

Young Adults with Type 1 Diabetes

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KEYWORDS

- Young adults • Type 1 diabetes • Health-care transition • Developmental challenges
- Marginalized youth • Targeted interventions

KEY POINTS

- Young adulthood is a unique phase in life with multiple developmental, social, and health-care changes that complicate type 1 diabetes self-management and can be associated with worsening of health and psychosocial outcomes.
- Young adults (YA) from marginalized groups experience negative social determinants of health, stigma, and effects of structural racism that are associated with high risk for even worse outcomes.
- We review evidence-based care approaches that improve outcomes for YA with type 1 diabetes, including health-care transition clinics, psychosocial care interventions, telehealth and mobile strategies, occupational therapy approaches, and mitigation or elimination of root causes of inequity to improve diabetes self-management.

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INTRODUCTION

Young adulthood (ages 18–30 years) is a unique developmental phase marked by multiple concurrent transitions, including physical, psychological, financial, and social changes that influence type 1 diabetes (T1D) self-management.^{1,2} Coinciding with these normative transitions, young adults (YA) with T1D face unique obstacles navigating the transition from pediatric to adult medical care. During this time, high-quality care is fragmented, resulting in suboptimal glycemic control, early microvascular complications, preventable hospitalizations, and premature mortality.³

Data from the T1D Exchange indicate that only 14% of youth with T1D in the United States achieve target glycemic goals (HbA1c). HbA1c levels increase during late adolescence and young adulthood and have worsened over time.⁴ In addition, diabetes technology use was lowest in the YA age group, with widening age disparity during the last decade.⁴ The SEARCH for Diabetes in Youth study further demonstrated that approximately one-third (32%) of YA with T1D had at least 1 diabetes-related complication (retinopathy, neuropathy, or nephropathy) at a mean age of 21 years.⁵ Moreover, mortality for YA with T1D was 1.5 times greater compared to YA without diabetes.⁶

There is a critical need to review and implement evidence-based strategies to improve outcomes and address care gaps for this vulnerable population.^{7,8} In this narrative review, we summarize the unique health-care considerations for YA with T1D, psychosocial risk factors and outcomes, racial-ethnic disparities, and evidence-based approaches to care.

SECTION ONE: UNIQUE HEALTH-CARE CONSIDERATIONS FOR YOUNG ADULTS WITH TYPE 1 DIABETES

The Intersection of Young Adult Development and Type 1 Diabetes

Common developmental challenges of young adulthood complicate diabetes self-management and health-care transition. This intersectionality can be seen when YA have to balance typical daily activities with the demands of diabetes care. YA often report that balancing diabetes and “life” is challenging,⁹ especially when related to work/school, relationships, and finances.¹⁰ Diabetes-related tasks can also interfere with sleep, which can lead to disruptions in glycemia among YA.^{11,12}

Differentiating from one’s family is a key task during young adulthood²; yet, parental involvement is highly beneficial during this time, especially while transitioning to adult health care.^{13–16} Compared to those without T1D, YA with T1D are more likely to identify as “adults,” suggesting that the demands of T1D may increase perceived independence, self-sufficiency, and responsibility.¹⁷

Additionally, social relationships are central to YA, yet the benefits of receiving peer support related to diabetes are not always straightforward.^{18,19} In certain situations, diabetes-specific support from peers is beneficial, especially when YA are satisfied with the support received.¹⁸ However, the involvement of peers in diabetes care can also lead to negative consequences. For example, diabetes technology can be negatively influenced by romantic relationships with regard to the sensitivity of wearing technology and lack of T1D partner support.²⁰

Young adulthood is also unique because it represents a peak time for the onset of mental health symptoms.^{21,22} Although all people with diabetes are at an increased risk for diagnosis of psychological conditions,²³ challenges associated with living with and managing T1D may exacerbate emotional and psychological distress during young adulthood.²⁴ YA with T1D experience increased rates of depression, anxiety, and eating disorders compared with both YA without diabetes²⁵ and adolescents with diabetes.²⁶

YA with T1D and depression describe their depression as negatively affecting their physical, emotional, and social well-being.²⁵ Depressive symptoms have also been associated with higher HbA1c and somatic symptoms (eg, lethargy, sleep difficulty), which highlights the complexity of the relationship between diabetes and depression.²⁷ Anxiety disorders in YA with T1D have also shown to be associated with higher HbA1c levels, rates of diabetic ketoacidosis (DKA), and hospital admissions than those without anxiety disorders.²⁸ In addition, anxiety symptoms are associated with less engagement in self-management behaviors, more depressive symptoms, and greater fear of hypoglycemia.²⁹ Female YA with T1D experience twice the risk for engaging in disordered eating behaviors and receiving eating disorder diagnoses than peers without diabetes.^{30,31} Furthermore, one study quotes that up to 40% of YA women with T1D omit insulin for weight loss.³²

Finally, diabetes distress is also highly prevalent in YA with T1D. Compared with older adults, YA with T1D experience greater diabetes distress and engage less in diabetes self-management.³³ Diabetes distress describes the stress and burden of living with and managing diabetes but may not represent depression or anxiety, although it can be considered a precursor. Diabetes distress also resulted in YA reporting feeling less ready to transfer to adult care, poorer self-management skills, and lower health-related quality of life, as well as predicting higher HbA1c levels.^{34,35,36}

Disparities in Outcomes for Young Adults with Type 1 Diabetes from Minoritized Groups

YA from minoritized groups exhibit poorer health outcomes than NHW peers, which is attributed to systemic inequities.^{37–41} The SEARCH for Diabetes in Youth study has shown a disproportionate increase in the prevalence and incidence of T1D among YA from minoritized groups, with the incidence among Hispanic youth increasing 3.5 times as fast as non-Hispanic White (NHW) youth.⁴² Among YA in the T1D Exchange, mean HbA1c levels were 10.3% among non-Hispanic Black (NHB) and 9.2% among Hispanic YA, compared with 8.3% among NHW YA, after adjusting for insurance type and socioeconomic status (SES; $P < .001$).⁴³ In addition, NHB YA had higher rates of DKA, severe hypoglycemia, and the lowest rates of insulin pump and continuous glucose monitor (CGM) use compared with NHW YA. Furthermore, among 300 YA with T1D in the Young Adult Racial Disparities in Diabetes (YARDD) study, NHB YA had 2.26% points higher mean HbA1c than NHW YA, despite accounting for differences in SES, and were attributed to disparities in lower use of diabetes technology use, higher diabetes distress, and lower self-rated diabetes self-management.³⁸ Longitudinal studies of HbA1c trajectories have demonstrated that NHB and Hispanic youth have higher HbA1c levels at diabetes diagnosis and have the most rapidly increasing HbA1c levels, increasing the risk of diabetes-related complications in young adulthood.⁴¹ In addition, quality of life has been shown to be lowest among minoritized youth with T1D and could be exacerbated in the YA years.⁴⁴

Reasons for these disparities in outcomes include negative influences of social determinants of health (SDOH), lower social support, financial barriers, and inequity in health-care access and delivery.³⁷ SDOH are heightened in the YA period given increased independence during this life stage, which can worsen factors such as residential and financial instability, transportation challenges, and food insecurity.⁴⁵ In addition, disparate use of diabetes technology may account for some of the glycemic disparity. Stark differences in rates of technology uptake among NHB YA persist after accounting for SES, demographics, and health-care factors.^{4,38,46} Even where universal coverage for technology is offered, inequities in adoption and use remain.⁴⁷ These barriers to universal adoption may reflect implicit bias in clinic processes and communication strategies

at the provider and health-care system levels, such as limited shared decision-making, inadequate tailoring of therapeutics, and cumbersome insurance authorization processes,^{48–50} which considered together with the care needs of YA, only exacerbate the influences of structural racism, stigma, health-care trauma, and resultant poor outcomes for minoritized YA with T1D.⁴⁹

SECTION TWO: EVIDENCE-BASED STRATEGIES TO IMPROVE OUTCOMES FOR YOUNG ADULTS WITH TYPE 1 DIABETES

New Health-care Delivery Models

Health-care transition clinics

Overwhelming evidence shows that YA with T1D transitioning from pediatric to adult diabetes care experience higher HbA1c, psychological issues, hospitalizations, and mortality in the transfer period, when loss to follow-up care is at its highest.^{3,39,51–53} Moreover, a lack of YA-centered care delivery results in poor clinic attendance and higher HbA1c levels.⁵⁴ Prolonged transfer time from pediatric to adult clinics has also been shown to be associated with higher HbA1c and increased hospitalization days after transfer to adult care.⁵⁵ The American Diabetes Association and other professional societies have published guidelines to facilitate the transition from pediatric to adult T1D care.⁵⁶ Structured transition programs have resulted in improvement in glycemic outcomes, more consistent follow-up in outpatient care, decreases in hospital admissions, and reduction in the length of stay for DKA readmission.^{57–60}

Successful components and strategies of health-care transition clinics is covered more in depth in this issue by Malik and colleagues in the article titled “Incorporating the Six Core Elements of Health Care Transition in Type 1 Diabetes Care for Emerging Adults.” In brief, an overview of the literature yields more high-quality studies testing transition preparation and transfer coordination versus receivership roles. One study from Australia used a diabetes educator as a transition clinic coordinator, reminder calls and rebooking missed appointments, and phone support for sick day management demonstrating reduction in HbA1c ($9.3 \pm 2.17\%$ to $8.8 \pm 1.9\%$, $P < .001$), maintenance of clinic attendance, and reduction in DKA hospital admission rates by 30%, with maintenance of effects at 30 months posttransition.⁵⁷ Another study from the United Kingdom showed that transferring care to a collaboration of combined pediatric and adult providers or transfer of care to a dedicated YA transition clinic was associated with improved clinic attendance at follow-up.⁶¹ A multicenter randomized controlled trial in Canada testing effects of a transition coordinator showed improvement in clinic attendance (mean [SD] number of visits 4.1 [1.1] vs 3.6 [1.2], $P = .002$), patient satisfaction, and diabetes distress compared with standard care among 205 YA with T1D, but benefits were not sustained 12 months post-intervention.⁶⁰ Another study from the United States testing the LEAP (Let’s Empower and Prepare) program focused on structured diabetes education and access to a transition coordinator at a YA diabetes clinic, demonstrating reduction in HbA1c levels, less hypoglycemia, and improvement in overall well-being at 12 months compared with standard care.⁶² Finally, with more focus on receivership versus preparation or transfer coordination, a preliminary study of 71 YA with T1D transitioning from pediatric care to a YA T1D program in adult care demonstrated reduction in HbA1c levels, improved glucose monitoring, and program satisfaction.⁶³ Overall, the data demonstrate that implementing a structured transition program is overwhelmingly beneficial. More research needs to be done on the receivership side to understand the role of adult care in maintaining follow-up and mitigating long-term complications. In addition, more standardization of transition programs is needed to facilitate implementation and dissemination.

Telehealth interventions

Before the coronavirus disease 2019 (COVID-19) pandemic, telehealth and telemedicine accounted for less than 1% of health-care visits.⁶⁴ In early 2020, rapid regulatory changes necessitated by lockdowns and social distancing led to exponential growth in telehealth.^{65,66} Studies conducted before and during the COVID-19 pandemic have found equivalent or superior influences on glycemia and high satisfaction levels among people with T1D receiving care via telehealth, including those from marginalized communities.^{67–69} Among YA with T1D, telehealth has been used successfully for clinic visits, peer group sessions, group diabetes education, and self-management interventions, and may address known care gaps for this vulnerable group.

The CoYoT1 Clinic intervention for YA with T1D, which combines telehealth clinic visits and virtual peer groups, has shown the benefits of telehealth-delivered clinic visits and peer groups. Telehealth, as compared with in-person care clinic visits, increased visit frequency^{70,71} and decreased physician-related distress.⁷¹ In one study, these benefits were attributable to improvements among Latinx YA.⁷² Telehealth visits also improved quality of life and were cost-neutral relative to in-person care.⁷³ Virtual peer group sessions for YA with T1D improved diabetes-related distress and problem-solving,⁷⁴ and the combined telehealth/virtual peer group intervention improved diabetes distress, self-efficacy, diabetes-related communication, and depressive symptoms.⁷⁵ A study of group telehealth transition education for YA with T1D confirmed the feasibility of such an approach.⁷⁶ Finally, a study evaluating a telehealth occupational therapy self-management intervention for YA with T1D demonstrated improvements in the performance of diabetes-related occupations (eg, meal preparation, checking glucose), with comparable engagement to in-person care.⁷⁷

Best practices for successful implementation of telehealth care delivery models to improve outcomes for YA with T1D include flexibility in scheduling after hours and rescheduling to accommodate for frequent changes in work and school schedules; improving consistent communication with YA by leveraging technology to provide a means of contact other than phone calls to the clinic or portal messages; and ensuring that YA from socially and geographically marginalized communities are offered unique approaches with telehealth to minimize access issues that could exacerbate health inequities. Thus, when designed with YA needs and versatility in mind, telehealth can be an accessible, impactful, and transformative care model for YA with T1D. As coverage for telehealth changes since declaring the COVID-19 emergency, various influences on access to care, medical, and psychosocial outcomes should be studied, especially for YA who may be particularly vulnerable to such shifts in health care.

Psychosocial and Behavioral Care Interventions

Psychosocial care

Guidelines identify the need for psychosocial care throughout the life span of people with T1D.⁷⁸ Psychosocial care can vary in form and may include behavioral health consultation within a clinic setting, individual or family counseling, or therapy by a mental health professional, home-based intervention for individuals with higher social needs, or peer/social support groups.⁷⁹ Although such guidelines for psychosocial care across the life span are impactful, few psychosocial interventions are designed specifically for YA with T1D.⁸⁰ Interventions designed for this age group would ideally address key developmental issues such as assuming independent responsibility for diabetes care, promoting adaptive health behaviors, and reducing risky behaviors. Efforts have been made to identify the core outcomes that should be targeted by such interventions (eg, diabetes-related quality of life).⁸¹ Existing interventions designed for YA include formal peer support groups⁸² and informal online peer communities, both

of which have led to adaptive outcomes.^{83,84} A review reported that most intervention studies including YA-targeted education, self-management, transition, and general support.⁸⁵ Although no studies specifically targeted diabetes distress, participants often experienced a reduction in distress, likely due to social and emotional support. Further, one study found that YA perceptions about the consequences of diabetes and their control over it predicted various psychosocial outcomes 5 years later, but there was no association with glycemia.^{86,87} This suggests that adequate psychosocial support targeting one's experience of having diabetes has the potential to improve psychosocial well-being regardless of glycemic outcomes. More psychosocial interventions are needed targeting YA. Fortunately, YA have reported interest, especially in programs emphasizing reeducation and incorporating technology.⁸⁸

Online and mobile health interventions for peer support and diabetes self-management

Research suggests that youth and YA may benefit from online social interaction, especially when seeking to connect with others with similar developmental and/or health conditions.⁸⁹ YA often use social media to look up general health information, supplement clinical care, and obtain support from others.^{89,90} Social media offers YA with T1D the opportunity to engage with and create content related to their diabetes-related experiences.⁹¹ A qualitative study found that online activities of YA with diabetes were diverse and complex, including production and consumption of online content. This study also highlighted that social media engagement with diabetes-related resources and content varied based on YA engagement with sources of support offline.⁹²

Mobile health (mHealth) interventions (eg, delivered by involving technology, including mHealth apps) have demonstrated promise in supporting diabetes self-management. In contrast to the research using mHealth apps for adolescents with T1D,⁹³ few studies have evaluated this approach with YA. In a cross-sectional survey assessing the use of mHealth tools to deliver self-management support to YA with T1D, engagement with mHealth apps was lower than expected, related to the lack of awareness of available apps, expectations that apps would not be helpful, and privacy concerns.⁹⁴ Participants showed strong interest in using text messaging for diabetes self-management support.⁹⁴ This study also noted that the access, frequent use of, and convenience of mobile devices in this population presents promise for using mHealth to provide information and support to YA with T1D.⁹⁴ Preliminary results from an ongoing study engaging YA users in developing an mHealth app to support diabetes self-management⁹⁵ indicated that YA had positive impressions of the app and described the intervention positively in terms of promoting self-management through peer support and sharing information with health-care professionals.⁹⁶ Another ongoing randomized trial is currently testing an app that sends daily and weekly messages to YA about self-management goals and goal adherence, with the aim of improving glycemic outcomes.⁹⁷ Future research in this area will guide the direction of interventions to support YA using mobile and digital platforms.

Integrated Social and Medical Care Interventions

YA with T1D have a high degree of social needs and challenges influencing their care, predicting worse short-term and long-term glycemic and mental health outcomes.³⁷ These findings support the need to test more interventions that tailor care where SDOH and inequities in health care are targeted to reduce disease self-management challenges and improve outcomes.^{59,98}

Agarwal and colleagues conducted semistructured individual interviews in a cohort of underserved YA with T1D to examine interactions with health-care providers.⁴⁹ Results revealed lack of shared decision-making and inadequate incorporation of

preferences and biases of YA into conversations on treatment decisions. In addition, multistakeholder user-centered design workshops identified that key elements needed for deciding on T1D technology included social needs management and linkage, peer and family support, and visual and hands-on education.⁴⁸

Several interventions are ongoing to address unmet social and health-care needs for YA with T1D to target root causes of inequity; however, more are needed. One study found that clinical practice transformations, such as social needs management, CGM device trials, and provider bias training resulted in a 4-fold increase in CGM prescriptions for YA with T1D, with no differences among Hispanic, NHB, and NHW YA.⁹⁹ Additionally, an ongoing randomized controlled trial is testing whether a T1D-specific community health worker model offering social needs screening and management, peer support, and navigation to T1D technology, will improve T1D technology uptake, HbA1c levels, and consistency of outpatient care utilization for minoritized YA with T1D.¹⁰⁰ More studies are urgently needed to understand whether co-management of social and health needs will improve outcomes effectively for minoritized YA with T1D.

SECTION THREE: SUMMARY AND FUTURE DIRECTIONS

YA with T1D require tailored interventions to meet their unique developmental, diabetes-related, and health-care transition needs. Furthermore, there is a critical need to accelerate the study of adaptable practices that specifically address diabetes self-management, care engagement, and psychosocial care in this vulnerable population, to optimize the dose of clinical intervention planned.

Future directions should include more focus and testing of YA-specific evidence-based care strategies that leverage the unique aspects and preferences of YA with T1D. Dissemination, implementation, and cost-effectiveness of care models need to be studied to successfully generalize and disseminate high-quality care approaches. Finally, medical education needs to be modified to teach health-care providers on care approaches that foster trust and rapport with YA, that demonstrates how trust influences outpatient follow-up, self-management, medical outcomes, and mental health for YA with T1D. Prioritizing intervention in young adulthood can significantly and positively alter the trajectory of adulthood, and reduce cost and mortality across the adult life span.

CLINICS CARE POINTS

- YA with T1D need tailored care approaches that incorporate the competing personal and social constraints of young adulthood. Emphasis on creating new habits to solidify diabetes self-management, HbA1c, and treatment of mental health conditions to prevent diabetes complications during this vulnerable period is recommended.
- For minoritized YA with T1D, unmet social needs must be addressed and incorporated into diabetes care plans, with referrals to appropriate community resources if available.
- Screening YA with T1D for diabetes distress, depression, anxiety, disordered eating, and other mental health conditions is integral to care. Planning for early intervention with referrals to a mental health provider trained in diabetes is also advised.
- Transition from pediatric to adult health care should be a planned organized process, which includes transition preparation, transfer completion, and long-term maintenance in adult care.
- Telehealth and mobile health strategies may be particularly effective in YA with T1D, offering new care access and peer support opportunities that are not otherwise possible for in-person care.

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