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Moving forward to the future of healthcare

Jason A. Wolf

The Beryl Institute / Patient Experience Journal, jason@pxjournal.org

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Editorial

Moving forward to the future of healthcare

Jason A. Wolf, PhD, CPXP, The Beryl Institute/Patient Experience Journal, jason@pxjournal.org

Abstract

To say this moment in our shared global history feels shaky or uncertain for so many is not a statement of despair. Rather, it is acknowledging a reality through which we can best act and hopefully step through. As of the time this editorial will publish, well over 50 million cases of COVID-19 will have been reported. This is a reality all of humanity is sharing together; it is a challenge that healthcare is being called on to tackle. The work of people around the world to care for the sick, to find the right treatments and vaccines and the efforts of so many of our global citizens trying to do what they can to care for their families, friends and communities by doing the basics – wearing a face covering, maintaining physical distance, limiting the size of gatherings and more – is heroic. More so, I suggest it is human. Over the seven years of publishing PXJ, never could we have dreamt of this moment; but in many ways, we were always preparing for it. For in bringing together the diverse voices of our world, in weaving together ideas, stories and evidence we knew and now espouse, we are ready to support one another. We are truly stronger together. There is a time of work ahead as well as a time for healing, for working tirelessly to close gaps, to lower the temperature of rhetoric, for conversations on common ground and finding a path forward. Through your work in reading, contributing and engaging, we each can and will do our part. There are great possibilities ahead as we seek "a light of meaning," and those possibilities must forever guide us.

Keywords

Human experience, The New Existence, COVID-19, community, patient experience, equity, respect, future

A tenuous time

To say this moment in our shared global history feels shaky or uncertain for so many is not a statement of despair. Rather, it is acknowledging a reality through which we can best act and hopefully step through. As of the time this editorial will publish, well over 50 million cases of COVID-19 will have been reported. This is a reality all of humanity is sharing together; it is a challenge that healthcare is being called on to tackle.

The work of people around the world to care for the sick, to find the right treatments and vaccines, and the efforts of so many of our global citizens trying to do what they can to care for their families, friends and communities by doing the basics – wearing a face covering, maintaining physical distance, limiting the size of gatherings and more – is heroic. More so, I suggest it is human.

At the very heart of humanity is our capacity to care for something more than ourselves. While our animal instincts have always been set on survival, our distinguishing characteristic has been in our desire to survive with others. We are a connected species, even when we are apart. It is what in many ways has made this pandemic so challenging. For in its harsh realities, it has changed what we can and should do, it has pushed us apart physically and required more of us to stay in touch and connected. It has put

strains on us emotionally; it has challenged us socially; it has undermined us economically, and yet we still push on. That is the nature of our time, but that is the strength of our shared humanity. We always walk towards something greater. We aspire for something that reaches beyond ourselves for our families, our children, our neighbors. This moment in time perhaps exemplifies that reality like no other.

This too has been exemplified in the social fissures we have experienced globally, where issues of social justice crash over political tremors. Many around the world have watched as the United States worked through an election cycle where all the symptoms of this moment were present - stress and concern, disconnection and disdain - yet I believe, and not naively, that this tension so many witnessed and lived was grounded at its core on the hopes of all who were part of that churn. I believe that people at the core want to do what is right and good for their family. I believe people want to do what is right and good for their communities. And while I too recognize there are people with ill intent, narrowed views, or an unwillingness to see the value in equity, the beauty in difference, or the potential in all – I believe that people essentially believe in the capacity for good, for progress and for the future.

This will take work, as some resist the steps forward, the passing of an era; yet, alone, the transformation of a world

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is not an easy task. But in all the concern and pain we have collectively experienced around the world in this year alone – from pandemic to social injustice – we must acknowledge not only that we can do something to move forward or even that we must. We must also acknowledge that people want to move forward and that many just need a path to follow, new ideas to consider and to know they are not on this journey alone. That is the essence of human experience that is needed at this moment. That is the power of our shared humanity we must harness at this time. That is what we will see more of in the efforts to explore and frame The New Existence for healthcare shared further below. And in all we have pulled together in our collective efforts, from the seeds of hope sprout the possibilities for our future, one we create in the steps we take today.

As we close our seventh volume of Patient Experience Journal (PXJ), we traverse the milestone of over 340 articles published and more than 700,000 articles downloaded in the less than 7 years since we first published. Once every 5 minutes someone has accessed PXJ since April 2014 in over 200 countries and territories around the world. That is one of the streams of evidence I believe underlines our shared search for purpose and our shared contribution to hope. In our efforts to elevate a conversation on experience in healthcare through our narratives and cases, through expanding evidence and the very boundaries of our work, the opportunities we must seize in this moment are boundless. Yes, this is a tenuous time, but we stand ready to move forward.

A focus on the future today

As we release Volume 7, Issue 3 of PXJ, at The Beryl Institute we too are excited to introduce The New Existence,² an action plan for the future of healthcare. The New Existence reflects a framework for action that aligns efforts to ensure the human experience at the heart of healthcare flourishes through the current health crisis and beyond. Born from the realities of the moment, The New Existence reflects a global perspective on actions that can lead us forward.

In the close of *Human Experience 2030: A Vision for the Future of Healthcare*,³ I wrote "The future of human experience is not waiting for us to arrive. It is waiting for us to build it together." That is what was exemplified in the work surrounding The New Existence. It is grounded in the reality that there is no normal to which we can, or should, return. Rather, we are called upon to co-create a new existence for healthcare.

In bringing together over 1000 voices from the global community, The New Existence offers a path that addresses the opportunities of our time, by taking action and addressing the very issues of our time. The process of

inquiry and reflection on what our new existence must be was not intended to erase all we have done and known, but rather to reinforce the strengths of what we know and underline a commitment to step forward with a shared purpose for what we know we can become. In the end, it is a humble response to the tenuous time in which we find ourselves.

The framework for action is grounded in a set of foundational agreements:

- This work is born from our common experience in this moment
- We are all humans in healthcare and must recognize and act together on what impacts us
- We insist on equity in healthcare
- We commit to working better together, through and beyond this moment
- We will come out of this crisis as better human beings, organizations and systems

The agreements align purpose with intent but also move us from philosophy to action. The framework itself is built on four segments of focus and a set of associated actions. The four segments and their framing action statements follow:

- Care Teams. Redefine and advance the integrated nature of and critical role patients and their circle of support play on care teams.
- Governance & Leadership. Reimagine, redefine and reshape the essential role of leadership in driving systematic change.
- Models of Care & Operations. Co-design systems, processes and behaviors to deliver the best human experience.
- Policy & Systemic Issues. Advocate for equitable institutional, governmental and payor policies, incentives and funding to drive positive change.

This focus on the future is offered with purpose to meet the moment and walk through it. Representing the voices of so many, it reveals a bigger opportunity as well. That at times like these, we must come together to find meaning. In introducing The New Existence, I shared a quote from Carl Jung:

As far as we can discern, the sole purpose of human existence is to kindle a light of meaning in the darkness of mere being.⁵

At times like these, we must come together to make meaning. At times like these, we must come together to light a path forward. And this commitment reflected in The New Existence was found in the contributions of so many in our latest special issue on <u>Sustaining a Focus on Human Experience in the Face of COVID-19</u> and in the pages of this issue that follow.

Our issue

Volume 7, Issue 3 has the distinction of publishing at this critical time, one that could be deemed a moment in which scholarship suffers. Yet what we have found is our greatest level of contribution and what will be our largest issue to date with almost 260 pages engaging in patient experience and the human experience in healthcare. The tone of this issue remains grounded in the topics of our time – how we are addressing COVID-19 and the challenges of healthcare disparity.

The issue opens up looking at the issue of patient engagement and experience in relation to the pandemic⁶ and is followed by a thoughtful reflection on the impact COVID has had on us as people. We dig in on the conversation of disparities from the eyes of a healthcare student and what these lessons both reveal and call on us to consider⁸ and explore the impact of care and experience as it relates to the LGBTQ community.9 In addition, a broad global perspective is again reflected in this issue, touching on the breadth of experiences and regions around the world. From new models of pediatric care in Denmark, 10 to patient reported experience and supporting the terminally ill in Australia, 11,12 to online resource use in the United Kingdom, 13 to primary care in Nigeria, 14 to looking at the experience of care in Hong Kong, 15 the contributions of our authors reflect the true global nature of this work. They also reflect, as this collective issue does, the very breadth of experience as a topic, how it can be influenced and what it ultimately impacts.

The broad range of topics comprising this issue reflects the very breadth of The New Existence itself of how our care teams, leadership, models of care and policy and systemic issues all matter in driving the best in experience and outcomes for all today and to the future of healthcare. The realization that the experience conversation has always been an integrative and integrated one is essential. For in all that people bring to this work, we recognize and must acknowledge all that can be done for humans in healthcare. Thank you to all our contributors in this landmark issue.

Stronger together

What is reflected on the pages that follow, as well as in issues past, and what is reflected in the actions of The New Existence are one essential idea – that in standing with and for one another we are stronger together. This is not to suggest we must all think alike, believe the same things or even have the same hopes and dreams. It does mean, though, that we must acknowledge one another for our humanness, speak and act acknowledging the dignity of and respect deserved for all human beings. It is in our inability to do so that we do the greatest harm, we make

the lesser of choices and we erode versus build up our communities.

Our research¹⁶⁻¹⁸ at The Beryl Institute has shown again and again, and year after year that people want to be listened to, communicated to in a way they can understand and treated with dignity and respect. These ideas matter for all people, of all perspectives that honor the humanity of all people at their core. The New Existence is offered as a unifier of ideas. The research shared on the pages of PXJ reveals the stories and evidence that support it. But in the end, the opportunity for where we go from here is not built on the foundations of ideas alone; it is grounded in a commitment to aspiration with action, to purpose with progress.

Over the seven years of publishing PXJ, never could we have dreamt of this moment, but in many ways, we were always preparing for it. For in bringing together the diverse voices of our world, in weaving together ideas, stories, and evidence we knew and now espouse, we are ready to support one another. We are truly stronger together.

There is a time of work ahead as well as a time for healing, for working tirelessly to close gaps, to lower the temperature of rhetoric, for conversations on common ground and finding a path forward. Through your work in reading, contributing and engaging, we each can and will do our part. There are great possibilities ahead as we seek "a light of meaning," and those possibilities must forever guide us.

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