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Diabetes Stigma and Clinical Outcomes in Adolescents and Young Adults: The SEARCH for Diabetes in Youth Study

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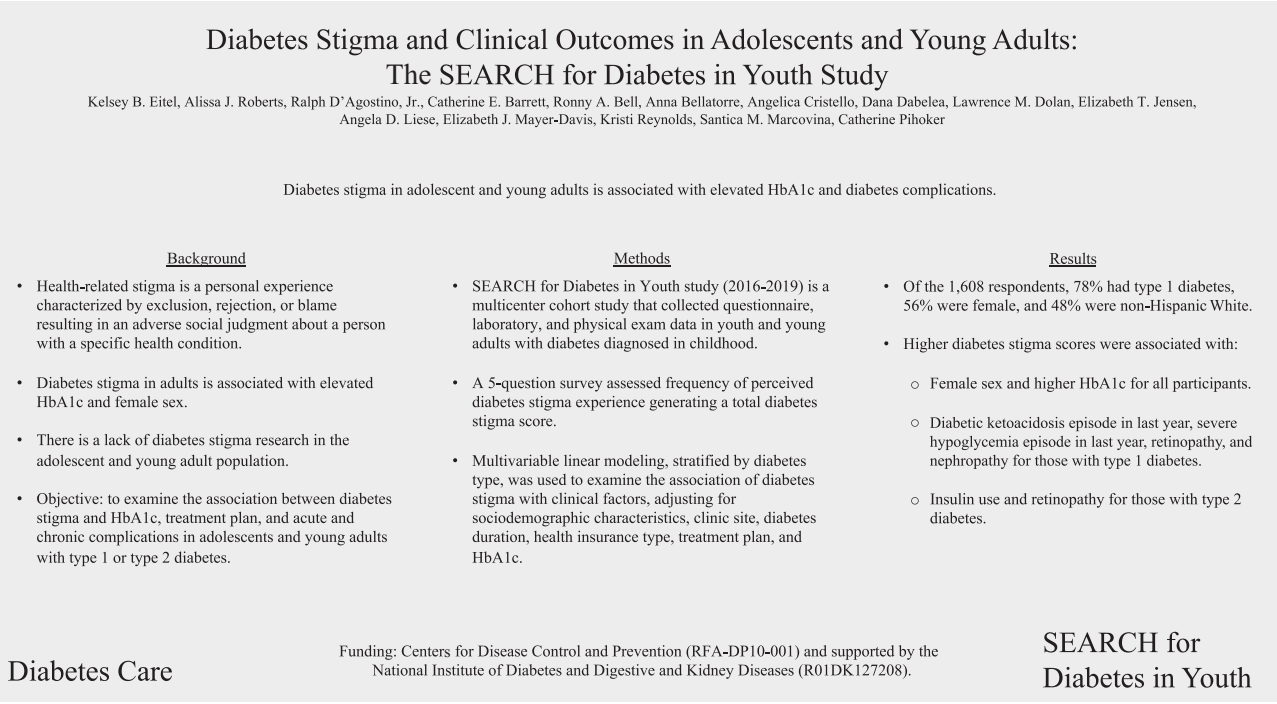

ARTICLE HIGHLIGHTS

- Diabetes stigma in adolescents and young adults with type 1 or type 2 diabetes is associated with female sex, elevated HbA_{1c}, and some chronic complications.
- In participants with type 1 diabetes, a higher diabetes-related stigma score is associated with having had diabetic ketoacidosis and a severe hypoglycemia episode in the past year.
- Participants with type 2 diabetes have higher diabetes-related stigma scores associated with insulin use.
- Diabetes stigma is important to address in comprehensive diabetes care, especially in the adolescent and emerging adult period, as this is a key time for developing personal identity and autonomy.

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ORIGINAL ARTICLE

OBJECTIVE

To examine the association between diabetes stigma and HbA_{1c}, treatment plan and acute and chronic complications in adolescents and young adults (AYAs) with type 1 or type 2 diabetes.

RESEARCH DESIGN AND METHODS

The SEARCH for Diabetes in Youth study is a multicenter cohort study that collected questionnaire, laboratory, and physical examination data about AYAs with diabetes diagnosed in childhood. A five-question survey assessed frequency of perceived diabetes-related stigma, generating a total diabetes stigma score. We used multivariable linear modeling, stratified by diabetes type, to examine the association of diabetes stigma with clinical factors, adjusting for sociodemographic characteristics, clinic site, diabetes duration, health insurance, treatment plan, and HbA_{1c}.

RESULTS

Of 1,608 respondents, 78% had type 1 diabetes, 56% were female, and 48% were non-Hispanic White. The mean (SD) age at study visit was 21.7 (5.1) years (range, 10–24.9). The mean (SD) HbA_{1c} was 9.2% (2.3%; 77 mmol/mol [2.0 mmol/mol]). Higher diabetes stigma scores were associated with female sex and higher HbA_{1c} ($P < 0.01$) for all participants. No significant association between diabetes stigma score and technology use was observed. In participants with type 2 diabetes, higher diabetes stigma scores were associated with insulin use ($P = 0.04$). Independent of HbA_{1c}, higher diabetes stigma scores were associated with some acute complications for AYAs with type 1 diabetes and some chronic complications for AYAs with type 1 or type 2 diabetes.

CONCLUSIONS

Diabetes stigma in AYAs is associated with worse diabetes outcomes and is important to address when providing comprehensive diabetes care.

Health-related stigma is defined as a personal experience characterized by exclusion, rejection, or blame resulting in an adverse social judgment about a person with a specific health condition (1). Stigma has been well documented with HIV/AIDS, epilepsy, and mental illness (2–4). Community stigma leads to internalized stigma, resulting in adverse clinical and psychosocial outcomes (4). To our knowledge, the largest quantitative study

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of diabetes stigma used unvalidated questions to survey 5,422 people, of whom 96% were adults, and found that 76% of people with type 1 diabetes and 52% of people with type 2 diabetes perceived diabetes-related stigma (5).

There is a limited body of research examining the association between diabetes stigma, sociodemographic variables, and clinical outcomes. In a survey of 1,594 adults with type 1 diabetes, higher diabetes-related stigma scores were associated with female sex, younger age, and shorter diabetes duration (6). Diabetes stigmatization is associated with elevated HbA_{1c} (5,7,8) and having at least one episode of severe hypoglycemia in the past year (7). In Australia, use of validated Diabetes Stigma Assessment Scales 1 and 2 among adults with type 1 (n = 959) and type 2 (n = 1,129) diabetes demonstrated that diabetes stigma is associated with depressive and anxiety symptoms and diabetes distress, whereas associations with diabetes self-care and HbA_{1c} were interpreted as being statistically significant but not clinically meaningful (9). A qualitative study of adults with type 1 diabetes in Australia found that participants perceived or experienced diabetes-related stigma by association with type 2 diabetes and as blame, negative social judgments, exclusion, rejection, or discrimination (10). These perceptions or experiences led to several consequences of diabetes-related stigma, including emotional distress, impact on identity, further perpetuation of type 2 diabetes-related stigma, and reluctance in disclosing their diagnosis, especially in the workplace and social settings (10).

Adults with type 2 diabetes who report experiencing diabetes-related stigma tend to have a higher BMI, use insulin, and have higher HbA_{1c} (5). A qualitative study among adults with type 2 diabetes showed internalized diabetes-related stigma led to a change in attitude toward social participation and management of their diabetes as recommended (11), which may include delaying or skipping insulin injections. Another study of adults with type 2 diabetes found that those who perceived or experienced diabetes-related stigma were unwilling to disclose their diagnosis and believed that people with type 1 diabetes did not experience diabetes-related stigma (12).

The adolescent and young adult (AYA) population may be especially vulnerable to stigma because of the emphasis on personal identity, peer relationships, and establishing autonomy from parents at this developmental stage (13). Additionally, AYAs with diabetes tend to have increased HbA_{1c} levels during the adolescent period (14) and time of transition from pediatric to adult care for their diabetes (15–17), making this an important time to provide psychosocial support. One study has examined diabetes-related stigma in AYAs with type 1 diabetes (n = 380) and found a diabetes-related stigma prevalence of 65.5% (7). Additionally, AYAs who endorsed experiencing diabetes-related stigma had double the odds of having HbA_{1c} >9% (75 mmol/mol) or having at least one episode of severe hypoglycemia in the past year (7).

The aim of this study was to determine the frequency of diabetes stigma in AYA participants in the SEARCH for Diabetes in Youth (SEARCH) study with type 1 or type 2 diabetes and assess the association of diabetes stigma with clinical characteristics and outcomes, such as diabetes type, diabetes treatment plan, continuous glucometer (CGM) use, HbA_{1c} levels, acute complications, and long-term complications. To our knowledge, this research will be the first large, quantitative study of diabetes stigma in AYAs to include and stratify by both type 1 and type 2 diabetes. It will also address the current gaps in the literature, including the associations of diabetic ketoacidosis (DKA), long-term complications, insulin pump use, and CGM use with diabetes-related stigma in AYAs.

RESEARCH DESIGN AND METHODS

Study Overview and Procedures

SEARCH is a multicenter study following the clinical course of type 1 and type 2 diabetes among youth in the U.S. SEARCH recruited participants from a membership-based health plan site in southern California, several other geographic sites (Washington, Colorado, Ohio, South Carolina, and selected American Indian reservations in Arizona and New Mexico under the direction of Colorado). At study visits, participants completed informed consent and assent when applicable, provided blood and urine samples for laboratory assessments, had a physical examination, and completed questionnaires. Individuals in selected incident years (2002–2006, 2008, and 2012) were invited for follow-up visits. These visits included additional questionnaires, blood samples, and a physical examination. A local institutional review board for each of the study sites approved this study protocol.

Study Population and Eligibility

This study included SEARCH participants who were diagnosed in youth with type 1 diabetes or type 2 diabetes, completed an in-person SEARCH 4 cohort follow-up visit, were 10 to 24.9 years of age at the cohort visit, and completed a survey regarding diabetes-related stigma. The SEARCH 4 cohort study visits were conducted from 2016 to 2019 and were the fourth funding phase of the study.

Variables

Demographic characteristics collected at the cohort visit included age, sex as recorded in the medical record, age at diabetes diagnosis, current health insurance, and self-reported race and ethnicity, in order to consider racial and ethnic social constructs and the impacts on diabetes care and outcomes. Participants self-identified their race and ethnicity as one or more of the following categories: American Indian, Alaska Native, Asian, Hispanic, Multiracial, Non-Hispanic Black, Non-Hispanic White, or Pacific Islander. The SEARCH surveys did not collect self-reported gender. For participants aged ≥18 years, information on the highest education level attained and employment status was collected. For participants aged <18 years, information on the highest parental education level of the two parents and employment status was collected. Clinical characteristics included diabetes type determined by physician report, diabetes treatment plan, CGM use, BMI, HbA_{1c} levels, self-reported DKA episode in the past 12 months, self-reported hospitalization in the past 12 months, self-reported severe hypoglycemia episode in the past 12 months, diabetic retinopathy, nephropathy, and dyslipidemia. The in-person visit included a physical examination and the collection of blood and urine samples for assessments of diabetic retinopathy, nephropathy, hypertension, and dyslipidemia. The presence of diabetic retinopathy was determined by grading digital fundus images collected during the in-person visit, as previously described (18). Nephropathy was defined as an albumin to creatinine ratio ≥30 μg/mg or estimated glomerular filtration rate <60 mL/min/1.73 m^2. Dyslipidemia was defined as LDL cholesterol

level >100 mg/dL or triglyceride level >150 mg/dL.

Treatment plans for participants with type 1 diabetes were categorized as insulin pump, multiple daily injections defined as long-acting insulin plus short- or rapid-acting insulin at least twice daily, and other injections defined as only short-acting insulin or only long-acting insulin. Treatment plans for participants with type 2 diabetes were categorized as oral medications, oral medications plus any insulin, insulin only, and no medications. BMI was categorized as <25 kg/m^2 (or <85th percentile), 25–30 kg/m^2 (or 85th to <95th percentile), and ≥30 kg/m^2 (or ≥95th percentile), using percentile for participants aged <18 years and absolute BMI for those aged ≥18 years. The SEARCH 4 cohort completed five questions assessing diabetes-related stigma, as further detailed in the next section.

Key Independent Variable

The SEARCH 4 diabetes-related stigma survey was developed in 2014 on the basis of expert opinion and existing literature at the time, including the second Diabetes Attitudes, Wishes, and Needs (DAWN2) study that assessed psychosocial outcomes in people with diabetes across 17 countries (19) and the Browne et al. (10) qualitative study previously described. At that time, there were no widely used validated surveys for assessing diabetes-related stigma in AYAs. The Barriers to Diabetes Adherence Measure for adolescents was validated in 2011 and had a stigma component to the survey, which focused on social engagement and blame (20).

The first three questions of the SEARCH 4 diabetes-related stigma survey assess perception or experience of diabetes stigma and the last two questions ask about consequences of diabetes stigma (Table 1). Participant answers were scored on a 6-point Likert scale: never (1 point), less than once a year (2 points), a few times a year (3 points), a few times a month (4 points), at least once a week (5 points), and almost daily (6 points). The total diabetes-related stigma score was determined for each participant by adding up their responses for a total score ranging from 5 to 30 points, with the higher number indicating greater perception or experience of diabetes-related stigma.

A principal components analysis showed an Eigenvalue score of 2.77 for the total diabetes stigma score. The Eigen vectors for each stigma question ranged from 0.40 to 0.47, indicating they all contributed to the total diabetes stigma score relatively equally. In addition, the Cronbach α values for each stigma question ranged between 0.72 and 0.77, which indicates that the variables do work well with the score and there is good internal consistency.

Statistical Analyses

Descriptive statistics were calculated for all variables of interest. For categorical measures, we examined counts and percentages; for continuous measures, we examined means and SDs. Each measure was examined in the full participants' data set and then stratified by diabetes type (type 1 vs. type 2). Next, we examined a series of general linear models to determine which variables were associated with diabetes-related stigma score. We performed these analyses stratified by diabetes type. In each model, we examined the β coefficients from the fitted models and corresponding *P* values to determine the strength of the association between the measures and diabetes-related stigma scores.

Seven different models were fit that examined different sets of variables and their association with diabetes-related stigma score. The base model included HbA_{1c} level (measured continuously), treatment plan, race/ethnicity, age, sex, clinic site, duration of diabetes, education level of participant or parent, and health insurance. In model 2, we took the base model and added employment status of participant or parent. In model 3, we took the base model and added household income. In model 4, we refit model 1, replacing HbA_{1c} measured on a continuous scale with HbA_{1c} defined as a three-level ordinal variable: <7% (53 mmol/mol), 7–9% (53–75 mmol/mol), and >9% (75 mmol/mol). In model 5, we added CGM use to the base model. In model 6, we took the base model and then examined a set of acute outcomes (namely, DKA episode in the past year, severe hypoglycemia episode in the past year, and hospitalization in the past year). In model 7, we removed the acute outcomes and examined a set of diabetes complications and comorbidities (namely, retinopathy, nephropathy, and dyslipidemia). All analyses were performed using SAS (version 9).

Data and Resource Availability

The data that support the findings of this study are available from the SEARCH study, but restrictions apply to the availability of these data, which were used

Table 1—SEARCH 4 diabetes-related stigma survey

Question	Experiences or perceptions of stigma	Consequences of stigma
1. How often do people assume things about you because of your diabetes?	Blame and judgement	
2. How often do you feel that you are treated unfairly or differently from others because of your diabetes?	Treated differently	
3. How often do you think negative thoughts about yourself because of your diabetes?	Self-stigma	
4. How often do you change your diabetes management because people assume things about you, because you are treated differently, or because you have negative thoughts about yourself due to your diabetes?		Diabetes management
5. How often do you do things differently, like change how frequently you go out with friends or travel because people assume things about you, because you are treated differently, or because you have negative thoughts about yourself due to your diabetes?		Social engagement

under license for the present study and, therefore, are not publicly available. Data are available, however, from the authors upon reasonable request and with permission of the SEARCH study.

RESULTS

Of the 1,608 participants included, 78% had type 1 diabetes, 56% were female, and 48.5% were non-Hispanic White (Table 2). For all participants, the mean (SD) age at diagnosis was 10.7 (4.49) years and the mean (SD) age at the SEARCH 4 cohort visit was 21.7 (5.11) years. Participants with type 2 diabetes tended to be older at diagnosis (14.3 [SD 2.66] years) and at time of cohort visit (24.6 [SD 4.31] years) compared with those with type 1 diabetes (9.7 [SD 4.37] years at diagnosis and 20.8 [SD 5.01] years at cohort visit). Of all participants, 14.9% had an HbA_{1c} value at the American Diabetes Association–recommended level of <7% (53 mmol/mol). The average (SD) HbA_{1c} was 9.2% (2.3%; 77 mmol/mol [2 mmol/mol]). The average (SD) diabetes-related stigma score was 10.9 (5.4) for participants with type 1 diabetes and 9.8 (5.6) for participants with type 2 diabetes.

Table 2—Characteristics of included SEARCH 4 participants

	Type 1 diabetes	Type 2 diabetes	Total sample
n (%)	1,255 (78.0)	353 (22)	1,608 (100)
Sex			
Female	668 (53.2)	235 (66.6)	903 (56.2)
Male	587 (46.8)	118 (33.4)	705 (43.8)
Age at cohort visit (years), mean (SD)	20.8 (5.01)	24.6 (4.31)	21.7 (5.11)
Diabetes duration (years), mean (SD)	11.1 (3.36)	10.3 (3.54)	10.9 (3.42)
Race/ethnic group			
American Indian or Alaska Native	9 (0.7)	29 (8.2)	38 (2.4)
Asian or Pacific Islander	20 (1.6)	6 (1.7)	26 (1.6)
Hispanic	268 (21.4)	86 (24.4)	354 (22)
Multiracial	67 (5.3)	11 (3.1)	78 (4.9)
Non-Hispanic Black	179 (14.3)	154 (43.6)	333 (20.7)
Non-Hispanic White	712 (56.7)	67 (19.0)	779 (48.5)
Highest education			
≥High school	802 (63.9)	293 (83.0)	1,095 (68.1)
<High school	444 (35.4)	59 (16.7)	503 (31.3)
Aged ≤18 years	9 (0.1)	1 (0.3)	10 (0.6)
Employment status			
Employed	615 (49.0)	188 (53.2)	803 (49.9)
Unemployed	136 (10.8)	72 (20.4)	208 (12.9)
Student	71 (5.6)	13 (3.7)	84 (5.2)
Disabled	19 (1.5)	38 (10.8)	57 (3.5)
Other/do not know	30 (2.4)	19 (5.4)	49 (3.0)
Aged ≤18 years	384 (30.0)	23 (6.5)	407 (25.3)
Insurance types			
Private	909 (72.4)	156 (44.2)	1,065 (66.2)
Public	208 (16.6)	105 (29.7)	313 (19.5)
None/unknown	138 (11.0)	92 (26.1)	230 (14.3)
BMI (kg/m^2)			
<25	640 (51.0)	24 (6.8)	664 (41.3)
25–29.9	376 (30.0)	65 (18.4)	441 (27.4)
≥30	238 (19.0)	264 (74.8)	502 (31.2)
HbA_{1c}			
<7% (53 mmol/mol)	147 (11.7)	92 (26.1)	239 (14.9)
7–9% (53–75 mmol/mol)	576 (45.9)	61 (17.3)	637 (39.6)
>9% (75 mmol/mol)	532 (42.4)	200 (56.7)	732 (45.5)
Total diabetes stigma score by question*,†, mean (SD)	10.9 (5.4)	9.8 (5.6)	10.7 (5.5)
1: Blame and judgement	3.2 (1.7)	2.7 (1.8)	3.1 (1.7)
2: Treated differently	1.8 (1.3)	1.6 (1.3)	1.8 (1.3)
3: Self-stigma	2.5 (1.7)	2.3 (1.8)	2.4 (1.7)
4: Diabetes management	1.7 (1.3)	1.6 (1.3)	1.7 (1.3)
5: Social engagement	1.6 (1.2)	1.6 (1.3)	1.6 (1.2)

Data are given as *n* (%) unless otherwise indicated. *See Table 1 for list of questions. †Questions were score on a 6-point Likert scale: never (1 point), less than once a year (2 points), a few times a year (3 points), a few times a month (4 points), at least once a week (5 points), almost daily (6 points).

Type 1 Diabetes Outcomes

Table 3 shows the multivariable linear modeling outcomes for participants with type 1 diabetes. For those participants, higher diabetes-related stigma scores were associated with higher HbA_{1c} ($P < 0.001$). Female sex was associated with a 1.96-point higher diabetes-related stigma score compared with male sex ($P < 0.001$). The only significant difference for race/ethnicity was that those who identified as multiracial had a 1.53-point lower diabetes-related stigma score than those who identified as non-Hispanic White ($P = 0.0274$). No statistically significant association was found between diabetes-related stigma scores and education, employment status, health insurance, or use of an insulin pump or CGM. Household income less than $25,000 was associated with a 1.16-point higher diabetes-related stigma score compared with a household income of $75,000 or greater ($P = 0.03$).

When adjusted for HbA_{1c}, the presence of a DKA episode ($P = 0.0003$) and a severe hypoglycemia episode in the past year ($P = 0.002$) were both associated with higher diabetes-related stigma scores. Independent of HbA_{1c}, the presence of retinopathy ($P = 0.0002$) and nephropathy ($P = 0.04$), but not dyslipidemia, were associated with higher diabetes-related stigma scores (β coefficient, 1.94 and 1.16, respectively).

Type 2 Diabetes Outcomes

Participants with type 2 diabetes had a similar pattern of higher diabetes-related stigma scores being associated with female sex ($P = 0.002$) and higher HbA_{1c} ($P = 0.009$), as shown in Table 4. There was no significant association between diabetes-related stigma scores and race/ethnicity, education, employment status, household income, health insurance, or CGM use. Use of insulin only was associated with a 1.79-point increase in

Table 3—Multivariable linear models of continuous total diabetes stigma score, sociodemographics, HbA_{1c}, treatment plan, and acute and chronic complications for type 1 diabetes

Models* and variables	Total diabetes stigma score, β (SE)	*P* value
Sociodemographics, HbA_{1c}, and treatment plan		
Female sex	1.96 (0.30)	<0.0001
Racial/ethnic group		
American Indian or Alaska Native	−0.48 (1.76)	0.7836
Asian or Pacific Islander	0.71 (1.20)	0.5520
Hispanic	−0.23 (0.43)	0.5896
Multiracial	−1.53 (0.69)	0.0274
Non-Hispanic Black	0.40 (0.49)	0.4127
Non-Hispanic White	Ref	
Highest education < high school	0.34 (0.45)	0.4503
Insurance type		
Public	Ref	
Private	−0.18 (0.43)	0.6608
None or unknown	0.21 (0.60)	0.7150
Continuous HbA_{1c} (%)	0.46 (0.08)	<0.0001
Treatment plan		
MDI	Ref	
Other injections	−1.07 (0.79)	0.1741
Pump	−0.23 (0.33)	0.4897
Employment status		
Employed	Ref	
Unemployed	0.02 (0.51)	0.9644
Student	−0.07 (0.67)	0.9095
Disabled	1.54 (1.29)	0.2332
Other/do not know	−0.74 (1.02)	0.4673
Household income (USD)		
<25,000	1.16 (0.53)	0.0310
25,000–49,000	0.71 (0.48)	0.1428
50,000–74,000	0.12 (0.51)	0.8035
≥75,000	Ref	
Missing data	0.52 (0.43)	0.2333
Categorical HbA_{1c}		
<7% (53 mmol/mol)	−2.05 (0.52)	0.0001
7–9% (53–75 mmol/mol)	−1.41 (0.33)	<0.0001
>9% (75 mmol/mol)	Ref	
CGM use	−0.50 (0.32)	0.1235
Acute complication (in the past year)		
DKA episode	1.61 (0.44)	0.0003
Severe hypoglycemia episode	1.60 (0.52)	0.0022
Hospitalization	−0.39 (0.50)	0.4343
Chronic complication		
Retinopathy	1.94 (0.52)	0.0002
Nephropathy	1.16 (0.57)	0.0416
Dyslipidemia	0.41 (0.32)	0.2088

MDI, multiple daily injections; Ref, reference. *Model 1 (baseline model; sociodemographic, HbA_{1c}, and treatment plan) adjusted for age, clinic site, duration of diabetes. Model 2 (employment status), model 3 (household income), model 5 (CGM use), model 6 (acute complications), and model 7 (chronic complications) adjusted for race/ethnicity, sex, treatment plan, continuous HbA_{1c}, age, clinic site, duration of diabetes, education level, and insurance. Model 4 (categorical HbA_{1c}) adjusted for race/ethnicity, sex, treatment plan, age, clinic site, duration of diabetes, education level, and insurance.

diabetes-related stigma score (*P* = 0.04), and using insulin plus oral diabetes medication was associated with a 2.03-point increase (*P* = 0.02) compared with no medications. There was no statistically significant association between diabetes-related stigma scores and DKA episode, severe hypoglycemia episode, or hospitalization in the past year. Retinopathy was associated with a 1.98-point increase in diabetes-related stigma score (*P* = 0.02), but nephropathy and dyslipidemia were not associated with a difference in diabetes-related stigma score.

CONCLUSIONS

We have shown that diabetes-related stigma in AYAs with type 1 or type 2 diabetes is associated with female sex and elevated HbA_{1c}, but not with education, employment status, health insurance, or use of an insulin pump or CGM. There was no consistent pattern seen between race and ethnicity and diabetes-related stigma. We found that in participants with type 1 diabetes, there was an association between diabetes-related stigma and DKA episode in the past year, severe hypoglycemia episode in the past year, retinopathy, and nephropathy, all independent of HbA_{1c} level. In participants with type 2 diabetes, diabetes-related stigma was associated with insulin use and independent of HbA_{1c}, with retinopathy.

The adolescent and emerging adulthood period is marked by an emphasis on peer relationships, personal identity, and establishing autonomy (13), which may make AYAs with diabetes particularly vulnerable to stigma. Elevated HbA_{1c} levels have been well documented during the adolescent period (14,15) and during transition from pediatric to adult care (16–18). We have shown that diabetes stigma in AYAs is associated with elevated HbA_{1c} levels for type 1 and type 2 diabetes, which is consistent with reports in earlier literature (5,7,8). Qualitative research has demonstrated that community health–related stigma can lead to internalized self-stigma (2–4). This diabetes-related self-stigma is associated with decreased self-care behaviors (11,21), which contribute to elevated HbA_{1c} levels, in turn increasing risk for DKA (22), retinopathy, nephropathy, neuropathy, and cardiovascular disease (23,24). Similar to previously reported studies, we have demonstrated that diabetes stigma is associated with female sex (5–7). Female sex is also associated with a higher burden of other psychosocial comorbidities, including depression (25), diabetes distress (26), and disordered eating behaviors (27).

Independent of HbA_{1c}, we have shown that higher diabetes-related stigma scores are associated with acute complications

Table 4—Multivariable linear models of continuous total diabetes stigma score, sociodemographics, HbA_{1c}, treatment plan, and acute and chronic complications for type 2 diabetes

Models* and variables	Total diabetes stigma score, β (SE)	*P* value
Sociodemographics, HbA_{1c}, and treatment plan		
Female sex	2.00 (0.66)	0.0026
Racial/ethnic group		
American Indian or Alaska Native	0.46 (1.49)	0.7579
Asian or Pacific Islander	−0.21 (2.44)	0.9316
Hispanic	−1.02 (1.05)	0.3344
Multiracial	0.46 (1.81)	0.7986
Non-Hispanic Black	−0.38 (0.85)	0.6548
Non-Hispanic White	Ref	
Highest education < high school	0.88 (0.84)	0.2972
Insurance type		
Public	Ref	
Private	1.26 (0.73)	0.0862
None or unknown	−0.42 (0.84)	0.6187
Continuous HbA_{1c}	0.30 (0.11)	0.0091
Treatment plan		
No medications	Ref	
Oral medication	1.57 (0.94)	0.0974
Insulin and oral medication	2.03 (0.89)	0.0234
Insulin only	1.79 (0.87)	0.0411
Employment status		
Employed	Ref	
Unemployed	−0.46 (0.79)	0.5576
Student	1.39 (1.65)	0.3998
Disabled	0.53 (1.13)	0.6408
Other/do not know	−0.12 (1.35)	0.9282
Household income (USD)		
<25,000	0.83 (1.38)	0.5474
25,000–49,000	0.51 (1.37)	0.7093
50,000–74,000	2.89 (1.81)	0.1103
≥75,000	Ref	
Missing data	0.12 (1.34)	0.9250
Categorical HbA_{1c}		
<7% (53 mmol/mol)	−2.18 (0.81)	0.0076
7–9% (53–75 mmol/mol)	−0.84 (0.83)	0.3133
>9% (75 mmol/mol)	Ref	
CGM use	−0.22 (0.79)	0.7774
Acute complication (in the past year)		
DKA episode	0.60 (1.16)	0.6031
Severe hypoglycemia episode	1.73 (1.51)	0.2512
Hospitalization	−0.08 (0.84)	0.9186
Chronic complication		
Retinopathy	1.98 (0.88)	0.0258
Nephropathy	−0.48 (0.81)	0.5461
Dyslipidemia	−0.88 (0.78)	0.2654

Ref, reference. *Model 1 (baseline model; sociodemographic, HbA_{1c}, and treatment plan) adjusted for age, clinic site, duration of diabetes. Model 2 (employment status), model 3 (household income), model 5 (CGM use), model 6 (acute complications), and model 7 (chronic complications) adjusted for race/ethnicity, sex, treatment plan, continuous HbA_{1c}, age, clinic site, duration of diabetes, education level, and insurance. Model 4 (categorical HbA_{1c}) adjusted for race/ethnicity, sex, treatment plan, age, clinic site, duration of diabetes, education level, and insurance.

such as DKA episodes and severe hypoglycemia in AYAs with type 1 diabetes. Similarly, Brazeau et al. (7) found that diabetes-related stigma in AYAs was associated with increased rate of severe hypoglycemia over 1 year (odds ratio 1.86; 95% CI 1.05–3.31), although DKA episodes were not examined. To our knowledge, our study is the first to examine the association of diabetes-related stigma and DKA in AYAs. We did not find an association with diabetes-related stigma and DKA or severe hypoglycemia in participants with type 2 diabetes, likely in part due to having fewer participants and because DKA and hypoglycemia occur less frequently with type 2 diabetes than type 1 diabetes. Additionally, only 56% of participants with type 2 diabetes were using insulin, which increases the risk for hypoglycemia (28).

Long-term complications associated with higher diabetes-related stigma scores included retinopathy and nephropathy for type 1 diabetes and retinopathy for type 2 diabetes when controlling for HbA_{1c}. Hansen et al. (6) found diabetes-related stigma experienced by adults with type 1 diabetes was associated with having at least one diabetes complication. Our study, to our knowledge, is the first to examine long-term complications and their association with diabetes-related stigma in AYAs. The SEARCH study previously has shown that diabetes-related complications and comorbidities (namely, retinopathy, nephropathy, neuropathy, arterial stiffness, and cardiovascular autonomic neuropathy) are prevalent in the AYA population with type 1 diabetes, with 23.2% having one complication and 4.7% having two complications (29). Medical and behavioral interventions, including addressing diabetes-related stigma in the pediatric and adolescent period, may prevent or delay diabetes-related complications. Additionally, a public health initiative on decreasing community diabetes-related stigma through public education may be considered to increase awareness of the cause of diabetes and what it looks like to live with diabetes. Interventions for reducing mental health stigma include presentation of facts, which can be effective at changing attitudes, and social contact or first-person narratives, which have been shown to reduce stigma (30).

In AYAs with type 2 diabetes, we have shown that insulin use is associated with increased experience of diabetes-related stigma, which is consistent with findings in previously reported literature (5). Interestingly, in our study, technology use such as an insulin pump and CGM was not associated with diabetes-related stigma score. To our knowledge, there have been no quantitative studies examining diabetes-related stigma experience related to

insulin pumps and CGMs. There have been qualitative studies assessing patients' perceptions of insulin pumps, with demonstration that women were more concerned about body image related to and social acceptance of the insulin pump (31).

Most prior studies examining diabetes stigma focused on adults (5,6,8–12). To our knowledge, there is only one previous study of diabetes stigma specifically in the AYA population (n = 380), and people with type 2 diabetes were excluded (7). Our study is unique in its large sample size of AYAs and distribution of participants across the U.S. Additionally, the diabetes-related stigma score was stratified by type 1 diabetes and type 2 diabetes. This is important because it has been well documented in the literature that the ways in which diabetes-related stigma is experienced may vary based on type of diabetes (5,10,12).

Our study is limited in that it is a cross-sectional analysis and had fewer AYAs with type 2 diabetes than with type 1 diabetes. Our five-question diabetes-related stigma survey is not validated. Next steps could include conducting a larger prospective study using a validated diabetes-related stigma questionnaire and collecting and analyzing psychosocial variables, such as socioeconomic status, depression, diabetes distress, disordered eating behaviors, and quality of life. Future studies can also include longitudinal assessment of diabetes-related stigma to further elucidate the causal and temporal relationship between diabetes stigma and clinical outcomes.

Conclusion

Diabetes-related stigma in AYAs is associated with female sex, elevated HbA_{1c}, and retinopathy, in addition to DKA and severe hypoglycemia in those with type 1 diabetes and insulin use in those with type 2 diabetes. It is critical to address diabetes stigma in comprehensive diabetes care, especially in the AYA period, as this is a key time for developing personal identity and autonomy in addition to transitioning to adult diabetes care.

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References

1. Weiss MG, Ramakrishna J. Stigma interventions and research for international health. Lancet 2006; 367:536–538
2. Turan B, Budhwani H, Fazeli PL, et al. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. AIDS Behav 2017;21:283–291
3. Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurol 2005;4:171–178
4. Yanos PT, DeLuca JS, Roe D, Lysaker PH. The impact of illness identity on recovery from severe mental illness: a review of the evidence. Psychiatry Res 2020;288:112950
5. Liu NF, Brown AS, Folias AE, et al. Stigma in people with type 1 or type 2 diabetes [published correction appears in Clin Diabetes 2017;35:262]. Clin Diabetes 2017;35:27–34
6. Hansen UM, Olesen K, Willaing I. Diabetes stigma and its association with diabetes outcomes: a cross-sectional study of adults with type 1 diabetes. Scand J Public Health 2020;48:855–861. Epub 2020 Apr 27.
7. Brazeau AS, Nakhla M, Wright M, et al. Stigma and its association with glycemic control and hypoglycemia in adolescents and young adults with type 1 diabetes: cross-sectional study. J Med Internet Res 2018;20:e151
8. Capistrant BD, Friedemann-Sánchez G, Pendsey S. Diabetes stigma, parent depressive symptoms and type-1 diabetes glycemic control in India. Soc Work Health Care 2019;58:919–935
9. Holmes-Truscott E, Ventura AD, Thuraisingam S, Pouwer F, Speight J. Psychosocial moderators of the impact of diabetes stigma: results from the Second Diabetes MILES - Australia (MILES-2) Study. Diabetes Care 2020;43:2651–2659
10. Browne JL, Ventura A, Mosely K, Speight J. 'I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes. BMJ Open 2014;4:e005625
11. Kato A, Fujimaki Y, Fujimori S, et al. A qualitative study on the impact of internalized stigma on type 2 diabetes self-management. Patient Educ Couns 2016;99:1233–1239
12. Browne JL, Ventura A, Mosely K, Speight J. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. BMJ Open 2013;3:e003384
13. Andrews JL, Ahmed SP, Blakemore SJ. Navigating the social environment in adolescence: the role of social brain development. Biol Psychiatry 2021;89:109–118
14. Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB. Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. Diabetes Care 2001;24:1536–1540
15. Malik FS, Sauder KA, Isom S, et al.; SEARCH for Diabetes in Youth Study. Trends in glycemic control among youth and young adults with diabetes: the SEARCH for Diabetes in Youth Study. Diabetes Care 2022;45:285–294
16. Lotstein DS, Seid M, Klingensmith G, et al.; SEARCH for Diabetes in Youth Study Group. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. Pediatrics 2013;131:e1062–e1070
17. Kapellen TM, Müther S, Schwandt A, et al.; DPV initiative and the Competence Network Diabetes Mellitus funded by the German Federal Ministry of Education and Research. Transition to adult diabetes care in Germany-High risk for acute complications and declining metabolic control during the transition phase. Pediatr Diabetes 2018;19:1094–1099
18. Mayer-Davis EJ, Davis C, Saadine J, et al.; SEARCH for Diabetes in Youth Study Group. Diabetic retinopathy in the SEARCH for Diabetes in Youth Cohort: a pilot study. Diabet Med 2012; 29:1148–1152
19. Nicolucci A, Kovacs Burns K, Holt RI, et al.; DAWN2 Study Group. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. Diabet Med 2013;30:767–777
20. Mulvaney SA, Hood KK, Schlundt DG, et al. Development and initial validation of the barriers to diabetes adherence measure for adolescents. Diabetes Res Clin Pract 2011;94:77–83

21 Kato A, Fujimaki Y, Fujimori S, et al. Association between self-stigma and self-care behaviors in patients with type 2 diabetes: a cross-sectional study. BMJ Open Diabetes Res Care 2016;4: e000156
22. Cengiz E, Xing D, Wong JC, et al.; T1D Exchange Clinic Network. Severe hypoglycemia and diabetic ketoacidosis among youth with type 1 diabetes in the T1D Exchange clinic registry. Pediatr Diabetes 2013;14:447–454
23. Nathan DM, Genuth S, Lachin J, et al.; Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. N Engl J Med 1993;329: 977–986
24. Diabetes Control and Complications Trial (DCCT)/Epidemiology of Diabetes Interventions and Complications (EDIC) Study Research Group. Intensive diabetes treatment and cardiovascular outcomes in type 1 diabetes: the DCCT/EDIC Study 30-year follow-up. Diabetes Care 2016;39: 686–693
25. Hood KK, Huestis S, Maher A, Butler D, Volkening L, Laffel LM. Depressive symptoms in children and adolescents with type 1 diabetes: association with diabetes-specific characteristics. Diabetes Care 2006;29:1389–1391
26. Iturralde E, Rausch JR, Weissberg-Benchell J, Hood KK. Diabetes-related emotional distress over time. Pediatrics 2019;143:e20183011
27. Nip ASY, Reboussin BA, Dabelea D, et al.; SEARCH for Diabetes in Youth Study Group. Disordered eating behaviors in youth and young adults with type 1 or type 2 diabetes receiving insulin therapy: the SEARCH for Diabetes in Youth Study. Diabetes Care 2019;42:859–866
28. Akram K, Pedersen-Bjergaard U, Borch-Johnsen K, Thorsteinsson B. Frequency and risk factors of severe hypoglycemia in insulin-treated type 2 diabetes: a literature survey. J Diabetes Complications 2006;20:402–408
29. Sauder KA, Stafford JM, Mayer-Davis EJ, et al.; SEARCH for Diabetes in Youth Study Group. Co-occurrence of early diabetes-related complications in adolescents and young adults with type 1 diabetes: an observational cohort study. Lancet Child Adolesc Health 2019;3:35–43
30. Thornicroft G, Mehta N, Clement S, et al. Evidence for effective interventions to reduce mental-health-related stigma and discrimination. Lancet 2016;387:1123–1132
31. Ritholz MD, Smaldone A, Lee J, Castillo A, Wolpert H, Weinger K. Perceptions of psychosocial factors and the insulin pump. Diabetes Care 2007;30:549–554