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Self-rated health among American adolescents with type 1 diabetes in the T1D Exchange Clinic Registry

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ABSTRACT

Background: The goal of this study was to examine the self-rated health (SRH) of adolescents with type 1 diabetes (T1D)

Methods: A logistic regression analysis of baseline data from adolescents in the United States included in the T1D Exchange Clinic Registry in 2010–2012 was conducted. Participants were 13–18 years old at the time of enrollment in the registry and had been diagnosed with T1D at least one year before enrollment (n=5799). Results: Half (49.0%) of the participants were female, 46.3% were ages 16–18 years, 22.5% were non-white, 35.7% did not have private/military health insurance, and 78.8% had HbA1c levels > 7.5%, indicating poor T1D management, 20.7% reported having diabetes-related stress often or very often, and 46.4% used insulin injections or pens rather than a pump. In total, 10.3% (n=600) of the participants rated their health as poor or fair and 59.3% (n=3439) rated their health as very good or excellent. Participants with poor or fair SRH were more likely than those with very good or excellent SRH to be female (adjusted OR = 1.7(1.4, 2.1)), 16 to 18 years old (OR = 2.1(1.7, 2.5)), and non-white (OR = 2.7(2.2, 3.4)), to be without private or military insurance (OR = 2.4(2.1, 3.0)), to have HbA1c levels > 7.5% (OR = 3.3(2.4, 4.7)), to report having diabetes-related stress often or very often (OR = 6.1(5.1, 7.2)), and to use an injection or pen rather than a pump (OR = 2.1(1.6, 2.4)).

Conclusions: Because adolescents with T1D who report lower SRH are more likely to have uncontrolled blood glucose and frequent diabetes-related stress, use of pumps and stress-reduction strategies may improve SRH among adolescents with T1D.

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1. Introduction

Adolescents with type one diabetes (T1D) report lower health-related quality of life (HRQoL) than peers without diabetes. ¹⁻³ HRQoL refers to individual's sense of wellbeing after considering the impact of an illness or treatment on an individual's physical, psychological, emotional, and social functioning. ^{4,5} Healthy People 2020 prioritized improved quality of life for adolescents and adults with diabetes. ⁶ Assessments of HRQoL among adolescents with T1D can assist with the identification of the factors that contribute to lower quality of life in this population and the selection of the best interventions for improving HRQoL.

Self-rated health (SRH) is often used in diabetes research as a single-question comprehensive measure of HRQoL, including among adolescents with T1D. ^{7–12} A single question about SRH is a simple but valid way to elicit information about an individual's perceived health status. ¹³ Validation studies have shown that SRH is significantly correlated with morbidity and mortality, ^{11,14–17} and that it is a reasonable indicator of subjective HRQoL and well-being. ^{9,12,18} SRH responses are generally consistent with the health scores of the Short Form 36 health survey (SF-36), a commonly-used tool for evaluating HRQoL. ¹⁹

The aims of this study are to describe the SRH of adolescents with T1D and to determine the association of sociodemographic and diabetes-related factors with SRH in this population. In particular, the goals were: (1) to determine the proportion of adolescents with T1D who have poor or fair self-rated health and the proportion with very good or excellent SRH; (2) to identify the sociodemographic characteristics associated with lower SRH; (3) to examine the associations between indicators of T1D self-management and SRH; and (4) to identify whether insulin delivery methods are associated with adolescents' SRH.

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2. Materials and methods

The T1D Exchange Clinic Registry is a public database that provides online access to demographic data, treatment regimens, and clinical outcomes related to T1D.²⁰ The Registry was created in August 2010 in response to the need to have a public large-scale register of patients with T1D in the United States. The Registry is coordinated by the Jaeb Center for Health Research, a nonprofit clinical research institute based in Tampa, Florida.²⁰ By 2012, the Registry had enrolled 25,762 patients with T1D from 68 participating clinics across the U.S. who had agreed to participate in this longitudinal study. The registrants' ages range from infancy to 93 years old, and they represent the demographic diversity of the United States. Each participating clinic's Institutional Review Board (IRB) approved the research protocol prior to enrolling participants. Adult participants (ages 18 and older) provide written consent for participants; adolescents provide assent after consent is granted by a parent or legal guardian.²⁰

This analysis examines cross-sectional Registry data collected by new enrollees between 2010 and 2012. The inclusion criteria for this analysis included: (1) age between 13 and 18 years at the time of enrollment: (2) having a diagnosis of T1D at least one year prior to enrollment in the registry; (3) having an HbA1c > 6.4%, which indicates having diabetes, (4) using insulin as a treatment; and (5) completing the SRH question in the enrollment survey data.

2.1. Self-rated health measurement

The SRH question used in this study asked "In general, how would you rate your health?" and had a five-point ordinal scale of response that ranges from poor to excellent. This SRH question has been validated over time, ⁹ in diverse gender and cultural groups, ²¹ and in adolescent populations. ¹³ For the regression models in this study, the responses were categorized into two independent groups—"very good" or "excellent" (VG/E) versus "poor" or "fair" (P/F)—with the middle "good" response group excluded so that the more extreme answers could be compared. This approach has strong precedent in prior studies. ^{10,22} The baseline survey was completed by the adolescent and/or a parent or guardian; there were no significant differences in the distribution of SRH response recorded by adolescents and those recorded by parents or guardians.

2.2. Other variables

In the Registry, gender was reported as female, male, and transgender. Because only one registrant was transgender, analyses comparing participants by sex did not include transgender youth. Participants were divided into early adolescents (age 13 to 15.99) and late adolescents (16 to 18.99) for age-group analyses. For analyses by racial/ethnic group, non-Hispanic white participants were compared to other participants, who were categorized in the Registry as black or African non-Hispanic, Hispanic or Latino, native Hawaiian or other Pacific Islander, Asian, American Indian or Alaskan native, and more than one race. For health insurance analysis, participants with private or military insurance were compared to all other participants, including those who were uninsured, those with other types of healthcare coverage (Medicaid, MediGap, Medicare, Indian Health Service, other state or government plans, or single service plans), and those who did not know their insurance status or did not wish to disclose it. In the United States, private and military insurance is provided for adolescents through their parents' employers. The other types of insurance coverage (such as Medicaid) are typically available only to lower-income households, including those in which the adults are unemployed or have been classified as having a permanent disability.

Health insurance status can therefore be considered a proxy for socioeconomic status.

HbA1c data obtained from the medical chart of the participant at time of enrollment in the Registry were used as an indicator of metabolic control. Based on the most recent definitions of metabolic control from the International Society for Pediatric and Adolescents Diabetes (ISPAD) in 2015 and the American diabetes Association (ADA) in 2016, HbA1c levels less than or equal to 7.5% (58 mmol/mol) were considered to indicate better control and higher levels were classified as poor control. 23,24 Participants rated their diabetes-related stress on a five-point Likert scale at the time of enrollment. For this analysis, participants reporting having diabetes-related stress often or very often were classified as having high stress, and those reporting diabetes-related stress never, rarely, or sometimes were categorized as having low stress. The insulin delivery method at time of enrollment was recorded in the Registry as one of four options: pump, pen, injections, or combinations of these. For this analysis, insulin delivery was dichotomized into one group for use of an insulin pump (alone or in combination with other delivery systems) versus exclusive use of injections or pens.

2.3. Statistical analysis

After examining the characteristics associated with registrants in each of the five SRH categories, we used logistic regression models with poor or fair (P/F) SRH versus very good or excellent (VG/E) SRH as the dependent variable to examine the relationships between SRH and demographic characteristics, HbA1c levels, diabetes-related stress levels, and insulin delivery methods. The results are reported as odds ratios (OR) with 95% confidence intervals (CIs). We used multivariable models to examine the associations between SRH and other variables after adjusting for sex, age, race, and insurance status. The goodness of fit for each model was tested using Hosmer-Lemeshow tests. Analysis was conducted using SPSS version 22 (SPSS Inc., Chicago, USA).

3. Results

This analysis included 5799 adolescents in the Registry who met the inclusion criteria summarized in Fig. 1. The sociodemographic and health characteristics of the included participants are presented in Table 1. Of the sample, 51% were male; 53.7% were between 13 and 15 years; 77.5% were white non-Hispanic; 64.3% had private or military insurance; 78.8% had HbA1c levels >7.5% (59 mmol/mol), indicating sub-optimal T1D management; 92.3% reported having low diabetes-related stress (indicated as sometimes, rarely or never); and 53.6% used an insulin pump rather than injections or pens. The majority of the participants reported their self-rated health (SRH) as very good (37.6%), good (30.4%), or excellent (21.7%), but 8.9% ranked their SRH as fair and 1.4% listed their SRH as poor (Table 1).

After dropping those with the middle "good" self-health rating, 85.1% of the participants rated their health as very good or excellent (VG/E) and 14.9% of rated their health as poor or fair (P/F) (n=600). Adolescents with P/F SRH were more likely than those with VG/E SRH to be female (adjusted OR = 1.7 (1.4, 2.1)), be 16 to 18 years old (aOR = 2.1 (1.7, 2.5)), be non-white (aOR = 2.7 (2.2, 3.4)), not have private or military insurance (aOR = 2.4 (2.1, 3.0)), have HbA1c levels >7.5% (59 mmol/mol) (aOR = 3.3 (2.4, 4.7)), report having diabetes-related stress often or very often (aOR = 6.1 (5.1, 7.2)), and use an injection or pen rather than a pump (aOR = 2.1 (1.6, 2.4)) (Table 2). The overall model was significant (Nagelkerke $r^2 = 0.358$; p < 0.001), and the Hosmer-Lemeshow's goodness-of-fit test (p = 0.66) indicated a good model fit.

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