Medical Xpress

Study underscores need to improve communication with moms of critically ill infants

August 16 2012

Irish playwright George Bernard Shaw once described England and America as two countries separated by a common language.

Now research from the Johns Hopkins Children's Center suggests that common language may also be the divide standing between mothers of critically ill newborns and the clinicians who care for them.

The study, published August 16 in the *Journal of Perinatology*, found that miscommunication was common, and that the most serious breakdown in communication occurred when mothers and clinicians discussed the severity of the baby's condition. Misunderstanding was common even when both the doctor and the mother agreed their conversations went well, suggesting a startling lack of awareness of the problem, the researchers say.

"One thing that we, clinicians, must always keep in mind is that talk doesn't equal communication, and just because we spoke with a parent we cannot assume that our message got across," says senior investigator Renee Boss, M.D., M.H.S., a neonatologist at Hopkins Children's Center.

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.

"Poor understanding of a baby's prognosis can lead to maternal frustration and dissatisfaction with the treatment plan, which ultimately undermines the goal of teamwork between families and clinicians," says study lead investigator Stephanie de Wit, M.D., a former neonatology fellow at Hopkins, now an attending neonatologist at MedStar Franklin Square Medical Center.

The findings, based on a survey of 101clinician-mother pairs, underscore the need for physicians and nurses to carefully gauge maternal understanding of the complexity of a baby's diagnosis, to communicate regularly with families and to help parents become more meaningful participants in their infant's care, de Wit says.

For their study, the researchers asked clinicians (physicians, neonatal nurse practitioners, nurses and respiratory therapists) and English-speaking mothers whose newborns were treated at The Johns Hopkins Hospital neonatal intensive care unit (NICU) to fill out questionnaires about their discussions of the baby's condition and prognosis. Most clinicians (89 percent) and mothers (92 percent) 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. In other words, the Hopkins team says, being satisfied with the conversation had nothing to do with how effective it actually was.

Nearly all mothers (94 of 101) could name at least one of their child's diagnoses and treatments. Yet, nearly half of the mothers (45 percent), disagreed with the clinicians' assessment of the severity of their baby's illness. Among mothers who disagreed with clinicians, nearly two-thirds (63 percent) believed the child was less sick than the clinician had

indicated. Even mothers of children with serious or life-threating conditions such as sepsis, extreme prematurity or bladder exstrophy minimized the severity of the disease and described their babies as "not sick," "somewhat sick" or "pretty healthy."

"When it comes to discussing a critically ill newborn's condition, parents and doctors often seem to be speaking the same, yet different, languages," de Wit says.

For example, de Wit explains, the word "sick" may have notably different meanings to clinicians and parents. Parents tend to perceive as "sick" as a child who is in discomfort, vomiting or feverish, but to a clinician "sick" usually means a serious condition with poor or uncertain prognosis, the researchers says.

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 summarize what she took away from the conversation.

The researchers caution that not all misunderstandings stem from failure to communicate.

"We cannot exclude the possibility that the sheer force of hope fueled unrealistically optimistic expectations, even when mothers fully grasped the objective reality of their child's condition," Boss says.

Provided by Johns Hopkins University School of Medicine

Citation: Study underscores need to improve communication with moms of critically ill infants (2012, August 16) retrieved 26 April 2024 from https://medicalxpress.com/news/2012-08-underscores-moms-critically-ill-infants.html

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