Attitudes to Pregnancy Risk and Conception among Women with Type 1 Diabetes
Executive Research Briefing

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The pregnancies of women with Type 1 diabetes have high rates of poor outcome in comparison to the general population, despite the St Vincent Declaration that called for the elimination of such differences. Clinical studies identify the importance of optimal glycaemic control prior to conception to reduce risk. This research sought to facilitate the development of preconception care and of education about the associated risks in conception and pregnancy. This has been achieved by exploring the attitudes to risk management and reproductive choices of a purposive sample of women with Type 1 diabetes using qualitative social sciences methodologies in order to capture their social contexts. Findings will help design intervention techniques that are responsive to the women's social context and also reduce the negative outcomes associated with such pregnancies.

Background

Epidemiological data show a continuing high rate of serious foetal abnormality among women with insulin dependent diabetes. The damage is caused to the foetus very early in pregnancy due to high levels of blood sugar. The way to improve outcomes for babies of women with diabetes is to assist them to prepare for pregnancy and control their blood sugar before they become pregnant. The first stage in this process of improving pre-pregnancy care to these women is to understand their perspective on pregnancy, diabetic control and accessing currently available services.

Key Research Objectives

1) Explore how women with Type 1 diabetes understand their condition, the risks that come with it and the implications of pregnancy and their reproductive choices.
2) Identify the social contexts that influence how women with diabetes identify and manage health and pregnancy risk.
3) Contribute to the development of preconception care for women with diabetes in Newcastle
4) Facilitate the development of a large study focused on developing and testing models of intervention based on the findings here.

About the Study

One hundred and forty women aged between 20 and 37 who were on the Newcastle Diabetic Centre database were randomly selected and sent a letter with an information sheet from the Diabetic Centre asking for their consent to take part in the study (45% response rate). Thirty-two women aged 20-35 were interviewed in the first round of interviews, including two at the pilot stage. Nine of the sample were mothers (including 1 who was currently pregnant); in total three were pregnant at the time of interview and 21 were neither pregnant, nor mothers. Three of the latter category had, however, experienced a pregnancy but not motherhood. Ten women were re-interviewed for the 2nd round of interviews and a further five women were involved in a focus group (four had been interviewed in the 1st round, one was new to the study and was chosen as she did not receive diabetic care from the Newcastle Diabetic Centre).

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The research was guided by an advisory group, which included a Consultant obstetrician, a Consultant Diabetologist, Local GPs, Specialist Diabetic Nurses, Medical Sociology Researchers and women with Type 1 diabetes.

The computer packages SPSS and NVivo were used to analyse the data.

Key Findings

Key Issues relating to mental well-being

- Many women suffered from periods of poor mental well-being, including; depression, anxiety and eating disorders, often resulting in periods of poor glycaemic control.
- The need for mental health support was not confined to diagnosis, negative body image or diabetes related complaints, but was often required at times such as a relationship break-up; failed attempts to get pregnant; or a pregnancy that ended in miscarriage.
- The lack of mental health support to help regain control was a prominent emerging theme.

Key Issues relating to management/control

- Good glycaemic control appeared to be most influenced by: positive mental well-being; Bolus/basal injection system; dietary support; knowing your body; and taking responsibility for health and pregnancy as a trigger for improved control.
- Poor glycaemic control appeared to be most influenced by: conflict over diagnosis; difficulties in daily management including food, occupational stress, body image and depression; failure of pregnancy; and failure of conception and coping post-birth.

Key Issues relating to health care support

- Overall there was a general consensus that the one-stop-shop provision of diabetic care at the Newcastle Diabetes Centre was highly rated.
- The greatest level of dissatisfaction about the service was in relation to the lack of continuity of care. Many disliked the fact that they would rarely see the same consultant twice resulting in a lack of any on-going relationship and repetition at each visit.
- Some women had problems understanding doctors whose first language was not English and respondents spoke of feeling like test subjects for training doctors rather than patients.
- The diabetic specialist nurses were viewed as a constant source of support and it was felt that the nurses understood a bit more about the reality of living with diabetes.

Key Issues for knowledge about Pregnancy Planning and risks involved

- Few women had ever received information about how sexual activity could impact on diabetes. Most believed this information should be available and repeated.
- The majority had been asked if they were planning a pregnancy. Most felt this was a 'closed' question offering little opportunity to discuss the implications of pregnancy, especially amongst those who were sexually active but not planning a pregnancy.
- Overall there was a relatively high level of knowledge with regards to how to approach the planning of a diabetic pregnancy. Awareness of the potential complications was generally limited to the risk of a 'bigger baby'.

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- Less than 50% of the sample was aware that a pre-conception clinic existed in Newcastle. More women who had experienced pregnancy than not were aware of this service.
- Only 10 of 24 pregnancies experienced between 14 women in this sample were diabetically planned. Two were planned pregnancies, but not diabetically. The remaining 12 became pregnant accidentally despite contraceptive use.
- For those whose pregnancies were accidental, most had a good knowledge about how and why to plan a pregnancy. They knew what to do but they had not been planning to become pregnant, raising the potential importance that contraceptive advice and education may play in reducing the level of diabetically unplanned pregnancies.

Key Issues relating to pregnancy support, birth and post-birth experiences

- Mothers were overwhelmingly positive about the care that they received within the pre-pregnancy stage and during their pregnancy, especially the regular phone contact with diabetic specialist nurses.
- However some mothers felt that because their anti-natal care was provided by the RVI, they missed out on general midwifery care and signposting to anti-natal activities for all mothers.
- Most had acknowledged the higher chance of a C-section, but when it came to the point of birth, they felt unprepared and cheated by the experience.
- Most mothers had been unable to breast-feed and said the issue had not been raised with them, either in terms of encouragement to breast-feed or information about how it may affect their diabetes.

Conclusions and policy implications

Provision of information and advice about general sexual health

The findings of this research show that few women felt that there was enough information available from any source (GP, Annual reviews, literature etc.) about sexual health, (inducing pregnancy awareness) and diabetes. This was seen to be important particularly for young people and newly-diagnosed individuals. Opinions about how to provide this information were varied and highlighted that no one method would capture all audiences. Different people react to different styles of information presentation and therefore if messages about sex and pregnancy are to reach all women with diabetes, then a number of methods should be employed.

Provision of information and advice about pregnancy

The findings of this research show that in general the level of knowledge about how to plan a diabetic pregnancy was high, although specific knowledge was less comprehensive as to why extra planning was required. Most women believed that more information should be provided about why to plan a diabetic pregnancy, but that this must be done in a positive fashion and not simply attempt to scare women into compliance. Most women felt that the annual review question of whether they were planning a pregnancy or not was a 'closed' question and did not offer sufficient impetus to start a discussion about pregnancy. Due to the fact that more than 50% of the pregnancies to this sample of women were completely accidental, the issue of increasing contraceptive awareness and competency must be considered important factors in decreasing the proportion of diabetically unplanned pregnancies.

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Women who utilised the pre-conception clinic at the Diabetic Centre found the service invaluable in terms of support and advice. However, less than 50% of the women were aware it existed and thought more advertising should be done both visually in waiting areas (leaflets, plasma screen) and by word of mouth via the diabetic specialist nurses.

Link to family planning

Many of the women suggested that a more effective way of getting the pregnancy planning message across to those women who are sexually active but not actually planning a pregnancy was through a link with family planning to the diabetes centre. One of the most favoured aspects of the Newcastle diabetes centre is the one-stop-shop nature of the service. Many therefore felt that if contraceptive advice and sexual health information was also available on-site, this would encourage more women to consider the implications of their sexual and contraceptive behaviour on their diabetes. A diabetic specialist nurse with family planning training was seen as the best person to head such a provision.

Mental health awareness

The findings of this research show that at present, the mental health support needs of this sample of patients were not being met. The aim of all professionals working in the field of diabetes is to promote good self-management and optimal glycaemic control at all times, and particularly for women with Type 1 diabetes at the point of pregnancy planning and conception. It is therefore crucial that all aspects of a woman's daily regime are explored including her mental well-being, rather than confining exploration to dietary habits, blood testing and insulin regime. It is also important to recognise that mental well being may be affected by many factors including: the diagnosis; delayed reaction to the diagnosis; negative body image; diabetic complaints; daily management pressures; relationship break-ups; employment stress; poor outcome of pregnancy; failure to conceive and pressures and fears associated with pregnancy.

How to obtain further details

The research team included Dr. Alison Hosie and Dr. Janice McLaughlin from the University of Newcastle and Dr. Gillian Hawthorne and Dr. Maggie Blott from Newcastle Diabetes Centre.

Copies of the full report and this briefing can be obtained from Dr. Janice McLaughlin by emailing **Janice.McLaughlin@newcastle.ac.uk**

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The views expressed here are those of the authors and not necessarily those of Newcastle PCT.