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Comment on MBRRACE-UK 2019 Perinatal Confidential Enquiry: Stillbirths and neonatal deaths in twin pregnancies

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In my role in the Publications team, I was responsible for publishing a new AIMS Guide to Twins Pregnancy & Birth which is now available through the AIMS website:www.aims.org.uk/shop/item/aims-guide-to-twin-pregnancy-birth. The book frequently mentions the specialist team, including obstetrician, midwife and sonographer all of whom will have training in twin pregnancies and birth, and who will care for those who are pregnant with twins. Generally, AIMS Guides should reflect what the current practice is in the maternity services, based on the various guidelines, policies, evidence and experiences.

I wondered whether the book over-emphasised the need for the specialist team, bearing in mind that the choice in how we are treated and what care we access is our decision. However, while the right to bodily autonomy holds in any situation, having read this book, the fully informed mother expecting twins would very likely welcome the guidance and support of the specialist team.

Imagine my shock, then, when nearing the completion of the publication process of this book, MBRRACE-

UK released their 'Perinatal Confidential Enquiry: Stillbirths and Neonatal Deaths in Twin Pregnancies' report,[1] with the consensus finding being that 'in just over half the pregnancies improvements in care were identified which may have made a difference to the outcome for the babies.'[2]

I can only say that the new AIMS Guide to Twins Pregnancy & Birth includes what SHOULD happen in a twin pregnancy, NOT what is universally current practice.

The MBRRACE-UK team report in the lay summary that 'around 740,000 babies are born every year in the UK, and 2 out of 64 babies born are twins,' so over 20,000 twins.[3] Twin pregnancies have higher risks for many reasons, including babies being born preterm. The report shows that '**much more could be done to reduce the risks for women and their babies, save lives and prevent physical, emotional and psychological harm for women and their families.**'[4]

The report focuses on **80** baby deaths in **50** twin pregnancies – of those, 54% of the care relating to the babies was poor, 'which may have affected the outcome,' with a massive 64% of poor care relating to the mother.[5] The report says that, 'for two fifths of women (20 of 50) care was not provided by a specialised multidisciplinary team as recommended by national guidance. For only 5 of the 50 women was care documented as including a specialist midwife and specialist sonographer involvement.'[6] This is completely contrary to the guidance published by NHS England, the National Institute for Health and Care Excellence (NICE), the Royal College of Obstetricians and Gynaecologists (RCOG), the Royal College of Midwives (RCM) and the College of Radiographers (CoR).

So, what are these organisations doing to ensure that the guidance they issue is being followed by Hospital Trusts, commissioners of services, obstetricians, midwives and sonographers? Why are the Nursing and Midwifery Council (NMC) and General Medical Council (GMC) not ensuring that registrants (midwives and doctors) keep their knowledge and skills up to date? Why aren't midwives and doctors recognising the limits of their competence and reporting their lack of training?

This quote from the RCM press release given after the report was released addresses those questions:[7]

> The number of baby deaths, even in twin pregnancies, is very small, but we know that twins are more likely to be stillborn or die soon after birth than babies from a pregnancy with one baby. The national guidance is there to prevent this, and it is on every maternity service to ensure that this guidance is followed. If there are barriers to this, whether due to staff shortages or lack of training, then those should be addressed.

The lay report is very easy to read, but to get the full details, do read the full report (which I found very harrowing). Below are just a few of the findings from the reviews:[8]

- Less than half the women were looked after by the specialist team recommended by all the agencies listed above.
- Senior obstetricians were not always available for every woman during labour and birth.
- Neonatal care doctors were not always available for parents when their babies were at risk of not

surviving.

- Those pregnant with twins sharing one placenta were not referred to the highest level fetal medicine centre for specialist input into their care when there were signs of complications.
- Bereavement care is very poor.

As in previous MBRRACE reports, not every death is being reviewed by the hospitals, those that were reviewed were of poor quality.

There is a clear CALL TO ACTION at the end of the report:[9]

Professionals should read the full report at www.npeu.ox.ac.uk/mbrrace-uk/reports, implement its recommendations and follow national guidance. If this were done, it is clear that future lives could be saved and national ambitions to reduce avoidable baby deaths might be achieved.

MBRRACE-UK has developed a checklist with clear guidance: make sure there is a SPECIALIST team of midwives, doctors and sonographers for twin pregnancies and births. A second opinion can be sought if there is concern about the care you are receiving.

The checklist is copied below together with details of further very specific support.[10]

What you should expect from your care – a checklist

- You should be seen in a specialist twins clinic run by a team of doctors, midwives and sonographers who have training and experience in twin pregnancies.
- You should be given a schedule of the appointments and scans at your first appointment. The importance of each one should be explained to you.
- The team should explain to you what to look out for if you go into labour early and what to do about it.
- If you think there is a problem during your pregnancy, or think you might be going into labour, you should be seen by a doctor experienced in the care of twin pregnancies. They should review you and are likely to scan your babies to check they are well.
- If you give birth and your babies are small or poorly, you and your partner should be asked about the care you would like them to be given, with advice from a neonatal care doctor. You should be involved in all decisions about what happens to them.
- If one or both of your babies sadly dies, you and your partner should be offered bereavement care and a referral for specialist support.
- If one or both of your babies sadly dies, you should be given clear information about consenting to a post-mortem and how it might help you understand why they died.
- If one or both of your babies sadly dies, a hospital review of what happened should take place, with input from all the hospitals where you and your babies received care. This is a review of whether your care was adequate for your circumstances. You should be informed and asked if you have any questions or would like to provide your perspective of your care.

Further support

- » 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 charities have helplines and support teams you can contact and information and resources you can use:
  Twins Trust supports families with twins, triplets and more: www.twinstrust.org
  Multiple Births Foundation supports families with twins, triplets and more: www.multiplebirths.org.uk
  Bliss supports families whose baby is born sick or too soon: www.bliss.org.uk
  Sands is a charity supporting families whose baby has died: www.sands.org.uk

The new AIMS Guide to Twins Pregnancy & Birth is now available (principal author Rebecca Freckleton) and the AIMS Guide to Resolution After Birth may help you if you have had poor care and/or a bereavement. Both are available from www.aims.org.uk/shop.

Action YOU can take NOW

If you are concerned about specialist services in your area, raise it first with your local Maternity Voices Partnership (MVP), a team comprising service users (people like you), their families, commissioners and providers (including midwives and doctors) who are working together to review and contribute to the development of local maternity care. AIMS has more information on how to find these groups here: www.aims.org.uk/journal/item/mvps-are-key.

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[1] Draper ES, et al. (eds.) on behalf of MBRRACE-UK (2021). MBRRACE-UK 2019 Perinatal Confidential Enquiry: Stillbirths and neonatal deaths in twin pregnancies. The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester: Leicester. www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-report-2020-twins/MBRRACE-UK_Twin_Pregnancies_Confidential_Enquiry.pdf.
[2] Ibid.
[3] MBRRACE-UK, 'Learning from deaths in twin pregnancies: Lay summary': www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-report-2020-twins/Learning_from_deaths_in_twin_pregnancies.pdf.
[4] Ibid.
[5] Ibid.
[6] Draper et al (2021).
[7] Royal College of Midwives, 'National guidance key to reducing baby deaths in twin pregnancy, says RCM': www.rcm.org.uk/media-releases/2020/december/national-guidance-key-to-reducing-baby-deaths-in-twin-pregnancy-says-rcm.
[8] MBRRACE-UK, 'Learning from deaths in twin pregnancies: Lay summary': www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-report-2020-twins/Learning_from_deaths_in_twin_pregnancies.pdf

[9] Ibid.

[10] Ibid.