

Need to improve communication with mothers of critically ill infants

Research from the Johns Hopkins Children's Center, published in the *Journal of Perinatology*, studying communication between mothers of critically ill newborns and the clinicians caring for them, found that miscommunication was common. The most serious breakdown in communication occurred when mothers and clinicians discussed the severity of the baby's condition.

The consequences of a communication breakdown, the researchers say, can be serious, hampering critical short-term and long-term treatment decisions and aggravating already high levels of parental stress, a situation often compounded by the new mother's own fragile medical state. The survey of 101 clinician-mother pairs showed that most clinicians (89%) and mothers (92%) described their conversations as productive, but when the investigators looked at the actual survey results they noticed a notable gap between maternal and clinician perceptions about the severity of a baby's disease.

Nearly all mothers could name at least one of their child's diagnoses and treatments, yet nearly half of the mothers disagreed with the clinicians' assessment of the severity of their baby's illness. Of these, 63% believed the child was less sick than the clinician had indicated. Even mothers of children with serious or life-threatening conditions such as sepsis, extreme prematurity or bladder exstrophy minimised the severity of the disease and described their babies as "not sick," "somewhat sick" or "pretty healthy". The investigators recommend that NICU doctors and nurses take the following steps to ensure effective communication:

- Talk with parents as often as possible and regularly update them on any treatments their baby needs and why.
- Be direct and unequivocal about the baby's condition, treatments and prognosis.
- Eliminate medical jargon, complex terminology and doctor speak.
- Be specific and define even the simplest terms and diagnoses.
- Be sympathetic and warm.
- Test maternal understanding by asking follow-up questions.
- Ask the mother to summarise what she took away from the conversation.

Imaging technique to improve diagnosis of seizures in babies

Researchers at The Rosie Hospital, Cambridge, led by Dr Topun Austin and funded by Action Medical Research, are investigating a new technique combining brain imaging and monitoring of electrical activity to improve early diagnosis and treatment of babies who suffer seizures.

In the UK over 2,000 newborn babies suffer seizures each year. Early diagnosis and treatment is vital, as seizures may cause lasting brain damage. However, they sometimes go unnoticed, as babies can have no obvious symptoms.

Around two or three babies in every 1,000 born alive also suffer from seizures within a month of birth. Babies born very prematurely are especially vulnerable, as are babies who suffer from a lack of oxygen during birth.

Babies who are suspected of suffering

from seizures are normally referred for an electroencephalogram (EEG).

"When babies have a seizure, there is a large amount of electrical activity in the brain, which we are measuring with EEG. But EEG has limitations, as it can only detect seizures occurring near the surface of the brain. It cannot detect abnormalities deeper within the brain," explains Dr Austin.

"The amount of oxygen in the brain also changes, which we measure with the new optical system. This system works by shining near-infrared light into the brain, which is harmless and non-invasive."

Dr Austin hopes the new combined technique will boost understanding of what's happening inside the brain during seizures: "The ultimate aim is to develop the new system for routine use at the cot-side."

Support World Prematurity Day 2012



This year 15 million babies will be born prematurely around the world, 60,000 right here in the UK.

On 17 November, World Prematurity Day, Bliss will join with other organisations around the globe to raise awareness of this very serious issue. As part of our commitment we are pleased to announce that we are the first UK charity to join the global alliance of charities that are concerned about premature birth. The aim of the group, which was set up and is overseen by the March of Dimes, USA, is to raise awareness of prematurity around the world and the issues faced by babies born too soon and their families.

Bliss, is asking everyone around the UK to get involved. Take part in some activity in the week leading up to 17 November and share with us on Facebook and twitter.

The international colour for World Prematurity Day is purple so you could light a purple candle or dress in purple to show your support. You could decorate your unit with purple balloons and streamers and take some photos and share with us on facebook. We'd love to see as many of you take part as possible and show your support!

For more information visit www.bliss.org.uk or email kellies@bliss.org.uk

Research priorities for preterm birth

The Social Science Research Unit (SSRU) at the Institute of Education, University of London, in collaboration with the James Lind Alliance (JLA), is conducting a survey to identify uncertainties about causes, prevention and care of premature babies. The Preterm Birth Priority Setting Partnership (PSP) will then prioritise the uncertainties for future research.

Health professionals and parents of preterm infants are invited to suggest topics that could be considered for future research into preterm birth care; this feedback will help to improve quality of care and outcomes at very preterm birth.

Seilin Uhm, who is coordinating the project, says: "So far we have gathered almost 400 uncertainties about preterm birth and caring for premature babies across the UK and Ireland." As the majority of responses have come from white, middle-class and well-educated populations, Seilin is particularly keen to get feedback from families from lower socio-economic or ethnic minority groups.

Healthcare professionals are invited to complete the survey online at www.surveymonkey.com/s/prembabies before 16 September 2012 and asked to encourage the parents of premature babies to participate in the survey.

For further details or to get involved, contact Seilin Uhm, s.uhm@ioe.ac.uk

Small Wonders National Change programme

In June, the child health charity Best Beginnings, working in collaboration with staff in more than 150 neonatal units, launched the Small Wonders National Change programme in England. Small Wonders is a major new initiative to drive and support cultural shift across the UK towards more family-centered care in ways designed to improve health outcomes and well-being of children born prematurely or sick.

At the heart of the change programme is the Small Wonders DVD which follows 14 families on their journey over the course of a year as they gain confidence in caring for their babies in hospital and at home. The DVD is divided into 12 films each covering a different aspect of caring for a premature and sick baby including 'Birth', 'Holding your baby', 'Expressing breastmilk', 'Preparing for home' and 'Bereavement'. Over 300 neonatal staff from across the UK have watched and given feedback on 'rough cuts' of the DVD and have been involved in piloting the DVD prior to its June launch. The final DVD is supported by 23 organisations including the NNA and BAPM.

Best Beginnings has secured charitable funding to enable free copies of the DVD to be distributed to all parents and staff in neonatal units across the UK for a year. The charity is committed to ensuring this valuable resource is being used as effectively as possible as part of a local change programme with multi-disciplinary staff engagement and a proper plan for dissemination to parents. For this reason, the DVDs are only being sent to a hospital if the neonatal unit has at least one Small Wonders Champion



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and has returned a planning form signed by the unit's clinical lead.

To date, 68,330 free copies of the DVD have been disseminated to 130 of the 171 hospitals in England and as more planning forms are received more DVDs are being sent out. Plans are now underway to launch Small Wonders in Scotland, Northern Ireland and Wales.

Across the UK there are currently 412 Small Wonders Champions.

If your hospital does not yet have copies of the Small Wonders DVD, you are interested in becoming a Small Wonders Champion and/or you are interested in finding out more about the Change Programme or NUCAT, please contact: smallwonders@bestbeginnings.org.uk

Be part of a landmark accreditation scheme for neonatal units

Following the recent launch of the Bliss Baby Charter Audit Tool, Bliss is enlisting the support of health professionals to help develop the audit tool into a new accreditation scheme for neonatal units.

Bliss is keen to involve neonatal staff and parents right from the very start of this pioneering initiative to help develop it into a world-class scheme. Key to the success of the accreditation scheme is ensuring that those who will participate in their own unit's accreditation are involved in how the

scheme is set up.

Bliss values the range of skills and knowledge on units across the UK and is keen to ensure that those involved in the project represent different aspects of care, unit levels and geographic areas. The charity wants to hear from neonatal staff from all disciplines, whether that be clinical, management, psychosocial or developmental – the more diverse the better. Support could include reviewing the scheme proposal, trialling part of the

scheme on a unit, gathering colleagues' views on principles of the scheme or attending focus group meetings. The most important qualifications to be part of this initiative are knowledge of a neonatal unit, a passion for family-centred care and enthusiasm for contributing to this project – you do not have to have been involved in similar projects.

If you would like to find out more about what is involved in this project and how you might be able to help please get in touch with morvenm@bliss.org.uk