



2021

## Reexamining “Defining Patient Experience”: The human experience in healthcare

Jason A. Wolf

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

Victoria Niederhauser

*The University of Tennessee Knoxville, College of Nursing, vniederh@utk.edu*

Dianne Marshburn

*East Carolina University College of Nursing, marshburnd@ecu.edu*

Sherri L. LaVela

*Department of Veterans Affairs (VA), Center of Innovation for Complex Chronic Care (CINCCCH), Health Services Research, Edward Hines Jr. VA Hospital; Department of Physical Medicine and Rehabilitation, Feinberg School of Medicine, Northwestern University, sherri.lavela@va.gov*

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Communication Commons](#), [Health and Medical Administration Commons](#), [Other Social and Behavioral Sciences Commons](#), [Public Affairs, Public Policy and Public Administration Commons](#), [Public Health Commons](#), and the [Social Justice Commons](#)

### Recommended Citation

Wolf, Jason A.; Niederhauser, Victoria; Marshburn, Dianne; and LaVela, Sherri L. (2021) "Reexamining “Defining Patient Experience”: The human experience in healthcare," *Patient Experience Journal*: Vol. 8 : Iss. 1 , Article 4.

DOI: [10.35680/2372-0247.1594](https://doi.org/10.35680/2372-0247.1594)

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

---

## Reexamining “Defining Patient Experience”: The human experience in healthcare

### Cover Page Footnote

This article is associated with the Culture & Leadership lens of The Beryl Institute Experience Framework. (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: [http://bit.ly/PX\\_CultureLeadership](http://bit.ly/PX_CultureLeadership)

## Reexamining “*Defining Patient Experience*”: The human experience in healthcare

Jason A. Wolf, PhD, CPXP *The Beryl Institute/Patient Experience Journal*, [jason@pxjournal.org](mailto:jason@pxjournal.org)

Victoria Niederhauser, DrPH, RN, *The University of Tennessee Knoxville, College of Nursing*, [vniederb@utk.edu](mailto:vniederb@utk.edu)

Dianne Marshburn, PhD, RN, NE-BC, *East Carolina University College of Nursing*, [marshburnd@ecu.edu](mailto:marshburnd@ecu.edu)

Sherri L. LaVela, PhD, MPH, MBA, *Department of Veterans Affairs (VA), Center of Innovation for Complex Chronic Care (CINCCCH), Health Services Research, Edward Hines Jr. VA Hospital; Department of Physical Medicine and Rehabilitation, Feinberg School of Medicine, Northwestern University*, [Sherri.Lavela@va.gov](mailto:Sherri.Lavela@va.gov)

### Abstract

In 2014, the authors came together with the explicit purpose of understanding how people were defining patient experience.<sup>1</sup> Our broad review and analysis of the literature led us to a few critical points. One, as our review showed, there was an absence of a commonly used definition around patient experience in healthcare. Two, while consistency in the use of one definition was not revealed, there was great alignment around central components seen as critical to patient experience. Three, we highlighted the recurrence of key concepts from the literature that are also found in the definition offered by The Beryl Institute that include: ‘sum of all interactions,’ ‘the influence of organizational culture,’ ‘patient perceptions,’ and the importance of considering experiences ‘across the continuum of care.’ While this initial inquiry took place seven years ago, we would suggest that these core definitional concepts are no less relevant today and, in fact, may have grown in significance, as those in healthcare have come to better understand the scope and scale of experience. Hence, the purpose of this paper is to assess how the definition has evolved to encompass novel and timely viewpoints that complement the original definition and understand how - and in what ways - the definition has advanced. The definition of patient experience was a significant milestone. It provided simple language for the truly complex nature of what patient experience is and has ultimately served as a foundation for framing the human experience in healthcare. The human experience in healthcare integrates the sum of all interactions, every encounter among patients, families and care partners and the healthcare workforce. It is driven by the culture of healthcare organizations and systems that work tirelessly to support a healthcare ecosystem that operates within the breadth of the care continuum into the communities they serve and the ever-changing environmental landscapes in which they are situated. The human experience in healthcare ultimately is the fruit born from the core of patient experience itself.

### Keywords

Patient experience, defining patient experience, human experience, interactions, culture, perceptions, continuum of care, environmental landscape, workforce experience, community experience, systemic racism, health inequity

### Looking back to look forward

In 2014, the authors came together with the explicit purpose of understanding how people were defining patient experience.<sup>1</sup> Our broad review and analysis of the literature led us to a few critical points. One, as our review showed, there was an absence of a commonly used definition around patient experience in healthcare. Two, while consistency in the use of one definition was not revealed, there was great alignment around central components seen as critical to patient experience. Three, we highlighted the recurrence of key concepts from the literature that are also found in the definition offered by The Beryl Institute that include: ‘sum of all interactions,’ ‘the influence of organizational culture,’ ‘patient perceptions,’ and the importance of considering

experiences ‘across the continuum of care.’ These concepts are essential to creating a consistent view of patient experience in order to provide greater focus on and clarity of action in addressing experience improvement overall.

While this initial inquiry took place seven years ago, we would suggest that these core definitional concepts are no less relevant today and, in fact, may have grown in significance, as those in healthcare have come to better understand the scope and scale of experience. Hence, the purpose of this paper is to assess how the definition has evolved to encompass novel and timely viewpoints that complement the original definition and understand how - and in what ways - the definition has advanced. We open by asserting our belief that the definition framed in 2014

does not need to undergo any significant change; nor does current literature reflect that how patient experience is defined be reconsidered. We do, however, believe that the core constructs we found in 2014 have evolved and must continue to evolve to address the expanding range of elements that are impacting experience outcomes globally. While patient experience will forever be a central and essential part of healthcare, in moving from healthcare to a system of health with additional actors, resources and demands,<sup>2</sup> we are called to address the human experience on which it is built.

This may be no more apparent than in the year just past and the moments in which we continue to find ourselves. As we live through – and healthcare systems and organizations around the world work tirelessly to tackle – a global pandemic and act with the needed awareness this crisis has raised on the clear impact of systemic racism and broader health inequities, the shared experience we have had as humans has never been greater. Almost no one has been left unaffected to some extent nor unaware of the seriousness of the time.

Through all of what we have witnessed, what we have experienced, what has risen up, what has been made clear and apparent is not just the clinical excellence on which healthcare was built, but more so the humanity that burns at its core. The need to care for communities, one another, as well as those working in healthcare and other essential services who have sacrificed so much in service to others has never been greater. The experience we have had (and continue to have) is a human one, and what has been laid bare is that the healthcare experience itself cannot be unidirectional, that is, focused solely on those served by healthcare, but it must also consider the needs and experiences of those who serve in healthcare and the experiences of the communities and environments in which healthcare organizations operate as well. Thus, the healthcare experience is a multifaceted, holistic human experience.

This idea was, in part, built into the original concepts of the definition of patient experience. By alluding to organizational culture, the implicit belief was that healthcare organizations needed to do what was right to ensure value-driven healthcare cultures where healthcare professionals were cared for and served as well. The COVID-19 pandemic has only emphasized that idea, that in caring for those who serve, the potential to provide better care for all those who healthcare serves rises. This realization brings us back to the core elements of patient experience found in our 2014 exploration and leads us to believe that reinforcing these ideas, while acknowledging the realities of how experience has evolved, will strengthen the definition by explicating what the human experience in healthcare is, can and should be.

## Reexamining the core elements

In exploring how the definition of experience has broadened, it is important to revisit the foundations on which it was built. The extensive review and synthesis of literature spanning the 14-year period from 2000 to 2014 published in the inaugural issue of *Patient Experience Journal* revealed a set of 18 articles that provided “a unique definition or set of concepts used to define patient experience.”<sup>1</sup> Those articles were reviewed for recurrent instances of terminology or constructs that could be generalized into the core elements of what comprise a comprehensive definition of patient experience.

This initial work revealed foundational concepts at the core of the evolving conversation of experience up to the publication of *Defining Patient Experience*<sup>1</sup> in 2014 (Figure 1) and has continued to hold true. In review, the core concepts assert, and we reinforce again here, that:

- Experience as an idea **crosses the continuum of care** and is not just limited to a specific care setting or just the clinical encounter of care but to all touch points through which one encounters a healthcare organization.
- Experience is **not simply about quantitative measures or survey results** which may capture insights into specific points or parts of a care journey but must be understood for all the interactions one has with a healthcare organization and the impact those have on an individual, their family and/or care partners.
- Experience remains grounded in the **expectations and perceptions** of those engaging with healthcare organizations. People in healthcare organizations come with a certain set of beliefs or hopes and through their experiences and observations frame realities that make each and every encounter unique.
- Experience is built on the principles of **patient-centered care**,<sup>3</sup> patient and family partnership and engagement, and the essential approaches reflected in these concepts must reach beyond just the clinical setting itself.
- Experience is **individual and personalized**, and the actions taken and processes put in place must support the uniqueness of each person’s encounter in the face of seeking process generalization and efficiencies.
- Experience is much **more than satisfaction**. Satisfaction is an indicator of moments of time, but experience captures all someone encounters, the perceptions they take with them and the stories they tell as a result, the importance and impact of which will be reflected further below.

In reflecting on this initial framing and the conversation on experience, we believe these core concepts continue to hold true. They shaped the identification and reinforcement of the key elements we believe essential to the definition of experience presented in concept in 2014 and seen actualized in practice since. The core elements and supporting concepts represent a simple but broad lens through which one can define experience, noting our intent then and a point to reinforce now is that we did not seek to land on a static definition, but rather create a dynamic and living framework that honored the active nature that experience represents.

The core elements – the sum of all interactions, organization culture, patient (and family) perceptions, and continuum of care, supported by the foundational themes of integration, person-centeredness and patient and family partnership – all remain essential to what experience is today. They remain purposefully simple and clear, broad and inclusive, open and challenging, as these ideas do not represent a basic checklist for how to “do” patient experience (as many seek). Rather, patient experience is reflected in how an organization lives and breathes, in how it engages those it cares for and serves well before any clinical interaction and well after. It is why we believe these concepts remain essential, while recognizing that the concept of experience has evolved. It is why we believe that this evolving perspective leads to a critical conversation on a more expansive consideration for experience overall.

### Expanding the framework

In the years since 2014, we have seen the use of our original definition of patient experience expanded. The seminal article has been downloaded over 40,000 times and, according to Google Scholar ([http://bit.ly/GoogleScholar\\_DefiningPX](http://bit.ly/GoogleScholar_DefiningPX)), cited in over 300 publications. The core concepts and challenges laid out in *Defining Patient Experience*<sup>1</sup> continue to be explored and applied. Its reference has been found in multiple languages and a range of healthcare settings globally. Its application ranges from those looking to define frameworks for better understanding and application of patient experience, to others exploring experience across care settings and in specialized areas of care aiming to advance the conversation on the experience provided.

### Reviewing new literature

In seeking to understand how this concept was continuing to be explored and applied, we reexamined the literature since 2014. Our intent here is not an all-encompassing literature review, but a more focused look into how the definition of patient experience has changed and evolved and an exploration of ideas on what a definition of experience can and should encompass. We conducted our review by searching Pub Med, Google Scholar, and the

first 7 volumes of *Patient Experience Journal*, using the following search terms: ‘patient experience + framework,’ ‘patient experience + definition,’ and ‘defining patient experience.’ After examining relevant titles and abstracts, we identified a total of 15 relevant articles across journals published from 2015 to early 2021 that reflected on or built upon the core concepts of the definition of patient experience.

We reviewed the set of selected articles (Table 1) for novel concepts across these pieces. We extracted key concepts that supplemented the framing of patient experience and/or offered new direction for the more far-reaching concept of the human experience in healthcare. None of the articles proposed a direct definition of experience. Rather, essential elements that helped people understand what experience entailed were identified and include:

- Commitment to strong and vibrant organizational cultures
- Leadership focus and commitment to support experience efforts
- Effective, open and clear communication
- Active partnership among all engaged, including values-based planning across all stages of healthcare
- Elevated awareness of the power of caring itself
- Positive and cohesive care team/staff
- Bidirectional support between those being served by healthcare and healthcare professionals providing service
- Educational and knowledge acquisition and transfer opportunities for all engaged
- Transparency of information
- Coordination and continuity of services/care
- Expanded methods for measuring outcomes that capture patient experiences, needs and preferences, such as qualitative approaches, narrative inquiry and participatory strategies
- Focus on outcomes beyond just experience survey metrics
- Reflection beyond the direct care setting, through transitions and into the third sector and community environments

We learned that although people have been less apt to formally define the human experience in healthcare, they have been fundamentally aligned with what experience is, what it encompasses and what elements are needed to enhance experience. The review of recent literature revealed foundational ideas that ultimately reinforce the core concepts originally presented in 2014, in addition to expanding the ground on which we believe a definition for the human experience in and with healthcare has, can and must evolve.

### ***Exploring expanding research***

We also felt it important to look beyond these articles to the research conducted in the years since 2014 by The Beryl Institute – the global community of practice committed to elevating the human experience in healthcare. In particular, we reviewed a set of studies intended to better understand how people across the healthcare ecosystem viewed human experience – that is, the experiences of patients, family members and care partners, those who work in healthcare and the communities they serve – and what they prioritized as the essential elements of it. Three studies explored the factors that both consumers of healthcare – patients, family members and the general population of healthcare users – and those working in healthcare saw as the items of greatest importance to a positive experience. The studies *Consumer Perspectives of Patient Experience 2018*<sup>4</sup> and *2021*<sup>5</sup> and *To Care is Human: The Factors Influencing Human Experience in Healthcare Today*<sup>6</sup> provide a clear and aligned set of priorities and provide insights into the elements essential to understanding, and therefore, defining the healthcare experience overall. Taken collectively, these provide insight to frame what experience is, can and must be for all engaged.

In the recurring studies on consumer perspectives, a few key issues pertaining to what is essential from the viewpoint of those who seek healthcare emerge and have been sustained over time. First and foremost, when asking people why a good patient experience is important, they noted that it is about their health, wellbeing, physical needs and their belief that a positive patient experience leads to good outcomes. This is followed by the fact that people want to be treated with respect, as a person, not a symptom, diagnosis or disease and that patient experience influences their future healthcare decisions.<sup>4, 5</sup>

Furthermore, the top items of importance to healthcare consumers were health outcomes, quality and safety, all reported as paramount and a key part of one’s patient experience. The top five items that consumers identified as important to their experience also reveal something critical to reinforcing and expanding a conversation on the human experience of healthcare. They include:

- Communicate clearly in a way I can understand
- Listen to me
- Provide a clear plan of care and why it is needed
- Ask me questions and try to understand my needs and preferences
- Treat me with courtesy and respect

These priorities reinforce critical insight first revealed in our 2014 paper in that experience is not something that happens to someone as a transaction, instead it is a relational concept that actively engages those who receive, provide and support the delivery of care equally.

Experience is not something people simply have, but rather it is created via *interactions* – communicate, listen, plan, ask questions, respect – that are fostered through participation in such practices as shared-decision making between patients and care partners and healthcare professionals. These behaviors of greatest importance to consumers are expected and must be expected by the organizations that provide healthcare. This sprouts from the *culture* of an organization, what is called for in behaviors and actions from people and cannot be generalized. Each patient, their family members and/or care partners gauge these encounters through their unique lens. Their experience is their *perception* of how these actions are taken and their experience, therefore, reflects their reality.

In recognizing that these priorities are not simply transactional but more so relational in nature, we raise the point that the patient experience people have is also grounded in the experiences of those who work in healthcare organizations. These are the expanding roots for ‘the human experience in healthcare.’ It is the experience these individuals have and the culture in which they operate that reinforces their expected behaviors and supports their actions. Relational ideas – the sum of all interactions – have two (or more) parties involved, and so all sides of these connections are influenced by the totality of individual experiences they have as a whole. For that reason, we cannot truly separate or isolate the experience of the healthcare workforce from that of those whom healthcare serves. While we may address them differently, we run great risk if we overlook one for the other. This careful and needed balancing act is necessary if we are to ensure the best in human experience in healthcare overall. This was supported by the insights offered in *To Care is Human*<sup>6</sup> as well.

The *To Care is Human*<sup>6</sup> study revealed the essential nature of this balanced perspective as it sought to understand the perspective of what those working in healthcare believed influenced a positive experience. In that exploration, high performing healthcare units were examined to determine if there was any distinction in those organizations generating a more positive patient experience as revealed in standard survey results. The top influential items identified from those working in healthcare show a powerful alignment to what consumers wanted as well, that is, ‘*effective communication with patients/families*’ and ‘*how patients/families are personally treated*.’<sup>6</sup>

Interestingly, the next most influential items to the patient experience overall were ‘*teamwork among the care team*,’ ‘*engagement level of employees*,’ and ‘*clinical team wellbeing*.’ This is a powerful revelation but one not all that surprising. It reinforced, from the perspective of those in healthcare, that the experience they provide will only be as strong as the people and teams that provide it. You cannot and must

not separate the way in which patients are engaged or the actions to support staff as isolated efforts. Rather, they are integrated and integral actions that optimize greater outcomes when aligned.

Initially, the term patient experience may have seemed to suggest a focus on only one side of the equation by the nature of the term itself. By definition, patient experience has always stood for and suggested much more. The examination of patient experience in our initial paper “recognizes that the recipient and deliverer of healthcare experience” are “human” and that “the broader needs of people engaged at any point on the healthcare spectrum” are part of the experience overall.<sup>1</sup> Interactions take relationships, and relationships include multiple perspectives. Consequently, a focus on the evolved term, human experience in healthcare, must include a commitment to people who are both providing and receiving care. A holistic human experience in healthcare must focus more broadly on the communities in which these cumulative encounters occur as well.

As noted in the review of new literature for the current paper and the aforementioned studies is that the human experience of care is not just a fleeting clinical moment but a lasting story that is shared well beyond the physical walls of any healthcare organization or any one individual. This includes consideration of care that is inclusive of the community. These stories are written at the point of interaction primarily between two (or more) human beings in a given environment. Any conversation on experience and ultimate understanding and application of a definition must include an environmental scan.<sup>7,8</sup> The way in which the environment impacts healthcare across communities has been no more evident than in the last year, as we have faced an unprecedented global pandemic and have seen the real implications and impact of systemic racism and broader health inequities.

### ***Reflecting on the global pandemic***

In the face of the current pandemic, we have witnessed and continue to see healthcare take action in ways it has not had to in a century. While we hope this article will be timeless, we acknowledge that it is, in fact, rooted in time. It is rooted at a time when for all that we just offered are priorities for humans in healthcare, we have experienced those needs in real time and they have been only amplified through the days of this health crisis. These realizations should not just vanish in the ether, but rather the lessons learned in both pain and victory should serve as seeds for how we would hope all have the ability to experience healthcare moving into the future.

In the face of all that was done to provide safe care and safe care environments, healthcare organizations globally made independent choices for how to manage the people in their own systems. They made heartfelt and sometimes

heartbreaking decisions on how, when or even if to engage family members or care partners in healthcare interactions during the pandemic.<sup>9,10</sup> Healthcare organizations worked to establish new means of connection through technology such as tablets and phones. They struggled with how to best ensure people were not alone at a time when a range of public health control measures, such as isolation and quarantine, were put in place for public safety.<sup>11</sup> They also struggled with the real inequities revealed by this virus. It exposed the cracks in our global healthcare system, where imbalance in health and healthcare led to segments of the population being disproportionately impacted by the pandemic.<sup>12</sup> The opportunity is clear; we must continue to strive to achieve equitably exceptional care for every human being within and across environments.

With focused efforts, even in the face of great challenge, to support the needs of all they serve, healthcare organizations also acknowledged and acted on the weight being carried by healthcare workers themselves. These individuals, across all roles, were showing up to work every day, living their purpose to care for others, oftentimes at the sacrifice of themselves and potentially their families. From setting up places to access food for staff, providing housing for healthcare workers who worried about the safety of exposing their families to COVID-19, to respite rooms and mental health support and clinical well-being initiatives, the efforts to take care of those who work in healthcare were and remain essential to successfully traversing the pandemic. The strength of any positive patient experience is grounded in the capacity of those delivering care to do so effectively, consistently and with compassion. It cannot be overlooked that the people in healthcare are essential to any experience equation.

### ***Reflecting on systemic racism and health inequity***

In this moment, as we have a conversation on the human experience in healthcare, we must not overlook the importance of addressing the issues of structural racism and the opportunities for advancing health equity that have been highlighted and now must remain at the forefront in today’s healthcare ecosystem. Racism has long been recognized as an issue embedded in societies that comes with high costs to individuals and segments of the population. To that end, we have learned and directly seen that silence and complacency are both corrosive and destructive to the broader human fabric of healthcare and society at large. We have also seen the impact of structural racism on inequities in health care.<sup>13</sup> Yet, this time of crisis has elevated these issues from ideas part of long-standing conversations of acknowledgment to a real, tangible and immediate call to action we believe must now be heeded.

Addressing racism and equity must be an essential action in addressing ‘the sum of all interactions’ and in every healthcare encounter. This must be addressed in order to optimize the human experience in healthcare for all.

Dismantling the impact of structural racism on healthcare will require reflection on the ways in which routine, accepted practices may have subtly acknowledged, but not truly acted on, these challenges. It is important now that healthcare professionals, public health experts, researchers, social scientists, and all individuals work to nurture environments that foster cultural humility and embrace our collective humanity.<sup>13,14</sup> That too must be found at the heart of any conversation of the human experience in healthcare and beyond.

This challenging time in our shared history, resulting from a global pandemic and the realities of structural racism, revealed just how vulnerable we are as human beings. It also revealed how truly connected we are as a world, for regardless of geographic or cultural boundaries, we all have been impacted by this crisis in some of the very same ways. It was and remains a shared experience that has called on the careful weaving of science and humanity. It has revealed the very essence of and need for a holistic human experience at the heart of healthcare.

### **Building on patient experience to define the human experience in healthcare**

The definition of patient experience was a significant milestone. It provided simple language for the truly complex nature of what patient experience is and has ultimately served as a foundation for framing the human experience in healthcare.

The rapid evolution in the recognition of the humanity in healthcare has required us to view the human healthcare experience not just as a person-centered process or relationship-based encounter. It is an intricate tapestry of human interaction both in the clinical and non-clinical settings across the continuum of care and into the communities served by healthcare organizations around the world. It must take into account the experiences of those who work in healthcare and the experiences communities have with healthcare organizations and systems overall. With this, we are called to build on the foundational definition and to expand our view as well.

We step in this direction to project these core concepts at every level they impact the experience people have in and with the global healthcare ecosystem. At the core of the ecosystem is the patient experience, which, having evolved from patients’ rights to advocacy, from service to experience, has moved from an idiosyncratic concept at the edges of the healthcare conversation to an essential reality. Yes, healthcare is built on science, but its execution is through, among and between human beings with needs and preferences, fears and insecurities, purpose and aspiration and a wish for something greater.

The idea of experience reflected in this reality is one that never forgets the person at the center but also acknowledges the family and team that surround, support and work with them and recognize the impact this has on and the commitment it requires to the communities in which these relationships exist. Much like at the core of a fruit containing the seeds from which it grows, so too is the core definition of patient experience reflected in the overall human experience in healthcare.

In reexamining the defining concepts, we expand the meanings as they apply to the human experience in healthcare (with new considerations italicized):

- **“The sum of all interactions”** continues to reflect that experience overall is a connected set of interwoven touchpoints between and among people throughout the healthcare ecosystem. These interactions are not just between patients and care providers, but *among all care team members, between care team members, families and care partners and within the context of various environments and communities* healthcare organizations serve.
- **“Shaped by an organization’s culture”** as intended was further reinforced since the definition’s initial introduction. The interactions where experience occurs are only as positive and effective as the people who engage in them and the organizational cultures that support and sustain expectations on how those encounters will go. The cultural environment where care occurs is *reflected in how organizations are led and directly impacts the experience of the healthcare workforce as well.*
- **“That influence patient perceptions”** sustains that what patients, their family members and/or care partners think and feel about the encounters they have are rooted in the interactions they have, grounded in the cultural expectations that frame those interactions and are the truest reflection of what people experience overall. *These remain the stories that are told, the way in which healthcare organizations are seen and talked about and have a lasting influence on human perceptions* of the social, emotional and physical outcomes that derive from all interactions in healthcare.
- **“Across the continuum of care”** reinforces that experience does not end and or have a set of distinct boundaries. Every individual experience with a healthcare organization or system starts when that person first becomes aware of the organization, whether a direct interaction or not, and it lasts well beyond the last encounter they may choose to have. This further reflects that *experience reaches beyond a clinical setting to the communities and broader ecosystem in which people live and healthcare organizations operate. This is not just a care journey across medical functions; it is a care lifecycle* that permeates the

entirety of the human experience in healthcare overall.

What our current review reveals and what the last several years reflect is that these core ideas of what patient experience represents hold true. They remain the essential elements of experience with one caveat – that the experience in healthcare that we seek to achieve, while centered on patients, radiates through the layers of the healthcare ecosystem to the healthcare workforce and the communities healthcare organizations serve. These ideas cannot, nor should they, be separated.

The layers that comprise the breadth of experience in healthcare reflects a human experience, the human experience in healthcare. (Figure 2) Expanding from the core concepts of the patient experience, the sum of all interactions, organization culture, perceptions and the continuum of care are reflected as well in the experience of the healthcare workforce and the healthcare experience of the communities in which we live. This idea has never been made more apparent than in the realities of the crises we continue to experience, but it is grounded in the very ideas essential to the initial experience conversation. While the core concepts of patient experience as defined helped frame the specific definition, they were not intended to nor should they be seen as limited to just those who healthcare serves directly. The healthcare ecosystem is impacted by all that and who comprise it, including

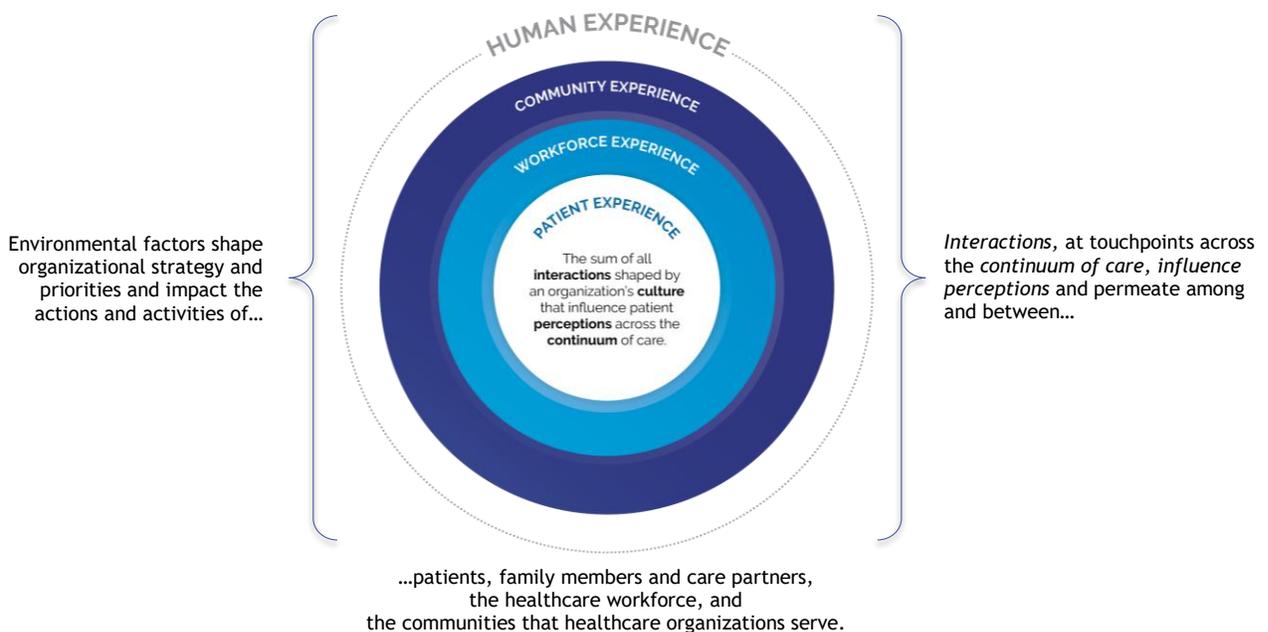
organizations and the healthcare workforce, patients, family members and care partners and the communities in which it operates. Collectively, these concepts reflect the human experience of healthcare.

With that, we offer that human experience as a term need not be directly defined, but rather framed conceptually for what it encompasses. First, human experience sustains at its core the definition of patient experience. As noted, the essential elements of the definition – interactions and culture – radiate across the landscape of healthcare encounters and across the strata of human experience.

Human experience also encompasses the vital and influential nature of the experience of those who work in healthcare. Studies have shown and continue to show the impact of workforce engagement on patient and provider outcomes<sup>15,16</sup> and underline the truly symbiotic nature of the experience of patients and the healthcare workforce. While each calls for unique actions to address, it should be recognized that those actions have an effect on both sides of the scale and require a delicate balancing act of caring to ensure the best in human experience.

The communities in which healthcare operates must also be an essential part of any experience conversation, recognizing the impact that healthcare organizations have in the communities they serve. This places great importance on the social determinants that impact the

**Figure 2. An integrated view of human experience in healthcare**



experience people have in healthcare – both personally and clinically. These social and community issues, including the realities of health disparities and inequity, all influence how people experience healthcare,<sup>17,18</sup> so any conversation on the human experience must also acknowledge the community and social levels at play that impact outcomes.

***The human experience – encompassing patient, workforce and community experiences – is not a move away from the foundational definition of patient experience but rather the positive and natural expansion of it.*** In thinking about how the definition of experience has evolved, it is evident that the core concepts on which it is built have not changed. In fact, the realization of what a focus on experience impacts has become ever clearer.

The human experience in healthcare integrates the sum of all interactions, every encounter among patients, families and care partners and the healthcare workforce. It is driven by the culture of healthcare organizations and systems that work tirelessly to support a healthcare ecosystem that operates within the breadth of the care continuum into the communities they serve and the ever-changing environmental landscapes in which they are situated. The human experience in healthcare ultimately is the fruit born from the core of patient experience itself.

### Leading forward

As we closed our 2014 article we shared:

We offer these ideas not in the promotion of one idea over another, but in recognizing that in existing work and in the shared themes we uncovered there is a strong set of related concepts from which to grow. This will be critical to ensure patient experience remains a viable, respected, and highly embraced part of the healthcare conversation, as we believe it should.<sup>1(p 13)</sup>

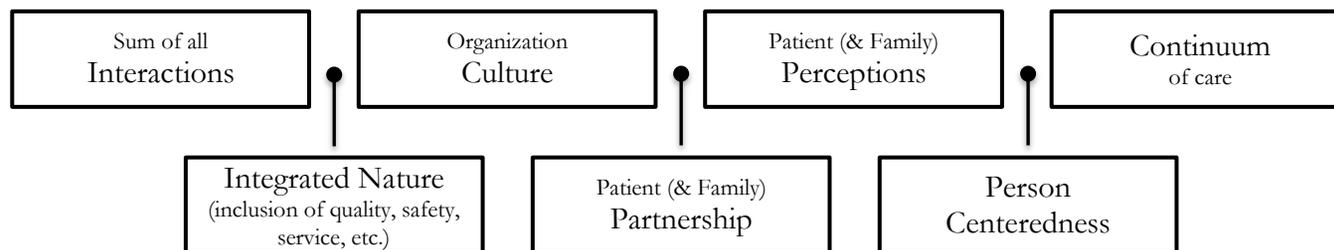
That idea of a concept on which to grow has truly taken root as the experience conversation has blossomed globally. The human experience in healthcare ultimately is a living idea in which each part has an impact and influence on the other. To look at experience as anything less than this integrated system of relationships and outcomes would undermine its ultimate intent. When we focus on the experience provided in healthcare, we honor the humanity of the system and the people in it; this leads to the results and outcomes we know all deserve. That is why the definition of patient experience holds true and has evolved; that is why a commitment to the broader human experience in healthcare must be acknowledged, understood and acted upon. It is what we all expect and hope for from a healthcare system grounded in the idea of human beings caring for human beings.

### References

1. Wolf JA, Niederhauser V, Marshburn D, LaVela SL. Defining Patient Experience. *Patient Experience Journal*. 2014;1(1):7-19.
2. Hoffman SJ, Cole CB. Defining the global health system and systematically mapping its network of actors. *Globalization and Health*. 2018;14(1). doi:10.1186/s12992-018-0340-2
3. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*. San Francisco, Calif: Jossey-Bass; 1993
4. Wolf JA. *Consumer perspectives on patient experience 2018*. The Beryl Institute; 2018.
5. Wolf JA. *Consumer perspectives on patient experience 2021*. The Beryl Institute; 2021.
6. Wolf JA. *To Care is Human: The Factors Influencing Human Experience in Healthcare Today*. The Beryl Institute; 2018.
7. Charlton P, Doucet S, Azar R, Nagel DA, Boulos L, Luke A, Mears K, Kelly KJ, Montelpare WJ. The use of the environmental scan in health services delivery research: a scoping review protocol. *BMJ Open*. 2019;9(9):e029805. doi: 10.1136/bmjopen-2019-029805.
8. Porterfield DS, Hinnant LW, Kane H, Horne J, McAleer K, Roussel A. Linkages between clinical practices and community organizations for prevention: a literature review and environmental scan. *Am J Public Health*. 2012 Jun;102 Suppl 3(Suppl 3):S375-82. doi: 10.2105/AJPH.2012.300692.
9. Aquilia A, Grimley K, Jacobs B, et al. Nursing leadership during COVID-19: Enhancing patient, family and workforce experience. *Patient Experience Journal*. 2020;7(2):136-143. doi:10.35680/2372-0247.1482
10. 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.
11. Wolf JA, Ipsen T. Maintaining Human Experience in a New Era of Virtual Connection. The Beryl Institute; 2020.
12. Polyakova M, Udalova V, Kocks G, Genadek K, Finlay K, Finkelstein AN. Racial Disparities In Excess All-Cause Mortality During The Early COVID-19 Pandemic Varied Substantially Across States. *Health Affairs*. 2021;40(2):307-316. doi:10.1377/hlthaff.2020.02142
13. Johnson-Agbakwu CE, Ali NS, Oxford CM, Wingo S, Manin E, Coonrod DV. Racism, COVID-19, and Health Inequity in the USA: a Call to Action. *J Racial Ethn Health Disparities*. 2020 Nov 16:1–7. doi: 10.1007/s40615-020-00928-y. Epub ahead of print.

14. Bailey ZD, Feldman JM, Bassett MT. How Structural Racism Works - Racist Policies as a Root Cause of U.S. Racial Health Inequities. *N Engl J Med*. 2021;384(8):768-773.
15. Daugherty Biddison EL, Paine L, Murakami P, Herzke C, Weaver SJ. Associations between safety culture and employee engagement over time: a retrospective analysis. *BMJ Quality & Safety*. 2015;25(1):31-37. doi:10.1136/bmjqs-2014-003910
16. Dempsey C, Assi MJ. The Impact of Nurse Engagement on Quality, Safety, and the Experience of Care. *Nursing Administration Quarterly*. 2018;42(3):278-283. doi:10.1097/naq.0000000000000305
17. Williams DR, Costa MV, Odunlami AO, Mohammed SA. Moving Upstream. *Journal of Public Health Management and Practice*. 2008;14(Supplement). doi:10.1097/01.phh.0000338382.36695.42
18. Lathrop B. Moving Toward Health Equity by Addressing Social Determinants of Health. *Nursing for Women's Health*. 2020;24(1):36-44. doi:10.1016/j.nwh.2019.11.003

Figure 1. Definitional themes and recurring constructs for inclusion and consideration in patient experience improvement efforts<sup>1</sup>



Elements	The sum of all interactions	shaped by an organization’s culture	that influence patient perceptions	across the continuum of care
Expanded Description	The orchestrated touch-points of people, processes, policies, communications, actions, and environment.	The vision, values, people (at all levels and in all parts of the organization) and community engaged and involved with the organization.	What is recognized, understood and remembered by patients and support people. Perceptions vary based on individual experiences such as beliefs, values, cultural background, etc.	In all facets of the healthcare system, in all encounters, in all settings from non-clinical proactive experiences, to long term care or hospice and across the spectrum of services.
Supporting Themes (for patient experience improvement) and alignment with elements	<b>Integrated Nature</b> reinforces that experience from the patient perspective is singular and aligned, not simply a collection of distinct or disparate efforts. It is encompassing of all encounters whether they include quality, safety or service, and these efforts should be coordinated and aligned to support a “one-experience” mindset. [Includes: Beyond survey results, more than satisfaction]		<b>Person-centeredness</b> recognizes that the recipient and deliverer of healthcare experience are at their core human beings. As a component of experience, this reinforces that process or protocol should not trump the broader needs of people engaged (in almost all cases) at any point on the healthcare spectrum. [Includes: Aligned with patient-centered care principles]	
		<b>Patient &amp; Family Partnership (&amp; Engagement)</b> acknowledges that patients, families and members of their support network are active participants in the care experience and must be engaged as participant owners in their encounters. The voices of these individuals are not only significant in situations of care, but also in planning, ongoing operations and change/improvement efforts. [Includes: Focus on expectations, focus on individualized care]		

**Note:** As mentioned above, the most consistent supporting themes are presented in this graphic, but we suggest other practices or concepts may also be proven to support patient experience improvement and performance.

**Table 1. Reviewing recent literature: Themes and sources (Listed alphabetically by title)**

Article Title	Year	Publication	Key Findings Related to Framing Experience	Article Citation/URL
A Strategic Framework for Improving the Patient Experience in Hospitals	2017	Journal of Healthcare Management	Key elements essential to improving patient experience include culture, communication, information transparency, patient engagement, consumer accessibility, empathy and a focus on quality outcomes.	Birkelien NL. A Strategic Framework for Improving the Patient Experience in Hospitals. <i>J Healthc Manag.</i> 2017;62(4):250-259. doi:10.1097/JHM-D-17-00071.  <a href="https://pubmed.ncbi.nlm.nih.gov/28683048/">https://pubmed.ncbi.nlm.nih.gov/28683048/</a>
Building national consensus on experiences of care	2015	Patient Experience Journal	The narrative of a good experience includes individual items such as being involved as an active partner in care, being treated as an individual, being communicated to way in which I desire and organizational items such as strong, committed leadership who provide clear strategy and model behaviors and a focus on workforce engagement.	Baranski A, Churchill N, Staniszewska S. Building national consensus on experiences of care. <i>Patient Experience Journal.</i> 2015;2(1):118-123. doi:10.35680/2372-0247.1065  <a href="https://pxjournal.org/journal/vol2/iss1/17/">https://pxjournal.org/journal/vol2/iss1/17/</a>
Capturing patient experience to improve healthcare services	2019	NursingStandard	Effective experience includes respect, patient participation, involvement of family/care-partners, effective communication, trusted treatment and coordination of care/smooth transitions among other things, all of which have been seen as positively associated with good healthcare outcomes.	Goodrich J, Fitzsimons B. Capturing patient experience to improve healthcare services. <i>Nurs Stand.</i> 2019;34(8):24-28. doi:10.7748/ns.2018.e11177.  <a href="https://pubmed.ncbi.nlm.nih.gov/30382654/">https://pubmed.ncbi.nlm.nih.gov/30382654/</a>
Development and reliability of a patient experience inventory tool for hospitals	2020	Patient Experience Journal	In identifying how to best assess experience efforts, four pillars: leadership, education and development, data and analytics and patient-and-family centeredness all were identified as essential elements to measure successful experience efforts.	Barden A, Giammarinaro N, Bashkin N, Lutsky L. Development and reliability of a patient experience inventory tool for hospitals. <i>Patient Experience Journal.</i> 2020;7(1):100-104. doi:10.35680/2372-0247.1396  <a href="https://pxjournal.org/journal/vol7/iss1/13/">https://pxjournal.org/journal/vol7/iss1/13/</a>

**Table 1. Reviewing recent literature: Themes and sources (Listed alphabetically by title) - continued**

Article Title	Year	Publication	Key Findings Related to Framing Experience	Article Citation/URL
Exploring the dimensions of patient experience for community-based care programmes in a multi-ethnic Asian context	2020	PLOS ONE	Looking at experience outside a western perspective , the findings highlighted eight key themes of patient experience: ensuring care continuity, involvement of family, access to emotional support, ensuring physical comfort, coordination of services between providers, providing patient education, importance of respect for patients, and healthcare financing	Foo C, Tan YL, Shrestha P, et al. Exploring the dimensions of patient experience for community-based care programmes in a multi-ethnic Asian context. PLoS One. 2020;15(11):e0242610. Published 2020 Nov 25. doi:10.1371/journal.pone.0242610.  <a href="https://pubmed.ncbi.nlm.nih.gov/33237953/">https://pubmed.ncbi.nlm.nih.gov/33237953/</a>
Key drivers of patient experience in ambulatory paediatric cardiology	2017	Cardiology in the Young	Determined that cheerfulness of the practice, a cohesive staff, and a care provider explaining problems and conditions were key aspects to a positive experience.	Allam SD, Mehta M, Ben Khallouq B, Burrows JF, Rosen P. Key drivers of patient experience in ambulatory paediatric cardiology. <i>Cardiol Young</i> . 2017;27(8):1585-1590. doi:10.1017/S1047951117000841.  <a href="https://pubmed.ncbi.nlm.nih.gov/28516822/">https://pubmed.ncbi.nlm.nih.gov/28516822/</a>
Patient Experience: A Call to Action for Nurse Leadership	2018	Nursing Administration Quarterly	Nurse leaders should consider reframing the patient experience as a focal point for their organization's strategic approach and tactics. This involves facilitating a dialogue about the organization's patient experience definition; building a strong, positive organization culture; creating processes to ensure the engagement of all voices; ensuring a focus across the continuum of care; and addressing the key drivers of patient experience excellence.	Niederhauser V, Wolf J. Patient Experience: A Call to Action for Nurse Leadership. <i>Nurs Adm Q</i> . 2018;42(3):211-216. doi:10.1097/NAQ.0000000000000293.  <a href="https://pubmed.ncbi.nlm.nih.gov/29870486/">https://pubmed.ncbi.nlm.nih.gov/29870486/</a>
Patient Experience: The field and future	2017	Patient Experience Journal	Reaffirmed the 7 core concepts of the definition of patient experience - Sum of All Interactions, Organization Culture, Patient Perceptions, Continuum of Care, Integrated Nature, Patient and Family Partnership, and Person Centeredness show up consistently in research in Patient Experience journal.	Silvera GA, Haun CN, Wolf JA. Patient Experience: The field and future. <i>Patient Experience Journal</i> . 2017;4(1):7-22. doi:10.35680/2372-0247.1220  <a href="https://pxjournal.org/journal/vol4/iss1/3/">https://pxjournal.org/journal/vol4/iss1/3/</a>

**Table 1. Reviewing recent literature: Themes and sources (Listed alphabetically by title) - continued**

Article Title	Year	Publication	Key Findings Related to Framing Experience	Article Citation/URL
Patient Experience: The New Heart of Healthcare Leadership	2017	Frontiers of Health Services Management	Reinforces the importance of the core concepts of experience and suggests they remain essential to understanding and address experience. Calls for a strategic and integrated perspective on experience as healthcare leaders focus on experience as an all-encompassing strategy versus a singular or distinct strategic pillar.	Wolf JA. Patient Experience: The New Heart of Healthcare Leadership. <i>Front Health Serv Manage.</i> 2017;33(3):3-16. doi:10.1097/HAP.0000000000000002.  <a href="https://pubmed.ncbi.nlm.nih.gov/28319978/">https://pubmed.ncbi.nlm.nih.gov/28319978/</a>
The four Ps of patient experience: A new strategic framework informed by theory and practice	2018	Health Marketing Quarterly	Suggests four Ps of patient experience, which include: trained autonomous physicians, multidisciplinary partners, alternative places of care delivery matched to patient conditions and needs, and standardized yet flexible processes.	Kash BA, McKahan M, Tomaszewski L, McMaughan D. The four Ps of patient experience: A new strategic framework informed by theory and practice. <i>Health Mark Q.</i> 2018;35(4):313-325. doi:10.1080/07359683.2018.1524598.  <a href="https://pubmed.ncbi.nlm.nih.gov/30551728/">https://pubmed.ncbi.nlm.nih.gov/30551728/</a>
Understanding the Patient Experience: A Conceptual Framework	2020	Journal of Patient Experience	As a person moves across the continuum of care <sup>4</sup> they engage as person with an experience of health, a patient with an experience of disease of illness and a user with an experience of healthcare services. It is suggested that this framework reinforces the centrality of the patient's human experience across the continuum of care.	Oben P. Understanding the Patient Experience: A Conceptual Framework. <i>J Patient Exp.</i> 2020;7(6):906-910. doi:10.1177/2374373520951672.  <a href="https://pubmed.ncbi.nlm.nih.gov/33457518/">https://pubmed.ncbi.nlm.nih.gov/33457518/</a>
Unraveling the meaning of patient engagement: A concept analysis	2017	Patient Education and Counseling	The analysis revealed four defining attributes of patient engagement: personalization, access, commitment and therapeutic alliance. Patient engagement is defined as the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care.	Higgins T, Larson E, Schnall R. Unraveling the meaning of patient engagement: A concept analysis. <i>Patient Educ Couns.</i> 2017;100(1):30-36. doi:10.1016/j.pec.2016.09.002.  <a href="https://pubmed.ncbi.nlm.nih.gov/27665500/">https://pubmed.ncbi.nlm.nih.gov/27665500/</a>

**Table 1. Reviewing recent literature: Themes and sources (Listed alphabetically by title) - continued**

Article Title	Year	Publication	Key Findings Related to Framing Experience	Article Citation/URL
Visioning a hospitality-oriented patient experience (HOPE) framework in health care	2020	Journal of Service Management	From a hospitality lens, a framework for addressing experience begins with a central shared vision and three core principles, building an experience culture that sees patients as cognitive, emotion and social beings, creating a service environment that supports that recognition and must have a multistakeholder approach in experience design and build from cocreation by all engaged.	Hunter-Jones P, Line N, Zhang JJ, Malthouse EC, Witell L, Hollis B. Visioning a hospitality-oriented patient experience (HOPE) framework in health care. <i>Journal of Service Management</i> . 2020;31(5):869-888. doi:10.1108/josm-11-2019-0334.  <a href="https://doi.org/10.1108/JOSM-11-2019-0334">https://doi.org/10.1108/JOSM-11-2019-0334</a>
What do patients really want? An in-depth examination of patient experience in four Australian hospitals	2019	BMC Health Services Research	Good communication and high-quality information at arrival and discharge were found to be important to patients.	Rapport F, Hibbert P, Baysari M, et al. What do patients really want? An in-depth examination of patient experience in four Australian hospitals. <i>BMC Health Services Research</i> . 2019;19(1). doi:10.1186/s12913-019-3881-z.  <a href="https://link.springer.com/article/10.1186/s12913-019-3881-z#Sec23">https://link.springer.com/article/10.1186/s12913-019-3881-z#Sec23</a>
Working collaboratively to develop a patient experience definition and strategy to inform clinical commissioning	2015	International Practice Development Journal	Patient experience is affected by expectations, includes the whole experience of services, is broader than satisfaction to the outcomes of care. It is framed by being respected, listened to and understood, involved in decision making. It is reflected across services and coordinated across the health, social and third-sector services. It is shaped by staff having a positive and engaged experience as well.	Sanders K, Ben Omar S, Webster J. Working collaboratively to develop a patient experience definition and strategy to inform clinical commissioning. <i>International Practice Development Journal</i> . 2015;5(2):1-23. doi:10.19043/ipdj.52.002.  <a href="https://www.fons.org/Resources/Documents/Journal/Vol5No2/IPDJ_0502_2.pdf">https://www.fons.org/Resources/Documents/Journal/Vol5No2/IPDJ_0502_2.pdf</a>