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Editorial

Why JHA? Why Now?

Erin T. Paquette, MD, JD, MBe, HEC-C, FAAP[1,2]

[1] Critical Care, Ann & Robert H. Lurie Children's Hospital of Chicago, [2] Associate Professor of Pediatrics (Critical Care), Northwestern University Feinberg School of Medicine and Law, Northwestern University Pritzker School of Law, by courtesy

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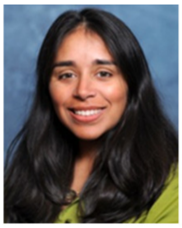
Journal of Health Advocacy



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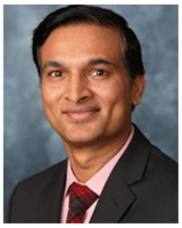
JD MBe



Vamshi Rao, MD

With publication of the inaugural content of the *Journal of Health Advocacy (JHA)*, as co-Editor-in-Chief, I cannot help but reflect on the last several years that brought this vision of *JHA* to realization. Central to that vision is the conception of advocacy intentionally and broadly as activities that endeavor to—or actually do—promote system changing action in the pursuit of health equity and justice within society.

We met weekly during the last several years, in the shadows of COVID and its aftermath, to talk about the need for a journal solely dedicated to sharing advocacy. We talked about the hundreds of people we know who publish a range of other types of research but who have been doing advocacy work for years, decades even, yet there had not been a dedicated place where they could share this work, which we also knew was sitting on their shelves, waiting for this moment. But I did not feel that need so personally until I needed advocacy most.

Co-incident with the development of *JHA*, I had a recent and extensive experience with the health care system as a patient. That experience not only showed me how powerless I could feel, but that advocacy is power and must be far more than an academic endeavor.

As a pediatric intensivist, though I am familiar with "running a room" in the intensive care unit and directing the care of a critically ill child, as I was laying on a hospital gurney in the emergency department (ED), swarmed by nurses, respiratory therapists, trainees at multiple levels, and the attending in charge of the room, I felt small and helpless. For a moment, I caught the eyes of the attending who was surveying the room to ensure the attempts to avoid more aggressive resuscitation were carried out. I read the uncertainty in his gaze as my eyes often held the same when managing a challenging case. In and out of consciousness, the last image I recall from that ED visit was my husband backed against the opposite side of the room, with a wall of ED staff dividing him from me. He too seemed smaller than I recalled and wholly overwhelmed. In that state, I truly was powerless and wholly dependent on those around me to make the right choices, to act in my interest.

In the ensuing years, marked by my own increasing morbidity, these themes of uncertainty and lack of specific attention to the trauma of my repeated presentations for emergent and critical illness would replay themselves in multiple hospital systems. I realize now that each of those experiences presented opportunities for advocacy, either at the local hospital system level or more broadly—and, unlike for most other patients, I was aware of those opportunities.

For example, when multiple therapeutic options had been trialed to treat a suspected disease, but without an official diagnosis, it took individual patient-level advocacy by several physicians in collaboration with surrogate decision-makers to attempt to employ a new treatment modality, fully knowing its risks. This process involved convening ad-hoc divisional and hospital level committees to discuss my case prior to implementing treatment. This system-level action ultimately resulted in me successfully receiving a treatment to which I had a positive response. Without these actions taken by multiple people at multiple times, a negative response or no response was far more likely.

I also acknowledged, as a patient far more so than as a clinician, that along with recurrent hospitalizations also comes the high possibility of a range of difficult unexpected events—driven less by my own disease than by the system itself.

During those COVID years, on multiple occasions, EDs and entire hospitals were operating above expected patient capacity, which led to "boarding" patients in the ED, an undesirable and potentially dangerous situation for any patient. This is a problem that has been reported and followed at a national level, and one that is still in need of a larger systemic solution. For me, this meant that I spent prolonged time intubated and on sedation in the ED, which led to new medical issues: two serious pressure injuries. One episode resulted in increased infection risk, while the other led to a long-lasting inability to walk.

Moreover, my situation was further complicated by the national crisis of subspecialist shortages, making the wait time for an outpatient appointment longer than the time in which it might have been possible to intervene to address the pressure injury and avoid more long-lasting damage.

This case, my experience, further highlighted for me that even when individual patient-level opportunities for advocacy exist, and even when those actions are taken, it is still necessary to address the deeper, more complex issues that we collectively face in contemporary healthcare using a multisystem approach.

While I have taken similar actions for my patients in the past, I knew then that our vision for *JHA* was far more important than I ever recognized. That's because these conversations must continue, so that we can avoid situations like I experienced and work harder and more collaboratively to ensure that every patient can receive the same kind of response, in their best interests.

By sharing my experience, I hope that more people will recognize some of the kinds of patient issues that require advocacy and will have the tools they need to act on those issues to change outcomes for patients and families and communities—and themselves.

As the first journal to focus specifically on health advocacy, the new *Journal of Health Advocacy (JHA)* aims to encourage and support these conversations. *JHA* is a comprehensive home for multiple types of advocacy related work and action, including relaying personal narratives, similar to my story above, and describing opportunities for advocacy through to complex studies evaluating implementation of advocacy-based interventions that may address multisystem responses.

My situation raised several system-defining questions and prompted potentially system-changing actions that would be welcome additions to *JHA*. It also generated a number of advocacy-defining empirical questions that might be included in empirical manuscripts published in *JHA*, such as, what is the epidemiology of patient boarding and subspecialist shortages with prolonged wait times? How are patient outcomes affected by these problems?

Similarly, my patient experience further highlighted for me the potential for the kinds of system-changing actions that our journal also aims to publish, such as, what system changes are necessary to prevent the problems described? Combined public health and regulatory or legislative measures will likely be required. Should patient boarding be prohibited by public payers, accreditation, or licensing bodies? Should graduate medical education (GME) funding be differently appropriated to prevent or respond to shortages? When boarding or subspecialist shortages necessarily result in sub-standard levels of care, can and should hospitals/public health departments or state/federal governments declare public health states of emergency with crisis level conditions, triggering accessibility of public health resources? How would each of these approaches be justified? And who should be involved in addressing them and being accountable?

By focusing on these types of questions, in each journal publication, we endeavor to highlight the system-changing dimensions of the problems presented and the actions needed to promote positive change in the pursuit of health equity and justice.

As we launch the first issue of *JHA*, we feature two papers on engaging in advocacy, one to address burnout and the other to share what it takes to organize for policy change—where and when there is no other option, and two original research articles discussing interventions designed by students to improve competency in caring for persons with disabilities (PWD) and to prevent injury by offering firearm safety screening in a student-run primary care setting. These two manuscripts focus on advocacy needed within the healthcare system to improve patient outcomes and provider engagement. These follow our recently published first primer on engaging in health advocacy, and an election brief to provide content relevant to health-related issues and to acknowledge the role of the vote in advocacy. Prior to this, our most recent blog focused on the importance of registering to vote.

It is serendipitous and deeply fulfilling that our first papers should echo our early discussions years ago about the why and the why now for *JHA*.

As co-Editor-in-Chief, a member of several advocacy bodies, a pediatric intensivist, and a patient who has seen first-hand the need for all levels of advocacy, I am deeply committed to sharing advocacy activities across a wide spectrum of publications, personal and scholarly, and look forward to the rich discussions that this new journal will no doubt shortly provoke.

Thank you for reading.

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ACKNOWLEDGEMENT

As this first "issue" launches, I—and the entire JHA editorial team—are deeply indebted to the passion and purpose that Co-EiC Vamshi Rao brought to identifying the need for JHA and assembling the team I am grateful to be part of in turning the vision of JHA into reality. While we miss his presence as Co-EiC, we remain inspired by his presence on our Editorial Board where he will continue his legacy of passion for health and advocacy.

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