

Letter to the Editor

Parent, family and carer empowerment and neonatal mortality: Stretching the boundaries for neonatal units

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Neonatal deaths i. e deaths in the first 28 days of life have only been recognised as a distinct entity within the category of child deaths in the UK since the 1950s ([GB Historical GIS/University of Portsmouth, 2018](#)). Globally, they account for 2.6 million deaths yearly,; approximately 7000 neonatal deaths per day. As overall infant and child mortality improves, neonatal deaths statistically assume a larger contribution to infant and child deaths, and have become a more visible area to target towards improvements in population health. This is reflected in worldwide figures, where neonatal mortality contributed to 41% of deaths under 5 in 2000, increasing to 46% in 2016 ([United Nations Inter-agency, 2017](#)). In England, neonatal deaths contributed to 71% of all deaths in infancy ([Public Health England, 2014](#)).

In working towards driving improvements in neonatal mortality rates in England, there exists confidential enquiries on neonatal deaths (MBRRACE - Mothers and Babies; Reducing Risk through Audit and Confidential Enquiries across the UK) ([Watson et al., 2016](#)), Public Health England reports on infant mortality, and outputs on regional (Neonatal Operational Delivery Network) mortality rates for select groups of preterm babies from the Neonatal Data Analysis Unit. All of these reports, and more, are highlighted to neonatal units/regions, and are intended to spearhead initiatives within such units and regions, for change for the better.

For neonatal intensive care units and teams around them bearing the brunt of these higher neonatal mortality rates, what sorts of initiatives are needed in order to make a difference in mortality outcomes, and can they work? The argument appears clear for optimised nurse staffing ([Watson et al., 2016](#)). Similarly, optimising safe, evidence based or consensus medical and nursing care, robust reviews of mortalities and complex morbidities, and sound clinical governance, are intuitively critical. Preterm births account for the majority of neonatal deaths ([United Nations Inter-agency, 2017](#); [Public Health England, 2014](#)). Key measures to ensure that neonatal pathways are in place for the most appropriate place of birth and care for the most premature of babies born under 26 weeks gestation may contribute to an improvement in their mortality figures ([Marlow et al., 2014](#)). But, simply improving clinical care provided, and in the correct place, is probably not enough.

Mortality rates are influenced by social factors ([Kim and Saada, 2013](#)), and neonatal units on their own have limited influence on these. For example, in understanding key associations/risk factors for infant mortality in Wolverhampton, prematurity, congenital abnormalities, sudden infant death, being born at low birth weight, at extremes of maternal age, late presentation for antenatal care, smoking, and lack of breast feeding were identified ([Pillay et al., 2017](#)). With the exception of sudden infant death, these associations are far upstream, before birth, and strongly influenced by obstetric and social factors. Simply optimising care pathways and post-natal care for these babies, within the neonatal unit, will do little to extinguish their risks for mortality. A much more inclusive, multidisciplinary and imaginatively diverse approach is likely to be needed for the future, and these may include avenues of intervention and support that we have not yet defined.

In the meantime, while social interventions are key and largely the domain of public health, there may be some value in focussing on individual parent/family/carer empowerment in reducing the risks of mortality for their baby. The literature is replete with evidence that maternal education, improves infant, child and even maternal mortality. These relate to general education which empowers women to make smarter decisions regarding the care of their baby, prenatal care, and care of themselves including basic hygiene and nutrition, and immunisations. Perhaps an avenue for neonatal units to explore is empowering parents, families and carers through engagement in them understanding the regional mortality risks for their baby, and their future babies, and what they could do to minimise these where possible. Such awareness of risk factors for infant mortality may provide families/carers with knowledge that could drive longer term change not just for the subsequent pregnancies, but in a cascade effect, for close family members.

In a project on parent education on the risks of mortality in Wolverhampton, parental uptake for the education on understanding risks for mortality were uniformly accepted and supported, and evidence that it can make a difference has already emerged (Pillay et al., 2017). Simply educating parents on basic of life support, management of the choking child and how to recognise that their baby is ill may be empowering to parents/carers, allowing them to initiate preventative intervention earlier (Karlsen et al., 2011), which may be life-saving. This educational approach is unlikely to yield results that are tangible in linking to mortality directly, but in the indirect benefits of parent, family and carer partnership and ownership of reducing the risks for mortality of their own. Family integration of neonatal care has come to the fore in this country; the next steps on awareness of how best to reduce the risks for infant mortality, especially those born preterm, should theoretically be easier.

References

GB Historical GIS/University of Portsmouth, Wolverhampton MB/CB through time | Life and Death Statistics | Infant Deaths, A Vision of Britain through Time, Date accessed: 22nd July http://www.visionofbritain.org.uk/unit/10136544/cube/INF_DEATHS, 2018.

Karlsen S., Say L., Souza J.-P., et al., The relationship between maternal education and mortality among women giving birth in health care institutions: Analysis of the cross sectional WHO Global Survey on Maternal and Perinatal Health, *BMC Publ. Health* **11**, 2011, 606 <https://doi.org/10.1186/1471-2458-11-606>.

Kim D. and Saada A., The social determinants of infant mortality and birth outcomes in Western developed nations: a cross-country systematic review, *Int. J. Environ. Res. Publ. Health* **10** (6), 2013 Jun 5, 2296–2335, <https://doi.org/10.3390/ijerph10062296>.

Marlow N., Bennett C., Draper E.S., Hennessy E.M., Morgan A.S. and Costeloe K.L., Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study, *Arch. Dis. Child. Fetal Neonatal Ed.* **99** (3), 2014 May, F181–F188, <https://doi.org/10.1136/archdischild-2013-305555>, Epub 2014 Mar 6.

Pillay T., Porter K. and Marson S., Developing an early life parent education programme in response to high infant mortality rates, *J Neon Nurs* March 2017 <https://doi.org/10.1016/j.jnn.2017.02.005>.

Public Health England, Facts and Figures on Infant Mortality and Stillbirths, 2014, National Child and Maternal Health Intelligence Network

<http://webarchive.nationalarchives.gov.uk/20170302101718/http://www.chimat.org.uk/maternity/factsandfigures>. Date, Accessed 22 July 2018.

United Nations Inter-agency, Group for Child Mortality Estimation (UN IGME), 'Levels & Trends in Child Mortality: Report 2017, Estimates Developed by the UN Inter-agency Group for Child Mortality Estimation, 2017, United Nations Children's Fund; New York.

Watson S.I., Arulampalam W., Petrou S., et al., The effects of a one-to-one nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study, *Arch. Dis. Child. Fetal Neonatal Ed.* **101** (3), 2016 May, F195–F200, <https://doi.org/10.1136/archdischild-2015-309435>, Epub 2016 Feb 9.