**ABSTRACT**

**Objective:** Women with diabetes have increased risks of pregnancy-related complications. Knowledge of preventing these risks can be helpful. This paper describes the understanding and knowledge of diabetes and reproductive health of adolescent females with type 1 diabetes (T1D).

**Research Design and Methods:** For this secondary analysis, a descriptive mixed-method design was employed using baseline data from adolescents enrolled in a preconception counseling (PC) intervention study (READY-Girls program) targeting adolescent women with diabetes to enhance reproductive health awareness, knowledge, beliefs, decision-making skills, and behaviors. Participants (aged 13-20 yrs) were recruited from 2 university-based diabetes clinics. Content analysis was used to identify recurring themes on 3 open-ended computer-based questions regarding the understanding of diabetes and pregnancy, contraception, and PC; kappa coefficients were used to assess inter-coder agreement. Subscale scores from multiple-choice vignettes were computed in terms of 100% correctness (<70% indicated low levels) for knowledge of diabetes and pregnancy, contraception, and PC. Qualitative and quantitative results were compared.

**Results:** Participants (n=101) were on average 15.8 yrs, 21% were sexually active with a mean age at sexual debut of 15.3yrs. Overarching themes from qualitative data were that participants knew “little or nothing” and had misconceptions regarding diabetes and pregnancy, contraception, and PC. Inter-coder agreement for content analysis was high. Knowledge scores were low (diabetes and pregnancy, 64.5%; diabetes and contraception, 79.8%; PC, 67.5%).

**Conclusion:** Risky behavior and low knowledge scores confirmed their perceived lack of understanding from the open-ended questions regarding diabetes and pregnancy and PC. Teens had greater knowledge of contraception. Diabetes education should include PC and reproductive health for teens with diabetes.
INTRODUCTION

Because women with diabetes may have increased risks of pregnancy-related complications, the American Diabetes Association (ADA) [1] recommends that preconception counseling (PC) be incorporated into routine diabetes clinic visits for all women of child-bearing age starting at puberty. The goals of preconception care are to educate and counsel individuals about diabetes and pregnancy; to achieve and maintain excellent glucose control; to identify, evaluate and treat complications of diabetes and risk factors for adverse maternal and fetal outcomes before pregnancy, and to postpone pregnancy until it is safe and wanted [2]. Assessing women’s knowledge regarding reproductive health, clarifying misconceptions and providing evidence-based information during PC is imperative to prevent adverse pregnancy outcomes [3, 4, 5, 6].

Knowledge of these reproductive health-associated risks and the benefits of PC can help prevent complications. READY-Girls (Reproductive-health Education and Awareness of Diabetes in Youth for Girls) [7, 8] is a PC program developed by our team, and is specifically tailored for female adolescents with type 1 and type 2 diabetes (T1D and T2D) to enhance reproductive health awareness, knowledge, beliefs, decision-making skills and behaviors. The ADA’s fundamental components of PC [2] were incorporated into the program. Several of the successful components of teen pregnancy prevention programs (e.g., abstinence as one method of family planning/pregnancy prevention, delay of sexual initiation, improving communication, and skills building) [9, 10] were also integrated into the READY-Girls program that was formatted as a multi-media awareness educational program [11]. The efficacy of READY-Girls has been validated through several randomized control trials (RCT) [12, 13, 14], and it was shown to be cost-effective [13].

In preparation of the most recent RCT [14], which focused on minority teens with T1D and T2D, the READY-Girls program and questionnaires were modified using a mental models approach. Following the well-established mental models methodology [15], this research first used a formal model developed by health professionals [16] to identify the most critical relevant concepts, which were confirmed by the literature. Semi-structured interviews were then used to reveal the adolescent females’ “mental models” of diabetes, reproductive health, and PC. This approach systematically assessed the teens’ understanding of a topic identified as a relevant concept. Common misconceptions or gaps in their understanding helped guide the development of a knowledge questionnaire and the content for the educational component of READY-Girls.

The Knowledge Questionnaire [17] was revised as a multiple choice format with problem-solving vignettes for a broad age range (13 to 20 years) of Caucasian and African American (AA) adolescent females with T1D and T2D. A multi-site RCT was then conducted to evaluate the effects of the modified multi-media READY-Girls intervention (2 part DVD and book) on diabetes and reproductive health awareness, understanding, knowledge, attitudes, intention and actual behavior (e.g., using effective family planning, seeking PC, and initiating discussion with health professionals), and hemoglobin A1C [14]. Participants were randomized into either a treatment group who received the READY-Girls program (over 3 consecutive sessions) or a usual care group, stratified on sexual activity, age, and type of diabetes. As part of standard care, participants of both groups received the March-of-Dimes preconception counseling pamphlets which are available for the general public.

The aim of this report is to describe both the understanding (qualitative data) and knowledge (quantitative data) of diabetes and reproductive health in adolescent females with type 1 diabetes using baseline data from this RCT.

RESEARCH DESIGN AND METHODS

A secondary analysis with a mixed-method approach was used to describe the baseline data in the READY-Girls RCT. Data were collected by having participants complete self-reported validated questionnaires that were built on a computer-based platform; laptop computers were available in a private room at each of the diabetes clinic sites. These questionnaires were given at baseline, pre and post at each intervention session (3 months and 6 months), and at the 12-month follow-up. The methods and sample for the RCT have been described in detail elsewhere [14]. Prior to randomization, all participants completed both open-ended items (understanding) and a close-ended measure (knowledge) about reproductive health concerning diabetes and pregnancy, diabetes and contraception, and PC. Open-ended data were collected prior to the administration of the knowledge questionnaire.
Research

Participants

Adolescent females with T1D and T2D (13-20 yrs) were recruited from 2 large university-based Children’s Hospital diabetes clinics. Eligibility criteria included: having diabetes for at least one year, and the ability to read and understand the assent form and the questionnaires. Adolescent females with diabetes were ineligible to participate if they were pregnant, had a diagnosed chronic illness other than diabetes, participated in a pilot study or any other PC study, were a ward of the state or an emancipated minor, or were mentally challenged. The protocol, questionnaires and READY-Girls materials were approved by the Institutional Review Board (IRB) at both institutions, and teen consent or teen assent and parental consent were obtained from all participants.

Across the 2 study sites, a total of 548 girls met the inclusion criteria for age. Reasons for not enrolling were: ineligible because they did not meet other inclusion criteria, loss of contact, clinic cancellations, and refusal. Moreover, most eligible patients with type 2 diabetes at these sites were already enrolled in the TODAY study [18] which precluded them from participating in other studies. Because only 9 subjects had T2D, they were excluded from these analyses. Potential subjects for our study were recruited by the nurse face-to-face in the clinic or by phone utilizing the phone numbers (cell or landline) on file. In regards to race, participants self-identified by checking all categories that applied. NIH definitions for race were used. This paper reports on results from the 101 participants (from a possible n=109) that had completed data from the knowledge questionnaire and for the 3 open-ended items related to their understanding of diabetes and reproductive health.

Measures

Understanding of diabetes and reproductive health was measured by 3 open-ended items, “What do you know about diabetes and… 1) pregnancy, 2) contraception, 3) preconception counseling?”

Knowledge of diabetes and reproductive health was evaluated by 80 items; the total scale measured knowledge of diabetes and pregnancy, puberty, contraception, sexuality, general family planning, general diabetes, and PC. The split-half method was used to measure instrument reliability and to statistically separate items to differentiate the pre-test version from the post-test version. This paper reports on the baseline pre-test results (half of the items found in each total scale). Questions were multiple choice problem-solving vignettes developed through the mental models technique with groups of expert health professionals and teens with diabetes [16, 17]. For each subscale the number of correct items were determined and expressed in terms of percentage of items correct, where < 70% constituted a low score. (A standard threshold for performance on a test such as knowledge attainment is 70% [19]. Total scale: Cronbach’s alpha =.71; test-retest reliability r = 0.76). To correspond the qualitative and quantitative data that describe the understanding and knowledge of diabetes and reproductive health, only 3 of the pre-test subscales were chosen for this investigation: diabetes and pregnancy (14 items), diabetes and contraception (2 items) and PC (14 items) [17]. We wanted to use measures whose content were comparable across the qualitative and quantitative domains of our data stream.

Qualitative Data Coding and Analysis

Narrative responses for the 3 open-ended questions were coded according to content analysis and recurring themes by 2 research associates familiar with the content. Themes were confirmed by a 3rd reviewer. Kappa coefficients were used to correct for chance agreement and were computed to assess inter-coder agreement.

Data Analysis

SAS (version 9.3, SAS Institute, Inc., Cary, NC) was used for quantitative data analysis. Sociodemographic characteristics, reproductive health behaviors, and knowledge subscale scores were described using standard descriptive statistics, including means, standard deviations, and ranges (reported as maximum - minimum) for continuous type variables (e.g., age, knowledge subscale scores), and frequency counts and percentages for nominally scaled categorical variables (e.g., race, ever sexually active).

RESULTS

The 101 female participants had a mean age of 15.8 years (range = 13-19); and 12.8% (n=13) were African American. Twenty-one percent (n=21) were sexually active, and of those, 50% (n = 11) had at least one episode of unprotected sex, with a mean age of sexual debut of 15.3 years (range = 12-18).
Several major themes resulted from the content analyses regarding participants’ understanding of diabetes related to pregnancy, contraception, and PC. (See Table 1) The primary theme that emerged for all 3 items was that adolescent females with diabetes perceived their understanding to be “little to nothing.” Moreover, 82% of the sample reported “little to nothing” as their perception of understanding for diabetes and PC. Some of the more common misconceptions about diabetes and pregnancy were: “I can’t get pregnant” and “I’ll have trouble getting pregnant.” However, almost half mentioned that they could have a “high risk pregnancy.” After a review of the qualitative data, the inter-coder agreement was high with a kappa coefficient of 0.97.

Overall, the quantitative results of the targeted subscale scores from the knowledge questionnaire were low. (See Table 2) Because PC was the major focus of this report, analysis of the knowledge subscales specifically related to PC were reported. Participants had greater knowledge of diabetes and contraception but lacked adequate knowledge for diabetes and pregnancy and PC (mean knowledge subscale scores <70%).

### Table 1: Participants’ Understanding of Diabetes and Reproductive Health - Qualitative Data

<table>
<thead>
<tr>
<th>Open Ended Question</th>
<th>Answer Themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you know about diabetes and pregnancy? (n=101)</td>
<td>“Little to nothing”</td>
<td>22.5%</td>
</tr>
<tr>
<td></td>
<td>Misconceptions</td>
<td>31.5%</td>
</tr>
<tr>
<td></td>
<td>“High Risk Pregnancy”</td>
<td>46%</td>
</tr>
<tr>
<td>What do you know about diabetes and contraception? (n=101)</td>
<td>“Little to nothing”</td>
<td>70.5%</td>
</tr>
<tr>
<td></td>
<td>Misconceptions</td>
<td>14.5%</td>
</tr>
<tr>
<td></td>
<td>“Some effect on diabetes”</td>
<td>15%</td>
</tr>
<tr>
<td>What do you know about diabetes and PC? (n=98)</td>
<td>“Little to nothing”</td>
<td>82%</td>
</tr>
<tr>
<td></td>
<td>Misconceptions</td>
<td>9.5%</td>
</tr>
<tr>
<td></td>
<td>“Helpful before becoming pregnant”</td>
<td>8.5%</td>
</tr>
</tbody>
</table>

### CONCLUSION

Similar to previous findings [12, 13], some adolescents that participated in this study had early and unsafe sexual practices and appeared to lack the understanding and knowledge that could prevent unplanned pregnancies. Overall, these study participants reported having only a minimal understanding of how diabetes is related to pregnancy, contraception, and PC. At baseline, most participants had not yet had any discussion with their health care team regarding these topics. By a mixed-method approach, low quantitative knowledge scores mirrored the qualitative open-ended responses for pregnancy and PC. Although their knowledge subscale score for diabetes and contraception was higher, their perceived understanding was still “little or nothing.” A higher score in the contraception category could be a reflection on the information most middle school and high school students may receive in general sex education courses in their school curriculums [20]. This finding, coupled with their ability to recognize that they have a “high risk pregnancy,” can be used as a springboard to deliver evidence-based information and counseling that will promote healthy reproductive health behaviors. This additional information may also
lead to planned pregnancies in their future that are safe and wanted.

Developmentally tailored PC, like the READY-Girls program [7, 8], could be beneficial for adolescent females with diabetes to provide accurate information and alleviate misconceptions. The READY-Girls program received high ratings of satisfaction regarding utility, format, usability, ease of understanding, and enjoyableness [12, 21]. READY-Girls was adopted by the ADA to be the model preconception counseling program for teens with diabetes. The book was retitled, “Diabetes and Reproductive Health for Girls,” and is published and distributed by the ADA on their website at no cost [22]. The National Diabetes Education Program (NDEP), co-sponsored by the Center for Disease Control (CDC) and National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at NIH, has added the READY-Girls program to their listings of available resources on their website.

Our program of research also provided the evidence, and served as a catalyst, for the ADA to change the PC start time to “puberty” in their 2009 Practice Recommendations [1]. Initiating PC at puberty prior to sexual activity is imperative. Because sexual activity may precede fertility, health professionals could initiate these discussions earlier than puberty at their discretion. In addition, PC should be given at each clinic visit to all women with diabetes of child-bearing age. As mentioned, the goals of PC are to educate and counsel about diabetes and pregnancy; to achieve and maintain ideal glucose control at conception and throughout the pregnancy; to identify, evaluate and treat complications of diabetes and risk factors for adverse maternal and fetal outcomes before pregnancy; and to postpone pregnancy until it is safe and wanted [1, 2]. PC has 3 phases: Raising Awareness, Overview Planning, and In-Depth Planning [23]. The “Awareness Phase” should be given to all women with diabetes starting at puberty regardless of their plans for a pregnancy. The focus is on counseling about the risks of uncontrolled diabetes on pregnancy, the benefits of preconception care to reduce the risks, and the importance of family planning to prevent unplanned pregnancies [23, 24]. Obtaining a sexual history [25] is imperative along with discussing the patient’s health beliefs about fertility and family planning [24, 26, 27]. The other two phases of PC focus on the counseling and care of women actively planning a pregnancy [23].

The results and conclusions of this secondary analysis should be interpreted with regards to the following limitations. First, there may be limited generalizability given that participants were recruited from two sites. Secondly, probes were not used with the open-ended items to solicit more in-depth information. Thirdly, given the nature of the multiple choice vignette style question used in the knowledge questionnaire, it is not possible to separate the general contraception questions from those that relate to diabetes. Fourthly, the measures were self-reported, which could introduce bias. Lastly, these analyses were only conducted on participants with T1D.

Future studies should consider women with T2D and a larger, more diverse sample. It will be important to assess the role of social and contextual factors in evaluating the effectiveness of READY-Girls or other PC programs, and thus tailoring them for delivery with increasingly diverse populations (e.g., Hispanic, African American). And although the READY-Girls program was developed specifically for teens that have either type 1 or 2 diabetes, preconception counseling could also be expanded to women with pre-diabetes and those at risk for gestational diabetes (GDM), informing them of their risks and the prevention of GDM and its complications.

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REFERENCES


