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A commitment to hope

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Abstract

On April 1, we made the decision to reconfigure our scheduled special issue on Behavioral Health to the topic of this issue - *Sustaining a Focus on Human Experience in the Face of COVID-19*. In the midst of crisis, we were uncertain how people would respond to this call or even if they could in the face of the realities they were addressing each day. Yet, the research, cases and stories started to arrive. The contributions in this special issue represent a patchwork of powerful insights and a historic record to document this moment. What we have brought together includes the best of real-time insights and research, powerful stories and personal reflections that are so central to this time, one that has called on all of us to dig deeper, ask ourselves personal and essential questions and remind ourselves what really matters overall. We are deeply moved and inspired by the speed, thoughtfulness and comprehensive nature with which our contributors engaged, many of whom were tackling this crisis but still took time to contribute to a conversation beyond themselves. That may be the most powerful lesson of all: that in struggling with each of our own personal or individual organizational issues, we remained called to come together to share something beyond ourselves. As you review the pages that follow, we challenge you to uncover a new idea or practice; discover an inspiration or opportunity to reflect, release or breathe; find a seed of hope. For in the generous and both heartfelt and thoughtful words of our contributors, we not only capture this moment in our history, we also feed the roots of possibility from which we will all spring in the days ahead.

Keywords

Human experience, COVID-19, community, patient experience, leadership, systemic racism, health inequity, hope

The power of agility

Just over 4 months ago, we held our first community briefing at The Beryl Institute on the current health crisis. At that time, we were seeing staggering numbers impacting people around the globe and a rising wave sweeping the shores of the United States. In that conversation, I shared:

We now find ourselves in a challenging and critical time for healthcare organizations and the people they serve globally, and at this moment, the importance of our work to ensure a commitment to human experience is tantamount. In that too is a commitment that we reinforce the importance of health and safety and the actions it takes to ensure we can fulfill on healthcare's promise of being first and foremost human beings caring for human beings. Times like these require thoughtful consideration, heartfelt commitment and clear action. With the current rapid spread of Coronavirus globally, we are reminded of how essential our healthcare systems are and how fundamental the experience provided remains. From what we have seen and heard in conversations from you and others about the hard realities this crisis is raising, it too has become clear that the humanity at the heart of healthcare has never

been more relevant or needed. This is not just a scientific or medical crisis, but a societal challenge that will call for the best of what we can do in supporting one another.¹

The community response, not just among those engaged in the Institute but across the global healthcare ecosystem, was profound. A deeply rooted connection of what it means to serve in healthcare and what healthcare means to those it serves lights up the dark skies for, in this moment, the humanity of healthcare continues to shine.

In the weeks since that first convening of the community, people have come together and stood together, lessons have been learned, practices and resources shared, stories told of loss and success, joy and grief. It all has represented the rapid nature and the powerful agility by which the people of healthcare and the organizations they comprise responded to the moment in which we continue to find ourselves.

And, yet, we still cascade amidst the pandemic rapids, their churn hastened by inconsistent policy, while global citizens overall, and the people of healthcare specifically, paddle harder to push through. This stress on our humanity and the societal bonds that weave us together were pulled

further apart. For as we were looking to gain solid footing at a time of health crisis, we were faced, in particular in the United States, with the broader societal issues of systemic racism and social inequity revealed in healthcare by the outcomes of the COVID-19 crisis itself. As parallel currents emerged and the rapids churned harder, we were called to think deeper and to act with even greater intention. These are two fights on which we must never relent. It is in this commitment that this special issue and one to follow in July 2021 have both emerged.

Refocusing with purpose

On April 1, we made the decision to reconfigure our scheduled special issue on Behavioral Health to the topic of this issue - *Sustaining a Focus on Human Experience in the Face of COVID-19*. In the midst of crisis, we were uncertain how people would respond to this call, or even if they could, in the face of the realities they were addressing each day. Yet, we continued to hear the stories from people tackling this crisis head on – about rapid research, about the agility to apply new practices and processes, about implementations that were thought to need years happening in weeks, to the powerful personal stories of pure physical and emotional exhaustion, to a reawakening of the purpose that called people to this work. The range of emotions and challenges this moment has placed on so many is palpable from being socially separated to economic hardships, from the pressures of home schooling, to the inability to see or care for loved ones, all of which has placed downward pressures on each one of us and society overall.

In the face of this, the research, cases and stories started to arrive. They represent a patchwork of powerful insights and a historic record to document this moment. In all, 32 pieces fill the pages of this issue, including this editorial and our special issue 2021 call for submissions. What we have brought together on these pages includes the best of real-time insights and action research² in which the practices were designed, implemented, and studied in the moment. The benefit of time was not afforded our authors, but the opportunity to look at what was implemented, what was learned, and the long-term or lasting impact of these efforts remains. We hope that we will have the opportunity to return to these efforts as we move through and beyond this crisis. You will also find powerful stories and personal reflections that are so central to this time, one that has called on all of us to dig deeper, ask ourselves personal and introspective questions to remind ourselves what really matters most.

While I cannot cite every piece in this opening editorial, I can offer that we are deeply moved and inspired by the speed, thoughtfulness and comprehensive nature with which our contributors engaged. Many of the leading organizations tackling this crisis took time to contribute to

a conversation beyond themselves. That may be the most powerful lesson of all: that in struggling with each of our own personal or individual organizational issues, we remained called to come together to share something beyond ourselves.

In early April, I wrote a blog for The Beryl Institute Community entitled *The Essence of Human Experience in the Face of COVID-19* in which I offered:

“I have started almost every email, conversation, webinar or call in the last few weeks with a simple wish that you, your families and colleagues are safe and well. Each morning as I hear my two boys rustle themselves awake, I am reminded of how precious our lives are, how important the people around us remain and how every moment we have is one to appreciate for its essence and to contribute to making better with our every breath. This is no different than in our shared efforts to address COVID-19 as a community, to stand with each other during this crisis and to sustain and ensure that a focus on human experience is not lost in these critical times.”³

That is exactly what I saw our community do overall, and in the case of this special issue, what our almost 100 authors contributed. This too is what our associate editor, Geoffrey Silvera, saw as we pulled this issue together. His reflections follow.

A COVID Reflection

“Everyone has a plan until they get punched in the mouth.”
- Mike Tyson, Heavyweight Boxing Champion

Healthcare systems across the globe have all been punched in the mouth, fiercely and precisely. The question, as we recoil, is what happens next. While it may feel as though we’ve just been sucker punched with surgical precision, we miraculously find ourselves still on our feet, for the moment. Healthcare systems, globally, have found a way to survive. Most patients are surviving. Many, far too many, will not. Healthcare providers, though weary, are dedicated to see this through to the end. While this global pandemic has had deleterious effects on all healthcare systems, it has specifically exposed every vulnerability of the U.S. healthcare system.

As I write this, the U.S. has just surpassed 150,000 COVID-related deaths.⁴ The combination of a population with high rates of chronic disease, inconsistent access to healthcare facilities, workforce shortages and inequality with regard to health outcomes hindered the U.S. system before the fight even began. In addition, the U.S. system’s unique and complex private-public payer mix added additional vulnerability around the sustainability of healthcare facilities across the country. As patients with COVID entered hospitals, patients who would normally sustain hospital operations were forced to stay clear to avoid transmission. Workers were furloughed, some still

on furlough. Many workers were fired. Some workers, deemed too essential to fire, are being overworked and forced to work in unsafe conditions. We find ourselves arriving to the fight near-sighted but without glasses, our strong hands tied behind our backs, and everyone in our corner keeps telling us to keep punching, but they have never seen a foe like COVID.

We will not win this fight outright. We have been tasked with defeating an unconquerable foe, and though we are battered and bruised, we have met the challenge with compassion, ingenuity, diligence and commitment to our highest values, to our highest callings. No, we may not win this fight, but because of what I have seen in this special issue, I am confident that our healthcare systems will survive.

What allows us to continue moving forward is a singleness of purpose, global solidarity and a sustained dedication to the patient experience. Some of what is cataloged in this issue are tactics that will get us through this crisis and will not be implemented again except for similar crises; others will forever change the way we deliver care. Time will reveal which of these strategies are stopgaps and which are revolutions, but they are all a reflection of who we are.

We are fighters.

A Commitment to Hope

That idea that we remain fighters is truly reflected on the pages that follow. As we look at the ideas that fill this issue from sustaining person-centeredness⁵ to telehealth⁶, the voices of nurse leaders⁷ to caring for the workforce⁸, refocusing the work of volunteers to activating the community^{9,10}, and linking the pandemic's realities with the issues of health inequity it has further elevated^{11,12}, we cannot view this crisis as a moment that will simply end. I added in my April blog:

“We are reminded of the vigilance this crisis will take. If we pull up on the reins of our essential efforts too soon, we will find ourselves slowing before the finish. And I believe that as we look at this crisis, we will never truly get beyond it. 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 is, or will be, 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.”³

The question of where we go from here remains a fundamental one. The data show that peoples' engagement in healthcare services are down in the last six months and even 20% of all U.S. citizens are “not comfortable at all” with going to a hospital at this time.¹³ There will be a need to reduce fear, reinforce a commitment to safety and focus

on consistent and thoughtful plans that will ensure consistent action. This brings us back to the need to not relent. The numbers say in the U.S. alone we could hit 230,000 deaths by November. Even now with a policy of universal masking, we would still potentially hit 200,000, and if we see an easing of mandates, we could be at 250,000 or more. This crisis truly calls on all of us to act in order to succeed and move through this moment. The lessons we started gathering here provide a foundation for those first steps.

As we look to what a new existence will call on us to do, we first must recognize this has been, and will remain, a long road to travel. These last 20 weeks alone have felt like a lifetime, but with that time comes insights, learning, knowledge, understanding, resilience and, yes, hope. This hope comes from the belief that all of what we are experiencing here and now is helping us to see that there is no way to go “back” to what was nor is there a “new normal” to which we will eventually arrive. A new existence will call on us to take fundamental actions that we have seen exemplified on the pages of this special issue: that we must take action to ensure integrated and active care teams that engage the voices of all in the experience inclusive of patients and care-partners; that we will reinforce the role of leadership and effective governance ensuring transparency and clear vision; that new models of care will need to emerge to ensure clinical excellence and reestablish consumer confidence and comfort in seeking care; and that the underlining systemic issues and the policies that guide healthcare are challenged and reframed for the benefit of all who engage in healthcare globally.

On that last note, we are excited to share a critical opportunity and a commitment to action in addressing the systemic issue of racism and inequities that have rooted themselves in healthcare. We invite you to consider a submission as research, a case study or a personal narrative of how you have been impacted by or are working to impact racial inequality, health disparities and discrimination on the human experience in healthcare. Our special issue for July 2021: *The Impact of Inequity & Health Disparities on the Human Experience* is now open and accepting submissions through April 1, 2021.¹⁴

This crisis has created a moment of pause for many. We can even say it has created strain, fear and distress. But I would assert that it has not stopped us nor squelched what we remain to believe is possible. As you review the pages that follow, I challenge you to uncover a new idea or practice; discover an inspiration or opportunity to reflect, release or breathe; find a seed of hope. For in the generous and both heartfelt and thoughtful words of our contributors, we not only capture this moment in our history, but we also feed the roots of possibility from which we will all spring in the days ahead.

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