

# “Diabetes Just Tends to Take Over Everything”: Experiences of Support and Barriers to Diabetes Management for Pregnancy in Women With Type 1 Diabetes

Harsimran Singh,<sup>1</sup> Karen Ingersoll,<sup>2</sup> Linda Gonder-Frederick,<sup>2</sup> and Lee Ritterband<sup>2</sup>

## ■ ABSTRACT

To optimize clinical outcomes, women with type 1 diabetes are advised to consistently achieve blood glucose levels in their target range before becoming pregnant. However, following this recommendation can be clinically and psychologically challenging for patients. We explored women’s experiences of pregnancy-related diabetes management and any barriers and support systems affecting their self-management. Fifteen semi-structured telephone interviews were conducted with a nationwide sample. Interviews focused on women’s perceptions of barriers hindering pregnancy-related diabetes management and support systems facilitating their self-management. Audio recordings were analyzed using inductive thematic analysis. Results indicated significant impairment of psychological health and overall quality of life in women with type 1 diabetes who were pregnant or planning pregnancy. Most participants reported a lack of support and empathetic engagement from their health care team, which affected their clinical management. Guilt and concerns about high blood glucose levels, constant pressure to meet glucose targets, and difficult interactions with health care professionals were a few of the primary themes with regard to barriers to optimal management. Patient-centered programs that provide effective clinical and psychosocial support for women who are preparing for pregnancy with preexisting diabetes are urgently needed so that these women feel adequately supported and empowered to undertake pregnancy.

Self-care is a crucial aspect of optimal type 1 diabetes management (1). However, the ability to self-manage can be compromised by a variety of physical, intellectual, emotional, and social factors that may become especially challenging in the context of pregnancy. The progressive increase in postprandial glucose and insulin response during late gestation is difficult to manage in women with preexisting diabetes (2). Pregnancy in women with preexisting diabetes presents as high-risk because of the increased possibility of obstetric and neonatal complications associated with both hyper- and hypoglycemia (3–5). Additionally, a higher risk of late fetal loss and neonatal mortality

exists in pregnancies complicated by type 1 diabetes (6,7). Preconception and early pregnancy care are recommended for all women with diabetes who are contemplating pregnancy (8–10). During pregnancy, optimized glycemia is the most effective management for women to reduce the risk of obstetric and neonatal complications (11).

Despite overwhelming evidence that preconception planning in type 1 diabetes reduces a multitude of risk factors, it remains an underutilized resource (12–14). Furthermore, the implementation and uptake of such services have been inadequate and disappointing (15). Achieving clinically recommended glycemic targets using

<sup>1</sup>Mary & Dick Allen Diabetes Center, Hoag Memorial Hospital Presbyterian, Newport Beach, CA

<sup>2</sup>Center for Behavioral Health and Technology, Department of Psychiatry and Neurobehavioral Sciences, University of Virginia, Charlottesville, VA

Corresponding author: Harsimran Singh, harsimran.singh@hoag.org

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self-management skills is challenging for most people with type 1 diabetes (1,16). However, these circumstances are far more pronounced for women with preexisting diabetes who are pregnant or preparing for pregnancy because they need to follow a rigorous self-care regimen not just for a healthy conception, but also throughout pregnancy for optimal outcomes (12). Several reports have identified the negative psychological impact of the demanding (although essential) management regimen on these women, who experience a greater degree of anxiety, worry, and stress compared to women with low-risk pregnancies (17–19).

There is a dearth of literature investigating barriers to care and support systems to facilitate optimal blood glucose management around pregnancy for women with preexisting diabetes. The few studies that have explored these factors have generally been conducted in populations outside of the United States (17,19,20). The aim of this study was to use a structured qualitative approach to explore women's experiences with and perceptions of pregnancy-related diabetes management and support systems that hinder or facilitate their self-management efforts.

## Methods

### Setting, Participants, and Data Collection

The study was approved by the institutional review board of the University of Virginia in Charlottesville (IRB-HSR Study #16668).

Adult U.S. women ( $\geq 18$  years of age) with type 1 diabetes who were fluent in English and were either pregnant, planning pregnancy for the immediate future, or had experienced a previous pregnancy were invited to participate in a phone interview. Given the narrow range of the target population and to maximize recruitment, it was decided to conduct the interviews over the phone unless participants were local to the study site and wished to come to the study office

for an in-person interview. Potential participants were informed that the purpose of the study was to identify barriers to and supports for blood glucose management around pregnancy. Participants were recruited using advertisement flyers that were sent for distribution to diabetes-specific clinics around the United States. Potential participants could indicate interest by contacting the investigator (H.S.), who reviewed study procedures and the consent process with them and scheduled interviews at dates and times convenient for participants. Interviews were conducted between March and April 2013. To achieve data saturation, 10–15 people were recruited, with the possibility of conducting additional interviews, if necessary.

In all, 27 women indicated interest in the study. Three of these women could not be contacted to discuss next steps despite their indicated interest, and nine others were lost to scheduling difficulties (i.e., missed scheduled interviews, reported time constraints, and inability to keep interview appointments). Subsequently, 15 women participated (Table 1). Interview questions were

designed to explore four areas: 1) patients' perspectives on being pregnant or planning pregnancy with diabetes (e.g., What are some of the factors that you considered important while planning your pregnancy?), 2) barriers to achieving recommended blood glucose targets (e.g., What are some of the challenges around achieving and maintaining recommended blood glucose goals?), 3) support networks that facilitated achieving recommended targets (e.g., How does your family/significant other help you in your efforts to achieve/maintain your blood glucose goals?), and 4) concerns around pregnancy with diabetes (e.g., Could you discuss some of your concerns with being pregnant while having diabetes?). Interviews were conducted using open-ended questions with follow-up clarification questions as needed.

All interviews were conducted over the phone between April and May 2013 by an investigator with a background in health psychology and skills in motivational interviewing. Interviews were audio-recorded and later transcribed and ranged from 30 to 50 minutes in length. The interviewer also wrote notes and reflections

**TABLE 1. Participant Characteristics (n = 15)**

	<i>n</i> (%) or mean $\pm$ SD
Age, years	34 $\pm$ 9
Married	15 (100)
Currently contemplating pregnancy	5 (33) Two with previous successful pregnancies; three with previous unsuccessful pregnancies
Currently pregnant	3 (20) No previous successful or unsuccessful pregnancies
Previously pregnant	10 (67) Not pregnant or contemplating pregnancy
Diabetes duration, years	21 $\pm$ 11
Regular CGM users	10 (67) All also used an insulin pump
Regular insulin pump users	13 (87) 10 were also using CGM
MDI regimen	2 (13) Used MDI only

*MDI, multiple daily injection.*

immediately after each interview to document specific findings from each interaction.

**Transcription and Analysis**

All audio recordings (*n* = 15) were transcribed and analyzed using inductive thematic analysis (21). Important steps of the analysis included 1) coding and analyses of completed, transcribed interviews while continuing fresh data collection (conducting new interviews) to ensure sample saturation, with each transcript reviewed and coded independently by two researchers; 2) review and revision of previously developed codes as analysis progressed and with any new information identified during ongoing interviews; 3) comparison of information across interviewees to identify codes that held strong across the sample; and 4) subsequent categorization of codes into themes that reflected the information gathered. Authors met regularly to review and discuss developing themes and supporting quotations. The lead author (H.S.) also reviewed three randomly selected transcripts assigned to the other authors to check for accuracy of codes, themes, and supporting quotations. Any disagreements were discussed, and analysis was revised where required.

The study team met periodically to review and discuss the proposed themes, excerpts, and general coding notes to resolve discrepancies, if any existed. As the final stage, the resulting themes, supporting excerpts, and coding tables were reviewed by another investigator experienced in qualitative research to identify any gaps or coding-related concerns. Clear themes had emerged from the data analyses, and no new information was generated that required further investigation from the final interviews. Hence, the study team agreed that data saturation had been achieved.

**Results**

Participant characteristics are summarized in Table 1. All 15 participants were married, with a mean age of 34

years (SD 9 years) and a mean duration of type 1 diabetes of 21 years (SD 11 years). Ten participants used a continuous glucose monitoring (CGM) system, and 13 used an insulin pump to manage their diabetes. All participants using a CGM were also using an insulin pump. Ten women had previously been pregnant, three were pregnant at the time of the interview, and five were trying for or contemplating pregnancy in the immediate future (within 0–4 months from the time of their interview).

The sections below summarize the experiences and perspectives shared by participants during the interviews (Table 2). Representative participant quotations are included, identified by participant number.

**Theme 1: Primary Concerns Around Pregnancy and Diabetes**

Participants presented a variety of concerns in relation to comanaging pregnancy and diabetes. Although there was an underlying excitement about becoming pregnant and successfully having a baby, significant worries were shared regarding the potential impact of women’s diabetes on the health and development of their

baby during gestation. The majority of participants were also very anxious at the prospect of their babies being diagnosed with type 1 diabetes at birth or later in life. They expressed concern that they would feel very guilty if that were to happen and would “wonder whether it was a selfish decision to have tried to become pregnant.” As one participant put it:

*“I don’t like the possibility of my children having a chance to become diabetics. I asked my [obstetrician] and . . . I know that they won’t be born diabetic, but just putting them at risk for possibly becoming diabetic . . . nobody wants that for their child.” (P7)*

High blood glucose during pregnancy was very anxiety-provoking for participants. Women understood that high blood glucose could be potentially harmful for their pregnancy and developing babies. This resulted in feelings of guilt, panic, and stress around blood glucose monitoring.

*“The hardest part was the guilt associated with the high blood sugars. . . . You get this huge sense of guilt of, ‘You know, this*

**TABLE 2. Emerging Primary and Subthemes from Patient Interviews**

1.	Primary concerns around pregnancy and diabetes
1.	Potential impact on baby’s health and development
2.	Managing unexpected high blood glucose readings
2.	Barriers disrupting efforts to meet blood glucose targets
1.	“Constant pressure” to meet blood glucose targets was frustrating
2.	Following a regimented diet (especially carbohydrate counting) was a challenge during pregnancy
3.	Competing life demands, including accommodating additional clinical appointments
3.	Association with health care professionals
1.	Need for emotional support and encouragement
2.	Disapproval with use of scare tactics to meet blood glucose targets
4.	Support systems facilitating blood glucose management
1.	High self-motivation to have a successful pregnancy (healthy baby)
2.	Significant others (partner, mother)
3.	Reliable and easy access to health care professionals

*isn't just affecting me right now, it's affecting the baby, too,' and you just want to get it down as quickly and safely as possible . . . that feeling of knowing that you're affecting the child is a huge weight to have on your shoulders.” (P14)*

Participants generally felt that high blood glucose often occurred unexpectedly, which created uncertainty regarding how best to avoid it in the future. Management of hyperglycemia was also reported to be stressful because of any potential consequences related to overtreatment. Participants emphasized the need to be able to contact their diabetes management team as soon as possible to manage such “emergency” situations.

*“ . . . These high blood glucose levels would just strike out of nowhere sometimes. I would do exactly the same thing as I did the day before, but my blood glucose would be spiking. It was so scary . . . and then I would rush to get my nurse on the phone ASAP. Those times were always excruciating . . . I mean, I knew what had to be done, but I do not want to swing the other way [have hypoglycemia] . . . everything was so unpredictable.” (P1)*

### **Theme 2: Barriers Disrupting Efforts to Meet Blood Glucose Targets for Pregnancy**

Participants felt “constant pressure” from their clinic teams to achieve their recommended glycemic targets, and this was considered the most frustrating and challenging aspect of their diabetes management. A few women felt that they had to be “obsessive” about glucose monitoring during pregnancy. However, despite their best efforts, participants experienced frequent glycemic fluctuations that were not ideal and led them to feeling guilty, anxious, and helpless. “It seemed like I could never win this battle,” one participant said.

*“I tested my blood sugar more than I should have. . . . I would say at least 10–12 times a day. . . . I was overly cautious, which I think is a bad thing because then I would end up overtreating if my sugar was a little elevated or not where I wanted [it] to be.” (P6)*

Constant nutrition monitoring, and specifically carbohydrate counting, was another demanding aspect of diabetes management for pregnancy. Participants shared that they had missed out on “enjoying their pregnancy” because of their need to be regimented about their diet and blood glucose values. They wished for more freedom to eat and drink what they liked during pregnancy.

*“You have to always be prepared. You have to say, ‘Okay, well, . . . what am I going to eat for lunch today, and how many carbohydrates is that?’ Being pregnant, sometimes you just get hungry, and you are like ‘ . . . Well, I guess I will just have to eat sugar-free Jell-O again.” (P4)*

Routine and competing life demands such as job-related stressors were also frequently reported as barriers to optimal blood glucose management. The majority of women in the sample were formally employed and discussed how work schedules interfered with their diabetes management (e.g., blood glucose monitoring and management of glycemic fluctuations), making it more challenging than usual. Participants understood the significance of additional health care interactions required during pregnancy; however, they found these visits difficult to accommodate in their schedule and also reported feeling anxious and guilty about missing diabetes-related appointments because of other commitments.

*“My work schedule interferes. I work full-time, which can bring*

*its own stressors. It definitely takes away time that I could be using to take care of myself. . . . between all the doctor’s appointments and missing work . . . and having poor compensation is an added stressor for sure.” (P7)*

*“Diabetes just tends to take over everything . . . you know . . . there is work, there is stuff at home, you are pregnant, and then there is diabetes to deal with. You cannot always have diabetes front and center, can you?” (P15)*

### **Theme 3: Association With Health Care Professionals**

The majority of women highlighted a difficult relationship with their providers, especially when they were planning for pregnancy or trying to become pregnant because they did not think the providers had been supportive of their decision. Participants considered support and encouragement from their health care team as essential for their confidence to undertake pregnancy, and when this backing was missing, patients were left angry, shocked, and disappointed. Participants often reported changing providers to get someone more “sensitive,” “positive,” and encouraging. Most women did not think their providers offered much information regarding why they were being discouraged from trying to become pregnant, which in turn affected patients’ perceptions of their personal well-being and their trust in the health care team.

*“My primary care physician flat out told me, ‘You should not get pregnant. It’s going to be miserable and hard with your blood sugars.’ I said, ‘Thanks, but I want to be a mom!’ Last summer, I started looking into adoption because they said I might never become pregnant.” (P5)*

*“I still remember running to my husband after my appointment [with the doctor] just in tears that I would not have children . . . , that I could not have children because of my diabetes, and that my blood glucose fluctuated so much. It was like our world ended!” (P3)*

Participants specifically expressed disapproval and disappointment in response to the providers’ perceived use of “scare tactics” to get them to either avoid pregnancy or manage their blood glucose to clinical targets. They felt they were “doing their best” to manage their blood glucose but that their health care team often did not acknowledge their efforts or challenges surrounding blood glucose management, which left them unmotivated to attend future clinical appointments.

*“The nurse practitioner would say things to me like, ‘Don’t you want the daughter that you have to grow up with a mom?’ Just scary terms to try and get me to do what they wanted.” (P13)*

*“They are so mean! They tell you that 200 mg/dL will kill your baby, or that’s how they make you feel. . . . I think that’s because they’re used to gestational diabetes, where you kind of have a little bit more control over those 200s, but with type 1, you’re going to see those 200s every day or every 2 days. . . . It’s really hard to be as perfect as they expect.” (P9)*

*“When I went into the first appointment, they said, ‘Okay, we know that you have diabetes, but even with all this good control, we want you to know that you can still have a stillborn anytime in these 9 months. It’s not going to be easy. You could have a big baby or a small baby, and it has a high chance of cerebral palsy, and it could get this,*

*that, and the other.’ . . . It was horrifying!” (P15)*

#### **Theme 4: Support Systems Facilitating Blood Glucose Management for Pregnancy**

All participants understood the significance of optimal diabetes self-management in preparing for pregnancy. Achieving a successful pregnancy that resulted in a healthy baby was their primary motivating factor in making all the recommended changes to their lifestyle and achieving optimal blood glucose control. Although participants frequently mentioned the difficulties around diabetes management for a healthy pregnancy, they reported that it was “all worth it” for having a healthy baby.

*“I have a responsibility to care for my child . . . and to care for this baby inside of me. . . . For me, I wasn’t going to let anything get in the way. . . .” (P3)*

*“With the pregnancy, I had someone depending on me, that I was responsible for . . . in my own body! It’s not that my body was that important, but that little baby was. . . .” (P11)*

Because of the complex and often frustrating aspects of blood glucose regulation for pregnancy, participants highly valued effective support, especially informational (relating to diabetes management) and psychological (emotional support and encouragement) support. Almost all participants highlighted the importance of emotional and practical support from their spouse (or their own mother) as being significant in their efforts to manage diabetes successfully on a daily basis. Most participants also discussed having reliable and easy access to certain members of their health care teams (largely nurses or certified diabetes educators [CDEs]) as being crucial for

their successful diabetes management efforts.

*“My biggest support system is my husband. He is very encouraging and is concerned that I stay healthy for our baby. There was a diabetes exhibition this past weekend, and he came with me. We went to lectures in diabetes, in eye care, and current treatment in diabetes. He wants to engage, encourage, and help me.” (P5)*

*“My CDE is wonderful because she is like my cheerleader. She is trying to get me through my goals . . . and even though things aren’t always the greatest, she will point out the positive things. . . .” (P1)*

#### **Discussion**

This study of the experiences and perceptions around blood glucose management in relation to pregnancy among women with type 1 diabetes identified numerous factors hindering and facilitating diabetes management. Themes identified from the data emphasize that psychological health and overall quality of life may be significantly impaired in women with type 1 diabetes while preparing for or during pregnancy. Participants reported struggles to balance their burdensome and often uncertain diabetes management regimen with their routine life demands to achieve a successful pregnancy. A few other studies from outside of the United States that explored pregnancy in this patient population have also presented compelling accounts of women feeling vulnerable, hostile, uncertain, guilty, and extremely anxious throughout the process (18,20,22–24). Implementing preconception programs that help women with type 1 diabetes feel empowered and positive about their pregnancy experience, while also providing information about any potential risks and support for managing these risks, could meet an important need.

Time constraints and routine life stressors were commonly reported as barriers to optimal glycemic management and were probably intensified in this patient group compared to others with diabetes because of the additional burden of routine clinical appointments in preparation for and during pregnancy. Developing opportunities for clinical interactions with such women that do not necessitate in-person clinic visits, such as via the use of telehealth when possible, might help to reduce the additional burden of clinical appointments to some extent, while also allowing these patients to initiate clinical contact when needed.

Participants also reported disappointment and frustration with members of their health care team who were not supportive of their decision to try to become pregnant or who used scare tactics to pressure them into being more rigorous about their diabetes management and control. Negative clinical interactions further added to participants' emotional vulnerability and caused feelings of abandonment, hopelessness, and anger about the lack of support and insensitivity.

Lack of support and empathetic engagement by health care professionals for this patient population has been discussed in reports of studies conducted in other countries (24). Resentment toward and lack of trust in the health care team during a sensitive and complex time such as pregnancy can be especially damaging for both psychological and clinical outcomes. Managing diabetes while trying to become pregnant or during pregnancy can be a demanding process, and a comfortable patient-provider relationship is pivotal for optimal outcomes. Participants also highlighted encounters with members of their health care teams who recognized their hard work and supported them throughout the pregnancy process. In a challenging health situation such as pregnancy complicated by diabetes, patients benefit

when their health-related successes (no matter how small) are acknowledged and commended by their health care team. Participants indicated a considerable need for their health care team to support them to reduce their fears and anxieties around pregnancy.

Targeted interventions that provide opportunities for women to clarify their concerns around diabetes and pregnancy and discuss experiences with others in a nonjudgmental and positive manner could prove beneficial in addressing the psychological concerns often experienced in this patient population. Building in time as part of usual consultations to encourage patients to highlight their diabetes-related successes and frustrations might be an effective strategy to bond with them and understand their barriers and support systems. Developing support groups for women, in which they can meet others in similar situations, might also help to normalize overriding concerns and promote effective problem-solving. Managing pregnancy with diabetes as part of a multidisciplinary team approach involving mental health professionals such as psychologists and social workers also helps in prioritizing patients' psychological health alongside their clinical outcomes. This psychological and social well-being subsequently is likely to contribute to good pregnancy outcomes for both mothers and babies (22).

Support from family members and significant others was discussed by participants as a crucial facilitator of their efforts to manage their diabetes. All women in the sample were married and shared how their husbands played a key role in supporting and encouraging them. Again, this underscores the need for effective emotional support in this patient population to enable them to feel positive and confident about their pregnancy experience (24).

A key strength of this study is that its design allowed for an exploration of patients' experiences and

perceptions of specific barriers that hindered their efforts to manage their diabetes for pregnancy and facilitators that supported them in their attempts to achieve a successful pregnancy. As a result, the study contributes significantly to the literature by highlighting experiences of women from the United States; findings also contribute to the limited literature on psychosocial experiences of this patient population, with implications for patient care.

A limitation of the study is the small sample size ( $n = 15$ ), and a follow-up study involving a larger participant pool is encouraged to confirm or improve these findings. Despite contacting all major endocrinology clinics and diabetes centers in the United States for study recruitment, the study response rate was surprisingly low. The majority of study participants originated from three states: California, Florida, and Illinois. However, despite the small sample, clear themes emerged from participants' accounts of their experiences, which highlight crucial gaps in their care and should be addressed.

Among other barriers, women discussed their need for psychological support from their clinical team as an essential aspect of care while preparing for pregnancy. The American Diabetes Association recommends preconception counseling for all women with childbearing potential, and this study emphasizes the need to assess and support the psychological health of women with preexisting diabetes in preparation for pregnancy. Health care consultations and other clinical encounters that are specifically developed to offer psychological and clinical support to this patient population help patients feel empowered, engaged, and positive about their pregnancy experience. Similar studies are recommended that include members of health care teams caring for this patient population to understand their views and approaches to care.

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## Duality of Interest

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

## Author Contributions

H.S. conducted the study, researched data, and wrote the manuscript. K.I. researched data and contributed to the manuscript. L.G.-F. contributed to the data-related discussions and the manuscript. L.R. reviewed and edited the manuscript. H.S. 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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