

# Live Tweeting the Discovery of a New Coronavirus Disease 2019–Related Syndrome in Children

## To the Editor:

In the midst of the coronavirus disease 2019 (COVID-19) outbreak, a novel pediatric hyperinflammatory syndrome was reported (1, 2). Affected children showed overlapping features of Kawasaki disease and toxic shock syndrome and required hospital and PICU admission (2, 3).

Names for this new clinical syndrome flourished. A statement by the Centers for Disease Control and Prevention named this new syndrome as multisystem inflammatory syndrome in children (MIS-C) (4). At the same time, the World Health Organization suggested multisystem inflammatory syndrome (MIS), and the National Health Service in the United Kingdom suggested pediatric multisystem inflammatory syndrome—temporally associated with severe acute respiratory syndrome coronavirus 2. Several conversations about this condition have swirled around. Also, multiple hashtags across the Pediatric Critical Care social media community surged. To date, this syndrome has not been uniformly named. Our aim was to assess the evolving discussion surrounding the naming of this a novel disease through the analysis of its evolution around the Twitter hashtag #PedsICU.

We prospectively examined the weekly trends in MIS-C–related hashtags in the PICU Twitter community. The #PedsICU hashtag was monitored through a social media analytics tool for healthcare (Symplur Signals, LLC, Upland, CA) from April 1, to October 20, 2020. After extracting all tweets containing #PedsICU, we reviewed MIS-C–related hashtags (#PIMSTS, #MISC, #PIMS, #kawasakidisease, #MIS\_C, #Kawasaki, #PMIS, #EnfermedadDeKawasaki, #KawasakiLike, #MIS, and #ToxicShock).

A total of 94,853 tweets by 17,159 users with 237,108,508 impressions using #PedsICU were recorded. #PIMSTS and #MISC were the hashtags most widely used. The MIS-C hashtag was found in 5,698 of all the #PedsICU tweets (7.2%) by 1,742 users, showing a strong involvement of the community. Stakeholder groups were identified including healthcare providers (34.8%), physicians (22.5%), and healthcare organizations (6.5%). The users distribution (**Fig. 1A**) mainly reflected the countries with higher disease impact (United States, United Kingdom, Spain, France, and Italy).

Peaks of discussion occurred at the time of the publication of the first case series and key articles on the topic, with highest engagement between May and July 2020, when each peak reached more than 400 tweets a week (**Fig. 1B**).

Our study (3), published in a recent issue of *Pediatric Critical Care Medicine*, found that a great variety of hashtags were used to describe MIS-C in children. Two of them were the most commonly used: #PIMSTS and #MISC. It

Anna Zanin, MD, MSc<sup>1</sup>

Alberto Garcia-Salido, MD, PhD<sup>2</sup>

Miguel Rodríguez-Rubio, MD<sup>3</sup>

Anna Camporesi, MD<sup>4</sup>

Rolando Ulloa-Gutierrez, MD<sup>5</sup>

Maria Elena Villar, PhD, MPH<sup>6</sup>

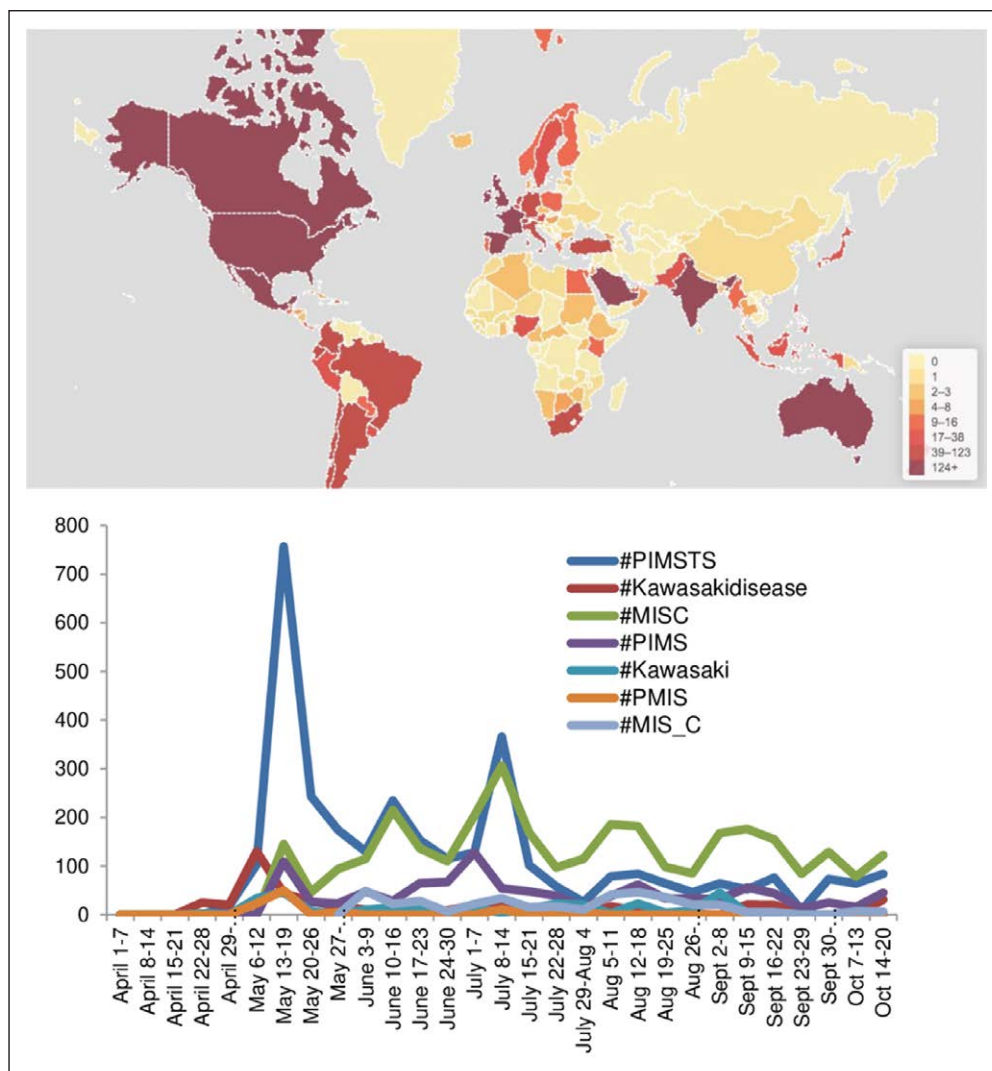
Sebastián González-Dambrauskas,  
MD<sup>7</sup>

Sapna R. Kudchadkar, MD, PhD,  
FCCM<sup>8</sup>

Christopher L. Carroll, MD<sup>9</sup>

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**Figure 1. A,** Locations of users. **B,** Stakeholders and groups activities in the #PedsICU dataset over time.

is known that social media leads to rapid discussion and dissemination. However, during the COVID-19 pandemic, early information was not always accurate, and there was a rush to be “the first” to publish or to tweet. In the case of this new syndrome, disparate names may have hampered discussion and understanding. Better coordination between societies and stakeholders, including consistent terminology and naming, is important during a fast moving crisis. Unfortunately, our network analysis did not examine direct and indirect influence of superusers on this conversation.

The #PedsICU community represents a valuable source of information-sharing and dissemination, although the content shared through social media (active tweeting in the “online world”) may not reflect

the real clinical impact at the bedside (offline world and MIS-C real prevalence) of some online conversations. The “higher impact” of MIS-C recorded in some countries could be related also to a relevant media discussion driven by the users. Social media users’ perception of the scale of the MIS-C clinical problem deserves further investigation.

Naming is an important process that requires coordination and needs a lot of curation to ensure that accurate information is widely shared and promoted (5). As we experienced during 2020, a clear strategy that provides easy access to information in real time in an accountable and equitable way is important. As we observed, a universally recognized hashtag could help coordinate such an effort in social media platforms.

- 1 *Pediatric Intensive Care Unit, San Bortolo Hospital, Vicenza, Italy*
- 2 *Pediatric Intensive Care Unit, Hospital Infantil Universitario Niño Jesús, Madrid, Spain*
- 3 *Department of Pediatric Intensive Care, Hospital Universitario La Paz, Madrid, Spain*
- 4 *Pediatric Intensive Care, Children’s Hospital V Buzzi, Milano, Italy*
- 5 *Servicio de Infectología Pediátrica, Hospital Nacional de Niños “Dr. Carlos Sáenz Herrera”, San José, Costa Rica. Red de Enfermedad de Kawasaki en América Latina (REKAMLATINA)*
- 6 *Department of Communication, Steven Cruz Institute for Science, Media & Technology, Miami, FL*
- 7 *Cuidados Intensivos Pediátricos Especializados (CIPe), Casa de Galicia, Red Colaborativa Pediátrica de Latinoamérica (LARed Network), Montevideo, Uruguay*
- 8 *Department of Anesthesiology and Critical Care Medicine, Department of Pediatrics, and Department of Physical*

Medicine and Rehabilitation, Johns Hopkins University  
School of Medicine, Baltimore, MD

9 Pediatric Intensive Care Unit, Department of Pediatrics,  
Connecticut Children's Medical Center, Hartford, CT

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