



Published in final edited form as:

Can J Diabetes. 2021 July ; 45(5): 411–416. doi:10.1016/j.jcjd.2021.01.011.

A Multi-Site Examination of Depression Screening Scores and Correlates Among Adolescents and Young Adults with Type 2 Diabetes

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Abstract

Aims: To evaluate self-reported depressive symptoms and clinical outcomes during routine screening for adolescents and young adults with type 2 diabetes (T2D), and examine associations among depressive symptoms, demographic, and clinical characteristics.

Methods: The Patient Health Questionnaire (PHQ) was administered to 197 adolescents and young adults with T2D using the PHQ-2 or PHQ-9 in routine pediatric diabetes care at 4 academic medical centers. Data from electronic health records were extracted from the screening date and 12 months prior.

Results: Adolescents and young adults with T2D (Mean age=16.85; 57% male; 77.2% non-White) completed the PHQ as part of routine diabetes care. On the PHQ, 19.3% of adolescents and young adults endorsed elevated depressive symptoms (PHQ score ≥ 10) and, among a subsample with item-level data (n=53), 18.9% endorsed thoughts of self-harm. Subsequently, 50.0% of those

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Author Contributions. S.A.M., J.C.K., and M.M. conceptualized the study. All authors contributed to planning the study, interpreted results, and critically revised and completed the manuscript. S.A.M. and the Vanderbilt Institute for Clinical and Translational Research (VICTR) aggregated and cleaned data for the study. C.A.M. and S.A.M. performed data analyses. S.A.M. and M.M. are the guarantors of this work and take responsibility for the integrity of the data and accuracy of analyses.

Author Disclosures: None

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with depressive symptoms had a documented referral for mental health treatment in the electronic medical record following the positive screening outcome. Older age, shorter diabetes duration, higher hemoglobin A1C, being non-Hispanic white, more blood glucose checks per day, and being prescribed oral medications were significantly associated with more depressive symptoms.

Conclusions: Screening for depressive symptoms identifies individuals in need of referral for mental health treatment. A focus on self-harm assessment, standardized methods for documentation of symptoms and mental health referrals, and increased referral resources are needed.

Keywords

depression; screening; patient health questionnaire (PHQ); pediatrics; health services

Introduction

Type 2 diabetes (T2D) prevalence among youth has dramatically increased in recent years [1], and up to 18% of adolescents and 24% of young adults in the U.S. have indicators of pre-diabetes, suggesting rates of T2D will continue to rise in the future [2]. Youth-onset T2D is associated with a host of acute and chronic complications and comorbidities, including psychosocial risk [3]. Further, T2D disproportionately affects adolescents and young adults from historically disadvantaged racial/ethnic backgrounds and youth with lower socioeconomic status, exacerbating challenges that youth may experience with lifestyle change and T2D self-management. This can place youth at higher risk for mental health concerns [4]. This complex interplay among sociodemographic risk and disease presentation underscores the need to assess and treat mental health needs as part of routine care for youth with T2D.

Screening for depressive symptoms in youth with diabetes using an age-appropriate, valid self-report measure is recommended as part of standard diabetes care [5, 6]. However, much of the current screening literature focuses on youth with type 1 diabetes and less is known about screening procedures and outcomes among youth with T2D [7, 8]. Recent studies suggest that up to 22% of youth with T2D report elevated depressive symptoms using self-report measures [9–11]. Yet the Pediatric Diabetes Consortium found only 16% of youth with T2D and elevated depressive symptoms had engaged in any mental health treatment during the prior 12 months [10]. Further, no studies to date have examined rates of suicidal ideation in youth with T2D. The lack of attention to youth with T2D, who endorse higher rates of depressive symptoms than youth with type 1 diabetes [10, 11], suggest that many at-risk youth are not identified and may not be connected with appropriate mental health resources.

There is much to be learned about real-world outcomes from depression screening for youth with T2D. Prior studies have generally utilized self-reports of depressive symptoms from youth enrolled in research studies [9, 10]. However, the unique sociodemographic characteristics associated with youth-onset T2D may affect research enrollment and retention, and research samples of youth with T2D may not be representative [4]. Research with youth with T2D has been inconclusive about associations among depressive symptoms

and demographic characteristics such as sex, family income, age, and race/ethnicity [10–15] and diabetes clinical characteristics, such as BMI and hemoglobin A1C (A1C) levels [16, 17]. Further, these complex associations among demographic and clinical characteristics and depressive symptoms have not been fully explored in diverse groups of youth with T2D.

The study aimed to evaluate the presence of elevated depressive symptoms and suicidal ideation in youth with T2D presenting for outpatient diabetes care. It was hypothesized that a significant portion of youth with T2D would endorse depressive symptoms and suicidal ideation, but few would be engaged with mental health services. Further, guided by prior research, it was hypothesized that relevant demographic and clinical characteristics, such as race/ethnicity, insurance status, and glycemic control (A1C), would be associated with elevated depressive symptoms.

Methods

The study sample included adolescents and young adults with T2D between the ages of 12 to 24 years with a completed Patient Health Questionnaire (PHQ) as part of routine clinical care over a one year period. Additional inclusion criteria were: duration of T2D > 6 months, electronic health record (EHR) documentation of an A1C level in the previous 3 months, and no more than 8 medical clinic visits in the prior 12 months. Patients with a diagnosis of type 1 diabetes, maturity onset diabetes of the young (MODY), or unknown diabetes diagnosis were excluded. Four pediatric diabetes clinics provided data from EHRs for the study: Children’s National Hospital in Washington, DC, Vanderbilt University Medical Center in Nashville, TN, University of Florida in Gainesville, FL, and Stanford University School of Medicine in Palo Alto, CA. Each clinic utilized its own electronic health record for the care of youth with T2D. Clinics provided screening data from all patients with a documented PHQ administration who were seen for a clinic visit in the same one-year period (April 1, 2016 - March 31, 2017); data were extracted from the medical chart, formatted using a standardized data dictionary, screened for accuracy and anonymized at each site, and sent to the data aggregating center (Vanderbilt University) so that all data could be combined in a deidentified master dataset.

Patient Health Questionnaire (PHQ)

The Patient Health Questionnaire (PHQ) is a brief self-report measure of depressive symptoms. Completion of the PHQ asks respondents to rate how often they have been bothered by specific symptoms over the previous 2 weeks using 4 response options ranging from ‘Not at All’ (0) to ‘Nearly Every Day’ (3) [13]. The PHQ-9 is comprised of 9 items that align with diagnostic criteria for major depressive disorder, with one of the items assessing suicidal ideation and/or risk of harm-to-self (hereafter, “harm-to-self”). The total score is summed, resulting in a categorization of Minimal (0–4), Mild (5–9), Moderate (10–14), Moderately Severe (15–19), and Severe (20–27) depressive symptoms. The PHQ-9 is a valid measure that has been used extensively with adolescents and young adults [18–20]. A score of 10 has demonstrated adequate discrimination among adults diagnosed with and without major depressive disorder (AUC = 0.95) [21], and the measure is sensitive to change over time [22]. The PHQ-9 for adolescents has identified a cutoff of 11 to indicate elevated

depressive symptoms in teens [19]; however, as our clinic samples included both adolescents and young adults, each site opted to use the more inclusive adult cutoff of 10 to indicate a need for further assessment and/or mental health resources [8, 23].

The PHQ also is available in a brief 2-item measure [24] that assesses frequency of depressed mood and anhedonia. The 2-item version is used as a screener, and elevated scores suggest a need to administer the additional 7 items from the PHQ-9. Thresholds of 2 or 3 on the PHQ-2 have been used for screening in adolescents [20]; the site administering the PHQ-2 opted to use the more inclusive cutoff of 2 to indicate a need for administration of the PHQ-9. There were n=58 individuals with item-level data from the PHQ-2 or the PHQ-9 for analyses; the remaining individuals had a total PHQ score only.

Screening Procedures and Electronic Health Record Data

Each site used procedures for administering the PHQ developed to best fit clinic resources and workflow. One site administered the PHQ-2 followed by the PHQ-9 if warranted (a score of 2), and 3 sites administered the PHQ-9 only. Three sites collected PHQ item-level data; 1 site documented total PHQ score only. Additionally, 1 site did not collect data related to blood glucose (BG) values. The PHQ was administered at varying frequencies based on individual site procedures, ranging from every diabetes clinic visit to once every year. Only the first administration of the PHQ for each patient was used for the current study, and data were retrospectively collected from the respective EHRs for the 12 months prior to completion of the PHQ.

Demographic and Clinical Data—The demographic and clinical data from the date of the depression screen (or closest in time to the depression screen) were used for all patients, along with other clinical data from the prior 12 months. Data extracted from EHRs included: age, sex, race/ethnicity, insurance type (public or private), diabetes duration, most recent A1C level (and date A1C was collected), height/weight (to calculate BMI), insulin use, diabetes oral medications (e.g., metformin), mean number of BG checks per day and mean BG level from in-clinic glucose meter download, DKA episodes, diabetes hospitalizations, number of clinic visits, and clinical actions taken in response to depression screening. Time frames associated with meter data were limited to 7 to 90 days. Mental health diagnoses, including depression, anxiety, and externalizing behavioral disorders (e.g. conduct disorder, hyperactivity), were identified by International Classification of Diseases (ICD) codes in the EHR.

Mental Health Treatment—Mental health treatment was coded if: 1) a clinic note included a patient or caregiver report of the patient's psychological, behavioral, or psychiatric treatment; or 2) the EHR included outpatient therapy visits or specific medications used to treat depression, anxiety or behavioral disorders (e.g. SSRIs, SNRIs, central alpha agonists, methylphenidate).

Clinical Actions Resulting from PHQ Screening—Follow-up clinical actions based on PHQ responses were documented in the EHR. All sites initiated clinical action for a PHQ-9 score indicating at least moderate depressive symptoms (10 total score) or any

endorsement on the harm-to-self PHQ item. The following actions were coded: 1) no need for response; 2) provision of mental health referrals and/or resources; or 3) immediate transfer to the emergency department for psychiatric evaluation.

Statistical Analyses

Descriptive results were generated using parametric statistics for normally distributed data and non-parametric statistics for non-normal distributions. A linear regression model with maximum likelihood estimation was conducted in Stata v15, accounting for the clustering of individuals within study sites, to examine predictors of PHQ scores. Predictors included both demographic and clinical variables.

Results

Sample Characteristics

The current study includes 197 adolescents and young adults with T2D; see Table 1 for descriptive statistics on the sample's demographic, clinical, and healthcare utilization characteristics. Oral medication was prescribed for 77.55% of youth and 63.45% were prescribed insulin. The mean number of days of BG monitoring data available was 43.02 days (SD 32.57, range 11–90). The mean number of BG checks per day was 1.30 (SD 1.15).

PHQ Scores

Of the N=197 participants, n=41 had only scores based on the PHQ-2 and the remaining n=156 had scores based on the PHQ-9. Regardless of PHQ version, distribution of PHQ score categories for adolescents and young adults with T2D were as follows: minimal 62.9% (n=124), mild 17.8% (n=35), moderate 13.2% (n=26), moderately severe 5.1% (n=10), and severe 1.0% (n=2). Combining the moderate or above categories (Score \geq 10), 19.3% (38/197) of youth with T2D endorsed elevated depressive symptoms.

Two sites utilized the PHQ-9 and had complete item-level data (n=53). At these two sites, the PHQ item related to harm-to-self was endorsed in 18.9% (10/53 with item-level data on the harm-to-self question). Endorsement of the harm-to-self item (n=10) was distributed across PHQ-9 score categories as follows: minimal 0% (0), mild 20.0% (2), moderate 50.0% (5), moderately severe 30.0% (3), and severe 0% (0) Mental Health Diagnosis, Treatment, and Referral Rates

Prior depression diagnoses were identified in 8.3% of youth with T2D (18/197). Other related mental health diagnoses were 2.8% mood disorders (not depression), 3.2% anxiety disorders, and 4.6% externalizing behavior disorders. Of those individuals with a prior depression diagnosis, 38.9% (n=7/18) were in mental health treatment.

All sites used a cut-off score of \geq 10 or endorsement of the harm-to-self item for a mental health referral. Among those endorsing moderate or above depressive symptoms (n=38), 50.0% received a referral for mental health treatment resulting from screening documented in the EHR (n=19/38). Of those who were not referred, 15.8% (n=3/19) were already in mental health treatment and 84.2% (n=16/19) were not in treatment. Of those individuals who were administered the PHQ-9, had item-level data (n=53) and endorsed the harm-to-

self item (n=10), 10% (1/10) had documentation of treatment for depression and 80% (8/10) had a referral for mental health treatment.

Regression Model

Table 2 presents standardized regression coefficients for youth with T2D with PHQ scores as the dependent variable. Older age, shorter diabetes duration, higher A1C levels, being non-Hispanic white, more BG checks per day, and being prescribed oral medications were significantly associated with more depressive symptoms.

Discussion

This multi-site study of pediatric depression screening utilized extensive EHR data from 4 pediatric diabetes care centers to evaluate the rates of elevated depressive symptoms, harm-to-self, and referrals for and engagement in mental health treatment among adolescents and young adults with T2D. The current findings inform rates of depressive symptoms in youth with T2D and opportunities to improve screening practices, including demographic and clinical characteristics associated with more depressive symptoms and increasing referrals for mental health treatment with documentation in the EHR.

In this study of youth with T2D presenting for routine diabetes care over a one year period, 19% reported moderate or greater depressive symptoms. These rates are similar to other studies of youth with T2D that found 15 – 22% of youth with elevated scores using the Beck Depression Inventory (BDI) or the Children’s Depression Inventory (CDI) [9, 10]. The current findings support the use of the PHQ with youth with T2D; the rates of elevated depressive symptoms in our sample are similar to other studies of youth with T2D using different measures and participants were able to complete the measure as part of routine care. Further, the PHQ is brief, valid, and freely available for use [21].

Rates of depressive symptoms in adolescents and young adults with T2D were twice those of youth with type 1 diabetes assessed in the same clinics [25]. This confirms previous research that has consistently found higher rates of depression amongst youth with T2D compared to youth with type 1 diabetes [10, 26]. The rates of endorsement of harm-to-self found in the current sample are higher than previous studies in youth with type 1 diabetes, with 18.9% of youth with T2D indicating thoughts of harm-to-self in the past two weeks [7, 27–29]. Item-level data related to harm-to-self was only available for two of the four sites; however, as very few studies have reported on suicidal risk in youth with T2D [30], this information about relatively high rates of harm-to-self risk is critical to consider when developing screening programs and ensuring adequate mental health referrals and resources.

Referrals for mental health services increased appropriately with PHQ scores or endorsement of the harm-to-self item. However, it is concerning that a significant portion of adolescents and young adults with elevated PHQ scores did not have a documented mental health referral in the EHR, including those individuals who had no indication of prior or current mental health treatment. Further, 20% of youth endorsing the harm-to-self item did not have a documented referral for mental health treatment and only 10% were in active mental health treatment. These findings underscore the importance of routine screening with

standardized documentation of mental health history, depression screening scores, and mental health referrals in the EHR. For example, electronic completion of the PHQ, with documentation in the EHR and automatic alerts or recommended actions, could improve tracking of mental health referrals. This safeguard also helps to ensure all steps in the depression screening process are completed, and enhances the ability of health care providers to track symptoms across time.

Older age, shorter diabetes duration, higher A1C levels, being non-Hispanic white, more BG checks per day, and being prescribed oral medications were associated with higher PHQ scores. As with other studies with youth with T2D, sex and insurance type was not associated with depressive symptoms in this sample [11]. Challenges in managing glycemia and more frequent T2D care recommendations may contribute to negative mood, as higher A1C levels and more BG checks per day were all associated with elevated depressive symptoms. It is interesting that oral medication use was associated with higher depressive symptoms, but insulin use was not. This could reflect an adjustment to a more recent diagnosis of diabetes, as oral medications are often the first line of treatment for youth with T2D [3]. These findings can be used to identify adolescents and young adults with T2D who may need additional mental health support, including providing psychosocial assessment and support to youth soon after a diagnosis of T2D and providing targeted support for older adolescents and young adults, especially those who are engaging in frequent daily care tasks for T2D management (e.g., more BG checks per day).

Study findings offer important avenues for improvements in clinical care for adolescents and young adults with T2D. Despite advances in screening, there remain significant challenges in ensuring consistent access to and engagement with appropriate mental health care once risk is identified. Further, elevated depressive symptoms were associated with elevated glycemic levels and daily diabetes care behaviors, suggesting that tailored treatment needs to include strategies that address both mood and diabetes management [30]. As T2D disproportionately affects youth from lower income households and from racial/ethnic minority backgrounds, it is important that treatments are culturally-sensitive and easily accessible in the communities in which the youth live. It is critical that longitudinal research evaluate changes in depressive symptoms and engagement in treatment over time to better inform the complex associations among mood and diabetes indicators in this vulnerable population.

This study had several limitations. There are inherent challenges of retrospectively collecting data from real-world clinical settings, and it is not known how many patients with T2D presented for care but did not complete the PHQ as part of routine clinical care. Additionally, different practice locations engaged in tailored screening and documentation procedures unique to their respective sites. All data associated with PHQ, clinical, and demographic characteristics were derived from EHR data collected within the prior 12 months of screening. It is likely that mental health diagnoses and related treatment indicators were underreported in this sample given inconsistencies in where and how this information was documented in the EHR. Further, only 2 out of the 4 sites used the full PHQ-9 with all patients and reported item-level data to evaluate endorsement of the harm-to-self item, resulting in a smaller sample for evaluation of this indicator. Furthermore, we were unable to

determine the potential relationship between depression and all of the different diabetes management approaches (e.g., oral medicine alone, insulin alone, and/or the combination of insulin and oral medicine) given the small sample size of patients on insulin alone in the current study. Therefore, future studies may want to specifically explore depression symptoms within the context of various clinical intervention subgroups to determine key times to assess. Finally, we recognize that youth with T2D may be cared for in a variety of settings, including primary care, family medicine, and adolescent medicine, and the population of adolescents and young adults with T2D followed in specialty endocrinology care may not be representative of the overall population of youth with T2D. However, given the documented challenges of enrolling diverse youth in research studies, this clinic-derived sample is an important extension of current research and offers a real-world examination of diabetes clinical care and depression screening.

Conclusions

This multisite study contributes to a growing body of literature that documents the incidence rates of depressive symptoms and the need for appropriate referral services and adequate mental health follow-up resources in pediatric diabetes care. Adolescents and young adults with T2D have significant risk of experiencing depressive symptoms as well as sociodemographic risk factors that may contribute to barriers to obtaining mental health treatment. Using the EHR to identify routine practice patterns provided a unique opportunity to characterize the assessment and referral practices for youth with T2D in a specialty care setting.

Acknowledgements.

The authors would like to thank the Vanderbilt Institute for Clinical and Translational Research (VICTR) for assistance with the Research Derivative and data aggregation (Vanderbilt); Cheyenne Reynolds and Savannah Summy for data extraction and collection (University of Florida).

Funding. Research reported in this publication was supported by the National Center For Advancing Translational Sciences of the National Institutes of Health under Award Numbers UL1TR002243 and UL1TR001427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Key Messages

- Adolescents and young adults with type 2 diabetes are at increased risk for experiencing depressive symptoms and suicidal ideation.
- Improved processes for referral for mental health services and documentation in electronic health records (EHRs) are needed.

Table 1.

Characteristics of study participants

	Mean (SD)	Median	Range	N
Age at Screening (Years)	16.85 (2.11)	16.83	12.25–22.70	197
Sex (% Male)	56.85	-	-	197
Race				197
% Black	49.24%	-	-	
% Non-Hispanic White	22.84%			
% Other Race/ethnicity	27.91%			
Insurance (% Public)	59.69	-	-	196
Diabetes Duration (Years)	3.42 (2.79)	2.52	0.5–14.67	196
On Insulin Only (%)	17.35			196
Oral Medication Only (%)	31.63			196
On Insulin and Oral Medication (%)	45.92			196
A1C (%)	8.56 (2.61)	8.00	4.6–14.0	194
A1C (mmol/mol)	70	64	27–130	
BMI (kg/m ²)	37.56 (8.23)	36.64	21.01–63.62	98
Average BG Level (mg/dL)	188.33 (79.88)	170	0–425	100
DKA Events (%)	1.02 (0.12)			197
Diabetes Hospitalizations (% with 1 or more)	11.16			197
Clinic Visits (n/year)	2.46 (1.44)	2	0–7	197
BG Checks (n/day)	1.31 (1.15)	1.00	0.07–4.93	103
PHQ	4.52 (5.16)	2	0–21	197

Table 2.

Summary of multivariate associations of participant characteristics and PHQ scores (n=197)

	Coef.	Robust Std. Err.	p-value	[95% Conf. Interval]
BMI	-0.073	0.121	.548	[-0.310, 0.165]
Age at Screening	0.382	0.065	< . 001	[0.253, 0.511]
Sex (male)	-0.264	0.829	.750	[-1.888, 1.361]
Race (non-Hispanic white)	0.468	0.079	<. 001	[0.311, 0.624]
Insurance (private)	-0.755	0.754	.316	[-2.233, 0.721]
Diabetes Duration	-0.056	0.010	< . 001	[-0.077, -0.036]
A1C	0.494	0.048	<. 001	[0.401, 0.588]
Average BG Level	0.002	0.001	.116	[-0.005, 0.005]
Insulin	-1.269	0.817	.120	[-2.871, -0.332]
Oral Medication	0.812	0.378	.032	[0.071, 1.553]
# BG Checks per Day	0.999	0.457	.030	[0.103, 1.895]