

Preconception care for women with type 1 or type 2 diabetes mellitus: a mixed-methods study exploring uptake of preconception care

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

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Scientific summary

Background

Diabetes mellitus is increasingly recognised as a global epidemic and is one of the most common medical conditions in pregnancy. Rates of diabetes mellitus during pregnancy are rapidly increasing and are seen to be a serious public health concern. These increased rates are mainly due to the rapid rise in type 2 diabetes mellitus (T2DM) and it has been suggested that this is, in turn, associated with an increased prevalence of overweight and obesity in the population, although rates of type 1 diabetes mellitus (T1DM) have also risen, albeit less sharply. In the UK, 1 in 250 pregnancies is affected by diabetes mellitus. Between 1995 and 2012 there was an increase in prevalence of T1DM of 162% and of T2DM of 354%. This research is important now and in the future because rates of diabetes mellitus in pregnancy are high and are likely to increase further both in the UK and globally.

In the UK (and globally), previous research indicates that the majority of women with pre-existing diabetes mellitus do not seek preconception care (PCC). The complications that arise from poorly managed diabetes mellitus during pregnancy, birth and early motherhood are well documented, in that they carry considerable risks to women and children as well as posing an unnecessary financial burden on health services and society. These complications include an increased risk of spontaneous abortion and perinatal mortality, congenital abnormalities and caesarean section.

Pre-existing diabetes mellitus is associated with significantly higher rates of obstetric complications and maternal and neonatal morbidity and mortality. Previous research indicates that improving the uptake of PCC for women with pre-existing diabetes mellitus would add significant anticipated value, such as a reduction in adverse outcomes, to the health service provision already in place. A full spectrum of modifiable risk factors are associated with diabetes mellitus, which means that women with diabetes mellitus of childbearing age stand to benefit from PCC. These modifiable risk factors include optimisation of blood glucose levels, folic acid supplementation and supported lifestyle changes. Preconception services provide advice and support to enable positive behaviour change, which can have a positive impact on pregnancy, childbirth and early parenting. There is significant clinical evidence from the UK and other countries to suggest that PCC can play an important role in risk factor modification.

Policy imperatives, such as the National Institute for Health and Care Excellence (NICE) guidelines and quality standards, strongly recommend PCC for women with pre-existing diabetes mellitus. There is also general agreement in the literature on the practical arrangements for PCC, including the role of multidisciplinary care teams. In spite of these recommendations and practices, PCC has been described as 'a black hole with services struggling to provide accessible and timely services' (Hawthorne G, Modder J. *Maternity services for women with diabetes in the UK. Diabetic Medicine* 2002;**19**:50–55) and, more recently, researchers have called for a 'fresh look' at service provision. The proposed project provides this fresh look to inform preconception service provision and delivery that could enable more women with pre-existing diabetes mellitus to access care that could have a significant impact on health and on the disease burden.

Aims and objectives

The project aimed to:

- understand why women with diabetes mellitus of childbearing age do, or do not, access PCC, with a view to informing services
- investigate the views of staff and stakeholders to explore existing and future provision of PCC.

The objectives of this project were to:

- systematically review the descriptive research on PCC for women with diabetes mellitus of childbearing age and establish themes and gaps in knowledge
- identify views on the provision of, and facilitators of and barriers to the uptake of, PCC through qualitative work.

Design and methods

Design

The project was designed in several phases to generate new insights in order to understand the facilitators of and barriers to uptake of PCC for women with pre-existing diabetes mellitus. A systematic review of the literature was carried out to generate a narrative synthesis that would identify themes and gaps in existing knowledge. Qualitative interviews with women were also conducted in order to explore issues relating to pregnancy planning, diabetes mellitus and uptake of PCC.

Setting

Given that women with pre-existing diabetes mellitus receive care across primary and secondary care settings, the qualitative interviews were based in two main settings: (1) 11 general practices in the Sandwell and West Birmingham Clinical Commissioning Group and (2) two PCC and antenatal clinics in the Heart of England NHS Foundation Trust.

Participants

The participants comprised women with pre-existing diabetes mellitus of childbearing age and of either white British or Pakistani origin. Women with pre-existing mental health issues and women with gestational diabetes mellitus were excluded from the study.

Analysis

For the systematic review of the descriptive literature, two main approaches were used to analyse the studies. First, each study was summarised by extracting the following details from the study: study aim, participant characteristics, method of data collection, method of data analysis and study context. Other data were extracted as part of the quality appraisal process. Second, the studies were imported into the qualitative data analysis software program NVivo 11 for Mac (QSR International, Warrington, UK) and an inductive thematic analysis was carried out. The purpose of carrying out the thematic analysis was to produce a narrative synthesis of the selected studies in order to identify common themes, gaps in knowledge and to generate new knowledge.

All interviews were audio-recorded with the permission of respondents. Anonymised transcripts were imported into NVivo. NVivo was used to support the analysis of the data using thematic analysis and the method of 'constant comparison'. A 'factual' profile of each participant was also written and reported to capture some of the complexity of individual cases.

Each data set was subjected to both separate and integrated analysis to enable identification and comparison of significant themes between and within the reviewed literature and the interviews with women.

Ethics approval

A favourable ethics opinion was granted from The Open University Human Research and Ethics Committee (HREC) and the South Central – Berkshire National Research Ethics Service Committee (reference 15/SC/0026). NHS research and development (R&D) permissions were also gained from the lead site for the project which issued relevant letters of approval and access.

Patient and public involvement

Service users were involved in the design of the study, the ethics application and in the design of all of the patient information forms and consent forms. Lay readers have been involved in reviewing the final project report and the plain English summary.

Research findings and results

For the systematic review, 496 records were identified through database searching and an additional 12 identified through other sources. Databases searches were performed in November 2014 and December 2015, from 1980 to 2015, and included Academic Search Complete, Applied Social Sciences Index and Abstracts (ASSIA), British Nursing Index (BNI), Cumulative Index to Nursing and Allied Health Literature (CINAHL), The Cochrane Library, ProQuest Dissertations & Theses Database, Interim, Maternity and Infant Care, MEDLINE, PubMed, ScienceDirect, Scopus and Web of Science. After removing duplicates, 472 records remained and were screened by two reviewers. Following screening, 49 full-text articles were read to assess for eligibility. Eighteen studies were included in the systematic review and qualitative synthesis, and a narrative summary of study quality was included.

It was the original intention of the project to interview up to 48 women with pre-existing diabetes mellitus of childbearing age about their views and experiences of PCC. Following considerable difficulties with recruitment, especially in primary care, 12 women were interviewed as part of the study. Nine of the participants had T1DM and three had T2DM. Three participants were Pakistani in origin and nine were white British.

In analysing the data derived from the systematic review and the in-depth interviews, four key findings emerged.

1. There is a lack of clarity over what PCC for women with diabetes mellitus comprises and how it is perceived.
2. On the basis of this and following a reconceptualisation of PCC, pregnancy planning, fertility and contraception must be core elements of that care. This raises issues about the required levels of expertise needed for practitioners to deliver that care effectively.
3. There is a lack of clarity about who is responsible for the delivery of PCC to women with diabetes mellitus and, if a reconceptualised model of PCC has pregnancy planning, fertility and contraception at its core, then that impacts significantly on whose responsibility its delivery becomes and the required levels of expertise needed to deliver good care. Further distinctions can be made between women with T1DM and T2DM, as their care tends to be managed in different settings.
4. The quality of care delivery is dependent on a form of care that is based on partnership working, is woman centred and individualised, and values the need for continuity. Such care needs to be about enabling women to make changes that are positive rather than treating them as women at risk of failure.

Conclusions

The number of women interviewed in this study is not dissimilar to other similar qualitative studies in that sample sizes, by their nature, tend to be modest. However, the number of interviews carried out did fall short of the original intentions of the project. That said, the qualitative findings are generally supportive of the findings of the systematic review.

The study findings indicate that reconceptualising PCC to place a greater emphasis on pregnancy planning, fertility and contraception would ameliorate some of the existing barriers to uptake of care. Clarification on

who is responsible for the delivery of PCC to women with pre-existing diabetes mellitus is required, as is ensuring that the correct expertise is available so that opportunities for giving information are maximised. Relationships between women and health professionals should be based on a partnership approach that encourages mutual trust and respect focusing on positive change, rather than negative outcomes.

Further research, in order of priority, should focus on:

- investigation of the views of stakeholders involved in the commissioning, design and delivery of PCC services for women with pre-existing diabetes mellitus
- further investigation of the views and experiences of minority and ethnically diverse groups, including the experiences of women who do not speak English
- the role of family and other support in pregnancy planning and PCC
- the management of diabetes mellitus in neonatal care and its role in breastfeeding.

Registrations

This study is registered as PROSPERO CRD42014015592 and ISRCTN12983949.

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