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## **Cover Page Footnote**

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## Lessons for patient experience from the voices of pediatrics and children's hospitals

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### Abstract

This special issue on patient & family experience in children's hospitals and pediatric care underlines pediatrics' position as a leader in the experience journey. In pediatrics and children's hospitals significant efforts are made to ensure the environment is welcoming and comfortable, there is a commitment to communicating to patients – the children that are cared for – in a way they can understand, and there is a clear intention of engaging family members as an integral part of the care experience. In acknowledging that this is a special issue on pediatrics, we would miss a significant opportunity if we were not to look for and find the lessons that can be applied across healthcare settings. It is this capacity to transcend boundaries in which true experience improvement will be realized.

### Keywords

Pediatrics, Children's Hospitals, patient experience, patient- and family-engagement, interdisciplinary teams, high reliability, zero harm

### Note

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### Welcome

Welcome to Volume 5, Issue 2, a special issue on patient & family experience in children's hospitals and pediatric care. In many ways, pediatrics has been a leader in the experience journey by the very nature of the work. In pediatrics and children's hospitals significant efforts are made to ensure the environment is welcoming and comfortable, there is a commitment to communicating in a way patients – the children cared for – can understand, and there is a clear intention of engaging family members as an integral part of the care experience. While the setting may dictate these are the right things to do, efforts in this space have reinforced the value of truly executing in this way. And what we find in this simple summary of practice is in many ways a framing of the core elements that all patients expect and desire of experience regardless of the setting they find themselves.

Special issues have taken on an important role at *Patient Experience Journal* (PXJ). Through this addition to our publication we have been able to elevate both broader ideas impacting patient experience efforts such as last year's special issue on patient involvement and this year's focus on children's hospitals and pediatric care. We will continue the cycle in 2019 with a focus on the role of technology and innovation in patient experience.<sup>1</sup>

Also, special issues take a commitment and focus to ensure their successful realization. For this issue we were fortunate to have Stefan Agamanolis, PhD, Senior Director, Patient Experience at Akron Children's Hospital, serve in this capacity as Guest Editor. First, of all a special thank you to Stefan for his focus, commitment and support in producing this issue. As Stefan shared in considering this opportunity, he was inspired by the needs he continues to see in healthcare related to patient experience. These very same needs are what motivated the creation of PXJ now over 4 year ago. Stefan shared:

*There remains a need for better research to understand connections between various practices/interventions and effects in the "experience" domain, and effects on safety, outcomes, business, and other domains in turn. While the evidence for various practices is clearly building, even today the domain of patient experience is still a large collection of anecdotes and pearls of wisdom, which can undoubtedly be very helpful in building up an organizational effort, but still feels unsatisfying to the data-oriented and science-minded agents you often find in healthcare.*

That very idea of adding rigor to intention is what is central to the work of PXJ and the broader and expanding research endeavors you see taking place addressing the human experience in healthcare. This special issue drives

at that very idea by providing a combination of personal narratives, research and cases that help frame both what works and what still needs to be discovered in patient experience. This happens in many ways not just related to the pediatrics setting addressed here. It also reinforces the opportunity across the healthcare continuum.

This idea is elevated in the commentary by Biblow and Toomey in which they offer:

*“There is incredible work underway in pediatrics and now is the time to push further, faster. In many ways it is about going back to the fundamentals of what drew us to this work in the first place... We have a unique opportunity to not only transform the experience of care in pediatrics, but to help be a model of excellence for our counterparts across the full continuum of care.”<sup>2, p.5</sup>*

This idea of giving, not only to elevate one’s own contribution, but also for the sharing of ideas and to push the boundaries of knowledge, is essential to the patient experience endeavor. In acknowledging that this is an issue on pediatrics, we would miss a great opportunity if we were not to look for and find the lessons that can be applied across healthcare settings. It is this capacity to transcend boundaries in which experience improvement will be realized. In hearing from all voices each of us can open ourselves to new possibilities.

Patient experience endeavors overall can and must learn from the efforts in pediatrics and children’s hospitals. They must be open to reaching even farther to find answers in places that historically in healthcare we may not have been willing to explore due to protocol, cultural constraints, systems dynamics or even a lack of awareness of where learning could come from. The intention of expanding this awareness shapes the underlying value of the pages that follow.

## Lessons for Patient Experience

Earlier this year, I authored the paper, *What Patient Experience Can Learn from Child Life Professionals*,<sup>3</sup> in collaboration with the Association of Child Life Professionals, in which the idea that we must look for answers in places we may not have traditionally looked was reinforced. In fact, there is much we can learn from places we might otherwise overlook in healthcare. To miss these opportunities only impedes our greater collective progress.

An essential function in many children’s care settings, child life remains a quiet partner whose principles are central to all patient experience attempts to achieve. First, in acknowledging patient experience as “the sum of all interactions”<sup>4</sup> one has and that those interactions frame an experience that drives the outcomes healthcare organizations aspire to including clinical excellence, financial outcomes, consumer loyalty and community

reputation,<sup>5</sup> what was learned in that exploration of the role of child life was that its core principles and the impact that they had both clinically and personally were not just stated ideas, but as Sylvia Hernandez, a family member engaged with Children’s Mercy Hospital (an organizational also featured in this special issue addressing Family Experience Tracers<sup>6</sup>) said:

*“Child life specialists have in a way stepped in to be trauma navigators for us, they are teachers, and empower us. They help us cope, to be aware, and not afraid to deal with what is in front of us. Some of us are probably more resilient than others, but [with child life] the exam room or the patient room becomes the classroom and they are the teachers for us to navigate health care in a way that we can digest it given the amount of trauma we’re under or experiencing.”<sup>3, p.11</sup>*

This example elevates a conversation central to child life that was found to be clearly translatable to all healthcare settings; namely that patients and families are asking for healthcare providers to address and child life professionals are working to deliver on three core ideas: (1) meet me where I am, (2) help me understand, and (3) provide me comfort and support. These ideas were elevated again in the findings of the study Consumer Perspectives on Patient Experience 2018.<sup>7</sup> In asking general consumers what was most important to them in patient experience they replied “listen to me”, “communicate to me in a way I can understand” and “treat me courtesy and respect”.

The “so what” here is that the very ideas that frame the work of child life were the ideas that people told us were most important to them. There were practices in place at the edges of healthcare already that were touching the very heart of healthcare people were searching for. It is in this connecting of opportunity and possibility that this issue itself creates an opportunity for impact. We must be willing to look in places we may otherwise not consider in understanding and addressing patient experience.

From Stefan’s call for rigor, to Biblow and Toomey’s challenge to influence peers across the continuum, I challenge you to read for the ideas that will impact you as researcher, faculty or practitioner. What will influence how you teach, what you explore or the practices you implement. That is the powerful dimensionality I hope this issue pushes you to consider, and more so an ideal that PXJ represents overall in its contribution to elevating a commitment to the human experience in healthcare.

This issue brings us a wonderful tapestry of personal narrative, research efforts and outcomes focused cases from individuals and healthcare organizations around the world. For just a taste, Nancy Michaels challenges us through the story of her son to consider what medicine can learn from pediatrics, suggesting the ability to elevate expectations could change the very way we communicate

and enact care.<sup>8</sup> Didier et al. take us to the heart of evolving interdisciplinary clinical practice to understand perceptions of its value, levels of engagement and ultimate impact.<sup>9</sup>

In a rapidly changing healthcare culture these evolving ways of operating will have foundational influence over the experience of people across care settings. Kirby et al. raise a conversation that has exploded on the healthcare landscape on high reliability by pushing an interesting question and providing a powerful lesson from practice. While there has been limited research on engaging patients and families in the development of safety and reliability efforts to achieve zero harm, the team at Boston Children's aimed to create a process to ensure this could happen.<sup>9</sup>

These three examples from the fourteen articles in this issue quickly show how these ideas from engaging patient voice, to interdisciplinary practice, to high reliability are vital to the pediatrics space, but have far lasting reach beyond the boundaries of this setting. That is why seeing this opportunity as an opportunity for broader lessons for patient experience becomes an essential lens as you enter this issue.

### Where Can't We Go from Here!

Coming back to Stefan's challenges to expand rigor and the opportunity elevated to expand from who we learn and where we apply these ideas is where I hope you step off into the pages that follow. The essence of PXJ is not only to serve as an academic repository for research, but also as a catalyst for thinking and doing. In exploring this issue, we can take our next steps with a grounding in the foundations of what is essential to experience and with an eye towards what we can learn in expanding its boundaries. That is the opportunity a focus on experience in healthcare affords. If we remain true to that idea, we need not ask the question, "where do we go from here?" Rather we can declare with vision, clarity and intent, "where can't we go from here!" That is the possibility we must continue to create on this experience journey we travel together. Enjoy the issue.



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