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Moving from talk to action: A commitment to ensuring equity must ground our efforts to transform the human experience

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Abstract

When we first introduced the call for submissions for this special issue last August, we were still churning in the first wave of the COVID pandemic. Just three to four months from the start of an unending rash of unexpected and harsh realities that we were faced with in healthcare and in society at large, we too found that the moment was revealing all the weaknesses and wounds that had existed in the foundations of the healthcare system from well before the pandemic hit. Our own research at The Beryl Institute in 2020 reinforced a quiet reality: that people do experience discrimination in healthcare. In fact, 35% of Black Americans reported experiencing some sort of discrimination often or sometimes,¹ and this unquestionably has an impact on their care. The challenges that healthcare has long faced in ensuring equitable access, care, treatment and outcomes were only further laid bare by the crisis. And there is still much work to do. The road that led to this Special Issue reveal that truth and the articles shared on these pages confirm it. But they too show us seeds of possibility, that when we focus on what is right for all who healthcare aspires to serve, then we can truly achieve the greatest in human experience for all. And that is exactly what every person ultimately deserves.

Keywords

Human experience, equity, health disparities, systemic racism, COVID-19, patient experience, experience measurement, diversity, quality, inclusion

There is work to be done

When we first introduced the call for submissions for this special issue last August, we were still churning in the first wave of the COVID pandemic. Just three to four months from the start of an unending rash of unexpected and harsh realities that we were faced with in healthcare and in society at large, we too found that the moment was revealing all the weaknesses and wounds that had existed in the foundations of the healthcare system from well before the pandemic hit. Our own research at The Beryl Institute in 2020 reinforced a quiet reality: that people do experience discrimination in healthcare. In fact, 35% of Black Americans reported experiencing some sort of discrimination often or sometimes,¹ and this unquestionably has an impact on their care. The challenges that healthcare has long faced in ensuring equitable access, care, treatment and outcomes were only further laid bare by the crisis. The evidence of disparities seen in an unfathomable imbalance in hospitalizations and death for Black, Hispanic and Asian people only amplified all we knew to be true.²

These were not surprising realities. The evidence has long existed of a deeply rooted, systemic racism that has sustained this imbalance. But this time in which we find ourselves has raised new opportunities to take the

unspoken truth and make it tangible, to call it for what it is, and to commit to something more than talk.

A lot has been researched and written about equity and inclusion in the last year. The recent study, *State of Patient Experience 2021*, underlined an emerging organizational commitment to addressing this issue with “health equity and addressing disparities” emerging as a top factor driving organizations’ experience strategies and “addressing health equity and disparities” emerging as a top area of investment for organizations in the next three years.³ The data clearly reflects a statement of commitment. Healthcare organizations are also responding by investing in dedicated leadership to directly address diversity and inclusion. But statements of ideals or the creation of roles only carry weight if they lead to action and change. I would offer the proof still awaits.

The *Declaration for Human Experience*, which I wrote about to open Volume 8, Issue 1,⁴ begins to push us towards what we can do versus what we can simply say in addressing this critical work. As the Declaration states: “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: [with the first commitment being] Acknowledge and dismantle systemic racism and prejudice, tackle disparities and provide the highest-quality, most equitable care possible.⁵ This statement and the

overall declaration suggests it is time for action beyond acknowledgement; it is time for change beyond conversation.

It is that reality that frames both the significance of this issue and the opportunity it presents. For in all the amazing contributions that we received and those that will follow, there remains so much more to be done. For every topic explored in this issue, for every incredible idea shared, for every piece of evidence revealed, we too realized that the work to understand the impact of inequity and healthcare disparities on human experience still has miles to go. We are just moving beyond acknowledgment of the issue to begin to explore what we can truly do about it. As revealed in some of the very conversations here in this issue, such as in my discussion with Dr. Julia Iyasere of the NewYork-Presbyterian Dalio Center for Health Justice,⁶ we are just finally at a place where we can name these issues without trepidation or hesitation. To simply say without equivocation that systemic racism exists versus insinuating it is there in data is a tremendous step forward. It underlines the first few brave steps it will take among many if we are to truly live out our commitment to dismantle racism, disparities and inequity that impede our ability to provide a truly human experience for all. That is what this issue helps us see, for in all it shares, we can now see where we must dig deeper, look further, push harder. That is what our authors here help us do. It is what I hope each of you as researchers or practitioners, patients or care partners carry forward as your own call to action. Yes, there is work to be done.

Moving the Work Forward

Moving the work forward calls on us to begin to align our words and actions. This special issue begins to set the foundation to do just that. With a pair of incredible commentaries about the exponential challenges of being a person of color, combined with being a concerned mother and caretaker and all that comes with it shared beautifully by Nikki Montgomery⁷ and the unspoken acknowledgement of racism embedded in healthcare and the implications that has on the outcomes we realize as shared by Dr. Ron Wyatt,⁸ we are immediately exposed to the raw human nature of this conversation. If we cannot address the very issues these authors raise, how can we say we are truly committed to and ever able to effectively offer excellence in the human experience?

As noted before in my powerful conversation with Dr. Julia Iyasere as part of our *To Care is Human* Podcast series, we touched on the realities of being raised to break the barriers we see and to name the challenges we know exist without fear so that we can truly do something about it.⁶ This bias for action is seen in a number of our pieces, for instance in Brinkman and team's work to explore sociodemographic impact on survey response bias, a

powerful conversation if we are to truly understand and effectively use data.⁹ This idea of measurement and how we can and must be better listeners to diverse patient voices is explored by Monica Green and her team as they look at how to honor underrepresented voices in the most critical of care experiences.¹⁰

Rachel Schmitz and team took us from measurement to access, another critical issue we must continue to address in looking at the impact of barriers to care through the lenses of the LGBTQ+ Latinx community.¹¹ Our issue is anchored by a powerful case from the new Sutter Health Institute for Advancing Health Equity which suggests that if we are to take action on issues of health equity, we must capture data on which we can act.¹² While I did not name every piece here, the common thread they reveal is our need to listen to diverse voices with respect, we must seek to understand fully what they are saying and we must work to capture data that hears, honors and acts on all they ultimately experience. We must uncover the barriers to care and to equitable outcomes, and we must break them down. Our authors collectively reinforce the very reflections we took from this last year and a half. That the time for talk, while the conversations are still important, must give way to an era of action.

Moving to Action

In the end, a publication such as this can only scratch the surface of an issue. It can help reveal the range of perspectives and the angles by which we can and must explore. It can underline unmistakable facts and point out the significant gaps in evidence, knowledge or practice we still need to fill. In all, by bringing these voices together on these pages, we hope the collective power of these words serve as a catalyst for something more. We cannot and must not let the conversation on equity and disparities fade, but we also cannot simply sustain this as just a discussion.

The opportunity revealed through our authors and the parallel realities being shared across The Beryl Institute community is that if we are to drive lasting change, we must acknowledge the issues at hand as something that is critical and worthwhile work. I have not heard anyone suggest it was anything but that. So now, the work must begin. If we are to dismantle racism and disparities, if we seek to ensure equity, we must be relentless in our commitment to show how these issues challenge our capacity to provide the best in human experience AND we must be ready to show that when we tackle these very issues, we are in effect working to elevate the human experience itself.

Those who chose healthcare as a profession most often chose it for a purpose, some even for a calling, but all tackle the work of caring for others with a relentless

pursuit of compassion, dignity and respect. These ideas are what buoy the very idea that, at the heart of healthcare, we are and will forever remain human beings caring for human beings. If we hold to that truth, then we must work with unending vigor to ensure that all human beings are honored for who they are, how they look, what they believe or who they love, and we must work with unwavering focus to ensure we build and sustain systems and processes that honors this and, above all else, removes the barriers that impede these possibilities.

There is still much work to do. The road that led to this special issue revealed that truth and the articles shared on these pages confirm it. They too show us seeds of possibility, that when we focus on what is right for all who healthcare aspires to serve, then we can truly achieve the greatest in human experience for all. And that is exactly what every person ultimately deserves.

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