

ISPAD Clinical Practice Consensus Guidelines 2009 Compendium

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

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Catherine Pihoker^a,
Gun Forsander^b,
Joseph Wolfsdorf^c and
Georgeanna J Klingensmith^d

^a Department of Pediatrics, Children's Hospital, Regional
 Medical Center, University of Washington, Seattle, WA, USA;

^b Division of Diabetes, The Queen Silvia Children's Hospital,
 Gothenborg, Sweden; ^c Division of Endocrinology, Children's
 Hospital Boston, Harvard University, Boston, MA, USA;

^d Department of Pediatrics, Barbara Davis Center and The
 Children's Hospital, University of Colorado Denver, Aurora, CO,
 USA

Corresponding author:

Georgeanna J Klingensmith
 Department of Pediatrics, Barbara Davis Center and The
 Children's Hospital, University of Colorado Denver, Mail Stop
 A140 PO Box 6511, Aurora Court, Aurora, CO, 80045, USA.
 Tel: (303) 724-6769;
 fax: (303) 724-6779;
 e-mail: georgeanna.klingensmith@ucdenver.edu

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Introduction

This section of the ISPAD Consensus Guidelines 2006–2008 recommends structures for diabetes ambulatory care and stresses the importance of the structures and processes of care that best allow periodic determinations of clinical outcomes with the goal of defining structures and processes that will improve these outcomes. Cost of care is an important part in the evaluation of diabetes care and is addressed in this guideline, although cost-effectiveness of care in pediatric diabetes is an area in which there are insufficient data and that requires additional study. The importance of other settings for diabetes care, especially schools and camps, is also addressed. Specific recommendations for the medical aspects of diabetes care are presented in other sections of the guidelines; those for insulin treatment (1), assessment and monitoring of glycemic control (2), nutritional management (3), diabetes education (4), and microvascular and macrovascular complications (5) are especially recommended in association with this Ambulatory Care Guideline.

Diabetes is primarily managed in the outpatient/ambulatory setting. The importance of regular, ambulatory ongoing diabetes care assessment for youth with diabetes is essential to maintaining optimal glucose control and to monitor for risk factors for acute and chronic complications. The components of medical care include structure, processes, and outcomes (6). Examination and reexamination of these components will allow for continually improving the quality of care delivered to children with diabetes using the tools and resources available. As a chronic disorder managed over many years, it should be anticipated that approaches to all aspects of medical care will change over time. Additional guidelines from other organizations may be helpful for review (7–11).

Structure of care

- The Specialist Multidisciplinary Diabetes Care Team for children and adolescents should consist of

- Pediatrician specializing in diabetes or endocrinology (or physician with a special interest 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 and/or psychologist trained in pediatrics and with knowledge of childhood diabetes and chronic illness (12).
- The team should recognize the family and child as an integral part of the care team. Their importance as members of the child's care team should be emphasized from the day of diagnosis

The multidisciplinary team is very 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/physician. Nevertheless, these practitioners should have ready access to facilities and advice provided by the Diabetes Care Team in regional centers of excellence (13–15) (C, E).

- General aims of the Diabetes Care Team should be to provide
 - Expert practical guidance and skill training.
 - Consistent repeated diabetes education and self-management training.
 - Up-to-date advice on insulin management, daily glucose monitoring techniques, and recommended monitoring for comorbidities, complication risk factors, and complications.
 - Thoughtful introduction of new therapies and technologies as diabetes management evolves.
 - An understanding of, and support for, the psychosocial needs of the family, aiding in the child's and family's adjustment to, and care of, diabetes.
 - Current information on research in diabetes to patients and regional physicians.
 - Ongoing contributions to advancing clinical practice through development and evaluation of new technologies and the most optimal application of new and existing technology in clinical practice.

Diabetes is a condition requiring skilled self-management in the home and local environment (E).

- The Diabetes Care Team should have the resources to develop strong links, clear communication, and common working practices with
 - The child and family at home.
 - The young person at school or college/university.
 - Primary health care providers.

- Other pediatricians and health care 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.
 - The teams from district or regional centers might organize outreach clinics when there are difficulties for children and families traveling to the regional centers if adequate reimbursement for this service is available (14, 15) (C).
 - 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) (A, C).

In all areas, telecommunication directly with the patient and/or their family has also shown benefit.

Increasingly, sophisticated computer interfacing with blood glucose (BG) meters, continuous glucose sensors, insulin pumps, and insulin pens allows patients to interact directly with the Diabetes Team between visits, which may result in improved diabetes management (16–18).

- Appropriate reimbursement must be available for these non-face-to-face services for Diabetes Care Teams to utilize these newer technologies in a sustainable fashion (13) (B, E).

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 accepted written protocols for management of diabetic ketoacidosis (DKA) and other presentations of childhood diabetes (19, 20).

- Provision of practical care guidance at diagnosis including the education required to allow the family to feel confident in providing diabetes care at home with a basic understanding of the pathophysiology of diabetes and its treatment.
- Psychosocial support for the child and family.
- Written materials in a format and language the family can best understand.
- Domiciliary/outpatient/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 and adequate reimbursement for Diabetes Team Care is available for extensive outpatient diabetes management and education. Backup hospitalization must also be available in case of metabolic deterioration.

The importance of providing ‘a good start’ with confident, clear, positive messages, support, and advice cannot be overemphasized (E).

The first 6 months

- Frequent contact with the Diabetes Care Team is necessary to help manage the changing requirements of diabetes in its early phases.
- Contact may be by frequent clinic appointments, home visits, and telephone or other methods of communication and usually consists of a combination of these methods.

Ongoing diabetes care consultations

It is common practice for the diabetes care of children and adolescents to be reviewed in outpatient clinics at least three or four times per year or more often if particular 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
 - General health and well-being.
 - Height, weight and body mass index (BMI) (entered and tracked on appropriate growth charts).
 - Blood pressure with reference to age-appropriate normal levels.
 - Physical examination to include thyroid, cardiac, abdominal (for hepatomegaly), and skin [especially for injection and self blood glucose monitoring (SBGM) sites].
 - Insulin types, doses, and injection/insulin delivery devices.
 - Insulin adjustments for glucose value, food, and exercise.
 - Glycemic control, including hemoglobin A1c (HbA1c) and analysis of home BG records.
 - Hypoglycemia history, including determination of hypoglycemia awareness.
 - Intercurrent health problems (infections, disabilities, enuresis/nocturia, diabetes-related emergency and hospital/emergency visits, and other pediatric and developmental problems).

- Changes in developmental performance, education (particularly school absences/problems), leisure, and sport activities and psychosocial progress.
- Symptoms relevant to associated comorbid conditions, for example hypothyroidism and celiac disease.
- New health conditions, including disordered eating behavior.
- All current medications.
- Diabetes-specific knowledge appropriate to the age of the patient, including the family’s knowledge of sick day management and hypoglycemia, including avoidance, identification, and treatment.

- 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.
 - A written copy of the plan provided to the family at the conclusion of the visit outlining any changes made to the child’s diabetes management as well as indicating the past successes of the family.

It is good clinical practice to organize an ANNUAL REVIEW of care to include

- Physical development and well-being with particular emphasis on
 - Growth.
 - Pubertal development.
 - Associated conditions (goiter/thyroid disease, celiac disease, other autoimmune conditions, skin or foot problems).
- Additional new pertinent family history (new diabetes or other endocrine diagnoses, cardiovascular events/diagnosis).
- Review of diabetes care goals.
 - Assessment of the family’s and child’s adjustment to diabetes and age-appropriate transfer of care to the child/adolescent.
 - Determination of barriers to successful diabetes management, including needle fears.
 - Assessment if diabetes care plan is optimally intensified, taking the above assessments into consideration.
- Review by a nutritionist of nutritional plan and dietary management.
 - Review of physical activity and adjustments made in therapy for activity.
- Assessment by a diabetes nurse educator of diabetes-specific knowledge appropriate to the age of the patient as well as the family’s diabetes knowledge.

- Assessment for depression and disordered eating in children > 10 yr of age.
- Reinforcement of age-appropriate information on driving, employment, smoking, sex, pregnancy, drugs, and alcohol.
- Review of current medicines, supplements (including complementary and alternative therapies).
- Assessment of understanding of risks for complications and care plans to minimize these risks and provide age-appropriate information.
- Complications risk screening in those from 11 yr with greater than 2 yr of diabetes duration, including blood pressure review and microalbumin measurement and ophthalmologic evaluation. Lipid screening at puberty (12 yr) 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 in (16)].
 - If risk factors for complications are found, additional evaluation and treatment may be indicated (5).
- Assessment for co-morbidities, especially including hypothyroidism (usually with an annual TSH) and celiac disease (usually every two years; more often if symptoms are present).
- Education concerning the need for routine dental care (unattended dental caries, periodontal disease, gingivitis).

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

The patient and his/her family should always be complimented for the blood testing they have been able to do at home, and the record should never be used to criticize the child or family for failing to reach glucose targets. The records are best used as a tool to identify patterns and trends, identify and solve problems, and teach improved diabetes self-management skills.

Many models of care exist that aim to improve communication of home BG records, insulin dosing, dietary, and exercise information between the child, adolescent/family and the specialist diabetes teams.

Examples of useful clinical management tools include

- Personal handwritten records, monitoring diaries.
- Electronic personal data records.
- BG meters with memory capacity (\pm computer/telephone links).
- Insulin pens and pumps with memory of insulin doses/pump functions \pm BG records incorporated into the pump memory (\pm computer links).
- Continuous glucose sensors with memory capacity (\pm computer links).

The ability to download data from BG meters, insulin pens, pumps, and continuous glucose sensing devices to view the actual data from the child/ adolescent's home care at each clinic visit provides very 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 is in need of additional help or supervision from the family or a supportive adult. These data also can be valuable teaching tools to demonstrate the effect of daily behaviors and diabetes care behaviors on glucose outcomes and can be used to encourage beneficial changes in behavior. It should be emphasized that BG meter memories and clinic downloads of the monitor data are not substitutes for regular review at home of BG readings by the patient and his/ her family.

Increasingly, these devices may 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. While this may lead to improved diabetes management, diabetes teams will need to determine whether adjustments in staffing requirements will be needed to accommodate this new technology. Additionally, some mechanism to reimburse for these services, or provide adequate staff to provide these services, will also need to be in place for these services to become readily available (E).

Dental care

Regular Dental Care is important, as caries in adults with diabetes may be comparable to the normal population, while gingivitis and paradontitis is more common (21, 22). Children and adolescents with higher HbA1c were in one study found to have higher glucose levels in the saliva and more caries (23).

Transition to adult clinics

The transition to adult care is inevitable. This transition occurs at different ages in differing care settings, and there is no age when transition is smoothest. This transition is difficult for many youth, and lack of consistent care may follow transition in 30–40% of patients. Even in those who remain in care, reports of metabolic control in the 2 yr after transition vary (24). Discussion about transition to another care team or provider at several visits before transition has been found to help young people prepare for transition. In addition, providing counseling on how care and care

practices may differ in adult clinics has been suggested to be helpful to teens (25) (B, E).

- A planned transition to adult diabetes care improves outcomes and helps to ensure continuity of care during this critical time (26, 27) (B).
- The age of transfer to an adult clinic varies according to individual and local circumstances and traditions (28–30) (E).
- A combined adolescent/young adult clinic with both pediatric and adult diabetes specialists may be the optimal model of transition to adult care (31, 32) (E).

Care for minority children and children of recent immigrants

Globalization and migration are great challenges to the health care systems of the developed and, sometimes, the developing world. 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 health care by immigrant and minority families may be different than that of the country's majority inhabitants. Recognition of these perceptions and differences requires cultural sensitivity, careful inquiry, and knowledge of the family's social circumstances.

In dealing with differences in access to diabetes care, it is mandatory to realize that proper care requires not only attention to usual medical needs but also attention to varying needs of support required by minority and immigrant families to access and optimally utilize medical care.

- Licensed interpreters must always be used when needed. If a licensed interpreter is not available, a non-family interpreter is optimal, the child or other family member should only be used as an interpreter if no other option is available.
- Culturally sensitive tool boxes must be developed including a set of tools for communication, counseling, and encouraging empowerment and for altering preconceptions or negative and unhealthful beliefs about diabetes.
- Assistance in accessing care is an essential part of appropriate, comprehensive diabetes care.
- Knowledge of a family's cultural and religious beliefs can be critical to providing care, for example diminished marriage prospects and stigma of a chronic disease may delay or prevent the family from providing urgent or necessary daily diabetes treatment (33).

Outcomes of care and quality improvement, including evaluation of structure and processes of care outcomes as well as biological outcomes

Record keeping, quality improvement, data management, and information services

Increasingly, it is apparent that diabetes care centers need methods to evaluate the quality of the diabetes services they provide and the outcomes of management. Continuously improving outcomes of care is essential to the health of children with diabetes.

Outcomes to be evaluated can be divided into

- Processes of care outcomes and
- Biological outcomes.

Improvements in processes of care generally precede improvements in biological outcomes. The impact of changes in the structure of care on biological outcomes is less well studied in pediatric diabetes.

Tracking relevant outcomes is essential to the quality improvement process. Information from quality improvement programs indicates that these programs can increase recommended processes of care such as frequency of HbA1c determinations and insulin injections as well as lead to improvement in meeting guidelines for ophthalmological and renal microalbumin excretion screening (34). Meeting the guidelines for microalbumin excretion screening leads to earlier detection of abnormal albumin excretion; treatment with an angiotensin converting enzyme (ACE) inhibitor or ACE receptor blocker therapy has been shown to reverse this abnormality with anticipated decrease in risk for nephropathy (35, 36) (A). Likewise, recognition of early background retinopathy offers the opportunity to intensify and improve glycemic control with the anticipated decrease in rate of progression to proliferative retinopathy (37, 38) (A). 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 (39) (B).

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%, the multicenter Hvidore study has shown that most centers are unable to achieve a mean HbA1c of, 7.5% in the majority of children, especially in adolescents (40).

To collect outcome data required for assessment of quality improvement, either paper or, more conveniently, computer records must be regularly used to collect the necessary quality 'benchmark' information. Analysis at 3- to 12-month intervals is required to determine improvement or deterioration over time allowing changes to be made when necessary.

Outcome data may be collected with

- a register or database including
 - incident cases
 - prevalent cases
 - clinic attendances
 - emergency department visits or hospitalizations
- and
- standardized clinic data sheets (hard copies and computer databases) eg

The Basic Information Sheet for Children & Adolescents (Implementation of the St Vincent Declaration) is an example of a template that collects most important benchmark outcome data. This template may be used for single center or multicenter collection of clinic data (Fig. 1, Basic Information Scale),

or

- A computerized medical record that includes requisite outcome data from which the benchmark outcomes can be extracted.

Table 1 gives examples of indicators of both processes of care and biological outcomes of diabetes care important to pediatric diabetes services (41).

Adequate data management and statistical analysis capabilities are required to analyze outcome data for quality improvement assessment.

Processes outcomes: determination of the adequacy of the structure required to provide care, the education provided, and the Diabetes Care Team's performance of recommended care outcome markers

Markers of care include the

- Composition of the diabetes care team,
- Facility available to the team and patients, including resources and space for patient care and education,
- Performance and documentation of initial and ongoing diabetes education following current guidelines,
- Performance and documentation of 'benchmark' care practices, including screening for risks for complications and presence of complications and comorbidities.

Markers of care also include patient performance outcomes, including

- Mean frequency of diabetes care visits,
- Mean frequency of self-BG testing.

Biological outcomes are the results of the laboratory values or physical findings including

- Growth parameters
 - Height and height percentile.
 - Weight and weight percentile.

- BMI and BMI percentile.
- Percentage of type 1 diabetes (T1DM) with BMI > 85%ile.
- Percentage of T1DM with BMI > 95%ile.

- Risk factors for long-term complications
 - Mean HbA1c value as well as mean values by age.
 - Rates of microalbuminuria.
 - Rates of abnormal lipid levels.
 - Rates of abnormal ophthalmologic examinations.
- Rates of acute complications
 - Rate of severe hypoglycemic episodes.
 - Rate of DKA episodes.
 - Rates of emergency department visits and hospital admissions.
- Evidence of other autoimmune disease (thyroid, adrenal, and celiac).
- Patient and family quality-of-life (QoL) assessment.
- Patient and family satisfaction with care assessment.

Comparisons of individual center results is an important part of quality improvement

Individual centers can compare their outcomes to

- Published guidelines.
- Other pediatric diabetes centers.

Consortiums of diabetes centers or study groups that have agreed to collect and publish longitudinal data, such as the Hvidovre Study Group, the German Diabetes Quality Control Initiative and the US SEARCH for diabetes study group, have provided helpful outcome data from multiple pediatric diabetes centers.

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 biological outcomes, but additional studies are needed to fully define best care practices. However, these data sets 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.

The ultimate goal is to provide care that results in normal growth and development, a high 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, developing into independent, healthy adults (E).

Basic Information Sheet
for Children and Adolescents
Implementation of the St. Vincent declaration

Drift

Basic Patient Data: Number [], Date of Birth []/ []/ [], Sex Male Female

Diagnosis: IDDM NIDDM Other Diabetes since []/ []/ []

Reason for Consultation/Admission: Consultation or Admission Routine Newly diagnosed

Risk Factors/Background: Smoker op/day [], Alcohol Split family Ethnic minority Known present user of narcotic drugs

Self-monitoring: Blood glucose self-monitoring []/week, Urine glucose self-monitoring []/week

Education (during last 12 months): Complications , Self-Adjustment , Education given: in Hospital , at outpatient , at camp . Education given to: Patient , parents/others , kindergarten/school

Measurements (most recent values in the last 12 months): Weight [] kg, Height [] cm, Date of measurement []/ []/ [], Blood pressure []/ [] mmHg, HbA1c []% (Does the child have persistent hypertension ?), Microalbuminuria [] (up/min , up/24hrs , up/dl), Proteinuria [] (up/24hrs , up/dl). Is your local reference chart applicable for this person? . Is the child shorter than -2 SD .

Examination: Eyes Examined within last 12 months . By funduscopy , fundus photogr. , fluorescein angiogr. . Refractive error L R . Photocoagulations last 12 months: Cataract , Retina seen . If YES: Non-proliferative RP , pre-proliferative RP , proliferative RP . Advanced glab. eye disease . Visual acuity L: [] / [] R: [] / []. Adolescence: Pubic hair [] Tanner 1-3, Menarche []/ []. Feet Examined within the last 12 months . Glove/size used , Tanning/burn used . Is there clinical peripheral neuropathy . Injection Sites: Injection sites normal .

Quality of Life Emergencies last 12 months: Severe hypoglycaemia , Diabetic ketoacidosis , Doctor Outpatient visits , Hosp. admissions due to diabetes , Hospital Days .

Management: Diet only , OAD , Insulin injections [] (number/day), Insulin pump , Total daily insulin dose [] (units/day). Long acting insulin , Short acting insulin , Pre-mixed insulin .

Additional Treatment: Hypertension , Dyslipaemia , Thyroid disease , Coeliac disease , Angiotensin drug , Nephropathy , Glucocorticosteroids .

Physician [], Signature [], Date []/ []/ []

Fig. 1. Treatment decision tree for type 2 diabetes in children and adolescents.

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 of their diabetes management plan. The school should never discourage or alter a medical treatment plan that is regarded by the diabetes team to be optimal for the child. The child has the right to receive adult support for diabetes care from school personnel during school hours, outdoor school activities, when at school

sponsored events away from school, and should natural disasters occur at school (E).

- School personnel must be trained to provide or supervise all diabetes care prescribed by the diabetes team (E).
- School personnel must be supportive of providing diabetes care and encourage diabetes management during school hours (E).

The treatment required may include

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

Treatment	Quality indicator
Normal growth	Percentage of patients with height < 3rd percentile
Normal physical development	Average BMI in diabetic children compared with non-diabetic children
	Percentage of patients with BMI > 85th percentile
Normal pubertal development	Mean age at menarche in girls with diabetes
Low rate of acute	Frequency of severe hypoglycemia in all patients
	Frequency of severe hypoglycemia in all patients younger than 5 yr of age
	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
	Mean HbA1c achieved in all patients
	Mean HbA1c achieved in adolescent patients
	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 not 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 not receiving antihypertensive therapy
	Percentage of patients with hypertension not receiving lipid-lowering therapy
	Mean HbA1c achieved in all patients
	Mean HbA1c achieved in adolescent patients
Optimal social adjustment	Average number of days spent in hospital
	Average number of days where school was missed because of diabetes
	Percentage of patients on flexible insulin regimen (beyond remission)
	QoL in patients with diabetes
	QoL in parents of patients with diabetes
	Percentage of patients missing 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.

- Insulin administration by injection or with an insulin pump.
- Testing BG in young children and older newly diagnosed children and adolescents until they are capable of performing the task independently.
- Identification and treatment for hypoglycemia, both mild–moderate and severe.

Even though the majority of teens are generally independent with diabetes management at school, all individuals with diabetes may require assistance with management of hypoglycemia. 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 (E). A

recent report found 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).

Most national diabetes associations and organizations provide published guidelines for school care and recommendations and programs to assistant school personnel and families to coordinate diabetes care in schools (43, 44). The American Diabetes Association, as part of their Safe at School program, has educational slide presentations especially for school personnel, which may be downloaded from their website, www.diabetes.org/schooltraining. By 2009, a DVD with similar information is anticipated to be available as well. The International Diabetes Federation also

makes educational materials available to school personnel, and another example of material for teachers can be found at www.diabeteskidsandteens.com.au under 'teachers and schools'. Reports indicate that school personnel can become comfortable with the complex medical care children with diabetes require (45).

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 attend diabetes camps annually (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 all or most of the campers also having diabetes. For many children, this is an opportunity to meet other children with diabetes and learn how to manage diabetes in a healthy way (47–51). During their diabetes camp experience, many children learn how to care for their diabetes in a camp setting and may 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 in the management of children with diabetes (E),
- 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 backup facilities to handle emergencies (E),
- All staff trained in the recognition of hypoglycemia and its treatment,
- Medical staff trained in the identification and treatment of early ketosis and when referral to a medical facility should be initiated (E),
- 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 (E),

- A plan to maintain a log of BG levels and insulin doses for each camper. 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 recognize that the primary goal of camp is to provide an enjoyable recreational experience for each child in a safe environment.

Other out of clinic activities which the Diabetes Team may provide

The Diabetes Care Team may be involved in helping to organize

- Local (and national) support groups.
- Advanced education sessions (e.g., advanced insulin pump classes).
- 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.

- To accomplish this aim, data are needed in large pediatric populations including
 - Biological outcomes data as indicated above.
 - Relative costs of different insulin regimens and their respective health outcomes. Relative costs of varying glucose monitoring techniques, including frequency and accuracy of monitoring and their impact on health outcomes.
 - Relative costs of providing a specialized diabetes team.
 - Anticipated effects on the overall major drivers of diabetes health care cost.
- Acute complications resulting in emergency department visits and/or admissions to hospital, and
- Chronic complications of long-term microvascular and macrovascular disease as well as the resultant lost work productivity for patients and family members.

Costs of insulin regimens and BG monitoring

Costs of diabetes care have increased dramatically in the past 10 yr with the introduction of analogue insulin, increased use of insulin pumps, and recommendations for increased frequency of BG testing. If continuous glucose sensor technology use increases, as it undoubtedly will, this will also add to the cost of daily care. Personal expenses for diabetes care vary widely around the world with costs 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 health care decisions.

Countries and health care 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 analogues and newer technologies requiring those choosing these technologies to bear up to 100% of the cost.

- Currently, analogue insulins (both rapid acting and long acting) are 1.3 to 4 times as expensive as recombinant human regular and NPH insulin. However, both rapid-acting and long-acting analogues 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 analogue 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 outcome with a beneficial overall lifetime cost [weighing lifetime injection therapy using an multiple daily injection (MDI) regimen with NPH as the basal insulin vs. insulin pump therapy] (54, 55) (B).
 - Studies are in progress to attempt to assess the benefit of continuous glucose monitoring, leading to studies in closed loop systems in improving health outcomes in youth with diabetes (56) (C).

Overall analysis of diabetes health care costs and utilization

It has been well documented that in adults, diabetes imposes 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. 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 health care expenditure in primary health care, outpatient and inpatient care, and prescribed drugs. The additional cost per person with diabetes in children was 3930 Euro (58). Additional data on cost of diabetes care in children with both T1DM and type 2 diabetes 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 health care policy.

Recommendations

Structure of diabetes care:

The child or adolescent with diabetes and their family should be cared for, from the outset, by members of a team of specialists, all of whom should have training, expertise, and understanding of both diabetes and pediatrics, including child and adolescent development (E). The team should provide consistent, current care with the integration of current technology to match available resources and the individual child's/family's needs. (E)

The diabetes care team should recognize the family and child as an integral part of the care team. Their importance as members of the child's care team should be emphasized from the day of diagnosis (E)

The multidisciplinary team is very 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/physician. These practitioners should have ready access to facilities and advice provided by the Diabetes Care Team in regional centers of excellence (13–15) (C, E).

The Diabetes Care Team should provide

- Specialized hospital medical care.
- Expert comprehensive ambulatory care of diabetes and associated pediatric conditions.
- Thoughtful introduction of new therapies and technologies as diabetes management evolves.
- Expert advice on issues related to diabetes such as exercise, travel, etc.
- Advice for care at school, camps, and other venues where children with diabetes require care when away from home.
- Screening for complications, risk for complications, and comorbid conditions.

- Emergency telephone or other support 24 h a day to patients and families
- Advice and support to physicians and health care professional providing diabetes care in areas of low population density where immediate access to a Diabetes Care Team is not possible.

The Process of diabetes care should include:

- A care visit every 3 months for a re-evaluation of diabetes management and review of home management records
- An annual visit with greater attention to dietary assessment, laboratory screening, educational updates and psychosocial needs as well as long-term complication screening and screening for comorbidities
- A planned transition to adult diabetes care which improves outcomes and helps to ensure continuity of care during this critical time (26, 27) (B). The age of transfer to an adult clinic varies according to individual and local circumstances
- Special attention to minority children and children of recent immigrants to provide
 - Culturally sensitive communication, counseling, and encouragement for altering preconceptions or negative and unhealthful beliefs about diabetes (33).
 - Assistance in accessing care

Care should be aided 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 to identify areas of structure and process of care needing improvement to improve outcomes including metabolic and other health outcomes, e.g. microvascular and macrovascular complications, satisfaction with care, and QOL and to identify and rectify health care disparities (E).

The Team should compare their outcomes to regional and national/international benchmarks for improvement of care (E).

The ultimate goal is to provide care that results in normal growth and development, a high 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 for 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 to collecting and providing these data to, and with the help of, governments and health care agencies. (E)

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