

# Knowledge gaps, fears common among parents of children with drug-resistant bacteria

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Knowledge gaps and fear -- some of it unjustified -- are common among the caregivers of children with a drug-resistant staph bacterium known as MRSA, according to the results of a small study from the Johns Hopkins Children Center. These caregivers thirst for timely, detailed and simple information, the researchers add.

The study's findings, published online in *The Journal of Pediatrics*, underscore the need for healthcare staff to do a better job in educating [parents](#), while also addressing concerns and allaying fears, the investigators say.

"What these results really tell us is not how little parents know about drug-resistant infections, but how much more we, the healthcare providers, should be doing to help them understand it," says senior investigator Aaron Milstone, M.D., M.H.S., a pediatric infectious disease specialist at Hopkins Children's.

Conducting bedside interviews with 100 parents and others caring for [children](#) hospitalized with new or established MRSA, or methicillin-resistant *Staphylococcus aureus*, the investigators found that nearly one-fifth (18 of the 100) had never heard of MRSA. Some of the children in the study were symptom-free carriers who were hospitalized for other reasons, while others had active MRSA infections. This increasingly common antibiotic-resistant bacterium causes skin and soft-tissue

infections in healthy people, but can lead to invasive, sometimes fatal, infections in seriously sick patients and in those with weak immune systems.

To prevent the spread of MRSA to other patients, Hopkins Children's in 2007 began screening all children admitted to its intensive-care units. They are then screened weekly until discharge.

In the study, 29 of the 100 caregivers said they didn't know that their child had MRSA, but only nine of these cases involved newly identified cases, meaning that 20 children had been diagnosed with MRSA during past hospitalizations, yet parents and guardians were unaware. Investigators said the caregivers expressed frustration and confusion with the delayed revelation, a finding showing the importance of promptly communicating any and all new information to parents and doing so in plain language.

Among the 71 caregivers who knew of their child's MRSA diagnosis, 63(89 percent) revealed concerns, 55 (77 percent) worried about subsequent MRSA infections, and more than half (36) worried about their child spreading MRSA to others. Widespread uncertainty existed among them about whether to share the news with the child's school, primary-care pediatrician or home nurse. Some parents said they didn't understand the difference between having an active infection and being a carrier.

Eleven of the 71 (16 percent) caregivers said their child's MRSA diagnosis would lead to social stigma, fearing isolation both by friends and at school.

To help address these fears, physicians and nurses caring for children with MRSA should ask parents repeatedly if they have lingering concerns or questions, the researchers note. And they should take extra

care to relieve worries among parents about future infections in the child or the fear of their child spreading MRSA to others. This can be done by putting the risks in perspective and by giving clear, specific risk-minimizing instructions tailored to each child's situation and health status, the researchers say.

Because children with MRSA do not pose a serious risk to healthy people outside of the hospital, restricting play time with friends and schoolmates is unjustified and doing so can be psychologically damaging to a child, the researchers say.

"An old axiom in pediatric medicine says that when you treat a child, you treat the whole family, so it is up to the physicians to ensure that the family understands what MRSA is and, more importantly, what it is not," Milstone noted.

"As physicians, we often focus too much on accurate diagnosis and effective treatment and not enough on helping patients and their families make sense of the diagnosis and what it means to them," says lead investigator Arnab Sengupta, M.B.B.S., M.P.H., formerly of Hopkins and now a pediatric resident at University of Illinois at Chicago.

Indeed, parents who received such guidance reported feeling less stressed and having fewer concerns about MRSA.

As the mother of one patient put it, "The best way to destigmatize MRSA is to inform the parent and the child what MRSA is and what their exact status is. That makes life easier."

The research was funded by the National Institutes of Health.

Other investigators in the study include Trish Perl, M.D. Ms.C., and Cynthia Rand, Ph.D., both of Hopkins.

**More information:** Conflict-of-interest disclosure: Aaron Milstone and Trish Perl receive grant support from Sage Products, Inc. Perl is on the advisory board and has received honorarium from Pfizer and BioMerieux, and was on the advisory panel for Theradoc, Inc., manufacturer of infection surveillance systems. She has received honorarium from 3M, a manufacturer of drug-delivery and infection-prevention systems.

The terms of these arrangements are being managed by The Johns Hopkins University in accordance with its conflict-of-interest policies.

Provided by Johns Hopkins Medical Institutions

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