



Quality of life in young adults with type 1 diabetes

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ABSTRACT

Introduction: Challenges of young adulthood with type 1 diabetes (T1D) include transitioning to adult care, increased T1D self-management responsibilities, and normal developmental transitions. Recognizing patterns of health-related quality of life (HRQOL) across a demographically and clinically broad range of young adults with T1D may help identify who needs additional support as they transfer to adult healthcare. We hypothesized that young adults from specific demographic and clinical groups would report lower HRQOL.

Methods: At baseline of a behavioral RCT (≤ 2 months after last pediatric T1D clinic visit), 100 young adults ($M_{age}=19.9 \pm 1.3$, $M_{A1c}=8.8 \pm 2.0\%$) self-reported demographics and HRQOL; A1c was analyzed via point of care or dried blood spot. ANOVAs and t-tests were used to compare HRQOL by demographic (gender, race/ethnicity, insurance, school enrollment) and clinical variables (device use, A1c).

Results: Diabetes-specific HRQOL differed significantly by gender and school enrollment; females and young adults enrolled in school reported higher HRQOL. There were no significant differences in HRQOL across race/ethnicity, insurance type, and diabetes technology use.

Conclusion: Monitoring HRQOL may be helpful to identify diabetes-specific psychosocial needs during the transition from pediatric to adult healthcare. Patterns suggest males and those not in school may benefit from additional support.

Type 1 diabetes (T1D) is one of the most common chronic medical conditions in young adulthood,¹ and the prevalence is increasing.² Managing T1D is multifaceted and demanding, and involves frequently checking blood glucose, counting carbohydrates, monitoring nutrition, and calculating and administering insulin injections.³ Young adulthood is a vulnerable time for people with T1D, as they often transition from pediatric to adult care and increase diabetes self-management responsibilities.⁴ In addition to changes in T1D management, young adults with T1D must navigate a challenging developmental period characterized by social, educational, occupational, and financial changes.⁴ Although efforts have been made to support young adults with T1D during the transition to adult healthcare,⁵ they remain at risk for poor

glycemic outcomes, elevated diabetes distress, hospitalization, and T1D complications.^{6–8}

Health-related quality of life (HRQOL) is a person-reported outcome which reflects individuals' social, emotional, behavioral, and overall well-being in relation to their health.¹ HRQOL is consistently related to diabetes-related health outcomes (e.g., HbA1c, self-management behaviors),^{9,10} and the American Diabetes Association recognizes HRQOL as a key health outcome that requires screening and support as part of routine diabetes care.¹¹ However, little is known about patterns of HRQOL in young adults with T1D, and even less among those from demographically and clinically diverse groups. People with T1D who are non-Hispanic Black/African American, Hispanic/Latinx, and of lower

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socioeconomic status experience stark disparities in glycemic outcomes, psychosocial well-being, and access to high quality diabetes care.^{12–14} These experiences may contribute to unique challenges to diabetes-specific psychosocial adjustment and T1D-specific HRQOL.

Recognizing patterns of HRQOL among young adults with T1D may help characterize positive and negative aspects of life with T1D and identify sub-groups that need additional support as they transfer to adult healthcare. These data are necessary to improve transition outcomes for young adults with T1D. In this study we described patterns of HRQOL across young adults with T1D from a range of demographic and clinical groups as they were transitioning from pediatric to adult care. We hypothesized HRQOL would be lower for young adults from non-Hispanic Black/African American and Hispanic/Latinx groups, those with public insurance, those who did not use diabetes technology (insulin pumps, continuous glucose monitors [CGMs]), and those with higher HbA1c, based on documented patterns in diabetes care and outcomes. We did not have specific hypotheses about participant school enrollment or gender.

Research design and methods

We used baseline data from an IRB-approved behavioral intervention trial for young adults transitioning from pediatric to adult care. As outlined in the study protocol,¹⁵ trial eligibility included age 17–25, T1D duration ≥ 1 year, and English fluency. Participants were enrolled at the point of leaving pediatric diabetes care. Exclusion criteria included: serious medical, cognitive, or mental health comorbidity that would preclude the ability to provide informed consent or participate in the intervention and participation in another intervention study six months prior to enrollment.

Participants completed surveys via a HIPAA-compliant online portal. Participants self-reported health insurance type, diabetes technology use (pump, CGM), school enrollment, gender, race, and ethnicity. HbA1c was collected via documented values in electronic health records or dried blood spot.¹⁶ Participants completed the Type 1 Diabetes and Life (T1DAL) - Young Adult version (T1DAL-YA), an instrument which assesses type 1 diabetes-specific HRQOL for young adults age 18–25.¹⁷ This 27-item measure yields a total HRQOL score and four subscale scores: Emotional Experiences & Daily Activities (diabetes-related psychosocial functioning), Handling Diabetes Well (positive aspects of living with type 1 diabetes), Peer Relationships (interpersonal relationships and support), and Healthcare Experiences (experiences within the healthcare setting). Total scores range from 0 to 100, with higher scores indicating better HRQOL. The T1DAL-YA has demonstrated good internal consistency and reliability in young adults age 18–25 with type 1 diabetes.¹⁷ We also observed good internal reliability on the T1DAL-YA in the present study, ($\alpha=.88$).

Statistical analysis

Analyses were completed in SPSS v.29. Bivariate correlations, mean comparison t-tests, and ANOVAs were conducted to compare HRQOL by demographic (i.e., gender, race/ethnicity, insurance, school enrollment [e.g., college, tech school] and clinical variables (i.e., device use, HbA1c).

Results

Participants were 100 young adults with T1D. They were 58 % ($n = 58$) female, 33 % ($n = 33$) had public insurance, 68 % ($n = 68$) were in school (i.e., high school, 2-year college or tech school, graduate program), and had varied race/ethnicity: 25 % ($n = 25$) Hispanic/Latinx, 12 % ($n = 12$) non-Hispanic Black/African American, 54 % ($n = 54$) non-Hispanic White, and 9 % ($n = 9$) more than one/all other races/ethnicities. Mean HbA1c was 8.8 ± 2.0 %, 76 % ($n = 76$) used CGM, and 56 % ($n = 56$) used an insulin pump.

Table 1 presents T1DAL-YA total and subscale scores across demographic and clinical groups. Young adults in school had significantly higher T1DAL-YA total scores ($p < .01$), Handling Diabetes Well subscale scores ($p < .01$), and Peer Relationship subscale scores ($p = .02$). Females had significantly higher Handling Diabetes Well subscale scores than males ($p = .02$). T1DAL-YA total scores and all other subscale scores were not statistically different by gender, insurance type, race/ethnicity, or device use. Higher T1DAL-YA scores (Total score and two subscales: Handling Diabetes Well, Healthcare Experiences) were significantly correlated with lower HbA1c.

Discussion

These data demonstrate a pattern of moderate-range T1D-specific HRQOL across demographic and clinical groups of young adults with T1D. This knowledge advances our understanding of HRQOL during the developmentally and medically high-risk period of transitioning between pediatric and adult healthcare systems. In contrast to research reporting difficulties with self-management and suboptimal glycemic outcomes in college students with T1D,¹⁸ our results suggest potential resilience in HRQOL among a sample that includes young adults with T1D who are and are not in college. Links between better HRQOL and lower HbA1c and patterns of relatively higher scores in subscales representing positive aspects of HRQOL (e.g., managing diabetes challenges, social support) support this interpretation.¹⁹ Consistent total or subscale T1DAL-YA scores by race, ethnicity, and insurance type suggests similar HRQOL in the moderate range, in contrast to other known health disparities. Mechanisms of resilient outcomes, such as high HRQOL, may occur at multiple levels, including individual (e.g., benefit-finding, adaptability), family (e.g., supportive family dynamics), and interpersonal (e.g., social support, telling others about T1D, trust with healthcare providers),^{19,20} Supporting a wide range of factors that may be protective for HRQOL through clinical intervention may help prevent deteriorations in HRQOL for young adults. Additionally, similar HRQOL scores across diabetes technology types differs from some previous research,²¹ but may suggest adding more complex devices does not detract from HRQOL.

The finding that young adults in school reported higher T1DAL-YA total scores and higher subscale scores for Handling Diabetes Well and Peer Relationships indicates better T1D-specific well-being. Students may have greater access to emotional support (e.g., university counseling centers) and opportunities for social support (e.g., university-based diabetes groups²¹), which are associated with positive psychosocial and diabetes clinical outcomes.^{22,23} Being enrolled in higher education may also facilitate access to healthcare (e.g., free/low cost university health centers, student health insurance), which may benefit diabetes management and HRQOL. It is also possible there are differences in young adults who do and do not attend college. For example, some research indicates that young adults who do not attend college have fewer close friends, are more impulsive, and have more difficulties with emotion regulation than those who attend college.²⁴ These factors may have implications for lower diabetes-specific HRQOL and may warrant targeted supports for young adults with T1D who are not in college.

In contrast to other research,¹⁰ women scored higher on the T1DAL-YA Handling Diabetes Well subscale which may reflect higher self-efficacy in managing diabetes-related challenges compared to male counterparts.²⁵ Clinician efforts to highlight successful aspects of diabetes management may help increase confidence in self-care. Alternatively, women may experience more protective factors for HRQOL (e.g., social support)²⁶ than males. Exploring social support networks with young adult males with T1D may facilitate help-seeking when needed.

Limitations

Our study is not without limitations. While we experienced

Table 1
Participant characteristics (n = 100) and associations with T1DAL scores.

	T1DAL Total Score (M ± SD)	T1DAL Subscales (M ± SD)			
		Emotional Experiences & Daily Activities	Handling Diabetes Well	Peer Relationships	Healthcare Experiences
Full Sample	66.1 ± 15.5	55.3 ± 22.2	73.0 ± 20.2	74.9 ± 21.0	79.8 ± 17.3
Gender					
Females (n = 58)	68.2 ± 15.6	56.9 ± 22.9	77.2 ± 19.2	77.3 ± 19.2	82.1 ± 15.7
Males (n = 42)	63.3 ± 15.2	53.2 ± 21.3	67.3 ± 21.0	71.4 ± 23.0	76.6 ± 19.0
<i>T-test by Gender</i>	t(97) = 1.57, p = .12	t(98) = .82, p = .42	t(98) = 2.48, p = .02 *	t(96) = 1.39, p = .08	t(97) = 1.53, p = .13
Race/Ethnicity					
Hispanic/Latinx (n = 25)	63.5 ± 17.1	51.4 ± 23.8	70.3 ± 21.4	74.0 ± 23.2	81.0 ± 18.0
Non-Hispanic Black/African American (n = 12)	65.8 ± 15.7	58.4 ± 22.6	74.0 ± 16.8	62.2 ± 22.0	75.0 ± 21.2
Non-Hispanic White (n = 54)	68.6 ± 14.6	58.2 ± 21.0	75.1 ± 20.0	78.9 ± 18.8	80.8 ± 16.7
More than One and All other Races/Ethnicities (n = 9)	59.1 ± 15.7	44.7 ± 22.5	66.7 ± 23.8	69.0 ± 21.0	77.1 ± 14.3
<i>ANOVA by Race/Ethnicity</i>	F(3,95) = 1.32, p = .27	F(3, 96) = 1.34, p = .27	F(3, 96) = 0.65, p = .59	F(3, 94) = 2.33, p = .08	F(3,95) = 0.47, p = .70
Insurance Type					
Public/No Insurance (n = 33)	63.9 ± 16.8	52.1 ± 24.6	72.1 ± 22.5	73.6 ± 23.7	77.2 ± 19.3
Private Insurance (n = 53)	67.2 ± 13.7	56.5 ± 19.3	73.6 ± 17.7	75.8 ± 18.6	81.4 ± 16.1
Unsure of Insurance Type (n = 13)	67.4 ± 19.6	58.9 ± 26.9	73.1 ± 24.8	74.2 ± 24.5	80.3 ± 16.9
<i>ANOVA by Insurance Type</i>	F(2,96) = 0.50, p = .61	F(2, 97) = 0.60, p = .55	F(2, 97) = 0.06, p = .94	F(2, 95) = 0.11, p = .89	F(2, 96) = 0.60, p = .55
School Enrollment					
Enrolled in School (n = 68)	69.1 ± 14.8	57.8 ± 21.8	77.2 ± 17.8	78.2 ± 20.8	81.3 ± 16.1
High School n = 3					
4-year-college n = 48					
2-year college or tech school n = 16					
Graduate program n = 1					
Not Enrolled in School (n = 32)	59.8 ± 15.4	50.0 ± 22.3	64.1 ± 22.3	70.0 ± 19.9	76.6 ± 19.4
<i>T-test by School Enrollment</i>	t(97) = -2.88, p = <.01 *	t(98) = -1.65, p = .10	t(98) = -3.17, p = <.01 *	t(96) = -2.31, p = .02 *	t(97) = -1.29, p = .20
Diabetes Technology Use					
Continuous Glucose Monitor (n = 76)	67.7 ± 15.2	57.1 ± 21.8	74.6 ± 18.8	76.4 ± 21.0	80.4 ± 17.7
Blood Glucose Meter (n = 24)	61.1 ± 15.8	49.8 ± 22.8	68.0 ± 23.9	69.7 ± 20.5	77.9 ± 16.3
<i>T-test by CGM use</i>	t(97) = -1.83, p = .07	t(98) = -1.40, p = .16	t(98) = -1.40, p = .16	t(96) = -1.35, p = .18	t(97) = -0.63, p = .53
Insulin Pump (n = 56)	68.8 ± 15.6	57.9 ± 23.6	76.0 ± 18.7	78.4 ± 18.2	81.7 ± 16.8
Injectors (n = 44)	62.6 ± 14.9	52.0 ± 20.0	69.2 ± 21.6	70.2 ± 23.6	77.4 ± 17.8
<i>T-test by Insulin Pump Use</i>	t(97) = -2.01, p = .05	t(98) = -1.34, p = .18	t(98) = -1.69, p = .09	t(96) = -1.94, p = .06	t(97) = -1.22, p = .22
Diabetes Clinical Outcomes					
<i>Correlation with HbA1c</i>	r(97) = -.30, p = <.01 *	r(97) = -.19, p = .06	r(97) = -.46, p = <.001 *	r(96) = -.16, p = .12	r(96) = -.23, p = .02 *

challenges in recruitment following delays to the COVID-19 pandemic¹⁵ resulting in a smaller than desired sample size, our cohort was more representative of the larger population of young adults with T1D than other published studies. A larger sample may reveal additional patterns in the data and increase the generalizability of the conclusions. Further, our results may not apply to those who speak languages other than English, who may experience greater barriers to diabetes management and HRQOL in the United States.²⁷ The cross-sectional study design precludes causal inferences about factors related to HRQOL, and subsequent studies could include a wider range of demographic, clinical, and psychosocial factors, such as information about neighborhood factors, social support, or family relationships, to gain a more comprehensive understanding of HRQOL in young adults with T1D.

Conclusion

Universal or routine monitoring of HRQOL before and during the transition from pediatric to adult care may be warranted to identify T1D-specific needs. Indeed, efforts to promote HRQOL are recommended as part of routine diabetes care by the American Diabetes Association.¹¹ As approaches to diabetes care, behavioral support, and education continue to evolve (e.g., through technology advances [AI]),²⁸ HRQOL screening and management should be incorporated as part of routine T1D care. The clinical implications of our findings include targeting young adults experiencing poorer HRQOL – including those at higher risk: males and those not in school – with clinical efforts to address specific individual HRQOL challenges. Future research is warranted to test behavioral

intervention strategies that provide tailored counseling and support for individuals' unique HRQOL strengths and needs with the ultimate goal of improving diabetes outcomes in young adulthood and across the lifespan.

Ethical Considerations

This study used data collected from participants who completed baseline measures for a behavioral intervention trial. The study protocol for the trial was reviewed and approved by the Institutional Review Board at Baylor College of Medicine, approval #H-45360.

Consent to Participate

Written informed consent was obtained electronically from all participants.

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CRediT authorship contribution statement

Baudino Marissa: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Hilliard Marisa E:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Devaraj Sridevi:** Writing – review & editing, Resources, Investigation. **Butler Ashley M:** Writing – review & editing, Supervision, Conceptualization. **Minard Charles:** Writing – review & editing, Investigation, Formal analysis, Data curation. **Anderson Barbara J:** Writing – review & editing, Funding acquisition, Conceptualization. **McKay Siripoom:** Writing – review & editing, Conceptualization. **Lyons Sarah:** Writing – review & editing, Investigation, Conceptualization. **Tang Tricia S:** Writing – review & editing, Funding acquisition, Conceptualization. **Streisand Randi:** Writing – review & editing, Investigation, Funding acquisition, Conceptualization. **Carreon Samantha A:** Writing – review & editing, Investigation, Formal analysis.

Declaration of Competing Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability

Data will be made available on request.

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