Published in final edited form as:

Arch Pediatr Adolesc Med. 2012 January ; 166(1): 95–96. doi:10.1001/archpediatrics.2011.767.

Communicating With Parents About Newborn Screening The Skill of Eliciting Unspoken Emotions

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Every screening program engages in a battle to maximize benefits and minimize harms.¹ While concerns about harms from screening often focus on physical ones such as unnecessary testing or treatment, psychological harms can be equally damaging and lasting, living on with the patient long after the screening process has ended.² It is the potential for identification of heterozygotes (ie, carriers) through newborn screening to cause psychological harm that Farrell and colleagues³ examine in their study published in this issue of the *Archives of Pediatrics & Adolescent Medicine*.

The study investigators audiotaped and analyzed resident and attending physician conversations with standardized patients to evaluate how well physicians assessed parents' emotional response after learning that their child had been identified as a carrier for sickle cell or cystic fibrosis. The theory behind the study is that eliciting and understanding parents' emotional reactions is critical to identifying parents at risk for persistent psychological distress resulting from the experience. Notably, Farrell and colleagues raised the bar for these physicians by instructing standardized patients not to provide any emotional cues (verbal or nonverbal) during the encounter. So physicians had to take the initiative to inquire about psychological or emotional distress, a behavior that Farrell and colleagues termed *precautionary empathy*.

How did the physicians do? Unfortunately, most failed even when graded on a curve (i.e., when they received credit for meeting partial criteria): 27% met full criteria for at least 1 precautionary empathy communication and 56% met partial criteria.³ The results for 3 specific precautionary empathy communications (open-ended assessment for emotion, caution about future emotion, instruction about emotion) are even more disheartening. First, of the 143 physicians who participated, only 1 uttered a definite open-ended inquiry about emotion (8 met partial criteria). Second, despite the fact that anticipatory guidance is a foundation of pediatric practice, no physician met full criteria for cautioning patients that this current experience could stir up emotions in the future (e.g., caution about future emotion). Finally and sadly, the most common type of precautionary empathy communication exhibited was the physician instructing the patient how to feel by using phrases like "this is not something you need to worry about" (23% transcripts met definite criteria and 39% met partial).

The fact that some physicians do not excel at communication is unlikely to come as a shock to anyone who has interacted with the health care system or is familiar with research in this area. Yet this study highlights an interesting and understudied aspect of physician-patient communication in newborn screening, and of pediatrics more generally: a physician's skill

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Financial Disclosure: None reported.

Disclaimer: The views expressed herein are not necessarily those of the University of Michigan or the NICHD.

in assessing parents' unspoken emotional reactions. To date, most efforts to improve the quality of communication about newborn screening have focused on conveying accurate disease information to parents, which is important.⁴⁻⁵ Carrier screening in particular has a tragic history wrought with misinformation and discrimination regarding sickle cell carriers.⁶ Therefore, it is critical that physicians explain to parents that children identified as carriers for cystic fibrosis or sickle cell have genetic variants that they can pass on to offspring but that the children do not have the disease.

Farrell and colleagues remind us that transfer of information about newborn screening results is not a sterile, scientific process but rather one cloaked in emotion. Being told that a test result suggests that your healthy-appearing child might have a disease can be an emotionally jarring experience for parents. Within this emotional fog, it may be difficult for parents to process information effectively. Even if the child is ultimately determined not to have disease, the experience can leave some parents with a tarnished perception of their child's health, either because they continue to misunderstand the result⁷ or because despite understanding the result, their confidence in their child's health has been shaken.⁸ Since patients will not always share their inner thoughts and feelings with physicians, it is critical that physicians elicit these unspoken emotions. Otherwise, parents and children may continue to suffer in silence and/or present to the physician later on with issues related to a prior traumatic medical experience.⁹

While attempts are being made to teach communication skills as a part of a physician's training,¹⁰ Farrell and colleagues are to be commended for highlighting another communication skill that we might consider incorporating into training for pediatricians across the professional spectrum, from medical students to attending physicians. Their Communication Quality Assurance method provides a useful starting point for developing a tool to measure "precautionary empathy." Hopefully, future work will provide data on the effect of this tool on patient outcomes.

Some might argue that by promoting "precautionary empathy" communication we are asking the pediatrician to play psychiatrist. This is simply not the case. Psychiatrists focus on treating psychopathology, not normal emotional reactions. Dismissal of the pediatrician's role in assessing parents' and patients' emotional status is a narrow view of medical practice that fails to appreciate the complex relationship between the physical and psychological aspects of both communication and medical care. Furthermore, as enthusiasm for screening (both genetic and nongenetic) continues to increase, pediatricians (both primary care and subspecialists) will increasingly confront the challenge of communicating about "nondisease"² and pseudodisease¹¹ (when a patient's screening and diagnostic test results [e.g., biochemical, cellular, genetic] are abnormal but do not cause symptoms of disease).

As our screening and diagnostic technologies outpace our understanding of disease processes, patients and parents will naturally turn to their physicians to help them understand and process these issues. It will be the physician's responsibility to ensure that healthy patients do not embrace the "sick" label¹² so that in striving to prevent disease we remain mindful of our duty to preserve health among the healthy.

Acknowledgments

Funding/Support: Dr Tarini was supported by K23 Mentored Patient-Oriented Research Career Development Award K23HD057994 from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

Role of the Sponsor: The NICHD did not have any role in the design and conduct of the study; the collection, analysis, and interpretation of the data; and the preparation, review, or approval of the manuscript.

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