AIMS For a better birth...

Support for loss

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Nadia Higson reviews berevement support in early and late pregnancy

Women's experiences of the care they receive following bereavement have not been included in any previous national surveys. A report1 by NHS Improving Quality was therefore commissioned at the end of 2013 to review the support that exists both within and outside the NHS for women and families experiencing the loss of a baby through miscarriage or stillbirth.

The report aimed to highlight to stakeholders, such as commissioning groups, the needs of women experiencing the loss of a baby in early or late pregnancy; to identify gaps in the care available and opportunities to work in partnership; and to acknowledge good practice and encourage others to reflect on it. The authors say 'Our aim is not to apportion blame but to begin open and honest discussions in order to ensure that all women receive excellent care.'

The report looked at support for bereavement at different stages of pregnancy: early loss (defined as up to 13 weeks), late loss (13-24 weeks) and stillbirth (after 24 weeks).

The authors sought input from the 12 Strategic Clinical Networks for Maternity, Newborn, Children and Young People in England, plus numerous local and national charities, and the Royal Colleges, but perhaps the most helpful feature is the inclusion of personal stories from bereaved parents (many drawn from Patient Opinion Portal www.patientopinion.org.uk) which help to illustrate the importance of timely and sensitive support. Mothers and their families will have different needs depending on their individual circumstances, but the attitudes of the staff providing care, and the surroundings in which it is given, can make a huge difference to the experience. It should hardly come as a surprise that many women in this situation 'find it distressing to be around newborns or to be with other pregnant women' and yet all too often they are being cared for in such settings, and by staff without specialist training.

Much of the information in the report draws on the work done by national charities or other bodies outside the NHS, which highlights the lack of comprehensive national data on the availability and quality of services for women undergoing the trauma of miscarriage. However, although support is clearly patchy and can be hard for women to locate, there are many examples of good practice and collaborative working which the authors hope will be taken forward to improve care in the future.

Attitudes to miscarriage can be dismissive - charities are a lifeline

Even among family members, the impact of miscarriage, especially if it occurs in early pregnancy, may not

be appreciated. Women who have not yet shared the news of their pregnancy may find it particularly hard to then talk about their miscarriage.

It isn't known for sure how many women suffer an early miscarriage (before 13 weeks) as often they are cared for in the primary sector, but it seems that many are left to cope with little or no support. According to the Miscarriage Association website (www.miscarriage association.org.uk) nearly half did not feel well informed about what was happening to them and only 29% felt well cared for emotionally. As one mother quoted in the report said, 'No-one handed out leaflets/contacts to support groups. It felt that there was little for early miscarriages.'

It appears that national and local charities are often filling the gap left by the NHS in providing both information and emotional support to women and their families after a miscarriage. According to the report, 'It appears that very few areas are not covered in some way by local charities. The size, number and what support is provided, however, varies across the country ... the authors have been impressed with the speed of response and what is available with limited funding.' The national charities such as the Miscarriage Association often have their own local groups, and smaller local charities draw on information provided by the national charities. Having often been founded and run by parents who have experienced the loss of a baby, local groups can 'offer a level of enthusiasm, depth of understanding and support that is commendable.'

Parents may want to remember their baby, however early the loss is. A number of local charities provide opportunities to do this, for example providing memory boxes, spaces for quiet contemplation or memorial services, but this is not available everywhere.

Increasingly people seek support via the internet and social media, but internet search engines are not always good at identifying local groups. The authors note that NHS Choices highlights national charities, but suggest it could do more by providing a postcode search for local support.

Lack of specialist resources is a challenge to delivering good care

Ideally, women experiencing pain or bleeding in early pregnancy would be seen promptly at an Early Pregnancy Unit (EPU) for diagnosis and care. There are over 200 EPUs in England but fewer than 20 appear to offer the seven-day service recommended by NICE2 Many do have extended opening hours, but some are only open for a few hours a day. Larger hospitals may offer an Emergency Gynaecological Unit which can provide assessments when the EPU is closed. These may be open 24/7, but as they deal with a range of gynaecological problems the staff will not necessarily have the specialised skills to support women who are miscarrying.

Worryingly the report says that 'In the absence of provision of the specialist areas women often find themselves in Accident and Emergency units, gynaecology wards and sometimes even general surgical beds where the staff may not have the time or the skills to offer the level of compassionate support and advice needed.'

Similarly, mothers going for a scan to check for a suspected miscarriage may find themselves waiting alongside other expectant parents: 'Laura felt that the hardest thing was watching the others. She couldn't stop crying and felt that it wasn't good for the other people there either.'

NICE guidelines for care of women suffering a late miscarriage (between 13 and 24 weeks) are due in 2016, but many hospitals have developed their own. Sometimes a separate bereavement suite is available for mothers experiencing a late miscarriage as well as for stillbirths; however, according to Sands,3 the gestation at which women will be admitted to these or to the maternity ward varies from 14 to 24 weeks. This means that some women find themselves having to give birth - sometimes even to a baby who is showing signs of life - in a gynaecological ward - causing great distress to the mothers, their families and the staff.

Those admitted to the main maternity ward may find themselves distressed by the presence of other babies: '...due to shortage of beds I was moved to the maternity department where I was put in a side room and forgotten

Early Pregnancy Unit A special unit within a hospital staffed to deal with common early pregnancy issues and worries. From chickenpox to bleeding, nausea to pregnancy loss, cravings and diet to exercise. There are 200 units in the UK involving doctors, midwives, ultrasonographers, nurses and support staff. For more information visit: www.earlypregnancy.org.uk

All through the night I lay awake and crying to myself as the newborn, very newborn baby next door cried all through the night as if it was in my own room.' Clearly what is needed is a dedicated area away from the main maternity ward, but all too often this is not available to women having a late miscarriage.

Staff need training, and support too

Staff report struggling to provide good emotional support in the face of their own workload and competing priorities. One positive move is the growing number of specialist Bereavement Midwives; however in smaller hospitals the staff can lack the necessary experience and training. This is also the case for newly-qualified midwives who may have had limited exposure during their training to mothers and families dealing with a loss.

Midwives and other healthcare professionals may be given training, and be able to seek support from their colleagues when faced with emotionally challenging situations - but who looks after agency or support staff?

'Whilst many Trusts will offer general bereavement training as part of their training programmes it is

very likely that they will be targeted at the professional groups, but consideration should also be given to the ancillary and support staff who are often on the side lines but still can be impacted.' Some hospitals have already introduced training for all staff who may come into contact with bereaved parents.

Building on best practice through collaboration A key theme of the report is the value of working in collaboration, both within the NHS and between the NHS and the charitable sector. There are good examples of this, but often hospitals and especially primary care staff seem to be working in isolation.

Both the Miscarriage Association and Sands have been working with the Royal Colleges for many years, as well as producing their own surveys, guidelines and training offers. The Miscarriage Association is currently investigating the needs of partners of women who miscarry, and wants to look at the needs of young people and those with limited English or communication difficulties.

The Association of Early Pregnancy Units (AEPU) is encouraging units to collaborate and share resources, and offers education and networking with the aim of raising standards of care. It also provides information for women, including details of their local unit. AEPU has been working with the Miscarriage Association on elearning resources for staff.

Developing specialist services

There are a number of examples of good practice in the hospital sector, with awards from the Royal College of Midwives and others to encourage and share these ideas. An increasing number of Trusts are seeing the value in appointing one or more Bereavement Midwives who can provide training and also directly support other staff in 'difficult conversations', as well as supporting parents and signposting them to other helpful services or groups.

Some hospitals have developed a Bereavement Service for women who lose a baby at any gestation. As well as specialist support from a Bereavement Midwife while in hospital such services may include assessment of the woman's emotional well-being once home; telephone support at home; one or more face-to-face follow-up meetings with the Bereavement Midwife, often including one with a consultant after a few weeks; referral to other services such as counselling or support groups; and help with practical issues such as funeral arrangements.

Recommendations

The authors note that the Strategic Clinical Networks are in the process of setting out their priorities. None has so far identified support for loss as a focus, but many have included maternal mental health, which should provide an opening for exploring ways to reduce the emotional impact of a loss on women's long-term mental well-being.

The report identifies a number of areas where the NHS could work in partnership with the charitable sector and the Royal Colleges, including:

- 'Set up or utilise existing mechanisms to actively encourage the sharing and/or spread of best practice.
- 'Bring together a national stakeholder event promoting best practice. Delegates and presenters should be from all areas - primary care, A&E, and acute care and charities.
- 'Work in partnership with the Royal Colleges and charities to follow up on the uptake of NICE guidelines and toolkits such as the Sands audit tool.
- 'Work in partnership with the Miscarriage Association to take forward their work on the needs of young people and fathers.
- 'Consider working with NHS Choices to improve the access to local charities through the search facility on their website.
- 'Undertake an in-depth audit of training in terms of provision access and uptake across all staff who may come into contact with women who undergo loss in pregnancy and their families, to ensure that patient experience is everyone's business.
- 'Review ways of engaging with bereaved parents to seek feedback on experience of care across the pathways.
- 'Widen the scope of work to include support for termination of pregnancy and neonatal death.' We can only hope that these recommendations will be picked up and acted upon, because, in the words of one Bereavement Midwife, 'If there's ever a time to get right care it's during this time.'

References

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2. NICE (2012) Ectopic pregnancy and miscarriage: Diagnosis and initial management in early pregnancy of ectopic pregnancy and miscarriage. NICE, December 2012.
3. Sands (2010) Bereavement Care Report. http://www.uk-sands.org/sites/default/files/SANDS-BEREAVEMENT-CARE-REPORT-FINAL.pdf.