Published in final edited form as:

Pediatr Diabetes. 2014 August ; 15(5): 384–388. doi:10.1111/pedi.12099.

Routine Behavioral and Mental Health Screening in Young Children with Type 1 Diabetes Mellitus

Ian Spencer Zenlea, MD¹, Lauren Mednick, PhD², Jennifer Rein, LICSW¹, Maryanne Quinn, MD, MPH^{1,3}, Joseph Wolfsdorf, MB, BCh^{1,3}, and Erinn T. Rhodes, MD, MPH^{1,3}

¹Division of Endocrinology, Boston Children's Hospital, 333 Longwood Avenue, 6th Floor, Boston, MA, United States, 02115

²Department of Psychology, Boston Children's Hospital, 300 Longwood Avenue, Boston, MA, United States, 02115

³Department of Pediatrics, Harvard Medical School, 250 Longwood Ave, Boston, MA, United States 02115

Abstract

Background—The American Diabetes Association and International Society for Pediatric and Adolescent Diabetes recommend that providers of diabetes care receive training in the recognition of psychosocial problems related to diabetes.

Objective—To report the results of routine behavioral/mental health screening for children with type 1 diabetes mellitus (T1D) seen in a multidisciplinary pediatric diabetes program.

Subjects and Methods—This was a cross-sectional study of children with T1D ages 4 – 11 years, who underwent behavioral/mental health screening as part of their diabetes care. Screening utilized the Strengths and Difficulties Questionnaire (SDQ) Parent Proxy Version, and scores were reviewed by a social worker. SDQ scale and total difficulties scores were compared by gender, visit type, age, T1D duration and HbA1c. Scores were also compared to age-appropriate normative data for children in the United States (US).

Results—SDQ Parent Proxy Version total difficulties and scale scores did not differ by patient or visit characteristics. Compared with normative data for US children, a greater proportion of children with T1D ages 4 – 7 and 8 – 10 years had borderline/abnormal scores on the emotional symptoms scale ($p = 0.01$ and $p = 0.03$, respectively), suggesting risk for psychological disorders, such as anxiety and depression.

Conclusions—Our findings suggest that children less than 11 years old with T1D may have greater emotional symptoms as compared to their age-matched healthy peers. Pediatric diabetes care providers, with access to mental health services, should consider incorporating routine behavioral/mental health screening for children less than 12 years old in their practice.

Keywords

behavior; mental health; children; diabetes mellitus, type 1; screening

INTRODUCTION

The American Diabetes Association and International Society for Pediatric and Adolescent Diabetes recommend that the diabetes care team receive training in the recognition, identification, and provision of information and counseling on psychosocial problems related to diabetes^{1,2}. Moreover, the identification of psychosocial adjustment problems, depression, eating disorders, and other psychiatric disorders should be conducted at planned intervals by mental health professionals². Assessment for these difficulties at diagnosis has been shown to identify patients at risk for early emerging complications and nonadherence³. Although important for all youth with type 1 diabetes mellitus (T1D), ongoing assessments are particularly important in young people not achieving treatment goals or who have chronically poor metabolic control (high hemoglobin A1c [A1c] levels, recurrent diabetic ketoacidosis)^{1,2}, as the presence of psychological disorders in adolescents with T1D has been linked to poor diabetes self-care³⁻⁹.

In October 2009, the Diabetes Program at Boston Children's Hospital (BCH) undertook a quality improvement project to evaluate the feasibility of implementing routine behavioral and mental health screening during visits for adolescents with T1D. In February 2011, screening was expanded to include children ages 4 – 11 years old using the Strengths and Difficulties Questionnaire (SDQ) Parent Proxy Version¹⁰. Although studies have examined the prevalence of behavioral and emotional difficulties in adolescents with T1D^{9,11-14}, there have been few reports about potential mental health concerns of children less than 12 years old⁷. This report of routine behavioral and mental health screening of children 4 – 11 years old with T1D adds to the limited data for this age group.

METHODS

This was a cross-sectional study of children with T1D ages 4 – 11 years old receiving care in the Diabetes Program at the Longwood Medical Campus of BCH between February 2011 and October 2012. Screening occurred in the following settings: (i) social work (SW) visits for children with newly diagnosed T1D (ii) individual or group SW visits per protocol for children with established T1D transitioning to continuous subcutaneous insulin infusion (CSII) therapy; (iii) SW visits by referral for psychosocial concerns; and (iv) during a routine diabetes care visit with a medical provider. Prior to each visit, a parent or adult caregiver completed the SDQ Parent Proxy Version, which was available in English or Spanish¹⁰. The social worker reviewed the questionnaire for all screening settings.

The SDQ Parent Proxy Version is a brief, 25 item, behavioral screening questionnaire that assesses positive and negative attributes across 5 scales: 1) emotional symptoms (5 items); 2) conduct problems (5 items); 3) hyperactivity-inattention (5 items); 4) peer relationship problems (5 items); and 5) pro-social behavior (5 items)¹⁰. A total difficulties score is calculated by summing the scores of the emotional symptoms, conduct problems,

hyperactivity-inattention, and the peer problems scales¹⁰. Scales are scored from 0 to 10, and total difficulties score ranges from 0 to 40. For all scales, except prosocial behavior, higher scores are associated with worsening symptoms. Scale scores could be prorated if at least 3 items were completed. Computer-based, automated scoring of the SDQ was performed by the social worker in the Diabetes Program using an online tool¹⁵. The BCH Institutional Review Board approved this study.

Patient characteristics included age, gender, primary language, duration of T1D, and glycosylated hemoglobin A1c (A1c), either from the date of screening or if not performed concurrently, the most proximal value prior to screening. A1c values were obtained either by point of care testing [DCA Vantage Analyzer (Siemens Healthcare Diagnostics)] or by whole blood laboratory testing (Turbidimetric Inhibition Amino Assay). Visit type was characterized as (i) SW visit for newly diagnosed T1D; (ii) individual or group SW visit for CSII therapy transition; (iii) SW visit by referral for psychosocial concerns; or (iv) routine visit with medical provider with SW review. The outcome measures were SDQ Parent Proxy Version scale scores and total difficulties score. Due to small cell sizes, the borderline and abnormal results were collapsed into a single category.

Data analyses were performed with SAS version 9.3 (SAS Institute, Inc, Cary, NC). Descriptive statistics were presented as proportions, medians and interquartile ranges, or means and SD, as appropriate. For bivariate analyses, chi-square test and Spearman rank-order correlation were used to assess the relationship between SDQ Parent Proxy Version scores and patient and visit characteristics. The SDQ Parent Proxy Version Scores were also compared to age-appropriate normative data for children in the US¹⁶. To perform these analyses, patient age was categorized according to the age categories in the normative sample (4 – 7, 8 – 10, and 11 – 14 years old). Although not reported here, youth in our sample who were 12 years old or greater were screened using a different instrument. The proportion of children in our clinical sample with borderline/abnormal scores on each scale was compared to the proportion of children with borderline/abnormal scores in the normative sample using the binomial test. Statistical significance was defined as a P-value less than 0.05.

RESULTS

From February 2011 through October 2012, 130 children were eligible for screening. Descriptive statistics are presented in Table 1. Only 9 (7%) of patients did not complete screening, and no parent or adult caregiver refused screening. Mean age was 8.2 ± 2.2 years, and median duration of diabetes was less than 1 year [interquartile range (IQR) 0, 1]. More than half the patients were female (57%). Half of the children (50%) were newly diagnosed with T1D. HbA1c values were unavailable in three children. Mean HbA1c was $8.6 \pm 1.7\%$ (70.5 ± 18.6 mmol/mol).

In one child, only the SDQ Parent Proxy Version total difficulties score was available. For the sample, mean (SD) SDQ Parent Proxy scores were: total difficulties, 6.8 (5.5); emotional symptoms, 2.3 (2.1); conduct problems, 1.0 (1.5); hyperactivity-inattention symptoms, 3.0 (2.3); peer relationship problems, 1.4 (2.5); and prosocial behaviors, 8.8 (2.3). Aggregate

SDQ Parent Proxy Version total difficulties and scale scores were not correlated with HbA1c or duration of T1D and did not differ by gender, visit type, or age category (data not shown). There were also no differences in scores between those being evaluated for a new diagnosis of T1D vs. other reasons. Compared with normative data for US children, a greater proportion of children with T1D ages 4 – 7 and 8 – 10 years old had borderline or abnormal scores on the emotional symptoms scale ($p = 0.01$ and $p = 0.03$, respectively) (Table 2). The distribution of scores of the children with T1D did not differ from the normative sample in terms of total difficulties, conduct problems, hyperactivity-inattention symptoms, peer relationship problems, or prosocial behaviors.

DISCUSSION

This is a report of the SDQ Parent Proxy Version scores for children ages 4 – 11 years old with T1D, which to our knowledge is the first of its kind in the literature. The aggregated SDQ Parent Proxy Version scores did not differ by age, gender, or visit type and were not correlated with HbA1c or T1D duration. Although there were no detectable differences in the study sample for most SDQ scales as compared to the population norms, a greater proportion of children ages 4 – 7 and 8 – 10 years old had higher scores on the emotional symptoms scale, which screens for symptoms of emotional disorders, such as anxiety and depression. Even though clinically the manifestation of emotional symptoms might be seen as an acute reaction to diagnosis of T1D, in this study, emotional symptoms scores did not differ by duration of diagnosis or visit type. These finding suggests that significant emotional difficulties in youth with T1D may begin to manifest in early childhood even outside the context of a new diagnosis of diabetes. Given the challenges associated with psychological disorders and the management of T1D in adolescence, it is possible that earlier detection and treatment of such psychosocial problems could prevent emotional difficulties in adolescence and, ultimately result in improved glycemic control.

To our knowledge, there are no published studies directly comparing youth with T1D to youth with other chronic diseases; however, similar studies using the SDQ Parent Proxy Version, have shown that, elevated behavioral and emotional disorders in other chronic diseases including chronic kidney disease¹⁷, asthma, neurological disorders, and other chronic illnesses¹⁸, had more emotional and behavioral problems than children without chronic illness¹⁸. However, differences between the studies, including country of origin and subject ages, make comparison across studies difficult.

There are several limitations that should be considered when interpreting the results of this study. First, the results reported were from a screening instrument, and we do not have follow-up data on the children to know whether any with positive screens have been formally diagnosed with an emotional disorder. Second, we do not yet have longitudinal data to determine whether the emotional symptoms persist. Third, insufficient power from a small sample, due to the use of a different screening instrument for youth ages 12 and older, may have limited our ability to detect a difference in the emotional symptoms scores for the older children as compared to the normative sample. Fourth, distinguishing emotional symptoms from hyperglycemic symptoms (e.g., fatigue, concentration difficulties, restlessness, changes in appetite, and irritability) may be difficult for some parents and

speaks to the need for ongoing screening, and formal evaluation when indicated. Lastly, in this study, the majority of screening occurred during visits with a social worker. Given the often limited availability of mental health services in the US health care system,^{19,20} this may limit the generalizability of the findings.

The study demonstrates the feasibility of incorporating behavioral and mental health screening for children less than 12 years of age as a component of diabetes care in a multidisciplinary pediatric diabetes program. Behavioral and mental health screening in this age group was well accepted by parents or adult caregivers. Although the sample sizes were relatively small, these findings suggest that children less than 12 years old might have more emotional symptoms as compared to the normal population. Further studies, with larger sample sizes, should be performed to validate our findings. Additional, longitudinal studies should also be conducted to determine whether emotional symptoms manifesting in childhood persist into adolescence and adulthood. If symptoms do persist, identifying and treating emotional difficulties in early childhood could potentially result in decreased morbidity in adolescence and adulthood and improve diabetes outcomes. Based on these results, diabetes care providers, who have access to mental health services, should consider incorporating routine behavioral and mental health screening for children less than 12 years old in their practice.

Acknowledgments

The project was supported by the Diabetes Clinical, Training and Education Fund at Boston Children's Hospital. Dr. Zenlea was supported by NIH Training Grant 5 T32 DK007260-34 and the Harvard Medical School Fellowship in Patient Safety and Quality. We thank Amelia Beard for providing administrative support to implement the project. We thank Carly E. Milliren for providing statistical support. This work was published, in part, at the American Diabetes Association 72nd Annual Scientific Sessions, June 8-12, 2012, Philadelphia, PA.

Abbreviations

T1D	type 1 diabetes mellitus
US	United States
SDQ	Strengths and Difficulties Questionnaire
A1c	hemoglobin A1c
BCH	Boston Children's Hospital
SW	social work
CSII	continuous subcutaneous insulin infusion
IQR	interquartile range

References

1. Standards of medical care in diabetes--2012. *Diabetes Care*. Jan; 2012 35(Suppl 1):S11–63. [PubMed: 22187469]
2. Delamater AM. Psychological care of children and adolescents with diabetes. *Pediatr Diabetes*. Sep; 2009 10(Suppl 12):175–184. [PubMed: 19754628]

3. Schwartz DD, Cline VD, Axelrad ME, Anderson BJ. Feasibility, acceptability, and predictive validity of a psychosocial screening program for children and youth newly diagnosed with type 1 diabetes. *Diabetes Care*. Feb; 2011 34(2):326–331. [PubMed: 21216856]
4. Hood KK, Huestis S, Maher A, Butler D, Volkeneing L, Laffel LM. Depressive symptoms in children and adolescents with type 1 diabetes: association with diabetes-specific characteristics. *Diabetes Care*. Jun; 2006 29(6):1389–1391. [PubMed: 16732028]
5. Lawrence JM, Standiford DA, Loots B, et al. Prevalence and correlates of depressed mood among youth with diabetes: the SEARCH for Diabetes in Youth study. *Pediatrics*. Apr; 2006 117(4):1348–1358. [PubMed: 16585333]
6. McGrady ME, Laffel L, Drotar D, Repaske D, Hood KK. Depressive symptoms and glycemic control in adolescents with type 1 diabetes: mediational role of blood glucose monitoring. *Diabetes Care*. May; 2009 32(5):804–806. [PubMed: 19228870]
7. Hood KK, Rausch JR, Dolan LM. Depressive symptoms predict change in glycemic control in adolescents with type 1 diabetes: rates, magnitude, and moderators of change. *Pediatr Diabetes*. May 12.2011
8. Stewart SM, Rao U, Emslie GJ, Klein D, White PC. Depressive symptoms predict hospitalization for adolescents with type 1 diabetes mellitus. *Pediatrics*. May; 2005 115(5):1315–1319. [PubMed: 15867041]
9. Bernstein CM, Stockwell MS, Gallagher MP, Rosenthal SL, Soren K. Mental Health Issues in Adolescents and Young Adults With Type 1 Diabetes: Prevalence and Impact on Glycemic Control. *Clin Pediatr (Phila)*. Sep 17.2012
10. Goodman R. The Strengths and Difficulties Questionnaire: a research note. *J Child Psychol Psychiatry*. Jul; 1997 38(5):581–586. [PubMed: 9255702]
11. Kovacs M, Goldston D, Obrosky DS, Bonar LK. Psychiatric disorders in youths with IDDM: rates and risk factors. *Diabetes Care*. Jan; 1997 20(1):36–44. [PubMed: 9028691]
12. Jaser SS, Dumser S, Liberti L, Hunter N, Whittemore R, Grey M. Seasonal trends in depressive symptoms in adolescents with type 1 diabetes. *Diabetes Res Clin Pract*. May; 2012 96(2):e33–35. [PubMed: 22325159]
13. Northam EA, Matthews LK, Anderson PJ, Cameron FJ, Werther GA. Psychiatric morbidity and health outcome in Type 1 diabetes--perspectives from a prospective longitudinal study. *Diabet Med*. Feb; 2005 22(2):152–157. [PubMed: 15660731]
14. Grey M, Whittemore R, Tamborlane W. Depression in type 1 diabetes in children: natural history and correlates. *J Psychosom Res*. Oct; 2002 53(4):907–911. [PubMed: 12377302]
15. [Accessed May 12, 2013] Welcome to the original SDQ scoring site. 2012. <http://www.1eq1.info/index.html>
16. [Accessed May 12, 2013] Information for researchers and professionals about the Strengths & Difficulties Questionnaires: Normative Data From the United States of America. 2012. <http://www.sdqinfo.com/USNorm.html>
17. Marciano RC, Soares CM, Diniz JS, et al. Behavioral disorders and low quality of life in children and adolescents with chronic kidney disease. *Pediatric nephrology (Berlin, Germany)*. Feb; 2011 26(2):281–290.
18. Hysing M, Elgen I, Gillberg C, Lundervold AJ. Emotional and behavioural problems in subgroups of children with chronic illness: results from a large-scale population study. *Child: care, health and development*. Jul; 2009 35(4):527–533.
19. Mental Health: Culture, Race, and Ethnicity: A Supplement to Mental Health: A Report of the Surgeon General. Rockville MD: 2001.
20. Mental health: a report of the Surgeon General. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health; Rockville MD: 1999.

Table 1

Characteristics of patients eligible for screening (N=130)

Variable	N (%)
Age (years) ^a	8.2 (2.2)
Duration of DM (years) ^b	0 (0, 1)
Sex (female)	75 (57)
Hemoglobin A1c (%) [(mmol/mol)] ^a	8.6 (1.7) [70.5 (18.6)]
Primary Language	
English	125 (96)
Spanish	3 (2)
Other	2 (2)
Visit Type	
SW* visit for newly diagnosed type 1 DM	65 (50)
Individual or group SW visit for CSII [†] therapy transition	34 (26)
SW visit for clinical concerns	18 (14)
Routine visit with medical provider with SW review	13 (10)
Completed Screening	121 (93)
Reason not completed (N=9)	
Refused	0 (0)
Comprehension/developmental issue	1 (1)
Language issue	3 (2)
Not given form by receptionist	2 (2)
Other reason	1 (1)
Unknown	2 (2)

^a Mean (SD)^b Median (25th, 75th percentile interquartile range)

* social work

[†] continuous subcutaneous insulin infusion therapy

Table 2

SDQ Parent Proxy Version Scores: Comparison to US Normative Data

Age Category	SDQ Scale Category	Clinical Sample		US Population Norm	P value
		N	%	%	
Age 4 – 7 years	Total difficulties	38			
	Normal (0 – 13)		94.7	87.7	0.28
	Borderline & Abnormal (14)		5.3	12.3	
	Emotional Symptoms	38			
	Normal (0 – 3)		73.7	89.0	0.01
	Borderline & abnormal (4)		26.3	11.0	
Age 8 – 10 years	Total Difficulties	63			
	Normal (0 – 13)		85.7	87.1	0.85
	Borderline & Abnormal (14)		14.3	12.9	
	Emotional Symptoms	62			
	Normal (0 – 3)		75.8	86.7	0.03
	Borderline & Abnormal (4)		24.2	13.3	
Age 11 years *	Total Difficulties	20			
	Normal (0 – 13)		90.0	85.7	0.88
	Borderline & Abnormal (14)		10.0	14.3	
	Emotional Symptoms	20			
	Normal (0 – 3)		80.0	83.9	0.81
	Borderline & Abnormal (4)		20.0	16.1	

* The normative US sample included children 11 – 14 years of age.