Preconception Counseling in Women With Diabetes: The SEARCH for Diabetes in Youth Study

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Preconception counseling is recommended for all women with diabetes starting at puberty to convey the importance of optimal diabetes management for maternal and fetal outcomes. This study included 622 female participants from the SEARCH for Diabetes in Youth study with a mean age of 22.2 years (range 14–35 years). Only 53.7% reported ever receiving preconception counseling, which was significantly lower among women seeing pediatric providers than those seeing adult or all-age providers. Older age and history of prior pregnancy were associated with increased odds of reporting having received preconception counseling. Identification of barriers to delivering preconception counseling to young females with diabetes and strategies to overcome them are needed to reduce the risk for pregnancy complications and adverse offspring health outcomes.

KEY POINTS

- Preconception counseling is recommended for all women with diabetes, given the importance of optimal diabetes management for maternal and fetal outcomes.
- This study found that half of female adolescents and young adults with diabetes reported not receiving preconception counseling, especially those who were younger or with no history of prior pregnancy.

Female adolescents and young adults (AYAs) with diabetes, particularly those with poor glycemic control, are at an increased risk of miscarriage and congenital malformations (1). Much of the risk of congenital malformations (e.g., anencephaly, congenital heart disease, renal abnormalities, and caudal regression) is related to hyperglycemia during the time of organogenesis at 5–8 weeks' gestation, before some women even know they are pregnant, which makes optimal periconception glycemic control important (2).

Studies of mothers with type 1 diabetes have found a dose-dependent relationship of higher periconception and early pregnancy A1C levels with increased risk of poor pregnancy outcomes, including pregnancy loss and major congenital abnormalities (3–5). In pregnant women with type 1 diabetes, a periconception A1C >6.9% was associated with a significantly higher risk of adverse outcomes, including congenital malformations and perinatal mortality (6). Women with type 2 diabetes also have an increased risk of adverse pregnancy outcomes. A U.K. study demonstrated that women with either type 1 or type 2 diabetes were at higher risk for preterm delivery, having a large-for-gestational-age infant, having an infant with congenital anomalies, and stillbirth or neonatal death (7). Elevated A1C and high BMI were identified as modifiable risk factors for perinatal death (7). Given that hyperglycemia is a teratogenic factor for pregnant women with diabetes, the American Diabetes Association (ADA) recommends a periconception A1C <6.5% to minimize these risks (2).

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Planning pregnancy has been shown to significantly decrease adverse pregnancy outcomes (8). A recent meta-analysis demonstrated that, among women with type 1 or type 2 diabetes, preconception care, and specifically pre-pregnancy care aimed at health promotion, glycemic control, screening, and diabetes treatment, improved perinatal outcomes and decreased the risk of congenital malformations (9). The ADA recommends that preconception counseling be incorporated into routine diabetes care "starting at puberty and continuing in all women with diabetes and reproductive potential" (2).

Preconception counseling and care for female AYAs with diabetes is complicated, as late adolescence also corresponds with a time during which patients may be moving toward transitioning care from pediatric to adult care providers. This period of transition is known to be associated with worse glycemic control and acute diabetes complications for AYAs with type 1 or type 2 diabetes (10,11). It is unclear how the provision of preconception counseling is affected by this transition of care or whether diabetes care provided by a pediatric provider, adult care provider, or provider who sees patients of all ages may affect the proportion of AYAs receiving preconception counseling. Thus, the aim of this study was to examine the characteristics of female AYAs in the SEARCH for Diabetes in Youth study (SEARCH) who reported receiving preconception counseling according to age-group, provider type, and diabetes type, as well as other clinical and demographic factors. Given that women with poor glycemic control are at particularly high risk for poor outcomes with an unintended pregnancy, a secondary aim was to examine the association of self-reported receipt of preconception counseling with A1C values obtained during the study period.

Research Design and Methods

Study Overview and Procedures

SEARCH is a multicenter study aimed at understanding the burden and clinical course of diabetes among youth in the United States. It recruited youth in five geographical and health system sites in the United States, including California, Washington, Colorado, Ohio, and South Carolina. In 2002, SEARCH began conducting population-based surveillance of youth-onset (<20 years of age at diagnosis), nongestational diabetes (12). Participants and/or the parents of minor participants completed informed consent and assent (when applicable), had blood and urine samples obtained, completed a physical exam, and completed questionnaires. Questionnaires included demographic and clinical questions pertinent to participants' age-group and length of time in the study. Individuals diagnosed with diabetes in specific years (2002–2006, 2008, and 2012) were invited for follow-up visits (hereafter called cohort visits). These cohort visits included additional questionnaires, collection of blood and urine samples, and a physical exam. Data from the cohort study visit referred to as SEARCH 4 were used for this study, in addition to baseline visit data. Local institutional review boards for each study site approved the protocol.

Study Population and Eligibility

This study included SEARCH participants who were diagnosed with type 1 or type 2 diabetes in 2002–2006, 2008, or 2012; completed an in-person SEARCH 4 cohort visit in the 2016–2019 period (n = 1,673); were female at birth (n = 946); were ≥14 years of age (n = 885); and completed surveys examining whether they had received preconception counseling (n = 872). Only those who had complete data for race/ethnicity, diabetes duration, diabetes provider type, A1C, insurance type, pregnancy history, and whether they were living with a significant other were included (250 were excluded). After applying these criteria, data from 622 participants with type 1 or type 2 diabetes were included in the analysis.

Variables

Demographic Characteristics

Characteristics collected at the baseline visit or during case ascertainment and validation included age at diabetes diagnosis, self-reported race and ethnicity, and sex. Demographic characteristics collected at the subsequent cohort visit included current age, highest parental education level, current health insurance, diabetes provider type, status regarding living with a spouse/significant other, and history of prior pregnancy. Diabetes provider type was obtained via participant self-report to the question, "Which of the following best describes your current diabetes provider?" Answer choices included "pediatric provider who treats mainly children," "he/she treats patients of all ages, including children and adults," "an adult provider who treats mainly adults," or "not sure."

Clinical Characteristics

Clinical characteristics included diabetes type (provider determined), insulin regimen, use of continuous glucose monitoring, calculated BMI, and A1C area under

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the curve (AUC) using all available values from baseline and follow-up visits (median of 3 values). Overweight or obesity status was categorized from raw BMI (for those ≥18 years of age) or age- and sex-adjusted percentiles (for those <18 years of age), specifically <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). Additionally, females' contraceptive use was assessed from current medication lists, which would include reported oral, injectable, and implantable forms of contraceptives. Diabetes type was determined by provider documentation in the medical record 6 months after diagnosis through full medical record abstraction by trained staff.

Outcomes

Recall of preconception counseling was assessed at the cohort visit by the response to the question, "Has your doctor ever talked to you about diabetes and pregnancy and how diabetes can affect you during pregnancy and the developing baby before birth and around the time of birth?" Those who answered "yes" or "no" were included. Those who answered "don't know" (n = 18) were included in the "no" category because they did not recall meaningful preconception counseling.

Statistical Analyses

Participant characteristics were summarized as mean ± SD for continuous variables and count (%) for categorical variables. Associations between participant characteristics and reported receipt of counseling were evaluated using χ^2 or Fisher exact tests for categorical variables and t tests for continuous variables. Associations for variables of interest were further evaluated using unadjusted and adjusted logistic regression models modeling odds of reported receipt of counseling. Results are reported using odds ratios (ORs) with 95% CIs. Directed acyclic graphs were generated to identify a minimally sufficient set of variables for adjustment for determining the association between covariates of interest and preconception counseling. Covariates of interest were age at visit, A1C AUC, provider type, diabetes type, and history of prior pregnancy.

Results

Participant characteristics overall and by receipt of preconception counseling are presented in Table 1. At the cohort visit, participants had a mean age of 22.2 ± 4.5 years, a mean A1C AUC of 8.8 ± 1.7%, and a mean diabetes duration of 11.4 ± 3.3 years. Seventy-nine percent of participants had type 1 diabetes, and the remainder had type 2 diabetes. Half of the participants were receiving care from an adult provider, and 34.1% were receiving care from a pediatric provider (for whom the mean age was 18.1 ± 2.3 years [range 14–26 years]). The remaining women (15.9%) were receiving care from a provider who treats all ages.

Only 53.7% reported ever receiving preconception counseling, which significantly differed by provider type (P <0.001). Receipt of preconception counseling was lower among women seeing pediatric providers (36.3%) and roughly equivalent for those receiving care from adult (63.0%) or all-age providers (61.6%) (P <0.001). Those who received preconception counseling had a higher mean age at diagnosis, older age at cohort visit, higher A1C AUC, and longer diabetes duration. The majority of participants (64.6%) with public health insurance reported receiving preconception counseling compared with half of participants (50.1%) with private insurance (P = 0.013). Additionally, receipt of counseling was more often reported by those who were living with a spouse/significant other (77.6 vs. 52.7% of those not living with a spouse or significant other), had a history of prior pregnancy (91.5 vs. 44.8% among those who had never been pregnant), or were on a multiple daily injection insulin regimen (61.2 vs. 48.4% of those using an insulin pump and 47.2% of those not on insulin).

Multivariable logistic regression modeling demonstrated that those with older age at the cohort visit (adjusted OR 1.20 [95% CI 1.15–1.25]) and history of prior pregnancy (adjusted OR 7.44 [95% CI 3.61–15.32]) were at increased odds of reporting preconception counseling (Table 2).

The association of reported receipt of counseling with A1C AUC, while significant in the unadjusted model, was attenuated in the adjusted model (A1C AUC OR 1.14 [95% CI 1.04–1.25] and adjusted OR 1.11 [95% CI 1.00–1.24]). The associations of reported receipt of counseling with provider type were also attenuated in the adjusted models (adult vs. pediatric diabetes provider type OR 2.99 [95% CI 2.08–4.25] and adjusted OR 1.11 [95% CI 0.67–1.83]; all ages vs. pediatric diabetes provider type OR 2.81 [95% CI 1.72–4.60] and adjusted OR 1.17 [95% CI 0.65–2.12]). This remained the case when grouping adult and all-age provider types vs. pediatric provider type (OR 2.94 [95% CI 2.09–4.15] and adjusted OR 1.13 [95% CI 0.70–1.81]).

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TABLE 1 Characteristics by Self-Reported Receipt of Preconception Counseling in Female SEARCH 4 Participants

Characteristic	*n*	Overall*	Reported Preconception Counseling* (*n* = 334)	Did Not Report Preconception Counseling* (*n* = 288)	*P*†
Age at diagnosis, years	622	10.8 ± 4.1	11.8 ± 3.8	9.6 ± 4.2	<0.0001
Age at cohort visit, years	622	22.2 ± 4.5	23.7 ± 4.4	20.5 ± 3.9	<0.0001
Diabetes duration, years	622	11.4 ± 3.3	11.9 ± 3.1	10.9 ± 3.3	<0.0001
A1C AUC, %	622	8.8 ± 1.7	9.0 ± 1.8	8.6 ± 1.6	0.0057
Diabetes type	622				0.2647
Type 1		491 (78.9)	258 (52.5)	233 (47.5)	
Type 2		131 (21.1)	76 (58.0)	55 (42.0)	
Diabetes provider type	622				<0.0001
Pediatric provider		212 (34.1)	77 (36.3)	135 (63.7)	
Treats all ages		99 (15.9)	61 (61.6)	38 (38.4)	
Adult provider		311 (50.0)	196 (63.0)	115 (37.0)	
Race/ethnicity	622				0.0717
Asian/Pacific Islander		23 (3.7)	7 (30.4)	16 (69.6)	
Hispanic		124 (19.9)	66 (53.2)	58 (46.8)	
Native American		6 (1.0)	5 (83.3)	1 (16.7)	
Non-Hispanic Black		159 (25.6)	92 (57.9)	67 (42.1)	
Non-Hispanic White		308 (49.5)	162 (52.6)	146 (47.4)	
Other		2 (0.3)	2 (100.0)	0 (0.0)	
Education level	614				0.0294
Less than high school		471 (76.7)	241 (51.2)	230 (48.8)	
High school or more		143 (23.3)	88 (61.5)	55 (38.5)	
Insurance type	622				0.0132
Private		443 (71.2)	222 (50.1)	221 (49.9)	
Public		127 (20.4)	82 (64.6)	45 (35.4)	
Other/none		52 (8.4)	30 (57.7)	22 (42.3)	
Lives with a spouse or significant other	622				<0.0001
Yes		147 (23.6)	114 (77.6)	33 (22.4)	
No		351 (56.4)	185 (52.7)	166 (47.3)	
Minor; question not asked		124 (19.9)	35 (28.2)	89 (71.8)	
History of prior pregnancy	622				<0.0001
Yes		118 (19.0)	108 (91.5)	10 (8.5)	
No		504 (81.0)	226 (44.8)	278 (55.2)	
Insulin regimen	613				0.0060
Insulin pump		287 (46.8)	139 (48.4)	148 (51.6)	
Multiple daily injections		273 (44.5)	167 (61.2)	106 (38.8)	
No insulin		53 (8.6)	25 (47.2)	28 (52.8)	
CGM use	612				0.0730
Yes		208 (34.0)	101 (48.6)	107 (51.4)	
No		404 (66.0)	227 (56.2)	177 (43.8)	
On some form of female contraception	622				0.6467
Yes		62 (10.0)	35 (56.5)	27 (43.5)	
No		560 (90.0)	299 (53.4)	261 (46.6)	
	621				0.9118

Continued on p. 181 »

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« Continued from p. 180

TABLE 1 Characteristics by Self-Reported Receipt of Preconception Counseling in Female SEARCH 4 Participants (Continued)

Characteristic	*n*	Overall*	Reported Preconception Counseling* (*n* = 334)	Did Not Report Preconception Counseling* (*n* = 288)	*P*†
BMI, kg/m^2 (or percentile)					
<25 (or <85th)		217 (34.9)	116 (53.5)	101 (46.5)	
25–30 (or 85th to <95th)		192 (30.9)	101 (52.6)	91 (47.4)	
≥30 (or ≥95th)		212 (34.1)	116 (54.7)	96 (45.3)	

Data are mean ± SD or *n* (%). *Column percentages are displayed for the overall column (sum to 100% across rows in the column), and row percentages are displayed for preconception counseling category columns (sum to 100% across the counseling columns for a given row). †*P* values assessing the association between reported receipt of preconception counseling and demographic and clinical characteristics were evaluated using χ^2 or Fisher exact test (categorical variables) or *t* test (continuous variables).

Discussion

In this study of female AYAs with diabetes, a little more than half of participants reported receiving preconception counseling, despite their high risk for unintended pregnancy and poor glycemic control (1,13). Although our findings are comparable to rates of preconception counseling of pregnant women with diabetes in England (13) and higher than reported in U.S. studies looking at counseling with primary care providers (1), our study confirmed that female AYAs with diabetes are not receiving preconception counseling at optimal rates.

Studies examining the sexual practices in female adolescents with type 1 diabetes have found that many of these individuals are at increased risk for an unintended pregnancy, as well as for sexually transmitted infections, and many do not feel comfortable discussing contraception with a health professional (14–16). Equally concerning, a study of diabetes health care providers and adolescents with diabetes demonstrated that 50% of diabetes providers were very uncomfortable discussing pregnancy or contraception, and only 10% of adolescents had discussed pregnancy or contraception with a provider (17). Thus, previously identified potential barriers to preconception counseling include a lack of comfort from both the patients' and providers' perspectives, possibly leading to suboptimal counseling rates. Given that preconception counseling is associated with improved pregnancy outcomes (8,9,13), our findings underscore the need for diabetes providers to increase preconception counseling to this population.

TABLE 2 Covariates of Interest and Multivariable Models Predicting Odds of Reporting Receipt of Preconception Counseling

Variable of Interest	Unadjusted		Adjusted*	
	OR (95% CI)	*P*	OR (95% CI)	*P*
Age at visit (1-year increase)	1.20 (1.15–1.25)	<0.0001	1.20 (1.15–1.25)	<0.0001
A1C AUC % (1-unit increase)	1.14 (1.04–1.25)	0.0066	1.11 (0.999–1.24)	0.0533
Diabetes provider type (overall test)		<0.0001		0.8670
Adult versus pediatric provider	2.99 (2.08–4.29)	<0.0001	1.11 (0.67–1.83)	–†
Treats all ages versus pediatric provider	2.81 (1.72–4.60)	<0.0001	1.17 (0.65–2.12)	–†
History of pregnancy (yes vs. no)	13.28 (6.79–25.99)	<0.0001	7.44 (3.61–15.32)	<0.0001

*Adjustment variable lists for each variable of interest informed by directed acyclic graphs, as follows: age at visit was adjusted for clinic site only with no additional adjustments recommended by graphs; A1C AUC adjusted by clinic site, age at visit, whether on birth control, diabetes provider type, diabetes type, whether living with spouse/significant other, race/ethnicity (four categories: Asian/Pacific Islander/Native American/other, Hispanic, non-Hispanic Black, and non-Hispanic White); diabetes provider type adjusted by clinic site, age at visit, diabetes type, and insurance type; and history of pregnancy adjusted by clinic site, age at visit, whether on birth control, whether living with spouse/significant other, and race/ethnicity. †*P* values for pairwise contrasts for categorical variables with two or more groups are not presented if the *P* value for the overall test is >0.10.

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This is the first study comparing rates of preconception counseling received from pediatric providers versus nonpediatric providers. We observed that participants obtaining care from pediatric providers were less likely to receive preconception counseling, although this finding was no longer evident in adjusted models. A study of adolescents in the United States from 2006 to 2010 reported that only 26.9% of sexually experienced females aged 15–19 years reported receiving contraceptive information from a health care provider (18). Other studies have described pediatricians' comfort levels with discussing and providing contraception and assessed the need for improvement, particularly around long-acting, reversible contraception knowledge and placement (19,20). Previous work has also highlighted that pediatric subspecialists endorse low levels of discussing reproductive care, with one-third never or rarely discussing reproductive health care and one-third never speaking privately to adolescents (21).

Barriers that pediatric subspecialists have reported include insufficient time for counseling and the presence of family members or partners (21). This finding highlights one of the challenges unique to pediatric care in that visits involve addressing the needs and concerns of the entire family rather than just the patient, and often, finding time to focus exclusively on the adolescent patient during a clinic visit can be a challenge. Intentionally setting aside time to meet privately with adolescent patients is one way to work on overcoming this barrier. Older age was significantly associated with reported receipt of counseling in the adjusted model; thus, the difference in provider type and counseling seen in the unadjusted model may be driven by younger-aged females seeing pediatric providers compared with providers who see adults or patients of all ages and patients' age affecting receipt of preconception counseling.

In our study, those who received preconception counseling were older and more likely to have public health insurance, to be living with a spouse/significant other, to have had a prior pregnancy, and to be on a multiple daily injection insulin regimen compared with those who did not report receiving preconception counseling. Other studies examining factors associated with preconception care in women with diabetes have found that those who seek or receive preconception care are more likely to be married or living with a partner, to racially identify as White, to have markers of higher socioeconomic status, and to have type 1 or insulin-dependent diabetes (13,22).

Some of the associations seen in the SEARCH population compared with other studies of women with diabetes, such as older age, may be related to the wider age range and younger mean age of this AYA population. Other studies that evaluated these clinical and demographic associations only included women with diabetes who were pregnant and thus were not exclusively focused on AYAs. The AYA population is unique given challenges already highlighted around the time of transition to adult health care, increasing independence, and often worse glycemic control and thus should be approached differently compared with women with diabetes who are already pregnant.

We found that females with poorer glycemic control over time were more likely to receive counseling. This finding likely is attributable to providers' awareness of the higher risk that individuals with poor glycemic control have for adverse maternal and fetal outcomes should they become pregnant affecting their patient counseling practices. However, this association was attenuated in the multivariable model.

Quality improvement work has been published focusing on improving preconception counseling for females with diabetes and describes systematically incorporating into diabetes clinics preconception counseling questionnaires that assessed when patients had their last menstrual cycle and whether they had received preconception counseling (23). Interventions including documentation-based prompts and brochure distribution were implemented in this clinic and resulted in an increase from 30 to 74% (28 of 38) of females of childbearing potential in the clinic reporting receiving preconception counseling (23). Further quality improvement work focusing specifically on the AYA population could help develop systems and tools to improve consistent preconception counseling.

A strength of this study is that it included a large, geographically diverse sample of AYA females with type 1 or type 2 diabetes diagnosed in youth. A limitation is that it is based on self-report of preconception counseling rather than objective documentation of counseling provision. In the TODAY (Treatment Options for Type 2 Diabetes in Adolescents and Youth) study of adolescents with type 2 diabetes, few participants (13%) who became pregnant recalled having received preconception counseling, despite counseling being a standard part of the study protocol (24). It is challenging to discern when looking at studies of preconception counseling such as in the SEARCH population whether preconception counseling is not given or just not

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remembered. Another limitation is that, although this study sought to assess preconception counseling around diabetes and pregnancy, we were unable to assess whether that counseling occurred in the setting of a pregnancy, which would thus be considered more accurately to be prenatal counseling rather than preconception counseling. We still refer to all counseling reported here as preconception counseling, given that it can be applied to future pregnancies in any instance; however, we recognize that there may be a limitation regarding the exact timing of the counseling provided. Additionally, when asked about preconception counseling, the question does not specify which doctor provided this counseling. Some of the counseling received may have been from primary care or gynecology providers rather than diabetes care providers; thus, rates of preconception counseling from diabetes care providers specifically are likely lower. Future directions for this work include further evaluation of barriers to the receipt and recall of preconception counseling in this population and targeted interventions to improve rates of counseling.

Conclusion

Many female AYAs with diabetes in the SEARCH for Diabetes in Youth study reported not receiving preconception counseling, especially those who were younger or did not have a history of prior pregnancy. Efforts to deliver preconception counseling consistently beginning at puberty and to overcome barriers to counseling for female AYAs with diabetes are warranted, given the high risk for adverse pregnancy complications in this population.

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DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS

A.J.R., K.S., and E.T.J. conceptualized and designed the study, contributed to data interpretation, drafted the initial manuscript, and reviewed and revised the manuscript. J.M.S. and R.D. completed the data analyses, contributed to data interpretation, and reviewed and revised the manuscript. F.S.M., C.P., N.S.B., S.E., D.J.P., D.D., and A.B. conceptualized and designed the study, contributed to data interpretation, and critically reviewed the manuscript for important intellectual content. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work. A.J.R. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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