



2020

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Recommended Citation

Wolf, Jason A. (2020) "The essential nature of experience in a time of crisis and beyond," *Patient Experience Journal*: Vol. 7 : Iss. 1 , Article 1.

DOI: [10.35680/2372-0247.1451](https://doi.org/10.35680/2372-0247.1451)

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The essential nature of experience in a time of crisis and beyond

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Abstract

As we have engaged with community members around the world, the last few weeks have provided a unique window into the face of this crisis as we have seen not only the deadliest days on record, but have also had some of the most hopeful conversations at the same time. While we are and still will face challenges in the weeks to come, we too have seen humanity elevated in profound and powerful ways. While it can be offered with little argument that things will never be the same, in moving forward, we too can assert and I believe, that the ideas that have been fundamental to healthcare experience will remain essential for all served by and serving in healthcare. The themes that emerge in this issue, while not planned for this crisis, quite appropriately reinforce what we have seen elevated by this moment in history in which we find ourselves; that all voices matter, that collaboration and partnership matter, that listening and acting matter, that learning and agility matter, and that perseverance matters. To say we are in a time of challenge would not do this moment justice. We are facing tragedy and suffering. We are seeing inequity and systemic weaknesses revealed. We are seeing support elevated and commitment fortified. And we are experiencing a global community drawn together around a shared experience in ways few alive have ever experienced nor deemed possible. That reality, our shared reality, is where we find the essential nature of experience. In the ability to ensure the best in connectedness in a disconnected world; to see deeper into patients' eyes and into our neighbors' souls. These are all fundamental building blocks to a shared human experience. One we can all attest is imperfect, but one we too should all agree deserves our greatest attention.

Keywords

Human experience, patient experience, innovation, agility, community, person-centeredness, perseverance, new existence

A New Volume for a New Era

I first, as always, want to express my wishes that you, your colleagues, your loved ones and friends are safe and healthy at this time. I too welcome you to our 7th Volume of Patient Experience Journal (PXJ) as we publish on the final day of 6 years of contributing to the evidence on patient experience. As we hit this milestone, we too will cross the threshold of over 600,000 article downloads around the world. This data point reinforces the very real value of a conversation on experience in healthcare, the evidence that supports it, the practices that drive it and the global perspective that weaves it together. This may be no more important than at this time in our history.

As we have engaged with community members around the world, the last few weeks have provided a unique window into the face of this crisis as we have seen not only the deadliest days on record, but have also had some of the most hopeful conversations at the same time. As I shared in my April 2020 Patient Experience blog¹:

“At a time when days feel like weeks where people are either charging in to care for others on the front lines, supporting it from afar, showing up to provide essential services in so many needed industries such as food stores

and pharmacies or by doing their part by staying home to flatten the curve, teaching their children or providing care for elders at home, this crisis has called on all to contribute, and it will take all of us to succeed. That premise of all of us together is fundamental to the essence of human experience at the heart of healthcare.”

This forever reinforces a point so essential to all we do that at the heart of healthcare we are human beings caring for human beings. It is also important that we recognize that 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 we are and still will face challenges in the weeks to come, we too have seen humanity elevated in profound and powerful ways.

In my blog I shared how human experience is making itself present¹:

- Even in the face of limited visitation policies, organizations are finding technology and other means to connect people to one another, to enable those in isolation to feel less alone and

provide a face and voice of comfort, even if not in person, at the end of life. We are working more to ensure we connect as people...that is the essence of human experience.

- We are seeing the human spirit personified in the efforts of so many on the front lines of care hidden behind masks and screens putting a picture of themselves with a smile and even a note about who they are as a person on the front of their gown. We are working to break down barriers and structures to the people we are...that is the essence of human experience.
- Caring for healthcare teams has been elevated to new heights from social-emotional needs of having support lines and respite rooms to ensuring basic needs are met in providing internally- developed markets to provide for food and sundry needs for those focused on healing others. The breadth of support for those who serve has never been so evident and tangible, even in the face of some of the challenges those providing care still face...this recognition and effort too is the essence of human experience.
- While most charging into the trenches of this crisis, from doctors and nurses to environmental service and food service workers and so many others, would not call themselves heroes, the recognition of their sacrifice in the face of potential danger is real. This is the same for all providing essential services in grocery stores or pharmacies, transporting goods or delivering food. These individuals are the synapses of a physically distanced society and the bond on which it will be connected once again. We too see an outpouring of appreciation and acknowledgement from the blaring sirens of fire and police departments, to the flashing car lights, street signs and chalk art appearing outside hospitals and care centers, simply to say thank you. These gestures remind us that what binds us is and must remain stronger than what divides us...that is the essence of human experience.

This essence of human experience has come to a powerful balancing point in this crisis. We now must acknowledge all that is foundational and essential to where we go from here, all while we look to what we must enact, sustain or create as a result of this crisis to carry us forward. Let us start with the roots from which we will grow.

Foundational Work

While it can be offered with little argument that things will never be the same, in moving forward, we too can assert and I believe, that the ideas that have been fundamental to healthcare experience will remain essential for all served by and serving in healthcare. As we review the very pieces in

this issue, all of which were submitted and in process well before this crisis took hold, we see the very essence of what must remain our bedrock in the search for evidence and innovation in experience research and practice.

These fundamentals of communication and accessibility, quality and safety, dignity and respect all only serve to solidify where the experience effort moves from here. In my most recent editorial in Volume 6, Issue 3, I offered five points in looking to the future of experience²:

1. Experience efforts will reach more broadly to the issues facing the populations healthcare serves.
2. An expanding global conversation will shift the centers of experience excellence.
3. Measurement will move away from static and lagging points of data.
4. Consumer voice will bend policy direction and ultimately leadership action.
5. A focus on human experience will root itself at healthcare's core

When I look to those points, it seems as if this crisis has called on us to begin to address them all. From global systemic solutions, to rapid innovation and policy change, this crisis has spurred a speed in healthcare many believed was not possible, but we knew was deeply needed. This has been reinforced by the most recent release of PX Pulse³ from Ipsos & The Beryl Institute where consumers of healthcare across the US once again reinforced that experience matters significantly to them and will influence their healthcare decisions. In addition, the survey revealed the continued importance of individuals to be treated as human beings, with dignity and respect. This crisis has only elevated that need for human connection in the face of isolation, physical distancing and safety protocols that have turned the proximity of person-centeredness inside out.

Yet organizations have responded robustly and rightly so. What PX Pulse revealed that even in the early days of this crisis over one-third of all consumers preferred virtual opportunities for basic care needs such as discussing initial symptoms or follow-up discussions after care. What we learned in just the last two-months was not only the agility with which organizations could implement virtual connections, but the positive way in which it was both delivered and received in incredibly trying times. This commitment to and ultimately expansion of foundational work is part of what may never change again. It is also foundational work that we found revealed in this opening issue of Volume 7.

Insights from Volume 7, Issue 1

While, as I noted, the pieces published in this issue were all in process prior to the full arrival of COVID-19, the ideas they convey reinforce the very issues we must continue to address as we move through this crisis. In general the pieces touch on our need to listen and engage the voices of patients and families⁴ and engage them as partners and members of their care teams⁵, the means by which we can and must more effectively gauge and act on patient input⁶ and how we engage in a whole team approach to not just ensure effective care⁷, but to how we train professionals⁸ as well. The themes that emerge in this issue, while not planned for this crisis, quite appropriately reinforce what we have seen elevated by this moment in history in which we find ourselves; that all voices matter, that collaboration and partnership matter, that listening and acting matter, that learning and agility matter, and that perseverance matters.

That last point is brought to life in the opening commentary and narrative by Justin Sandler⁹, a cancer survivor, and his wife/caregiver, Mary Lou. As he shares his story of care and recovery, we are reminded of how we will need to remain vigilant in caring for patients and their caregivers during and through this crisis. Aptly to today, Justin reminds us “with each challenge lies a choice. And we can choose to do whatever it takes to overcome our obstacles...” That may be no more relevant or evident than today.

New Existence

To say we are in a time of challenge would not do this moment justice. We are facing tragedy and suffering. We are seeing inequity and systemic weaknesses revealed. We are experiencing a challenge to science and an opportunity to reinforce facts. We are seeing support elevated and commitment fortified. And we are experiencing a global community drawn together around a shared experience in ways few alive have ever experienced nor deemed possible.

That reality, our shared reality, is where we find the essential nature of experience. In the ability to ensure the best in connectedness in a disconnected world; to see deeper into patients’ eyes and into our neighbors’ souls. These are all fundamental building blocks to a shared human experience. One we can all attest is imperfect, but one we too should all agree deserves our greatest attention.

The future we are stepping into daily is one in which we will be called to constantly reflect and we cannot and should not lose the lessons learned. I shared in my blog, “as we look at this crisis, we will never truly get ‘beyond’ it. It will forever shape our thinking, our psyche, our collective persona and how we as healthcare professionals

and human beings overall will act in our steps moving forward.

This is not a pessimistic tone, but rather one grounded in optimism for all we will have and will continue to learn. I do not believe we will have a post-COVID era, or even a new “normal.” Nothing about this situation is, will be, (nor should it be perceived as) normal...but rather, we will have a new existence where much of what we espoused and worked so hard to put in place before this crisis will remain essential.

There have been growing conversations on capturing lessons learned and sustaining effective practices, rebalancing care models and leaning in on policy changes, reinforcing the silver lining and recharging our workforce and yes, giving ourselves time to honor those we lost. There are practices we have put in place driven by need, opened up by change in policy or easing of regulation, supported by agility and ultimately most if not all have proven to be good for our work, grounded in all we knew we could and should be doing and supporting all we believe we can and must do moving forward.

This is not just an opportunity to catch and share practices, it must be a time to elevate and advocate for policy and changes that will enable us not only to better respond in time of crisis, but also elevate the human experience in all we do for care.

And in the face of all we have seen there is great heroism all around. While some are fighting this on the clinical front lines, others are tackling it on the social, others are contributing to the battle by staying home, caring for elders or teaching children. This is not a crisis overcome by the actions of some, but must and will be a move to new existence driven by the collective efforts of all.”¹

Where We Go From Here

As we look to what lies ahead our commitment to a new existence will be driven by real work. At The Beryl Institute we will be working to engage our global community in identifying will be necessary in our “new” healthcare world. This effort “Planning for New Existence” is focused on generating what we think new existence will look like, what it will call on us to do in practice, process and policy and what it will ask of us as people in moving healthcare forward. The process will be one in which the voices of the community shape the ideas and outcomes. And all are invited to contribute.

You can also contribute by sharing your own stories in our refocused PXJ special issue for July/August 2020 in which we are asking for your stories and cases of how you have elevated human experience in the face of this crisis.¹⁰ We

will also be called to think about some of the realities we will face in moving forward, namely:

- Addressing the fears & needs of patients, families and consumers of care
- Ensuring permanency in proven practices developed
- Navigating financial challenges
- Tackling systemic issues only heightened by this crisis
- And all the while refreshing ourselves in preparation for any resurgence

It is not often that you are called to write a piece like this in the midst of such an historic moment in time. Too, it is a uniquely powerful time in which we can and will act. As we launch our 7th volume, this is not a reality we could have imagined, yet at the same time it is one – as revealed in all the work of those who have contributed to and read these pages over our first 6 years – we have been prepared for all along. And while we can all say we are never truly ready for a crisis of this proportion or impact, the collective spirit and commitment we have built together will guide us forward in the days, weeks and months to come.

I can think of no greater group of people to build the ideas for new existence with, or to continue our work in elevating the true importance of human experience, not only in healthcare, but in society. I wish you safe and healthy days ahead and I am filled with hope as we stand together in travelling the steps before us.

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