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Majority of stillbirth cases remain unexplained, suggesting post mortem investigation needs to be refined, GOSH research finds

Analysis by a Great Ormond Street Hospital (GOSH) led team looking at the effectiveness of different elements of the post mortem process shows that, despite full standard investigation, in the majority of cases of stillbirth the cause remains unknown. The papers highlight the need for further research to improve post mortem techniques to better detect a cause of death.

The findings from the research, funded by the stillbirth and neonatal death charity Sands, are highlighted in a collection of six papers published in the journal *Ultrasound in Obstetrics and Gynecology*. The series of articles are significant as they challenge the accepted thinking on the diagnosis and causes of stillbirth and earlier deaths in the womb from 12 to 24 weeks, and the value of specific elements of the traditional post mortem process.

Post mortem examinations are traditionally considered the best way of working out how a person has died. The examination involves several different elements, and developments in scanning techniques over recent years means that more information can now be gathered by less invasive approaches.

GOSH consultant paediatric pathologist Professor Neil Sebire and colleagues have now carried out a detailed analysis of findings from a large number of post mortem examinations investigating stillbirth and earlier deaths in the womb to see which aspects of the examinations provide the most information about why the baby had died.

The team reviewed the value of the autopsy and examination of tissue samples under the microscope, as well as the effectiveness of analysing the placenta and reviewing case notes for determining cause of stillbirths and earlier intrauterine deaths in over 1,000 cases. They found that clinical review identified the cause of death in about 20% of cases, with placental examination providing a cause in about another 20%, whilst carrying out invasive post mortem examination identified the cause of death in only a small percentage of cases.

Professor Neil Sebire, GOSH consultant paediatric pathologist and lead researcher, said: "Overall, post mortem examination remains the most effective way of determining how a person has died. However, this research highlights that, in the case of stillbirths, analysing information such as the clinical circumstances and examination of the placenta, without the use of invasive techniques, allows us to get almost as much information. The problem is that using current methods, even including full autopsy, we are still often not able to find out why the baby has died. It's therefore vitally important that we advance better ways of properly investigating these cases by developing new, more refined techniques. This will ensure we can support families in the best possible way."

In addition to this finding, the papers also suggest that the importance of having an apparently small baby as a risk factor for stillbirth may have been overestimated. In many cases, the stillbirth may

have actually occurred when the baby was normal in size but weight loss occurs after death. While having a small baby in utero is certainly linked to increased stillbirth risk, this finding challenges the likely impact of identifying small babies to prevent stillbirth.

Professor Basky Thilaganathan, Editor in Chief of *Ultrasound in Obstetrics & Gynecology* (UOG), said: "Sebire and colleagues produce convincing data to demonstrate that fetal body weight decreases substantially between intrauterine demise and postnatal weight assessment. This suggests that the majority of stillbirths considered to be small for gestation by birth weight, were likely to have been appropriately sized at the time of death. This finding questions the fundamental rationale and potential effectiveness of current health policy that is solely focused on the detection and elective birth of small fetuses to reduce the risk of stillbirth."

Clea Harmer, Chief Executive of Sands, said: "When a baby dies before birth, the most pressing question for parents is why? This study reveals how much we can expect to learn from the way post mortems are done today and highlights just how many gaps there are in our knowledge. These gaps won't close without continued and expanded funding for research, and access to good-quality pathology services for all parents when their baby dies.

"We are pleased to have been able to fund such an important study with money raised from bereaved parents themselves who remain determined that other families should not suffer as they have done."

Professor Neil Sebire's work is supported by Great Ormond Street Hospital Children's Charity. The project is one of over 1000 being carried out at Great Ormond Street Hospital and the UCL Great Ormond Street Institute of Child Health as part of their research programme.

Contact information

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Notes to editors

About Great Ormond Street Hospital for Children NHS Foundation Trust

Great Ormond Street Hospital is one of the world's leading children's hospitals with the broadest range of dedicated, children's healthcare specialists under one roof in the UK. The hospital's pioneering research and treatment gives hope to children from across the UK with the rarest, most complex and often life-threatening conditions. Our patients and families are central to everything we do – from the moment they come through the door and for as long as they need us.

Great Ormond Street Hospital, with its academic partner, the UCL GOS Institute of Child Health, has a world leading research portfolio. Its programme is made possible through many different funding sources, such as government and charitable funding, including from Great Ormond Street Hospital Children's Charity. You can help us to provide world class care for our patients and families. For more information visit www.gosh.org

About the Journal

<u>Ultrasound in Obstetrics and Gynecology</u> (UOG), published by Wiley, is the official journal of the <u>International Society of Ultrasound in Obstetrics and Gynecology</u> (ISUOG) and is recognised as the leading peer-reviewed journal on imaging within the field of obstetrics and gynecology, publishing important research from all parts of the world.

ISUOG is a charity and membership association encouraging exceptional research and education in ultrasound and related imaging within the field of obstetrics and gynecology. ISUOG has been in existence since 1991 and, with over 13300 members in 128 countries, is the leading international society representing professionals in ultrasound for obstetrics and gynecology.

About Wiley

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About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents who were devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss. Since that time, they have supported many thousands of families whose babies have died, offering emotional support, comfort and information. Today Sands operates through the UK with three aims: to support anyone affected by the death of a baby; to work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible care; and to promote and fund research that could help reduce the loss of babies' lives. Sands website can be found at www.uk-sands.org

For further information or to speak to parents who have experienced the stillbirth of their baby, please contact the Sands press office on 0203 598 1959 or communications@uk-sands.org