Comparing the care of Asian and White women whose babies died



Lay Summary

Around 700,000 babies are born every year in the UK, and around 3,500 of these babies die before, during or shortly after birth. The most recent figures show that even though the overall proportion of babies dying has reduced over the past 5 years, there are still big differences in the proportion of babies from different ethnic groups who are dying. Asian babies are over one and a half times more likely to be stillborn or die within the first 28 days after birth than White babies.

This enquiry looked at the pregnancies of 34 Asian women and 35 White women in 2019, where the baby was stillborn or died within 28 days of birth. The aim was to review the quality of care, as it was recorded in the medical notes, and to find out whether different care may have made a difference for the baby and the mother. The care the babies and their mothers received was compared with care outlined by national guidelines for best practice, by a group of clinical experts. The enquiry also compared the care given to Asian women and White women to see if it was different.

The care reviewed included when mothers were pregnant; care during labour and birth; care for their baby once born; postnatal and bereavement care after the baby died; and any tests or investigations that took place to understand what happened and where improvements in future care are needed.

The clinical experts looked at whether the care women and babies received may have contributed to the babies' deaths. They also looked at the quality of emotional and psychological help and support provided for women, both during their pregnancy and when their baby died. This included the offer of a post-mortem and the quality of local hospital death reviews to understand why the baby died.

The enquiry could only look at what was written in the medical notes. This means that the experts couldn't take into account things that weren't always written down, such as how staff spoke to women or how they behaved. The experts also couldn't get feedback from the families involved, because the names of the families were kept anonymous. To make sure that the voices of bereaved Asian parents are heard alongside learning about clinical care, the charity Sands have conducted a "Listening Project". You can read about this on their website.

Key Findings

For both groups of women, high quality care was found in a minority of the baby deaths which were reviewed. Many deaths may have been prevented with better care.

- » For Asian women, in around 1 in 4 baby deaths, the care was assessed as poor. For White women the care was poor in around 1 in 2 baby deaths. If care had been better it may have prevented the baby from dying.
- » For around 3 in 5 mothers, care after their baby died was assessed as poor. If it had been better, it may have meant bereaved mothers were likely to have been better supported in their physical and emotional health.
- » In both groups, the care was assessed as good for only around 1 in 4 of the deaths reviewed.

Care of vulnerable women

- » Women's ethnicity, nationality and citizenship status was not always correctly written in the notes. This may have made it harder for staff to offer the personalised care the woman needed.
- » When a woman's first language wasn't English and she needed an interpreter, this wasn't always provided. Sometimes, family members were used as interpreters instead of professionals. This meant the woman might not have received the information she needed or been able to talk about some things in private. More Asian women than White women needed an interpreter, or had difficulties reading or speaking English.
- » Some women faced challenges in their personal lives which were not always recognised or taken into account when planning their care. This meant that some women didn't receive the additional support they needed. These challenges were more common amongst White women, but language barriers may have made it more difficult to recognise them in Asian women.

Care during pregnancy (antenatal care)

- » Antenatal care was assessed as good for 1 in 4 Asian women and 1 in 3 White women.
- » Blood tests to check for a condition that causes high blood sugar, called gestational diabetes, were not offered to 1 in 5 Asian women. Almost all the White women who should have been tested were offered a test.

Care during pregnancy (antenatal care) - continued

- » All the Asian women should have been offered a high dose of Vitamin D to take during their pregnancy, but only 1 in 10 were.
- » Around 1 in 3 Asian women declined screening for chromosomal conditions when it was offered. Almost all White women chose to accept the offer of screening.

Care during labour and birth (intrapartum care)

» The experts didn't identify any specific differences between the quality of care received by Asian women and White women during labour and birth, but it was assessed as poor for 1 in 2 women in both groups.

Care of the baby after birth (neonatal care)

» For babies who died within 28 days of birth, care of the baby after birth was assessed as poor for 1 in 2 babies. The experts didn't identify any specific differences between the quality of care received by Asian babies and White babies.

Care after birth and death (postnatal and bereavement care)

- » Medication to stop breast milk was more likely to be offered to, and accepted by, Asian women than White women.
- » The quality of bereavement care was good for most women, but White women were more likely to be seen by a midwife once they had left hospital.
- » Most parents were offered a follow-up appointment to discuss what happened and how they were coping.
- » After the meeting, most parents received a letter summarising what they talked about, but this wasn't always directly addressed to them. For 2 in 3 Asian parents the letter was addressed to their GP instead, compared with 1 in 4 White parents. 1 in 3 parents didn't receive a letter at all.

Tests and investigations to find out what happened when babies died (post-mortem and hospital review)

- » A post-mortem examination was carried out for 1 in 5 Asian baby deaths, compared with 1 in 2 White baby deaths.
- » Almost all deaths were reviewed by the hospital using the Perinatal Mortality Review Tool (PMRT). The hospital reviews were more positive than the conclusions reached by the confidential enquiry panels, but this wasn't affected by the mother's ethnicity.
- » Many reviews were carried out by only one doctor or midwife instead of a group, or by a small group without enough of the right specialists.
- » Where deaths were reviewed, parents were given the opportunity to ask questions and say how they felt about the care they received. Most parents said they didn't have any questions, but fewer Asian parents asked questions than White parents. Only one set of parents whose first language wasn't English asked any questions.



About MBRRACE-UK

MBRRACE-UK is a team of researchers, clinicians and representatives of parent groups and charities. Every year we collect and analyse data about baby deaths from UK hospitals. We then use this data to identify the different groups of women and babies who are at risk of stillbirth and neonatal death. Every two years an independent group of experts choose a group of women and babies for MBRRACE-UK to look at in more detail. The medical notes for the women and babies are reviewed by clinical experts, in a process called a confidential enquiry. The findings from each enquiry are then used to write recommendations for improving the care of women, babies, and their families.

You can learn more about MBRRACE-UK on our website.

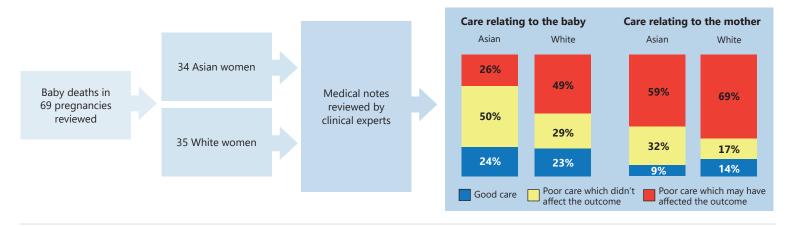
Lay summary written by MBRRACE-UK and Jenny Douglas (Open University), Sandra Igwe (The Motherhood Group), Nana-Adwoa Mbeutcha (Black Mums Upfront), Benash Nazmeen (University of Bradford), Selena Palmer (University of Leicester), Janet Scott (Sands). Design and layout by Ian Gallimore.

Icons: <u>Care</u> by James, <u>Chromosome</u> by Koson Rattanaphan, <u>Diabetes</u> by Pablo Rozenberg, <u>Discussion</u> by Vectorstall, <u>Diversity</u> by Iconathon, <u>Focus</u> by Jo, <u>Language</u> by Adrien Coquet, <u>Letter</u> by Prasad, <u>Magnifying Glass</u> by Milinda Courey, <u>Risk Factors</u> by Nur Lita, <u>Vitamin</u> by Jauhari, from <u>nounproject.com</u>.

© 2023 The Infant Mortality and Morbidity Studies, Department of Population Health Sciences, University of Leicester.

Comparing the care of Asian and White women whose babies died







Women's ethnicity, nationality and citizenship status was not always correctly written in the notes.

All women should be asked about their ethnicity, nationality and citizenship status, and it should be written in the her notes. Care should be planned based on each woman's specific needs.



When a woman's first language wasn't English and she needed an interpreter, this wasn't always provided. More Asian women needed an interpreter.

Women should be offered information about maternity care in different ways. An interpreter should be offered at each appointment, if the woman needs one to understand the information she is given or to talk to her doctor or midwife.



Some women faced challenges in their personal lives which were not always recognised or taken into account when planning their care. These challenges were more common for White women

Information about women's personal and social risk factors should be written in the notes, and updated throughout the pregnancy, so that extra support can be offered if it is needed.



Asian women were more likely to decline screening for chromosomal conditions when it was offered. Almost all White women chose to accept the offer of screening.

Women should be given information about antenatal screening tests, translated where necessary. If a woman chooses to have any of the tests, she should be offered an appointment to talk about the results and her future choices.



Blood tests to check for gestational diabetes were not offered to 1 in 5 Asian women. Almost all White women who should have been tested were offered a test.

All women with risk factors for gestational diabetes, which includes all Asian women, should be offered a test between 24 and 28 weeks of pregnancy.



All the Asian women should have been offered a high dose of Vitamin D to take during their pregnancy, but only 1 in 10 were

All women should be offered Vitamin D to take during pregnancy, and women with darker skin or a BMI over 30 may be offered a higher dose.



Bereavement care was good for most parents, but White women were more likely to be seen by a midwife once they had left hospital.

Family-centred bereavement care, in line with the National Bereavement Care Pathway, should be offered to all parents.



Almost all baby deaths were reviewed using the Perinatal Mortality Review Tool. The hospital reviews were more positive than the conclusions reached by the confidential enquiry panels.

Hospitals should make sure that reviews are carried out by enough people from the right specialties. At least one of these people should be from another hospital.



When a review did take place, most parents didn't have any questions or talk about their experience, especially if they didn't speak English.

As part of the review process, parents should be supported to ask questions and talk about their experience, to ensure they receive answers about why their baby died.



Most parents had a follow-up meeting with their consultant to review their care, but not all had a personalised letter summarising what they talked about. Asian parents were less likely to receive a letter than White parents.

All parents should have a follow-up meeting (jointly with their obstetrician and neonatal doctor, if appropriate) to review their and their baby's care, and a clear and personalised written summary should be given to the parents.

Messages for women and families



What you should expect from your care – a checklist

- ✓ At your first appointment, you should be given a <u>list of the appointments</u> and scans that you should have during pregnancy. The importance of each should be explained to you.
- ✓ You should be offered an interpreter at each appointment, if you need it.
- ✓ You should be asked about your ethnicity, nationality and citizenship status so this is correct in your notes.
- ✓ You should be asked about your safety at home and offered help if you need it.
- ✓ You should be asked about how you feel and be supported to say what you need.
- ✓ You should be offered Vitamin D to take throughout your pregnancy.
- ✓ If you are Black or Asian, you should be offered a blood test to check for a condition that causes high blood sugar, called gestational diabetes.
- ✓ If you have had gestational diabetes before, you should be offered a blood test after your first appointment.
- ✓ If your baby dies, you and your family should be offered bereavement care.
- ✓ If your baby dies, you and your partner should be given clear information about the different types of <u>post-mortem</u> and <u>how it might help you to understand why your baby died</u>.
- ✓ If your baby dies, a <u>hospital review</u> of what happened should take place, using the Perinatal Mortality Review Tool. This is a review of whether your care was right for you and your baby. You should be told that a review is going to take place, and asked about your experience of your care and if you have any questions.
- ✓ If your baby dies, you should be offered a meeting with a doctor to talk about what happened and your future care. Afterwards, you should be sent a letter which says what you talked about, and answers any questions you have.

Further information and support

- » The NHS has a web page with information about trying for a baby, pregnancy, labour and birth.
- » If you have a concern about your care, raise it with the team looking after you.
- » Every hospital has a Patient Advice and Liaison Service (PALS), who can help you if you do not feel you are being listened to.
- » If you want independent advice about your care, these organisations have helplines and support teams you can contact and information and resources you can use:

<u>Tommy's</u> provides expert, midwife-led advice for parents before, during and after pregnancy.

Bliss supports families whose baby is born sick or too soon.

Sands is a charity working to save babies' lives and support bereaved families.

Willow's Rainbow Box supports women and families experiencing pregnancy following baby loss.













