

The experiences of pregnancy and childbirth in women with diabetes; development of a research protocol.

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Abstract:

Aims: To conduct an audit in order to 1) identify the key concerns of women with diabetes in their experience of maternity service provision, 2) incorporate those concerns in the development of a research proposal, and 3) identify appropriate ways of collaborating with service users for the purposes of health services research.

Methods:

As part of the development of a research proposal to investigate the experiences of women with diabetes during pregnancy and childbirth, three discussion groups were convened. Women with either pre-existing or gestational diabetes who had experienced the full range of maternity service provision whilst having their baby were invited to meet the researchers to provide their views on a range of topics.

Results:

Particular concerns identified by the women included high expectations of service provision often unfulfilled in practice, problematic relationships with health care professionals and experiences of fragmented care. None of the attendees had been involved in any research activities in the past, and all indicated that they were interested in collaborating in the development of a research proposal to investigate issues around diabetes and pregnancy.

Conclusions:

This audit has demonstrated that it is possible to engage with service users in order to identify the concerns of women with diabetes who have experienced maternity service provision. Informal discussion groups are an acceptable way of gaining insights into the experiences of women with diabetes during pregnancy. Future challenges include the merging of different priorities to promote further research.

Introduction

A recent report from the Confidential Enquiry into Maternal and Child Health (CEMACH) has highlighted the continued existence of high rates of morbidity, and the development of complications during pregnancy for women with diabetes¹(CEMACH 2007). Diabetes is the most common medical complication in pregnancy and is associated with increased risk of obstetric complications, including congenital abnormalities, increased rates of caesarean delivery and perinatal mortality¹. Rates of diabetes during pregnancy are increasing and remain a serious public health concern, as highlighted in the Diabetes National service Framework² (NSF).

Whilst clinical outcomes for both mother and child remain poorer for women with compared to those without diabetes, there are some signs that diabetes management during pregnancy is improving³ (Waddingham). Current recommendations for the care of women before and during pregnancy focus on medical considerations, especially the aim to achieve tight blood glucose control^{4,5} (NICE, Holt 2008). The psychosocial impacts of pre-natal care are less well recognised and rarely considered. Although there is little evidence to date, psychosocial factors may be affected alongside medical outcomes and thus require incorporation into future research.

In the U.K. there has been a recent increase in recommendations relating to the involvement of service users in both research and health care delivery⁶(DoH 2003). The development of the Expert Patient Programme, the involvement of lay people in diabetes education programmes as well as involvement at both primary and secondary care level, are all examples of the way in which service users are now involved in care. However, the number of lay people involved remains small and often discourages those from the less affluent or less articulate sections of society. It is our contention that in order to improve services for women during pregnancy more evidence is required; evidence that needs to come from services users from a range of backgrounds and experiences. Investigation of the healthcare experiences of women with diabetes during pregnancy could provide vital opportunities to

improve both medical and psychosocial outcomes, and could inform health service provision. Therefore an audit was conducted with the following aims:

- 1) to identify the key concerns of women with diabetes in their experience of maternity service provision,
- 2) to incorporate those concerns in the development of a research proposal which includes the views of both lay people and health care personnel,
- 3) to identify appropriate ways of collaborating with service users for the purposes of health services research.

Methods

Women who had recently experienced the full range of maternity services provision within the Heart of England NHS Trust, who were known to the diabetes midwife (SC), were contacted via telephone and invited to meet in the diabetes centre for an informal discussion in order to hear their opinions on how maternity services for women with diabetes could be improved. Women's views on priorities for research and service user involvement in the research process were also sought.

Women were contacted who had either pre-existing diabetes or who had developed gestational diabetes during their most recent pregnancy. Refreshments were provided and travel expenses reimbursed. The diabetes midwife attended the discussions, which were audio-taped with the women's permission, along with one (CL) or two of the authors (CL, SE). Three broad topics were discussed: services before and during pregnancy, researching the experiences of pregnant women with diabetes, and involving lay people in research.

After the discussions, a research proposal was developed and sent to all the women who indicated they would like the opportunity to comment on it. Telephone contact was made with all these women two weeks after the proposal was sent out, in order to obtain their views. Written comments were also obtained, where this was preferred by the individual. These views were incorporated in to a research proposal, which has now been submitted for funding consideration.

Results

Discussion groups

A total of 30 women were invited to take part in the informal discussions; 5 women declined and 13 women attended on one of three occasions (see Figure One). Twelve women were unable to attend on the pre-arranged day; 5 of whom contacted us on the day and said they were unable to attend for health reasons (their own or their child's). Of the 7 women who were unable to attend either of the first two meetings, only 1 was able to attend a sub-sequent meeting.

[Figure One about here]

Three meetings were held and most women attended with their babies (ranging in age from 6 weeks to 6 months old), which ensured a high degree of informality and encouraged a spirit of camaraderie between the women. Many of the women had voiced their relief that they were able to bring their baby, as being unable to do so would have excluded them from participating. The women also agreed that joining in the discussions could be of benefit both to them and other women with diabetes:

“I think it's good to share views and to give feedback really on our experiences through pregnancy, and if we can help other mums who are pregnant at the moment or will be, I think it benefits them”

At the first meeting all had pre-existing diabetes; 2 women had Type 1 diabetes, and 3 had Type 2 diabetes. Three women attended the second meeting; one of whom had Type 2 diabetes and two had had gestational diabetes. Five women attended the third meeting, all of whom had had gestational diabetes. All meetings lasted approximately 90 minutes.

Service provision

In general there were high expectations of the service provision for women with diabetes during pregnancy; however this was reported as often unfulfilled in practice. Problematic relationships with health care professionals were identified; especially the lack of rapport between patient and professional over an extended period of time. This was identified as particularly difficult during pregnancy

because the women were expected to attend ante-natal clinic approximately every two weeks. It was clear that each woman responded to and developed relationships with the different health care professionals working in the diabetes ante-natal clinic in specific ways, with some women preferring a female doctor, and others preferring what was described as a 'medical approach' where the focus was mainly on blood sugar levels. Other women were clear that they wanted more from their ante-natal care than what they perceived as an over-riding concern with medical management of diabetes:

“ ...the diabetes side was fantastic, but may be just a bit more support with just being pregnant”

“It just dominates the pregnancy all the way through, takes all the joy out of it”

“Immediately you become high risk – it's in your notes. You'll probably be... induced early and it just changes everything so quickly”

In all three discussion groups women reported feeling that the health care professionals' over-riding concern was with their diabetes, in particular blood glucose levels and insulin treatment, at the expense of a more positive experience of pregnancy and childbirth. Some women attended diabetes ante-natal clinics that were jointly run between the diabetologist and the obstetrician, and these were perceived to be a positive development in service delivery, particularly because of improved communication between the two health care professionals. Experiences of labour were varied but overwhelmingly the need, on the part of the health care professionals, to maintain close monitoring of blood sugar levels was seen as problematic and impinging on events. The difference between ante-natal care, where the responsibility for blood sugar control lay with the mothers, and care during labour, where control was taken away from mothers (and involved intravenous infusion, sliding scales of insulin etc) was stark.

“I had one (a drip) in each hand, disabling really”

“I had two drips in...they made me walk all down the ward into the lift with these drips on trolleys...”

Knowledge about the need for dietary intake to be balanced with insulin levels, both during and after pregnancy, and the impact on breastfeeding were both areas identified as requiring further improvement within secondary care. A number of the women were separated from their baby immediately after the birth when they were sent to the special care baby unit for further monitoring.

“they didn’t take her off straight away – so we did have her for about an hour....that was hard there were three women with their babies crying all night (in the ward room she shared) then there’s me. I felt like I didn’t have a baby”.

Many of the women reported only seeing health care professionals in the secondary care setting, and did not have access to a community midwife during pregnancy. Not only did this reinforce the medicalised nature of their pregnancy, it also engendered feelings of isolation as they spent their time in large busy hospital clinics, rather than at more local primary care settings. The majority of the participants were in favour of the development of an alternative support system for mothers-to-be, described as a ‘buddying’ system. This would involve linking mothers who had experienced diabetes during pregnancy with new or expectant mothers. One woman had experienced something similar, albeit ad hoc:

“They gave my name to a young girl and she phoned me at home – I can’t remember her name – she was a godsend as I hadn’t a clue what was going on. We were going through the same things, we were the same kind of age and that really helped.”

Not all the women felt they would use such a system, particularly because they felt the need to rely more on professional health when it came to managing their diabetes. More education from health care professionals, on aspects such as diet, was also identified as important. A gap between information received from diabetologists and information from midwives and obstetricians was still in evidence.

“When you’re in labour ...it would have been nice to have a diabetes nurse or doctor to reassure you that everything’s alright... although I had the drip in I don’t remember anyone talking to me about my diabetes”.

“My insulin drip came out and no one seemed sure whether they should put I back in or not”.

“On the labour ward when my blood sugar was so high, nobody there knew why it was and what to do about it...you’ve got a new baby who needs attention but your blood sugars are through the roof...”

Involvement in the research process

None of the women we met had been involved in health services research in the past, but all were interested in being involved in a range of ways in the development of a research proposal to investigate issues around diabetes and pregnancy. A range of suggestions for research topics were identified, including investigating the use of induction at 38 weeks, researching the different experiences of women with different types of diabetes, and identifying ways of sharing stories of diabetes during pregnancy.

All the women made suggestions in terms of protocol design, and half were interested in being involved in other aspects of the research process including data collection and belonging to an ‘investigative team’. Alternative ways of collecting data were discussed with both quantitative and qualitative methods considered. The women identified surveys as a useful method of collecting data, particularly if people wished to remain anonymous. Discussion or focus groups were seen as a useful way to share experiences.

Development of a research proposal

All the women we met indicated they would like to comment on the research proposal, and 6 women provided either written or verbal feedback. All those contacted after the discussions reported feeling pleased that they continued to be consulted and that their feedback was important in the proposal’s development. The proposal was initially developed between academics and practitioners, including a diabetologist, a diabetes nurse midwife and a diabetes specialist nurse with responsibility for working with minority ethnic groups, particularly women from South Asian backgrounds. The latter practitioner was included as, due to the

language limitations of the authors, only English-speaking women had been invited to discuss their concerns. Given that the maternity services are provided in an area with a large minority ethnic population, consideration needed to be given to the needs of these women. A key aspect of the research proposal was ensuring the involvement of service users in both the research process as well as developing any recommendations for practice. A first draft of the grant proposal was circulated to all the women who had indicated they would like to comment on it. Both the content and the layout of the proposal were commented on.

“I’ve reviewed and feel that the content is good, it explains what the research is aiming to do and it has a lot of meaningful information. I feel that the layout could be improved and have made comments below”.

“Would it be appropriate to put somewhere in the value for money section about the potential to assist with diet control (by improved support) and hence reduced costs to NHS throughout pregnancy and birth – seems to me that insulin controlled=early induction=increased likelihood of c-section = ditto for future pregnancies”

“I think this is an excellent project and I do hope you get funding as it could make a huge difference to the care given to expectant ladies who unfortunately develop GDM...”.

Discussion

This report has demonstrated the possibilities of working with service users in order to audit and develop services in secondary care. There are limitations to our work, including the low number of women who felt able to meet us to discuss their experiences, in spite of appearing willing when contacted by telephone. For those we were able to contact, poor turnout on the day was mostly due to illness which is to be expected in this group (i.e. women with small babies). Our contacts have so far been limited to English-speaking women; however our research proposal has been designed to include the views and experiences of women from South Asian communities as well. A recent report has highlighted the low take-up of health services among minority ethnic groups, and stressed the need for more diverse

provision ⁷ (Stuart, 2008). Indeed, consultation with minority ethnic groups and involvement in the design of services remains low ⁸ (Begum, 2006). Our previous research has demonstrated that it is possible to engage with individuals from South Asian communities, particularly if qualitative methods of research, such as focus groups, are used ⁹ (Lloyd).

Reconciling the concerns of service users with those of the health care professionals may be challenging. In our work with these women this was particularly evident with regard to their perceptions of an over-riding concern with blood sugar control at the expense of a more holistic approach to care during pregnancy. The amount of feedback we received from the women may have been influenced by the presence of the diabetes nurse midwife. However we were not carrying out a rigorous piece of research but rather an informal audit of services in order to begin to identify the key concerns of service users prior to developing a research proposal. Furthermore our need to find out about their experiences needed to be balanced with the ability of the midwife to provide answers to many of the questions the women had, including both medical and service delivery queries.

Talking together as a group which included both practitioners, academics and service users has led to a greater understanding of the issues from a range of perspectives. It has also led to a sharing of stories which was seen in a very positive light by the women themselves. Challenges remain in securing the engagement of service users, not just in terms of participating in terms of health services research, but also in terms of active partnership with health care professionals.

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Flow chart of service users participating in the development of a research protocol on pregnancy and diabetes:

