

# “Also For My Sake”: A Grounded Theory on the Motivation of Women with Type 1 Diabetes during the Journey of Pregnancy

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## Abstract

**Background:** International focus on lowering pregnancy related complications in women with type 1 diabetes has improved the outcome for both mother and child remarkably. However, research has shown that pregnancy is an extremely demanding and vulnerable time for this group of women and that glycemic levels deteriorate after birth. Little is known of the factors influencing the glycemic control in the post-birth period and this particular period seems unexplored. Therefore, the aim of this study was to explore and illuminate the potential factors influencing glycemic control after birth in women with type 1 diabetes.

**Method:** Grounded Theory was applied to explore the pregnancy journey among postpartum women with pre gestational type1 diabetes. The women were theoretically sampled from 2007-2016. For two of the first ten sampled women, self-determined motivation seemed to improve the journey, why we subsequently explored the importance of self-determined motivation by sampling seven women with presumed higher self-determined motivation from earlier guided self-determination interventions.

**Results:** A total of 17 women aged 20-45 years with pre gestational type1 diabetes were included in the study. A five-stage theory was developed with a core category, “Also for my sake,” explaining how greater self-determined motivation increased the women's ability to manage the challenges of pregnancy and having a newborn. They 1) more easily achieved the green light for pregnancy; 2) perceived pregnancy as enjoyable and manageable; 3) had only a short child-first stage with less attention to their diabetes; 4) recognized and managed a child-or-me dilemma; and 5) achieved a child-and-me balance by prioritizing their long-term health and glucose management.

**Conclusion:** Higher self-determined motivation before pregnancy seems to ease the pregnancy journey, with a potential positive long-term impact on glucose control.

## Introduction

In pregnancy with Type1 Diabetes (T1D), improving blood glucose in women before and during pregnancy successfully reduces birth defects, perinatal mortality and preterm delivery [1-5]. However, HbA1c levels typically rise to pre-pregnancy levels or higher after delivery [6-9].

This post-pregnancy deterioration may be due to exhaustion from the emotional burden of pregnancy [10-12] and concerns about the child's health, which increase the incidence of anxiety and depression [13,14]. Fear of hypoglycemia may also contribute to the deterioration; 29-45% of women with T1D experience severe hypoglycemic events during pregnancy [15,16] despite frequent insulin adjustment appointments with healthcare providers [17-19]. Transitioning to motherhood presents many challenges. Previous blood glucose management strategies no longer suffice [14,20,21] because insulin requirements are halved and breastfeeding both reduces insulin requirements by an additional 20-25% and increases energy needs [22]. Few studies examine the effect on postpartum women with T1D of advice from healthcare professionals (HCPs) about postnatal changes, including psychological reactions, sleep deprivation, altered circadian rhythm and hormonal changes [23]. It is also unclear whether HCP recommendations to maintain higher glycemic levels after pregnancy [17] can have undesirable effects.

Self-determination research demonstrates that intrinsic motivation predicts success at achieving and maintaining significant goals [24]. Self-concordance research similarly shows that goals that are aligned with one's values and beliefs are more easily achieved and maintained and associated with higher satisfaction [25]. These concepts may affect how women perceive challenges and accomplishments throughout pregnancy, but little is known about their effect among pregnant women with T1D. Consequently, we extended research initiated in a Danish pilot study [26] with

the aim of exploring motivational factors among women with T1D during their pregnancy journeys.

**Methods**

We applied Grounded Theory as described by Glaser [27]. Using theoretical sampling, we identified pregnant women with T1D receiving care in 2007-2016 at a Danish hospital specializing in diabetes. The hospital is responsible for preparing women with T1D for pregnancy and following them throughout gestation to address glycemic control. Obstetricians and midwives at another hospital performed pregnancy-related monitoring. Health care in Denmark is public and free of charge.

We began by examining data from the pilot study [26] and continued to include as participants women with pre gestational T1D who had successfully completed a pregnancy and given birth to a live-born child with no birth defects. We excluded women who could not read or write Danish.

In the outpatient clinic, women gave permission for the authors to contact them by email or text message to provide information about the study purpose and expected length of interviews. Women who did not respond to initial messages were contacted by phone after two weeks. After the authors provided oral and written information in a face-to-face meeting, the women signed written informed consent. Only one woman declined participation, citing serious illness among close relatives. All participants could choose the interview date, time and location to accommodate their daily routines. Interviews lasted an average of 49 minutes (range, 17-90) and were carried out three weeks to 24 months after delivery. All interviews were recorded and transcribed verbatim.

In keeping with a basic premise of Grounded Theory [27], theoretical sampling and data analysis were conducted as an ongoing process using the constant comparative method to identify a core category, related categories and subcategories. During initial analyses, the idea emerged that women managed challenges of the pregnancy journey according to the degree to which their motivation was characterized by autonomy, perceived competence and relatedness with HCPs [28-30], which are collectively referred to hereafter as Self-Determined Motivation (SDM). Among the first ten women sampled, we assessed two as having a high level of SDM, based on

such statements as, “My blood glucose hasn’t caused me that much concern, because I have had a good regulation from the beginning. I’ve eaten correctly and had good regulation throughout my diabetes period” (W5) and “We’ve had it in the family, so I know a lot about type1 and how to live with it, instead of living for it” (W9).

To explore the significance of SDM in pregnancy among women with T1D, we needed a sample of women with varying degrees of SDM before pregnancy. Women who had participated in earlier interventions and could thus be assumed to have a higher level of SDM were available at the hospital, and we consequently decided to continue the theoretical sampling among them. Of seven included women, two had participated in a randomized controlled trial [31] four had participated in an unpublished pregnancy-preparation intervention, and one woman had participated in both. This sampling procedure was in accordance with an idea proposed by Dewey [32] who, among others, inspired the originators of grounded theory [33]. Dewey proposed that cases must sometimes be self-constructed:

Theoretically, one sample case ‘of the right kind’ will be as good a basis for an inference as a thousand cases; but cases of the ‘right kind’ rarely turn up spontaneously. We have to search for them, and we may have to ‘make’ them [32, p. 175].

Although these cases were not constructed specifically for this study, they did not appear spontaneously. They were available as a result of participation in previous interventions. Figure 1 illustrates the sampling strategy.

All authors took part in the analysis. Two authors (L. D., V. Z.), who started the initial pilot study in 2007 [26] ensured continuity of the research process over time. K.H.-K. and K.W.K. enabled continuation of the study and theoretical saturation.

**Ethics**

All participants were guaranteed anonymity and informed that withdrawal was possible at any time and would not influence their treatment in any way. The study was approved by the Danish Data Protection Agency, j.nr. 2012-41-0099.

**Results**

**Participants**

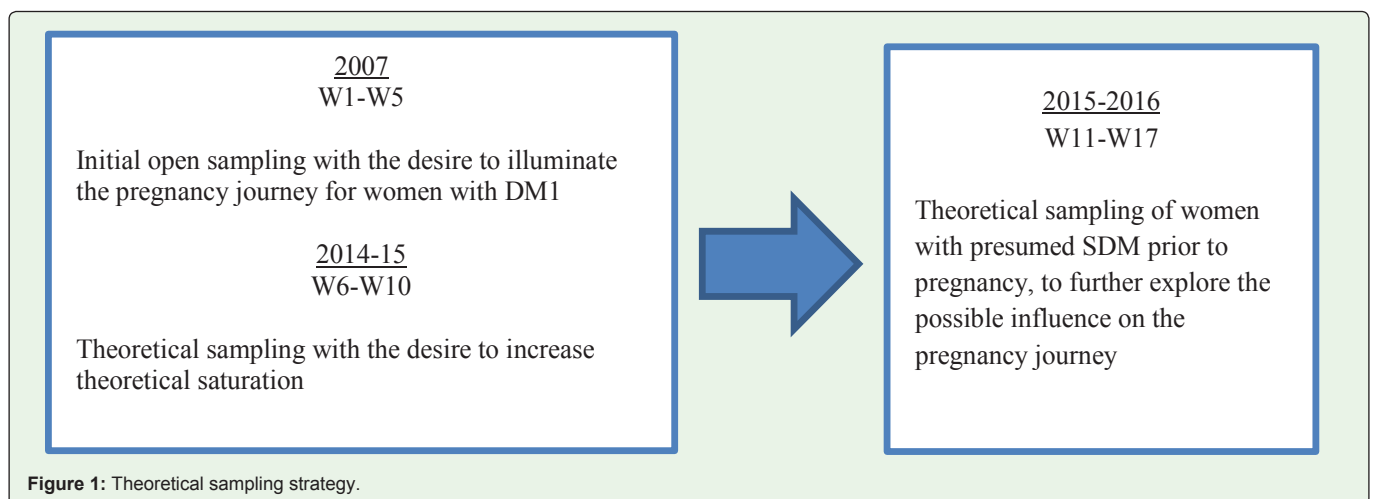


Figure 1: Theoretical sampling strategy.

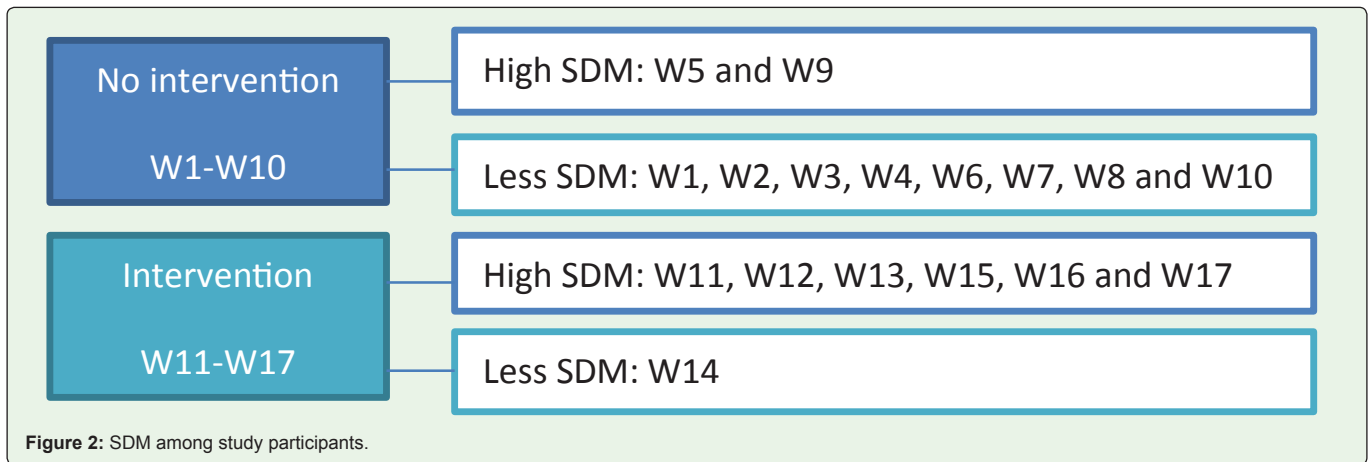


Figure 2: SDM among study participants.

Seventeen women aged 20 to 45 years with pre-gestational T1D diagnosed at 3 to 30 years of age were included in the study. All women received usual pregnancy care. In addition, due to a history of poor glycemic control and lack of illness integration, seven women had previously been offered a self-determination-based intervention. Guided Self-Determination (GSD) consisted of semi-structured reflection sheets and conversations with HCPs [31,34]. Three of these women had a current or former history of an eating disorder. Study participants were categorized as having higher (8) or lower levels (9) of SDM, as illustrated in figure 2.

**The grounded theory: Also for my sake**

The constant comparative analysis resulted in a grounded theory with the core category of “Also for my sake” (Figure 3), which explained how SDM influenced five stages of the pregnancy journey: 1) the green light for pregnancy was more easily achieved, 2) pregnancy

was perceived as enjoyable and manageable; 3) a “child-first” stage with a diminished focus on T1D self-management was shortened; 4) a “child-or-me” dilemma was recognized and openly managed ; and 5) a “child-and-me” balance was reached that reflected the ability to prioritize one’s long-term health and glucose management.

**Also for my sake**

The core category of “Also for my sake” reflects an attitude associated with higher SDM and of major concern throughout pregnancy. The core category content reflected an overall ability to prioritize self-management. This was achieved by eight women, regardless of previous glycemic control, unaided or with support from HCPs. Nine women with lower degrees of SDM did not achieve this goal; they did not manage to simultaneously balance their health and their child’s health.

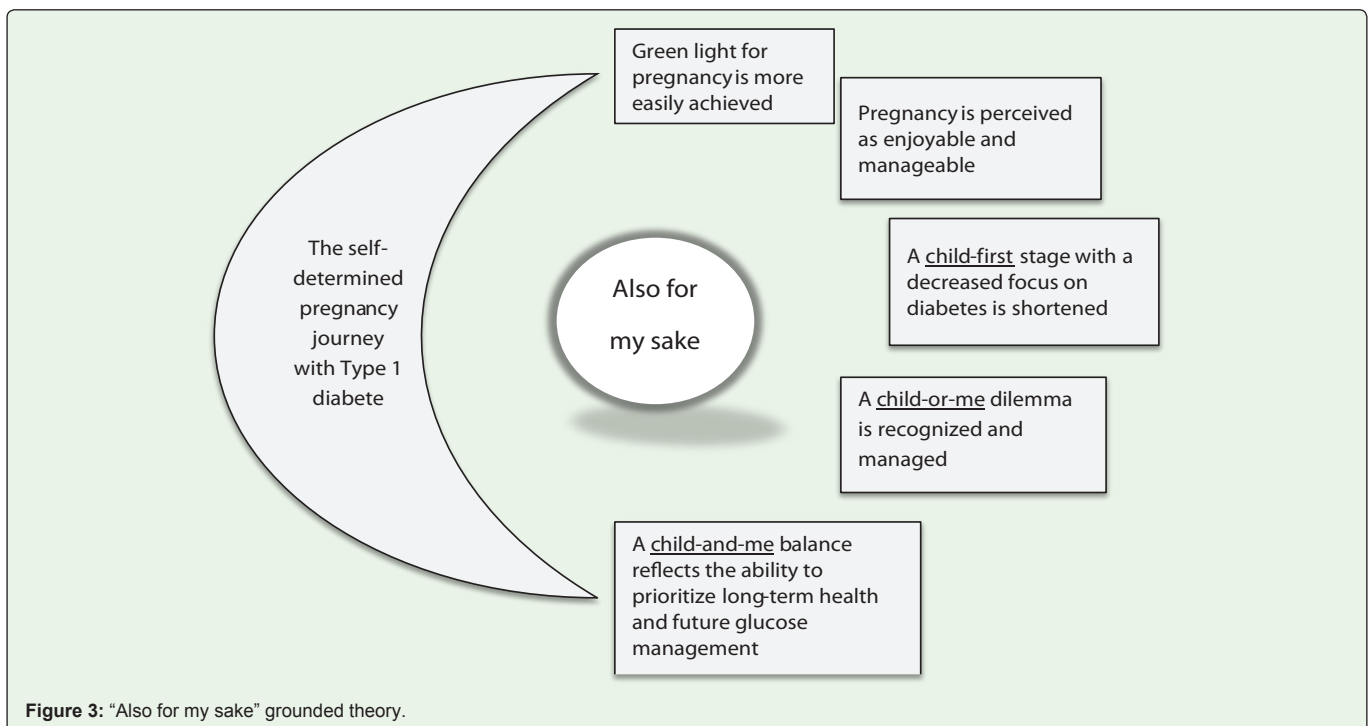


Figure 3: “Also for my sake” grounded theory.

### Getting a green light for pregnancy

All informants described challenges in achieving the green light for pregnancy of a glycated hemoglobin level of 53 mmol/mol or below, especially women who had needed support from HCPs to reach acceptance and illness integration. Their health behavior patterns such as missing HCP appointments and not performing necessary self-management tasks of T1D prevented them from achieving the necessary HbA1c control. Thinking that any effort would be fruitless, some women had lost faith in their ability to ever control their disease and become pregnant. Five women gave full credit to the earlier intervention for reaching levels low enough to get a green light for pregnancy. Of the five, two had had HbA1c levels above 100 mmol/mol for several years.

### Perceiving pregnancy as enjoyable and manageable

For women with less SDM, pregnancy was experienced as particularly challenging and exhausting. Their efforts to prioritize their T1D arose solely from their wish for a healthy child. Managing their T1D, with externally imposed requirements for tight HbA1c regulation and constant self-control, was all consuming: "The diabetes has been overwhelming. Finally the blood sugars completely took over my life" (W1, diagnosed at age 5).

In contrast, women with more SDM described pregnancy as a particularly good period in their lives. Achieving satisfactory blood glucose levels produced feelings of pride, fulfillment and improved physical well-being, which was a novel experience for some.

Being pregnant was a good period, and the time before that was also really good. I felt...I was proud of myself that it could be done, even for me with my history, which had been...uphill (W12, diagnosed at age 8).

One woman with higher post-intervention SDM compared her current pregnancy experience to her first pregnancy, which she described as having been dominated by fear and anxiety. She also reported that new tools made her feel competent and in control.

Actually, if you compare the two pregnancies, so much has happened. The first time I felt a big finger pointing at me, and everything was terrible. There was nothing positive in my first pregnancy ... If you are given the tools, which I have been this time, then it is at least 50% less difficult than it was the first time (W15, diagnosed at age 3).

This informant was conscious of her newfound competence and enjoyed the experience of challenges that were easier to manage and diminished external control.

For women with less SDM, the birth of a healthy child was a tremendous relief after an exceptionally challenging pregnancy. For those with higher SDM, a healthy child was the fulfillment of a positive expectation. For all women, the happiness of becoming a mother was quickly interrupted by new T1D management challenges.

### Shortening a child-first stage with less focus on diabetes

After delivery, participants lacked specialized assistance adjusting insulin levels to address their changed needs. Advice from HCPs was limited to suggesting they aim for higher glycemic levels to avoid hypoglycemia. One woman described her experience of this information in relation to her discharge from the maternity ward:

I don't think I had the best experience in regards to my diabetes and the hospital, after I gave birth. They came and told me which insulin dose I should take, and then they gave me the pamphlet [standard recommendations on blood glucose regulation]. OK, it's great that I can be discharged, but I haven't talked to a diabetes doctor yet. No one has looked at my measurements. What now? I felt as if I went out the door without any control at all (W2, diagnosed at age 19).

All women, regardless of preparation, described the time after returning home with a newborn as turbulent. They experienced a severe lack of energy and described everyday life as chaotic and unpredictable, with room for nothing but the child's needs. A newborn and related challenges took precedence over established self-care routines, and managing T1D became less of a priority.

The first week was chaotic. Three hours after having dinner I could sit there and look at the insulin pen; 'oops, by the way, there was surely something there': I didn't measure my blood glucose. I did nothing. So it has been turbulent (W1, diagnosed at age 5).

Informants experienced the comprehensive support they had received from HCPs during pregnancy as disappearing overnight. Simultaneously, they struggled with making room to manage their T1D while taking care of a new baby. All attention was focused on the child. This led to a feeling of abandonment: "That focus on you, where it is all about you - and then suddenly you are completely left to yourself. That was extremely hard". (W15, diagnosed at age 3). Informants' partners also transferred their focus to the child, as illustrated by the following quote:

During my pregnancy we talked about my diabetes every day and looked at my numbers every single day. And we adjusted them - not every day - but often. We don't do that anymore... when I ask him about my glucose values or try to get help from him, then he's not interested. He doesn't have the time. He would rather focus on [the child] (W3, diagnosed at age 27).

The challenges of everyday life with an infant required informants to continuously prioritize their child. Participants felt that it was almost impossible to consider both their T1D and their child. However, the women with higher pre-pregnancy SDM demonstrated a stronger capacity to take action and seek the help they needed to regain lost control, as expressed by a woman who compared her first and second pregnancy:

I think I was better prepared [after GSD] because I had taken control and I dared to do the things I had to. But I have to admit, I wrote my doctor: 'Can I come see you?' And then she said: 'Well are you in trouble?' And then I said: 'No but I have a need' (W15, diagnosed at age 3).

Several women expressed feeling that they had earned the right to a break from T1D after a challenging and demanding pregnancy. However, women with higher SDM described prioritizing T1D in the weeks following delivery as a temporary situation.

It's fine [handling T1D postpartum] but not the most important thing at that time. It's this little human being. But I clearly believe that with the preparation I had [GSD], you find your way back much easier (W12, diagnosed at age 8).

## Recognizing and managing a child-or-me dilemma

The urgent need to resume managing T1D quickly became apparent, resulting in an emerging dilemma for informants of needing to choose between caring for their child and caring for themselves. One woman described an experience of hypoglycemia and needing to choose between leaving her screaming child in the bedroom to get some juice from downstairs or bringing the child with her and risking falling down the stairs and hurting them both: "I actually know how to prioritize. I would always put him first, but in this situation, putting him first might be to leave him and see to the hypoglycemia first" (W1, diagnosed at age 5).

Women with higher SDM more frequently verbalized difficulties with T1D. They expressed thoughts about how to prioritize T1D again. In motherhood, they could draw on their experiences and apply tools they had learned from interventions. They believed that good glycemic control was an achievable goal, which enabled them to start regaining control after the first turbulent period.

I also feel that I do know what has to be done. Not just with the numbers - also up here [points at her head] - quietly make the right decisions, change a little bit at a time and, then it all just flows easier. And that is the most important lesson I brought with me from GSD; to believe that I can do it, I have the necessary tools... If it goes off track, then I can get back on track I couldn't have done that before GSD. At that time I thought like: 'This? This will never succeed'. 'I can't do anything'. 'This is shit'. 'Everything is wrong' (W12, diagnosed at age 8).

Women recalled the combination of good glycemic control during pregnancy, a sense of physical well-being and the feeling of being in control of T1D as a successful experience. For many of the women, such an experience had been previously unattainable for years-if not the entire duration of their disease-especially for those who had needed an intervention. One woman described her wish to repeat this experience as her major motivational factor for glycemic control.

I felt great inside, you know deep down, because my blood sugars were so pleasant. I actually felt really, really well. Afterwards I've actually told my practitioners that if possible, I would like to fight my way back down again, because I felt so well. Not because I knew that my levels were good, but because I physically felt so great being at that level and not having those large fluctuations. (W11, diagnosed at age 3).

Women with more SDM reflected on finding a way to balance both the baby and T1D in everyday life. They all recognized that the responsibility for managing their disease was theirs alone. "I'm the one who has to do it. The Diabetes Hospital can't help me in that way. They can support me... but... I have to do the actual work myself, I am aware of that" (W12, diagnosed at age 8).

In contrast, among women with less SDM, the shift of attention away from their T1D quickly became a permanent condition. Several informants realized that their good glycemic regulation during pregnancy was related to the many appointments and assistance from HCPs, rather than their own improvement.

I have grown accustomed to the blood glucose values being doubled digits. But I would rather that they weren't. I can certainly

feel that I have to be careful; I have to watch out that I don't return too much to the life from before [the pregnancy] (W6, diagnosed at age 12).

The women with less SDM were less aware that they had lost control. In some cases, they fell back into old behavior patterns.

Somehow ... I had hoped that it would have become a part of me, right? That I had accepted my diabetes as it was, right? But now I think that I've returned to my old habits pretty quickly (W14, diagnosed at age 30).

## Achieving a child-and-me balance

For the women with more SDM, the final stage was no longer about choosing between caring for oneself or caring for a child. T1D self-management and taking care of the child were simultaneously managed in a child-AND-me balance.

Well you are used to it [T1D], that is, measuring your blood glucose and stuff. Of course it's a different thing when you have a little one - it takes a little longer ... Well you practically have both hands free when you are breastfeeding right? So if the blood glucose meter is right next to you, then you can measure it while breastfeeding. I don't think that I have given it as much thought as I had imagined I would (W5, diagnosed at age 26).

Either without assistance or through the GSD intervention, women with more SDM seemed to reach this balance with less effort than they had anticipated.

This course helped me get the important things under my skin again so I was the one in control [of T1D]. And I think that was actually why the process was so relaxed and natural for me (W11, diagnosed at age 3).

They successfully implemented the knowledge and skills acquired through pregnancy, and the positive experiences provided sustained motivation for optimal glycemic regulation.

I became much more familiar with the insulin pump. How you adjust it. I also learned that it pays off to measure your blood sugar many times during the day. I learned this from the pregnancy. Because there I saw what I was able to reduce it to [the HbA1c] (W16, diagnosed at age 3).

A few women with higher SDM were even able to critically examine the previously mentioned instructions from HCPs to aim for higher glycemic levels to avoid hypoglycemia. They had developed sufficient self-confidence and belief in their own abilities to make autonomous decisions, manage T1D, and sustain good glycemic regulation. One woman had blindly complied with similar instructions from her HCP after her first childbirth and experienced deteriorated glycemic control as a result. She explained how she reacted quite differently when her second child was born, after the experience from her first pregnancy and having increased her SDM after an intervention.

I refused to aim as high as they advised me to do the second time. I knew what it would lead to. So I actually went lower than they recommended, after I got home. It had something to do with me being in control of my own life and my diabetes and I knew what would be best for me (W15, diagnosed at age 3).

Conversely, the women with less SDM more frequently followed HCPs' instructions regarding higher glycemic levels, despite being aware of the possible consequences. They continued to use these instructions as a reference point—even as an excuse—for several months after delivery, despite having ceased breastfeeding and knowing that it did not apply any longer.

They tell you that [blood glucose levels] should be, or not 'should be', that they're acceptable up to 14, and I just thought: 'Oh boy!' I've thought about it but unfortunately I have kept it in my mind: 'Oh well, it's OK that the blood sugar is at 14 (W6, diagnosed at age 12).

All women with less SDM soon realized that the good regulation in pregnancy was not due to their efforts alone; it was more accurately attributed to the frequent appointments and active help from HCPs. During pregnancy, they felt in control and expected that maintaining it after birth would be easy. Disappointed, they felt resigned to old habits or followed unhealthy behavior patterns.

Finally I actually waited to take my insulin until after I had eaten, because I never knew when or how much [food] I would be able to have [laughing] (W6, diagnosed at age 12).

In contrast to women with more SDM, who found a child-and-me balance, women with less SDM appeared to have an attitude to future glycemic control characterized by a lack of awareness of the long-term implications of their actions: "Now I am the only one affected."

## Discussion

The grounded theory described in this article explains the importance of SDM throughout pregnancy for women with T1D. Although the importance of self-determination and motivational aspects for diabetes in general have been widely researched [35], studies focusing on diabetes and pregnancy are scarce. To our knowledge, our study is the first to explore the significance of SDM before, during and after pregnancy for women with T1D, including mechanisms likely to influence long-term glycemic control after delivery. We consider the theory to be saturated because it is coherent, embraces patterns seen in all 17 theoretically sampled women with various degrees of SDM and includes women previously struggling with long-term suboptimal regulation.

The grounded theory offers insight into mechanisms that influence the ability of women to integrate T1D into life as a mother months or even years after delivery. As previous research has indicated, the horizon of interest in T1D management among pregnant women among HCPs tends to end at childbirth [1,2,10,21,26]. In our study, this finding appeared to also apply to relatives. Both HCPs and partners seemed to lose interest in informants' glycemic control after birth. This resulted in women feeling abandoned during a critical period in which, according to transition research, they still need support [14,21].

Prior research reports extraordinary vulnerability during pregnancy, an elevated risk of complications and an increased HbA1c after giving birth, but interventions have not yet focused on these difficulties [10,14,20,21,36]. Intervention research has just begun to examine supporting women with T1D during this vulnerable period [37]. Advancements in T1D that decrease risks of fetal and maternal morbidity and mortality during pregnancy by improving

glycemic control are remarkable and important [1,2]. However, the motivation behind decreased glycemic control may also be of major importance, considering its influence on postpartum regulation. This is particularly important because women with T1D have an elevated mortality rate compared to both men with T1D and the general population [38]. In younger adults, the sex difference in T1D is evident in the disparity in glycemic control; girls and younger women more often have persistently poor control [39,40] and are 17% more likely than men to have multiple complications [41]. Additionally, evidence that glycemic control deteriorates after delivery to levels that are worse than those before pregnancy has not been addressed [6-9].

The 'Also for my sake' grounded theory may help explain why women with T1D have fewer children than women in the general population, including their siblings without diabetes [42,43]. Many people have a basic need to reproduce and start a family; thus, being childless or infertile has the potential to negatively affect identity and self-image [44].

The recommendation of HCPs before new mothers leave the hospital is to maintain higher blood glucose levels. This seems to reflect their concerns about the heightened risk of hypoglycemia as a result of breastfeeding. Though given with the best intentions, the imprecise nature of this advice can be harmful. Some participants followed the advice despite an awareness of the detrimental effect, and others, especially those with lower SDM, let the advice function as an excuse for maintaining high glycemic levels even months after stopping breastfeeding. In contrast, when several women with more SDM explicitly refused to follow this advice, they demonstrated an example of constructive non-compliance as described by Thorne [45]. The greater SDM that is inherent in autonomous judgment reduced postpartum vulnerability to both questionable advice and a perceived loss of interest from HCPs and partners. This is consistent with Sheldon and Elliot's description of the importance of self-concordant goal striving, in which goals that are consistent with a person's values and inner beliefs are easier to obtain and maintain and are connected with higher satisfaction [25]. Self-concordant goal striving among women with higher SDM may explain why they associated their pregnancy with greater levels of joy and well-being. Although all the women in our study experienced an objectively successful, full-term pregnancy, we note that for some this success seemed to depend entirely on the engagement of HCPs during pregnancy. It follows, therefore, that only those with higher SDM were able to maintain focus and prioritize T1D after delivery.

Our study has several limitations. First, we only used qualitative data in our judgment of the degree of SDM exhibited by informants. No cut point divided study participants into high and low SDM groups, but scores on variables such as Perceived Competence with Diabetes (PCD), autonomous motivation measured by Treatment Self-Regulation Questionnaire (TSRQ) and relatedness with HCPs measured by Health Care Climate Questionnaire (HCCQ) may have provided a way to quantify SDM levels [46-51].

Continuous theoretical sampling of informants spanned nine years. One might expect an evolution in treatment strategies over time, which could have created a study limitation, related to time-related differences in experiences, for example, an increase in insulin pump use. However, this appeared to not be the case because the treatment strategy in Denmark during this period was unchanged

[52]. Additionally, insulin pen and pump users are both represented in the sample, and the observed variations in the women's reports appear independent of the period during which they participated in the study.

The procedure of theoretically sampling women who had participated in an earlier SDM-increasing intervention might be considered unconventional. Although these cases were available at the hospital and not constructed for our investigation, we still regard the procedure as an example of Dewey's [32] recommendation that selecting the right cases sometimes involves cases that have been constructed. We note that our procedure in no way tested the impact of the GSD intervention, the impact of which has already been documented among women aged 18 to 35 years with T1D [31]. The procedure succeeded in its intended purpose of generating a sample that included women with the necessary variation in degrees of SDM and those with prior significant difficulties managing their diabetes, who turned out to be rich informants.

The grounded theory "Also for my sake" illustrates how consistent challenges of becoming a mother with T1D were reduced in women with strengthened SDM—even for those who initially had demonstrated resistance, lack of illness integration and long-term suboptimal regulation. We therefore hypothesize that improving glycemic control in pre pregnancy care for women with T1D using SDM-supporting interventions should be further investigated. Our findings suggest that this approach may result in a threefold benefit: increased joy and well-being during pregnancy, reduced vulnerability in early motherhood and the chance for improved long-term glycemic control.

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