



Young Adults With Type 1 Diabetes Preparing to Transition to Adult Care: Psychosocial Functioning and Associations With Self-Management and Health Outcomes

Ana M. Gutierrez-Colina,¹ Sarah Corathers,^{2,3} Sarah Beal,^{1,2} Holly Baugh,¹ Katie Nause,¹ and Jessica C. Kichler^{1,2}

¹Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH; ²Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH; ³Division of Endocrinology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH

BACKGROUND | Young adulthood is a vulnerable developmental period associated with increased risk for suboptimal health outcomes in youth with type 1 diabetes. Psychosocial factors have been associated with self-management and glycemic control in younger populations, but the extent to which these associations exist among young adults is poorly understood. This study aimed to examine the psychosocial functioning of young adults with type 1 diabetes and associated clinical outcomes.

METHODS | Participants included young adults ($n = 44$) between the ages of 18 and 23 years in a pediatric setting who were preparing to transition to adult care. All participants completed self-report measures of psychosocial functioning at baseline as part of this longitudinal observational study. Outcome data included glycemic control, frequency of blood glucose monitoring, and self-management ratings at baseline and 1-year follow-up.

RESULTS | Young adults with type 1 diabetes reported higher levels of depressive symptoms, lower self-efficacy, and more risk behaviors compared with previously published scores for adolescents. Young adults also reported greater resilience and transition readiness than their younger counterparts. Psychosocial variables were differentially related to glycemic control and frequency of blood glucose monitoring both cross-sectionally and longitudinally.

CONCLUSION | This study provides key information about the psychosocial functioning of young adults with type 1 diabetes. It identifies relevant psychosocial factors that are associated with meaningful health outcomes during the transition preparation period. These findings may inform the development of clinical programs aimed at promoting transition preparation and health outcomes in young adults with type 1 diabetes.

Type 1 diabetes is characterized by insulin deficiency that requires checking blood glucose levels frequently and coordinating those levels with the amount and timing of insulin administration, dietary intake, and physical activity. Achieving near-normal blood glucose levels prevents or delays the onset of medical complications (1). Adequate glycemic control, however, can be incredibly difficult to achieve for individuals with diabetes, particularly during young adulthood.

Young adulthood, often defined as the developmental stage between the age of 18 years and the mid-20s (2–4), is a particularly vulnerable period during which near-normal glycemic levels can be difficult to achieve (5). Some of the transitions that characterize this developmental period, including shifts in living situation, social relationships, and

responsibility for disease management, can challenge optimal glycemic control (5,6). Preparing to transition to adult care culminates in the movement from the structured support of family, school nurses, and established pediatric health care providers, into an unfamiliar system in which adult providers expect significantly higher levels of autonomy and independence, often with limited consideration of young adults' (YAs') psychosocial functioning or readiness to assume such responsibility.

In addition to increased demands for diabetes self-management during this transitional period, YAs must also integrate health care responsibilities into other competing demands that are typical of the transition to adulthood (e.g., college attendance and part-time employment). The challenges of coordinating all of these developmental tasks, along with

Corresponding author: Jessica C. Kichler, Jessica.Kichler@cchmc.org

<https://doi.org/10.2337/ds19-0050>

©2020 by the American Diabetes Association. Readers may use this article as long as the work is properly cited, the use is educational and not for profit, and the work is not altered. More information is available at <https://www.diabetesjournals.org/content/license>.

YAs' paradoxical motivation for immediate reward and discounted risk to future health, may explain not only why YAs are generally less healthy compared with adolescents (7), but also why YAs with type 1 diabetes are at risk for interrupted care and poor outcomes during the span of life between late adolescence and the mid-20s (8–12). Interestingly, even when YAs feel prepared to transition and do not experience a significant gap between pediatric and adult care, they still do not achieve optimal glycemic control after the transfer of care (13). These findings highlight the transition period as a crucial developmental epoch marked by increasing demands for diabetes self-care and independence, as well as increased risk for lack of follow-up, insufficient screening, poor disease management, and acute disease complications (e.g., diabetic ketoacidosis and hypoglycemia).

The severity of these suboptimal outcomes underscores the importance of identifying modifiable psychosocial factors that are associated with clinical outcomes (e.g., glycemic control as measured by A1C, frequency of blood glucose monitoring [BGM], and self-management ratings) in this patient population. Unfortunately, very few studies have been conducted with YAs who are preparing to transition to adult health care settings but who are still receiving care from pediatric providers.

The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians recommend planning to promote a successful transition (14), defined as “the purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented health care systems” (15). Identifying barriers to and facilitators of this process is a foundational step toward successful transition planning.

Some barriers to a successful transition to adult care have been identified for youth with type 1 diabetes, including inadequate access to adult providers and competing interests of emerging adulthood (16). However, minimal research exists on psychosocial factors specific to YAs and how they may affect health outcomes. Most of the literature examining psychosocial correlates of health outcomes (e.g., self-efficacy, depression, distress, quality of life, and self-management) has focused on adolescents with type 1 diabetes (17–21), but not on YAs exclusively, despite these two developmental periods being distinct in terms of maturity and independence, and the existing literature demonstrating that YAs experience generally poorer health compared with adolescents (7). Therefore, the current study aimed to 1) describe the psychosocial functioning of individuals with type 1 diabetes between the ages of 18 and 23 years, 2) compare these findings to previously published scores of adolescent/pediatric samples, and 3) determine

which psychosocial variables are associated with important clinical outcomes (i.e., A1C, frequency of BGM, and self-management ratings) over a 12-month period, during which YAs are preparing to transition to adult diabetes care.

Design and Methods

Procedure

This observational, longitudinal study was conducted in an urban tertiary referral pediatric hospital in the Midwest region of the United States. The study was approved by the hospital's institutional review board, which granted a waiver of written consent and deemed participants' electronic agreement to participate to be appropriate and sufficient.

Eligible participants were approached by a diabetes educator or research assistant during routine care visits in the diabetes clinic. Participants were invited to participate in the study, and those interested gave permission to be contacted in the future. No data or informed consent were obtained at the time of the clinic visit to minimize disruptions in clinic flow. After the diabetes visit, a study research coordinator followed up with YAs who had expressed interest in the study. Informed consent was obtained electronically from all participants. After consenting, YAs received study questionnaires via an online survey or through the mail (if a paper-and-pencil format was preferred).

Twelve months later, an e-mail message/paper-and-pencil packet was sent to each participant's e-mail/home address with the link to the survey questionnaires to obtain follow-up data. Participants were given 3 months to complete the measures at each time point (both at baseline and at 12-month follow-up), and automated reminders were sent up to five times. Compensation included \$15 and \$20 for baseline and follow-up assessments, respectively. Periodic e-mail/mail contact for study reminders were sent throughout the year using a secure e-mail system or delivery via the U.S. Postal Service to aid in study retention. Only participants who completed all baseline measures had the opportunity to complete the 12-month follow-up assessment.

Participants

All YAs (aged 18–23 years) with type 1 diabetes who were seen in the Cincinnati Children's Diabetes Clinic, had recently (<4 months) completed a transition assessment tool (see Measures section below for details) as part of their standard clinical care, and were not planning to transfer to adult diabetes care within the next 12 months were eligible to participate in the study. Potential participants were excluded if they 1) had a coexisting diagnosis of cognitive impairment

or pervasive developmental disorder or 2) were not fluent in English.

Forty-four YAs participated in the study (mean age 19.9 ± 1.26 years); 50% were female and 91% were Caucasian (with 6.8% African American and the remaining Asian and Hispanic). Participants had a mean duration of diabetes of 9.7 ± 4.7 years and a mean baseline A1C of $8.61 \pm 1.69\%$. Approximately 23% of participants used continuous glucose monitoring (CGM), and 82% used an insulin pump. The YAs' mean BMI was 25.67 ± 3.81 kg/m². More than 91% of participants planned to obtain a college or graduate degree in the future, and the YAs reported anticipating moving out of their family of origin's home at a mean age of 21.5 years (range 18–26 years).

Measures

Demographics and Clinical Information

The YAs completed brief questionnaires assessing demographic characteristics (e.g., age, race/ethnicity, and income/education) and diabetes clinical characteristics (e.g., diabetes duration and insulin treatment regimen) at baseline.

Self-Care Assessment

Participants completed the Self-Care Inventory–Revised (SCI-R) (21–23), a self-report questionnaire designed to evaluate self-management of the diabetes regimen across a series of self-care activities (e.g., BGM and attending appointments) (21). Items on this instrument are rated on a 5-point Likert scale, with higher scores indicating better diabetes self-management. Adequate internal consistency ($\alpha = 0.87$) has been reported (21). Internal consistency (Cronbach's α) for this measure was 0.85, indicating good scale reliability. Scores in the current study were compared with previously published SCI-R scores in a group of youth with type 1 diabetes aged 12–17 years (24).

Quality of Life Assessment

Participants filled out both the Pediatric Quality of Life (PedsQL) 4.0 Generic Core Scale and the PedsQL 3.2 Diabetes Module Young Adult Report (25,26). The Generic Core Scale is a 23-item questionnaire assessing self-reported health-related quality of life in the domains of physical functioning and psychosocial functioning. These ratings are assessed with a 5-point Likert scale, with higher scores reflecting better quality of life. The Diabetes Module is a 33-item measure designed to capture aspects related to the quality of life of YAs with type 1 diabetes on two subscales: diabetes symptoms and management (27). These instruments are valid and reliable (19,28). Internal consistency (Cronbach's α) for these measures ranged from 0.91 to 0.92, indicating excellent scale reliability. Participants' scores were compared with previously published quality

of life scores in a group of youth with type 1 diabetes, aged 2–21 years (29).

Diabetes Distress Assessment

On the Diabetes Distress Scale (DDS-2) (17), participants rated the degree to which two potential diabetes-related problem areas distressed or bothered them during the past month using a 6-point Likert scale (i.e., how overwhelmed they feel about their diabetes and how often they feel they are failing at their diabetes management). Mean item scores of ≥ 3 have been determined to be of clinical significance (17). Internal consistency (Cronbach's α) for this measure was 0.84, indicating good scale reliability. YA scores in the current study were compared with previously published DDS-2 scores in adolescents with type 1 diabetes between the ages of 15 and 18 years (30).

Depression Assessment

On the Center for Epidemiological Studies Depression (CES-D) scale (31), participants rated the frequency with which they had experienced 20 depressive symptoms in the past week. Scores between 16 and 23 are indicative of individuals in the mild range risk for clinical depression, and scores ≥ 24 are in the moderate to severe risk range. Higher scores indicate more depressive symptoms. Internal consistency (Cronbach's α) for this measure was 0.66, indicating lower scale reliability. Depression scores were compared with previously published CES-D scores in a group of youth with type 1 diabetes between the ages of 10 and 21 years (32).

Diabetes Self-Efficacy Assessment

On the Self-Efficacy for Diabetes (SED) scale (18), participants endorsed on a 5-point Likert scale (ranging from “very sure I can't” to “very sure I can”) the degree to which they believed they could complete 24 tasks related to diabetes management and control. Higher scores indicate greater self-efficacy for diabetes care. Internal consistency (Cronbach's α) for this measure was 0.97, indicating excellent scale reliability. Scores were compared with previously published self-efficacy scores in adolescents with type 1 diabetes, aged 12–17 years (33).

Diabetes-Related Strengths and Resilience Assessment

The Diabetes Strengths and Resilience Measure for Young Adults (DSTAR-YA) (34) is a 21-item measure that assesses YAs' sense of mastery of their diabetes management skills, social interactions around diabetes management, and emotional reactivity to diabetes-related challenging situations. This measure was adapted from the Resiliency Scales for Children and Adolescents (RSCA) (35) by Hilliard et al. (34,36). Higher scores indicate greater perceived strength. Internal consistency (Cronbach's α) was 0.76 for the current measure,

indicating acceptable reliability. Participants' resilience scores were compared with previously published DSTAR scores for adolescents with type 1 diabetes, aged 14–18 years (34).

Life Satisfaction Assessment

On the Satisfaction With Life Scale (SWLS) (37), participants endorsed on a 7-point Likert scale (ranging from “strongly disagree” to “strongly agree”) the degree to which they agreed with five items related to their life satisfaction. Internal consistency (Cronbach's α) for this measure was 0.95, indicating excellent reliability. Participants' scores were compared with previously published SWLS scores in an adolescent sample of youth between the ages of 14 and 17 years (38).

Transition Readiness Assessment

The Transition Readiness Measure (TRM) assesses participants' self-reported confidence, importance, and readiness to 1) transfer responsibility for health care from parent to child and 2) transfer from pediatric to adult health care (39). Each of the six individual items are anchored on a 5-point Likert scale (ranging from “not at all ready/confident/important” to “very ready/confident/important”). The TRM has been validated in young adults and is predictive of subsequent role attainment in adulthood (38,39). Scores were compared with previously published transition readiness scores for youth with type 1 diabetes, aged 12–22 years (40).

Participants also completed the Readiness for Emerging Adults with Diabetes Diagnosed in Youth (READDY) questionnaire (41). READDY is a 46-item measure that assesses a diabetes-specific transition construct derived from recommendations of the American Diabetes Association and *Understanding Diabetes* (42). Participants reported on a 5-point Likert scale (ranging from “I haven't thought about this” to “yes, I can do this”) how confident they are in each of the four domains: diabetes knowledge, insulin self-management, navigation, and health behaviors. This measure was administered as part of routine clinical care within ~4 months before enrollment in the study.

Risk Behavior Assessment

On the Youth Risk Behavior Survey (YRBS) (43), participants provided information about their body weight and health behaviors, including substance use (i.e., smoking/chewing tobacco, alcohol use/binge drinking, and drug use). These questions were derived from a subset of items from the Centers for Disease Control and Prevention's standard high school YRBS survey (43). Specifically, items on illicit drug use were collapsed to include all drugs, and an additional item about intentional insulin omission to lose weight was added based on prior literature (44). Previously published data from high school students who participated in the Youth Risk Behavior Surveillance Study (43) and previously published

data on insulin misuse among adolescents (45) were used as comparisons to participants' risk behavior frequency scores.

Electronic Medical Record Review

Patients electronic medical charts were reviewed to collect the following data: age, current insulin regimen, use of CGM, frequency of BGM, A1C, and transition assessment (READDY) scores during the study period. Participants' BGM frequency was compared with published data from adolescents aged 13–17 years who participated in the T1D Exchange clinic registry (46).

Statistical Analyses

To determine the extent to which attrition may have introduced bias into this study's analyses, bivariate comparison tests (i.e., t and χ^2 tests) were performed comparing those who completed follow-up assessments and those who did not by psychosocial and demographic and clinical variables. Descriptive statistics were then computed to examine demographics and frequency data to provide summary information about YAs' characteristics at baseline.

To understand how this sample differed from other populations of adolescents, t tests were used to compare our sample of YAs to previously published norms of adolescents across study measures; when adolescent-only norms were not available, general norms that included adolescents in addition to other developmental age-groups (e.g., children) were used. Detailed information on the specific normative groups used to compare the YA participants in this study is provided above in the descriptions of each measure.

Preliminary analyses were conducted to evaluate demographic and clinical variables significantly related to baseline study measures to guide subsequent correlational analyses. Based on these results, bivariate or partial correlational analyses were conducted between baseline psychosocial measures and both baseline and 12-month follow-up data for the outcome variables of interest (i.e., A1C level, frequency of BGM, and self-management ratings). In instances where demographic or clinical characteristics were associated with baseline measures ($P < 0.05$), partial correlations were reported; otherwise, bivariate correlations were reported. All statistical analyses were conducted using SPSS v. 25 statistical software (IBM Corp., Armonk, NY).

Results

Attrition

Attrition analyses revealed that 23 YAs did not complete follow-up data. There were no significant differences with regard to

psychosocial, clinical, or demographic variables between YAs who completed follow-up measures and those who did not.

Psychosocial Functioning in YAs With Type 1 Diabetes

Table 1 provides the mean scores for all study measures. For diabetes distress frequencies, 14.3% of the YAs met the clinical cutoff (mean items score ≥ 3) at baseline. Similarly, at baseline, 31% of the YAs met the cutoff (total score 16–23) for being mildly at risk for depression, and 9.5% met the cutoff (total score ≥ 24) for moderate to severe risk of clinical depression. The frequency of high-risk behaviors (i.e., rates of alcohol use, smoking, and drug use), as self-reported by the YAs, is outlined in Table 2.

Comparison With Pediatric Samples

Table 1 presents detailed results of how baseline measures for the YA sample compared with previously published norms in pediatric samples. In brief, results showed significant differences between the two groups in several domains,

including self-efficacy, diabetes distress, resilience, transition readiness, self-management, and BGM frequency. Specifically, the YA sample exhibited more depressive symptoms, less self-efficacy, less self-management, and less frequent BGM compared with pediatric samples. In contrast, they also demonstrated greater resilience, less diabetes distress, and generally more transition readiness.

Associations Between Psychosocial Functioning and Clinical Outcomes

Guided by preliminary analyses, bivariate or partial correlations were conducted to examine associations between variables of interest. Significant partial correlations were found between several baseline measures and clinical outcomes of interest. Specifically, diabetes distress ($r = 0.42, P \leq 0.05$), resilience ($r = -0.60, P \leq 0.01$), life satisfaction ($r = -0.49, P \leq 0.05$), psychosocial quality of life ($r = -0.54, P \leq 0.05$), and YAs' confidence in their ability to take full responsibility for their care ($r = -0.46, P \leq 0.05$) were significantly correlated with baseline A1C. Partial correlations also indicated that

TABLE 1 YA-Reported Measures at Baseline and Comparisons to Published Scores

Measure	Baseline Scores	Published Scores in Adolescents	t
Diabetes distress			
DDS-2	Male: 0.89 (1.01) Female: 2.11 (1.60)	2.0 2.8	-4.68* -2.01
CES-D	Male: 14.22 (5.90) Female: 17.91 (5.15)	9.8 (7.90) 11.6 (9.10)	3.18† 5.75*
Self-efficacy			
SED	3.45 (0.72)	4.16 (0.50)	-6.367*
Resilience			
DSTAR	51.50 (7.92)	49.00 (7.90)	2.045‡
Quality of life			
PedsQL Diabetes Module	Symptoms: 66.11 (17.04) Management: 81.20 (16.47)	65.53 (16.01) 79.19 (15.29)	0.205 0.733
PedsQL Generic Core Module	Psychosocial: 83.86 (15.78)	79.53 (15.73)	1.622
SWLS	21.76 (7.53)	24.10 (5.90)	-1.914
Transition readiness			
TRM responsibility	3.74 (0.95)	3.31 (0.90)	2.696‡
TRM responsibility importance	4.34 (0.59)	4.63 (0.60)	-2.873†
TRM responsibility confidence	3.89 (1.05)	3.85 (0.99)	0.201
TRM transfer readiness	3.74 (0.85)	3.00 (1.10)	5.158*
TRM transfer importance	3.71 (0.89)	3.74 (0.90)	-0.170
TRM transfer confidence	3.69 (1.08)	3.59 (1.13)	0.525
Diabetes-specific transition readiness			
READDY knowledge	4.61 (0.38)	4.55 (0.75)	0.986
READDY navigation	4.58 (0.54)	4.14 (1.33)	5.43*
READDY health behaviors	4.88 (0.26)	4.25 (1.34)	16.665*
READDY insulin self-management	4.88 (0.26)	4.71 (0.78)	4.046*
Self-management and BGM			
SCI-R	2.58 (0.70)	3.89 (0.49)	-11.04*
BGM (times/day)	3.66 (2.94)	5.2 (2.1)	-3.354†

All score data are mean (SD) or mean only. * $P < 0.001$. † $P < 0.01$. ‡ $P < 0.05$.

TABLE 2 Frequency of Self-Reported History of High-Risk Behavior Among YAs

High-Risk Behavior	Baseline Frequency	National Rates
Cigarette smoking	17.60	41.10
Chewing tobacco	2.90	8.80
Cigar smoking	14.70	12.60
Alcohol use	58.80	66.20
Binge drinking	32.40	20.80
Drug use	26.50	40.70*
Insulin omission for weight management	5.90	30.00†

Data are percentages. *National rates based on comparison with endorsement of marijuana use. †Comparison group of adolescents with diabetes.

measures of transition, including the READDY health behaviors domain ($r = -0.48, P < 0.05$) and the READDY insulin self-management ($r = -0.53, P < 0.01$) subscales were significantly associated with A1C at 12-month follow-up.

Partial correlations revealed that the READDY health behaviors subscale ($r = -0.65, P < 0.01$) was significantly correlated with BGM frequency at baseline. Similarly, the PedsQL diabetes symptoms ($r = -0.81, P < 0.01$) and management ($r = -0.64, P < 0.05$) subscales, the READDY navigation subscale ($r = -0.68, P < 0.05$), and YAs' confidence in their ability to take full responsibility for their health care from the TRM ($r = -0.71, P < 0.05$) were all significantly correlated with frequency of BGM at 12-month follow-up.

Bivariate correlations indicated that the following measures were significantly correlated with baseline scores of self-management: self-efficacy ($r = 0.45, P < 0.01$), resilience ($r = 0.60, P < 0.001$), scores on the PedsQL diabetes symptoms ($r = 0.38, P < 0.01$) and management ($r = 0.60, P < 0.001$) subscales, PedsQL generic psychosocial quality of life ($r = 0.44, P < 0.01$), and YAs' confidence in their ability to take full responsibility for their health care from the TRM ($r = 0.38, P < 0.05$), as well as their rating of how important it is for them to take full responsibility for their health care from the TRM ($r = 0.34, P < 0.05$). In addition, the SED self-efficacy ($r = 0.59, P < 0.03$) and the PedsQL diabetes management ($r = 0.71, P < 0.01$) scores were significantly related to self-management scores from the SCI-R at 12-month follow-up.

Discussion

This study provides descriptive information on the psychosocial functioning of YAs with type 1 diabetes and documents psychosocial domains that are associated with important

clinical outcomes during this vulnerable developmental period. Our findings revealed that YAs exhibit higher-than-average rates of emotional concerns compared with adolescents, with ~40% of YAs in our sample being at risk for depression. These rates are slightly higher than those reported in samples that include young adults with type 1 diabetes (5) and highlight the prevalence of psychosocial concerns in this age-group. Although the ADA recognizes the unique needs of YAs during this transition period (12), these results stress the need for ADA's position statements (47) and guidelines for behavioral health screening (including depression) in youth to also highlight and specifically address the needs of this unique vulnerable group of YAs.

We also found that male YAs reported less diabetes distress compared with male adolescents and that female YAs reported similar levels of diabetes distress compared with female adolescents. These findings are consistent with prior literature demonstrating that diabetes distress differentially affects males and females (32), with young women being particularly vulnerable to experiences of distress. Thus, the routine use of a brief diabetes distress assessment measure (two items) may be warranted to identify and address those YAs who are experiencing elevated levels of distress. This information may be used to guide the selection of standardized assessments tools that capture clinically meaningful domains of psychosocial functioning among YAs who are preparing to transition to adult health care settings.

YAs also endorsed significantly lower levels of self-efficacy, less engagement in self-management, and less frequent BGM compared with pediatric norms. In contrast, they had similar levels of quality of life and greater readiness to transfer to adult care and assume diabetes care responsibility compared with younger populations of individuals with type 1 diabetes. It is possible that the normative developmental drive for greater independence, along with improvements in transition skills over time, is affecting YAs' desire to assume greater responsibility for their medical care. Simultaneously, YAs' perceptions of their self-efficacy and self-management may be lower because they are still developing many of the skills necessary for independent diabetes management, and they increasingly recognize the need for ongoing family support to ensure successful management.

As a result, when a diabetes clinic sets out to assess these aspects of transition readiness, it would be valuable to determine whether clinicians are interested in YAs' perceptions of self-efficacy for diabetes-specific tasks versus global ratings of YAs' desire to assume responsibility for those transition tasks, since the two may differ. Although none of the transition measures used in the current study directly measured demonstrated skills or in vivo practice, future

research is needed to examine how to foster YAs' mastery so their desire for independence is matched by their perceptions of self-efficacy. Further, given YAs' higher perceptions of resilience compared with the pediatric sample, clinicians may use YAs' perceived diabetes-related strengths to increase their transition readiness, as well as their perceptions of self-efficacy and mastery of diabetes self-management tasks.

YAs in this sample also reported slightly higher rates of some high-risk behaviors, including binge drinking and cigarette use compared with national rates. Although other high-risk behaviors were comparable to or lower than national averages, the health consequences of high-risk behaviors for YAs with type 1 diabetes can be particularly serious. For example, alcohol and tobacco use place YAs at increased risk for suboptimal glycemic control and complications (48,49). Therefore, asking about high-risk behaviors among YAs during routine assessments in diabetes clinics is crucial. A transition preparation curriculum that overtly addresses, educates, and prepares all YAs for intentional decision-making when engaging in high-risk behaviors is an important aspect of transition planning. Furthermore, ensuring that transition programs additionally include assessment of psychosocial functioning, perceived diabetes-related strengths, and transition readiness to provide anticipatory guidance and intervention is key to promoting positive health outcomes within this YA population.

Relations between baseline psychosocial measures and both baseline and 12-month follow-up outcomes (i.e., glycemic control and BGM frequency) showed that most study measures were associated with baseline A1C but not with A1C values at the 12-month follow-up. Consistent with the pediatric literature (20,50), psychosocial measures of quality of life, distress, self-efficacy, and resilience were associated with A1C in YAs, highlighting the need for continued research efforts that seek to characterize the psychosocial functioning of this vulnerable population and its impact on clinical outcomes. Importantly, only transition readiness in the health behaviors and insulin self-management domains were significantly associated with A1C at the 12-month follow-up, indicating that perceptions of transition readiness may be particularly important indicators of longitudinal indices of glycemic control.

Consistent with this pattern of findings, YAs' confidence in their ability to take full responsibility for their care and to navigate the health care system was related to BGM frequency during the 12-month follow-up period, suggesting that those who are more confident in their abilities to manage diabetes and feel ready to interact with adult health care settings engage in BGM more frequently. Given the importance of frequent BGM for positive outcomes (51), assessment and fostering of transition readiness skills may be particularly important.

It is notable that this study was completed around the time the U.S. Food and Drug Administration first approved CGM-based insulin dosing, and since then, there has been a large growth in the use of CGM as a meaningful alternative to frequent BGM using a glucose meter. Future research should examine how psychosocial variables for YAs with type 1 diabetes may be related to CGM use and measures of glycemic outcomes beyond A1C (52).

Finally, baseline measures of self-efficacy, resilience, quality of life, psychosocial functioning, and transition were related to self-management ratings, which replicates similar patterns in the pediatric literature (50,53). Most importantly, self-efficacy and aspects of diabetes quality of life were the only variables associated with self-management behaviors during the study follow-up period, stressing the importance of building these skills in YAs as they prepare to transition to adult care. Taken together, these findings stress the need to develop transition programs that foster the promotion of these psychosocial skills to maximize the likelihood that YAs will have optimal clinical outcomes after transferring to adult care.

Despite the contributions of this study, its results should be interpreted in light of several limitations. Our sample size was small, and as a result, findings are preliminary and await replication, particularly as they relate to longitudinal outcomes. Despite the relatively small sample size, the descriptive findings are a first step in this area of research and add to the paucity of information available on this subpopulation of individuals with type 1 diabetes. Furthermore, it is our hope that these findings will promote future efforts to conduct high-quality research that informs clinical endeavors aimed at improving the psychosocial care and health outcomes of YAs with type 1 diabetes.

The attrition rate for the study was also high, which highlights the unique challenges of working with the YA population. The creative incorporation of innovative methods (54) to improve retention in longitudinal studies during the developmental period of young adulthood will be beneficial in obtaining representative samples that can be followed over time through the entire transition process from pediatric to adult care. Multisite collaborations are likely to play a key role in obtaining larger samples and advancing our understanding of how to best serve this vulnerable population.

ACKNOWLEDGMENT

The authors acknowledge the recruitment efforts of Caitlyn Clark, an undergraduate work-study student at the University of Cincinnati, for this project.

FUNDING

This work was funded by an internal grant to J.C.K. from the Division of Behavioral Medicine and Clinical Psychology at the Cincinnati Children's Hospital Medical Center.

DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS

A.M.G.-C. analyzed and interpreted the data and wrote the manuscript. S.C. and S.B. contributed to the conception and design of the study and critically reviewed the manuscript. H.B. and K.N. contributed to acquisition of data and critically reviewed the manuscript. J.C.K. contributed to the conception and design of the study, analyzed and interpreted the data, and wrote the manuscript. All authors approved the submitted manuscript. J.C.K. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

REFERENCES

1. White NH, Cleary PA, Dahms W, Goldstein D, Malone J, Tamborlane WV; Diabetes Control and Complications Trial (DCCT)/Epidemiology of Diabetes Interventions and Complications (EDIC) Research Group. Beneficial effects of intensive therapy of diabetes during adolescence: outcomes after the conclusion of the Diabetes Control and Complications Trial (DCCT). *J Pediatr* 2001;139:804–812
2. Benson JE, Elder GH Jr. Young adult identities and their pathways: a developmental and life course model. *Dev Psychol* 2011;47:1646–1657
3. Bonnie RJ, O’Connell ME; National Research Council and Institute of Medicine Committee on Developing a Strategy to Reduce and Prevent Underage Drinking. Introduction: the challenge. In *Reducing Underage Drinking: A Collective Responsibility*. Bonnie RJ, O’Connell ME, Eds. Washington, DC, National Academies Press, 2004, p. 13–32
4. Tanner JL, Arnett JJ. The emergence of emerging adulthood: the new life stage between adolescence and young adulthood. In *Routledge Handbook of Youth and Young Adulthood*. Furlong A, Ed. New York, NY, Routledge, 2016, p. 50–56
5. Monaghan M, Helgeson V, Wiebe D. Type 1 diabetes in young adulthood. *Curr Diabetes Rev* 2015;11:239–250
6. McManus M, Fox H, O’Connor K, Chapman T, MacKinnon J. *Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care*. Washington, DC, National Alliance to Advance Adolescent Health, 2008
7. Mulye TP, Park MJ, Nelson CD, Adams SH, Irwin CE Jr, Brindis CD. Trends in adolescent and young adult health in the United States. *J Adolesc Health* 2009;45:8–24
8. Weissberg-Benchell J, Wolpert H, Anderson BJ. Transitioning from pediatric to adult care: a new approach to the post-adolescent young person with type 1 diabetes. *Diabetes Care* 2007;30:2441–2446
9. Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB. Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care* 2001;24:1536–1540
10. Palta M, Shen G, Allen C, Klein R, D’Alessio D. Longitudinal patterns of glycemic control and diabetes care from diagnosis in a population-based cohort with type 1 diabetes: the Wisconsin Diabetes Registry. *Am J Epidemiol* 1996;144:954–961
11. Wills CJ, Scott A, Swift PG, Davies MJ, Mackie AD, Mansell P. Retrospective review of care and outcomes in young adults with type 1 diabetes. *BMJ* 2003;327:260–261
12. Peters A, Laffel L; American Diabetes Association Transitions Working Group. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children With Diabetes, The

Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). *Diabetes Care* 2011;34:2477–2485

13. Garvey KC, Wolpert HA, Rhodes ET, et al. Health care transition in patients with type 1 diabetes: young adult experiences and relationship to glycemic control. *Diabetes Care* 2012;35:1716–1722
14. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group; Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182–200
15. Blum RWM, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions; a position paper of the Society for Adolescent Medicine. *J Adolesc Health* 1993;14:570–576
16. Pierce JS, Wysocki T. Topical review: advancing research on the transition to adult care for type 1 diabetes. *J Pediatr Psychol* 2015;40:1041–1047
17. Fisher L, Glasgow RE, Mullan JT, Skaff MM, Polonsky WH. Development of a brief diabetes distress screening instrument. *Ann Fam Med* 2008;6:246–252
18. Grossman HY, Brink S, Hauser ST. Self-efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care* 1987;10:324–329
19. Hilliard ME, Lawrence JM, Modi AC, et al.; SEARCH for Diabetes in Youth Study Group. Identification of minimal clinically important difference scores of the PedsQL in children, adolescents, and young adults with type 1 and type 2 diabetes. *Diabetes Care* 2013;36:1891–1897
20. Hood KK, Huestis S, Maher A, Butler D, Volkening L, Laffel LM. Depressive symptoms in children and adolescents with type 1 diabetes: association with diabetes-specific characteristics. *Diabetes Care* 2006;29:1389–1391
21. Weinger K, Butler HA, Welch GW, La Greca AM. Measuring diabetes self-care: a psychometric analysis of the Self-Care Inventory–Revised with adults. *Diabetes Care* 2005;28:1346–1352
22. La Greca A, Swales T, Klemp S, Madigan S. Self care behaviors among adolescents with diabetes [Abstract A42]. Presented at the 9th Annual Sessions of the Society of Behavioral Medicine, Boston, MA, 27–30 April 1988
23. Greco P, La Greca A, Ireland S, et al. Assessing adherence in IDDM: a comparison of two methods [Abstract]. *Diabetes* 1990;40(Suppl. 1):A165
24. Vaala SE, Hood KK, Laffel L, Kumah-Crystal YA, Lybarger CK, Mulvaney SA. Use of commonly available technologies for diabetes information and self-management among adolescents with type 1 diabetes and their parents: a Web-based survey study. *Interact J Med Res* 2015;4:e24
25. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001;39:800–812
26. Varni JW, Delamater AM, Hood KK, et al.; Pediatric Quality of Life Inventory 3.2 Diabetes Module Testing Study Consortium. PedsQL 3.2 Diabetes Module for children, adolescents, and young adults: reliability and validity in type 1 diabetes. *Diabetes Care* 2018;41:2064–2071
27. Varni JW, Curtis BH, Abetz LN, Lasch KE, Piau EC, Zeytoonjian AA. Content validity of the PedsQL™ 3.2 Diabetes Module in newly diagnosed patients with type 1 diabetes mellitus ages 8–45. *Qual Life Res* 2013;22:2169–2181
28. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL in type 1 and type 2 diabetes: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales and Type 1 Diabetes Module. *Diabetes Care* 2003;26:631–637

Downloaded from <http://diabetesjournals.org/spectrum/article-pdf/33/3/255/505598/diasespecs190050.pdf> by guest on 15 September 2024

29. Forsander G, Bøgelund M, Haas J, Samuelsson U. Adolescent life with diabetes: gender matters for level of distress: experiences from the national TODS study. *Pediatr Diabetes* 2017;18: 651–659
30. Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas* 1977;1: 385–401
31. Lawrence JM, Standiford DA, Loots B, et al.; SEARCH for Diabetes in Youth Study. Prevalence and correlates of depressed mood among youth with diabetes: the SEARCH for Diabetes in Youth study. *Pediatrics* 2006;117:1348–1358
32. Kichler JC, Kaugars AS, Ellis J, Alemzadeh R. Exploring self-management characteristics in youths with type 1 diabetes mellitus: does membership in a glycemic control category matter? *Pediatr Diabetes* 2010;11:536–543
33. Hilliard ME, Iturralde E, Weissberg-Benchell J, Hood KK. The Diabetes Measure for Adolescents with Type 1 Diabetes (DSTAR-Teen): validation of a new, brief self-report measure. *J Pediatr Psychol* 2017;42:995–1005
34. Prince-Embury S. *Resiliency Scales for Children and Adolescents: A Profile of Personal Strengths (RSCA)*. San Antonio, TX, Pearson Education, 2006
35. Hilliard ME, Weissberg-Benchell J, Hood KK. Psychometric properties of a diabetes resilience measure for adolescents [Abstract]. *Diabetes* 2014;63:A324
36. Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction With Life Scale. *J Pers Assess* 1985;49:71–75
37. Neto F. The Satisfaction With Life Scale: psychometrics properties in an adolescent sample. *J Youth Adolesc* 1993;22:125–134
38. Beal SJ, Crockett LJ. Adolescents' occupational and educational aspirations and expectations: links to high school activities and adult educational attainment. *Dev Psychol* 2010;46:258–265
39. Crockett LJ, Beal SJ. The life course in the making: gender and the development of adolescents' expected timing of adult role transitions. *Dev Psychol* 2012;48:1727–1738
40. Beal SJ, Riddle IK, Kichler JC, et al. The associations of chronic condition type and individual characteristics with transition readiness. *Acad Pediatr* 2016;16:660–667
41. Corathers SD, Yi-Frazier JP, Kichler JC, et al. Development and implementation of the Readiness Assessment of Emerging Adults With Type 1 Diabetes Diagnosed in Youth (READDY) tool. *Diabetes Spectr* 2020;33:99–103
42. Chase HP. *Understanding Diabetes*. 11th ed. Denver, CO, Barbara Davis Center for Childhood Diabetes, 2006
43. Kann L, Kinchen S, Shanklin SL, et al.; Centers for Disease Control and Prevention. Youth risk behavior surveillance: United States, 2013. *MMWR Suppl* 2014;63:1–168
44. Snyder LL, Truong YK, Law JR. Evaluating substance use and insulin misuse in adolescents with type 1 diabetes. *Diabetes Educ* 2016; 42:529–537
45. Bryden KS, Neil A, Mayou RA, Peveler RC, Fairburn CG, Dunger DB. Eating habits, body weight, and insulin misuse: a longitudinal study of teenagers and young adults with type 1 diabetes. *Diabetes Care* 1999;22:1956–1960
46. Miller KM, Beck RW, Bergenstal RM, et al.; T1D Exchange Clinic Network. Evidence of a strong association between frequency of self-monitoring of blood glucose and hemoglobin A_{1c} levels in T1D Exchange clinic registry participants. *Diabetes Care* 2013;36: 2009–2014
47. Chiang JL, Maahs DM, Garvey KC, et al. Type 1 diabetes in children and adolescents: a position statement by the American Diabetes Association. *Diabetes Care* 2018;41:2026–2044
48. Barnard KD, Dyson P, Sinclair JM, et al. Alcohol health literacy in young adults with type 1 diabetes and its impact on diabetes management. *Diabet Med* 2014;31:1625–1630
49. Reynolds K, Liese AD, Anderson AM, et al. Prevalence of tobacco use and association between cardiometabolic risk factors and cigarette smoking in youth with type 1 or type 2 diabetes mellitus. *J Pediatr* 2011;158:594–601.e1
50. Hilliard ME, Harris MA, Weissberg-Benchell J. Diabetes resilience: a model of risk and protection in type 1 diabetes. *Curr Diab Rep* 2012;12:739–748
51. Guilfoyle SM, Crimmins NA, Hood KK. Blood glucose monitoring and glycemic control in adolescents with type 1 diabetes: meter downloads versus self-report. *Pediatr Diabetes* 2011;12:560–566
52. Agiostratidou G, Anhalt H, Ball D, et al. Standardizing clinically meaningful outcome measures beyond HbA_{1c} for type 1 diabetes: a consensus report of the American Association of Clinical Endocrinologists, the American Association of Diabetes Educators, the American Diabetes Association, the Endocrine Society, JDRF International, the Leona M. and Harry B. Helmsley Charitable Trust, the Pediatric Endocrine Society, and the T1D Exchange. *Diabetes Care* 2017;40:1622–1630
53. Rohan JM, Huang B, Pendley JS, et al. Predicting health resilience in pediatric type 1 diabetes: a test of the Resilience Model framework. *J Pediatr Psychol* 2015;40:956–967
54. Goldberg JH, Kiernan M. Innovative techniques to address retention in a behavioral weight-loss trial. *Health Educ Res* 2005;20: 439–447