

## ISPAD Clinical Practice Consensus Guidelines 2014 Compendium

# The delivery of ambulatory diabetes care to children and adolescents with diabetes

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### Executive summary and Recommendations

From the outset, the child or adolescent with diabetes and relevant family should receive care from a multidisciplinary diabetes team comprised of specialists with training and expertise in both diabetes and pediatrics, knowledgeable of child, and adolescent development (E). The Diabetes Care Team should emphasize that the family and child are the central members of the care team (E). Clear and consistent communication around education and the treatment plan is essential. The treatment plan should integrate current technology commensurate with available resources and the individual child's/family's needs (E). The multidisciplinary team is unlikely to be available in areas of low population density and where childhood diabetes rarely occurs. In these circumstances, care is likely to be provided by a locally based pediatrician or general (family) physician, who should have ready access to advice and expertise of the Diabetes Care Team in regional centers of excellence (1–3) (C, E).

The Diabetes Care Team should provide:

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This article is a chapter in the *ISPAD Clinical Practice Consensus Guidelines 2014 Compendium*. The complete set of guidelines can be found for free download at [www.ispad.org](http://www.ispad.org). The evidence grading system used in the ISPAD Guidelines is the same as that used by the American Diabetes Association. See page 3 (the Introduction in *Pediatric Diabetes* 2014; 15 (Suppl. 20): 1–3).

- Specialized hospital medical care.
- Expert comprehensive ambulatory care for diabetes and associated pediatric conditions.
- Introduction of new therapies and technologies as diabetes management evolves.
- Expert advice on issues related to diabetes such as exercise, travel, and other special life events.
- Advice for care at school, camps, and other venues where children with diabetes require care when away from home.
- Screening for comorbid conditions, complications, and risk of complications.
- Emergency telephone or other support 24 h a day to patients and families.
- Extra attention, including psychosocial evaluation and support, is needed for children who are 'high-risk', e.g., poor glycemic control [hemoglobin A1c (HbA1c) >8.5% (64 mmol/mol)] and/or frequent urgent visits or hospitalization.
- Advice and support to physicians and healthcare professionals who provide diabetes care where

immediate access to a Diabetes Care Team is not possible (B, E).

Processes of diabetes care should include:

- A visit at least every 3 months for a re-evaluation of diabetes management and review of home management records, as well as evaluation of growth, development, and general health.
- An annual visit with assessment and review of dietary knowledge, self-management skills and behaviors, and psychosocial needs, screening for comorbidities and risk factors for long-term complications, identification of barriers to care, and educational updates.
- A planned transition to adult diabetes care which improves outcomes and helps to ensure continuity of care during this critical time (4, 5) (B, E). The age of transfer to an adult clinic varies according to individual and local circumstances.
- Culturally sensitive communication, counseling, and encouragement for altering preconceptions or negative and unhealthful beliefs about diabetes (6).
- Assistance to access care.

Care is facilitated by electronic or paper tools such as clinic information sheets (E) to track each child's progress and to develop clinic benchmarks to compare to regional and national/international benchmarks for improvement of care (E).

### Outcome of care

The Diabetes Care Team should monitor outcomes for their patient population in order to identify areas of structure and process of care that could improve metabolic and other health outcomes (E). Comparing regional and national/international benchmarks is useful for improving outcomes (E) (7).

The ultimate goal is to provide care that results in normal growth and development, high quality of life (QoL), and lowest possible risk of acute and long-term complications. This is best accomplished by helping children and families become proficient in self-management, remain motivated throughout childhood and adolescence and allow children to develop into independent, healthy adults (E).

Cost of care and treatment cost to benefit outcomes data over the child's lifetime are critical to providing optimal care to children with diabetes. A high priority should be given for collecting and providing such information to governments and healthcare agencies. Governments and policy makers must be involved so that adequate resources are provided for high-quality diabetes care. Continuous support from the International Diabetes Federation and other responsible organizations is essential for uninterrupted

care of children in developing countries. Advocacy efforts and community education can promote awareness and understanding of diabetes, improving the safety and well-being of children with diabetes [E].

### Introduction

This section of the ISPAD Consensus 2014 Guidelines outlines recommendations for diabetes ambulatory care, including periodic assessments of clinical outcomes, as well as best and emerging practices. Resources and costs are important considerations in processes of care. The availability of resources varies widely among countries, within countries, and among patient populations. Some children have access to new technologies, whereas others have limited access even to insulin and other basic diabetes supplies. Comparisons of ambulatory diabetes care practices and cost effectiveness of care are important areas for which there are limited data. The delivery of care in settings such as schools and camps is also addressed. Specific recommendations for certain elements of ambulatory care, including insulin therapy, assessment and monitoring of glycemic control, nutritional management, diabetes education, screening for and management of microvascular and macrovascular complications, and type 2 diabetes, are addressed in detail elsewhere in the ISPAD guidelines, which should be consulted in conjunction with this chapter.

Diabetes is primarily managed in the outpatient or ambulatory setting. The importance of regular, ongoing ambulatory diabetes care assessment for youth with diabetes is essential to maintain optimal glucose control and to monitor risk factors that predispose to acute and chronic complications. The components of medical care include structure, processes, content, and outcomes. Structure of care describes how delivery systems are organized and financed; processes of care describe how care is delivered; content of care describes what is being delivered, including treatment and education that affect outcomes (8). Intermittent critical re-examination of these components provides an opportunity to continually improve the quality of care delivered using available tools and resources. Because diabetes is a chronic disorder, approaches to all aspects of medical care, undoubtedly, will change over time. It may also be helpful to review guidelines from other organizations, both national and international (9).

### Structure of care

The goal of treatment is to promote a high QoL, normal growth and development, and avoidance of severe short- and long-term complications. The insulin regimen should, ideally, mimic physiologic insulin

secretion and aims to restore normal metabolism. Insulin affects the metabolism of carbohydrate, protein, and fat, and is necessary for normal growth. The main aim of daily insulin treatment is to achieve good glycemic control without undermining the psychological health of the patient and family. Striving for normoglycemia, i.e., maintaining plasma glucose concentrations near to or within the narrow physiologic range is extremely demanding but essential for optimal health outcomes. People with type 1 diabetes (T1DM) who fail to take sufficiently good care of their health can, in the long term, suffer severe complications that can gravely impair quality and length of life (10). These complications of diabetes also lead to substantial societal costs, and the high prevalence of the disease makes it a big public health challenge. Both the ethical and economic consequences are further aggravated by the fact that T1DM generally appears at an early age. It is a challenging task to educate and support effective self-care among children and adolescents with T1DM and their caregivers, not least those with a non-privileged and minority social background. Disparities in care and outcomes exist – less intensive treatments, poorer glucose control, and increased rates of DKA are reported in less advantaged children (11–14).

Healthcare staff should strive to determine each young person's status regarding risk perception, knowledge, perceived control, as well as perceived benefits and costs of health behavior. The diabetes team must use age-appropriate educational tools and the child must be treated in the context of her psychosocial environment, which requires the multidisciplinary team to have a high level of cultural competence.

Diabetes care is best delivered by a multidisciplinary team. The team should consist of:

- Pediatrician specializing in diabetes or endocrinology (preferred), or physician with a special interest (and training) in childhood and adolescent diabetes.
- Diabetes nurse specialist or diabetes nurse educator.
- Dietician (or nutritionist).
- Pediatric social worker with training in childhood diabetes and chronic illness.
- Psychologist trained in pediatrics and with knowledge of childhood diabetes and chronic illness (12).

From the day of diagnosis, it should be emphasized that the immediate family and child are the central members of the care team. School nurses, day care staff, teachers, and others who care for children often play an important role in the child's diabetes care, and may serve as a liaison between the child and the medical team.

A multidisciplinary team is unlikely to be available in areas of low-population density and where childhood diabetes rarely occurs. In these circumstances, care

usually is provided by a local pediatrician or general (family) practitioner, who should have ready access via electronic means of communication to the Diabetes Care Team at a regional center of excellence (13–15).

- General aims of the Diabetes Care Team should be to provide individualized care that best meets the needs of the child and family.
  - An understanding of and support for the psychosocial needs of the child and family, aiding in the child's and family's adjustment to age-appropriate self-management of diabetes.
  - Expert practical guidance and skill training.
- Consistent repeated diabetes education and self-management training.
- Up-to-date advice on insulin management, blood glucose (BG), and ketone monitoring techniques, and monitoring comorbidities, risk factors of complications, and complications. Consistent and sensitive articulation of individualized biochemical goals (BG and HbA1c targets). A consistent philosophy concerning glycemic targets within the diabetes team and within the family influences HbA1c outcomes (15). Contact with other children and families with diabetes and support groups.
- Current information on research in diabetes for patients and regional physicians.
- Ongoing contributions to advancing clinical practice through the optimal application of existing and new technology and the development and evaluation of new technologies.

Diabetes requires skilled self-management in the home and local environment. The Diabetes Care Team should have the resources to develop strong links, effective communication, and shared practices with:

- The child and family at home, and extended family members or guardian.
- The young person at day care, school, or college/university.
- Primary healthcare providers.
- Pediatricians and other healthcare providers in areas of low population density/low diabetes prevalence.

The organization of the Diabetes Care Team, its size, and its location will depend on geographical and demographic characteristics. In general, for members of the pediatric diabetes team to obtain sufficient experience, the number of patients should be at least 150. The number of practitioners depends on local circumstances; a suggested guide to optimal resource allocation per 100 patients: 1.0 diabetes nurse, 0.75

pediatric diabetologist, 0.5 dietitian, and 0.3 social worker/psychologist (16).

Teams from district or regional centers often organize outreach clinics to accommodate children and families living in remote areas. Adequate resources are needed to sustain such services (14, 15).

- In some areas, two-way telecommunication utilizing video – computer technology and local medical staff to facilitate the telemedicine visit allows for more efficient and effective distant care (13, 17, 18).

Computer interfacing with BG meters, continuous glucose sensors, insulin pumps, and insulin pens allows patients to interact directly with the Diabetes Team between visits, which may improve diabetes management (16–18).

- Appropriate reimbursement must be available to support these essential non-face-to-face services in order to insure that Diabetes Care Teams can afford to sustain the use of these technologies (13).

### Processes of care

Generally accepted good clinical practice for the successful management of children and adolescents with diabetes includes the following:

At onset

Easy access (24 h a day) for rapid diagnosis and initiation of treatment with availability of written protocols for management of diabetic ketoacidosis (DKA) and other presentations of childhood diabetes (19, 20).

- Provision of practical care guidance at diagnosis includes the education required to enable the family to feel confident to provide diabetes care at home and have a basic understanding of the pathophysiology of diabetes and its treatment. It is important to create a partnership between the care providers and the child and family allowing for shared decision-making and a long-term relationship based on trust.
- Psychosocial support for the child and family. This includes identifying and addressing detrimental health beliefs, e.g., the team may need to provide reassurance that diabetes is not contagious, so the child does not need segregation.
- Written and/or pictorial age-appropriate materials in a format and language the family understands.

Ambulatory management of children at the time of diagnosis is possible in some centers with appropriate resources, but can only be recommended when

members of the Diabetes Care Team are experienced in the outpatient initiation of insulin therapy, management, and education, and adequate reimbursement for ambulatory diabetes team care is available. Hospital facilities must also be available in case of metabolic deterioration.

The importance of providing ‘a good start’ with clear, positive messages, support, and advice, cannot be overemphasized. Education and proactive discussion around common problems that can occur, such as insulin omission, may help decrease the risk of such problems arising later.

Diabetes is an expensive condition to manage. The treatment regimen prescribed from the onset should be appropriate for the family’s economic and educational status. For example, regular and NPH insulin is far less costly than analogs; insulin vials cost less than cartridges for use in pens, meters that use less expensive strips can be as accurate as those with advanced features. Insulin syringes and testing lancets can be reused for the same person with reasonable care. These and other cost saving methods should be advised to families who have limited means (1, 2).

Pictorial educational materials and simple instructions are essential for illiterate families. It is also important to address practical issues around home diabetes management. A person testing BG and injecting insulin several times a day would inevitably generate huge numbers of ‘sharps’ (needles and lancets) on a regular basis. Families must be taught and frequently reminded to safely dispose of these sharps. This can be done in a variety of ways, appropriate to the local conditions. If nothing else is available, parents can be asked to collect all sharps in a thick-walled metal or plastic container (e.g., shampoo bottle) and bring them on each visit to the clinic for safe disposal (3). Insulin cannot be exposed to extreme temperatures. After purchasing the insulin, the family must be taught how to transport and store it. Insulin inadvertently frozen must be discarded. At the other extreme, insulin becomes less potent after exposure to warm temperatures: at temperatures of 32 and 37°C, loss of potency started after 3 wk, whereas at 25–26°C, potency was retained by the end of 4 wk. In areas where ambient temperatures may be as high as 45–48°C, and where refrigeration is not available, insulin can safely be stored in local cooling devices (see Fig. 1) with which temperatures of about 25–26°C can be achieved (19, 20). Poor glycemic control may be due to using insulin that has lost its potency, but this is often overlooked.

The first 6–12 months

- In the first months to year after diagnosis, many children experience a partial remission and insulin



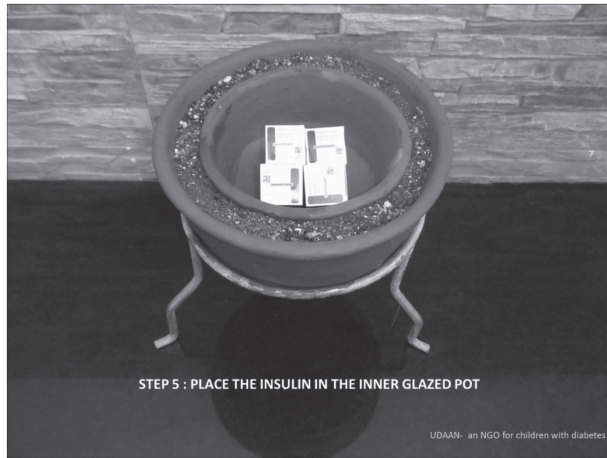


Fig. 1. “Home remedy” for insulin storage courtesy of Dr Archana Sarda, Aurangabad, India.

requirements may decrease dramatically. Frequent contact with the Diabetes Care Team is necessary to help manage the changing insulin requirements typical of the early phases of diabetes. Contact may occur through frequent clinic visits, home visits, and telephone or other methods of communication. Depending on local circumstances, contact often occurs through a combination of these methods.

- Insulin treatment should not be discontinued even if the insulin requirement is very low, and patients should be encouraged to continue to perform regular daily self-monitoring of blood glucose (SMBG).
- Screening for a cognitive or mental health disorder soon after diagnosis will identify individuals (either child or caregivers) at higher risk of being non-adherent to self-care. Five–ten percent of all children suffer from a neurocognitive disorder and at least 2% from a psychiatric disorder. The combination of a cognitive or mental health disorder with diabetes or the presence of a psychiatric disorder in a parent/care giver increases the likelihood of inadequate or incorrect self-care. These patients need special attention and treatment.

### Ongoing diabetes care

It is common practice for the diabetes care of children and adolescents to be reviewed in an outpatient clinic every 3 months, or more often if difficulties in managing diabetes are recognized or the child is very young. Outpatient visits with members of the Diabetes Care Team should include assessment of the following:

- General health and well-being.
- Height, weight, and body mass index (BMI) (data recorded and tracked on appropriate growth charts, on which mid-parental height is marked). Weight status can give a general indication of glycemic

control, with weight loss suggesting elevated blood sugars.

- Blood pressure with reference to age-appropriate normal levels.
- Physical examination should include thyroid gland, cardiac, abdominal (for hepatomegaly), feet (for corns, ingrown toenails, and other lesions as well as neurological function, e.g., light touch, vibration sense), and skin, especially injection, catheter insertion, and self-monitoring sites, for evidence of lipohypertrophy, lipodystrophy, or infection. Providers should reinforce rotation of injection or catheter insertion sites.
- Insulin types, doses, and injection/insulin delivery devices. Adequacy of storage and transport of insulin, injection technique and, if insulins are being mixed, mixing technique.
- Insulin adjustments for BG values, food, and exercise.
- Glycemic control, including HbA1c and analysis of home glucose monitoring data (glucose meter readings, continuous glucose monitoring (CGM), urine glucose/ketone monitoring, symptoms of nocturia and hypoglycemia). Check glucose values stored in the glucose meter memory for accuracy of information reported by parents/child. The HbA1c and home monitoring should be used in a complementary fashion to assess glycemic control: a lower HbA1c which is due to recurrent hypoglycemia does not mean better glycemic control! Regularly check home glucose meters for accuracy with a reference method of plasma glucose measurement at the clinic, particularly if glucose meter values are not consistent with HbA1c. Home-based meters can differ by 10–15% or more from a laboratory measurement.
- Assess hypoglycemia history, including determination of hypoglycemia awareness, method of treating hypoglycemia, and access to glucagon.
- Intercurrent health problems (infections, enuresis/nocturia, diabetes-related emergency and hospital/emergency visits, and other pediatric and developmental problems).
- Changes in developmental performance, education (particularly school absences/behavioral problems), leisure and sport activities, and psychosocial progress.
- Symptoms relevant to associated comorbid conditions, such as fatigue or abdominal pain that might suggest hypothyroidism or celiac disease, respectively. In the presence of symptoms or signs, given the predisposition to autoimmune conditions, additional evaluation may be indicated. For example, with weight loss, anorexia, unexplained hypoglycemia or decreasing insulin requirements, look for hyperpigmentation and consider evaluating the patient for

possible primary adrenocortical insufficiency (cortisol, perhaps ACTH and 21-hydroxylase antibodies). If a goiter is present, consider evaluating thyroid function [thyroid stimulating hormone (TSH), free or total T4 and perhaps thyroid peroxidase antibodies].

- New health conditions, including disordered eating behavior.
- All current medications and supplements.
- Diabetes-specific knowledge appropriate to the age of the patient, including the family's knowledge of ongoing diet and insulin dose adjustments, sick day management, when and how to monitor for ketosis to prevent ketoacidosis; and recognition of situations that increase the risk of hypoglycemia and how to prevent and treat hypoglycemia.

The outcome of each visit should include:

- An individualized plan of diabetes care incorporating the particular needs of each child/adolescent and family designed to optimize the child's diabetes outcome. This plan may include updated specific calculations for carbohydrate counting and insulin sensitivity (correction doses for hyperglycemia and BG targets).
- A written copy of the plan is provided to the family at the conclusion of the visit outlining any changes made to the child's diabetes management, including results of HbA1c measurement (including individual HbA1c target) and screening tests for comorbidities.
- Motivational discussion including the family's and child's understanding of general treatment goals and an understanding of the medical rationale behind these, e.g., good glycemic control is associated with lower risk of microvascular and macrovascular complications. Because children and adolescents find problems occurring in the distant future difficult to comprehend, immediate benefits of good control (looking better, feeling better, better academic performance, greater ability to make occasional modifications in diet) may be more effective incentives.

It is good practice to provide an annual review of care that includes:

- Physical development and well-being with particular emphasis on growth and pubertal development, BG testing and insulin injection sites, and/or cannula insertion sites for pump or CGM users.
- Additional new pertinent family history (e.g., new diabetes or other endocrine diagnoses, cardiovascular events/diagnosis).
- Review of diabetes care goals.

- Assessment by a diabetes nurse educator of diabetes-specific knowledge appropriate to the age of the patient, and the family's diabetes knowledge.
- Assessment of the family's and child's adjustment to diabetes and age-appropriate transfer of responsibility for self-care to the older child/adolescent.
- Determination of barriers to successful diabetes management, including needle fears, fear of hypoglycemia (parent and child) misconceptions about diabetes (e.g., diabetes is not transmitted by contact), financial condition, interaction with family members and other significant persons, and concealment of diabetes in important situations (sports, driving, etc.).
- Assessment as to whether the diabetes care plan is optimally intensified, taking the above assessments into consideration.
- Review by a nutritionist of the nutritional plan and dietary management. Parents may be encouraged to bring a food diary recording the last few days' diet to inform the consultation with a dietitian about individualized dietary advice and insulin dose adjustment.
- Review of physical activity and adjustments made in therapy for activity.
- Psychosocial assessment (e.g., single vs. two-parent, joint families, sibling issues, household stability, marital stress, parental support, discrimination at school or work place)
- Education concerning the need for routine dental care. Adults with diabetes have a higher incidence of gingivitis and periodontitis compared to the general population (21, 22). Poor glycemic control in children and adolescents has been associated with higher salivary glucose levels and more caries (23).
- Screening for depression and disordered eating.
- Reinforcement of age-appropriate information.
- For adolescents, review of precautions is necessary for safe driving, adverse effects of tobacco, alcohol, marijuana and other substances, sex and contraception, and preconception counseling. It is often appropriate to request parents/care givers to wait in another room so that these topics can be discussed candidly with the adolescent.
- Review of all current medicines and supplements, including complementary and alternative therapies.
- Assessment of understanding the risks of complications and care plans to minimize these risks.
- Assessment of comorbidities. This includes screening for thyroid dysfunction and celiac disease in asymptomatic children, with an annual TSH, and measurement of tissue transglutaminase antibodies every 2 yr.
- Screening for complications and comorbidities from 10 yr of age with greater than 2 yr of diabetes duration, including blood pressure review and urine

microalbumin measurement and ophthalmologic evaluation. Lipid screening at puberty (12 yr of age) and then every 5 yr if within the acceptable risk range, or annually if not within this range [further details on complications screening are available (see reference 16)]. For children with a family history of a lipid disorder, screening should occur 6 months after diagnosis. Screening at diagnosis is less useful, as lipid abnormalities are common at diagnosis and improve once glycemic control improves. If risk factors for complications are found, additional evaluation and treatment may be indicated (5).

#### Evaluation of patient's home diabetes records – at diabetes care visits and between visits

The patient and his/her family should be praised for performing home glucose monitoring, and the record should never be used to criticize the child or family for failing to reach glucose targets. The records should be used as a tool to identify patterns and trends, identify and solve problems, and to teach diabetes self-management skills. Parents must be counseled to avoid condemning the child for values which are high or low. When possible, a glucose meter that stores glucose values should be used, as this allows for cross-checking to ensure that the values reported are genuine. It is not unusual for the parents or the child to write fictitious values, and care must be taken not to base dose changes on such values. Providers should explore barriers to testing and recording of true results.

There are many models of care that aim to improve communication of home glucose monitoring records, insulin dosing, dietary, and exercise information between the child/adolescent, family, and the diabetes team. It is important to emphasize to the child and family that the adjustments in insulin doses are often needed between clinic visits. The family should be encouraged to review and attempt to analyze the data before contacting the diabetes team for advice.

Examples of useful clinical management tools include:

- Personal handwritten records, monitoring diaries, or logbooks.
- Electronic personal data records. Several apps are now available.
- BG meters with memory capacity ( $\pm$ computer/telephone links).
- Continuous glucose sensors with memory capacity ( $\pm$ computer links).

The ability to download data from glucose meters, insulin pens, pumps, and continuous glucose monitors provides valuable insight into home management. These data often allow the diabetes team to identify

areas where adjustments need to be made in diabetes care plans and, more importantly, to identify areas where the young patient needs additional help or supervision from the family or a supportive adult. These data can also be valuable teaching tools to demonstrate the effect of behaviors and diabetes care practices on glucose outcomes and can be used to encourage self adjustment and beneficial changes in behavior. When patients or parents record or report fabricated glucose data, the meter memory can be used to discover such behaviors, which are an alert to the need for psychological counseling. It should be emphasized that glucose meter memories and clinic downloads of the monitoring data are not substitutes for regular review at home of BG readings by the patient and his/ her family. It is important to teach children, adolescents, and their parents to use trends and patterns regardless of the clinical management tool they use.

Increasingly, these devices can be downloaded onto the family's home computer or the manufacturer's website for family review and for transmission electronically to the Diabetes Care Team when families require advice on management. This allows more frequent contact between the family and the Diabetes Care Team for electronic or phone consultation. As this may lead to improved diabetes management, diabetes teams will need to determine whether adjustments in staffing requirements are needed to accommodate the additional time necessary to utilize this new technology, and some mechanism to reimburse for these services is essential.

Mobile phone usage among adolescents is becoming nearly ubiquitous and a high proportion of adolescents own smartphones (phones with a mobile computing platform). There has also been a proliferation of applications (apps) for smartphones designed to enhance diabetes self-management. These include apps for tracking data (e.g., BG values, insulin doses, and carbohydrates), apps for teaching and training, food reference databases, and social blogs. Although mobile health (mHealth) apps have the potential to improve chronic disease care beyond the traditional outpatient healthcare provider–patient encounter, there currently is a lack of evidence regarding their clinical effectiveness. It should also be appreciated that there are challenges such as lack of integration with the healthcare delivery system and potential threats to safety and privacy (21).

#### Nutrition

Nutrition is discussed elsewhere, but in general, the entire family should consume the same balanced diet recommended for the child with diabetes. Provided the family had a healthful diet before diagnosis, the

child can continue to follow the family's diet. The family should be taught how to handle food at festive occasions (small portion size of calorie dense foods, insulin dose changes, encourage activity) rather than avoid attending celebrations.

### Exercise

The child/ adolescent should be encouraged to participate fully in physical activities, and must be taught when to consume an extra snack and/or reduce the dose of insulin based on BG testing. This is important to reinforce especially in families where girls are not allowed much physical activity, and if diabetes is perceived as a disease (the 'ill' child should not be 'tired out'). If hypoglycemia has occurred during activity, intensive education may be needed to overcome the fear of future hypoglycemia.

### Transition to adult care

The developmental stage from the late teens through the twenties, referred to as emerging adulthood, is an especially challenging time for patients with T1DM, a period of life typified by competing educational, social, and economic priorities. The process of transition from pediatric to adult care is challenging for many youth. Numerous reports from centers in different countries, including those with universal health insurance systems, show that between 25 and 65% of young adults receive no medical follow-up; i.e., experience gaps between pediatric and adult diabetes care for significant periods of time (4, 22–28), decreased post-transition clinic attendance (5, 25, 26, 29), and patient dissatisfaction with the transition experience (25, 26, 30). Adverse diabetes-related outcomes, including poor glycemic control (31), increased post-transition diabetes-related hospitalizations (23–26, 28), emergence of chronic diabetes complications (6, 22, 28, 32–34), and premature mortality (6, 33, 35), have been reported in emerging adults.

To insure continued high-quality medical care, the transition process should be a planned, purposeful movement from a child-centered to adult-oriented healthcare system (36). A recent position statement from the American Diabetes Association, however, acknowledges the dearth of empirical evidence; therefore, recommendations are based on expert opinion and generally are not informed by high-quality clinical studies (37).

The age of transfer to an adult clinic varies by location and healthcare delivery system, and is influenced by local practices and resources, patient and family preferences, and national policies (26, 28, 38).

There are no empirical data to recommend an optimal age for transition to occur. A recent US

study of high school youth showed that those who had transferred to adult care before their final year of high school (i.e., at an earlier age) had worse glycemic control 1 yr after graduating from high school as compared with youth who remained in the pediatric healthcare system (and did not experience declines in glycemic control) (39). These observations suggest that early transition from the pediatric to the adult healthcare system may be associated with worse glycemic control (39).

Discussion about transition to another care team or diabetes care provider at several visits before transition occurs helps young people prepare for transition. In addition, providing counseling on how care and practices may differ in adult clinics may be helpful to teens (40).

Studies show that physician continuity and care coordination can help improve transition to adult care (27, 41). A planned, structured transition to adult diabetes care is expected to improve outcomes and helps to ensure continuity of care (42) and organized transition services may decrease the rate of loss to follow-up (27, 43).

Programs featuring transition coordinators or 'patient navigators' decrease post-transition gaps and improve post-transition clinic attendance and reduce DKA rates (43). The diabetes nurse has the potential to play a coordinating role to bridge the gap between pediatric and adult care (44).

Joint attendance of pediatric and adult diabetes care providers at the last pediatric clinic visit and first adult clinic appointment may be beneficial (41, 45).

Alternatively, a combined adolescent/young adult clinic with both pediatric and adult diabetes specialists has been proposed as an optimal model of transition to adult care (46, 47).

Further data are needed on best practices for transition of care. However, continued regular contact with a Diabetes Care Team is essential for late teens/young adults.

### Barriers to care

There are many potential barriers to optimal diabetes care. These include financial burdens, psychosocial instability including broken homes, poor adjustment to the diagnosis, detrimental health beliefs, limited or inconsistent access to insulin, food, supplies, and care. In addition to personal challenges, great disparities exist in the level of pediatric diabetes care available to children, resulting from a wide range of factors across the world, from huge imbalances of geographic, economic, and scientific development to gender discrimination. Disparities are most apparent between well-educated majority populations and less educated, poorer, racial–ethnic minority subgroups.



## Care for minority children and children of recent immigrants

Globalization and migration are great challenges to the healthcare systems of the developed as well as the developing world. With the urbanization movement in emerging countries, many children and their parents become newcomers in cities, or leave home alone with extended family members.

Barriers to treatment that affect the care of minority children as well as children of recent immigrants may be unfamiliar to the diabetes team and will negatively impact diabetes care in these children. Recognition of these barriers is necessary to optimize care, and novel ways to overcome these unfamiliar cultural barriers requires cooperation, communication, and the establishment of trust among all team and family members. Moreover, the perceived and, sometimes, actual access to healthcare by immigrant and minority families may be different than that of the country's majority inhabitants. Awareness of these perceptions and differences requires cultural sensitivity, careful inquiry, and knowledge of the family's social circumstances. Proper care requires not only attention to usual medical needs but also attention to the varying and unique need for support required by minority and immigrant families to access and optimally utilize medical care.

- Licensed interpreters must be used when needed. If a licensed interpreter is not available, a non-family member may serve as an interpreter. The child or other family member should only be used as an interpreter if no other option is available.
- Use of culturally sensitive tool boxes can aid in communication, counseling, diet advice, and encouraging empowerment and for altering preconceptions or negative and unhealthful beliefs about diabetes. An example of such materials is EthnoMed ([www.ethnomed.org](http://www.ethnomed.org))
- Assistance in accessing care is an essential part of comprehensive diabetes care. Travel to clinics can be extremely challenging for children in rural communities, especially during emergencies. It is very important to establish regional pediatric diabetes care centers to facilitate the implementation of standard diabetes care.
- Dietary patterns of migrant families may be very different and must be understood for effective dietary advice to be given. For example, south Asians have high carbohydrate diets, and many are vegetarians; conversely, communities originating in coastal areas may typically eat large amounts of sea food.
- Knowledge of a family's cultural and religious beliefs can be critical to providing care, e.g., fear of contagion, diminished job and marriage

prospects, and the stigma of a chronic disease may delay or prevent the family from providing urgent or necessary daily diabetes treatment (33). Such stigmatization may result in the family keeping diabetes a secret, which may prevent the child with diabetes from eating and/or taking insulin at the appropriate times, or force him/her to eat inappropriately, leading to hypoglycemia or ketosis. Moreover, this can also prevent adequate care being provided by teachers/classmates/colleagues in the event of emergencies such as hypoglycemia. Encouraging the family to inform at least a few critical persons such as the child's teacher or a close friend may be crucial for getting help in such circumstances. In addition, giving awareness talks in the schools attended by affected children may considerably reduce stigmatization. In some regions, female patients might not receive appropriate diagnosis and treatment due to gender discrimination.

- Diabetes may be a deterrent to education and job prospects. In some countries, diabetes makes the person ineligible for several government jobs. Educational institutions, especially with residential requirements, have been known to refuse admission to applicants with diabetes. This may translate into even further, lifelong, dependence on family for covering health costs. It is particularly important for the family to be encouraged to educate the child and improve future earning capacity, to ensure continuing treatment is affordable during adulthood. The Diabetes Care Team should also be alert to instances of such discrimination, and may be able to prevent it. Getting societal and political support can be crucial to challenge instances of discrimination, whether by diabetes professionals, support groups, or both working together.

## Attention to literacy and numeracy (of parents and child)

Deficiencies in literacy and numeracy can make diabetes education and management very difficult. Even relatively simple tasks such as reading and recording BG values and insulin doses may be difficult. Pictorial materials can be developed to cope with these situations. Innovative measures can be used, such as teaching the mother or child to draw the numbers because they cannot write them, providing premarked syringes (wrapped with colored tape to mark the dose), and using color coding to designate doses of insulin based on proximity of glucose reading to target range. Somewhat similar is the problem of multiple languages or dialects: educational and instructional materials may not be available in the local language.

## Quality of care, structure of care, processes of care and outcomes

Diabetes care centers need methods to evaluate the quality of the diabetes services they provide and the outcomes of their management. Improvements in processes of care generally precede improvements in clinical outcomes. The impact of changes in the structure of care on clinical outcomes is less well studied in pediatric diabetes.

Tracking relevant outcomes is essential to the quality improvement process. For example, the establishment of a system for benchmarking of diabetes treatment in Norway resulted in significant improvements associated with changes in management and the quality of screening assessments. Benchmarking combined with organized quality meetings and discussions improved diabetes outcomes (lower HbA1c levels and decreased frequency of severe hypoglycemia) on a national level (7). Quality improvement programs can result in improved adherence to recommended processes of care such as frequency of HbA1c determinations, ophthalmological, and urinary albumin excretion screening (34). Adherence to recommended guidelines for albumin excretion screening leads to earlier detection of abnormal albumin excretion; treatment with an angiotensin-converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) therapy has been shown to reverse this abnormality with anticipated decrease in risk of nephropathy (35, 36). Likewise, recognition of early background retinopathy offers the opportunity to intensify and improve glycemic control, which would be expected to decrease the rate of progression to proliferative retinopathy (37, 38). Regular ophthalmological screening may also identify those requiring urgent ophthalmologic treatment to prevent vision loss. The impact of quality improvement programs on HbA1c levels is less clear. Open benchmark reporting of outcome data from all pediatric diabetes centers, as has been done in Sweden over the past 10 yr, can identify best practices between centers and lead to improved glycemic control (39, 48, 49).

Although the level of glycemic control required to optimally decrease the risk of long-term complications is generally accepted to be an HbA1c of 7–8%, (53–64 mmol/mol). The multicenter Hvidore study has shown that most centers are unable to achieve a mean HbA1c of  $\leq 7.5\%$  (58 mmol/mol) in the majority of children, especially in adolescents (40). This observation has recently been confirmed among participants in the SEARCH for Diabetes in Youth Study and the T1D Exchange Registry in the USA (50, 51). A lower HbA1c achieved by getting frequent hypoglycemic episodes may not be desirable; thus, the level has to be seen in conjunction with the SMBG logs. In situations where the HbA1c and SMBG logs are

significantly mismatched and the SMBG is accurate, a hemoglobinopathy or other conditions affecting HbA1c should be suspected.

Necessary quality ‘benchmark’ information, must be collected from paper or computer records and analyzed at 3–12 month intervals, to determine improvement or deterioration over time. Standardized clinic data sheets, registries and databases all facilitate these efforts. Adequate data management and statistical analysis capabilities are required to analyze outcome data for quality improvement assessment. Table 1 gives examples of indicators of both processes of care and clinical outcomes important to pediatric diabetes services (41).

Markers of structure of care include the following:

- Composition of the Diabetes Care Team.
- Facility available to the team and patients, including resources and space for patient care and education.
- Access to care (availability for phone consultation 24 h/d, 7 d/wk).
- Performance and documentation of initial and ongoing diabetes education following current guidelines.

Comparisons of individual center results are an important part of quality improvement. Individual centers can compare their outcomes (e.g., monthly or annual reports) with published guidelines or other pediatric diabetes centers. Consortia of diabetes centers or study groups that have agreed to collect and publish longitudinal data, such as the Hvidore Study Group, the German and Austrian Diabetes Quality Control Initiative (DPV), the SWEET study, the UK Clinical Registry, the US SEARCH for Diabetes in Youth study group, and the T1D Exchange, have provided helpful outcome data from multiple pediatric diabetes centers (7, 13, 29, 50–55).

Individual center results have also been published, but consistent longitudinal data from individual centers are less available than those of study groups.

Multicenter studies have published analyses of some processes of care that may affect outcomes, but additional studies are needed to fully define best care practices. However, these datasets will allow pediatric Diabetes Care Teams to identify some processes of care that result in improvement in biological outcomes, improving quality of care for children throughout the world.

## Care of children in other settings

### Children with diabetes in the school setting

Children spend 40–50% of their waking hours in school. Diabetes care in school is an important part

Table 1. Examples of quality indicators reflecting the process and outcomes of diabetes care, relevant for pediatric diabetes. Adapted from (41)

Goal	Quality indicator
Normal growth	Percentage of patients with height >3rd percentile [adjusted for mid-parental height (MPH)]
Normal physical development	Average BMI in diabetic children compared with non-diabetic children
Normal pubertal development	Percentage of patients with BMI >10th and <85th percentile Mean age at menarche in girls
Glycemic control	Mean HbA1c achieved in all patients and by age group
Low rate of acute complications	Frequency of severe hypoglycemia in all patients and by age group Frequency of admission because of diabetic ketoacidosis after onset of diabetes
Prevention of microvascular complications	Percentage of patients with eye exams during the past year Percentage of patients with urine albumin extraction rate determined during the past year Percentage of patients beyond 5 yr of diabetes with diabetic retinopathy Percentage of patients beyond 5 yr of diabetes with diabetic nephropathy Percentage of patients with persistent microalbuminuria receiving angiotensin-converting enzyme inhibitors (or other interventions for microalbuminuria)
Prevention of cardiovascular complications	Percentage of patients with lipid levels available during the past year Percentage of patients with blood pressure recordings available during the past year Percentage of patients with hypertension Percentage of patients with hyperlipidemia Percentage of patients with hypertension receiving antihypertensive therapy Percentage of patients with dyslipidemia receiving lipid-lowering therapy
Intensive therapy	Percentage of patients on flexible insulin regimen Percentage of patients on insulin pumps Frequency of glucose monitoring
Multidisciplinary care	Percentage of patient who have met with nutritionist during the past year Percentage of patient who have met with diabetes educator in past year Percentage of patient who have had psychosocial assessment in past year
Optimal social adjustment	Average number of days spent in hospital Average number of days where school was missed because of diabetes QoL in patients with diabetes QoL in parents of patients with diabetes Percentage of missed appointments
Number of visits annually	Percentage of patients with ≥3 ambulatory visits annually Number of visits per patients per year and mean and median number of visits per patient per year

BMI, body mass index; HbA1c, hemoglobin A1c; QoL, quality of life.

of their diabetes management plan. The school should make provisions for the child to keep/carry meter and insulin and a place where testing and injecting can be done (e.g., class room itself, medical room, etc.). It should not alter a child’s prescribed medical treatment, but changes in activity patterns should be incorporated into the medical plan (e.g., extra snacks for extra activity). The child has the right to participate equally in all school activities, including outdoor activities and sponsored events away from school, and to receive adult support for diabetes care during school hours (E). At the same time, school staff should not allow the child to use diabetes as an excuse to manipulate situations.

- School personnel must be trained to provide or supervise care prescribed by the diabetes team. This includes access to food in case of potential

hypoglycemia (e.g., unusual play or physical activity), insulin dose verification and administration by injection or as a bolus with an insulin pump. The staff should be aware of factors that affect glucose levels, such as food intake and physical activity, and assist in insulin dose decisions or have a plan to communicate with parents as necessary. They must be provided contact numbers of parents and the health team for assistance in decision-making or emergencies.

- School personnel must be supportive of providing diabetes care and encouraging diabetes management during school hours.
- Testing BG in young children and older newly diagnosed children and adolescents until they are capable of performing the task independently. If CGM is used, school personnel should receive training and specific instructions about how to

respond to sensor data and when it is necessary to perform a BG measurement.

- Identification and treatment for all degrees of hypoglycemia. Although most teens are fairly independent with diabetes management at school, nonetheless, they may require assistance with management of moderate to severe hypoglycemia. A recent communication by members of ISPAD, the majority felt it was appropriate for school staff to administer glucagon in the event of emergencies (personal communications). Therefore, all school personnel should be trained to recognize hypoglycemia symptoms, initiate treatment, and when to call for assistance or how to treat severe hypoglycemia. A recent study showed that 75% of children in school experienced an episode of hypoglycemia requiring assistance from school personnel with a median number of five hypoglycemic episodes during one school year (42). Newer, easier to use formulations of glucagon are in development and should facilitate glucagon administration at home or school.

Most national diabetes associations and organizations provide published guidelines for school care and recommendations and programs to assist school personnel and families to coordinate diabetes care in schools (43, 44). These resources are available on websites, or as a DVD or in print. Examples are the American Diabetes Association, Safe at School program, with educational slide presentations designed especially for school personnel, ([www.diabetes.org/schooltraining](http://www.diabetes.org/schooltraining)), and the Australian Diabetes Council 'Management of Diabetes in School' ([www.diabeteskidsandteens.com.au/teachers\\_and\\_schools](http://www.diabeteskidsandteens.com.au/teachers_and_schools)). However, reports indicate that while school personnel can become knowledgeable about the complex medical care requirements of children with diabetes, many remain apprehensive about taking on the responsibility of providing diabetes care (45, 56).

#### Children with diabetes in organized camps

Many local and national diabetes organizations manage residential and day summer camps for children with diabetes, and it is estimated that worldwide, 15 000–20 000 children annually attend diabetes camps (46). Diabetes camps are usually staffed by professionals and volunteers trained in the management of children with diabetes. Diabetes camps offer children and adolescents the opportunity to enjoy a camping experience in a safe environment and to experience a setting where caring for diabetes is a shared experience with other campers who also have diabetes. For many children, this is an opportunity to meet other children with diabetes and learn healthy ways to manage diabetes

(47–51). During their diabetes camp experience, many children learn more about how to care for their diabetes and may subsequently be able to safely attend any camp of their choosing or enjoy a safe camping experience with their family. Certified camps specializing in the care of children with diabetes can be found on the Internet.

Many national organizations have position statements or guidelines for the care of children with diabetes in a camp setting. These are valuable references and should be reviewed by camp medical directors to ensure adherence to national standards (46).

Camps specializing in children with diabetes should have:

- Adequate staff trained to manage children with diabetes.
- Available insulin to meet the needs of the children.
- Knowledge of insulin dose adjustments for the increased levels of activity that are usual at camps.
- An understanding of how to adjust settings and maintain insulin pumps if they are used at the camp.
- The ability to test BG, urine or blood ketones, and have adequate facilities to manage emergencies.
- All staff trained to recognize and treat hypoglycemia.
- Medical staff trained to identify and treat early ketosis and when referral to a medical facility should be initiated.
- At least one staff member with knowledge of medical nutrition therapy, carbohydrate content of meals, and the principles of adjusting insulin doses for variable carbohydrate content of meals.
- A plan to maintain a log of each camper's BG levels and insulin doses. It is usual practice to provide a parent or guardian with a copy of this log at the end of camp.

Most camps provide some education in diabetes management either in planned, formal sessions or, more commonly, by taking advantage of helping campers 'learn by doing' and of 'teachable moments' to discuss one-on-one or in a group issues related to diabetes care and outcomes. Camp staff should understand, however, that the primary goal of camp is to provide an enjoyable recreational experience for each child and to interact with other children with diabetes in a safe environment (57, 58).

Other out of clinic activities in which the diabetes team may be involved includes the following:

- Local (and national) support groups.
- Advanced education sessions (e.g., advanced insulin pump classes, use of CGM).
- Resources (information leaflets/books, equipment, informational websites, etc.).
- Nutritional games/experiments/innovations.



- Discussion groups, activity days, visits, lectures, holiday events, camps, etc.

### Cost of care and cost benefit analysis

Analysis of costs of care is important in helping to determine appropriate recommendations for care and in health policy decision-making (59). Clearcut data are limited, but it should be obvious that regular home BG monitoring is cost-effective, as even care in an emergency department or a short hospital admission for hypoglycemia or ketoacidosis would exceed the cost of several weeks of home BG and blood ketone testing (60). Most studies are small and do not include long-term cost-effectiveness (61, 62). Moreover, safe intensive diabetes management aimed at near-normal glycemia is impossible without frequent BG monitoring. The cost of diabetes care has increased dramatically in the past 10 yr with the introduction of analog insulins, increased use of insulin pumps, and increased frequency of BG testing. As continuous glucose sensor technology use increases, this will also add to the cost of care. Personal expenses for diabetes care vary widely around the world with costs being prohibitive in some countries and completely paid for by the state or private health insurance in others. Regardless of the source of payment for care, information about cost-effectiveness is required to inform healthcare decisions.

Countries and healthcare systems are adapting differently to the increased cost of diabetes care. Some countries or health insurance systems are considering or have already restricted use of newer insulin analogs and newer technologies requiring those choosing these technologies to bear up to 100% of the cost.

- Currently, analog insulins (both rapid- and long-acting) are 1.3–8 times as expensive as recombinant human regular and NPH insulin. However, both rapid- and long-acting analogs have been shown to reduce the frequency of mild and moderate hypoglycemia. The short-term costs need to be assessed to determine if the long-term benefit results in lower lifetime costs, taking QoL, long-term complications, and life expectancy into account.
- Limited available information does allow some assessment of the outcome of current insulin analog regimens using intermittent capillary BG monitoring in an affluent society with calculation of a projected cost:benefit ratio over the lifetime of an adolescent (52, 53).
- These reports suggest that basal–bolus therapy and, more recently, insulin pump therapy produce better long-term outcomes with a beneficial overall lifetime cost [weighing lifetime injection therapy using a multiple daily injection (MDI) regimen with NPH

as the basal insulin vs. insulin pump therapy] (54, 55).

- Studies are in progress to attempt to assess the benefit of continuous glucose monitoring, leading to studies using closed loop systems to improve health outcomes in youth with diabetes (56). Data are emerging rapidly on the use of such early forms of closed loop systems as low glucose suspend in children, and implementation of more fully closed loop systems (63–67).

### Overall analysis of diabetes healthcare costs and utilization

It has been well documented that in adults, diabetes imposes a large economic burden (57); however, there is very little information on the cost of diabetes in children and adolescents, especially for those with type 2 diabetes (see chapter Type 2 diabetes in the child and adolescents). Yet such information is critical when assessing the economic burden of disease and evaluating the economic efficiency of diabetes prevention and control programs in this population. A recent population-based study conducted in Sweden reported that compared with the non-diabetic population, the direct medical cost for children with T1DM aged 0–14 yr was 7.7 times higher. These costs included healthcare expenditure in primary healthcare, outpatient and inpatient care, and prescribed drugs. The additional cost per person with diabetes in children was 3930 Euros (58). Additional data on cost of diabetes care in children with both T1DM and T2DM and cost-effective approaches to care are needed. In addition, data on the effect of different care models and practices on long-term outcomes are lacking. These data are essential to appropriate decisions in healthcare policy. In conclusion, as interventions to prevent long-term complications will reduce future healthcare expenditures and improve well-being; therefore, whenever possible, children with diabetes should be offered the most effective currently available care.

### Conflicts of interest

The authors have declared no conflicts of interest.

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