

## Frequency of preconception education for teenage patients with diabetes attending an academic Pediatric Endocrinology Clinic

Emily A. Boevers, MD, MA,<sup>1</sup> Janet I. Andrews, MD,<sup>2</sup> Craig H. Syrop, MD, MHCDS<sup>2</sup>

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### Abstract

*Purpose:* Diabetes mellitus (DM) in pregnancy produces adverse outcomes with significant human and economic costs. Potential lifetime cost savings of preventative preconception counseling for women with diabetes may reach \$4.3 billion (U.S.). Preconception education has been shown in prior research to improve knowledge of reproductive risks in an adolescent diabetic population and to improve future health outcomes. This study assessed the current extent of preconception DM-related reproductive risk education at a tertiary academic medical center to better inform the opportunity for a systematic quality improvement intervention.

*Methods:* We reviewed the electronic medical records (EMR) of females (N=70), ages 16-19, seen in the Pediatric Endocrinology clinic (2013-2016) and diagnosed with type 1 DM, type 2 DM, or insulin resistance. Any reproductive risks education documentation by providers, nursing or educators within Pediatric Endocrinology, or within consults to Nutrition or Obstetrics and Gynecology was reviewed and characterized.

*Results:* According to EMR documentation, patient education for nonreproductive medical needs and complications of DM were consistently present in this population: 96% of patients received general diabetes education

with at least 4/8 components. However, documented education regarding DM reproductive risks occurred for only 18% of the same patients while contraceptive use discussion occurred for 20%.

*Conclusion:* The potential benefits of preconception education may include achieving recommended glucose control preceding and during pregnancy with fewer downstream maternal and fetal adverse outcomes. Although limited by the single site, retrospective design and the unknown rate of reproductive education documentation failure, our findings reveal a performance gap of potential downstream medical significance. Recognizing this deficiency provides an opportunity for a population-based intervention to create improved health outcomes.

<sup>1</sup>Department of Obstetrics and Gynecology, University of Kansas Medical Center, Kansas City, KS

<sup>2</sup>Department of Obstetrics and Gynecology, University of Iowa Hospitals and Clinics, Iowa City, IA

### Introduction

Diabetes mellitus challenges maternal and fetal health both during and after pregnancy. The significant risks of

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**Corresponding author:** Emily Boevers, MD,MA, University of Kansas Medical Center, 3901 Rainbow Blvd, Kansas City, KS 66160, Telephone: 319-243-0332; E-mail: [eboeverssolverson@kumc.edu](mailto:eboeverssolverson@kumc.edu)

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diabetes during pregnancy include fetal anomalies, hypertensive diseases, macrosomia, birth injury, stillbirth, and neonatal hypoglycemia.<sup>1,2</sup> Periconception control of diabetes, as measured by hemoglobin A1C, has been shown to be a proportional and independent predictor of congenital anomalies in women with preexisting diabetes mellitus.<sup>3</sup> Adverse reproductive outcomes associated with diabetes have been estimated to cost \$4.3 billion.<sup>4</sup> Yet, it is not uncommon to observe women with pre-gestational diabetes registering for infertility or obstetrical care with poor metabolic control of their diabetes and an elevated glycosylated hemoglobin A1c (HbA1c). Multiple studies have shown that diabetic women who are educated by health care professionals experience improved HbA1c, fewer preterm births, and fewer adverse fetal outcomes.<sup>5</sup> The American Diabetes Association has recommended that women and adolescents with pre-gestational diabetes receive preconception care and that all adolescent girls receive preconception counseling prior to initiating sexual activity.<sup>6</sup> However, implementation of preconception counseling has been limited by clinical constraints including time and staff availability.<sup>5</sup> Additionally, provider discomfort with topics like pregnancy, contraception and preconception counseling is a limiting factor in the prevalence of reproductive health education.<sup>7</sup>

As diabetes becomes increasingly common in the general population, there are also more adolescents with this disease.<sup>8</sup> Previous studies have shown that among adolescents with diabetes,

reproductive health education involving printed books or CD-ROM have more sustained improvement in understanding than standard of care.<sup>6</sup> Charron-Prochownik et al. demonstrated that specialized preconception counseling for adolescents with diabetes reduced counseling barriers by providing at-home resources for adolescents and increased subjects' perceived benefits of support and receipt of preconception counseling.<sup>9</sup> A similar intervention by Rodgers Fischl found that subsequent follow-up preconception counseling sustained subjects' knowledge at a low financial cost and staff time.<sup>10</sup>

Adequate preconception education directed at the appropriate time in life and disease course is a challenge to be managed by specialists in Pediatric Endocrinology, Obstetrics and Gynecology, Adult Endocrinology and Nutrition. A failure to identify and address gaps in knowledge prior to pregnancy can produce significant adverse health outcomes. The purpose of this study was to assess the extent of preconception, diabetes-related reproductive education for adolescent female patients diagnosed with any variant of diabetes mellitus (DM) receiving care in the Pediatric Endocrinology clinic of a tertiary academic medical center. This population was selected as it represented a medically captive, life span appropriate group "at risk" for sexual activity and incurring the risks of diabetes in pregnancy.

## **Methods**

Patient preconception education was assessed by review of the electronic

medical record (EMR) for documentation of physician, physician assistant, nurse practitioner, nursing, and diabetes educator visits in the Pediatric Endocrinology clinic, consults to Nutrition, Obstetrics and Gynecology, and medication review. Inclusion criteria required patients to be female; to be English speaking; to have completed at least one visit in Pediatric Endocrinology; to be diagnosed with either type 1 DM, type 2 DM, or insulin resistance; and to be between the ages of 16 and 19 at the time of visits occurring in 2013 to 2016. Patients who were male or who were previously pregnant were excluded; patient visits occurring after a confirmed pregnancy were censored from this review. The following types of visits were reviewed: clinic visits to pediatric endocrinology, inpatient records with notes by Pediatric Endocrinology or Gynecology, consult or referral records by pediatric endocrinology, nutrition or obstetrics and gynecology were reviewed. Charts were additionally reviewed by searching for terms including: education, complications, risk, pregnancy, preconception, sex, birth, defects, contraception or intercourse. Medications were reviewed for use of contraception. This project was deemed exempt by our Institutional Review Board as it was confined to chart review and did not involve patient contact nor alter patient care.

**Results**

In total, 70 charts were eligible and reviewed for this analysis. Table 1 conveys the socio-demographic characteristics of subjects.

Table 1: Socio-Demographic Characteristics

<b>Race</b>		
African American	8	11%
Caucasian	50	71%
Hispanic/Latino	5	7%
Other	7	10%
<b>Payer</b>		
Commercial	40	57%
Medicaid	25	36%
Self-Pay	5	7%
<b>Age at Diagnosis</b>		
1-5	15	22%
6-10	21	30%
11-15	26	37%
16+	8	11%
<b>Disease Type</b>		
Type 1	47	67%
Type 2	16	23%
Other	7	10%
<b>Duration of Pediatric Endocrinology Contact</b>		
Less than 1 year	10	14%
1-2 years	7	10%
2-3 years	7	10%
3-5 years	10	14%
Greater than 5 years	36	52%

A majority of subjects were Caucasian; a minority were African-American or Hispanic-Latino or other. Most patients were commercially insured. The average age of diagnosis was 10.1 years; most patients were between 11 and 15 at the time of diagnosis, with a median age of 10 and interquartile range of 6. Most patient had type 1 diabetes (67.1%) and a minority had type 2 diabetes or another related diagnosis (insulin resistance, glucose intolerance, prediabetes.) Over half of

the patients had been seen in the Pediatric Endocrinology Clinic for over 5 years (51.4%), though the number of diabetes-related clinic visits per patient were not calculated in this review.

Tables 2 contains the frequency of educational topics documented in patient charts.

**Table 2: Frequency of Patient Education**

<b>General Education</b>	
Disease Process	79%
Nutrition	99%
Physical Activity	94%
Medication Safety	86%
Blood Glucose Monitoring	96%
Acute Complications	86%
Chronic Complications	63%
Psychosocial	44%
<b>Risks and Reproduction</b>	
Risky Behavior	20%
Reproductive Health Risks	19%
Contraceptive Use	34%

According to documentation found in the electronic medical record, education regarding the common needs and complications of diabetes are consistently addressed with pediatric patients. Patients are consistently educated about the diabetes disease process (79%) and importance of nutrition and physical activity (99% and 94%, respectively). Patients are well educated about medication safety and blood glucose monitoring (86% and 96%, respectively). Education regarding acute (86%) and chronic (63%) complications in diabetes is frequently

provided. Psychosocial considerations in diabetes are discussed with 44% of patients. General education is relatively complete for pediatric patients, with over 95% having at least 4 of the 8 components above.

Based on medical record documentation, education regarding reproductive risks is provided much less frequently than metabolic and nutritional complications. Discussions about risky behaviors for adolescents with diabetes, such as driving or drinking alcohol, were documented in only 20% of charts. Discussion about reproductive risks during pregnancy was documented in 19% of charts. The occurrence of documentation regarding contraception, with it either being discussed or noted in medication records in 34% of charts.

Of note, pediatric endocrinology providers and nutrition consultants did nearly all documented education. Of the 70 charts reviewed, only 5 (7%) had a referral to Obstetrics and Gynecology for additional management of their health care needs.

**Discussion**

These findings have many implications for improvement in reproductive risk counseling in the adolescent female diabetic population. The importance of such interventions should not be underestimated. The rate of pregnancy in teens aged 15-19 in 2013 was 24.9 per 1,000, with an average cost per labor and delivery hospitalization of \$4,300.<sup>11</sup> Important from a public policy perspective, over seventy percent of costs associated with teen childbirth were paid by Medicaid.<sup>11</sup> Approximately 70% of youth experience sexual debut

by age 18, making preconception education in pediatric clinics an imperative, especially within populations with high risks of reproductive complications.<sup>12</sup> Furthermore, potentially preventable adverse reproductive outcomes have high costs. With an estimated 2.2% of US births to women with currently diagnosed pre-gestational diabetes mellitus, the potential lifetime cost savings of preventative preconception counseling may be as high as \$4.3 billion.<sup>4</sup>

As models of compensation shift to drive value, care for chronic diseases like diabetes must adapt to better manage transitions and prevent complications. There is a growing imperative for team-based and cross-disciplinary healthcare that transcends the silos that currently isolate distinct clinical services. Justifiably, the initial and early medical care must focus heavily upon the most imminent problems of metabolic control, improved management and education regarding acute and chronic complications. As pediatric patients age into sexual maturity, however, more guidance must be given on complications of pregnancy with diabetes, prevention of sexually transmitted infections and pregnancy, and other risky adolescent behaviors. This analysis reveals a potential gap and opportunity for quality improvements in timeliness of care and patient-centeredness which could affect significant and measurable outcomes.

The potential benefits of redesigned preconception education include time savings in future visits, less provider burden over time, improved glucose control preceding conception and during pregnancy. The American College of

Obstetricians and Gynecologists recommends that preconception counseling be a part of all patients' care; for high-risk populations this is particularly vital as it can impact health care costs attributable to complications of maternal diabetes. As patients transition through changes in sexuality, or age out of pediatric care and into adult care models, it cannot be assumed that they received education about the potential complications of poorly controlled diabetes on pregnancy specific health outcomes. This must become part of the preventative healthcare discussion of both obstetrician-gynecologists and endocrinologists for adolescents and young adults. This data suggests that one mechanism for improvement may be utilizing referrals to Ob-Gyn more regularly in this population, particularly if pediatric providers do not feel adept at describing the reproductive risks they face.

This study only reviewed data accessible in the electronic medical record, so education may have occurred that was not documented. Additionally, this review collected only binary data about whether education took place; it did not quantify the proportion of visits that included education on a particular topic nor the type of provider who specifically provided the education. The data therefore do not show whether patients are receiving longitudinal education about reproductive risks. However, given the low frequency of reproductive education documented in this population, it is evident that process improvements can be made.

This review included only one specialized clinical setting with multiple

providers, and it is therefore unclear if these findings are broadly generalizable to other practices. However, it is likely that other providers also face challenges in addressing all of their patients' clinical and educational needs given time constraints in outpatient care. In order to continue to improve quality in healthcare, multiple goals must be considered: care must be safe, timely, effective, efficient, standardized and yet tailored to each patient. Providers in a variety of healthcare settings can learn from these findings and improve the consistency of education in their workflow using established, validated educational materials or by designing their own materials for a specific patient population.

Research exists about the effectiveness of systematic, age appropriate preconception care into pediatric and adolescent diabetes populations. Beyond increasing understanding of disease, future studies should assess whether better glucose control and measurable maternal and neonatal outcomes are found in patients who have had specific educational interventions and knowledge transfer versus standard care. The benefits of understanding these interventions and outcomes will help validate cost-effective interventions designed to improve patient knowledge, self-care and engagement. Additional investigation may also support interdepartmental collaboration to improve downstream patient care outcomes.

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