NICE guidance on pre-conception care: Its impact in ethnic minorities

Jackie Webb

The recent NICE Diabetes in Pregnancy (2008) guidance has brought pre-conception care into the domain of primary care. Prior to this the CEMACH reports of 2005 and 2007 had identified a worrying lack of pre-conception care within secondary and primary care. To this day, outcomes remain poor despite the assertions of the National Service Framework and the 1989 St Vincent Declaration. In this article, the author explores how the NICE guidance fits within integrated care. In particular, the use of an educational DVD to help South Asian women with diabetes overcome some of the cultural barriers to accepting care is discussed. The challenges faced by primary care are identified and an insight into pre-conception care from a secondary care perspective is given.

Article points

1. The St Vincent Declaration of 1989 identified the need to improve pregnancy outcomes for women with pre-existing diabetes so that they mirror those achieved in the non-diabetic population. Since then, no real progress has been made.
2. NICE has recognised that pregnancy planning in women with pre-existing diabetes is one of the most important aspects of their care.
3. Women from ethnic minorities face many challenges in their pursuit of health care: they are difficult to reach via mainstream channels.

Key words

- Pre-conception care
- Gestational diabetes
- NICE guidance
- Pre-conception clinic

The St Vincent Declaration of 1989 identified the need to improve pregnancy outcomes for women with pre-existing diabetes so that they mirror those achieved in the population without diabetes. Since then, no real progress has been made. This is despite Standard 9 of the National Service Framework that challenged the NHS to 'develop, implement & monitor policies that seek to empower and support women with pre-existing diabetes and those who develop diabetes during pregnancy, to optimise the outcomes of their pregnancy' (DoH, 2001). It can be argued that as the framework was launched without 'ring-fenced funds' that this is not surprising. Not only does it take drive and vision to change services, but in the ensuing years there have been so many changes in the NHS that it is difficult to retain a focus that is not fiscally driven.

In 2005 the CEMACH enquiry identified that 'women with diabetes are [still] poorly prepared for pregnancy' (CEMACH, 2007a). In 2007 CEMACH reported statistics such as 'only 17% of units in England, Wales & Northern Ireland offered structured multidisciplinary pre-conception care' and 'two thirds of women had sub optimal pre-conception care'; thus ensuring the drive to improve services for this group of people was re-focussed (CEMACH, 2007b).

In December 2005 the NICE diabetes in pregnancy guideline development process began. The author felt fortunate to be a part

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Page points

1. In the wake of the recent NICE guidance, early pre-conception care now sits firmly within the remit of primary care.
2. In our locality most people with type 1 diabetes are managed in secondary care for at least the first 2 years following diagnosis while those with type 2 or a previous diagnosis of gestational diabetes are managed by the primary care team.
3. Women with pre-existing diabetes of child-bearing age are not always encouraged to verbalise their desires to conceive; therefore, a clinic appointment is often a missed opportunity to raise the issue of pregnancy and confirm that the woman is aware of the need to access pre-conception care (Webb, 2006).

of the guideline development group and can attest to the robust and methodical systems and processes employed in developing NICE guidance. The resulting NICE diabetes in pregnancy guidance spans the period from pre-conception to post birth and, as with all NICE guidance, is thoroughly evidence based and will not disappoint those who enjoy controversy.

Impact on primary care

The general trend over the last 25 years in the UK has been of falling fertility rates at younger ages alongside rising fertility rates at older ages (Dunnell, 2007). This has led to a steady increase in the mean age of childbearing which has implications in women with pre-existing diabetes. Such women may have developed diabetes some years ago and therefore, are possibly at a greater risk of having already developed complications to their condition prior to planning a pregnancy.

Notwithstanding this, in the wake of the recent NICE guidance, early pre-conception care now sits firmly within the remit of primary care. Given the shift of diabetes care management from secondary care based clinics to a more integrated service delivered in primary care, the onus is now on GPs and practice nurses to deliver first-line pre-conception care.

Integrated care pathways as detailed in the government white paper *Our Health, Our Care, Our Say* (DoH, 2006) were designed as tools to incorporate and deliver national guidelines. The Department of Health defines integrated care as 'when both health and social care services work together to ensure individuals get the right treatment and care that they need' (DoH, 2006). The tripartite nature of an integrated care pathway – personalisation, efficiency and effectiveness – is uniquely placed to reshape services around the individual, reduce unnecessary variations, manage clinical risk and meet the requirements of clinical governance. These care pathways should improve navigation between services, thereby addressing some of the inequalities in access experienced by ethnic minority groups. The existence and use of such integrated care pathways should now allow transition between primary and secondary care to be more fluid and less of a 'nightmare' for the patient.

Most care providers and integrated clinical networks have (over the last few years at least) developed referral pathways for all aspects of chronic disease management. In our locality most people with type 1 diabetes are managed in secondary care for at least the first 2 years following diagnosis while those with type 2 or a previous diagnosis of gestational diabetes are managed by the primary care team. Thus, it follows that the majority of women with pre-existing diabetes will be managed by their primary care teams who are uniquely placed to offer multidisciplinary care such as smoking cessation, the management of teratogenic drugs, dietary advice, folic acid supplementation, contraception planning and structured education.

Improving awareness of need

A MORI research poll in 2006 identified that awareness of diabetes and its complications was extremely low in the black and ethnic minority population (Ipsos MORI, 2006). Women with pre-existing diabetes of child-bearing age were not always encouraged to verbalise their desires to conceive; therefore, a clinic appointment was often a missed opportunity to raise the issue of pregnancy and confirm that the woman is aware of the need to access pre-conception care (Webb, 2006). Even when this is not the case, the author feels that previously there was insufficient emphasis placed on the need to give pre-conception care at the appropriate time.

Other factors which undoubtedly impact on the uptake of pre-conception care services relate to the woman's ability or understanding of the need to access health care including communication-based and cultural barriers to understanding, as well as the physical difficulty of accessing a secondary care service (Williams and Riley, 2006).

NICE pre-conception care guidance

NICE has recognised that pregnancy planning in women with pre-existing diabetes is one of the most important aspects of their care. Previously (and in the authors experience) there has been little recognition of this fact which has

resulted in women with pre-existing diabetes conceiving with sub-optimal glycaemic control, and in most cases, while taking what are viewed as teratogenic medications such as statins, for example. Therefore, NICE (2008) suggests that starting from adolescence, at each contact with the patient, healthcare professionals within the primary care team will need to document the woman's intention regarding pregnancy and contraception use. They will need to discuss the importance of planned pregnancies and give advice and information about the benefits of optimal glycaemic control in the pre-conception period. NICE (2008) also suggests that at this stage this intervention should form part of and build on the woman's routine care. However, in the author's opinion, there will be a need for a dedicated clinic once the woman has verbalised a desire to plan for pregnancy.

One of the most important pieces of advice that this guideline gives is that women with pre-existing diabetes and those with an HbA_{1c} greater than 10% should be advised to avoid pregnancy (NICE, 2008).

Prior to this NICE guidance the author was constantly aware that the advice and information being given at a woman's first appointment in a secondary care based pre-conception clinic often had a negative impact as so much information relating to the potential harmful effects of poor glycaemic control, teratogenic medication, risk of complications and probable caesarean section had to be provided, that it was almost impossible for the woman and her family to visualise a non-medicalised pregnancy. Women often left the clinic wondering 'if it was all worth it', and fearful of potential outcomes. In the author's experience the amount of information given is daunting – even frightening – for women and their family.

Implementing the recent NICE guidance should prevent this, as advice and general information will be given at a significantly earlier stage and in some cases at diagnosis of diabetes. The need for planning, the reason for targets, changing medication and optimising control will hopefully be driven by the woman who will be more empowered to self-manage her diabetes and able to identify the timing and place of the intervention she needs.

This guideline formalises care and sets out the level of information that needs to be provided by healthcare professionals to give women the best chance of having a healthy pregnancy as detailed in the NICE user reference guide (NICE, 2008).

Our Pre-conception clinic

The pre-conception clinic at Heartlands Hospital, Birmingham, is part of the Heart of England Foundation Trust and was set up in 2002. It is a nurse-led clinic which currently operates from Heartlands Hospital twice a month. There is a clinic at Good Hope hospital with whom Heart of England merged in 2007; however, this article will focus on the service offered at Heartlands Hospital.

Referrals

Traditionally, referrals have been received from primary and secondary care, the latter generally coming from the main diabetes outpatient clinic and fertility service, both of which operate from within secondary care.

Referrals have also been received from the maternity service for women with pre-existing diabetes who have presented pregnant and had a poor outcome (such as a miscarriage) but who wish to conceive in the future. In addition, referrals have been received for women who have had previous gestational diabetes either needing insulin during their pregnancy or who have had a post-natal glucose tolerance test (GTT) showing impaired fasting or impaired glucose tolerance. However, since the NICE guidance (2008) it is expected that these groups of women will now be managed and optimised in primary care.

When the pre-conception clinic was started, GPs were informed of the service by way of an open letter inviting them to refer women with diabetes. Despite this, referral figures from primary care for women with diabetes or previous gestational diabetes remained very low. Further, the ante-natal service at the hospital still had women with pre-existing diabetes attending in the early stages of pregnancy who had poorly controlled diabetes or who were taking teratogenic medication.

With this in mind, a poster was produced

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2. Implementing the recent NICE guidance should prevent this, as advice and general information will be given at a significantly earlier stage and in some cases at diagnosis.
3. This guideline formalises care and sets out the level of information that needs to be provided by Healthcare professionals to give women the best chance of having a healthy pregnancy.
4. When the pre-conception clinic was started, GPs were informed of the service by way of an open letter inviting them to refer women with diabetes. Despite this, referral figures from primary care for women with diabetes or previous gestational diabetes remained very low.

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1. Evidently, many girls and women of child-bearing age with pre-existing diabetes were not receiving the care and information they needed pre-conceptually and there was no evidence to suggest that this was being provided by their primary care team. Although the number of referrals from primary care had increased it does not represent the number of women presenting pregnant with little or no advice.
2. All newly referred women are invited to attend their first appointment with their partner. Their initial appointment is for 1 hour due to the amount of information which needs to be given and received.
3. It is emphasised that maintaining tight glycaemic control pre-conception and during pregnancy is very hard work and the woman needs the support and encouragement of her partner and other family members during the pre-conception period and throughout pregnancy.

in English, Urdu and Bengali that was aimed at girls and women of child-bearing age with diabetes, inviting them to self-refer to the pre-conception clinic. The poster was sent to all GP practices within the then Eastern Birmingham and Solihull PCTs in 2003 and again in 2004 with the intent that it would be displayed in their waiting areas. It was also sent to community centres, Sure Start venues and outpatient locations across the then Eastern Birmingham and Solihull boroughs.

Sadly, there was little, if any, improvement in pre-conception care uptake, and in 2005, in women with pre-existing diabetes, there were several first-trimester miscarriages, two stillbirths and a termination at 24 weeks due to severe congenital malformation, all of which may have been avoided had pre-conception care been sought. It was felt by the hospital diabetes team that either it was failing to get the message of the need for preconception care across to healthcare professionals or the message was not being heeded by the community population. In essence both aspects of this viewpoint proved to be partially right.

From data collected at the hospital it was identified that, in 2005, less than 5% of referrals were received from primary care, in 2007 this figure was 30%. The remaining referrals coming from secondary-care based diabetes clinics, maternity and women self-referring.

Evidently, many girls and women of child-bearing age with pre-existing diabetes were not receiving the care and information they needed pre-conceptually and there was no evidence to suggest that this was being provided by their primary care team. Although the number of referrals from primary care had increased it does not represent the number of women presenting pregnant with little or no advice.

In 2007 the combined number of births at Heartlands and Solihull hospitals was 7500; over 500 of these were complicated by diabetes and of this number, 470 (94%) were from an ethnic minority background. The diabetes team receives between 8 and 15 referrals per week of women with gestational diabetes. Our-secondary care based antenatal diabetes clinics regularly see 50 women at Heartlands and 20 women at Solihull each week in the multidisciplinary antenatal diabetes clinics.

Our diabetes specialist midwife has an average caseload of 100 women. Currently, this breaks down to 5 women with type 1 diabetes, 11 with type 2 and 84 with gestational diabetes of whom 50% have been transferred to insulin therapy.

In a year there are approximately 1000 patient interventions and in 2007 insulin therapy was initiated in 276 women (gestational and type 2 diabetes).

Appointment structure

All newly referred women are invited to attend their first appointment with their partner. Their initial appointment is for 1 hour due to the amount of information which needs to be provided and discussed. Measures are being taken to make this first intervention more concise; however, it is important that this is not to the detriment of the overall content of the session.

Specifically, advice and information is given relating to the issues that are felt to be of greatest importance: the risks associated with parental consanguinity, which has been linked to congenital abnormalities (Richards, 1967); the need for 5mg folic acid daily; glycaemic control targets (HbA_{1c}<6.1%) are discussed as is the increased risk of hypoglycaemia associated with treatment intensification (DCCT Research Group, 1996). Further, it is emphasised that maintaining tight glycaemic control pre-conception and during pregnancy is very hard work and the woman needs the support and encouragement of her partner and other family members during the pre-conception period and throughout pregnancy.

Women with diabetes and their partners are invited to see a dietitian, who assesses diet and provides education and advice relating to foods which need to be avoided during the pre-conception and pregnancy period; they receive retinal screening with mydriasis if this has not been conducted in the previous 6 months.

Women with diabetes were reviewed every 2 months in the follow-up clinic with telephone intervention in between; however, the recent NICE guidance states that monthly HbA_{1c} needs to be performed which will have an impact on

the service we currently offer and we have yet to establish how this will be managed.

Once baseline blood, urine and eye screening results are available, women with diabetes are informed of these results, as is the GP (in a standard letter format which allows us to request the GP changes or adds to treatment where necessary). This procedure is replicated when women attend subsequent follow-up appointments.

For the majority of women following their initial clinic visit, in order to intensify treatment and improve control, those with diabetes have had their treatment regimen altered in an effort to optimise control. In many cases this has necessitated initiation of insulin therapy. However, given that most women will now receive pre-conception information and advice from their GP it is anticipated that referrals to our secondary care based clinic will decline (See *Box 1* for changes we need to make to heed NICE guidance).

This will give us the opportunity to review and perhaps be more creative with developing our services and therefore the recent NICE guidance is viewed as an opportunity rather than a threat.

Demographics of local population

The area which the Heart of England NHS Foundation Trust serves is mainly covered by two PCTs: Birmingham East and North PCT, and Solihull PCT. These PCTs have markedly different patient populations and prevalence of diabetes.

Birmingham East & North (BEN) PCT was formed in October 2006 following an amalgamation of Eastern Birmingham and Birmingham North PCTs. It covers a population of 437 000 divided among 16 wards, nine of which fall within the top 20% of the most deprived wards in the country. The PCT is served by 237 GPs in 82 practices.

In the east of the borough all of the wards covered are classified as urban and among the 25% least healthy in England (Introducing Eastern Birmingham PCT, 2006). In some areas non-Caucasian people (mainly South Asian people) make up 97% of the population. The prevalence of diabetes in BEN PCT is 4.0%, whereas the national figure is 3.6% and for Birmingham is 4.1% (QOF Database, 2006).

The Yorkshire & Humber Public Health Observatory (YHPHO, 2006) identified that diabetes is more prevalent in non-Caucasian populations. 4.3% of the Caucasian and mixed race populations have diabetes compared to 6.9% of those who are Asian or Asian British and 6.0% of those who are Black or Black British. Thus the local increased prevalence of diabetes may be in part due to the high proportion of South Asian people: however, the prevalence of diabetes has also been shown to increase with economic deprivation, as choices for and access to exercise, affordable food and health care are diminished.

Solihull has a population of 212 000 (Solihull CT, 2008) which consists mainly of relatively affluent White people (Solihull PCT, 2004). Solihull has a diabetes prevalence rate of 3.7% (QOF Database, 2006). There is some deprivation in the north of the borough, but, overall, less than 5% of Solihull's population is classed as living in a deprived area (Solihull PCT, 2004). The PCT has 31 GP practices (Solihull CT, 2008) and a proportion of non-White people of 5.4% (Solihull PCT, 2004).

Cultural barriers

Women from ethnic minorities face many challenges in their pursuit of healthcare: they are difficult to reach via mainstream channels; face inequalities in accessing healthcare; their first language may not be English; they may have literacy difficulties and their cultural or religious beliefs and lifestyles may affect healthcare delivery and management (Diabetes UK, 2006).

Cultural beliefs can modify illness perceptions. There is anecdotal evidence to suggest that innate interpretation of disease risk in ethnic minority cultures is different from western cultures. Concordance can be misrepresented as there are often dichotomies of belief associated with modern versus 'folk' medicine. Many people from ethnic minorities avoid the formal healthcare system due to the stigma associated with having a 'disease' and needing to attend hospital. This stigma is against the person and their family and can destroy marriage prospects, especially in young Asian women. Therefore, individuals often prefer to seek help from their own community,

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Box 1. Changes we need to make to heed NICE guidance.

- Improve individualised targets
- Explicit advice to avoid pregnancy if HbA_{1c} >10%
- Metformin use
- Folic Acid
- Tighten up procedures and advice
- Ketone testing
- Structured education
- Monthly HbA_{1c}

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1. The result of six months hard work entitled 'Zindagi Ka Saar' meaning 'The Essence of Life' was formally launched at the House of Commons on 19th March 2008 at a reception hosted by Adrian Saunders MP and attended by Dr Rowan Hillson National Clinical Director for Diabetes who congratulated Apnee Sehat on such a worthwhile project.
2. The DVD currently available in Hindi, Sylheti and English, will also be produced in Urdu. Importantly all translations will be available on the same disc.
3. Fortunately the timing of this could not be more opportune given the recent NICE Diabetes in Pregnancy guidance and the author is confident that primary and secondary care providers and the Asian community will find it a valuable resource.

mosque or traditional healers, for example, or sometimes even try to hide the fact that they have diabetes at all.

Given these very real barriers faced by Asian women and the high numbers of Asian families in our locality, together with the knowledge that many women were still unaware of the risks associated with diabetes and pregnancy, the author felt the need to find an alternative way to deliver education and information in a format and with a content that would attempt to break down these barriers and reduce stigma.

Previously, we had participated in dedicated 'Asian Awareness Events' at local schools and GP surgeries, produced flyers and dedicated Asian language posters, we had delivered education to Sure Start employees, provided interpreters in our clinics and encouraged 'word-of-mouth', clearly it was time to try something different. Greenhalgh (2005) identified high levels of satisfaction from patients receiving a group storytelling approach delivered in their own language. It appears that the cultural contexts which can be displayed in this process are possibly more meaningful to this population.

Development of an educational DVD

With this in mind the author approached Novo Nordisk in August 2007 for funding to develop a DVD in Asian and English languages which would address some of the issues such as the need for planning, attending appointments, testing blood glucose levels and taking insulin.

At the same time we became aware that Dr Shirine Boardman, Consultant Diabetologist, from Warwick Hospital had been successful in obtaining a grant from the Social Enterprise Fund at the Department of Health and was also keen to develop a short film under 'Apnee Sehat' ('Our Health'); a pathfinder Social Enterprise, specialising in preventative healthcare and social challenges faced by South Asian communities.

The pre-conception clinic at Heartlands Hospital is fortunate to be part of a wider group of consultants, specialist midwives and specialist nurses who form the West Midland Diabetes in Pregnancy Group and met and discussed with Dr Boardman their ideas relating to producing a culturally appropriate resource that would address the issues identified and hopefully go some way to breaking down the barriers between healthcare professionals and their patients.

Dr Boardman had invaluable previous experience of producing education in this short film format and was not only familiar with the entire process, but adroit at managing the script writing, casting and filming. The result of six months hard work entitled 'Zindagi Ka Saar' meaning 'The Essence of Life' was formally launched at the House of Commons on 19th March 2008 at a reception hosted by Adrian Saunders MP and attended by Dr Rowan Hillson National Clinical Director for Diabetes who congratulated Apnee Sehat on such a worthwhile project.

Zindagi Ka Saar has exceeded all the authors' expectations in terms of the messages that are deftly scripted and delivered by a well known Bollywood cast. It explores traditional Asian family values in Bollywood 'soap' style and at only 12 minutes long is very 'watchable'. The DVD is currently available in Hindi, Sylheti and English and will also be produced in Urdu. Importantly, all translations will be available on the same disc. It is anticipated that this valuable resource will be available within the next two months and will be fully marketed throughout the UK, with its obvious principal aim at supporting healthcare education in those populations whom the film is aimed at. Fortunately, the timing of this could not be more opportune given the recent NICE Diabetes in Pregnancy guidance and the author is confident that primary and secondary care providers and the Asian community will find it a valuable resource. ■

For more information about 'Apnee Sehat' visit http://www.apneesehat.net/.

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Many people from ethnic minorities avoid the formal healthcare system due to the stigma associated with having a disease and needing to attend hospital.

Front and back covers of the DVD 'Apnee Sehat' (Our Health).