Type 1 diabetes and pregnancy: a phenomenological study of women’s first experiences

Maria Woolley
Registered Midwife, MSc

Colin Jones
PhD, BAHons, CertEd, RN, Senior Lecturer/Research Lead in Advanced Practice

Joanne Davies
FRCOG, Consultant Obstetrician & Gynaecologist

Usha Rao
MBBS, MRCP, Consultant Physician in Diabetes and Endocrinology

David Ewins
MBChB, FRCP, Consultant Physician in Diabetes and Endocrinology

Sunil Nair
MBBS, MRCP, Consultant Physician in Diabetes and Endocrinology

Frank Joseph
MD, FRCP, Consultant Physician in Diabetes and Endocrinology

Abstract
The aims of this study were to explore women’s perceptions and experiences of being pregnant and having pre-existing type 1 diabetes mellitus, and to assess their physical, social, psychological, emotional and educational needs during their transition to motherhood.

The qualitative design incorporated a purposive sample of seven women in their first pregnancy, who participated in one-to-one interviews with a researcher at 15–20 and 32–36 weeks gestation, and at 6–8 weeks post-partum.

Qualitative analysis identified seven key themes from the data including: knowledge; physical and psychological impact; control and trust; catalyst to action; organisation of care and communication; attendance and intervention; expectations and systems.

This study has shown that most women with diabetes who become pregnant are resigned to the fact that their pregnancy is considered high risk, and are willing to play their part to achieve a positive pregnancy outcome. However, they would also like to ‘do the normal pregnant bit as well’, ‘normalise it and make it a nice experience’ and make it feel ‘less fragmented’. This woman-centred experience of pregnancy care, in women with type 1 diabetes mellitus, may motivate health professionals to revise their approach to care, prompt them to utilise the skills of each individual member of the multidisciplinary team to its full strength and potential, and assist in the provision of a positive, balanced and more holistic approach to care, specific to this client group. Copyright © 2015 John Wiley & Sons.

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Key words
diabetes; pregnancy; transitions; motherhood; changes; turning points

Introduction
Women with pre-existing type 1 diabetes mellitus (T1DM) account for 0.27% of the 650,000 women who give birth in England and Wales per year. Diabetes in pregnancy is associated with significant risks to the woman and her unborn child, and women with diabetes who are planning to become pregnant should be informed that establishing and maintaining good glycaemic control before conception and throughout pregnancy will reduce, but not eliminate, these risks.1,2

Pregnancies in women with diabetes are consequently treated and managed as high risk by a multidisciplinary team (MDT) which includes: obstetricians, diabetologists, diabetes specialist midwives, diabetes specialist nurses, dietitians and allied health care professionals.3 The care algorithm devised by NICE, which specifically targets ante-natal care for women with diabetes, is considered to be best practice in the management of women with pre-existing T1DM.1

The National Service Framework (NSF) for diabetes proposed the implementation of standards of care for women with pre-existing diabetes to empower and support them to have a positive experience of pregnancy and childbirth, promote physical and psychological wellbeing, and optimise the health of their babies.3

The NSF3 proposed that keeping women with diabetes and their partners fully informed and involved in decision making would promote a more positive birth experience, in view of the negative perception of highly medicalised and interventionist maternity care for women with diabetes. The transition to motherhood was identified as being particularly stressful and difficult by the participants in the study by Rasmussen et al.4

While medical care for pregnant women with diabetes is becoming standardised, with the implementation of the NICE guidelines, NHS trusts now need to focus on whether women feel that their social, psychological, emotional and educational needs are being met during their transition to motherhood in order to optimise their birth experience. There is some research within the
UK to establish whether pregnant women with pre-existing T1DM have similar experiences during their transition to motherhood. This qualitative, phenomenological, exploratory study aims to build on this and examine the participants’ own perceptions and experiences of being pregnant and having pre-existing T1DM, and whether the experience changes throughout pregnancy and the post-natal period.5–7

Methods
Participants with T1DM in their first pregnancy were interviewed to explore their perceptions and experiences of pregnancy and the early post-natal period.

Their physical, social, psychological, emotional and educational needs during their transition to motherhood were also evaluated. The protocol was approved by the National Research Ethics Service Committee Northwest-Cheshire (11/NW/0074) and informed consent was obtained from all participants.

Potentially eligible participants were recruited from the antenatal medical disorders clinic of a district general maternity hospital that has on average 3200 deliveries per annum. Twenty women with T1DM attended the unit in 2012. This equates to 0.62% of women annually, whose pregnancies are complicated by diabetes. Participants were eligible if: it was their first pregnancy; they had pre-existing T1DM; they were aged between 18–45 years with no other medical conditions, physical disabilities or serious mental health problems; and they had the ability to speak and read English. Eligible participants were selected and approached initially by members of the diabetes team or by the diabetes specialist midwife. Women who showed an interest in taking part in the study were given a Participant Information Sheet and were asked if they were interested in becoming involved on their subsequent clinic visit. Those who agreed were contacted directly by the researcher (MW). A purposive sample of seven women was recruited to the study.

Interviews were scheduled to be conducted at 15–20 weeks gestation, 32–36 weeks gestation and 6–8 weeks post-partum, and were arranged to coincide with pre-arranged clinic visits to minimise inconvenience. Two participants attended for all three interviews, while the remaining five attended only two interviews due to: scheduling problems; delay in response; pre-term delivery; and non-attendance. The interview attendance details are shown in Table 1. Each interview was carried out on a one-to-one basis with the researcher in an informal setting within the hospital. Each session lasted between 30–60 minutes and was terminated once saturation was reached. Saturation of the topic may not have been achieved, with the limited number of participants, but each interview was terminated once individual saturation was reached and themes became repetitive. Sessions were audio-recorded using two digital recorders. A series of open-ended questions were utilised during the first interview as listed below.

**Interview questions**
A series of open-ended questions were used as a starting point for discussion during the first interview, though participants were encouraged to introduce any topic they felt was important. Participants considered the following questions: (i) ‘Tell me about the services you hoped to receive as a person with pre-existing diabetes once you became pregnant?’; (ii) ‘Can you describe how you’ve been kept up to date with your progress and how you’ve been involved in managing your care?’; (iii) ‘How have you been supported, not only with regard to your medical condition but as a soon to be mother during your care?’; (iv) ‘What have been the positive and negative aspects of your care?’; (v) ‘If you could change anything about the care you have received what would it be and why?’; (vi) ‘Tell me about anything that could be done to improve the care you have received?’

**Data analysis**
Audio-recordings of the interviews were listened to on three occasions and transcribed verbatim by the researcher. Data analysis was undertaken utilising the Colaizzi method.8,9 Each transcript was read on six occasions as this enabled the researcher to gain greater familiarity with the phenomenon by becoming ‘fully immersed and marinated in the data’.10 Significant statements were then highlighted manually and extracted from the text and formulated into clusters of themes. Connections between the themes and sub-themes that were manifest in the data were explored, and the data were then condensed into seven emergent themes which gave a comprehensive description of the experience.9 This process allowed for verbatim quotes to be used within the study’s results section, increasing the trustworthiness of the interpretation and credibility of the findings.9 Interview transcriptions and themed data were read by the consultant diabetologist, and the themes were discussed with the research team until a consensus was reached, in order to verify the reliability of data collection and rigour in the analysis process.9

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>15–20/40 weeks gestation</th>
<th>32–36/40 weeks gestation</th>
<th>6–8 weeks post-partum</th>
<th>Total interviews attended</th>
</tr>
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<td>Yes</td>
<td>Yes</td>
<td>3</td>
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<td>7</td>
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<td>Yes</td>
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</tr>
</tbody>
</table>

Table 1. Interview attendance by participants
Women considering pregnancy or who become pregnant are then encouraged to work alongside the diabetes team to optimise their capillary blood glucose (CBG) and HbA1c levels to minimise the risks to both the mother and fetus.12 ‘...because we know the implications of being pregnant in diabetes ... we worked with them for about 18 months ... there was a dramatic change to the HbA1c...’ (Interviewee: 2).

The women felt that through education and support they were empowered to deal with their pregnancies:11 ‘We’ve been kind of able to enjoy the pregnancy ... doing the pre-pregnancy with the diabetes team has made the pregnancy a lot safer and less stressful; time invested has really paid off,’ (Interviewee: 2).

Education around fluctuations in insulin requirements was a source of concern. Although women were informed that their insulin requirements would, on the whole, increase as their pregnancy progressed, they were unaware that less insulin might be required in the early stages of pregnancy and in the early postnatal period which caused some anxiety and stress, where the education was not explicit. The effects of breast-feeding on CBG were also not fully explored, and in some cases impacted on decisions to breast-feed.

The knowledge that labour would be induced early elicited mixed reactions from the participants (even in the same participants), albeit they were all aware that this was to ensure the health of their baby.

‘...the thought of me going into labour uncontrolled, worries me more than them turning round and saying that they want to induce labour,’ (Interviewee: 4).

‘...Women were talking about their due dates “...if I go a day past I want to be inducted” and I thought ... you’re so lucky to be able to let it run its natural course. I know early induction is to keep me and him safe but...’ (Interviewee: 1).

Despite regular attendances with the MDT present, some participants stated that they used the internet as a source of information due to a feeling that certain information was not as explicit as it could have been.

‘...there are obviously reasons why they don’t tell you certain things at certain times,’ (Interviewee: 3).

‘...you say you’re not going to look on the internet, then you start looking on the internet ... and scaring yourself silly...’ (Interviewee: 4).

Physical and psychological impact

Women felt that the physical and mental effort that goes into maintaining their diabetic control within the optimum range, for a safe outcome for mother and baby, is not always acknowledged.13-15 The new challenges they had to endure also provoked feelings of resentment towards their chronic condition.16 ‘...it’s a hospital; it’s got to be medical. But it feels very medical ... and very much focused on ... the anxious side of things, the negative side of things,’ (Interviewee: 3).

‘...people forget I’m pregnant because there’s so much focus on my diabetes,’ (Interviewee: 2).

It just feels like it’s not quite realised ... how hard it can be ... it’s a constant, constant battle, the injecting is nothing. It’s everything else that goes with it that you have to control all the time,’ (Interviewee: 1).

‘Well I don’t know what is normal and what isn’t normal ... I was here once or twice a week, every week ... that just became my norm I guess,’ (Interviewee: 3).

Control and trust

Women and their family members felt that they were empowered by being treated as partners in their care.

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**Table 2. Demographics of participants**

<table>
<thead>
<tr>
<th>Interviewee</th>
<th>Ethnicity</th>
<th>Age</th>
<th>Age at onset of diabetes</th>
<th>Gestation at delivery</th>
<th>Delivery mode</th>
</tr>
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<tbody>
<tr>
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<td>26</td>
<td>38+1</td>
<td>Non-rotational forceps</td>
</tr>
<tr>
<td>2</td>
<td>White British</td>
<td>37</td>
<td>7</td>
<td>37+1</td>
<td>Emergency Caesarean section</td>
</tr>
<tr>
<td>3</td>
<td>White British</td>
<td>32</td>
<td>22</td>
<td>31+5</td>
<td>Emergency Caesarean section</td>
</tr>
<tr>
<td>4</td>
<td>White British</td>
<td>41</td>
<td>29</td>
<td>38+2</td>
<td>Emergency Caesarean section</td>
</tr>
<tr>
<td>5</td>
<td>White British</td>
<td>29</td>
<td>4</td>
<td>33+5</td>
<td>Elective Caesarean section</td>
</tr>
<tr>
<td>6</td>
<td>White British</td>
<td>35</td>
<td>24</td>
<td>37+4</td>
<td>Non-rotational forceps</td>
</tr>
<tr>
<td>7</td>
<td>White British</td>
<td>37</td>
<td>29</td>
<td>37+2</td>
<td>Emergency Caesarean section</td>
</tr>
</tbody>
</table>

**Results**

**Demographics**

Demographic characteristics of the participants are shown in Table 2. Diagnosis of T1DM was made in all participants by positive glutamic acid decarboxylase (GAD) antibody test or initial presentation with diabetic ketoacidosis.

**Themes identified**

Qualitative analysis identified seven key themes: knowledge; physical and psychological impact; control and trust; catalyst to action; organisation of care and communication; attendance and intervention; expectations and systems. Although each theme is presented separately, they are all interconnected and have common characteristics. Quotation marks are used to identify verbatim comments by the participants.

**Knowledge**

The importance of pre-conception care and planned pregnancy seems to be an integral part of the education programme for women with T1DM of child-bearing age.11 Participants commented that:

‘I’d had leaflets, sort of over the last 10 years going to diabetic clinic: “If you get pregnant, make sure you plan”,’ (Interviewee: 5).

‘...before you’re pregnant they give you information about ... what high blood sugar could do to a baby and it’s not nice reading; I should imagine it scares a lot of people to keep their blood sugars good,’ (Interviewee: 1).
‘...When I first came in and he [consultant diabetologist] talked to the midwife and then he spoke to me, and I liked that … it was nice … I felt really involved,’ (Interviewee: 2).

‘...my husband has been to every single appointment … they made him feel welcome … and he has got as much information as me … and we felt, we were in control, and we were managing my diabetes, with support, but they’re there for us if we need any more help,’ (Interviewee: 2)

Psychological difficulties arose once the management of their condition was taken away from them during the labour process.

‘I found it hard from the moment they took my pump off me till I got it back … because I’ve been diabetic for 27 years, to surrender that control … I’ve done my injections since the day I was diagnosed at seven, so to let go of it … I wasn’t allowed to keep insulin with me … that’s where I felt quite out of control,’ (Interviewee: 2).

‘They took me off my insulin pump … that sense of not being in control … It’s about trusting other people,’ (Interviewee: 3).

Catalyst to action

Participants were not always willing partners in their care, displaying suboptimal management of their condition, prior to the pregnancy.13

‘I was living at quite high sugars and I wasn’t taking insulin. I know exactly, what can happen, but it’s the thought of probably it won’t happen to me,’ (Interviewee: 4).

‘...It’s just laziness and … it wasn’t that I couldn’t be bothered, it was I’ll behave me’ self tomorrow, I’ll get on top of it next week an’ there’s always been an excuse,’ (Interviewee: 5).

Pregnancy seemed to be a determining factor in changing how participants managed their diabetes.

‘...becoming pregnant, when there’s somebody else involved in, the diabetes is, probably a big wake-up factor for anybody ...’ (Interviewee: 4).

‘It took getting pregnant for me to do this … to get off my backside and say I need to sort this out...’ (Interviewee: 5).

The women felt that the lifestyle changes they made during pregnancy had improved their short- and, hopefully, long-term health.31,13

‘But the whole process with the diabetes now, with the pregnancy, I’ve realised I will continue afterwards because what I thought were insurmountable mountains and I couldn’t do it and I couldn’t test my blood sugars four times a day and you know it just takes up too much of my time, I’ve realised that it doesn’t really … the real instigator is I’ll see the baby, I want to be around for as long as possible,’ (Interviewee: 4).

‘...that’s what’s making me at the beginning … because I was pregnant. But now it’s like, no I feel better. So I’m going to carry on this for me,’ (Interviewee: 5).

Organisation of care and communication

Individualised care, and a flexible, supportive, and readily accessible service, was viewed as empowering by the women.13

‘The Diabetes Team are always at the end of the phone … that gives us the confidence … if anything crops up we call them, they help us,’ (Interviewee: 2).

Of particular note was the relationship forged with the team. The women felt they were seen as individuals: ‘...as a person first, they got to know about you,’(Interviewee: 1), on a shared journey. Continuity of care, by specific team members was viewed as fundamental to the development of this relationship. Women found consultations with junior members of the health care team frustrating and felt that they knew nothing about their case prior to a consultation.11

‘Telling my story … I think was a big thing. Every time I met a new professional I had to explain. An’ it irritated me after a while, ‘cos I thought “Read the notes before you walk into the room to see me”’. (Interviewee: 3).

It is logistically difficult to maintain continuity of care to a few team members; however, attempts must be made to keep messages and advice consistent with effective note keeping and hand over as appropriate.

In cases where additional input from specialties such as nephrology was required, some participants felt that adequate communication between the different specialties was sometimes lacking.

The women felt that, although they were supported throughout the ante-natal period, the emphasis shifted during the delivery process:

‘...it was all diabetes focused. Once I went into labour it was all baby focused … it’s getting that even balance throughout,’ (Interviewee: 2).

Women’s experiences of midwifery input varied, but the majority felt that they had not had midwifery input at all, stating, for example: ‘...we haven’t seen a midwife since I’ve been pregnant,’ (Interviewee: 7). On the other hand, some women found it difficult to access midwifery input due to the demands of hospital appointments: ‘...the GP’s midwife was available to us but I just couldn’t get time off work with having so many appointments here,’ (Interviewee: 7).

Some women felt that community midwives inferred that ante-natal care would be provided by the hospital and therefore the women felt as if they didn’t ‘...want to bother the midwife,’ (Interviewee: 6).

For the few women who saw the community midwife there was a mixed reaction, from the bureaucratic completion of tick-lists to the ‘normalising’ effect of being ‘treated… like a pregnant woman not a diabetic woman with high blood pressure and “Oh there’s a baby as well”,’ (Interviewee: 3). The midwife’s role is regarded as pivotal in the provision of ‘that “normalising” side of things,’ (Interviewee: 7). She is regarded as the person who provides information on:

‘The fun aspects I suppose of being pregnant. Yes I’m diabetic, but I’m also just a normal person having their first experience of pregnancy. And I don’t know how to change a nappy or breast-feed just like everyone else...’ (Interviewee: 3).

The midwife is also seen as a go-between, linking all the specialties and providing ‘that coordination or that person in between that I can go to … but from a sort of being a “normal pregnant person” the bringing it all together...’ (Interviewee: 6).

The women felt that ‘all the other stuff is important and it’s got to be discussed and monitored but to just have a bit more of a balance.’ As one woman stated: ‘I’ve lived with diabetes for 20 odd years. I know it ... whereas I’ve never been pregnant before...’ (Interviewee: 2).
Attendance and intervention
The levels of intervention and attendance required elicited very mixed responses from the women, ranging from the effects on their work/life balance to expenditure due to parking fees. The initial reaction of most women on becoming pregnant was to ‘...pick up the phone to the diabetic team,’ (Interviewee: 4). One woman stated that ‘I’ve taken quite a lot of time probably, outside of work ... but it’s important to me to know that everything’s okay,’ (Interviewee: 4); while another stated that ‘it’s a pain in the backside coming week-in, week-out but it is good,’ (Interviewee: 2).

The range of emotions experienced is summed up succinctly by one woman who said: ‘it is a bit of a double-edged sword really, because if I hadn’t been in so often ... I’m sure I would have been on the phone instead,’ (Interviewee: 4).

The inclusion of the diabetes team as a member of the Medical Disorders Clinic in the Maternity Unit was seen as a very positive step:

‘The fact that the diabetes team are coming over here, to the Maternity ... it makes this a more “normal” pregnancy, although I’m here every week about my diabetes ... I would have felt segregated ... yeah segregated is the word ... I’d have felt “Yeah, oh God, I’m diabetic”’, (Interviewee: 5).

Expectations and systems
Ante-natal. The use of protocol-driven insulin infusions during active labour needed to be communicated more explicitly to women, as well as the fact that the midwife in attendance would be one who was rostered to be on duty that day and would be following this protocol with input from the consultant diabetologist, as required. When this message was not clear it contributed to the women deeming staff to be incompetent. In spite of stating ‘the midwife was absolutely lovely we can’t fault her, because she’s trained to be a midwife not trained in diabetes’, when adjusting the insulin regimen in labour one woman described the situation:

‘...she was taking it from like ... one unit an hour to two units an hour when I was running a little bit higher ... we were trying to say ... can we not try 1.5 kind of thing ... we were sort of trying to help her a bit ... we just got the impression she didn’t have much experience and she was doing the best she could ... it was like the blind leading the blind,’ (Interviewee: 2).

Women also interpreted a delay in the induction of labour process as being ‘stranded in limbo’ (Interviewee: 2) and that ‘nothing was being done to help it [labour] progress’ (Interviewee: 2).

Post-natal. After an ante-natal period of intense self-management, stringent dietetic and glycaemic control especially with an increased focus on carbohydrate counting, there were difficulties with some of the systems that were in place for the provision of snacks and meals on the ward in the post-natal period.

It was also difficult to manage insulin administration on the wards as women were forced to guess the content of their meals: ‘that’s about that many grams of carbs ... and at a time where I’m trying to get my diabetes under control ... can’t weigh it, can’t carb count it, I was guessing,’ (Interviewee: 2).

Many of the women were disappointed that they were unable to complete the programme of Parent-Craft Classes, due to early delivery, as they were slotted into standardised scheduling, and no allowance was made for their medical condition.

Discussion
This small exploratory study has revealed some interesting perspectives from women regarding their lived experiences of having T1DM, being pregnant and becoming a mother. The strength of this work is that it featured women in their first pregnancy so each experience was new and there was no bias from previous pregnancy-related episodes. A potential limitation to this study is that all of the participants came from a white British background (reflective of local population demographics) and these findings may not be reflective of the experiences of women from other ethnic groups and may require further examination.18 With the limited number of eligible participants, the demographic did not include any women in their teenage years. Investigation of women below 20 years of age may be pertinent to establish if their experiences correlate with those of the older participants in the study.

Surprisingly, the majority of women in this study were aware of the need and rationale for pre-conception care and stable HbA1c levels prior to considering a pregnancy, and worked closely with the diabetes team prior to and during their pregnancy to optimise both their health and that of the fetus.19,20 Those who had unplanned pregnancies felt compelled to contact the diabetic team as soon as their pregnancy was confirmed to ensure a positive pregnancy outcome. They were not as Spence et al.21 suggest ‘afraid to tell their team because they did not seek advice prior to conception’ nor did they have ‘a fear of being told off’.22 The women felt that this relationship was empowering, proactive and non-prescriptive and enabled them to maintain as ‘normal’ a lifestyle as possible during their pregnancy, with the increased input giving them the confidence that the pregnancy was proceeding normally and that any deviation would be acted upon quickly and appropriately.23–25

Pregnancy highlighted the fact that some of the women were still in denial about their condition, in spite of being diagnosed with diabetes for over 10 years. As previous work suggests26–28 women may need more psychological support in coming to terms with their condition ‘which is a significant physical and psychological burden for many individuals’,28 and in breaking down barriers to achieve control. They need the gamut of their complex needs to be met, in order to come to terms with their chronic condition and, as Dalfra et al. suggest, health care teams should help ‘patients learn to cope with their condition and solve the problems it poses’.20 It may be interesting to follow up the women who had previously demonstrated suboptimal management of their condition, and investigate whether they maintained their level of commitment and disease management once they became new parents.

Conversely, obstetric input was often viewed as medicalised and prescriptive and caused some women to disengage psychologically from...
Care for primigravid women with diabetes should find a balance between medical input and routine ante-natal care to attempt to normalise pregnancy as far as possible.

Women should be treated as partners in their care, acknowledging their expertise and effort in the management of their condition.

The expertise of each individual member of the multidisciplinary team should be utilised to its full potential to provide a holistic approach to care for women with diabetes.

Key points

- Care for primigravid women with diabetes
- Women should be treated as partners in their care
- The expertise of each individual member of the multidisciplinary team should be utilised to its full potential

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Declaration of interests

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References


