Diabetes and IT

Preconception counselling for women with diabetes: An online resource

Valerie A Holmes, on behalf of the Women with Diabetes project team

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Article points

1. Despite making up a relatively small proportion of the total antenatal population, women with diabetes are a high-risk group.
2. Women with diabetes have significantly higher rates of stillbirth, congenital malformation, miscarriage, pre-eclampsia, pre-term delivery and macrosomia.
3. Pre-pregnancy care significantly reduces the risk of adverse outcomes yet the majority of women continue to receive suboptimal pre-pregnancy care.
4. Primary care can play a major role in improving pregnancy outcomes for women with diabetes through preconception counselling.
5. An innovative online educational resource offers healthcare professionals a credible and useful tool to assist with the provision of preconception counselling.

Key words

- Preconception counselling
- Pregnancy
- Pre-pregnancy care

Author

Valerie A Holmes is a Senior Lecturer, Centre for Public Heath, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast.

Pre-pregnancy care impacts positively on pregnancy outcome, yet the majority of women continue to receive suboptimal support in this area owing to a lack of awareness about the importance of pregnancy planning. An innovative preconception counselling resource has been developed in Northern Ireland (originally as a DVD and later in an online format), in collaboration with end users to raise awareness of planning for pregnancy. This educational resource is now embedded in routine care in the region as a preconception counselling tool, being adopted by all diabetes care teams and many GP practices. It also recently received national recognition, winning the "Best improvement programme for pregnancy and maternity" category at the 2013 Quality in Care Diabetes awards. This article presents the background to the resource's development, as well as experiences from its production and roll-out.

Currently almost 5% of the UK population, male and female, has been diagnosed with diabetes (Diabetes UK, 2013). Based on the Confidential Enquiry into Maternal and Child Health (CEMACH) report (CEMACH, 2005), this figure translates to approximately 0.4% of all births within England, Northern Ireland and Wales occurring in women with pre-existing diabetes, either type 1 or type 2. The current figure is probably higher owing to the reported increasing incidence of type 1 diabetes in children (Patterson et al, 2012) and type 2 diabetes (International Diabetes Federation, 2013) over time, particularly with the emerging UK epidemic of type 2 diabetes in younger adults (Wilmot et al, 2010).

Despite making up a relatively small proportion of the total antenatal population, women with diabetes are a high-risk group, are at significantly increased risk of adverse pregnancy outcomes and require accessible multidisciplinary services – in both primary and secondary care settings – before, during and after pregnancy (CEMACH, 2007).

Diabetes and pregnancy: Risk of poor outcomes

Babies of women with diabetes are five times as likely to be stillborn and twice as likely to have a major congenital anomaly when compared with the general maternity population (CEMACH, 2005). Women with diabetes also have significantly higher rates of miscarriage, pre-eclampsia, perinatal mortality, pre-term delivery and macrosomia when compared with the background population. Poor glycaemic control, both before and in the early stages of pregnancy, is associated with poor pregnancy outcome (CEMACH, 2005).

Pre-pregnancy care: Reducing risk of poor outcomes

There is now substantial evidence that pre-pregnancy care is associated with a significantly lower risk of adverse pregnancy outcomes (Ray et al, 2001; Pearson et al, 2006; Murphy et al, 2010; Wahabi et al, 2010). Findings from two meta-analyses are summarised in *Box 1*.

Suboptimal pre-pregnancy planning

Despite the known risks of not preparing for pregnancy and the well-established benefits of achieving optimal glycaemic control before pregnancy, the CEMACH enquiry (2007) highlighted that women with diabetes were poorly prepared for pregnancy. Two-thirds of the women on whom the enquiry was based received suboptimal preconception care, with only a minority of women using any form of contraception in the 12 months before pregnancy. Indeed, in a more recent study reporting the effectiveness of a regional pre-pregnancy care programme for women with type 1 and type 2 diabetes (Murphy et al, 2010), 73% of women attending for antenatal care had not attended for pre-pregnancy care.

A recent qualitative study by Spence et al (2010) highlighted that while women with diabetes were generally well informed about the need to plan for pregnancy, awareness of the rationale for planning was only evident in parous women or those who actively sought advice. This lack of awareness about the rationale for planning pregnancies is likely to play a major role in the poor uptake of pre-pregnancy care services.

Women with type 2 diabetes

Women with type 2 diabetes have the same risks associated with pregnancy as women with type 1 diabetes (CEMACH, 2005). One-third of women in the CEMACH diabetes and pregnancy report had type 2 diabetes (CEMACH, 2007). Furthermore, women with type 2 diabetes were more likely to come from a deprived area, and half were from minority ethnic groups. In a recent study based in the north of England, Tripathi et al (2010) reported that women with type 1 diabetes of white ethnicity and of higher socio-economic status were more likely to receive preconception counselling, suggesting that women with type 2 diabetes may be less aware of hospital-based preconception care services. Given that the care of women with type 2 diabetes is firmly within the primary care setting, it will be important to explore if wider engagement of primary care with pregnancy planning in women with diabetes impacts on uptake of pre-pregnancy care among these women.

Box 1. Summary of findings from meta-analyses exploring the relationship between pre-pregnancy care and risk of adverse pregnancy outcomes.

Ray et al (2001)

In this meta-analysis of 14 cohort studies, a lower rate of major anomalies was reported among preconception care recipients (2.1%) than non-recipients (6.5%), a difference that equated to an RR of 0.36 (95% CI, 0.22–0.59). In addition, there were lower early first-trimester mean HbA_{1c} values (mean difference, 25 mmol/mol [2.3%]; 95% CI, 24–26 mmol/mol [2.1–2.4%]) in women receiving preconception care.

Wahabi et al (2010)

In this more recent meta-analysis, which included 12 cohort studies, preconception care was associated with a lower risk of congenital malformation (RR, 0.25; 95% CI, 0.16–0.37) and perinatal mortality (RR, 0.34; 95% CI, 0.15–0.75). Additionally, pre-pregnancy care was associated with a lower HbA_{1c} value in the first trimester of pregnancy (mean difference, 21.0 mmol/mol [1.92%]; 95% CI, 19.6–22.4 mmol/mol [1.79–2.05%]).

CI=confidence interval; RR=risk ratio.

Pre-pregnancy care services: Counselling and care

The concept of caring for women with diabetes prior to conception has two important components:

- Preconception counselling to raise awareness of the need to plan for pregnancy.
- Pre-pregnancy care (the additional support and care required to help a woman with diabetes to prepare for pregnancy).

Pre-pregnancy care

It is recommended that women seek pre-pregnancy care at least 6 months before pregnancy, where the main aim is to optimise blood glucose control in advance of conception (Temple, 2010). The National Service Framework for Diabetes (Department of Health, 2001) suggested that pre-pregnancy care be provided jointly by the adult diabetes service and maternity services, and the NICE guidelines on diabetes and pregnancy (National Collaborating Centre for Women's and Children's Health [NCCWCH], 2008) recommended that pre-pregnancy care be delivered by a multidisciplinary team. In practice, pre-pregnancy care is often delivered in the secondary care setting by a doctor, a diabetes specialist nurse or both (Temple, 2011).

A summary of the key NICE recommendations on preconception care are outlined in *Box 2*.

Preconception counselling

The importance of avoiding unplanned pregnancy, something that is covered in the NICE guidelines, should be an essential component of diabetes education for all women with diabetes of child-bearing potential, at every contact. This concept is central to preconception counselling, which should be an ongoing process between the healthcare professional and the person with diabetes, starting in adolescence. In addition, preconception counselling should include advice on how to access pre-pregnancy care (NCCWCH, 2008; Temple, 2010).

Primary care and preconception counselling

As highlighted above, the uptake of pre-pregnancy care is disappointing and future work is needed to further develop pre-pregnancy care services for women with diabetes in order to maximise uptake. A key aspect of pre-pregnancy care services is preconception counselling and, specifically, the concept of raising awareness of the need to plan for pregnancy (or advice on how to avoid an unplanned pregnancy), both among women with diabetes and among the relevant healthcare professionals. The NICE quality standard on diabetes in adults (NICE, 2011) requires that:

> "Women of childbearing age with diabetes are regularly informed of the benefits of preconception

Box 2. NICE diabetes in pregnancy guidelines recommendations on preconception care (these have been selected and adapted below, and so please refer to the guidelines for the full list; National Collaborating Centre for Women's and Children's Health, 2008).

Encouraging women with diabetes to seek preconception care

Starting from adolescence:

- Healthcare professionals should give information about the benefits of good preconception glycaemic control at each contact
- The diabetes care team should record the woman's intentions regarding pregnancy and contraceptive use at each contact
- The importance of avoiding unplanned pregnancy should be an essential component of diabetes education

Information and advice

Offer information, care and advice to women with diabetes who are planning to become pregnant before they discontinue contraception. Give advice and information on:

- The risks of diabetes in pregnancy and how to reduce them with good glycaemic control
- Diet, body weight and exercise, including weight loss for women with a BMI over 27 kg/m^2
- Hypoglycaemia and hypoglycaemia unawareness
- Pregnancy-related nausea or vomiting and glycaemic control
- Retinal and renal assessment
- When to stop contraception
- Taking folic acid supplements (5 mg/day) from preconception until 12 weeks of gestation
- Review of, and possible changes to, medication, glycaemic targets and self-monitoring routine
- Frequency of appointments and local support, including emergency telephone numbers

Safety of medications before and during pregnancy

Before or as soon as pregnancy is confirmed:

- Stop oral hypoglycaemic agents, apart from metformin, and commence insulin if required
- Stop angiotensin-converting enzyme inhibitors and angiotensin II receptor blockers and consider alternative antihypertensives
- Stop statins

glycaemic control and of any risks, including medication that may harm an unborn child. Women with diabetes planning a pregnancy are offered preconception care and those not planning a pregnancy are offered advice on contraception."

Hope had been raised in this area by NICE's proposed inclusion of preconception counselling in women with diabetes as a Quality and Outcomes Framework indicator (*Box 3*), although this has not come into effect for the round of changes for 2014–15.

Such an indicator could have proved particularly helpful, since one of the barriers to discussions about pregnancy planning that has been reported among women with diabetes is organisation of care, where a lack of continuity in terms of the healthcare professional makes it difficult to have "that conversation" (Spence et al, 2010). The primary care setting may offer more opportunity within practices to remove these barriers when compared with the secondary care setting.

A qualitative study by Mortagy et al (2010) explored the perspective of both GPs and secondary care health professionals on the role of GPs in delivering preconception care to women with diabetes. In the study, GPs reported very low numbers of women with diabetes who may become pregnant, while secondary care practitioners reported high numbers of women entering pregnancy unprepared. Overall, GPs agreed that they had an important role to play in preconception care but highlighted the need to be supported by evidence-based information on pre-pregnancy care benefits and access to information "to pass to patients."

A preconception counselling resource for women with diabetes

One of the challenges of providing preconception counselling is the need for suitable educational resources for women and, indeed, for healthcare professionals. Core to the NICE diabetes and pregnancy recommendations (NCCWCH, 2008) for outcomes and risk for the woman and baby is the recommendation that:

"healthcare professionals are to empower women with diabetes to make the experience of pregnancy and childbirth a positive one by providing information, advice and support that will help to reduce the risks of adverse pregnancy outcomes for the mother and baby."

To address this challenge, our project team, funded by Diabetes UK, and working together with healthcare professionals from the South Eastern and Belfast Health and Social Care Trusts, developed an educational DVD titled "Women with Diabetes – things you need to know (but maybe don't)".

The DVD covers preconception counselling for all women with diabetes (type 1 and type 2; planning or not planning a pregnancy). It also outlines the core concepts involved in pre-pregnancy care for those women thinking about having a baby, referring women to their GP or diabetes care team for support. Just as there are 9 months of pregnancy, the resource highlights "9 steps" involved in planning for pregnancy, in a pre-pregnancy checklist (*Figure 1*). In addition, the resource provides women with information on support available during pregnancy and information about what to expect during each trimester of pregnancy, during delivery and after delivery. Ultimately, this resource seeks to inform women about why they need to plan for pregnancy and the steps involved in the planning process, as well as providing additional information to help make the experience of pregnancy and childbirth a positive one.

The original DVD was developed under the direction of a multidisciplinary team, adhering to the NICE diabetes and pregnancy guidelines (NCCWCH, 2008). Importantly, it was designed and developed with continuous input

Page points

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2. One of the challenges of providing preconception counselling is the need for suitable educational resources for women and, indeed, for healthcare professionals.
3. To address this challenge, a project team headed by the author, working together with healthcare professionals from the South Eastern and Belfast Health and Social Care Trusts, developed an educational DVD titled "Women with Diabetes – things you need to know (but maybe don't)".

Box 3. NICE's proposed Quality and Outcomes Framework indicator for preconception counselling in women with diabetes (NICE, 2013), something which has not come into effect for the round of changes for 2014–15.

Indicator area: Diabetes mellitus

Indicator ID: NM70

The percentage of women with diabetes aged 17 or over and who have not attained the age of 45 who have a record of being given information and advice about pregnancy or conception or contraception tailored to their pregnancy and contraceptive intentions recorded in the preceding 12 months

Page points

1. The DVD described in this article has been embedded in routine care in Northern Ireland since 2010 and is currently being used as a preconception counselling resource by all diabetes care teams within the region.
2. To maximise availability of the resource to primary care, in Northern Ireland and beyond, the DVD has been converted to a website delivery format.
3. Primary care can play a major role in improving pregnancy outcomes for women with diabetes via preconception counselling.
4. It is critical that all healthcare professionals from primary and secondary care engaging with women with diabetes are aware of the importance of pre-pregnancy planning and have access to evidence-based learning resources.

from women with diabetes (Spence et al, 2013). The tone, key messages and format of the DVD were directed by findings of qualitative research to explore the needs and knowledge of women with diabetes (Spence et al, 2010), and women with diabetes reflected on various stages of the development process. The resource features eight women with the condition sharing their stories, views and experiences, alongside an evidence-based commentary. An evaluation of the DVD among 97 women with diabetes demonstrated that it was effective in increasing knowledge and enhancing attitudes of women with diabetes to pre-pregnancy care (Holmes et al, 2012).

The DVD has been embedded in routine care in Northern Ireland since 2010 and is currently being used as a preconception counselling resource by all diabetes care teams within the region. During the distribution phase of the project, all GP surgeries throughout the region were invited to request free copies for any of their patients not attending a diabetes clinic for annual review; however, only 34% of practices responded to the invitation. Thus, to maximise availability of the resource to primary care, in Northern Ireland and beyond, the DVD was subsequently converted to a website delivery format in March 2012 (see http://go.qub.ac.uk/womenwithdiabetes [accessed 19.03.14]). A link to the resource has been made available to GP practices in Northern Ireland via the primary care intranet.

The resource has recently received national recognition at the 2013 Quality in Care Diabetes awards, winning the "Best improvement programme for pregnancy and maternity" category.

Primary care can play a major role in improving pregnancy outcomes for women with diabetes via preconception counselling. The resource can be used in DVD or website format, and women can be directed to the website using a specially designed leaflet. A link for downloading this leaflet is available on the website to enable GP practices to direct women to the resource as part of the ongoing process of preconception counselling (see http://go.qub.ac.uk/womenwithdiabetes [accessed 19.03.14]). A QR code for the website has also been created (*Figure 2*), which could be added to posters displayed in places where women with diabetes are likely to visit, such as the GP surgery, community pharmacy and diabetes clinic.

Figure 1. The "9 steps to prepare for pregnancy" noticeboard, from the pre-pregnancy checklist within the Women with Diabetes preconception counselling resource described in this article.

It is critical that all healthcare professionals from primary and secondary care engaging with women with diabetes are aware of the importance of pre-pregnancy planning and have access to evidence-based learning resources. Therefore, our future knowledge transfer plans for this resource, funded by the Public Health Agency for Northern Ireland, include adaptation of the website for use within continuing professional development.

Other resources

Alternative approaches to preconception counselling have also been utilised throughout the UK:

- The Diabetes UK website hosts a short video clip titled "Rebel Rebel" to encourage women to plan pregnancy (available at: http://bit.ly/1jQNefH [accessed 19.03.14]).
- In East Anglia, a theoretically guided preconception leaflet (the EASIPOD [East Anglian Study for Improving Pregnancy Outcomes in Women with Diabetes] leaflet) was mailed annually to all women aged 16–45 years identified from specialist and primary care diabetes registers (Murphy et al, 2010). While women who had attended for pre-pregnancy care within this study were more likely to have read the EASIPOD leaflet, only 27% of women

Figure 2. QR Code for the Women with Diabetes website described in this article.

booking for pregnancy had attended pre-pregnancy care, leading the authors to suggest failings within the conventional models of engagement.

- The PROCEED (Preconception Care in Diabetes for Derby and Derbyshire) multifaceted approach directly addresses the care-model failings noted by Murphy et al (2010). This user-centred model for pre-pregnancy integrates care both "horizontally", across diabetes and obstetrics specialities, and "vertically", across primary and secondary care, and increased the rate of pre-pregnancy care to 70% (King, 2013), further highlighting the importance of engaging primary care.

Concluding thoughts

If we are to achieve an "every woman, every time" approach to preconception counselling and raise awareness of pregnancy planning, we need effective tools such as the "Women with Diabetes" resource described in this article. This resource has been designed by women with diabetes for women with diabetes and could easily be utilised by healthcare professionals in both primary and secondary care, throughout the UK and beyond, to raise awareness of planning for pregnancy. ■

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"Given that the care of women with type 2 diabetes is now firmly within the primary care setting, it will be important to explore if wider engagement of primary care with pregnancy planning in women with diabetes impacts on uptake of pre-pregnancy care among these women."