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Whose party is it anyway? An invitation from a patient experience advocate

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Abstract

In this commentary, the associate editor of Patient Experience Journal (PXJ) discusses the need to center the human experience in health care by celebrating its essential human, the patient. We have a duty to honor and uphold the dignity of the importance of patient priorities, needs, and preferences, and those of their families. We honor, empower, and celebrate the patient experience at the Patient Experience Journal. We do this not only for the sake of patients, but for our sakes as well, so that we might all delight in patient-centered healthcare systems across the globe.

Keywords

Patient experience, patient engagement, community

Birthdays are great, aren't they? Universally understood as a celebration of life. One of my favorite things about birthdays is that even though there is this general understanding of what a birthday celebration is, everyone has their own rich cultural and family traditions. Sure, some things are consistent, typically featuring obligatory singing and in most cases a cake or pastry with some form of flame, maybe some balloons. Growing up, my family had a tradition of a cake-race. The birthday person selects a friend or relative, two knives are lined up in the middle of the cake, everyone is gathered around the cake to sing, and then there is a big countdown, "3-2-1, GO!" and the racers drop their knives in opposing slices (typically the birthday person ends up winning).

Growing up in Miami, I was able to experience a variety of different cultural birthday celebrations and traditions from all over the world (a lot of "Sapo verdes" and "Buena Suertes"). As an adult, I moved north to live all over The Deep South from central Florida, both Carolinas, and now reside in Alabama. The irony of moving north to live in The South is not lost on me. I believe it was in Alabama that I first learned of the tradition that you should never cut the name on the cake. [I am still curious how many times that I violated this during those cake-cutting races.] When I asked about this tradition and its meaning, the response was:

We do not cut the name on the cake because we want to make sure that we all remember who it is that we are celebrating.

I will admit, the notion that anyone might be unaware of whose cake they are eating evokes a hilarious image as I imagine them mid-bite asking, "Whose party is it anyway?", and someone points to the cake as they roll

their eyes. There is, however, an important lesson in this tradition for us in the patient experience community.

For over two decades, we have been "celebrating" the patient experience (PX) movement.¹ And, much has been learned about the value of centering healthcare interactions and quality measurement on the experiences of patients and their families.¹ In trying to understand how the healthcare system influences patients, there is an apparent drift towards the consideration of how other individual's experiences influence patients' experiences. First, consideration of clinical professionals, then other health professions, and soon thereafter discussions of the entire healthcare workforce and staff in a seemingly endless ripple of influence on patient and family experiences. This seems to be fitting as The Beryl Institute paraphrases the patient experience as "The sum of all interactions...".²

But, being invited to the party does not put your name on the cake. The word "patient" has an important and significant meaning when discussing healthcare. Healthcare is a human social system. So, of course, when discussing the experience of any of the various humans in the system, there are going to be influences from the other humans in the system. But in the center of healthcare systems there is one human around which the system is to be built, the patient.

What is a physician without a patient?

What is a nurse without a patient?

What is any healthcare employee without a patient?

I believe all humans matter and that we all have dignity that must be acknowledged, respected, and protected. I also accept that the influence of every human on creating positive patient experiences is important to consider. But I am not a "human experience" advocate. I think we should

all be cautious about the distractions we introduce by talking about any of the “human experiences” in the healthcare system that are not patient experiences.

To state it plainly, if the physicians are well, and the nurses are well, and the employees are well, and the administrators are well, and the leaders are well, but the patient is not well, then no one is well.

Before we aspired to create patient-centered healthcare systems in the U.S., for example, we recognized the failures in our healthcare systems. The proposed solution ushered in by the PX movement was to create better systems based on the oft disregarded perspective of patients.¹ This is the entire proposition of the PX movement.¹ Human experience advocates might have you believe that this is somehow incomplete, that patients are germane to but only part of the story, that patients have one single, and necessarily limited, perspective on what creates a high-quality healthcare experience.

At a fundamental level, and at the core of my being, I think they have it wrong.

There is only room for one name on the cake.

I have a question that I always keep close to me. This question keeps me grounded and focused on my purpose, and I offer it here with full vulnerability, as I have not always lived up to this purpose. However, I'm more afraid of us all coming up short on meeting the moment for patient experience than I am to share my own failings.

The clarifying question is: *Does this improve patient lives?*

This question, of course, has significant motivational implications and practical suggestions for what I should be doing with my time. It compels me to confront the realization that if what I am doing does not have the potential to improve patient lives, then does it even matter? To quote another patient experience champion, Dr. Donald Berwick,

“I freely admit to extremism in my opinion of what patient-centered care ought to mean. I find the extremism in a specific location: my own heart.”³

I too find my zeal for patients in my heart, because I not only share in Dr. Berwick's dream of a better health system for patients but also in his fears as he states, *“I fear to become a patient. ... What chills my bones is indignity. The loss of influence on what happens to me.”³* His words penned over a decade ago still ring true today. Why should we not fear to become a patient? What evidence do we have that our dignity will be honored when we are most vulnerable?

But I have yet another fear. One that early pioneers of patient-centered care and prioritizing the patient experience might never have had. In contrast to our forefathers, who confronted apathy towards the patient experience, seemingly shouting into the void. My fear is marked by abundance, an embarrassment of riches. Today there is little question that experience matters, or that experience is a key indicator of value and service excellence. However, now we find ourselves at a point in history wherein everyone desires for their experiences to be considered as paramount. My fear is that the more we consider all experiences, the less we will be able to focus on the patients.

To be clear, I am not saying that other experiences do not matter; quite the contrary. I am saying they matter because, and only because, they might influence patients' experiences. Too often, I will view a presentation on employee engagement, as an example, marking it as key human experience outcome that benefits patients (somewhere down the line, one might assume) that then transitions to discussions of employee burnout, turnover, recruitment, and retention. Will addressing turnover positively impact patient lives? Perhaps, but have we confused the icing for the cake.

Everyone in healthcare is in it to care for and serve patients. Another patient advocate stated, *“We must be excellent in the discussion of how the results of our efforts can, and should, change the conversation around the practice of patient care.”²* That call to excellence ushered by me some years ago serves today as a reminder that we must keep our eyes fixed on the “humans” that drive our system. We focus on the essential experiential offering in our healthcare systems, the experience upon which all other experiences depend, the patient experience.

We do not cut the name on the cake.

It is important that we remain clear about why the sum of interactions are important.⁴ What is the meaning of these various interactions and influences, if not for the sake of patients? The patient experience is both foundational and paramount. As a global community of PX practitioners, scholars, and policy makers, we seek in this special issue to examine the “frontiers of the human experience.” We have a duty to honor and uphold the dignity of the importance of patient priorities, needs, and preferences, and those of their families. We honor, empower, and celebrate the patient experience at the Patient Experience Journal. We do this not only for the sake of patients, but for our sakes as well, so that we might all delight in patient-centered healthcare systems across the globe.²

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