

Involving women with gestational diabetes

By Clare Aspinall, Jan Hopkins and Sarah O'Brien

Gestational Diabetes Mellitus (GDM) (diabetes which occurs in pregnancy) increases health risks in pregnancy, the risk of developing GDM again and type 2 diabetes in later life. Women with GDM are highly managed in pregnancy, but the opportunity to support them once their baby is delivered, and reduce the risk of diabetes, is often overlooked. We conducted a qualitative study, with service users as co-researchers, to ask a group of women how they wished to self-manage their future risk of GDM and type 2 diabetes and how they wanted to be supported if at all. We also asked whether an intervention post pregnancy to advise and educate on risks of diabetes, weight and exercise was a good idea.

The project team included two service user researchers, a university researcher and a nurse consultant in diabetes based at a hospital trust. The service users were members of the diabetes service user support group, which the nurse consultant had helped to set up several years earlier at her trust. She made an informal approach to the group and asked them to nominate suitable co-researchers. To aid their decision, we provided them with clear information about the nature and extent of any commitment, the mentoring and training to be offered and the available financial recompense as per INVOLVE guidance. The only real stipulation was that candidates must have had a personal experience of diabetes during pregnancy. Two researchers were identified.

Part of our role was to mentor the service users and provide them with written and verbal guidance on good practice when preparing for and conducting qualitative research and to lightly steer the focus group and

ensure, for example, that participants' clinical questions were answered satisfactorily. However, this was a collaborative journey. To avoid tokenistic gestures, co-researcher involvement was embedded from design to dissemination. We met face-to-face and communicated via email.

Together we:

- identified the themes/questions to be included in the focus group
- designed project materials
- conducted several focus groups
- interpreted focus group data
- disseminated findings at the INVOLVE conference.

User involvement at the design phase was crucial since service users have invaluable insight, knowledge and experience of health services, which complements and challenges the researchers/health professionals' perspective. For example, the personal experience of the service users suggested an opening theme around women's experience at diagnosis, which the academic researchers had not considered. We reached a consensus and decided to lead with this theme.

The user led focus groups set a warmer tone since the service user researcher was able to identify, empathise and respond in a meaningful way to the participants whose experience mirrored her own:

“Being involved helped me to not feel so alone with my experience. It was almost a comfort to know other women felt the same feelings such as: stigma (is it because I am overweight?), lonely (not knowing any other woman with the condition), scared about the impact on you but most importantly your baby ...overwhelmed with information and medical jargon.”

Through their involvement in the diabetes users' support

group, the user researchers advocated on behalf of the wider patient group. In this study, they voiced the need for better outcomes for women with gestational diabetes:

“I felt a bit sad that women still felt these feelings even though my story is seven years old. I wish more was done to support these women and their families with a more long term focus. Some women had experienced GDM more than once.”

Involvement in the study had other personal rewards for the co-researchers as they felt a sense of achievement:

“I was very nervous leading the focus groups. It’s not as easy as the professionals make it look! So I feel I have added a new string to my bow.”

Involving service users brings many benefits. It challenges professional researchers and ensures that we focus on user priorities for research and identify outcomes which seek to improve patient care and experience. Our relationship with the user researchers was very harmonious and we learnt from them, but it does require the ‘professionals’ to accept that their way is not the only way of doing things. There were times when we wanted to intervene in the focus group, for example, and it would have been easier at points to ask our co-researchers to just rubber stamp our decisions, but then we would have diminished the benefits of a collaborative project.

We hope to secure funding to undertake a larger study to test the outcomes of an educational intervention for women with gestational diabetes and we will certainly invite service users to be co-researchers in this body of work.

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