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ISPAD GUIDELINES

ISPAD Clinical Practice Consensus Guidelines 2022: Diabetes in adolescence

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1 | SUMMARY OF WHAT IS NEW/DIFFERENT

- Modern insulin therapy produces normal or minimally delayed puberty.
- Despite recent technological advances in the care of diabetes, achieving optimal glycemic control during adolescence remains challenging.
- Peer support through online social media is an increasingly important source of advice.
- Motivational interviewing by psychologists is effective in optimizing outcomes in teenagers.
- Diabetes distress during adolescence may lead to less consistent use of insulin and other self-care measures with consequent increased glycemic variability.
- Mental health needs during adolescence may supersede other healthcare needs, requiring other specialty team involvement and prioritizing interprofessional communication.
- Mental health assessment is complex in adolescents and screening is recommended particularly for those experiencing recurrent diabetic ketoacidosis (DKA).
- Preconception counseling should begin during early puberty.
- A care ambassador/patient navigator leads to better transition outcomes.
- Screening for social determinants of health should be standard care in adolescents.

2 | EXECUTIVE SUMMARY, RECOMMENDATION & GRADING OF EVIDENCE

Adolescence is the transitional phase of development between childhood and emerging adulthood. Healthcare and emotional needs are distinctly different from younger children and mature adults.

Puberty

- Puberty is a period of physiological insulin resistance, exaggerated in adolescents with type 1 diabetes (T1D) (B).
- Pubertal developmental is normal or minimally delayed in the modern insulin era (B).
- Worsening of glycemic control is commonly reported in puberty and persists throughout adolescence (B).

Diabetes identity and communication

- Consider directing young people toward relevant local peer support groups and make them aware of the diabetes online community at diagnosis (B).
- Include asking in consultations about youth participation in peer support communities online and offline (what they learn and how these communities support them) (B).
- Supporting communication between the young person's family, their healthcare team, and school through individual health plans and school nurse support is advised (B).
- Encourage authoritative, helpful parenting styles with clear and realistic expectations (C).

Mental health

- Diabetes services should recognize the significant mental health burden of young people with T1D and have mental health clinicians trained in diabetes to support them (B).
- Screen to identify early markers of mental health problems requiring treatment (B).
- Episodes of DKA and chronically very high HbA1c are red flags for mental health problems (B).

Sexual health

- In order to increase awareness of the risks of unplanned pregnancy and suboptimal glycemic control, pre-conceptional counseling should begin in puberty in all girls (B).
- Hormonal contraception can be used, provided there are no microvascular complications and less than 20 years of disease duration; morbid obesity, severe hypertension, or the presence of multiple cardiovascular risk factors are contraindications for using combined hormonal contraception (E).
- Despite the absence of studies in teenagers with diabetes, long-acting reversible contraception is the contraceptive of choice in adolescents (B).

Becoming a young adult

- The transition from pediatric to adult care should be a planned, organized process (E).
- Youth mature at different rates and delay of transition based on the developmental needs of the young person may be appropriate to optimize outcomes (B).
- Transition planning, specifically utilizing care coordinators/patient navigators, can enhance post-transition clinic attendance and engagement (A).
- Screening for social needs should occur at least annually for all youth with diabetes and their families (C).
- Diabetes care plans should accommodate unmet social needs, with appropriate referral to community resources when appropriate (C).

3 | INTRODUCTION

Adolescence culminates in peak physical development, followed by psychological and cognitive maturation, autonomy, and social independence. The combination of rapid physical and sexual maturation with subsequent neuro-maturation creates a period of physiologic and behavioral vulnerability. This is especially relevant to the management of chronic illnesses such as diabetes in which the endocrine changes of puberty impact directly upon the physiology of glycemic control.

All adolescents vary in their adaptation and responses to change, and attitudes can be impulsive, questioning, and disruptive, often receiving a negative response from adults. Similarly in pediatric diabetes practice, highlighting the "difficulties" in interactions with adolescents and their behaviors is widespread. The clinical consequences of these behaviors are exemplified in data such as those from the T1D Exchange in the United States (Figure 1),[1] which showed a marked deterioration in glycemic control between the ages of 10 and 20 years. These findings are not isolated to the United States and are common across many other health-care settings, although not universal.[2,3] These disappointing outcomes have not arisen or persisted due to clinical inertia. On the contrary, there is a plethora of medical literature examining the issues around adolescents and diabetes, including

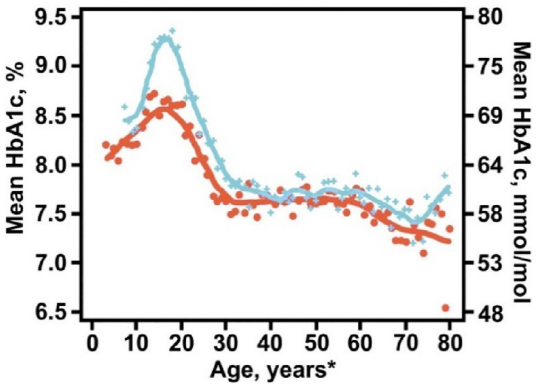

FIGURE 1 Serial data from the T1D exchange[1] highlighting adolescence as a period of deteriorating glycemic control over two time-intervals (2010–2012 in red and 2016–2018 in blue).

textbooks and chapters dedicated to this topic,[4–6] special guidelines[7] and over 13,000 papers published since 2000 that can be found under a PubMed search of "type 1 diabetes and adolescence."

There has also been a concomitant rise in the use of new strategies that promised increased ease of use and the potential for improved adherence. Despite all this clinical activity, we are arguably not making progress in improving diabetes-related outcomes for adolescents. This leads to the question, why suboptimal diabetes outcomes during adolescence are seemingly so unchanged? Adolescence is marked by physiological and behavioral changes, many of which affect blood glucose levels. These include pubertal endocrine changes leading to greater insulin resistance,[8] evolving neurocognition with lessened impulse control leading to erratic meal and exercise patterns,[9,10] suboptimal adherence to treatment regimens[11] and suboptimal impulse control with hazardous and risk-taking behaviors.[12,13] All of these changes are occurring in the context of an adolescent's developing autonomy and independence and in the face of chronic disease management, their need for ongoing support and some level of dependence on others. In adolescents with T1D there is robust evidence linking clinical outcomes to ongoing parental engagement.[14]

The other apparent phenomenon that militates against improved clinical outcomes during adolescence has been the enormous rise in mental health issues, particularly anxiety, depression, and disordered eating.[15] Self-evidently, a functional psyche is the foundation for the never-ending task of ongoing diabetes self-care. It is hard to maintain the tools of adaptive living such as motivation, cognitive flexibility, and a long-term perspective when one's psyche is injured. Consequently, mental health-care needs during adolescence may be so immediate and of such severity, that they will occasionally override other health-care needs in the short-term. This, in turn, will necessitate the involvement of other specialty health-care teams and a level of multidisciplinary health-care communication that is heightened and uncommon during other periods of diabetes management. The transitory and shifting nature of health-care priorities adds to the increased complexity of chronic disease management at this age.

The quest for optimal behavioral and physiological outcomes, including euglycemia, can be tremendously challenging for young people and their therapists. The purpose of this chapter is to direct the reader to the evidence that there is to help them achieve these outcomes, in a transitory, but nevertheless challenging period of diabetes management.

4 | ENDOCRINOLOGY OF PUBERTY

Puberty may be an accelerator for the onset of T1D and there is a peak in incidence during the peripubertal years.[16–18] There are gender differences in the age of onset of T1D, with younger age of onset in girls linked to their earlier start of puberty. The role of estrogen in modulating transcription of genes such as the IL-6 promoter, has been proposed to be one of the explanations for this variance.[19]

Transient pubertal insulin resistance (IR) occurs in those with and without diabetes and has implications for glycemic control and risk of complications.[20] This dip in insulin sensitivity is exaggerated in adolescents with T1D and is 33%–42% lower when compared to non-diabetic children.[8] IR is believed to be largely mediated by the pubertal peak in GH and IGF-1 levels which follow the same pattern of rise and fall. GH levels are higher in T1D at all pubertal stages, thereby providing credence to the observation of increased IR in T1D.[21] Mechanistically, GH affects the insulin signaling pathway at the post-receptor level, leading to a state of IR.[22] This pattern of increased GH and IR also leads to exaggerated ketogenesis in adolescents with T1D, which could predispose them to glycemic decompensation and DKA.[23]

Adolescence is also a period when glycemic control commonly deteriorates.[24] This occurs due to a combination of non-modifiable factors such as physiological IR, the effect of gonadal steroids, a rise in lean body mass leading to increased insulin requirements, and modifiable factors such as psychosocial and behavioral changes which lead to reduced adherence with treatment regimens along with a decline in physical activity.[22,25]

Puberty also confers an additive risk for the development of diabetic complications independent of the effect of glycemic control. Recent data suggest an increased risk of vascular complications such as proliferative retinopathy and nephropathy in individuals with a pubertal versus a post-pubertal onset of diabetes. This heightened risk is attributed to the effect of IR of puberty, the GH/IGF1 changes, androgens and the greater adiposity seen during adolescence.[26]

Diabetes can also adversely impact growth and pubertal development. Insulin and leptin are essential for normal GnRH neuronal function and a deficiency can therefore, lead to a state of hypogonadism. Studies from the early era of insulin treatment when suboptimal glycemic control was prevalent, reported a moderate-to-severe delay in the onset of puberty.[27,28] However, with the advent of modern insulin therapy, pubertal development is normal or minimally delayed and correlates with HbA1c levels.[29–31] Ovarian hyperandrogenism and menstrual irregularities are other commonly reported problems in adolescent girls with T1D.[28]

Similarly, severe growth abnormalities such as Mauriac syndrome are now rare. However, subtle impairments of growth have been related to glycemic control.[32,33] Blunting of the pubertal growth spurt with reduced peak height velocity have been described, though adult height is usually normal.[33–38] This growth impairment is attributed to changes in the GH/IGF1 axis with lower IGF-1, IGFBP-3 and increased IGFBP-1 levels reported in adolescents with T1D, due to hepatic GH resistance caused by decreased portal insulin concentrations.[32,34,35,37]

Body composition changes with increasing weight are also evident during puberty, with girls in particular showing increased fat mass as a side effect of the intensified insulin regimen and a subsequent state of relative leptin resistance.[26,33,35,39] This in turn makes them prone to a PCOS phenotype and may contribute to increased cardiovascular risk.[28,40] Body habitus changes may also impact negatively on body image and provoke the development of eating disorders and insulin omission for weight loss, leading to worsening glycemia and increased complications.[41,42]

5 | DIABETES IDENTITY AND COMMUNICATION IN ADOLESCENCE

5.1 | Communicating within the diabetes community

People (or parents of children) with diabetes spend most of their time managing diabetes alone.

- Peer support through online social media is an increasingly important source of advice.
- While interactions with the health-care team are important, peer support plays a crucial role in day-to-day management and improves self-management and physiological outcomes.[43]
- Understanding how communication within the diabetes community facilitates peer support and better self-management, can inform communication with the health-care team, and aid development of effective interventions.

There are three main sites of communication: the diabetes online community (DOC),[44,45] structured settings like peer support groups or peer mentoring programs,[46–49] and everyday conversations and interactions with family, friends or peers.[50]

Most communication within the DOC takes place on various social media channels like Facebook, Youtube, Twitter, or Instagram,[44,51] whereas peer support groups, mentoring, and communication with peers and family or friends happen to a large extent face-to-face or via text messages.[52] Young people with diabetes and their families turn to peer support, particularly for social and emotional support and sharing of personal experiences, but also for information about treatment options and reviews or discussion of new technology.[44,53–56] The DOC has effective ways of policing knowledge and making sure no misinformation is spread; overall the quality of information shared was rated as high and reliable in a scoping review of the literature.[44,57]

In communicating with each other, especially online, young people with diabetes draw on creative and humorous modes including visual[58] and textual materials. They emphasize that they are persons first and that diabetes is only one part of who they are.[59,60]

Analyzing communication within the diabetes community thus highlights the importance of social and emotional support, as well as the holistic, person-centered perspective that treats the individual in his/her own context.

- Youth should be directed toward relevant local peer support groups and made aware of the diabetes online community at diagnosis.
- Include asking in consultations about youth participation in peer support communities online and offline (what they learn & how these communities support them).
- Supporting communication between the young person's family, their healthcare team, and school through individual health plans and school nurse support is advised.

5.2 | School

Young people with diabetes experience greater absenteeism and exclusion from school, some poorer educational attainment and higher risk of unemployment.[61] Contributory factors include: lack of full-time school nurses, teacher knowledge of diabetes, access to diabetes tools, freedom to perform diabetes self-care, nutritional information in cafeterias, and communication between parents and school personnel.[62] Improved communication between the young person's family, their health-care team and the school through individual health plans and school nurse support seems effective and telemedicine in school may support individual case management.[63]

Students with T1D are concerned about 'being different' from their peers, which may inhibit self-care activities and lead to bullying.[63] They reported relying for support on a small number of trusted close friends[64] who could help at times of need while keeping their diabetes a secret from others. This peer support improves quality of life in school[65] and is associated with better glycemic control.[66] However, there is little evidence about how best to support young people to improve their resilience and coping in school or further education.[67] For detailed review refer to Chapter 22 ISPAD 2022 guidelines on "Management and support of children and adolescents with type 1 diabetes in school."

5.3 | Family

Several non-modifiable family demographic factors are associated with worse glycemic control, including ethnic minority status, public health insurance, families with a single parent or large numbers of children, reduced income and parental literacy.[68] Warm and supportive family interactions are linked with better outcomes, particularly in adolescent girls.[69] Authoritative, empathic parenting styles with clear and realistic expectations are correlated with better glycemic control and paternal involvement is important.[70] Adolescent perception of negative parental tones in discussions about diabetes was associated with worse glycemic control,[71] whereas autonomy-supportive communication is related to improved adherence.[72]

Diabetes-specific family conflict is associated with poorer glycemic control and reduced quality of life in teenagers,[70] suggesting that interventions focused on promoting family teamwork and communication or referral for family therapy may prove useful. Most studies have been US-based and cross-sectional and do not prove causality. However, a group intervention aiming to train families in teamwork around diabetes in the UK-proved disappointing, mostly due to poor attendance, suggesting more individualized approaches is required.[73]

5.4 | Interaction with health-care services

Many young people with T1D and their families report significant communication problems with health-care providers, with a mismatch in perceived priorities[74,75] and difficulties obtaining the information they required to effectively manage their diabetes.[11] A review of

psychoeducational interventions, mostly delivered by non-psychologists, reports a modest benefit on self-efficacy of adolescents with T1D though little impact on glycemic control.[76] Only a few studies utilized interventions delivered by members of the pediatric diabetes health-care team as part of routine care. Communication designed to facilitate behavior change known as motivational interviewing, which could be incorporated into routine clinic consultations, has shown promise when delivered by trained psychologists[77] but not when incorporated by trained pediatric diabetes health-care staff into routine consultations.[78] Nonetheless, there is good evidence that pediatric staff deemed to be "good communicators" are more effective in promoting adherence in the children they take care of[79] and that training in communication skills is worth investing in.

- Motivational interviewing by psychologists is effective in optimizing outcomes in teenagers.

6 | MENTAL HEALTH DISORDERS (ALSO REFER TO CHAPTER 15 ISPAD 2022 CONSENSUS GUIDELINES ON 'PSYCHOLOGICAL CARE OF CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES'

T1D seems an etiological factor in de novo psychiatric presentations or causes pre-existing subclinical mental health problems to tip into psychiatric diagnoses.[80]

Mental health assessment is complex in the context of adolescence and screening is recommended.[81] However, in clinical practice, indicators such as DKA admissions, very high HbA1c levels and insulin omission or overdose evident on continuous glucose monitoring (CGM), should be regarded as indirect evidence of possible mental health problems and assessed accordingly.[82–84]

Mental health problems in people with T1D can potentially lead to early complications and significantly early mortality,[85–87] usually through the interaction of mental health symptoms with insulin misuse. Mental health treatment should ideally be undertaken by clinicians with experience in diabetes.

- Mental health needs during adolescence may supersede other health-care needs, requiring other specialty team involvement and prioritizing interprofessional communication.
- Screening to identify early markers of mental health problems requiring treatment is advised
- Mental health assessment is complex in adolescents, and screening is recommended in those with diabetes, particularly those experiencing recurrent diabetic DKA or chronically very high HbA1c levels.

6.1 | Diabetes distress

Diabetes distress is the negative emotion or affect experienced by approximately 30% of adolescents with T1D.[88] Although not listed as a mental health disorder in the World Health Organization's International Classification of Diseases and Related Health Problems, diabetes distress has a complex relationship with the common mental health conditions, depression and anxiety disorders. The presence of diabetes distress can lead to over-diagnosis of depression and therefore clinical assessment is important to discern the cause.[89,90] It is the presence of diabetes distress long-term rather than depression per se that is more strongly associated with chronic hyperglycemia.[91]

- Diabetes distress during adolescence may lead to less consistent use of insulin and other self-care measures with consequent increased glycemic variability.

6.2 | Depression

Adolescents with depression present with a tendency to more somatic symptoms. Core features include low mood, no enjoyment and negative cognitions, although coexistent irritability or oppositional behavior may lead to missed diagnosis. Somatic symptoms such as fatigue and brain-fog may overlap with T1D symptoms from hypo- or hyperglycemia.[92] Questionnaire studies suggest 30% of youth with T1D have depression.[93] Care must be taken to ensure that diabetes distress regarding the burden of T1D is not misconstrued for depression and detailed assessment is necessary to ensure appropriate diagnosis and treatment. There is a high prevalence of depression symptoms in the early stages of diagnosis which usually resolve during adaptation.[94] Regular screening for depression and co-occurring anxiety and diabetes distress will help identify those most in need of intervention.[81]

- Depression may be confused with diabetes distress.
- Careful evaluation and screening for depression or diabetes distress.
- First line treatment for depression where available is cognitive behavioral therapy (CBT).[95]
- In the absence of access to talking therapies or in more severe cases that do not respond to CBT, use of antidepressant medication is indicated. Serotonin reuptake inhibitors (SSRIs) have the best evidence base for depression outcomes and improvements in glycemic control.[96]

6.3 | Anxiety disorders

Anxiety disorders in young people are characterized by intense anxiety in either specific or all areas of life and consequent avoidance of precipitating factors. Like depression, anxiety in adolescents can be masked by what appears to be irritability or stubbornness. In a population of adolescents with T1D, approximately 30% have significant anxiety symptoms and there is significant overlap with diabetes distress.[93]

Generalized anxiety is described as "free floating" with continual symptoms and no specific focus. There is substantial comorbidity with depression. As a counter to chronic uncomfortable feelings of anxiety, a person will compensate by avoiding as many stressful experiences as possible. In the context of diabetes, this could include not attending appointments, testing blood glucose or taking insulin.

Panic disorder is intense bursts of anxiety in which the person becomes overwhelmed by fear, often with prominent somatic symptoms such as sweating and tachycardia, as well as intense feelings of impending doom. Panic can occur out of the blue or be related to specific experiences, such as, for example, using public transport. Panic episodes can also be superimposed on a background of generalized anxiety. Panic disorder is particularly complicated in T1D, given the extensive overlap of panic symptoms and those of hypoglycemia.

First line treatment for anxiety disorders where available is CBT.[95] In the absence of access to talking therapies or in more severe cases, the use of antidepressant medication is indicated. Like depression, SSRIs have the best evidence base for effectiveness.[97]

6.4 | Drug and alcohol use

Studies indicate that adolescents with T1D are not more likely to experiment with alcohol or other substances, than their non-T1D peers.[98,99] However, young adult males with T1D are more likely to have a substance disorder diagnosis, suggesting that such problematic behavior may start earlier in life, during adolesence.[80,100] Clinicians should be aware that cigarettes, alcohol or drugs may be used by adolescents to manage diabetes distress. However, adolescents' knowledge of the risks regarding alcohol use for someone experiencing diabetes does not necessarily result in affected individuals following guidance on how to drink alcohol safely.[99]

6.5 | Eating disorders and body image

Eating disorders are seen more frequently in the T1D adolescent population,[101] with a varying prevalence of 1.6% using psychiatric criteria to 21% using specific tools designed for T1D.[101] Key from a diabetes clinicians' point of view, is the degree of overeating and insulin omission. Some people will have a binge eating picture with no under use of insulin and likely tending to develop obesity, whereas others will have a normal eating pattern, but have weight or shape concerns leading to insulin omission, usually with not very low BMI and high HbA1c. Most important to recognize is the degree of clinical risk associated with acute and chronic complications.[86] Screening tools are useful where services have varying experience in assessment for disordered eating.[102]

Treatment should maintain a shared focus between diabetes management and disordered eating, involving a specialist service or liaison between an Eating Disorder Service and diabetes clinicians.[103]

6.6 | Recurrent diabetic ketoacidosis

There is growing evidence for the association of recurrent DKA episodes and underlying mental health problems, including self-harm and personality function.[104] Although standard practice after DKA is re-education regarding sick day rules, mental health assessment prior to discharge is also advised. Services should use DKA recurrence as an indicator to suggest that an individual, their parent, or other key caregiver is struggling with their mental health or a frank psychiatric disorder. They should provide appropriate mental health intervention, thereby reducing risk of further DKA and risk of morbidity, poor quality of life and even early mortality from acute and chronic complications.[104]

7 | SEXUAL HEALTH

7.1 | Preconception counseling

Preconception counseling aims to promote self-care behaviors leading to healthy babies and mothers with diabetes. Frequently, medical care providers lack the knowledge to address reproductive issues in teenagers,[105,106] yet adolescents with T1D have inadequate knowledge about the risks of hyperglycemia during pregnancy.[107,108]

Preconception counseling should begin during early puberty,[7,109] as unprotected sexual activity in young women with significant hyperglycemia has substantially increased risks for the individual and their offspring.[107] The first phase of preconception care is "awareness counseling", provided well before the need for contraception or pregnancy care. Advice to young people regarding sexual health should consider religious, cultural and familial perspectives,[28,110] and a non-judgmental approach to sexual activity or sexual orientation is important.[111] The following should be discussed during medical visits[112]:

- the importance of optimal glycemic control before pregnancy to avoid risks to the developing embryo and fetus
- that ovulation is preserved and pregnancy may occur despite hyperglycemia or menstrual irregularities[113]
- family planning and contraception.

READY-girls is the only preconception counseling program that has been developed for young adolescents living with diabetes. This program has shown long-lasting benefits.[106,114] READY-girls is available free of charge in English (www.diabetes.org/ReadyGirls).

7.2 | Contraception

7.2.1 | Barrier methods

Male condoms offer the best protection against sexually transmitted disease (STD) and substantial protection against pregnancy.[115,116] Diaphragms, female condoms and coitus interruptus, a common practice among teenagers, are not recommended because they are associated with high pregnancy rates.

7.2.2 | Long-acting reversible contraception (LARC)

LARC, which includes intrauterine devices (IUDs) and the subdermal progestin implant, have become a first-line contraceptive choice for adolescents, even if they are nulliparous.[117–120] LARC offers better

protection against unintended pregnancy than oral contraceptives.[118] The effect of LARC on glycemic control in very young women with diabetes has not been evaluated though it is the contraceptive with the lowest risk of thromboembolism in women with diabetes.[121] Non-hormonal IUDs may be considered in young people in whom hormonal methods are contraindicated.[118] LARC does not protect against STDs nor are they associated with more episodes.

7.2.3 | Combined hormonal oral contraceptives (OCs)

Young people with diabetes without micro- or macro-vascular complications may use any hormonal method,[120] whereas those with complications should avoid using OCs, but may use IUDs or barrier methods.[118,120] Newer OCs with a lower estrogen dose (≤35 μg ethinyl estradiol) and newer progestogens are not associated with detrimental effects on glycemic control or weight,[122] though a recent epidemiological study suggested that OCs in young women with diabetes may be associated with a poorer cardiovascular risk profile.[123]

Young people with diabetes on OCs, should be monitored regularly for side effects. Diabetes per se is not a risk factor for venous thromboembolism,[120] but the association with other risk factors should be considered. Very obese individuals should be aware that hormonal contraception may have a decreased efficacy and higher risk of venous thromboembolism.[124] Hormonal patches have shown the highest risk of thromboembolism in adult women with diabetes.[121] Women should be educated about the signs of thromboembolism (abdominal pain, chest pain, headaches, blurred vision (eye), severe leg pain (ACHES)). Those with a history of thrombotic disease should not use combined hormonal contraception.[120]

Polycystic ovarian syndrome, menstrual abnormalities and hyperandrogenism are prevalent in young women with diabetes.[31,125] The use of an OC may be helpful.[28,126,127]

Progesterone-only OCs provide insufficient contraception for teenagers who are likely to forget the OCs. Sexually active young people should also be advised about the availability of the "morning after" hormone pill.[128]

7.2.4 | Hormonal injections

Medroxyprogesterone injections have been associated with decreased bone mass gain, which may be especially detrimental for adolescents with T1D. Combined hormonal monthly injection could be considered for youth with T1D with an erratic lifestyle who cannot have LARC but no safety study has been performed in youth with T1D.

7.2.5 | Adverse pregnancy outcomes in adolescents and young women with diabetes

Suboptimal glycemic control around conception increases the risks of congenital malformations, spontaneous abortion, and fetal death.[28,127,129–137] A planned pregnancy in a person with diabetes in optimal glycemic control and good health carries only slightly higher risks than those in the general population but not as elevated as previously reported in those with suboptimal glycemic control. However, most pregnancies in young women with diabetes are unplanned and associated with suboptimal glycemic control.[131,132,138,139] A fifth of live-born infants of unplanned pregnancies in adolescents with Type 2 diabetes had major congenital malformations, despite recommendations about early counseling on contraception and pre-pregnancy counseling.[140] Recent studies show worse outcomes in pregnancies in adolescents with diabetes and higher healthcare utilization during pregnancy,[137] including a higher risk of preeclampsia and larger babies than adult women with pregestational diabetes.[141] However, a nationwide Welsh study showed the similar outcomes of pregnancies in both teenage and older mothers with T1D though hospital admissions during the first year of life were five times more common in the babies of younger mothers.[135]

Access to expert pregnancy management should include:

- pre-pregnancy care in order to plan a healthy pregnancy;
- joint management by an obstetrician and physician with expertise in diabetes and pregnancy; and
- delivery in a hospital with expert maternal, fetal, perinatal, and neonatal care.

8 | BECOMING A YOUNG ADULT

8.1 | Study and examinations

Most adolescents and young adults will be required to complete major academic examinations. Providers should discuss the cognitive effects of hypoglycemia[142,143] and hyperglycemia.[144] Reasonable accommodations for formal or standardized testing should be provided to students with diabetes.[145] Accommodations should include free access to food (for treatment of hypoglycemia), drink, and lavatory, as well as diabetes equipment including blood glucose meter, CGM, and insulin delivery devices. Adjustments to insulin regimens and/or diet should be made according to maintain euglycemia during exams.

8.2 | Driving

Hypoglycemia is the main factor increasing driving risk in people with diabetes.[146–148] However, this risk is mitigated with glycemia awareness, stable glycemic control and no visual disability, to the extent that in most settings, youth with diabetes are able to drive non-commercial vehicles. Regulations vary in different countries.[147] Severe hypoglycemia in the preceding months may cause authorities in some areas to delay granting a license or result in suspension. Counseling should include information on relevant regulations and hypoglycemia prevention by blood glucose monitoring before driving, use of CGM and appropriate food intake.

8.3 | Employment

There should be no discrimination or stigma against people with diabetes in the workplace[149] Advice on employment and diabetes should include the following:

- recommendation to inform potential employers about diabetes;
- discussion of those careers that may be unavailable to persons with diabetes, e.g. police officer, firefighter, armed forces and certain public services, driving large goods vehicles or piloting airplanes (regulations vary among countries); and
- preparing for the workplace with responsible diabetes self-care.

8.4 | Young adulthood and leaving home

The developmental stage from the late teens through the twenties has been defined as "emerging adulthood," a period of significant competing educational, social, work, and financial priorities.[150–152] As young adults with diabetes experience competing life priorities and receive decreased parental support, adherence and glycemic control may decline. Young adults with T1D are at risk for acute complications as well as chronic microvascular complications and early mortality.[153–155] Young adults need specialized diabetes care and education, including counseling on diabetes self-management, healthcare navigation (e.g., maintaining supplies and appointments), and sick-day management.[151,152] In addition,[156] providing information about T1D for peers and colleagues – including risks, symptoms and treatment of hypoglycemia – is important as the young adult develops independence.

8.5 | Transition from pediatric to adult care

In addition to assuming increased self-care responsibility, young adults will eventually need to transfer from pediatric to adult diabetes providers. The transition from pediatric to adult care should be a planned, organized process rather than a sudden and unanticipated transfer.[151] Suboptimal transition and coordination may lead to fragmentation of care delivery and increased risk for adverse outcomes. Transition care challenges documented in the literature include inadequate transition preparation,[157–160] prolonged gaps between pediatric and adult care,[158,159,161,162] and increased post-transition diabetes hospitalizations.[163]

Age at transition varies according to the individual factors, the availability of appropriate adult diabetes services, and health system regulations. In some countries, youth must transition from pediatric to adult diabetes care at aged 18 years, whereas ongoing care until mid-20s is usual in other countries. Two observational studies from the U.S. suggest worse deterioration of glycemic control in young adults receiving adult care, compared to those still receiving pediatric care.[69,164] While further research is needed to delineate optimal transition age and predictors of success, delay of transition based on the developmental needs of the young person may be appropriate. Young adults with diabetes should continue to be seen by a diabetes team (whether pediatric or adult) every 3 months at minimum.

Some diabetes transition interventions have shown promising results, including dedicated young adult clinics,[165–167] intensive transition coordination efforts[168–170] and use of a care ambassador/patient navigator to support the transition process.[165,171–174] Recent randomized trials have shown increased clinic attendance and lower disengagement rates in young adults with appointment navigation/coordination support.[171,172,174] Based on the current body of literature, specific transition recommendations include the following:

- development and sharing of a clinic-specific transition care policy;
- transition preparation, education (including counseling on diabetes self-management, diabetes control and complications, differences between pediatric and adult systems, and health-care navigation) and readiness assessment by pediatric providers, ideally starting in the early adolescent years and at least 1 year prior to transition;
- discussion with the young person and their family as to the best time for transfer, based on preference and readiness, as well as regulations and availability of adult services;
- delay of transition until the early twenties may be appropriate for many, ideally with flexibility about transition age as the psychosocial maturity and circumstances of young adults vary widely;
- identification of an adult service able to provide for the needs of young adults with diabetes;
- documentation of a written clinical diabetes summary and transition plan;
- utilization of transition care coordinators/patient navigators to assist with appointment scheduling and attendance, records transfer, and tracking to avoid loss to follow-up; and
- direct communication and handover between pediatric and adult diabetes care teams.

9 | GROUPS NEEDING SPECIAL ATTENTION

For socially vulnerable groups, added biological, behavioral, and socioenvironmental factors can contribute to inequity in medical and psychological outcomes. The Social Determinants of Health are a set of factors beyond the personal choices and behaviors of individuals, related to the one's socioeconomic status, environment, and social relationships that greatly influence the one's overall health status.[175,176] Social determinant domains include economic stability, neighborhood and built environment, education, social and community contexts, and healthcare. Social determinants of health are directly tied to social vulnerabilities including economic status or social class, and can be further exacerbated by racial/ethnic status, gender, or geographic location, among others.[177] Globally, it is estimated that social determinants of health account for 45%–60% of the variation in health status and can result in large inequities in myriad health outcomes, including in diabetes, life expectancy, across continents, countries, states, and regional areas.[175]

Socially vulnerable adolescents with diabetes, disproportionally experience negative effects of social determinants, which act as competing priorities to diabetes self-management and major contributors to adverse health outcomes. Adolescents are in a vulnerable period of their lives where they are starting to become independent from the family unit and when economic, social, educational, and behavioral gaps may become more pronounced, especially in the context of social vulnerabilities.[178] Social vulnerability increases the risk of developing diabetes by 2-fold in youth[179–181] and furthermore contributes to double the risk of suboptimal glycemic control, 1.5 times higher complications, and 2 times higher premature mortality.[154,182,183] Moreover, low access to high-quality medical care and decreased care engagement compounds these health outcome risks, leading to delays in diagnosis and management and increased utilization of emergency care.[184–186] In countries and regions that systematically marginalize certain vulnerable groups such as women or racial/ethnic minorities, the unequal distribution of material resources and social advantages has grave effects on health and diabetes.[187–189]

- Consider screening for social needs at least annually for all youth with diabetes and their families (C).
- Diabetes care plans should accommodate unmet social needs, with appropriate referral to community resources when appropriate (C).

Special attention is needed for socially vulnerable adolescents with diabetes, to prevent progression to adverse outcomes. Ultimately, while cooperation of housing, food, governmental, and health sectors may be necessary, to impact diabetes outcomes at the population level,[179,190] interventions in the delivery of diabetes care may have significant impact. First and foremost, screening for social determinants of health and vulnerabilities should become a standard of care. The World Health Organization and numerous other international and national organizations have pushed for standardized screening measures to identify social determinants at the point of care.[190] Knowledge of the social determinant of health barriers such as underemployment, housing and utility insecurity, food scarcity, interpersonal issues or social isolation, and the lack of access to necessary medications could greatly impact diabetes care plans and mitigation strategies.[176,179] In addition, multiple local community-based resources are now available to aid material and mental health needs, which can be leveraged to enhance diabetes self-management for adolescents with diabetes.[179] Group diabetes care formats should be encouraged for socially vulnerable adolescents with diabetes, as peer networking has demonstrated improvement in care engagement and outcomes at this developmental stage and for marginalized youth who may not have strong social support networks for diabetes care.[191]

Overall, health-care providers, health-care clinics, and larger clinical systems need to create policies that promote and prioritize equitable care to all adolescents with diabetes. Programs that evaluate and treat diabetes in the social context are urgently needed. Several studies addressing housing, food security, and linkage to high-quality healthcare have shown promising improvements in diabetes outcomes among adults,[179] but few research studies and clinical interventions have focused on highly vulnerable adolescents who have unique developmental needs and require additionally tailored care.[178,192] In addition, the powerful force of unconscious or implicit bias and its effect on health-care delivery and care engagement, needs to be more fully realized in the care of socially vulnerable adolescents with diabetes, who are often already marginalized by health-care providers.[193] Ultimately, increased awareness and tailored care for socially vulnerable adolescents with diabetes, will improve generations of health outcomes into adulthood. For details, refer to ISPAD 2022 guidelines Chapter 25 on "Management of Diabetes in children and adolescents with Limited Resources."

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Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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