

National organizations tap researchers to establish registries, develop guidelines for treating children with COVID-19

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A paper and two editorials by University at Buffalo pediatrics researchers call attention to key issues in health care that the COVID-19 pandemic has brought to light; they also recommend guidelines for evaluating and treating children infected with COVID-19. All were published in *Progress in Pediatric Cardiology*.

As a result of the recommendations, the American Heart Association has requested that one of the authors, Steven Lipshultz, MD., chair a committee to develop a Scientific Statement on the Management and Treatment of Children with Cardiomyopathies, including COVID-19 and other viral and [inflammatory diseases](#). Lipshultz is the A. Conger Goodyear Professor and chair of the Department of Pediatrics in the Jacobs School of Medicine and Biomedical Sciences at UB.

The Children's Cardiomyopathy Foundation is also working with Lipshultz to fund a national registry of children with COVID-19 and these [cardiovascular complications](#) to augment his current National Institutes of Health funding of the Pediatric Cardiomyopathy Registry.

Lipshultz is credited with having helped establish the field of pediatric cardio-oncology and has been principal investigator of several landmark NIH studies on the causes and treatment of cardiomyopathy in children.

Disruption to health care

Lipshultz was corresponding author on the paper published online this week—titled "Disruption of Healthcare: Will the COVID Pandemic Worsen Non-COVID Outcomes and Disease Outbreaks?"—which discusses the far-reaching effects that the global pandemic is having on all aspects of health care.

Along with Lipshultz, UB co-authors on the paper include Gale Burstein, MD, commissioner of the Erie County Department of Health and clinical professor of pediatrics, and Dennis Z. Kuo, MD, associate professor and division chief of general pediatrics, both in the Department of Pediatrics at the Jacobs School. Kuo is also a physician with UBMD Pediatrics. Additional co-authors are Paul Barach, MD, of Wayne State University, Stacy D. Fisher, MD, of the University of Maryland, M. Jacob Adams, MD, and Patrick Brophy, MD, both of the

University of Rochester.

Citing fear and lack of trust in health care institutions as patients with other conditions avoid treatment because of COVID-19, as well as dysfunction in the ways that health care is paid for in the U.S., Lipshultz and co-authors describe in the paper the health care challenges that the COVID-19 pandemic has created.

"Apprehension about seeking care for non-COVID diseases, especially heart attacks and other cardiovascular problems, is leading to potentially lethal delays in seeking care, which will reverberate throughout [health care](#) systems for the foreseeable future," said Lipshultz.

The authors note that a critical factor in boosting confidence in the system's ability to care for patients with all diseases is accurate and effective communication with the public about risks from the novel coronavirus as well as non-COVID-19 diseases.

The paper states: "Uncertainty about the course and severity of the pandemic and the potential of a vaccine remains high; thus, effective risk communication is essential to ensure widespread adoption of evidence-based public health recommendations."

H1N1 lesson

The paper mentions, as an example, that in 2009, public acceptance of the H1N1 flu vaccine happened as a result of "access to clear and [accurate information](#) and confidence in the vaccine, which was enhanced when President Obama's daughters were immunized."

But the trust that Americans now have in the federal government to "do the right thing" has plummeted to 17%, according to research cited in the paper, and official actions during the pandemic have further eroded

public confidence.

The authors note that reporting of [accurate data](#) about the incidence of the disease and which populations are more at risk for COVID-19 and other diseases is also a factor that impacts public trust and perception.

The paper states: "Disease incidence and progression for many conditions can vary by ethnicity and COVID-19 may be no different. Even in the U.S., needed information about infections, hospital admissions, and deaths is not readily available in some regions as a result of economic concerns and political pressures."

Children with multisystem inflammatory syndrome

More readily available data on COVID-19 patients, especially the recent emergence of the Kawasaki-like syndrome called multisystem inflammatory syndrome in children (MIS-C), will be especially critical in determining how best to treat these children, Lipshultz notes in his editorial "Rethinking COVID-19 in children: Lessons learned from pediatric viral and inflammatory cardiovascular diseases," published in May.

He urges the establishment of patient registries, similar to what he and colleagues have done in the field of pediatric cardiomyopathy.

Such registries can help establish new classification systems and identify differences in the course of a disease and outcomes. In pediatric cardiomyopathy, these registries of patient data have cut in half the incidence of the failure of certain medical interventions.

In another editorial, "COVID-19 associated Multisystem Inflammatory Syndrome in Children (MIS-C) guidelines: a Western New York approach," published in May, Mark Hicar, MD, Ph.D., assistant

professor of pediatrics at UB and a physician with UBMD Pediatrics, and colleagues proposed new guidelines for evaluating children with COVID-19 who exhibit symptoms of MIS-C, which can have devastating effects on the cardiovascular system and other organs.

Because of the complexity of the issues involved with this condition, Lipshultz proposes that a multidisciplinary team should address such patients as soon as possible. And because of the possibility of rapid deterioration after presenting with initially mild symptoms, he strongly recommends follow-up within several days if a child with symptoms that may indicate MIS-C is discharged from the emergency department; he also proposes that providers be aware that transfer to a pediatric intensive care unit or higher level of hospital care may also be warranted.

"Decades of research studying cardiovascular diseases in children related to viral illnesses and their therapies has provided us with important lessons that we believe may be relevant to understanding the cardiovascular manifestations of COVID-19 in children," Lipshultz said.

More information: Paul Barach et al. Disruption of healthcare: Will the COVID pandemic worsen non-COVID outcomes and disease outbreaks?, *Progress in Pediatric Cardiology* (2020). [DOI: 10.1016/j.ppedcard.2020.101254](https://doi.org/10.1016/j.ppedcard.2020.101254)

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