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General and diabetes-specific stress in adolescents with type 1 diabetes

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Abstract

Background—Type 1 diabetes (T1D) is one of the most common chronic health conditions in adolescents in the United States. Adherence to the recommended treatment regimen has been reported as a source of stress for adolescents.

Aim—The purpose of this study was to examine the associations among general and diabetes-specific stress and glycemic control (HbA1c), self-management, and diabetes-specific quality of life (QOL) in adolescents with T1D.

Methods—A secondary analysis of baseline data (N = 320) from a randomized controlled trial was conducted. Adolescents completed validated measures of general and diabetes-specific stress, self-management, and diabetes-specific QOL. HbA1c levels were obtained from medical records.

Results—Over 50% of the sample scored at or above criteria for high general and diabetes-specific stress. Higher general and diabetes-specific stress was significantly associated with higher HbA1c, poorer self-management activities, and lower diabetes-specific QOL. Diabetes-specific stress accounted for a significant proportion of the variance in HbA1c, while general stress did not. General and diabetes-specific stress accounted for 40% of the variance in diabetes-specific QOL.

Conclusions—General and diabetes-specific stress are common in adolescents with T1D. Healthcare providers must be mindful of the sources of stress that adolescents with T1D face on a daily basis. General stress and diabetes-specific stress should be differentiated and may require different interventions to improve coping and outcomes.

Keywords

Type 1 diabetes; Mental health; Stress; Glycemic control; Quality of life

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Conflicts of interest statement

The authors of this manuscript certify that they have NO affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge or beliefs) in the subject matter or materials discussed in this manuscript.

1. Introduction

Type 1 diabetes (T1D) is one of the most prevalent chronic health conditions in youth, affecting 1 in 400 adolescents in the United States, and its incidence is rising [1]. The recommended treatment regimen is complex and demanding [1]. Adequate self-management of the treatment regimen is often a source of significant stress for adolescents and their families [20]. Self-management of the treatment regimen requires coordination of multiple domains, including complicated decision-making, frequent blood glucose monitoring, regular insulin administration, and close attention to diet and exercise [1]. Adolescents must also coordinate regularly with parents and healthcare providers [1]. Appropriate self-management behaviors lead to better glycemic control, which reduces the risk of acute and long-term complications [2]. Despite the importance of maintaining adequate glycemic control, only 40% of adolescents engage in adequate self-management behaviors [16] and only 29% maintain HbA1c levels at the target level [32].

Adolescence is a stressful developmental period during which all adolescents experience significant physical, cognitive, and psychosocial growth. Adolescents undergo important physical changes during puberty, such as the development of secondary sex characteristics, which are driven by hormonal fluctuations [20]. Adolescents begin to develop advanced critical thinking and reasoning skills. Psychosocially, adolescents must navigate evolving social interactions with family members and peers, establish a sense of autonomy, and develop new self-conceptions [20]. While all adolescents must learn to manage general life stress, adolescents with chronic health conditions face additional stress related to the self-management of the condition. Disease-related stress has the potential to negatively impact both the condition as well as typical developmental tasks.

Adolescents with T1D often feel overwhelmed by the daily T1D-related stress that they face as found in qualitative studies. They describe diabetes as “difficult, demanding, and never ending” [7] and they describe diabetes care as a significant source of stress [7]. They have also described their daily lives as a “pendulum swinging between being normal and being different” [18]. In addition to diabetes-specific stress, adolescents with diabetes also report struggling with the same personal and social stress unrelated to diabetes that their peers without diabetes face, including social interactions with family and friends, as well as their own emotional and physical development [15].

Because adolescents with T1D face several types of stress, it is important to identify the differential effects of general life stress compared to diabetes-specific stress, so that more tailored interventions can be developed [10]. While it is known that stress negatively impacts glycemic control and self-management [9,11], little is known regarding the specific impact of diabetes-specific stress compared to general stress during adolescence [15]. General and diabetes-specific stress has not been studied simultaneously, and the available studies have been primarily qualitative with small sample sizes [4]. Further research is needed to identify differences in the impact of general and diabetes-specific stress on adolescents with T1D. Thus, the purpose of this study was to examine the associations of general and diabetes-specific stress with glycemic control, self-management, and diabetes-specific QOL in adolescents with T1D. Our hypothesis was that general and diabetes-specific stress would be

significantly associated with the primary outcomes, glycemic control, self-management, and QOL. We also wanted to determine if these two types of stress contributed equally or differently to the primary outcomes.

2. Methods

In this cross-sectional study, a secondary analysis of baseline data from a randomized control trial was conducted. The aim of the parent study was to evaluate the effect of an internet-based coping skills training program on glycemic control and QOL compared to an internet-based education intervention for adolescents with T1D [13,29,30].

2.1. Participants and procedure

Eligible participants included adolescents with T1D aged 11–14 years who had been diagnosed for at least 6 months, had no other serious medical conditions, were able to speak and write English, were in a school grade appropriate to age within 1 year, and had access to high-speed internet (at home, community, or clinic). Participants were recruited from four university-affiliated outpatient clinical sites in the United States. Approval was obtained from the Human Subjects Review Committee of the Institutional Review Board at all four sites. A total of 518 adolescents with T1D were approached to participate in the study. Of these, 112 refused participation (most commonly due to time commitment or lack of interest), 78 passively refused participation, and 8 were excluded from the analysis due to ineligibility. A total of 320 adolescents completed baseline questionnaires on a password-protected, study-specific Web site.

3. Measures

3.1. Demographic

Demographic data (family demographics, including income, race/ethnicity, parent education, marital status, gender) were collected from parents or guardians. For this study, total family income was categorized as less than \$40,000, \$40,000–\$80,000, or greater than \$80,000. Age was a continuous variable. Race/ethnicity was dichotomized as white/non-Hispanic (64%) or non-white (36%). The non-white category included Hispanic/Latino (50%), Black or African American (30%), biracial (14%), or other (6%). We dichotomized these variables due to sample size and distribution of data. The non-white category comprised only one-third of the total sample when all races and ethnicities were combined. Further categorization would have limited power. Marital status of parents/-guardians was categorized as married/partnered or single/divorced, due to sample size and distribution of data.

3.2. General stress

General stress (defined as feelings of general stress over the previous month) was measured with the Perceived Stress Scale (PSS), a 14-item measure that assesses the degree to which an individual considers his or her life to be stressful over the previous month [5]. For example, the questions ask that a respondent report on perceived control over the important things in her or his life, perceived ability to cope with the tasks of daily living, and how

often the respondent felt overwhelmed by general life difficulties. The overall aim of the measure is to capture how unpredictable, uncontrollable, and overloaded respondents feel in their daily lives on a regular basis. A five-point Likert scale ranging from 0 (never) to 4 (very often) is used to rate the frequency of occurrence of each item. Total scores range from 0 to 56, with higher scores indicating greater general stress. A score greater than 20 indicates high levels of general stress [5]. This measure has previously been used in adolescents with T1D and sufficient reliability and validity has been demonstrated [26,29]. Cronbach's alpha was 0.80 in our sample.

3.3. Diabetes-specific stress

Diabetes-specific stress was measured with the Responses to Stress Questionnaire (RSQ), a 67-item measure that assesses diabetes-specific stress and coping and is developmentally specific to concerns of adolescents with T1D [6]. The first 10 items measure diabetes-specific stress, such as stress about telling others about the diabetes diagnosis or others noticing the insulin pump, stress about "bad numbers," stress about parental involvement in diabetes care, and stress about interference of diabetes in daily activities. The questions request that respondents report on the frequency of recent stress related to diabetes. While other aspects of the measure assess the degree to which these events have been stressful, as well as the perceived ability to control these events, we included only the first 10 items that measured the frequency of diabetes-specific stress. Diabetes-specific stress scores range from 0 to 30, with higher scores indicating greater stress. A score of 10 or higher indicates high diabetes-specific stress [6]. This measure has good reliability and validity in reports of both parents and children [6]. The Cronbach's alpha was 0.87 in our sample.

3.4. Glycemic control

Glycosylated hemoglobin (HbA1c) is routinely measured in patients with T1D and serves as an objective measure of glycemic control over the most recent 2–3 months. The ADA recommends a target HbA1c of 7.5% or below in adolescents [1]. The majority (80%) of analyses in our sample were performed using the Bayer Diagnostics DCA2000 (Bayer, Tarrytown, NY) that has a normal range of 4.2–6.3% and provides results in 6 min using a fingerstick blood sample. There were no significant differences between participants who were measured with the Bayer DCA2000 and those who used different methods [12].

3.5. Self-management

The Self-Management in Adolescents with Diabetes (SMOD-A) measure, a 52-item scale with a 4-point Likert scale, was used to assess self-management activities in adolescents with T1D [23]. The diabetes care activities subscale was used in this study to evaluate whether stress is associated with the frequency of daily activities required for adequate diabetes management. This subscale measures the frequency of daily activities recommended by the ADA that youth and their parents perform to care for the disease, such as carbohydrate counting and blood glucose monitoring [1,23]. Scores range from 0 to 45, with higher scores indicating greater frequency of self-management activities. Adequate reliability and validity has been demonstrated [24]. The Cronbach's alpha was 0.74 in our sample.

3.6. Quality of life

The diabetes-specific Pediatric Quality of Life (Peds-QL) questionnaire is a 28-item measure that evaluates QOL in adolescents with T1D [27]. This questionnaire contains five subscales, including general diabetes QOL, general T1D treatment QOL, specific T1D treatment QOL, worry, and communication. In each subscale, questions ask respondents to report on how much of a problem each type of stress has been over the past month. Answers range from “never a problem” to “almost always a problem.” Thus, while the RSQ asks respondents to evaluate the frequency of diabetes-specific stress, the Peds-QL asks respondents to report on the degree to which each type of stress has been problematic. QOL scores range from 0 to 100, with higher scores indicating better QOL. High reliability and validity have been established in both clinical and community samples. The total score was used in this study. Cronbach’s alpha was 0.87 in our sample.

4. Data analyses

Descriptive analyses were conducted using ANOVA or Chi-square to test for demographic differences related to general and diabetes-specific stress. Bivariate Pearson correlations were conducted to examine the relationship between general and diabetes-specific stress with each other and with HbA1c, self-management, QOL, and covariates (race, gender, age, income, and therapy type [pump or injection]), and also to evaluate the effect of multicollinearity. Multivariate linear regression analyses using proc reg in SAS 9.0 software (SAS Institute, Inc., Cary, NC, USA) were used to determine the effect of general and diabetes-specific stress on HbA1c, self-management, and diabetes-specific QOL, adjusting for potential covariates.

5. Results

5.1. Descriptive analyses

The final sample of 320 adolescents was 55% female and 62.2% non-Hispanic white, with a mean age of 12.3 ± 1.1 years (range 11–14 years), mean HbA1c of $8.46\% \pm 1.5$, and mean diabetes duration of 6.1 ± 3.5 years. Approximately 63% of families had an annual income of $< \$8,000$ and approximately 59% of adolescents used pump therapy (Table 1). The mean general stress score was 21.33 ± 7.9 (scores range from 0 to 56, with >20 indicating high stress) and the mean diabetes-specific stress score was 10.13 ± 4.6 (scores range from 0 to 30, with >10 indicating high stress). Sixty-two percent of the sample scored at or above criterion for high general stress and 52% scored at or above criterion for high diabetes-specific stress. The mean self-management score was 32.22 ± 5.7 , indicating high frequency of self-management activities. The mean diabetes-specific QOL score was 80 ± 8.3 , indicating high diabetes-specific QOL. Non-white adolescents reported higher general (24.07 ± 8.09 , $p < 0.01$) and diabetes-specific stress (10.99 ± 4.59 , $P < 0.01$) than White adolescents (general stress = 19.71 ± 7.35 , diabetes-specific stress = 9.63 ± 4.49). Adolescents with lower and moderate family income ($< \$40,000$ and $\$40,000$ – $\$80,000$, respectively) reported higher general stress (23.21 ± 8.17 , $p < 0.01$) and diabetes-specific stress (10.81 ± 4.36 , $p < 0.05$) than those with greater family income ($> \$80,000$) (general stress = 19.84 ± 7.25 ; diabetes-specific stress = 9.51 ± 4.67). There were no differences in

general stress or diabetes-specific stress with regard to gender, type of therapy, or marital status. There were 129 adolescents who scored above the cut-off on both general and diabetes-specific stress. Adolescents with high levels of both types of stress were 57% female, 58% low income, 56% Non-Hispanic Caucasian, with a mean age of 12.23 ± 1.11 years and a mean HbA1c of 8.4 ± 1.62 .

5.2. Bivariate analyses

Results of the bivariate analyses are presented in Table 2. As expected, general and diabetes-specific stress were correlated at 0.48 ($p < 0.01$). As general and diabetes-specific stress were correlated at <0.7 and therefore did not meet criteria for multicollinearity [33], they were both included in the same model. More general and diabetes-specific stress was correlated with higher HbA1c levels (0.21, $p < 0.01$; 0.22, $p < 0.01$, respectively), older age (0.16, $p < 0.01$; 0.15, $p < 0.01$), lower diabetes-specific QOL (-0.57 , $p < 0.01$; -0.52 , $p < 0.01$), lower frequency of self-management activities (-0.36 , $p < 0.01$; -0.30 , $p < 0.01$), and lower family income (-0.24 ; $p < 0.01$; -0.14 , $p < 0.01$), respectively. Stress was not correlated with gender or therapy type.

5.3. Multivariate analysis

Hierarchical multivariate linear regression models were estimated to examine the relationship between general and diabetes-specific stress on the primary outcomes, HbA1c, self-management, and QOL. Covariates in all models were dichotomous with the exception of age, entered into the model in the order listed below, and included age, race/ethnicity (White, non-Hispanic or non-White), gender (male or female), therapy type (injection or pump), and income ($< \$80,000$ or $> \$80,000$). First, each model was tested with either general stress or diabetes-specific stress alone after all of the above covariates. Next, general stress and diabetes-specific stress were entered into each model simultaneously after all of the above covariates.

After controlling for covariates, higher general stress was associated with higher HbA1c levels ($\beta = 0.02$, $p < 0.05$), fewer self-management activities ($\beta = -0.33$, $p < 0.01$), and poorer QOL ($\beta = -1.2$, $p < 0.01$) (Table 3). After controlling for covariates, higher diabetes-specific stress was associated with higher HbA1c levels ($\beta = 0.07$, $p < 0.01$), fewer self-management activities ($\beta = -0.33$, $p < 0.01$), and poorer QOL ($\beta = -1.24$, $p < 0.01$) (Table 4). When included in the same model, and after controlling for covariates, greater diabetes-specific stress was associated with higher HbA1c ($\beta = 0.06$, $p < 0.01$), accounting for 8% of the variance, while general stress was not ($p = 0.66$) (Table 5). Diabetes-specific stress ($\beta = -0.18$, $p < 0.05$) and general stress ($\beta = -0.19$, $p < 0.01$) were both negatively associated with self-management, accounting for 15% of the variance. Diabetes-specific stress ($\beta = -0.76$, $p < 0.01$) and general stress ($\beta = -0.61$, $p < 0.01$) were both negatively associated with QOL, accounting for 40% of the variance.

6. Discussion

Results from qualitative studies demonstrate that adolescence is a stressful developmental period for youth with T1D. Our analyses provide quantitative support for these qualitative

findings. In this study, adolescents reported high levels of both general and diabetes-specific stress, and higher levels of both types of stress were negatively associated with poorer glycemic control, self-management behaviors, and QOL.

In bivariate analyses, we found that adolescents from lower-income families reported both greater general and diabetes-specific stress than their peers from higher-income families. This finding is consistent with previous studies which have demonstrated that low-income is a risk factor for poorer outcomes in adolescents with T1D and that adolescents from low-income families report greater general stress levels than their peers from higher income families [14,22,32]. We also found that adolescents from racially diverse backgrounds reported both higher general stress and diabetes-specific stress than their Caucasian peers. African and American and Hispanic adolescents have been reported to have poorer glycemic control and poorer adherence to the treatment regimen than their Caucasian peers [28]. Thus, stress may be an important contributor to the poorer diabetes outcomes that adolescents from diverse racial and ethnic backgrounds experience.

In multivariate analyses, we examined general and diabetes-specific stress both individually and simultaneously. We found that reports of general and diabetes-specific stress were negatively associated with glycemic control, self-management behaviors, and diabetes-specific QOL when examined alone. When we examined general and diabetes-specific stress in the model simultaneously, we found that the associations changed. When included in the same model, general stress no longer contributed significantly to glycemic control, but diabetes-specific stress did. General and diabetes-specific stress levels were both still significant predictors of self-management activities and diabetes-specific QOL, but the point estimates of both types of stress decreased. Thus, when examined simultaneously, each type of stress had a different, but significant, relationship with our primary outcomes.

General and diabetes-specific stress levels accounted for a small amount of the variance in HbA1c and self-management. That is to say that while stress was an important factor, there are many other behavioral and psychosocial factors, such as disease duration, parent education, health care resources, and social support, that contribute to HbA1c and self-management. Conversely, QOL appears to be strongly associated with stress, as stress accounted for 40% of the variance, indicating that general and diabetes-specific stress levels contributed to a large proportion of QOL. Although our data are cross-sectional and thus causality cannot be determined, our results suggest that interventions aimed at improving general and diabetes-specific stress levels may improve HbA1c and self-management to some extent, and stand to potentially improve QOL to a greater extent.

There are several approaches that have potential to assist adolescents with coping after they screen positive for stress symptoms. Cognitive behavior therapy (CBT), for example, has high efficacy in adolescents and is a customizable approach [3]. For example, adolescents experiencing high levels of diabetes specific-stress may benefit from CBT designed specifically to help improve coping with the specific daily stress that occurs as a result of T1D, such as how to approach telling peers about diabetes. Adolescents at high risk for stress symptoms, such as females and minorities, may also benefit from group CBT, which facilitates social support along with promoting coping skills [8,25]. Another approach is a

emotional changes that occur during this time period. For example, a CBT-based intervention for this group might focus on changing thought patterns associated with school achievement and relationships with others. Adolescents who report high levels of diabetes-specific stress must learn to cope more efficiently with stress related to the daily tasks required by the diabetes treatment regimen, including regular blood sugar monitoring, insulin administration, and managing diet and exercise. For example, a CBT-based intervention for this group might focus on changing thought patterns associated with checking blood sugar in front of peers at school, or administering insulin at a birthday party. Interventions will likely be more effective if targeted to the type of stress that the adolescent perceives to be the most impactful. Clinicians must be attentive to the adolescent's description of his or her stress, and sensitive to the important impact of stress levels on adequate diabetes care.

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Table 1

Demographic characteristics.

Characteristic	N (%) or mean \pm SD
<i>Gender</i>	
Male	143 (45%)
Female	177 (55%)
Age (years)	12.3 + 1.1
White, non-Latino	204 (64%)
Non-white	114 (36%)
<i>Parent marital status</i>	
Single/Divorced	58 (21%)
Married/Partnered	251 (79%)
<i>Parent 1 education (years)</i>	
<12	15 (5%)
12	85 (27%)
>12	214 (67%)
<i>Therapy type</i>	
Conventional or basal injections	127 (43%)
Pump	182 (57%)
<i>Income</i>	
>\$40,000	65 (20%)
\$40,000–\$80,000	87 (27%)
>\$80,000	157 (49%)
HbA1c	8.46 \pm 1.5
<i>Stress</i>	
General stress (range 0–56)	21 + 7.9
Diabetes-specific stress (range 0–30)	10 + 4.5
Self-management (range 0–45)	32 + 2.2
Diabetes-specific QOL (range 0–100)	80 + 8.3

Table 2

Pearson correlations.

	General stress	Diabetes-specific stress
HbA1c	0.21 (p < 0.01) *	0.22 (p < 0.01) *
Self-management	-0.36 (p < 0.01) *	-0.30 (p < 0.01) *
QOL	-0.57 (p < 0.01) *	-0.52 (p < 0.01) *
Age	0.19 (p < 0.01) *	0.12 (p < 0.05) *
Race/Ethnicity	-0.27 (p < 0.01) *	-0.14 (p < 0.01) *
Gender	0.10 (p = 0.07)	0.02 (p = 0.69)
Therapy type	0.09 (p = 0.11)	-0.06 (p = 0.28)
Income	-0.24 (p < 0.01) *	-0.14 (p < 0.01) *
General stress		0.48 (p < 0.01) *

* Indicates significant (p < 0.05).

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Table 3

Multivariate linear regression model of general stress as a predictor of each of the three outcomes: HbA1C, self-management, and QOL.

	HbA1c beta (p-value)	Self-management beta (p-value)	QOL beta (p-value)
Adjusted R-Square	0.05	0.13	0.32
Age	0.12 (p = 0.09)	-0.32 (p = 0.60)	0.70 (p = 0.15)
Gender	0.06 (p = 0.61)	1.17 (p = 0.06)	1.06 (p = 0.32)
Therapy type	0.25 (p = 0.18)	0.98 (p = 0.12)	0.89 (p = 0.41)
Race	-0.25 (p = 0.38)	0.79 (p = 0.26)	-0.12 (p = 0.91)
Income	-0.24 (p < 0.01) *	0.01 (p = 0.26)	0.47 (p = 0.70)
General stress	0.02 (p < 0.05) *	-0.24 (p < 0.01) *	-0.82 (p < 0.01) *

* Indicates significant (p < 0.05).

Table 4

Multivariate linear regression model testing diabetes-specific stress as a predictor of each of the three outcomes: HbA1C, self-management, and QOL.

	HbA1c beta (p-value)	Self-management beta (p-value)	QOL beta (p-value)
Adjusted R-Square	0.10	0.10	0.27
Age	0.13 (p = 0.79)	-0.56 (p = 0.05)	0.14 (p = 0.78)
Gender	0.09 (p = 0.59)	0.85 (p = 0.17)	0.01 (p = 0.99)
Therapy type	0.33 (p = 0.05)	0.56 (p = 0.39)	-0.64 (p = 0.58)
Race	-0.23 (p = 0.20)	1.13 (p = 0.11)	0.87 (p = 0.48)
Income	-0.47 (p < 0.01) *	0.35 (p = 0.62)	1.99 (p = 0.09)
Diabetes-specific stress	0.07 (p < 0.01) *	-0.33 (p < 0.01) *	-1.24 (p < 0.01) *

* Indicates significant (p < 0.05).

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Table 5

Multivariate linear regression model testing general and diabetes-specific stress as a predictor of each of the three outcomes: HbA1C, self-management, and QOL.

	HbA1c beta (p-value)	Self-management beta (p-value)	QOL beta (p-value)
Adjusted R-Square	0.08	0.15	0.40
Age	0.12 (p = 0.09)	-0.37 (p = 0.18)	0.72 (p = 0.11)
Gender	0.08 (p = 0.62)	1.12 (p = 0.07)	0.83 (p = 0.40)
Therapy type	0.33 (p = 0.06)	0.79 (p = 0.22)	0.08 (p = 0.94)
Race	-0.22 (p = 0.23)	0.70 (p = 0.32)	-0.51 (p = 0.65)
Income	-0.25 (p = 0.20)	-0.01 (p = 0.99)	0.42 (p = 0.70)
General stress	0.005 (p = 0.66)	-0.19 (p < 0.01) *	-0.61 (p < 0.01) *
Diabetes-specific stress	0.06 (p < 0.01) *	-0.18 (p < 0.01) *	-0.76 (p < 0.01) *

* Indicates significant (p < 0.05).