

# Type 1 diabetes women's views about preconception care: A qualitative study†

Ana Cristina Paiva<sup>1</sup>, João Raposo<sup>1</sup> and Angus Forbes<sup>2</sup>

<sup>1</sup>Portuguese Diabetes Association APDP-ERC, Lisboa, Portugal; <sup>2</sup>Florence Nightingale Faculty of Nursing and Midwifery, King's College of London, UK

**Background:** Pregnancy in women with Type 1 diabetes mellitus (T1DM) is associated with increased complications for both baby and mother; such complications can be reduced with careful pregnancy planning. Preconception care (PCC) enhances pregnancy outcomes by helping women to optimize their glycaemic control, through supportive intervention. However, despite these benefits, the uptake and adherence to PCC is low. This qualitative study aimed to generate a better understanding as to why women may not utilize PCC, by eliciting the views and experiences of women with T1DM in relation to PCC.

**Methods/sample:** A sample of six women of reproductive age with T1DM undertook semi-structured interviews exploring their views on PCC. These interviews were tape-recorded, transcribed (*verbatim*) and analysed using interpretative phenomenological analysis to elicit themes that explicated the women's orientation and behaviour in relation to PCC.

**Results:** The analysis identified five key themes: the fear of complications (both for the mother and the baby); the style of communication from health care professionals (HCPs); the support of significant others; personal autonomy; and women's beliefs about PCC.

**Conclusion:** Overall, the findings suggest that women's uptake of, and engagement with, PCC is enhanced when HCPs adopt a supportive and positive approach, which addresses their anxieties in pregnancy preparation and encourages the health behaviours necessary for a good outcome for their baby.

**Key words:** Type 1 diabetes, Women's view, Preconception care, Pregnancy outcomes

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## Introduction

Type 1 diabetes (T1DM) is a lifelong disorder of metabolism. As the incidence of T1DM peaks in childhood and adolescence, many women have to manage their disease before and during pregnancy. T1DM and pregnancy can be associated with multiple complications and adverse outcomes for the baby and the mother. It has been shown that pregnancy outcomes can be significantly improved by intensifying therapies to achieve more stringent glycaemic control and removing any teratogenic medicines.<sup>1</sup> However, the process of achieving the level of glucose control required to improve pregnancy outcomes can be very demanding as it requires more frequent glucose monitoring and adjustments to insulin. Hence, women with T1DM require high levels of specialist support, prior to pregnancy, from a specialist team in a preconception care (PPC) clinic.<sup>2–6</sup>

While studies show that women who access PCCs achieve better outcomes than those who do not, only about half of women with T1DM planning pregnancy receive PCC<sup>1</sup> and it has been estimated that up to two-

thirds of pregnancies are unplanned.<sup>7</sup> Only a few previous studies have reported on why women may not use PCC, and the reasons identified by these studies include: a previous pregnancy with a good outcome without PCC<sup>8,9</sup>; the belief that they already managed their diabetes well<sup>9</sup>; and anxiety about pregnancy to the extent that it makes them fearful of addressing the issue. It is necessary to build on these studies and consider the views of women with T1DM on PCC to help identify better strategies to enhance their uptake and engagement with PCC. This study examines the views of women with T1DM on PCC to determine how these may influence their use of PCC.

## Method

The study's aim was to explore the views of women with T1DM in relation to PCC. To fulfil this aim, a qualitative design was adopted using interpretative phenomenological analysis (IPA) to enable a contextual exploration of the women's views and experiences from their perspective.

## Participants and setting

The research was conducted at APDP – Diabetes Portugal in Lisbon. The women were identified through

†Perceiving type 1 diabetes women's views about preconception care with an interpretative phenomenological analysis.

the APDP clinic's database. Following the IPA approach, a purposeful sample of six women with T1DM were recruited to provide different perspectives on PCC<sup>10</sup>; this included women who had and had not utilized PCC.

### Data collection

In keeping with the research approach, individual in-depth semi-structured interviews were undertaken. The women were encouraged to express what they feel and understand about PCC in the context of their experiences.<sup>11</sup> Interviews were carried out by the researcher at an APDP room according to women's availability, and ranged from 40 to 70 minutes. All data were audio-recorded and transcribed (*verbatim*). The researcher conducting the interviews (A-CP) also made notes following each interview to capture some of the non-verbal elements of the interviews.

In addition to the in-depth interviews with the women, data were collected on age, year diagnosed with diabetes, insulin type, additional significant health problems, and previous experience of any PCC advice they had received.

### Data analysis

The study data were analysed in six integrated phases following the principles of IPA<sup>12–14</sup> as illustrated in Figure 1 and detailed below:

- *Phase 1*: The entire text of the participant description and notes taken were transcribed *verbatim*, taking into account the pauses and nuances used in the women's speech. These transcripts were then read and re-read several times, while also playing the digital recordings to recall the women's voices and nuances.
- *Phase 2*: Initial notes were taken reflecting the researcher's observations and each line of text was characterized. Once immersed in the data, the researcher was able to identify and extract meaningful statements, reflecting the participants' experiences. These extracts were used to generate data summaries and preliminary interpretations by connecting different aspects of the transcription using coding. The initial coding and emerging themes were then validated by a second researcher (AF).
- *Phase 3*: During this phase, themes were identified by several re-readings and revisions of the initial coding

by examining the entire interview. Coded data segments were grouped into emerging themes in the order they arose within each interview.

- *Phase 4*: This phase involved identifying relationships between the emerging themes by clustering together similar themes to further refine each theme merging or integrating themes that expressed similar perspectives.
- *Phase 5*: In this phase, the themes were further organized and integrated to identify the superordinate themes to provide a final whole interpretation of the explored phenomenon in each interview.<sup>13</sup>
- *Phase 6*: Once the analysis of all the individual transcripts was complete, they were then considered collectively examining the full set of transcripts to identify similarities and emerging patterns between the emerging themes from each interview. Following this, the definitive themes were identified.

### Study ethics

The study was submitted to, and received approval from, APDP's ethic committee prior to its commencement.

### Findings

The details of the participants are summarized in Table 1. The participants ranged in age from 21 to 45 years, and two had a previous pregnancy; only one of which resulted in a live birth.

The identified superordinate themes and respective sub-themes expressed in relation to women's views of PCC are summarized in Table 2. The majority of the superordinate themes were experienced by all the interviewed women, but there were differences in how these were expressed reflecting their individual experiences. The themes are described below with extracts from the interviews.

#### Theme 1. Fear of complications

During the course of the interviews, one of the most often mentioned feeling about pregnancy was the fear of complications for both themselves and their offspring. This fear was also expressed in the context of guilt, as if somehow they feel a sense of responsibility for any complications that might happen to their baby during

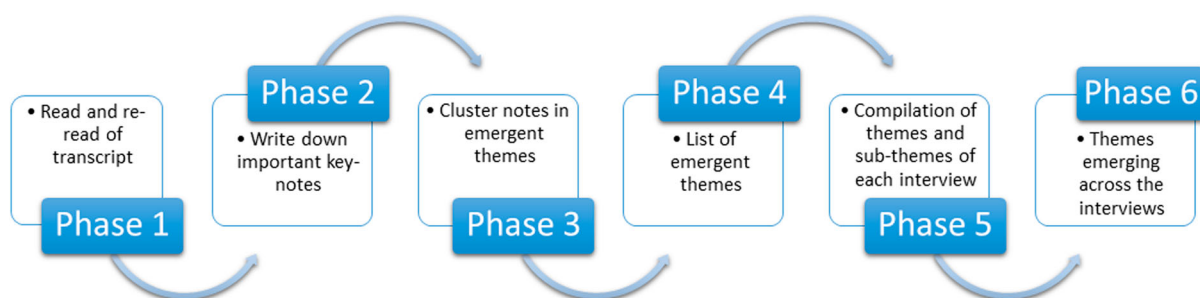


Figure 1 Data analysis phases.

**Table 1** Women’s demographic characteristics.

Name	Age	Previous pregnancy	Diabetes duration (years)	Education level	Insulin type
Ally	31	0	20Y	Higher technical	Insulin pump
Susy	32	1 live birth	10Y	Secondary school	Basal-bolus
Sally	43	1 miscarriage	10Y	University	Basal-bolus
Betty	45	0	15Y	University	Insulin pump
Anny	24	0	12Y	University	Insulin pump
Kathy	30	0	11Y	Higher university	Insulin pump

**Table 2** Superordinate themes and related sub-themes.

Superordinate themes	Sub-themes
Fear of complications	Complications for the mother Complications for the baby Guilt (of the Mother)
Information	Pregnancy information Contraception information Information and support for PCC Myths or Facts
Communication approach	Motivating communication Discouraging communication
External Support	Health Care Professionals Family Partner Peers
Autonomy	Managing the demands of diabetes Self-efficacy Lack of control

pregnancy. Such feelings led to ambivalence towards pregnancy planning as it was difficult for them to think positively about planning for pregnancy.

- Sally: ‘The one I’m most afraid of is the diabetic retinopathy, (...) after I was more reassured with respect to..., to foetal development, if there was no..., that part of the problems for the woman, I would be completely quiet’.
- Ally: ‘In addition to whatever mothers without diabetes have to be careful (...), we with diabetes we must have maximum attention’.
- Betty: ‘If it happened somewhat less positive situation, or if there were any complications, if I would not feel guilty (...)’.

**Theme 2. Information**

While all the women regarded information about pregnancy as being important, many women had not been given clear or purposeful information as to what they should do when planning for pregnancy or about PCC. There were variations in the type of information women

wanted; while some of the women wanted information on how to better manage their diabetes prior to pregnancy, others wanted to know more about how to become pregnant. Women received information from other sources, leading to conflicting messages about diabetes and having a baby. Some of this conflicting information was linked to myths about diabetes and pregnancy, which compounded their underlying fears. Some women thought that information from health care professionals (HCPs) about PCC was not very consistent or systematic, and often given in an ad hoc way.

- Ally: ‘through the years, I think there was occasional conversations... about that, if you know what you’re doing, what you have to do, but nothing specific. (...)’.
- Kathy: ‘(...) the fact that a person stop taking the pill, there were, an adaptation, but no. ..., me, for example did not know (...), this information ..., that there may be or not pregnancy immediately, right after the break, (...)’
- Ally: ‘(...) There is a lot of misinformation (...) It can also be myth... and may also be ... by what, what the society tells us over the years’ and sometimes leading to preconceived ideas, Betty: ‘the situations are a little, (...) sometimes are incorrect, and we end up thinking incorrectly about them’.

**Theme 3. Communication approach**

Interviewed women considered the HCP’s communication approach as a very important factor in their engagement with PCC. While the women found some of their interactions with the professionals to be understanding and supportive, others felt that their discourse with HCPs was reprimanding, threatening and sometimes patronizing. The women also voiced the need for HCP’s to personalize information to them and for it to be more reflective of their reproductive intentions.

- Ally: ‘(...) there is a very good relationship (...) I think it’s critical, but also understand that, that not everyone is able to have this professional delivery’
- Susy: ‘when I had my son, I had a kind of a healthy nag, by my family doctor.’, even scolding a less directive attitude ‘a healthy nag is, is telling me I should have been more cautious and I should not have gotten pregnant, well, at that time point’ is perceived as pointless,‘ (...) because at the time I thought: Ah! It is already done, why is she telling me this now?’
- Anny expresses how HCPs can sometimes use fear rather than supportive explanation:

‘(...) an approach with which I do not quite agree and that I think does not have much, does not have very good effect in most instances, which is the fear approach. There has never been reason to have this approach with me (...) I do not know if it has good effect on another type of, (...) of temperaments of people dealing with diabetes. (...) when I had gastroenteritis (...) the approach right from the start, was this: now you know, you threw up, the pill has no effect, beware. It was always in fear rather than information (...)’

#### Theme 4. External support

The women reported how external support can influence their reproductive behaviours and observance of PCC principles. This support comes from various sources, from partners, family members, peers and the health care team. It can both promote and inhibit positive pregnancy behaviours. When the support they received was encouraging, this helped women think positively about PCC. However, it could also have a negative influence, making women more vulnerable leading to thoughts of doubt and a duality of feelings about pregnancy. The support from HCPs was considered to be most helpful when it was in tune with the women’s perspectives.

Ally: ‘I think the health care team is important and we, we are all in tune, (pause), to row in the same direction, it is much easier’.

Anny: ‘there are times when we deal better at this than others, (...) but at all times I felt very well accompanied, I felt I could, if needed, I feel such a need, to talk to.., and to be advised and I was counselled’.

Family support could be more complex, reflecting the dynamics of the relationship with the family member. While some supportive relationships were encouraging, misplaced concerns triggered stress when issues were raised about their health and their future baby’s health. The beliefs held within the family have great influence on the pregnancy decision.

Betty: ‘(...) parents and sometimes, family (...), want to know a lot, sometimes on issues of deformations and problems of complications in women with diabetes (...) they hear about, become very fearful.... Sometimes it seems I have that cloak, that frame (...) Sometimes I think it does not affect me, but it is hither deep-down... In more private moments when they come here a little, sometimes have their impact.’

Partners were seen as the most important sources of support. Their support was generally very positive and was held from the perspective that they were in it together with the woman.

Susy: ‘My husband, he is more careful than me. (...), more cautious and makes me see that I really have to be more careful’

Betty: ‘mainly my husband says supporting every decision I make (...) because we are in this together.’

Peer support from others with diabetes was also seen as facilitative in how women approached PCC by sharing their experiences and giving reassurance to the women, especially when they had experienced a pregnancy.

Ally: ‘(...) peers who have had diabetes for many years as I, who have two children, for example, and that all goes well, both ran with babies as with the mother, so for me, these examples are key.’

Peer support also helped reduce the women’s anxiety about pregnancy.

Anny: ‘...already watched the testimony of several Type 1 diabetic mothers, who said it went well, they had absolutely no problems, had more than one child and pregnancies have always been very... very normal.’

#### Theme 5. Personal autonomy

The women verbalized how pregnancy would require changes in their behaviours/attitudes. Such changes challenged their personal autonomy as they would have to find the strength to increase their monitoring and self-management. For some women, this challenge created feelings of anxiety and conflicts with their own values and priorities threatening their autonomy as they may have to sacrifice themselves to intensify their metabolic control to ensure they have a healthy baby.

Anny: ‘Do the little things, make all the little steps... all as it should be...’

Sally: ‘I find it a very boring thing, which is..., multiple prick, which are much more than in the normal state’.

Sally: ‘I found it hard to keep my blood glucose levels controlled ..., because of time management, that thing of having to prick so frequently, with the type of schedule and routine that I have is very complicated (...) One of the great concerns I have is failing to maintain controlled glucose levels (...). I have managed to make adjustments but not yet reach the goals’.



The women expressed feelings of a loss of control, perceiving that the HCP will exert greater pressure on them to comply with the strict self-management behaviours for a successful birth outcome.

Ally: 'I do not like being controlled and I have diabetes for 20 years (...) I always decided alone, with great pride, but always decided alone, decide things alone (...) I know it will be months, of control and such (...) Why need to be on top of me, why I have to go more often to the consultations, this is already in my mind'.

Susy: 'I am a person who does not do out of obligation, is very complicated requiring me an obligation (...) all require obligation, to me is very complicated'.

## Discussion

Women's views regarding PCC appear to be shaped by the information they receive throughout their lives about pregnancy. This information has multiple sources (school, peers and HCP) and can have both positive and negative impact on their perceptions of PCC. The women emphasized the need for an individualized approach, reflecting the changes they experience in relation to the reproductive intentions from their adolescence into adult life. This emphasizes the importance of starting PCC from the outset of childbearing age and adapting it to their individual needs and intentions. While such an approach is espoused in many current guidelines,<sup>15,16</sup> and has been highlighted in previous studies,<sup>17,18</sup> there is a need for more robust systemic intervention to ensure this approach is better provided within the health care system.

The findings also show that many women feel conflicted in their PCC behaviours as there are many contradictory messages, myths and misinformation about diabetes and pregnancy. HCPs rather than challenging these contradictions and myths may impart/ reinforce them by failing to address them with the women. Overall, the women felt under supported by health professionals, particularly in developing their confidence in managing the daily difficulties they face in planning for pregnancy, as has been reported in previous studies.<sup>9</sup>

While all the women wanted to receive information and counselling about PCC, they would prefer this to be tailored to their current psychological and reproductive states, as reflected in previous studies.<sup>2,5,7,19</sup> The women also highlighted the need to involve their partners in pregnancy planning consultations. This finding is in-keeping with the study of Direção- Geral da Saúde,<sup>20,21</sup> which also identified partner participation in PCC as an asset.

The possibility of developing pregnancy complications had a particular influence on women's experiences which, in turn, influenced their behaviours often reducing their

self-efficacy, resulting in ambivalence and a sense of helplessness about any future pregnancy. Fear as, highlighted in Moretto's study,<sup>22</sup> is a constant in how women with a chronic disease view pregnancy, especially anxiety about the health of the baby. The women were also fearful of the extra demands that managing diabetes in pre-pregnancy and into pregnancy compounded their personal inertia. However, while most previous studies<sup>7,23,24</sup> found a low intention to adhere to PCC practices, some of the women in this research especially those not contemplating pregnancy in the near future, recognized the need for pre-pregnancy planning to decrease complications risks for both the baby and themselves.

The phenomenon of unplanned pregnancy is common, with women drawing attention to the information, they were given in adolescence, which emphasizes barrier methods to provide protection from sexually transmitted diseases, a perspective which was also found by Xaverius *et al.*<sup>25</sup> This method of contraception left them more vulnerable to conception, increasing their risk of an unplanned pregnancy.<sup>23</sup> This indicates that greater care is to be given by the HCP in the advice and support women receive regarding optimal methods of contraception.

The data suggest that enhancing women's autonomy in determining their reproductive health needs is important to them, and HCPs should work to enhance this by giving them supportive information to make informed choices. Such an approach may also help boost women's self-efficacy in relation to their confidence to make the behavioural changes required for achieving optimal glycaemic control. The women's accounts suggest that achieving this seems daunting, complicated and time-consuming; therefore, HCPs need to address this with a more motivational approach to the planning, as reflected in the recommendations of previous studies.<sup>14,17</sup>

The study also reveals the potential importance of peer educators and supporters in helping women in preparing for a diabetes pregnancy. All women agreed that peers, because their lively experiences are important in shaping their views and self-belief about having a successful pregnancy. Therefore, the potential of peer as educators should be considered either to provide one-to-one mentorship, or in group education following an experiential social learning approach.

## Study limitations

While the study has confirmed the findings of previous studies and provided some novel insights into the experiences of women with T1DM, it is important to recognize some of its limitations. One such limitation is the potential generalizability of the findings as all the participants were recruited from the same clinical context, and experiences of other women attending other clinics may be different reflecting variations in care delivery. However, while this is likely to be a potential bias, as the findings of the study are concordant with previous studies, it suggests that there is an underlying universality to women with T1DMs views of pregnancy. Another

potential limitation of the study was the sample size questioning how representative the accounts were. To address this, women were purposively selected to capture varying accounts from women who had and had not experienced pregnancy. The IPA methodology also emphasizes that small samples should be drawn to allow a sufficiently in-depth analysis of each interview.<sup>12</sup>

## Conclusions

The women's views of PCC identified in these interviews highlight some areas that could enhance the support provided to women in relation to pregnancy planning. Overall, the findings suggest that women need more targeted, supportive and individualized approaches that reduce fear and anxiety and build their sense of autonomy and control when they plan a pregnancy. They also emphasize the importance of including partners in PCC and the value of peer support. These concepts could be incorporated into education programmes for health professionals, women with T1DM and their partners to ensure a more supportive, consistent and integrated approach to PPC.

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