

# ISPAD Clinical Practice Consensus Guidelines 2022: Diabetes education in children and adolescents

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## 1 | SUMMARY OF WHAT IS NEW OR DIFFERENT

This chapter has been updated with additional details and references on educational approaches for multidisciplinary teams, including cultural adaptation, as well as a section on type 2 diabetes (T2D) in youth. Diabetes education and digital technologies as well as telemedicine, with increased adoption of video or phone appointments, has also been expanded and enhanced.

## 2 | RECOMMENDATIONS/EXECUTIVE SUMMARY

Education is the key to successful management of diabetes [E].

- To maximize the effectiveness of diabetes treatment and the advances in diabetes management and technology, including continuous subcutaneous insulin infusion (CSII) and continuous glucose monitoring (CGM), it is advisable that quality assured structured education is available to all young people with diabetes and their caregivers [E].
- The content, curricula and delivery of structured education needs regular review to ensure it suits the needs of people with diabetes within the community, matches local practice, changes with the changing maturity, and needs of the child and then adolescent; and reflects contemporary diabetes management methodologies and technology [E].
- Evaluation of structured educational programs should include a measurement of outcomes directly related to diabetes education such as the individual's achievement of self-selected diabetes care

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- goals; improved psychosocial adaptation; quality of life and enhanced self-efficacy, in addition to measures of glycemic control. Adequacy of glycemic control should encompass not only HbA1c, but other measures such as time in range, if available, and frequency of hypoglycemia [E].
- Educational interventions have a beneficial effect on glycemic and psychosocial outcomes in children and adolescents with diabetes [E].
  - Educational interventions shown to be effective include those:
  - Based on clear theoretical psychoeducational principles [E].
  - Integrated into routine clinical care (e.g., as an essential and integral part of care at diabetes onset and ongoing) [A].
  - Part of an ongoing process to provide education in individualized self-management and psychosocial support [E].
  - Involve the continuing responsibility of parents and other caregivers throughout adolescence [B].
  - Making use of cognitive behavioral techniques most often related to problem solving, goal setting, communication skills, motivational interviewing, family conflict resolution, coping skills, and stress management [A].
  - Utilize new technologies in diabetes care as one of the vehicles for educational motivation [A].
  - Health care professionals require appropriate specialized training in the principles and practice of teaching and education to implement successfully person-centered behavioral approaches to education, designed to empower young people and caregivers in promoting self-management [E].
  - A multidisciplinary education team sharing the same philosophy and goals and speaking with “one voice” has beneficial effects on glycemic and psychosocial outcomes [B].
  - It is important that goals and targets for blood glucose and HbA1c align with recommended international guidelines. A major task during the first weeks and ongoing after diagnosis of diabetes is to get the family to agree to pursue the same targets [E].
  - Telemedicine, which encompasses the use of video or phone appointments, between a person seeking care and the health care professional, offers an important alternative to in-person diabetes review for people who live in remote areas without access to professional counseling and diabetes education resources locally, as well as for routine diabetes care [B].
  - Advancements in technology, combined with widespread adoption of digital devices by people with diabetes and the diabetes team, have created an opportunity to leverage digital platforms to augment diabetes care [E].
  - Mobile and web-based applications are useful tools for diabetes self-management education to improve diabetes management [E].
  - Interactive web-based educational resources are widely used for device-specific training and education of people with diabetes [E].
  - Diabetes peers and/or diabetes youth leaders can reinforce the principles of living well with diabetes and support the learning of families, especially those living in remote or resource limited settings [E].

### 3 | INTRODUCTION

To maintain quality diabetes management, families perform a multitude of self-management tasks daily, responding to changes in activity, food, and physiology. The challenge for diabetes health care professionals is to deliver diabetes education that optimizes the family's knowledge and understanding of the condition and its treatment, while simultaneously assisting them to adjust to the impact of diabetes management on their everyday lives. In addition, parents need to combine managing their child's diabetes-related tasks alongside their usual parenting responsibilities. This challenge is even greater in low- and middle-income countries where limited resources may threaten access to insulin, food security, and the availability of the basic tools to manage diabetes such as glucose and ketone monitoring equipment. Diabetes education is a critical element of diabetes care, regardless of the intensity of the insulin regimen adopted. Diabetes management requires frequent and high levels of educational involvement at diagnosis and ongoing to support the children and adolescents as well as parents and other care givers.<sup>1,2</sup> This evidence informed guideline has been adapted and updated with the aim to describe universal educational principles, details regarding content, and organization of diabetes education in children and adolescents and provide consensus recommendations.<sup>3</sup> Many countries have developed their own set of guidelines, appropriate for their health services and cultural backgrounds.<sup>4-13</sup>

### 4 | DIABETES EDUCATION—DEFINITION AND UNIVERSAL PRINCIPLES

#### 4.1 | Definition

A universal definition of diabetes education does not exist. However, the following definition has been proposed:

*“Diabetes education is an interactive process that facilitates and supports the individual and/or their families, caregivers or significant social contacts to acquire and apply the knowledge, confidence, practical, problem-solving and coping skills, needed to manage their life with diabetes to achieve the best possible outcomes within their own unique circumstances.”<sup>14</sup>*

#### 4.2 | Empowerment and person-centered care

Regardless of insulin regimen used, the complexity of diabetes treatment requires that children with diabetes and their caregivers make numerous daily treatment decisions, necessitating empowerment of the child or adolescent and their caregivers. Empowerment in health care is defined as a motivational approach to assist people to make health-promoting behavior choices and/or changes.<sup>15</sup> In the field of

diabetes, empowerment is defined as the process of helping people discover and use their innate ability to gain mastery over their diabetes.<sup>16</sup> The approach is person-centered with the health care providers facilitating and providing information and knowledge to assist people in making informed decisions. Persons with diabetes should be empowered to know that they ultimately influence their own lives in making informed decisions about their diabetes. Children and adolescents with diabetes need to have age-appropriate understanding of diabetes and be empowered to participate in the management of their diabetes.<sup>4-7,16,17</sup>

#### 4.3 | Accessibility

Every young person with diabetes should have access to comprehensive structured education to help empower them and their families to manage their diabetes in an age-appropriate manner.<sup>4,6,9-13,18</sup> In addition to the child or adolescent and their primary caregivers, other care providers should have access to educational resources and staff and be included in the educational process.<sup>8,19</sup> Caregivers in nurseries or kindergarten and school teachers should have access to appropriate structured diabetes education.<sup>20-22</sup>

#### 4.4 | Personalized education

Educational programs should utilize appropriate person-centered, interactive teaching methods for all people involved in the management of diabetes. This approach must center around the child or adolescent with diabetes,<sup>4-8,11-13,18</sup> and be adaptable to meet the different needs, personal choices, individualized learning styles of young people with diabetes and their parents, in the context of local models of care. Diabetes education needs to be personalized to the individual's age, stage of diabetes, maturity and lifestyle, culture and learning pace.<sup>4,6,11,12</sup> The sharing of roles and responsibilities for the diabetes treatment tasks between the child or adolescent and their caregivers should be continuously clarified and considered in relation to the need for education.<sup>23,24</sup> This personalized diabetes educational approach remains an integral part of the psychosocial support for young people with diabetes and their families.

#### 4.5 | Multidisciplinary team

Diabetes education should be delivered by a multidisciplinary team of health care professionals who have a clear understanding of the special and changing needs of young people and their families as they transition through the different stages of life.<sup>4,7,8,11,25</sup> Multidisciplinary teams providing education should include, at a minimum, a pediatric endocrinologist/diabetologist or a physician trained in the care of children and adolescents with diabetes, a diabetes specialist nurse/diabetes educator/pediatric nurse, and a dietitian. Furthermore, a

psychologist, a social worker or a team member trained in mental health are recognized as essential members of the multidisciplinary team.<sup>6</sup> In areas with limited resources, it is not always possible to have all members of a multidisciplinary team and additional details are provided in the chapter "Limited Care Guidance" (2022 Consensus Guidelines Chapter 25 on Management of diabetes in children and adolescents in limited resource settings).

#### 4.6 | Education of the educators

Educators in the multidisciplinary team must take responsibility for maintenance of their professional development to remain up to date with their knowledge and skills. They should have access to continuing specialized training in current principles of insulin therapy, new diabetes technologies, advances in diabetes education, and educational methods as well as client engagement.<sup>4,6,8,11,12,26,27</sup>

#### 4.7 | Cultural adaptation

Cultural adaptation has been described as the modification of educational approaches to consider language, culture, and context in such a way that it is compatible with the client's cultural patterns, meaning, and values.<sup>28</sup> Due to increased mobility and migration, cultural and language differences may hinder communication and diabetes education. It is recommended that diabetes education is provided with professional translator services if appropriate, and educational material is offered in the family's native language where available.<sup>29</sup>

#### 4.8 | Ongoing engagement

Diabetes education needs to be a continuous process and be repeated on a regular basis for it to be effective.<sup>4-8,11,12</sup> The priorities for health care professionals in diabetes education may not match those of the child and the family. Thus, diabetes education should be based on a thorough assessment of the person's attitudes, beliefs, learning style, learning ability, readiness to learn, existing evidence, knowledge, and goals.<sup>30</sup>

Table 1 summarizes the philosophy of diabetes education in children, adolescents, and their parents.<sup>4,8,31,32</sup>

The knowledge base for some key universal principles is explained in the following sections.

### 5 | PROVIDING DIABETES EDUCATION

#### 5.1 | Diabetes education and the diabetes health care service

All members of the multidisciplinary diabetes team take part in delivering diabetes education. In the initial phase this will encompass key

**TABLE 1** Principles and practice of education in children, adolescents, and their parents/primary care givers

<b>1. Motivation</b>	<ul style="list-style-type: none"> <li>The learner needs to and/or have a desire to learn</li> </ul>
2. Context	<ul style="list-style-type: none"> <li>Where is the learner now?</li> <li>Where does the learner want to be later?</li> </ul>
3. Environment	<ul style="list-style-type: none"> <li>Learner-centered, comfortable, trusting</li> <li>Enjoyable/entertaining/interesting/“open”</li> </ul>
4. Significance	<ul style="list-style-type: none"> <li>Meaningful, important, links, or joins up</li> <li>Reward or gain</li> </ul>
5. Concepts	<ul style="list-style-type: none"> <li>Simple to complex in gentle steps (<i>short attention span</i>)</li> </ul>
6. Activity	<ul style="list-style-type: none"> <li>Constantly interactive</li> <li>Practical (<i>fitting into real life</i>)</li> <li>Goal setting and problem solving</li> </ul>
7. Reinforcement	<ul style="list-style-type: none"> <li>Repetition, review, summarize</li> </ul>
8. Reassess, evaluate, audit	
<b>9. Move forward (continuing education)</b>	

messages that include; (1) informing young people and their families that they have developed diabetes; (2) initiating diabetes education to explain and/or answer the many questions that arise immediately after receiving the diagnosis; (3) informing the child, adolescent, and their primary caregivers about current “best practices” for the management of diabetes; (4) information about how the young person, their family and support network can promote self-management of their diabetes after initial education and instruction.

To maximize the impact of education, a diabetes health care service must formally design what they need to teach and what the young person and family need to learn. A diabetes health care service for young people needs to develop their own, culturally appropriate:

**Diabetes education curriculum:** a detailed list of contents or subjects to be taught by the health professional and learnt by the young people with diabetes and their families.

**Diabetes education syllabus:** instructions on the delivery, depth of learning and learning outcomes, considering the needs of the person with diabetes, with content of different subjects and methods. Learning outcomes are “statements that describe the knowledge or skills students should acquire by the end of a particular assignment, class, course, or program, and help students understand why that knowledge and those skills will be useful to them.”<sup>33</sup>

National and regional programs<sup>9–12</sup> can and often are adopted by local health services, with sharing of educational resources from other centers, reliable external sources, diabetes support group organizations, and medical societies.

Each Multidisciplinary Diabetes Team needs to construct its own approach to their diabetes education program, based on their health professional numbers, the scope of their health provision resources and social structure of their health environment (Table 2). A check-list approach has been adopted at most diabetes centers, allowing aspects of the education program to be introduced at a manageable pace for the person with diabetes and with allocation of certain learning tasks to different members of the multidisciplinary team based upon their individual expertise.

A completed checklist does not necessarily mean that the young person with diabetes and the family have learned everything they need to know as diabetes education is not a “one off” process. Diabetes education requires constant review, depending on the needs of the person with diabetes and the family with ongoing maturation and adaptation. Many centers will give Education Updates at appropriate times that may include annual assessments with clinical review, starting or changing school, during the adolescent period, at the adoption of new diabetes technologies or with any dietary changes.

## 5.2 | Structured diabetes education programs

There are three key criteria that should characterize a structured educational program<sup>6</sup>:

- the program has a structured, written curriculum that is aligned with current clinical guidelines
- uses trained diabetes educators
- is quality assured

The evidence-base for the effectiveness of structured education versus informal unstructured education in improving glycemic control<sup>34–36</sup> and preventing severe hypoglycemia and restoring awareness of hypoglycemia<sup>37</sup> comes mainly from studies involving adults with diabetes. These studies have been performed mainly in North America, Australia, and Europe and have been extensively reviewed in various publications.<sup>6,8,34</sup> Diabetes self-management education programs are efficacious and cost-effective in promoting and facilitating self-management, improving children's diabetes knowledge, skills, and motivation, and have been shown to improve biomedical, behavioral, and psychosocial outcomes.<sup>38</sup>

There are few studies involving children and adolescents with type 1 diabetes (T1D) and their parents, and the evidence base for the effectiveness of structured education programs is limited.<sup>6,8,39,40</sup> Indirect evidence suggests that countries in which structured education are available for all have better outcomes with respect glycemic control.<sup>41–43</sup> Evidence to assess the impact of a structured education program in children with T1D, suggest that the structured education and support program in the year after diagnosis can improve short-term glycemic outcomes, measured as HbA1c, but this effect may not persist after discontinuing intensive coaching. This highlights the need for ongoing person-centered education.<sup>44</sup> A short-term (1 year) evaluation of a structured initial education program improved child and parent-reported outcomes.<sup>40</sup> Structured

**TABLE 2** Key education topics for review at diabetes diagnosis and ongoing engagement

At diagnosis	Continuing curriculum
Simple explanation of how the diagnosis was made, the cause of symptoms and need for lifelong insulin replacement. Reassure that with insulin replacement the child will quickly regain health and energy.	Pathophysiology, epidemiology, classification, and metabolism
Explore feelings of guilt or blame and discuss uncertainty about the cause of diabetes.	Explore child's/adolescent's understanding as they mature
Normalize grief and loss reaction to the diagnosis	Address psychological health and diabetes burnout
Discuss risk for siblings and interventions available to minimize risk	Revise as needed
Simple explanation of glucose and the relationship between food, blood glucose value, and insulin.	Explain other sources of glucose; that is, liver as a source of glucose
Simple explanation that insulin lowers the blood glucose value, rapid-acting insulin lowers it quickly and long-acting insulin lowers it slowly.	Insulin action and profile Adjustment of insulin Pump extended bolus functions Introduction to diabetes technology (if available)
Discuss the role and responsibility of family in the delivery and supervision of self-management tasks and the expectation for frequent follow-up.	Review who is doing what at each visit and encourage active parental involvement. Explore barriers to clinic attendance if missed appointments
Establish clear and consistent treatment targets and goals.	Revise frequently Goal setting focus on goals that are SMART: specific, measurable, achievable, realistic, and time-based Micro- and macro-vascular complications, screening protocol, and prevention
Focus on basic survival skills needed to manage diabetes from day one. Accomplishment of these skills will increase the caregiver's and child's confidence in their ability to manage.	Review these skills <ul style="list-style-type: none"><li>• As new devices or technologies are introduced</li><li>• As child/adolescent takes on self-management tasks</li><li>• If diabetes needs stabilization</li><li>• In response to episodes of DKA or severe hypoglycemia</li><li>• On diabetes camps</li><li>• When new caregivers are introduced to the family</li><li>• When child/adolescent is planning school camp/excursion</li><li>• During transition to adult service</li><li>• Whenever there are admissions other than due to diabetes or DKA</li></ul>
Assess competence in <ul style="list-style-type: none"><li>• SMBG and/or CGM, ketone monitoring</li><li>• insulin devices: injection, pen, or pump</li><li>• diabetes diary or downloading of data from pens, pump, glucose meters, and CGM</li><li>• carbohydrate counting tools</li><li>• insulin storage</li></ul>	
Basic dietetic advice including carbohydrate counting, importance of healthy eating, and meal-time routines.	Explain effect on glucose levels of different food components including protein, fat, fiber, and glycemic index; and discuss insulin therapy management strategies to optimize postprandial glucose levels
Promotion of healthy body weight.	Revise nutritional skills as the child grows and develops
Clarification of myths about food and diabetes, as well as beliefs about cure in the honeymoon phase.	Adapt nutritional interventions in response to new diagnosis, for example, celiac disease Screen for disordered eating
Explanation of hypoglycemia (symptoms, prevention, management), identify cards, bracelet, necklace.	Revise with introduction of new activities and new caregivers Practice reconstitution of glucagon
Explanation of hyperglycemia and diabetes ketoacidosis (symptoms, prevention, management).	Risk factors: hypoglycemia unawareness, young age Precautions with alcohol, and driving
Diabetes during illnesses; advise not to omit insulin and to call the diabetes team for advice.	Effect of intercurrent illness, hyperglycemia, ketosis, and prevention and identification of DKA Diet and fluids of sick days Sick day management plan (see chapter: Sick day management)
Integration of diabetes self-management tasks into family life, social activities, sports, and school.	Problem-solving and adjustments to treatment in everyday life, motivation, and coping with unexpected glucose fluctuations Review and revise school management plan annually Exercise, camp, holiday planning, and travel
Address questions about impact on future risk behaviors and aspirations for the child/adolescent	Information to teenagers about alcohol, tobacco, cannabis, and other illegal recreational substances (see chapter about adolescents) Information about contraception, sexuality, and pregnancy planning Information about employment
Membership in a diabetes association and other available support services	Explore opportunities for peer support and family support
Details of emergency telephone contacts and follow-up arrangements.	Update as required

education should be available to all persons with diabetes at the time of diagnosis and reinforced with regular teaching sessions after diagnosis and then annually or more frequently as determined by formal, regular individual assessment of need.<sup>4–12</sup> A review of relevant qualitative studies in pediatric and adolescent services showed that providing skills training using structured education to people does not necessarily result in participants adopting and sustaining recommended changes in behavior. To sustain diabetes self-management skills after attending structured education, it is recommended that support be provided over the longer-term by appropriately trained health care professionals in response to individuals' needs.<sup>6,27,45</sup> A study of structured education during the pediatric to adult transition period highlighted the importance of carbohydrate counting in predicting glycemic control.<sup>46</sup> This study emphasized that many persons diagnosed and educated in childhood may be more knowledgeable in diabetes management, but their practical skill in matching insulin dose and carbohydrate content is often suboptimal.<sup>46</sup>

Effective educational programs are carefully planned, have specific aims and age-appropriate learning objectives, which are shared with people with diabetes, their families, and other care givers<sup>4,6,8,17,47</sup> and are integrated into routine care. Ways to improve access to and uptake of diabetes self-management programs are needed globally in resource deficient regions.<sup>38</sup> Many less-resourced countries, which have a high rates of morbidity and mortality, may only be able to provide minimal education and ongoing support. All young people with T1D and their caregivers deserve quality care, with structured diabetes education from a diabetes team or health care professional experienced in pediatric diabetes.<sup>48</sup>

### 5.3 | Support programs and diabetes education

The interpretation of educational research is complex relating to the intersection of interventions frequently combining education, psychosocial, and psychotherapeutic methods.<sup>34,35</sup> The outcomes most likely to be directly affected by diabetes education are knowledge and understanding, self-management behaviors, and psychosocial adaptation.<sup>4,14</sup> These psychosocial and behavioral outcomes are key requirements for glycemic control.<sup>14</sup> Systematic reviews of psychoeducational interventions conclude that such measures have shown small to medium beneficial effects on glycemic control<sup>49–55</sup> and a somewhat greater effect on psychological outcomes.<sup>35,56,57</sup> The effects are more pronounced for children than for adults.<sup>56</sup>

Recently, a variety of support methods have been tried in conjunction with defined education programs that include motivational interviewing, life coaching, and a guided self-determination model. While all of these approaches appear to improve the psychological well-being and coping strategies of young people, there is often minimal improvement in glycemic control, measured as HbA1c. In addition, the impact is often of short duration, requiring repeated interventions.<sup>58–62</sup> Because both high glycemic variability and low glycemic variability may be associated with the same HbA1c value it is important to evaluate frequency of hypoglycemia and time in range, if available, when evaluating glycemic control.<sup>63</sup> Education may be seen

as an interface between clinical practice and research. Continuing research into diabetes and educational methods is important in improving clinical practice and should be prioritized by diabetes centers, individually as well as part of regional, national, and international networks and registries.<sup>4–7,12,14</sup>

### 5.4 | Delivery of diabetes education

Diabetes education is delivered by all members of the diabetes multidisciplinary team who complement each other by working within their scope of practice as guided by their subspecialty. All team members are responsible for assessing the educational needs of the family at each episode of contact and arranging referral to the most appropriate diabetes health care professional to address the family's identified learning needs.<sup>4,6–8,11,12,25</sup> The team should have a sound understanding of the principles governing teaching and learning.

The diabetes team should demonstrate skills consistent with the principles of teaching and structured education and also incorporate behavioral change management including counseling techniques into their therapeutic practice.<sup>26,27</sup> Tertiary level diabetes education and clinical management courses are available in some countries along with accreditation programs available to health care professionals wishing to achieve certification. Certified diabetes educators require proficiency in clinical practice, research, diabetes education, and counseling and frequently manage the coordination, delivery, and evaluation of education programs within their health facilities.<sup>64</sup> Guidelines should be developed and evaluated for core competencies for diabetes educators to help ensure quality education is provided to young people with diabetes and their caregivers.<sup>26</sup>

Multidisciplinary teams providing education should include, at a minimum, a pediatric endocrinologist/diabetologist or a physician trained in the care of children and adolescents with diabetes, a diabetes specialist nurse/diabetes educator/pediatric nurse, a dietitian, a psychologist, and a social worker.<sup>6</sup> Other professionals such as a play therapist or a Child Life Specialist can play an important role in the diabetes team by providing pedagogical preparation of children and young people for procedures and examinations and support in the educational process for the child with diabetes, parents, and siblings.<sup>65</sup> Furthermore, an occupational therapist can provide pedagogical and practical support, especially to children and adolescents with neuropsychiatric diagnoses.<sup>66</sup> In addition, there is value in trained health or life coaches in helping people with diabetes meet self-management goals.<sup>59</sup>

### 5.5 | Diabetes education—at diagnosis, settings, timing, and cultural considerations

#### 5.5.1 | Diabetes education at diagnosis

At diagnosis families may be unresponsive to education due to the emotional stress of the diagnosis or for practical reasons such as fatigue from sleep deprivation due to hospitalization. For this reason,

the education program should be tailored to meet the pace dictated by the family's readiness to learn. The initial focus should be on the acquisition of the practical "survival skills" required to manage the diabetes at home and address the immediate concerns expressed by the family. Time should be given for the skills to be practiced and basic concepts should be reviewed within the first weeks of diagnosis. The family should be given a structured plan for education so that they can arrange dedicated time for the education. At diagnosis, concepts are new, and the child or adolescent will need consistent messages and support from parents and other primary care givers. To ensure this occurs both parents or other primary care givers should be encouraged to attend all education sessions.

Initial learning should be reinforced by written guidelines and curricula. It should be accompanied by quality assured education materials (books, booklets, leaflets, websites, social medias, smart phone/tablet applications, games, and other resources) appropriate to the child's and adolescent's age and maturity.<sup>6,8</sup> Educational (electronic or printed format) materials should use appropriate language and a style that is easily comprehensible. For parents with limited literacy and/or poor numeracy special materials using diagrams, drawings, video clips, and other visual media are recommended.<sup>67,68</sup> All material should follow common therapeutic goals and a shared holistic approach.

Table 2 lists suggestions for the basic initial content of diabetes education at diagnosis and the extension of this content to be delivered and revised at regular intervals over the course of the family's contact with diabetes services. These topics provide a comprehensive basis for successful therapy and positive emotional coping for youth with diabetes and their caregivers. The topics should be adapted to ensure the diabetes education is appropriate to each individual's age, maturity, learning needs, and local circumstances. ISPAD 2022 Consensus Guidelines Chapter 10 on "Nutritional management in children and adolescents with diabetes" has a detailed explanation of the content and methods of delivering nutritional education.

The number of appropriate education hours for a newly diagnosed child or adolescent may depend on the health care system and individual characteristics of the person with diabetes and family. Data from a study in Germany showed that an average of approximately 30 h of theoretical and practical instruction was provided for the parents and/or the child/adolescent with T1D.<sup>69</sup> A study from Canada revealed that certified diabetes educators spent a median of 10.5 h per person with diabetes during the first year after diabetes onset.<sup>70</sup> Interestingly, this study also showed that greater teaching time was needed for young people with diabetes from higher socioeconomic backgrounds as compared with a lower socioeconomic level. It is, however, important that the number of education hours is adapted to the individual needs of the person with diabetes and their family.

### 5.5.2 | Settings, timing, and cultural background

#### *Initial education and diagnosis*

Due to the heterogeneity of health care systems and funding of diabetes care and education there is evidence supporting both inpatient

and ambulatory approaches to diabetes stabilization and initial education at diagnosis, and studies have shown no difference across relevant outcomes.<sup>32,62,69,71-76</sup> A recently published study in the UK health system shows strong evidence that there is no difference between home-based and hospital-based initiation of care in children newly diagnosed with T1D across relevant outcomes.<sup>62</sup>

#### *Continuing education*

Ongoing educational encounters most often take place in an ambulatory (outpatient, domiciliary, community) setting.<sup>4-8,11,12,77,78</sup> Where staffing levels, expertise and local circumstances do not permit this to occur, educational programs may be carried out in the hospital environment, either by individual teaching or in groups and whenever possible in a protected environment conducive to learning.<sup>71,73,76,78</sup> It is important to adapt the programs to families who may have low literacy and numeracy.<sup>79</sup> For families from different cultural backgrounds, the education needs to be adapted to their food habits and their health belief models.<sup>29</sup>

Age-appropriate, group education approaches directed at the specific needs of individuals can be at least equally effective as individual education and may be more cost effective.<sup>6</sup> In qualitative studies young persons with diabetes often report they appreciate group education. Adolescents also express that meeting others with the same condition and shared experiences can help mitigate the isolation of diabetes.<sup>61,80,81</sup> During the transition period from adolescence into adulthood there are specific education needs such as self-management and decision support, and group clinics.<sup>82-85</sup> Young people also benefit from workshops to prepare for the transition.<sup>86</sup> During the transition, parents also may need support in changing their role.<sup>22,87,88</sup>

The educational experience may be enhanced by peer group education or school friendships.<sup>31,89</sup> Diabetes residential and day camps organized by local and national diabetes organizations provide an additional opportunity for learning and review of diabetes management skills in a safe and supportive environment. From a diabetes education standpoint, diabetes camps appear to have an initial impact and are appreciated by young people with diabetes and their caregivers, which is mediated through psychosocial benefits.<sup>90-92</sup> The organization and aims of diabetes camps have been described in detail in the ISPAD Guideline for the delivery of ambulatory care (ISPAD 2022 Consensus Guidelines Chapter 7 on The delivery of ambulatory diabetes care to children and adolescents with diabetes). Educational activities at camp are most effective if they are matched to gender and age and embody empowerment principles.<sup>93</sup> Benefits include the opportunity for youth to foster relationships and share experiences in a safe environment.<sup>94</sup>

Digital education, which includes use of technology to promote self-management and support education, has become increasingly available in diabetes care and offers the ability to promote empowerment and self-management to youth and their caregivers.<sup>84,95</sup>

#### *Type 2 diabetes*

Youth with T2D may experience distinct challenges as compared with adolescents with T1D or adults with T2D. Treatment modalities that

include oral medications differ from T1D treatment and there is often a need for major lifestyle changes, related to food and physical activities. Youth with T2D and their caregivers often reside in minority communities with lower socioeconomic status and experience challenges related to financial and or residential instability. Diabetes educators should be aware of these potential complex psychosocial and cultural environments, which can make the lifestyle changes difficult to implement and may result in decreased engagement by youth with T2D self-managing their disease.<sup>96–98</sup> These adolescents may have a higher rate of psychological disorders, depression, stigmatization and eating disorders, and need psychological support and/or psychotherapy together with their parents.<sup>99</sup> The role of health care professionals and caregivers is to promote attendance at education sessions and encourage independent self-management regimens and self-care practices for optimal clinical outcomes.<sup>96,97,100</sup> Implementation of culturally specific education have shown improvements in self-management behaviors, which can help to minimize long-term risk of complications.<sup>101</sup> Studies also show that there is a lack of structured evidence-based diabetes education for people with learning disabilities, literacy problems and for non-English speakers.<sup>97</sup> See ISPAD 2022 Consensus Guidelines Chapter 3 on T2D in youth.

## 5.6 | Diabetes education and intensive treatment methods

Matching and adjusting insulin profiles to quantified food intake and exercise levels is an important part of any intensified diabetes management plan. More complex therapeutic regimens with multiple daily injections, use of different insulins and insulin analogs, CSII, as well as using CGM devices require comprehensive education and practical training. Structured age-specific education programs for adults, adolescents, or parents of younger children with T1D on the use of real-time CGM systems and data interpretation have shown improvements in knowledge, satisfaction, glycemic control, and acceptance of real-time CGM systems.<sup>102–104</sup> Using automated insulin delivery systems or hybrid-closed loop systems requires comprehensive education and reeducation of all family members on nutrition and carbohydrate counting, safety behaviors, and an understanding of the integration of these elements into the daily activities of the child/adolescent using the system.<sup>105–107</sup> A key prerequisite for these diabetes technologies is that all team members are appropriately trained and able competently to manage these systems.

Higher levels of education, health literacy, and understanding are often required for these interventions to be successful, which require significant investments of time, skill, and resources from the education team.<sup>4,8,11,108</sup> In this context, simply changing from one form of insulin regimen to another as the only means of intervention may not be appropriate and may not improve glycemic control.<sup>25,49</sup> The appropriate educational approach to the implementation of diabetes technology is holistic and should address treatment and lifestyle goals that addresses barriers, optimizes glycemic management and is centered around the child with diabetes. In this way, an intensified

management plan utilizing comprehensive structured education has a greater likelihood of success, especially if the educators are highly skilled and motivated.<sup>109,110</sup>

## 5.7 | Diabetes education and digital technologies

Advancements in technology combined with widespread adoption of digital devices by youths with diabetes, their caregivers and their clinicians have created an opportunity to leverage digital platforms to augment diabetes care. The available newer technologies include smart phone/web-based applications,<sup>55,111–114</sup> computer games,<sup>115</sup> text messaging,<sup>116</sup> and telephone reminders and telemedical support.<sup>117</sup> These technologies are most effective when they include interactive modes and utilize social media.<sup>34,53,118</sup> Evidence from group discussions with young people suggests that education using these newer technologies is attractive, and there is further scientific data to support its widespread use.<sup>114,118–121</sup> However, there is still a lack of robust data on effectiveness in relation to key outcome parameters.<sup>122,123</sup>

Technology-based diabetes teaching systems are interactive and aim to engage the user by age specific, animated, and entertaining applications. They are designed to serve different purposes such as tracking and monitoring blood glucose, activity/exercise, healthy eating, medication adherence, monitoring for complications, annual screenings, and problem-solving. Calorie/carbohydrate counting smart phone applications help people tackle the abstract concept of carbohydrate content in food. Smart phone applications have provided a comprehensive food database and easier access to nutrient data on less common foods including those found in restaurant chains. It can be important to check the source of the current application. Data from national nutrient databases can provide a more accurate carbohydrate content than data from open/crowd sourced information.<sup>124</sup>

Digital diabetes tools have been designed for coaching people with diabetes by personalized diabetes education.<sup>125</sup> Users define long-term goals, such as optimizing nutrition, decreasing blood glucose levels, and receive daily messages to attain specific goals and to reiterate essential concepts of diabetes education. The feedback loop sustained by two-way communication, where both sender and receiver are engaged, facilitated by way of technology offers the greatest favorable impact on glycemic control.<sup>126</sup> Small studies in pediatric and adult persons with diabetes have shown the benefit of using technology-based diabetes education on improving confidence, self-management, quality of life, and glycemic control outcomes.<sup>55,111–113,127,128</sup>

Telemedicine, that encompasses the use of video or phone appointments between a person with diabetes and their health care professional, has been particularly helpful for people with diabetes who live in remote areas and do not have access to professional counseling and diabetes education resources or were unable to visit clinics due to the COVID pandemic.<sup>129,130</sup> The communication and exchange of medical information are made possible through

**TABLE 3** Concerns, challenges, and learning opportunities for infants and toddlers, school age children and adolescents with diabetes

Group of children	Concern/challenges	Learning opportunities
Infant a toddlers 0–3 years	Total dependence on parents and caregivers for injections/management of pumps, food, and monitoring. Parents may feel increased stress, diminished bonding, and depressive feelings. Unpredictable erratic eating and activity levels. Difficulties in distinguishing normal infant behavior from diabetes-related mood swings, for example, due to hypoglycemia. Injections, infusion set and sensor insertions, and BG checks seen as pain inflicted by caregivers. Hypoglycemia is difficult for the child to communicate. Long-standing hyperglycemia may be even more harmful Care in nursery and kindergarten	Requirement of a trusting attachment between infant and caregivers. Support and education for parents Education about technical devices Education on prevention, recognition, risk, and management of hypoglycemia and hyperglycemia. Education for nursery and kindergarten staff Engagement with dietitian, Psychologists, child life support as needed
Preschool age 3–6 years	Care in nursery and kindergarten Need help to identify symptoms of high/low glucose values Learning the meaning of high/low glucose values	Education for nursery and kindergarten staff Family support Education for parents, from the whole team Age-appropriate education for the child Engagement with dietitian, psychologist, child life support as needed
School age 7–12 years	Adjusting to the change from home or kindergarten to school. Developing self-esteem and peer relationships. Increasing understanding and learning to help with injections, pump use, and monitoring Gradual development of the child's independence with progressive stepwise transfer of appropriate responsibilities Adapting diabetes to school programs, school meals, exercise, and sports. Not wanting to do self-management task in public. Negotiating supervision of diabetes management tasks. Progressive recognition and awareness of hypoglycemia symptoms	Education for school personal and others. Family support Advising parents on the gradual development of the child's independence. Age-appropriate education for the child Clarify the responsibility for self-management. Peer-education Engagement with dietitian, psychologist, and mental health support as needed
Adolescents	Accepting the critical role of continued parental involvement. High risk behavior, tobacco, alcohol, legal, and illegal drugs Importance of appropriate contraception Promoting independent, responsible self-management appropriate to level of maturity and understanding. Emotional and peer group conflicts Body image issues and weight gain and risk for disordered eating, insulin omission Ability to prioritize one's health	Learning from each other/ accepting each other's responsibility Psychologists on the team Reproductive health education Supportive technology tools Assessment of potential risky behaviors using "HEADSSS" communication tool to ask about: home, education and eating, activities/employment, drugs tobacco, alcohol, suicidality, sex, and safety Engagement with dietitian, psychologist and mental health support as needed Dietitian on the team Readiness and preparation for transition to adult clinic

videoconferencing during a telemedicine session. Clinicians provide real-time problem-oriented education for young people with diabetes by using telemedicine to facilitate better decisions by youths with diabetes and health care providers. Telemedicine has been successfully integrated into diabetes management by many diabetes centers of excellence to extend the reach of diabetes education and support when access to care is limited.<sup>131</sup> Telemedicine care has proven to be an effective add-on to regular out-patient care, but not a complete replacement for in person face-to-face counseling.<sup>132–135</sup>

There are some possible limitations to using high-tech diabetes tools for education purposes that are being addressed with the collaboration of technology experts, scientists, clinicians, and people with diabetes. Clinicians should warn their youth with diabetes regarding the potential inaccuracies, potential breach of confidentiality, and the risk of being overwhelmed by web-based information and guide their young people with diabetes and their caregivers to websites and mobile applications that are trustworthy.<sup>122,124</sup>

## 6 | AGE-SPECIFIC CHALLENGES AND OPPORTUNITIES

The features of normal development common to various ages and stages present unique challenges to diabetes management. For this reason, specific curricula and appropriate education materials and tools are recommended for children and adolescents of different age groups as well as for their parents and other primary care givers. School age children have expressed dissatisfaction that health professionals talk to parents and not to them, and there is some evidence that focused age-appropriate educational interventions are effective in children and families.<sup>50,52–54,57,136</sup> Table 3 identifies concerns, challenges, and learning opportunities common to the major developmental stages. The ISPAD guidelines chapters on caring for toddlers and preschool children and the chapter on adolescents with diabetes, provide more detailed information. (See ISPAD 2022 Consensus Guidelines Chapter 21 on Diabetes in Adolescence and Chapter 23 on Management of diabetes in very young children with diabetes).

## 7 | CONCLUSIONS

In conclusion, effective management of diabetes requires time, commitment, effort, and motivation. Age-appropriate, quality-assured structured diabetes education must be available to all young people with diabetes and their caregivers to maximize the effectiveness of their treatment. Diabetes education should be delivered by a multidisciplinary team of health care professionals who complement each other by working within their scope of practice as guided by their subspecialty. Diabetes education, designed to empower young people and caregivers in promoting self-management, starts at diagnosis and needs to be a continuous process, repeated regularly to ensure a positive long-term outlook. When new diabetes technologies become available, comprehensive structured education for educators, parents and children is a prerequisite for success.

### CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

### PEER REVIEW

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### AUTHOR CONTRIBUTIONS

For this guideline all authors have contributed with planning, literature review, drafting and writing the manuscript.

### DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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