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A call to action for human experience

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Abstract

As we open the 8th volume of Patient Experience Journal (PXJ), we all stand in a world much different than we did just a year ago. A year ago we were in the height of crisis, facing unknowns and uncertainty. We didn't know if we were tackling an issue that was weeks, months or years in front of us. We were truly not even sure what tomorrow might bring. As I shared in opening Volume 7, we were already experiencing something special in the midst of real tragedy. We were seeing light peeking through heavy clouds. I opened that issue sharing, "At the heart of healthcare, we are human beings caring for human beings, [and] at the heart of the actions and efforts of so many at this time of crisis, we find the true essence of the humanness of healthcare. Yes, the clinical excellence at healthcare's roots will ensure we save lives, but the efforts we are seeing to elevate the human experience now will ensure we honor those lives through and beyond this crisis as well." While this crisis challenged us in ways we have never seen, it equally highlighted the realities we knew already existed but had yet to fully address. The opportunity this reveals provides a significant moment of choice: do we perpetuate our efforts of the past or do we bend the arc for a new future? We are at a unique moment for our community, for our world...one we must not miss. Please join us in transforming the human experience by sharing your ideas via PXJ, taking action in your organizations, working to impact the communities in which you live and work, by signing and acting on the Declaration for Human Experience. That is the least we can do for one another in an industry, and I dare say a world, where we must forever be human beings caring for human beings. We are the human experience, and now is the time to act.

Keywords

Human experience, patient experience, workforce experience, community experience, health disparities, patient engagement, co-production, Declaration for Human Experience, The New Existence

Where we stand

As we open the 8th volume of *Patient Experience Journal* (PXJ), we all stand in a world much different than we did just a year ago. A year ago we were in the height of crisis, facing unknowns and uncertainty. We didn't know if we were tackling an issue that was weeks, months or years in front of us. We were truly not even sure what tomorrow might bring.

As I shared in opening Volume 7, we were already experiencing something special in the midst of real tragedy. We were seeing light peeking through heavy clouds. I wrote, "At the heart of healthcare, we are human beings caring for human beings, [and] at the heart of the actions and efforts of so many at this time of crisis, we find the true essence of the humanness of healthcare. Yes, the clinical excellence at healthcare's roots will ensure we save lives, but the efforts we are seeing to elevate the human experience now will ensure we honor those lives through and beyond this crisis as well."¹

I would suggest that it was our capacity to elevate our humanness that has had the greatest impact over this year. It is that need to elevate the human experience we realized

as so essential, and it is what calls us to action now. For in revealing the raw nature of our humanity, we were also exposed to some of our greatest opportunities as a society. The implications of inequity and disparities, long known, were pushed to the surface. The burdens on a healthcare workforce, long understood, were pushed to the brink. The need for connection and partnership in the face of separation was made clear.

While this crisis challenged us in ways we have never seen, it equally highlighted the realities we knew already existed but had yet to fully address. The opportunity this reveals provides a significant moment of choice: Do we perpetuate our efforts of the past or do we bend the arc for a new future? As Martin Luther King, Jr. shared now just over 53 years ago in a speech at the National Cathedral entitled *Remaining Awake Through a Great Revolution*, "We shall overcome because the arc of the moral universe is long, but it bends toward justice." That effort – to bend towards justice – is all this moment through which we are now living has called on us to do. And fundamental to realizing true justice is our willingness, I dare say our requirement, to address the human experience at the heart of all we do.

Where we must go

With this as a lens for today and a realization that our actions now must speak louder than our previous intent, The Beryl Institute community through the voices of members around the world has worked to shape the thoughts of what a New Existence for healthcare (as the largest human service sector in our world) can be and ultimately what we can and must be together as global citizens. The outcome, a *Declaration for Human Experience*, is grounded in the very realities I shared above. In the last year, the foundation of healthcare has shifted forever, exposing the systemic weaknesses and wounds that no longer go untreated. The devastating impact of systemic disparities, inequities and injustices faced by people of color and marginalized populations were made painfully apparent, and while our healthcare workforce never hesitated in responding in this moment of crisis, we know this service and sacrifice has come at a heavy price.

This moment reveals the need for a fundamental shift in our thinking, but more so in our actions. And as I have long said, there is no normal to which to return, and there is no “new normal” to which we will arrive. Normal suggests a new “typical state or condition.” But the moment in which we find ourselves now and the moments to follow will not be steady. They will rapidly evolve and dynamically shift.² There is nothing normal about the extraordinary and dynamic moment in which we find ourselves nor should there be in what we create together for our future. That is a call for a new existence. Existence is a way of living and being, driven by survival and a commitment to not only do, but sustain, what is right and true. And that commitment must be one where in healthcare we are willing to act on the patient experience, the workforce experience and the community experience – that is in total the human experience that binds us. As the declaration directly states³:

By elevating and transforming the human experience in healthcare, we can create a more effective, responsive and equitable healthcare system that results in better experiences and outcomes for patients of all backgrounds, a more supportive, energizing and collaborative environment for healthcare professionals and healthier communities that break down barriers to care.

We are called to lead courageously with the understanding that we are, first and foremost, human beings caring for human beings. In answering this call, we commit to:

- Acknowledge and dismantle systemic racism and prejudice, tackle disparities and provide the highest-quality, most equitable care possible.
- Understand and act on the needs and vulnerabilities of the healthcare workforce to

honor their commitment and reaffirm and reenergize their purpose.

- Recognize and maintain a focus on what matters most to patients, their family members and care partners to ensure unparalleled care and a commitment to health and well-being.
- Collaborate through shared learning within and between organizations, systems and the broader healthcare continuum to forge a bold new path to a more human-centered, equitable and effective healthcare system.

This call to action, this declaration, is not presented as words to read, but a commitment to take on. I ask, I invite, I encourage you to not only sign your name to this historic declaration, but also to join in this shared commitment by seeking ways we can address the very issues essential to achieving our new existence as we move through this crisis. You can take the first step by visiting transformHX.org.

This idea of acting to move forward is a powerful one. It is seen in small acts or large strategic commitments. It is seen at the bedside in a healthcare facility, via a telehealth visit across miles, in the embrace of a healthcare worker, in a vocal stand against racist actions. We cannot and we must not any longer mince words, and we must do good work. This good work too is seen in the thoughtful and comprehensive insights shared by our authors in this issue released at this most interesting time.

What we learned

The realities of all we have seen, of all we are called to do, are also woven into this very issue of *Patient Experience Journal*. As we open Volume 8 almost seven years to the day of our first issue in April 2014, we close in on 800,000 article downloads in over 200 countries and territories. This reflects the true global nature of this work and the rich and rigorous understanding of the value and impact a conversation on the human experience in healthcare truly reflects.

This issue and its 20 articles tells a story of our moment and reveals the continued commitment to push forward. We include an article I was honored to reengage in with my co-authors as we revisited the piece *Defining Patient Experience*⁴ from 2014. In *Reexamining “Defining Patient Experience”*: *The human experience in healthcare*, we find a clear evolution of the experience movement over the last seven years that has not only strengthened the core of patient experience but has truly underlined and reinforced the call for an integrated human experience in healthcare including the workforce and community experience noted above.⁵

In recognizing the foundational idea that we must approach experience from an integrated view, we also had

the chance to dig into one of the most pressing issues challenging our human experience during this pandemic around the issue of visitation in healthcare organizations. We share a powerful narrative from the family perspective of the real implications of the decisions we made and how it has touched so many personally.⁶ In the article, *The impact of COVID-19 visitation restrictions on patient experience and safety outcomes: A critical role for subjective advocates*,⁷ we see the real tangible impacts of visitation restrictions where data reveal that when visitation was fully restricted during the COVID crisis, safety outcomes got measurably worse. This effort to tackle the visitation challenge during the pandemic is also seen in a thoughtful research case exploring ways in which organizations looked to mitigate the impact of separation caused by changes in policy.⁸

This issue continues to dig into both an exploration of patient engagement as an approach in impacting experience⁹ and then the critical need to focus on how we listen to both patients and family members.^{10,11} It also explores how we engage people as partners in co-design and production of care.^{12,13} The issue too engages in the broader reach of the experience conversation touching on critical and often overlooked issues of mental health¹⁴ and understanding the role of caregivers supporting patients with dementia.¹⁵ We too explore the tactical implications of experience in looking at the impact of the role of the Chief Experience Officer¹⁶ and examining a model of accreditation for experience efforts from around the world.¹⁷

As we look to the future, I must also underline the critical importance of our pending special issue this July/August on the impact of inequity and health disparities on the human experience, an issue central to the declaration for human experience itself. We also hope to see more work on how we are engaging and supporting the healthcare workforce in impacting experience overall, so please consider your work and case efforts here for submission in the future.

Where we go from here

This issue comes at a time when we can be both fully reflective and cautiously hopeful. While the pandemic is not behind us, the tenor of our humanity has shifted from one of fear to one of possibilities ahead. As spring arrives with hope in the Northern Hemisphere, many of our colleagues entering winter are still facing dire challenges that has us realize we still have days of diligence ahead. Our continued vigilance in containing the virus only reflects the significant actions it will take as we move towards a true human experience in healthcare.

If we are to truly ensure The New Existence for healthcare, we must be willing to engage in all that a commitment to transforming the human experience calls

on us to do. And while we cannot and must not try to do it all at once in the face of doing nothing in the end, we need a path forward that ensures we commit to take action and then support one another in doing so. Journals in their own right, especially issues such as this, are snapshots in time, but they also can be catalysts, jumping off points, and evidence for what we can and must do. I hope in this issue you find that inspiration and in it you too find your call to act.

We are at a unique moment for our community, for our world...one we must not miss. Please join us in transforming the human experience by sharing your ideas via PXJ, taking action in your organizations, working to impact the communities in which you live and work and by signing and acting on the Declaration for Human Experience. That is the least we can do for one another in an industry, and I dare say a world, where we must forever be human beings caring for human beings. We are the human experience, and now is the time to act.

References

1. Wolf JA. The essential nature of experience in a time of crisis and beyond. *Patient Experience Journal*. 2020;7(1):1-4.
2. Wolf JA. There will not be a “new normal” but rather a New Existence for healthcare and human experience. PX Blog. May 2020. <https://www.theberylinstitute.org/blogpost/593434/347748/There-will-not-be-a-new-normal-but-rather-a-New-Existence-for-healthcare-and-human-experience>.
3. TransformHX. <https://www.transformhx.org>. Accessed April 26, 2021.
4. Wolf J, Niederhauser V, Marshburn D, Lavela S. Defining Patient Experience. *Patient Experience Journal*. 2014;1(1):7-19.
5. Wolf J, Niederhauser V, Marshburn D, Lavela S. Reexamining “Defining Patient Experience”: The human experience in healthcare. *Patient Experience Journal*. 2021;8(1):16-29.
6. Schlingen, Frye A. No visitors allowed: How health systems can better engage patients’ families during a pandemic. *Patient Experience Journal*. 2021;8(1):13-15.
7. Silvera G, Wolf J, Stanowski A, Studer Q. The influence of COVID-19 visitation restrictions on patient experience and safety outcomes: A critical role for subjective advocates. *Patient Experience Journal*. 2021;8(1):30-39.
8. Burshtein D, Powers D. An evaluation of the effectiveness of a unique patient experience response program that provided virtual, visual and emotional connectivity to patients and families during the COVID-19 crisis. *Patient Experience Journal*. 2021;8(1):40-44.

9. Bouabida K, Pomey M, Cyr G, Aho-Glele U, Chaves B. The paradoxical injunctions of partnership in care: Patient engagement and partnership between issues and challenges. *Patient Experience Journal*. 2021;8(1):5-12.
10. Aho-Glele U, Pomey M, de Sousa M, Bouabida K. An evidence-based tool (PE for PS) for healthcare managers to assess patient engagement for patient safety in healthcare organizations. *Patient Experience Journal*. 2021;8(1):45-58.
11. Duhn L, Gumapac N, Medves J. Safety participation at the direct care level: Results of a patient questionnaire. *Patient Experience Journal*. 2021;8(1):59-68.
12. Francis-Coad J, Edgar D, Bulsara C, et al. Partnering with patients to design a prehabilitation program for optimizing the patient experience through general surgery. *Patient Experience Journal*. 2021;8(1):135-147.
13. Fortuna K, Myers A, Brooks J, et al. Co-production of the quality of patient-centered outcomes research partnerships instrument for people with mental health conditions. *Patient Experience Journal*. 2021;8(1):148-156.
14. Safour W, Hovey R. Exploring mental health experience in individuals living with temporomandibular disorders. *Patient Experience Journal*. 2021;8(1):157-165.
15. Greto E. The value of community psychiatric services for the elderly's dementia caregiver group: Exploring the perspectives of participants. *Patient Experience Journal*. 2021;8(1):166-173.
16. Breen W, Choi S, Hearld K, O'Connor S, Rafalski E, Borkowski N. The association between an established Chief Experience Officer role and hospital patient experience scores. *Patient Experience Journal*. 2021;8(1):69-76.
17. Bezos C, Salazar R, Nahum M. Testing of Patients First in a real-world setting, as a patient experience accreditation tool for hospitals and clinics. *Patient Experience Journal*. 2021;8(1):184-191.