EDITORIAL

Can we break down barriers to excellent diabetes healthcare for teenagers with diabetes?

"Through proactive care strategies, pediatric diabetes care providers can help to break down barriers to excellent care for teenagers with Type 1 and 2 diabetes."

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In this commentary we will first define excellent care for teenagers with Type 1 diabetes (T1D) and Type 2 diabetes (T2D). Second, we will identify barriers to excellent diabetes care for teenagers with diabetes focusing on the barriers for which diabetes clinicians can potentially and proactively intervene.

In this post-Diabetes Control and Complications Trial (DCCT) era, for teenagers with T1D, excellent diabetes healthcare is defined as care that promotes a sustained reduction in the level of glycated hemoglobin to lower the risk of diabetic microvascular and neuropathic complications, while also ensuring that teenagers achieve normal developmental tasks of adolescence and optimal quality of life [1]. 'Diabetes burnout' is one of the most common barriers to achieving this optimal glycemic control and psychosocial development in teenagers with T1D. Excellent diabetes healthcare for teenagers with T2D is defined as care that lowers risk factors for the comorbidities and complications of T2D. Diabetes providers will need to negotiate with teenagers with T2D to promote realistic goals for optimal glycemic control and body weight through adherence to medication(s), increased physical activity and healthy eating to reduce the risk of T2D complications and comorbid conditions. To accomplish this, clinicians require an understanding of, and ability to work with, the common family and socioeconomic barriers to achieving excellent care for teenagers with T2D. For both teenagers with T1D and T2D, excellent diabetes care includes:

- Sensitivity to, and referral for the common adolescent psychological problems that are barriers to diabetes care – depression, anxiety, disordered eating and learning disabilities;
- Preparation for transition to diabetes care within an adult healthcare system with more independent management of diabetes, often far from the youth's known family and community.

Diabetes burnout is a barrier to excellent diabetes care for teenagers with T1D

One of the greatest barriers to optimal blood glucose (BG) control in teenagers with T1D is diabetes burnout – the emotional fatigue and mental exhaustion that come from repeatedly and unsuccessfully trying to manage diabetes. When teenagers

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with T1D carry the burden of diabetes management alone, often within a context of unremitting criticism from family and healthcare providers, this results in chronic feelings of failure in managing diabetes [2]. Through anticipatory guidance, diabetes clinicians can help to prevent diabetes burnout in their adolescent patients by promoting, prior to adolescence, positive family communication around BG monitoring, avoiding discussion of BG levels as 'good' and 'bad', rather talking about BG levels as 'high' and 'low' or 'in range' and 'out of range'. Diabetes clinicians can help patients and families anticipate and thus prevent diabetes burnout by introducing, before adolescence, the importance of sustained developmentally appropriate parental involvement in diabetes management (diabetes 'teamwork'), as well as sustained, positive family problem solving and conflict resolution skills [3].

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Given the context of a low socioeconomic status & family risk factors of many youth with T2D, unrealistic diabetes goals are barriers to excellent diabetes care

Diabetes clinicians require the support of a multidisciplinary team to address barriers to excellent diabetes care for teenagers with T2D. In the large, multisite TODAY study of youth with T2D, over 90% of teenagers with T2D had a first-degree relative with T2D [4]. Thus, many teenagers with T2D come from families who are already struggling with the intergenerational burdens of T2D complications. Youth with T2D often assume caregiving roles for parents and grandparents suffering from debilitating complications of T2D. Moreover, teenagers with T2D frequently have poor role models for the prescribed T2D lifestyle characterized by medication adherence, healthy eating and regular physical activity [5]. Addressing these family barriers with adolescent patients with T2D is essential: explaining that complications from T2D are not inevitable, and that by taking medications and maintaining a healthy weight, teenagers can prevent complications of T2D and reach their goals for young adulthood.

Teenagers with T2D are frequently from 'vulnerable populations' characterized by low family economic resources, low educational levels, minority racial/ethnic group membership, language barriers, poor health literacy, unhealthy but ethnically/culturally rooted nutrition practices and limited access to healthcare, especially preventive healthcare [6]. The 'diabetes team' caring for teenagers with T2D should include experienced social workers to address these economic and healthcare access barriers rooted in poverty, and diabetes nurses and dietitians to educate patients and family members about managing T2D within their family environment, and to work with teenagers to set realistic goals for increasing healthy eating and physical activity.

Psychological disorders are barriers to excellent diabetes care for teenagers with T1D & T2D

Depression, anxiety, eating disorders and learning problems are well-documented barriers to excellent care for teenagers with T1D [7,8] and T2D [9,10]. It is impossible for teenagers with T1D or T2D to maintain diabetes self-care skills or optimal health while struggling with depression, anxiety or an eating disorder. Therefore, diabetes clinicians should maintain an 'index of suspicion' for these conditions in order to make timely referrals to mental health providers for diagnosis and treatment. Very few diabetes clinicians have ready access to a diabetes-trained mental health provider. Therefore, diabetes clinicians will often have to create a 'team' when treating adolescents with diabetes and a psychological disorder. Contacting regional tertiary care pediatric centers and reaching out to local mental health associations can potentially help the diabetes clinician identify appropriate mental health providers to work with their teenage patients to overcome psychological disorders that interfere with optimal health and quality of life. Furthermore, it has been documented that when mental health problems in teenagers with diabetes are not treated during adolescence, these problems escalate in young adulthood, causing a vicious cycle of poor glycemic control, poor psychological health and deteriorating quality of life.

Lack of preparation for the transition from pediatric care is a barrier to excellent diabetes care for older adolescents & young adults

Whether caring for teenagers with T1D or T2D, diabetes care providers will need to prepare their patients for their eventual transition from pediatric to adult healthcare. There are many critical diabetes management skills that teenagers may not have learned during the course of their disease. When they leave the parental home and pediatric care providers, older teenagers with

diabetes need the skills to identify an adult diabetes care provider who they can work during young adulthood. Older teenagers with diabetes also need to learn skills for maintaining medication prescriptions, advocating for themselves in educational settings and in the workplace, and in some countries, securing and sustaining health insurance coverage.

Without preparation for the transition, teenagers with diabetes are at high risk for poor adherence to diabetes treatment and loss to medical follow-up. Loss to medical follow-up means that the older teenager or young adult does not receive screenings for complications that are critical for the prevention of complications during the young-adult period. Preparing teenagers with diabetes for the transition ahead helps to equip them with the skills to be a lifelong user of diabetes care and to lay a foundation during young adulthood for optimal glycemic control and optimal quality of life during their adult years with diabetes.

Conclusion

Through proactive care strategies, pediatric diabetes care providers can help to break down barriers to excellent care for teenagers with T1D and T2D. Diabetes burnout is one of the most common barriers to optimal glycemic control and healthy psychosocial development in teenagers with T1D. Diabetes clinicians can help patients and families anticipate, and thus prevent, diabetes burnout by stressing, before adolescence, the importance of sustained developmentally appropriate parental involvement in diabetes management (diabetes 'teamwork'), as well as positive family problem solving and conflict resolution skills. For teenage patients with T2D, providers need to work with experienced social workers and diabetes educators to negotiate realistic lifestyle change goals taking into account the high-risk family and low socioeconomic status environments in which many youth with T2D live. For both teenagers with T1D and T2D, pediatric providers also need to proactively identify appropriate mental health providers for diagnosis and treatment of the common mental health disorders facing teenagers with diabetes (depression, anxiety, eating disorders and learning disabilities). Maintaining a 'high index of suspicion' for these mental health problems during routine diabetes care visits will help in early identification and ensure that mental health problems do not sabotage diabetes management during adolescence. Finally, proactive preparation of patients and families for their eventual transition from pediatric to adult care systems is an important role of the pediatric team, equipping the teenager with skills to be an independent manager and user of diabetes care during young adulthood and beyond.

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