregiver’s unemployment, single parent, large family, child behaviour, child mood, social problems, family conflicts and parental stress. If three or more of these factors are present, the risk for poor glycaemic control is high.

These risk factors are all clinically well known and have been described in the literature.

The first factor, Medicaid insurance, is not applicable in countries with other insurance systems, but can be seen as the impact of poverty in the family. Material and social deprivation seems to be associated with glycaemic control. Caregiver’s unemployment and a single-parent household can also mean an economic burden and poverty.

Self-management of diabetes in children and adolescents involves shared but shifting responsibility for diabetes care and decision making between the child and their parents. There is also much published support for continued parental involvement and shared diabetes management during adolescence. Being a single parent, having a large family or parental stress can be a hindrance to support in diabetes self-management, as it takes a lot of time and effort to allow diabetes self-management to be a part of a stressful life.

The responsibility for the self-management is shared between the parents and the child. The child’s behaviour is important for glycaemic control. If the child has low executive functioning skills (for example, planning, problem-solving, organisation, and working memory), the risk for poor glycaemic control is high.

If the responsibility for diabetes self-management is not clearly defined between the parents and the child, such self-management may become insufficient. Continuous negotiations about the responsibility between the parents and the child are needed.
appear to be important determinants of metabolic outcomes in adolescents with diabetes. They are stronger predictors of metabolic control than age, gender or insulin treatment regimen. Children with lots of diabetes-related conflicts with their parents have higher HbA1c levels compared to those with less conflict, and the quality of the relationship is a critical factor in diabetes management.

Support and care for families with a newly-diagnosed child with diabetes

Children with diabetes who fail to reach a satisfactory level of glycaemic control, or have impeding factors in their daily life with diabetes, must receive extra support from the diabetes care team. There is some evidence that psychosocial interventions can improve glycaemic control in children. According to ISPAD’s guidelines, the interdisciplinary diabetes health care team should include professionals with expertise in mental and behavioural health, both psychologists and social workers. However, a recent survey among physicians working with paediatric diabetes in 47 countries revealed that nearly 30% of the teams did not have access to a mental health specialist.

High-risk patients often need more frequent medical as well as psychosocial support and follow up by their diabetes team. Another kind of valuable support may be support groups for parents of children with diabetes, where they can discuss problems and strategies together with others with similar experiences. Such groups were found to lessen feelings of isolation, particularly among mothers. Websites where parents can find other parents with whom to chat and who are in similar situations can be a possible source of support. To share experiences with others in similar situations seems to contribute to an inner sense of power and viability. Diabetes camps are another activity that can help the child to achieve a more positive attitude to diabetes. A vulnerable time when young people often fail in their diabetes self-management is when they move from child- and family-centred care to adult-centred care. This period is often referred to as the transition period. The diabetes care team has to be mindful of this transition period.

Clinical implications

When planning the care for a specific child in collaboration with the parents, it is important to be aware of factors that hinder or facilitate self-management. A screening tool can help clinicians to ask the right questions and find out where more support is needed.

Conclusion

Young people who live with diabetes 24 hours a day are vulnerable. Their lives – in all dimensions – affect, and are affected by, diabetes. In many cases, support from the diabetes care team is very important. The question is in what form this support should be provided and where the focus should be. To obtain a basis for such support requires that the diabetes care teams are aware of potential problems that exist. It is not enough to measure HbA1c. A psychosocial screening is also required. RI-PGC can be a valuable tool.

Anna Lindholm Ollinger, RN, PhD, Diabetes Nurse Janeth Lekssell, RN, PhD, Associate Professor

1Department of Clinical Science and Education, Karolinska Institutet, Södersjukhuset, Stockholm, Sweden
2Department of Medical Sciences, Uppsala University, Sweden
3School of Health and Social Studies, Högskolan Dalarna, Sweden

Declaration of interests

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References