The pregnancy journey for women with type 1 diabetes: a qualitative model from contemplation to motherhood

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Abstract
The purpose of this study is to describe and develop a model of the pregnancy journey for women with type 1 diabetes. We undertook a thematic analysis of written interactions (n=200; n=2060 text excerpts) with an online counselling support service from 93 women with type 1 diabetes.

Seven possible discrete phases in the pregnancy journey were revealed: Contemplation, Pregnancy planning, Conception, Pregnancy, Delivery/birth, and Motherhood or Pregnancy loss. Eight common themes were identified, varying in importance across phases. Diabetes-specific distress was most evident during Contemplation and Motherhood. During pregnancy, social identity and peer support were paramount. Negative emotions in Pregnancy, while connected to diabetes, also centred on the unborn baby. In Motherhood, diabetes-specific distress and depressed mood increased. Medicalisation was expected and offered reassurance during Pregnancy; however, some women still worried, with peer support offering the most reassurance.

In conclusion, women with type 1 diabetes potentially experience seven distinct phases of the pregnancy journey, with eight themes varying in significance across phases. Contemplation begins well before Planning or Conception, and women may seek support from non-mainstream sources. Mental health and emotional well-being varies qualitatively and quantitatively across phases (focusing on pregnancy-related distress, diabetes-specific distress and general maternal well-being), indicating a need for targeted assessment and support across the pregnancy journey. Copyright © 2016 John Wiley & Sons.

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Key words  
type 1 diabetes; pregnancy; pre-pregnancy; motherhood; qualitative study

Introduction
Type 1 diabetes is one of the most common pre-existing medical conditions complicating pregnancy, with potentially devastating outcomes for both mother and child if the condition is not managed well. Such complications include significantly elevated risks of obstetric and fetal complications including pre-eclampsia, prematurity, stillbirth, malformations, the fetus being large for gestational age and neonatal morbidity.1

Despite advances in knowledge and care, management of pregnancy for women who have type 1 diabetes remains challenging. The St Vincent’s Declaration of 1989 set as a five-year target, the reduction of adverse pregnancy outcomes in women with type 1 diabetes, to a level equal to that of women without diabetes.2 More than two decades later, Colstrup and colleagues, however, found the risk of adverse pregnancy outcomes in women with type 1 diabetes to be between two to five times that of the general population, concluding that the goals of the St Vincent’s Declaration had not been achieved.3

While pre-pregnancy counselling greatly improves these outcomes,4 many women do not engage in this process with their health care team.5 In order to improve outcomes we need to understand why women are not attending pre-pregnancy counselling and what their needs are before, during and post the pregnancy journey. Studies exploring the views of pregnant women who did not attend pre-pregnancy care have concluded that three issues need addressing: (1) integrated diabetes and reproductive health/contraceptive advice; (2) increased awareness of the potentially short interval between stopping contraception and conception; and (3) more intensive support between pregnancies, particularly for women with previous
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adverse pregnancy outcomes. Others have emphasised that pre-pregnancy care needs to make better use of social media and that health professionals could facilitate peer support to encourage uptake of pre-pregnancy services. However, as Rasmussen and colleagues note in their review, none of the studies undertaken to date have collected data before individuals were pregnant. Rather they have relied on retrospective accounts of women later on, with the inherent biases that may incur.

In addition to the lack of engagement with appropriate pre-pregnancy care, both diabetes-specific distress and general distress during pregnancy have been implicated as possible contributors to adverse pregnancy outcomes. Thus, in a small number of studies, it has been suggested that women with type 1 diabetes are more vulnerable to experiencing psychological distress during pregnancy than women without diabetes. Kozhimannil and colleagues reported that women with type 1 diabetes were at twice the risk of perinatal depression, while Katon and colleagues reported 54% higher odds of any antenatal depression in women with pre-existing diabetes compared to those without. Two reviews of the qualitative literature on diabetes in pregnancy also support these findings.

Studies documenting the demanding and stressful nature of diabetes during pregnancy tend to focus on blood glucose control outcomes, rather than the experiences of the mother and her need for support during pregnancy and motherhood. Berg and colleagues have also explored the experience of early motherhood and breast feeding for women with type 1 diabetes, although data were collected only after childbirth.

As noted in recent reviews, there are generally very limited data on the reported emotional experience of pregnancy for women with pre-existing diabetes especially from the woman’s perspective. Further, to our knowledge, no longitudinal studies have reported on data across the entire journey, from pre-pregnancy onwards. Given there are likely to be different challenges experienced by women at different stages of the journey, from conception to delivery (or miscarriage), we sought to describe the journey experienced by women with type 1 diabetes, and to develop a preliminary model of this journey to help inform future research and service provision.

Research design and methodology
As a first step in understanding the experience of women with type 1 diabetes surrounding pregnancy, the electronic ‘conversations’ held between the ‘Diabetes Counselling Online’ (DCO) service and women with diabetes were reviewed. DCO is a not-for-profit organisation, providing a free internet-based counselling service and psychosocial/informational support via social media predominantly to people with diabetes. DCO provides support largely to people whose needs have not been met by traditional diabetes care services, or who are unable to access traditional care services. This unique service is predominately used by Australians who comprise approximately 60% of users, followed by visitors from the USA and the UK.

All email counselling and ‘buddy’ requests (stored verbatim as hard copies) received by DCO between 2002 and 2012 were reviewed. Records were retained for analysis wherever pregnancy, parenting, motherhood (up to two years postnatal) or issues relating to these were mentioned by women who self-reported having type 1 diabetes. Further data were taken from discussions on the DCO pregnancy forum, ‘Your Stories’ and the ‘Your Stories’ Facebook group.

As DCO provides a standing website disclaimer about the potential use of data for research purposes, appropriate institutional ethics approval was granted to access anonymised, archived records of counselling and email buddy conversations. As the ‘Pregnancy and Parenting’ Facebook page supported by DCO commenced in 2011, individual consent was sought from the women accessing this page to participate in the study. Of these 23 women, eight (35%) consented to the use of their postings anonymously for the study. Data were collected from this page from December 2011 to August 2012.

In total, there were data available from 93 women with data sourced from email buddies (n=9), email counselling (n=48), ‘Your stories’ (n=9), the DCO pregnancy forum (n=19), and the ‘Pregnancy and parenting’ Facebook page (n=8). The number of interactions per woman ranged from 1–44. As this was a naturalistic study, country of origin data were available only for women who accessed the online counselling, email buddy services or Facebook page. All of these women were Australian.

De-identified transcripts were provided by DCO to the research team and entered into NVivo for analysis. One investigator (HE) undertook the initial analysis and coded transcripts thematically using a framework approach, which included reading and re-reading data numerous times, to ensure familiarisation. Each piece of written content was broken down into distinct blocks of text, with each block representing a single distinct issue as determined by the principal coder. An initial coding frame was developed, which was used to develop over-arching themes. Themes were reviewed and refined continually by the research team, until they were considered to best represent the data. The research team comprised three psychologists and a counsellor, of male and female genders, with and without children. The coding framework was reviewed and discussed several times by the research team. Once consensus was reached, all data were coded in NVivo and descriptive analysis undertaken.

Results
A total of 200 interactions by 93 women, recorded over a period of 10 years, were extracted generating 2060 text excerpts for coding and analysis. Percentages are shown to demonstrate frequency of content among the text excerpts. Analysis revealed seven distinct phases of the pregnancy journey: Contemplation (18% of text excerpts); Pre-pregnancy planning (4%); Conception (10%); Pregnancy (28%); Loss (3%); Delivery and birth (10%); and Motherhood (27%).
These phases were used to provide temporal structure for the data and to enhance understanding of women’s experiences over time.

Analysis revealed eight major themes (presented alphabetically below) across the seven phases of the pregnancy journey, which encapsulated the data and were identified as common across participants. See Table 1 for exemplar quotes.

**Balance and juggling** (5% of text excerpts): Participants wrote about a struggle to balance diabetes self-management against other aspects of life, such as work, family and social life. The priority afforded to diabetes self-management varied substantially across the journey. Initially, this became all consuming during ‘planning’ and ‘pregnancy’ but, in the postnatal phase, this became the least of the new mothers’ priorities.

**Health care professionals and medicalisation** (11% of text excerpts): Women were accepting of (and expected) medicalisation during ‘pregnancy’. They found, in particular, medical checks on the unborn baby’s gestation and health reassuring. At the time of ‘delivery and birth’, they also were accepting of this but were distressed by their lack of personal control over the delivery. Negative experiences across the journey included not wanting to tell health care professionals (HCPs) they were pregnant or to ask questions of HCPs due to past experiences or unrealistic expectations. Some women felt they understood their diabetes better than anybody else, and that this was not acknowledged by their HCPs. Positive experiences included receiving positive and affirming feedback from HCPs.

**Impact of diabetes on experience of pregnancy** (19% of text excerpts): How well women were managing their diabetes prior to becoming pregnant impacted upon the way they felt during ‘pregnancy’. Those who presented in ‘contemplation’ wanted to work on their sense of personal control in preparation for a possible pregnancy. During ‘pregnancy’, the unpredictability of diabetes was a major concern.

### Table 1. Exemplar quotes relating to the 8 themes identified across the pregnancy journey of women with type 1 diabetes. (Quotes relating to themes 5 to 8 are provided on the next page)

#### Balance and juggling

**Contemplation**

- Participant 10: ‘The problem for me is getting my head around what I can and can’t eat and understanding the GI [glycaemic index] system and just finding more motivation to stick to the diet, exercise. I still want to socialise with people without feeling abnormal’

**Motherhood**

- Participant 42: ‘I sometimes think that if I had just diabetes to concentrate on I’d be more than capable, but when you add anything else (family, work, school etc) diabetes seems to be pushed to the back. It seems it’s always easier to make some excuse to put anything else first, even though I’m very aware that ignoring diabetes is only putting a lot of strain on my body, and that it will come back as one of many complications. It feels very overwhelming. And I’ve never learnt a way to deal with it’

#### Health care professionals and medicalisation

**Pregnancy**

- Participant 34: ‘My scan is in a few weeks and I can’t wait – it will be a big relief to have it done’

- Participant 74: ‘I don’t want to ask a health professional because they quote HbA1c:s and targets like “under 7” which I know and am targeting – that doesn’t mean it always happens!! I’d appreciate anything anyone can share who has been there, done that’

- Participant 15: ‘I have just discovered that I am pregnant (7 weeks), not planned. I have seen an Endocrinologist once, and she put the scares up me’

- Participant 78: ‘I have had diabetes for 20 years and am currently 5 weeks pregnant. My Endo won’t see me because it’s been over a year since my last visit, so I am seeing my GP Nov. 16 to get a referral. I am worried it will be too late as my control is not great’

- Participant 29: ‘A lot of the time I feel I manage the diabetes myself, in that when I go to Endo he doesn’t really talk to me about that I don’t already know’

- Participant 15: ‘The Endo I saw this time was a lot better than the first one that I went to see. She actually said that I was doing a good job. I have to go back again next Wednesday’

- Participant 55: ‘She seems reasonably happy with my levels and makes continual adjustments … However, I feel that I have had too many readings above 10 and that my baby will be harmed’

#### Impact of diabetes on experience of pregnancy

**Contemplation**

- Participant 12: ‘My partner and I are thinking about having a child in the next year or so. I’m concerned about my diabetes and the impact it would have on the child and myself during pregnancy/childbirth’

**Motherhood**

- Participant 60: ‘But after having my baby the wheels fell off and my control went a bit crazy. I was either hypoing or having highs’

- Participant 5: ‘I wonder whether my control is as tight as it should be, whether having at least one hypo a day is normal, whether I am going to end up with a long list of ghastly complications if I don’t have “perfect control”, what if I lose consciousness one day when I’m at home with the kids by myself… the list is endless’

- Participant 72: ‘I found pregnancy a real juggle with sugar levels. My levels would drop suddenly when I’m at home with the kids by myself... the list is endless’

#### Knowledge seeking and application

**Pregnancy planning**

- Participant 24: ‘I’m wanting to start a family and I’m having trouble finding any information that doesn’t make it sound like I’m trying to be a horrible person to want to have a baby when I have diabetes’

- Participant 13: ‘I really want to get these [blood glucose levels] down as I want to be able to start planning a family but to do that my blood [glucose] levels need to be lower all the time’
Mental health and emotional well-being

Pregnancy
Participant 79

‘Has anyone had lack of control over their [blood] sugars during their pregnancy and still given birth to a baby without any abnormalities? I am 8 weeks and am starting to panic over sugar levels that refuse to stay in the optimal range regardless of what I do (obviously I am doing the best I can and taking no risks). I get high days (over 10) and single high readings other days and I start to panic. Anyone out there feeling the same?’

Pregnancy
Participant 25

‘I have been so stressed and racked with guilt whenever I have higher levels, and it has only been 3 weeks – I will be a nervous wreck by the end of the pregnancy!!!’

Motherhood
Participant 36

‘I have always had a really positive outlook on life but, since having my daughter, I seem to be worrying about my health all of the time. But the whole thing could be psychological because I am worrying so much. I am just scared of the future, I’m scared of being sick and in pain and of dying early. There is nothing happening health wise that I am worried about right now though, I am just worrying about things that “might” happen later on’

Motherhood
Participant 61

‘I don’t know what is going on. I feel very depressed, crying a lot. I just feel I have no-one to talk to or understand. My husband is there but I feel he can’t really understand what it’s like to know that this isn’t going away ever’

Motherhood
Participant 66

‘Sometimes I really don’t care if I take the insulin, then I realise if I don’t get my [blood] sugar under control I will not be around for my boys (they are 17 months and 3 years old)’

Motherhood
Participant 36

‘My health problems suck! I used to be so good at being happy and not letting my diabetes get in the way of my life but it really is getting in the way at the moment. My husband is getting sick of me being so emotional all of the time, but I am finding it really hard to deal with because my BGLs [blood glucose levels] are so crazy, and ever since having my daughter I seem to be a bit depressed in general’

Physical health: mother and child

Motherhood
Participant 34

‘I am trying really hard to rest and look after myself by exercising and eating well and I am trying to think very positively about the baby being OK and not having any problems’

Motherhood
Participant 29

‘...My daughter was born at … weighing 7 pound 8 ounces – 50cm long. You will be pleased to know that I managed to get my wish and went into natural labour (before being induced) and had her naturally without any pain relief. It was a good feeling to prove the Obs [obstetrician] wrong. She had one low blood sugar but as I had been expressing colostrum and freezing it since week 34 the nurses gave her some of that and it brought her levels back up’

Relationships: partner, family and baby

Motherhood
Participant 65

‘I have also had many joyous moments like when I gave birth to my kids, or when I got married’

Motherhood
Participant 36

‘I love being a mum. I find it really hard because I am so tired all of the time but I love it. I love being a mum because of the happiness that I see in her eyes. She is a great kid. I feel like she is a blessing (you know how the docs warn you that all of these things are going to be wrong with your baby because of your diabetes, but she turned out just fine). I love being proud of her achievements. I love cuddling and kissing her and knowing that I am her mum’

Social identity and relationships with peers

Conception
Participant 68

‘So, on I plod feeling like a pin cushion. Has anyone else been on this roller coaster and come out the other side smiling? Will I get to be a real mum (I am already a step mum) or more importantly will I get to create another little person with my darling husband who I love so much?’

Pregnancy
Participant 69

‘Anyway I hope it’s going well so far – when are you due? I’d love to hear how you have gone so I know what to look forward to (or dread!!!) I am calling out for all the support I can get from here. The last week has been very emotional for me’

Pregnancy
Participant 79

‘Has anyone had lack of control over their [blood] sugars during their pregnancy and still given birth to a baby without any abnormalities? I am 8 weeks [pregnant] and am starting to panic over [blood] sugar levels that refuse to stay in the optimal range regardless of what I do’

Table 1. Exemplar quotes relating to the 8 themes. (Continued from the previous page)
peaked during ‘pregnancy’ when the development of the unborn baby was all consuming.

Relationships: partner, family and baby (15% of text excerpts): Relationships with significant others, including partner, family and baby, peaked in importance during ‘motherhood’. At this stage, breastfeeding and the relationship between mother and baby was key.

Social identity and peer support (13% of text excerpts): Social identity and accessing peer support were critical in women feeling empowered about having the healthiest and most fulfilling experience possible. Reassurance was actively sought and this was highest during ‘pregnancy’.

**Distribution of theme codes by journey phase**

The codes for ‘impact of diabetes’ accounted for 19% of codes, with the ‘mental health and emotional well-being’ and ‘relationships’ codes being roughly equal and the most coded themes.

The analysis of journey phase indicates that most of the women’s interactions with DCO concerned the period of actual ‘pregnancy’, followed by ‘motherhood’ and ‘contemplation’ of pregnancy. However, themes are unevenly distributed across the journey; see Figure 1. For instance, the theme of ‘balance and juggling’ seemed most common when women were in ‘contemplation’ of pregnancy and in ‘motherhood’, but appeared less of an issue during ‘pregnancy’, although this theme was not one of the top three at any time point. Unsurprisingly, ‘mental health and emotional well-being’ issues peaked with the experience of ‘pregnancy loss’.

Figure 2 depicts the three most common themes expressed at each phase of the journey.

**Discussion and conclusion**

This study identified seven possible, distinct phases of the pregnancy journey for women with type 1 diabetes and eight themes, evident to varying degrees within each phase. Across these phases, written interactions indicated shifting priorities and varying informational and emotional support needs throughout the journey. This indicates that women are seeking informal pre-pregnancy counselling and advice from non-mainstream sources, rather than through traditional health care pathways. This is unsurprising given that other studies have reported negative perceptions of health professionals when it comes to pre-pregnancy advice. Connections with other women who have been or are currently pregnant appear to offer reassurance over and above that provided by health care providers.

The eight themes identified resonate well with previous studies that point to the challenges of balancing the demands of blood glucose management and the challenge of negotiating relationships with health professionals. This study validates and adds to previous small-scale (n=7–15) studies with our larger sample (n=93) providing more robust data and highlighting specific themes and issues.

‘Mental health and emotional well-being’ was identified as a strong theme, with the aspect of diabetes-specific distress changing in focus from mother, to baby and back to mother again. This extends the work of Rasmussen and colleagues, which examined changes from pregnancy to postnatal experiences. The changing nature of these issues experienced by women during the pregnancy journey suggests that one-off assessments of psychosocial issues may not be appropriate and that different assessment and approaches to facilitate coping at different time points may be required to reduce the negative impact of pregnancy on mental health and emotional well-being. A questionnaire focusing on both diabetes- and pregnancy-related well-being has been developed and offers the first opportunity to systematically consider the emotional impact of both pre-existing diabetes and pregnancy/motherhood.

Notwithstanding the large sample for a qualitative study, it is important to acknowledge that this analysis is based upon the ‘conversations’ of a somewhat select sample – that is, women seeking help via online sources, outside the normal private and public health care provision for diabetes and pregnancy. Although this study has the strength of identifying issues arising for women who may not be attending (or receiving the support they need from) traditional health care services, we do not recommend extrapolating these findings to all women with (type 1) diabetes. Given that the data were derived from naturalistic interactions with the DCO service, rather than via traditional research recruitment, we know little about demographic/clinical characteristics (e.g. age, diabetes duration, treatment
regimen, pregnancy history) of the sample. In addition, the data analysed include as many as 44 references from a single woman over the entire journey from ‘pre-pregnancy’ to ‘motherhood’, to one-off interactions at a single point in time. Therefore, this naturalistic sample is simultaneously longitudinal in some respects and cross-sectional in others. Further longitudinal research with more representative samples is needed to confirm or refine the model derived from these data. The key strength of this study is undoubtedly the quantity of data, with interactions analysed from 93 women, and 2060 coded data points. We believe this to be the most comprehensive qualitative exploration of pregnancy in women with type 1 diabetes to date.

**Implications/relevance for diabetes educators**

These findings indicate that the provision of resources for women contemplating, planning or during pregnancy and early motherhood needs to balance risk information with accounts of positive experiences and signposting to sources of peer support. If not, information about the risks and potential for poor outcomes may have a negative impact, with women less inclined to seek pre-pregnancy counselling.

We recommend that information resources (1) are delivered via a variety of sources/media that are relevant, accessible and able to be revisited when needed; and (2) include accounts of real-life experiences – to ensure normalisation of the experience of pregnancy with type 1 diabetes, offer reassurance to reduce distress and anxiety, and ensure that a woman’s own expertise and history in relation to their diabetes is respected and included in the collaborative development of management plans throughout the pregnancy journey.

While women with type 1 diabetes experience a pregnancy journey that appears similar to the standard pregnancy journey in terms of the seven phases identified, the eight themes suggest additional diabetes-specific challenges and greater risks to both physical and mental health outcomes among women with type 1 diabetes. Outcomes from this study suggest a high need for and acceptance of non-traditional health information sources and peer support for pregnant women with type 1 diabetes. The ability to augment and strengthen holistic care for women during this journey is an exciting prospect with the potential impact yet to be fully realised.

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**Declaration of interests**

Helen Edwards is the founder and Chief Executive Officer of Diabetes Counselling Online, a not-for-profit organisation that provides free online counselling and support for people with diabetes. All other authors declare no conflicts.

**References**

References are available online at www.practicaldiabetes.com.

**Key points**

- This study reports on perspectives of women with type 1 diabetes pre-pregnancy
- This study reports on the accounts of women with type 1 diabetes accessing support outside traditional health services to understand their pregnancy journey, concerns, experiences and support needs
- This model can potentially assist health care professionals anticipate the needs of pregnant women with type 1 diabetes to support their emotional well-being as well as their blood glucose regulation
References