

New study into life-threatening pregnancy condition calls for specialist centers

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A new study has revealed key steps for hospitals to improve care for pregnant mums and babies affected by a life-threatening condition.

In the UK today, almost one in every 100 babies is stillborn or dies soon after birth. Up to 100 women die every year during or just after pregnancy. A team of academics, clinicians and charity representatives, called MBRRACE-UK, has looked at how care for mothers and babies can be improved.

The report, commissioned by the Healthcare Quality Improvement Partnership as part of the Clinical Outcome Review Programmes, is led by a team from the University of Leicester. In its first perinatal report, the group has examined a condition known as [congenital diaphragmatic hernia](#) (CDH) which affects up to 400 pregnancies annually in the UK.

In this condition part of the diaphragm (a muscular sheet dividing the chest and abdomen) does not form which can lead to a number of complications- most commonly poor lung development. Ultimately around half of these babies do not survive and for those that do their management usually involves care from a range of specialists both before and after birth.

A total of 57 cases who were managed in 2009 and 2010 were included in the confidential enquiry drawn from across the UK. They represented a range of cases which were subject to detailed scrutiny by multidisciplinary panels of experts who considered every aspect of the

care.

The expert enquiry found:

- In the majority of cases - around two thirds - there was no evidence that any change of care could have improved the outcome for the mother or baby.
- However, even though there was no evidence that the outcome for the mother or baby was affected, there was a significant degree of inconsistency in how care was delivered to these mothers and babies in relation to every aspect of the care pathway.
- In most parts of the UK the service was not patient centred however alternative models providing a clear care pathway for CDH cases were identified in a small number of locations.
- There was wide variation across the UK in terms of how women and babies diagnosed with CDH were managed particularly in relation to cases diagnosed antenatally.
- There was a lack of consistency in the information provided regarding prognosis both in terms of content and also how the information was provided to women / couples.
- Many aspects of obstetric and neonatal care of these babies remain without an adequate evidence base.
- Although access to [neonatal intensive care](#) cots / surgical cots was not a common problem, in the few cases where there was difficulty it caused great distress.
- Follow up arrangements showed very marked differences between centres.
- Documentation of some aspects of care was frequently poor.
- Despite the variation in practice most cases received a high level of senior medical and nursing input throughout their course.

Key recommendations following the enquiry process include:

- Greater focusing of the acute care of affected mothers babies on a limited number of centres in order to facilitate the greater development of all aspects of the specialist expertise required;
- Development of a service specification for CDH to ensure the service becomes consistent and patient-centred.

Professor Elizabeth Draper, Professor of Perinatal and Paediatric Epidemiology at University of Leicester said: "The panel found many examples of good or excellent care, which included a clear pathway from diagnosis to follow-up and teams of people from different specialties working well together, led by consultants who were available around-the-clock. We found examples of excellent communication with and support for parents, e.g. encouraging mothers to breastfeed/express milk and giving families somewhere to stay during [acute care](#). Where babies died there were example of good follow-up bereavement support at the parents' home, helping them to create memories and mementoes of their baby."

In identifying aspects of poor care, Professor David Field, Professor of Neonatal Medicine at the University of Leicester, stated: "The current way in which the care for these babies is organised appears to have hindered the establishment of a patient centred care pathway and the establishment of on-going research and development."

He continued: "While having a smaller number of centres with dedicated services would mean some parents would have to travel longer distances than they currently do, it would make it easier to include all important elements of care, such as counselling and psychological support, especially for decisions about ending a pregnancy so parents can make an informed choice.

"It would also be easier to agree on the best way to manage the care and treatment of babies diagnosed with CDH and how to handle late

termination of pregnancy and set UK-wide standards. A smaller number of centres with dedicated services would facilitate bringing researchers together to work on scientific studies so that approaches to the care of [babies](#) with the condition to improve the evidence base upon which good quality care can be provided."

More information: To read the full report, MBRRACE-UK 2013/2014 Perinatal Confidential Enquiry - Congenital Diaphragmatic Hernia (CDH), see [oxfile.ox.ac.uk/oxfile/work/ex ...
d=199510E42A7B3937B4](https://oxfile.ox.ac.uk/oxfile/work/ex...d=199510E42A7B3937B4)

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