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An exploration of knowledge and attitudes related to pre-pregnancy care in women with diabetes

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Abstract

Aims Pre-pregnancy care optimizes pregnancy outcome in women with pre-gestational diabetes, yet most women enter pregnancy unprepared. We sought to determine knowledge and attitudes of women with Type 1 and Type 2 diabetes of childbearing age towards pre-pregnancy care.

Methods Twenty-four women (18 with Type 1 diabetes and six with Type 2 diabetes) aged 17–40 years took part in one of four focus group sessions: young nulliparous women with Type 1 diabetes (Group A), older nulliparous women with Type 1 diabetes (Group B), parous women with Type 1 diabetes (Group C) and women with Type 2 diabetes of mixed parity (Group D).

Results Content analysis of transcribed focus groups revealed that, while women were well informed about the need to plan pregnancy, awareness of the rationale for planning was only evident in parous women or those who had actively sought pre-pregnancy advice. Within each group, there was uncertainty about what pre-pregnancy advice entailed. Despite many women reporting positive healthcare experiences, frequently cited barriers to discussing issues around family planning included unsupportive staff, busy clinics and perceived social stereotypes held by health professionals.

Conclusions Knowledge and attitudes reported in this study highlight the need for women with diabetes, regardless of age, marital status or type of diabetes, to receive guidance about planning pregnancy in a motivating, positive and supportive manner. The important patient viewpoints expressed in this study may help health professionals determine how best to encourage women to avail of pre-pregnancy care.

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Keywords diabetes, pre-conception counselling, pregnancy, pre-pregnancy care

Introduction

Women with Type 1 and Type 2 diabetes face greater pregnancy-related risks compared with the general maternity population [1–4]. Elevated blood glucose during early pregnancy has been strongly correlated with fetal congenital anomaly and miscarriage [5,6]. Organogenesis is completed by week 8 of pregnancy and there is strong evidence that intensive glycaemic control before conception and during the first trimester of pregnancy reduces the incidence of birth defects to approximate that of infants of women without diabetes [7–9]. Consequently, pre-pregnancy care, which aims to improve pregnancy outcome by imparting knowledge and supporting women to change their behaviour, is an essential component of diabetes health care. Beginning in adolescence, women should be counselled about pregnancy-related risks and the need to use effective contraception to avoid unplanned pregnancy [10,11]. The key components of this care go beyond advice regarding glycaemic control: to ensure that women planning pregnancy are prescribed folic acid, stop potentially teratogenic drugs, are screened for diabetes-related complications and know how to contact their diabetes team once pregnant.

Recent literature would suggest that most women with pre-gestational diabetes enter pregnancy unprepared and only seek medical care upon realizing they are pregnant [12,13]. Advice-seeking behaviour is complex and influenced by many determinants, such as: socio-cultural factors; demographic factors; cognitive variables; access factors; and factors related to the disease [14]. An increased knowledge of the determinants of advice-seeking behaviour may give us a better understanding

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of how best to encourage women to engage with pre-pregnancy care.

The objectives of this study were to determine if women with Type 1 or Type 2 diabetes of childbearing age (with and without children) are aware of the need to optimize their health before pregnancy and to evaluate their knowledge and attitudes related to pre-pregnancy health care. Additionally, we sought to gain a better understanding of the barriers which discourage effective pregnancy planning.

Patients and methods

Focus groups involving women with pre-gestational diabetes were conducted to examine knowledge and attitudes related to pre-pregnancy care. The protocol was approved by the Office for Research Ethics Committees in Northern Ireland (08/NIR02/50).

Potentially eligible participants, identified from outpatient records at two National Health Service (NHS) hospitals, were mailed a study invitation letter from their consultant physician. Patients were eligible if they were women of child-bearing potential, aged between 16 and 40 years, had Type 1 or Type 2 diabetes and were English speaking. Women interested in taking part then contacted the research team directly. Participants were invited to attend one of four planned focus groups: Group A were young nulliparous (< 25 years, without children) women with Type 1 diabetes; Group B were older nulliparous women (≥ 25 years) with Type 1 diabetes; Group C were parous (with children) women with Type 1 diabetes; Group D were women with Type 2 diabetes of mixed parity (with and without children).

Four-hundred patients were invited to take part, of whom 90 (23%) contacted the research team to receive further information. Sessions were scheduled once groups were fully recruited (i.e. when 10 women per group were available to meet). Forty women were enrolled, of whom nine withdrew on the day (too busy, unwell or childcare problems) and a further seven did not attend their focus group. Therefore, 24 women participated, 18 with Type 1 diabetes and six with Type 2 diabetes.

Focus groups were facilitated by a research fellow (MS) and were conducted in an informal setting within the University. Participants were introduced on a first-name basis and gave informed consent prior to filling out a short demographic questionnaire (see Table 1). Participants were asked a series of open-ended questions as listed below. Each focus group session (lasting approximately 30–65 min) was audio recorded with two digital recorders. Following the session, each participant received a published guide to *Pregnancy and Diabetes* [15] and they were made aware that they could speak to a member of their diabetes care team about any issues raised. Participants were paid an honorarium of £20.00 for time and travel costs of study participation.

Table 1 Demographic details of study participants

	All groups (n = 24)	Group A* (n = 5)	Group B† (n = 7)	Group C‡ (n = 6)	Group D§ (n = 6)
Age (years)¶	30 (17–40)	17 (17–20)	29 (26–37)	39 (36–40)	30 (24–38)
Race					
White	20 (83)	5 (100)	7 (100)	6 (100)	2 (33)
Asian	4 (17)	—	—	—	4 (67)
Details about diabetes					
Type 1 diabetes	18 (75)	5 (100)	7 (100)	6 (100)	—
Type 2 diabetes	6 (25)	—	—	—	6 (100)
Diabetes duration (years)¶	12 (1–33)	7 (2–19)	21 (10–26)	22 (12–33)	2 (1–6)
Details about pregnancies					
Ever pregnant	11 (46)	—	1 (14)	6 (100)	4 (67)
Previous miscarriage	5 (21)	—	1 (14)	3 (50)	1 (17)
Nulliparous	14 (58)	5 (100)	7 (100)	—	2 (33)
Parous	10 (42)	—	—	6 (100)	4 (67)
Pregnancy plans					
No plans	14 (58)	5 (100)	2 (29)	6 (100)	1 (17)
Pregnant now	1 (4)	—	—	—	1 (17)
Thinking about/planning pregnancy	9 (38)	—	5 (71)	—	4 (67)
Pre-pregnancy advice					
Ever received advice	7 (29)	—	3 (43)	2 (33)	2 (33.3)

Data are n (%) unless otherwise indicated.
*Young nulliparous women with Type 1 diabetes.
†Older nulliparous women with Type 1 diabetes.
‡Parous women with Type 1 diabetes.
§Women with Type 2 diabetes.
¶Years are expressed as median (range).

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Focus group questions

A topic guide was developed to explore the knowledge and attitudes of the participants, reflecting the National Institute for Clinical Excellence care recommendations [11]. Prompts were used when necessary to keep the group discussion focused on the topic. Participants responded to the following questions: (i) Do women with diabetes need to plan their pregnancies more carefully than women who don't have diabetes? If so, why?; (ii) The majority of women with diabetes do not seek advice from health professionals before getting pregnant. As a woman with diabetes, why do you think women don't seek such advice?; (iii) As a woman with diabetes, what areas do you think would be important to address before deciding to try for a baby?; (iv) What other areas might be important to consider to ensure that a woman with diabetes is healthy before pregnancy, or is ready for pregnancy?; (v) How do you think pregnancy and delivery might be different for a woman with diabetes compared with a woman without diabetes?

Descriptive qualitative analyses

Focus groups were professionally transcribed verbatim and analysed by hand. Data analysis was undertaken using a conventional content analysis approach, described as analysis by topic by Morse and Field [16]. Initially, two authors (FAA, MS) read and reread each transcript, highlighting segments of data which were coded by identifying persistent words, phrases, themes or concepts [17]. Data were then grouped according to topic, allowing further identification of subgroups. Following coding, the data were categorized to reflect the overall sense of the data and the relationships between categories. Related categories were then grouped into themes. This was then followed by a discussion and comparison of the themes to verify accuracy of interpretation. Investigator reflexivity, verification of data and codes, and thinking theoretically were strategies used to ensure rigour in this analysis process [18].

Results

Demographics

Demographic characteristics of the participants are shown in Table 1. In the young nulliparous group (Group A: < 25 years; Type 1 diabetes), the age range was 17–20 years. In total, 29% reported having received pre-pregnancy advice and 38% reported that they were currently thinking about pregnancy.

Focus group themes

Qualitative analysis identified five main themes: knowledge; quality of relationships with healthcare professionals; organization of care; the impact of beliefs and attitudes on advice giving; and women's attitudes to pre-pregnancy care advice. Although the themes are presented separately, they are interrelated.

Knowledge

Across all groups, women were generally aware of the need to plan pregnancy; however, an awareness of the rationale for this was only realized in parous women or those who had actively sought pre-pregnancy advice. Apart from acknowledging that women with diabetes 'have really big babies', nulliparous women did not realize the full extent of pregnancy-related risks unless they had been proactive in asking for advice. One young nullliparous woman reported:

> 'The thing they most wanted to tell me about at this age (20 years) was to use some form of contraception, because you don't want to get pregnant without it being planned… but they don't say why it needs to be planned.' (Group A, Woman 2)

Among women who had never received pre-pregnancy advice, there was uncertainty about the issues to be addressed before pregnancy and questions about the time frame required for planning. One woman referred to a negative pregnancy experience, in which she was previously unaware of the importance of controlling blood sugar pre-pregnancy:

> 'I got a scan and I was told the baby's not going to survive—multiple abnormalities… I later found out, through my own research, that this was due to high blood sugars in early pregnancy. It's… I never knew those sorts of things could happen.' (Group B, Woman 2)

Even among parous women and those who had received pre-pregnancy advice, there was wide variability in the knowledge of recommended targets for good blood glucose control. While the majority of women were aware of the need for folic acid, few realized that the dose was higher than that recommended for the general maternity population or were aware of the rationale for use. When asked specifically about the issues to be addressed before pregnancy, women with Type 2 diabetes focused more on the importance of diet and exercise. Regardless of parity, women with Type 2 diabetes were aware that they may have to change from tablets to insulin injections, but the majority strongly felt this information came too late:

> 'I've only been told the second time I went [for clinic appointment], and they said "Oh, by the way, if you're planning to get pregnant, you know, you have to go on insulin". So I thought that's… I could have got pregnant all that time before!' (Group D, Woman 2)

Across all groups, the general practitioner, (GP), nurse or consultant were recognized as sources of information. The Internet was also a source for those particularly interested to learn more, or who had expressed negative feelings with regard to health professionals or the healthcare system. Participants also expressed a desire to learn from their peers; women agreed that it would be 'nice chatting and getting more information from friends who have diabetes'.

Quality of relationships with healthcare professionals

The perceived approach of healthcare professionals was reported as a major barrier to seeking pre-pregnancy advice. This was particularly evident in the young nulliparous group (Type 1

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diabetes) who viewed the health professional as authoritative and unsupportive to their needs:

> 'When I asked about having alcohol and what I should drink on a night out, he just said, "You should just drink water and that's it!" So that would put me off going back and asking more questions.' (Group A, Woman 2)

Young nulliparous women with poor glycaemic control reported that they felt 'judged' by the health professional and perceived them to be controlling and directive.

Older nulliparous women (Type 1 diabetes) commented that, although professionals were very knowledgeable, some can be 'hard to deal with on a professional level', and the women expressed a desire to get advice from an 'approachable' individual who understood their 'real life' and their difficulty of living with diabetes. Two knowledgeable women described positive relationships in which the health professional was viewed as supportive and caring, and interested in them as a person, and who offered a partnership approach should they become pregnant. Women in the group who expressed more knowledge about pregnancy described their consultant as being 'proactive' in talking about pre-pregnancy care and said they could talk openly with them.

The majority of parous women (Type 1 diabetes) reported a positive, helpful and supportive relationship with their diabetes team throughout their pregnancies. However, one third of these women reported subsequent breakdowns in communication with health professionals, which were attributed to a dislike/disagreement with advice given. For example, one woman said she would not seek advice as her health professional was opposed to the prospect of further pregnancies (because of the potential adverse implications for her own health):

> 'I don't want to hear you telling me I can't have more children, so I just went ahead.' (Group C, Woman 4)

Positive and negative relationships with health professionals were also evident within the Type 2 diabetes group. Most frequently, women perceived that health professionals didn't take their care seriously. For example, one woman preferred to shy away from advice as she felt doctors attributed all her problems to obesity and made her feel like she was unimportant:

> 'I feel that they look at me and say, "She's fat—just push her off to one side and that's it,"… that's how I feel all the time.' (Group D, Woman 1)

Another said:

> 'It's just the whole attitude, you know, it was like it didn't matter… maybe I'm just one person, but it's important for me if it's not for them.' (Group D, Woman 2)

Women with Type 2 diabetes also noted that relevant healthcare information was often provided briefly at the end of a clinic appointment, almost as an afterthought. While some women felt well prepared for pregnancy and supported, others believed that doctors were failing in their duty of care, because they negated to pass on important information:

> 'They [doctors] put me on tablets to control my diabetes, and that's how I feel I miscarried, because nobody told me to come off them.' (Group D, Woman 1)

Organization of care

All women believed that the healthcare system had a professional responsibility to ensure they were fully aware about all aspects of their health and able to make an 'informed decision'. For each group, the frequency of pre-pregnancy advice was inconsistent at times: some women were asked about their pregnancy plans at every clinic visit, whereas others were infrequently asked.

Older nulliparous women (Type 1 diabetes) acknowledged that 'lack of continuity' in their care made it difficult for them to establish a relationship with their team and to be proactive in seeking pre-pregnancy care:

> '…I don't get the same person, so I could never have that conversation.' (Group B, Woman 1)

Older nulliparous women also felt that doctors were too busy to give advice and expressed a desire to see a 'dedicated female' health professional for pre-pregnancy advice:

> 'They should have a dedicated female doctor that you could go for pre-pregnancy advice… I know the doctor I see is very nice and all, but sometimes he can't even be bothered lifting his head to look at me. You know it's a conveyor belt system—write the notes, okay. "Next one! Bye, see you next year!" ' (Group B, Woman 2).

Parous women reported both positive and negative feelings with regard to accessing health care. Most women felt that contact was no problem: 'they give you their mobiles and everything!' Furthermore, money was not perceived as a barrier to obtaining care in this population as one woman declared that the health care in the United Kingdom was free and easily accessible, negating worry about financial problems.

The impact of beliefs and attitudes on advice giving

Women reported that pregnancy advice was often provided in a manner which confirmed certain preconceived ideas and social stereotypes held by their health professional. For example, women perceived that they were more likely to be asked questions about their plans for pregnancy once they were married or engaged:

> 'The second they spotted an engagement ring, they said "Are you planning a pregnancy?"! Well, maybe I would have had one before I was engaged. Like I'm 27, so… just because there's an engagement ring on my finger doesn't mean all of a sudden I'm going to have a baby. I might have had one before that!' (Group B, Woman 1)

Women felt that the timing of advice reflected 'stereotypical' views about the appropriate time for planning pregnancy, which was not necessarily tailored to their personal plans or situation. Women acknowledged that it was inappropriate for health professionals to assume that unmarried women do not want or plan to become pregnant. Women felt that it was 'okay' to ask for

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pregnancy advice once engaged or married because it seems 'normal'; but discussing plans for pregnancies with doctors outside of marriage (especially when young) may be frowned upon:

> 'There might be a girl of 21 that thinks "I do want to have a baby, but are they going to look down on me if I'm 21 and not married?" and people that are maybe not planning on getting married but maybe want to have children. It's okay when you're married, or if you're engaged, and you're thinking, well, I'm planning towards this because it seems normal.' (Group B, Woman 5)

Within the young nulliparous group (Type 1 diabetes), women reported that pregnancy advice was often withheld until they reached the perceived 'right age'. This caused frustration among the group who viewed that there was no 'right age' when it comes to having a baby; they acknowledged that, as with alcohol advice, information was kept to a 'bare minimum' until a later age:

> 'But I was told—whenever you're older, come back when you're planning a baby, but never—teenagers, they don't tell you! Same with alcohol and things. Like they'll wait until you're the right age and then tell you, but even—there's no right age, I think, to… if you're having a baby.' (Group A, Woman 4)

Parous women (Type 1 diabetes) raised another issue: while they felt that knowledge had improved over the years and that pregnancy outcomes were now more positive, they reported that health professionals and family members had previously held the view that women with diabetes don't or can't have babies:

> 'Years ago, my GP would have said, "Diabetics don't have babies. You just don't!" and they would have told my mother that. When I was expecting, my family were horrified completely.' (Group C, Woman 2)

One older nulliparous woman with Type 1 diabetes also remarked:

> 'Years ago, in the family planning unit, the nurse used to say that her preference for diabetics was to have two kids before they were 21.' (Group B, Woman 7)

Women's attitudes to pre-pregnancy care advice

Young nulliparous women (Type 1 diabetes) were aware that having diabetes increased their risk of certain clinical complications and, thus, their pregnancy would automatically be associated with 'more risk factors' compared with women without diabetes. Despite expressing a strong desire to be prepared for pregnancy in advance, these women reported that it would be embarrassing to ask for pregnancy advice. They repeatedly acknowledged that not all pregnancies are intended, stating that if they did become pregnant they would be afraid to tell their team because they did not seek advice prior to conception:

> 'I was just told, if you're ever thinking of planning a pregnancy, come back and speak to us, but then I was thinking, if you weren't planning a pregnancy and you did get pregnant—you'd be scared to tell them.' (Group A, Woman 2)

Older nulliparous women (Type 1 diabetes) that had received pre-pregnancy advice, acknowledged the enormous pressure and personal responsibility felt:

> 'With the best will in the world, the buck's going to stop with you.' (Group B, Woman 1)

These women felt entirely accountable for the health of their future babies and were concerned and afraid that they may not be able to adequately control their blood sugar within suitable limits. This fear actually delayed pregnancy plans. Women considered the blood glucose targets for pregnancy to be too low and 'almost impossible' to achieve and started to think about the practicality of this in their everyday life. Despite reporting embarrassment as a barrier to seeking pregnancy-related advice at a younger age, all older nulliparous women acknowledged that there is an urgency to know more at a young age.

Parous women (Type 1 diabetes) reported that their blood glucose control was particularly good when planning pregnancy because their baby's health was at risk. However, women did acknowledge that pre-pregnancy care advice was not always followed because their pregnancy was unintended. A minority reported that health was due to 'luck of the draw' and not always necessarily related to glucose control, while many felt that they could control their own blood glucose and decide on the best time to conceive. Women felt that informing a health professional about their pregnancy plans would take away their control and, ultimately, they should be able to choose when to have children:

> 'It's so restrictive…they're planning when I'm going to have it, not when I want to have it.' (Group C, Woman 3)

Finally, women with Type 2 diabetes reported a variety of mixed experiences and attitudes. At one end of the spectrum, women reported feelings similar to the nulliparous group; they would feel guilty for not controlling their blood sugar during pregnancy and actively sought additional reading to help them cope, acknowledging that pregnancy was a potentially stressful time which required discipline regarding food choices. One woman actively avoided discussing her pregnancy plans because she was afraid that advice would deter her from having children:

> 'So I just took it blindly—whatever happens.' (Group D, Woman 6)

Discussion

This qualitative descriptive study has generated extensive information about knowledge and attitudes related to pre-pregnancy care in women with diabetes. The strength of this work is that it included women of varying age and parity, with both Type 1 and Type 2 diabetes; representative of the women in need of diabetes pre-pregnancy care advice.

Five themes emerged from our focus group data to reveal that, while women were generally aware of the need to plan pregnancy, the rationale for this advice was not realized in the majority of nulliparous women. While women did report

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positive healthcare experiences, the health professional was often viewed, irrespective of group, as being unsupportive to their needs. Predominately, young nulliparous women reported that they felt judged, while women with Type 2 diabetes felt that their needs were not a priority. For nulliparous women, timing of pre-pregnancy advice was often inconsistent, being withheld until a time deemed appropriate by the health professional, i.e. once engaged or older. Women desired pre-pregnancy care at an earlier age, but busy clinics, unfamiliar staff and embarrassment (especially when young), made it difficult for nulliparous women to be proactive in seeking advice. For parous women and those who had received pre-pregnancy advice there was an overall sense of feeling personally accountable for the health of their baby during pregnancy.

Perceived social stereotypes held by health professionals were identified as a barrier to women receiving or seeking pre-pregnancy advice. Despite United Kingdom teenage birth rates being the highest in Western Europe [19], young nulliparous women in this study failed to be counselled on pregnancy-related risks. Indeed, older women (≥ 25 years), in stable relationships yet not married, were shocked to discover that they did not fully understand the rationale for or the scope of pre-pregnancy care. Thus, irrespective of age, women are not getting adequate pre-pregnancy advice. Our findings, supported by previous work [20–22], emphasize the urgent need for health professionals to ask all women of reproductive age about their pregnancy plans, to hold back on preconceived ideas based on marital status or age and not to delay pregnancy advice until they perceive the time is right.

Knowledge of pregnancy-related risks on its own is not effective to prevent unplanned pregnancies [13,23,24] and the manner in which information is provided is also important [24]. Our research showed that a poor patient–provider relationship, exacerbated by a lack of staff continuity within busy clinics, made it particularly difficult for women to discuss pregnancy plans. Such barriers highlight the urgent need to deliver accessible information in a supportive way. Recently, multimedia technologies such as CD-ROMs and DVDs have proved to be feasible and effective educational interventions in raising awareness of reproductive health issues in women with diabetes. [25–27]. Furthermore, the potential benefits of peer support should also not be overlooked as women remarked that they enjoyed the focus group and found support in sharing experiences with someone of a similar age. For many women, this was their first opportunity to talk with another woman with diabetes. Further research is needed to explore the benefits of organizing informal meetings, possibly in collaboration with voluntary organizations. In such an environment, women could be educated in a group setting, learning from the experience of similar others, whether they are already pregnant, planning a pregnancy or have no intention of becoming pregnant.

To date, few qualitative studies have explored the knowledge and attitudes of women with Type 1 [20,24,28,29] and Type 2 diabetes [24,28,29] regarding pre-pregnancy care. While every attempt was made to be representative of women with Type 1 and Type 2 diabetes, a potential limitation was respondent bias; women who were highly motivated as a result of a previous adverse pregnancy outcome or a desire to be better informed may have been more likely to participate and thus we may have overestimated the awareness of the need to plan pregnancy among women with diabetes. Participants with an adverse pregnancy may also have been more likely to voice negative feelings in relation to the system of care and/or health professionals. Furthermore, as the majority of our study participants were White (reflective of background population demographics), our findings may not be generally applicable to women in other ethnic groups and further populations should be studied.

The knowledge and attitudes reported in this study highlight the need for women with diabetes, regardless of age, marital status or type of diabetes, to receive guidance about planning pregnancy in a motivating, positive and supportive manner. Patient viewpoints expressed in this qualitative study contribute to our understanding of how advice-seeking behaviour is regulated; which, in turn, may help health professionals determine how best to encourage women to avail of pre-pregnancy care.

Competing interests

Nothing to declare.

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