

Social workers and health staff's understanding of the patient experience: a conceptual framework

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Abstract

The patient experience is now globally recognized as an independent dimension of health-care quality. However, although patients, providers, health-care managers, and policy-makers agree on its importance, there is no standardized definition of the patient experience. A clear understanding of the basic concepts that make up the foundation of the patient experience is more important than a statement defining the patient experience. The fundamental nature of health care involves people taking care of other people in unique times of distress. Thus, the human experience is at the very core of understanding what the patient experience is. This article reviews a framework of the basic human experience of patients as they progress from being unique, healthy individuals to a state of experiencing both disease and health-care services. This novel framework naturally leads to a basic understanding of the patient experience as a human experience of health-care services.

Keywords patient experience, quality of care, patient satisfaction, patient's perception of care, health-care services quality, human experience

Introduction

Throughout the world, the patient experience is recognized as an independent dimension of health-care quality, along with clinical effectiveness and patient safety (1,2). Healthcare organizations across the United States are focusing on how to "deliver a superior patient experience" (3). Quality is a key driver of these industry-wide changes, as are the shifts in health-care policy that have tied hospital and physician compensation to patient experience measures, the focus on patient engagement, and the emergence of the consumer mindset (2,4).

Despite the increasingly important role that the patient experience occupies in health-care clinical practice, research, quality improvement efforts, and policies, there is no universal understanding of what the "patient experience" is, as evidenced by the lack of a standardized definition (4). Therefore,

patients, clinicians, policy makers, managers, and researchers have different interpretations of the concept (5). Although this has been called the "era of the patient" (6), experts have said, "it's no wonder that hospitals are struggling with the best way to provide it." After all, if you can't define what it is, you can't provide it—and you certainly can't measure it" (5). Thus, a clearer understanding of the patient experience will assist clinicians in improving that experience at the point of care, guide further research into the topic, and provide clear directions for quality improvement efforts and health-care policies.

There are several reasons for the lack of a formal definition or clear understanding of the patient experience. The patient experience is a multidimensional, multifaceted, and intimately connected concept with several subsections. Furthermore, framing definitions, even when concepts are well understood, is not a simple task. The Beryl Institute made a significant stride forward by providing a definition that highlights the integrated and multidimensional nature of the patient experience and the complexity of the framing task (4,7). They defined the patient experience as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care" (7). This definition identifies 4 critical themes for understanding the patient experience: personal interactions, organization's culture, patient and family perceptions, and continuum of care.

By itself, a definition is a statement that seeks to convey the understanding of a concept. The greater our

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understanding of the patient experience, the easier it is to frame a definition. As we continue to create a standardized definition, it is important to step back from its multidimensional nature and review its most basic concepts. One fundamental source for this concept comes from an article in the 2001 Institute of Medicine, which states, "health care is not just another service industry. Its fundamental nature is characterized by people taking care of other people in times of need and stress" (8). A central role in health care is, therefore, the humanity of both the patient and care provider throughout the process of providing health care. Both the physician and patient are people (9).

This article seeks to provide a general overview of the patient experience from the platform of who we are as human beings, whether we are patients or providers. It provides a conceptual framework that traces the patient's virtual journey from health, to the onset of disease, and through multiple encounters with health-care services. To fully appreciate the value of this conceptual framework, awareness of 2 important elements is required. First, although the patient experience concept is multidimensional and multifaceted, the health-care experience for the individual patient is unified; it is informed by a complex combination of the patient's personal life, as well as their own and their family's experiences within the health-care system at all levels of care.

Second, the word "patient" is used in this article with a specific meaning. There is intense debate about replacing the word patient with consumer, users, or clients; the argument for the change is that the word "patient" conveys the idea of passivity and does not correctly describe all patient populations, especially the "well patient" seeking preventive services (10,11).

In this article, we use the dictionary definition of patient: "a person receiving or registered to receive medical treatment" (12). However, the additional element of "suffering," which captures a critical element of the human experience of disease, is also incorporated. Thus, patient refers to a person suffering from a disease before and after they begin receiving or are registered to receive medical treatment.

The Experience Journey of the Patient

A recurrent and prominent theme in discussions of the patient experience is centering the patient's perception or perspective on the health care they receive (7,13). Healthcare providers who seek to understand the patient's perspective of their experience will obtain a greater understanding of the patient experience. Furthermore, it is important to note that the patient's overall health and disease experience begins before they enter the health-care system. This holistic experience from the patient's perspective is critical for a complete understanding of their experience within the health-care organization.

Phases and landmarks of the patient experience. When a patient contacts a health-care organization, assuming they are in a basic state of health, they begin a journey that consists of 3 phases or spheres of experiences with 2 critical landmarks. These phases and landmarks of the patient experience are illustrated in Figure 1.

- The patient, just as the provider, is a unique individual. A baseline state of health is used for the purpose of simplicity, as illustrated in the right column in Figure 1.
- The first landmark for the individual is the beginning of a process that moves them from the first column, person, to the middle column, patient. A patient, as we have stated, is a person who is suffering from a disease, but they are still the same unique person they have been.
- The second landmark occurs when this person suffering from a disease makes their first contact with medical care services regarding this disease. They become users or consumers of these services. While they interact with health-care organizations, they continue to be the same person they were before disease onset.

Importantly, the state of disease or the role of a person as a user of health-care services is dynamic. If the disease is cured, the individual who was a patient before is restored to the experience of health and is no longer a patient.

A Continuum and Unity

As Figure 1 demonstrates, the patient remains the same person they were before the disease onset, even after they contract a disease or begin utilizing medical services. The person's interactions with health-care providers—and not their disease or their role as consumers—are the key to understanding the fundamental nature of the patient experience.

The patient experience does not rely solely on the events that occur between themselves and health-care providers; their complex human experiences also influence their perception of the situation. For instance, while the patient seeks to understand the plan of care as the provider explains it (experience with medical services), they might also experience discomfort from their symptoms (experiences of the disease) and anxiety over making sure their kids are picked up from daycare (experiences in general life).

A journey through this continuum leads to a solid understanding of what health care currently refers to as the patient experience. As shown in Figure 1, this experience is also a human experience of a distinct occurrence or series of events called health-care service.

The Person: The Human Experience

The first column in Figure 1 lays the foundation for understanding the person who seeks medical care from health-care

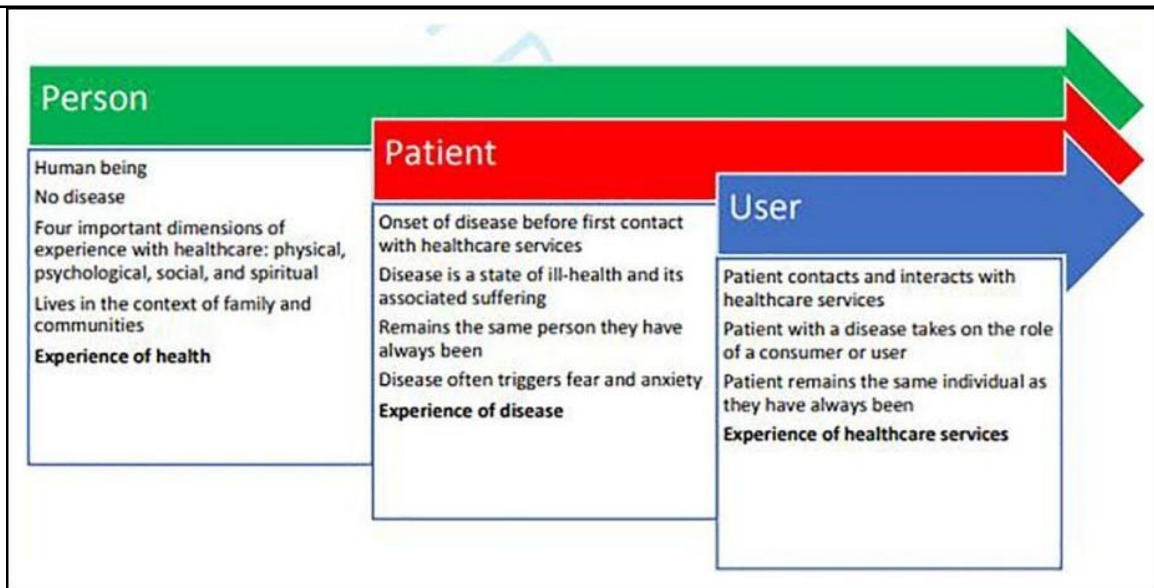


Figure 1 . A conceptual framework for understanding the patient experience. The arrows indicate the direction patients take in their journey through health-care encounters, which is hypothetically to the right Of the diagram. The person moves across the continuum, indicating that the patient or user of health-care services is the same unique human being they have always been. The arrow labeled "Patient" begins in the middle, indicating the person is not always a patient and becomes one with the onset of disease. The "User" arrow indicates that the person who has a disease only becomes a user of health-care services with their first interaction with the health-care system.

providers. Understanding the humanity of patients is the critical foundation upon which any successful patient-centered experience efforts should be built. The prominent role of our humanity distinguishes health care from other service industries (8). In "Harrison's Principles of Internal Medicine," Jameson et al stated, "Tact, sympathy, and understanding are expected of the physician, for the patient is no mere collection of symptoms, signs, disordered functions, damaged organs, and disturbed emotions. [The patient] is human, fearful and hopeful, seeking relief, help and reassurance" (14).

The patient is a human, and humanity harbors the secret to the elements of care that creates a superior patient experience. In a speech to Harvard Medical Students in 1926, Francis Peabody stated, "one of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient" (9, 15). This statement is as valid today as it was when it was first spoken. Our interest in the humanity of our patients naturally leads us to care for the person who is suffering from an illness and seeking help from the health-care system, rather than merely managing a case or disease. The human experience is, therefore, central to the overall conceptual understanding of the patient experience.

The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (16). This definition indicates that the human experience in health and disease is multidimensional and includes physical, mental, and social dimensions. Puchalski identified a fourth, spiritual dimension; she calls compassionate care "serving the whole person—the physical, emotional, social, and spiritual" (17); research has shown this to be important to many patients (18). The social dimension emphasizes the importance of engaging not only the patient but also their families and communities (19-21). Needham recognizes the multinational nature of the patient experience in stating that both emotional and physical experiences must be managed, highlighting 2 out of the 4 dimensions noted above (22).

The Patient: The Experience of Illness

As noted above, this article uses the word patient to refer to a person suffering from a disease before and after they begin receiving or are registered to receive medical treatment. It has a central role in the conceptual framework of Figure 1, as it preserves what is "distinctive about medical practice" (10) and what separates health care from many other service industries: a human being suffering from a disease seeks care from another human being who not only provides a service but also is moved with compassion and empathy for the one seeking help (8). Despite its limitations within the evolving landscape of health care, Dr. Raymond Tallis' comment regarding replacing the word patient, to "leave it well alone" (10), seems to be echoed by most patients and providers (23).

The onset of a disease marks the critical landmark of the transition from a person who is healthy to a person suffering from a disease before or after they are registered or begin receiving medical treatment. The individual, who we assume was previously healthy, begins to experience a disease in the psychological, physical, social, and spiritual dimensions. For example, a patient with a broken
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bone may experience not only physical pain and sight of a possible deformity but also the fear and anxiety of lifelong loss of movement or being admitted to a hospital for the first time.

Shale describes 3 aspects of the patient experience, including physiologic experiences of illness, customer service, and lived experiences of the illness (24). The patient's experience of an illness is a distinct aspect of their overall experience. The ultimate hope of medical care is to eliminate, reduce the impact of, or manage the varied psychological, physical, social, and spiritual experiences of illness, for both the patient and their families and communities. These distinct spheres of experiences, which simultaneously occur during every interaction between the health-care organization and the person, form the continuum of the patient's holistic experience of care.

The Experience of Health-Care Services

Health care is, "after all, a service" (2). Patients become users or consumers of health-care services when they begin using those services, starting with their first interaction across the continuum of care. Health-care service, as a continuum of all interactions with the patient, is experienced in the same 4-dimensional sphere of human experience, that is, physically, psychologically, socially, and spiritually. The patient experience, in essence, is the human experience of health-care services. The central reason for the existence of the health-care industry is to care for the patient: to manage their physical, psychological (emotional/mental), social, and spiritual health needs as presented.

The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) is a standardized, well-established, and extensively-validated instrument that measures the degree to which health-care services have managed to meet the aforementioned complex needs (13). The HCAHPS addresses specific aspects of interactions between the patient and the health-care organization, such as communication with doctors and nurses. The patient's experience begins with the onset of disease, which, however, the HCAHPS cannot capture. This is because the health-care system is not responsible for the prior, varied experiences that individual patients may have experienced in their illness before seeking care for this disease state. However, when these patients are under the care of a health-care organization, the degree to which the care services meet their needs, in the context of the family and community, is the healthcare service provider's direct responsibility. The HCAHPS scores give health-care service providers a quantitative measure to assess how well they are meeting the needs of their patients, families, and communities. They can then determine areas of strengths and weaknesses and clearly plan quality improvement changes across the continuum of care so that "patients would experience care" that is safe,

effective, patient-centered, timely, efficient, and more equitable" (8).

Conclusion

A proper, clear, and precise understanding of the patient experience will benefit the health-care industry and society in multiple aspects, including but not limited to establishing a tailored and personalized clinical bedside care, providing clear guidance for further research, stimulating consistent and sustainable improvements in medical care quality, and guiding health-care policy. The conceptual framework presented in this article, which seeks to clarify the centrality of the patient's human experience across the continuum of care, is only the beginning point for a better overall understanding of this multidimensional, multifaceted concept. The healthcare industry has not received the full benefit of the data provided by patient experience measurement tools. Given the potential impact on quality, safety, and cost of health care in general, research efforts should be made to not only create a standardized definition of the patient experience but also clarify its various components. The current methods of measurement and reporting should be improved in order to establish the best ways to incorporate the patient experience data into general health-care improvement efforts.

Authors' Note

NO research was performed on human or animal subjects and as such approval by an Ethics Committee or Institutional Review Board was not required. Similarly, no informed patient consents were obtained as these were not required.

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References

1. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3:e001570. doi: 10.1136/bmjopen-2012-001570
2. Manary MP, Jerant AF, Bertakis KD, Jerry B, Christine C, Jeremy DF, et al. The patient experience and health outcomes. *N Engl J Med*. 2013;368:201-203. doi:10.1056/NEJMp1211775
3. Stempniak M. The patient experience. Taking it to the next level. *Hosp Health Net*. 2013;87:
4. Wolf JA, Marshburn D, Lavela SL. *Defining Patient Experience: A Critical Decision for Healthcare Organizations*. The Beryl Institute; 2014.
5. Robinson J. What is the experience"? 2010. <https://news.gallup.com/businessjournal/143258/patient-experience.aspx> (accessed April 29, 2020).
6. Reiser SJ. The era Of the patient. Using the experience of illness in shaping the missions Of health care. *JAMA*. 1993;269: 1012-1017. doi: 10.1001/jama.1993.03500080060033
7. The Beryl Institute. *Defining patient experience*. 2020. <https://www.theberylinstitute.org/page/DefiningPX> (accessed April 29, 2020).
8. Institute of Medicine. *Crossing the quality chasm: a new health system for the 21st century*. 2019, <https://www.ncbi.nlm.nih.gov/pubmed/25057539> (accessed April 29, 2020).
9. Hurst JW, Francis W. Peabody, we need you. *Tex Heart Ins J*. 2011;38:327-8.
10. Neuberger J, Tallis R. We do need a new word for patients.

BMJ. 1999;318:1756-8. doi: 10.1136/bmj.318.7200.1756

11. Shevell MI. What do we call 'them'?: The 'patient' versus 'client' dichotomy. *Dev Med Child Neurol.* 2009;51:770-2.
doi:10.1111/j.1469-8749.2009.03304.x
12. Oxford University Press. Definition Of patient in English in Lexico.com. 2020. <https://www.lexico.com/en/definition/patient> (accessed April 28, 2020).
13. Centers for Medicare & Medicaid Services. HCAHPS: Patients' perspectives of care survey—Centers for Medicare and Medicaid Services. 2020. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HospitalQualityInits/HospitalHCAHPS> (accessed April 30, 2020).
14. Kasper D, Fauci A, Longo DL, et al. *Harrison's principles Of internal medicine.* McGraw-Hill Medical Publishing Division; 2018.
15. Peabody FW. The care of the patient. *JAMA.* 1927;88: doi:10.1001/jama.1927.02680380001001
16. World Health Organization. Constitution of the World Health Organization; 2020. https://www.who.int/governance/eb/who_constitution_en.pdf (accessed May 11, 2020).
17. Puchalski CM. The role Of spirituality in health care. *Proc (Bayl Univ Med cent).* 2001;14:352-7. doi:10.1080/08998280.2001.11927788
18. Best M, Butow P, Olver I. Do patients want doctors to talk about spirituality? A systematic literature review. *Patient Educ Couns.* 2015;98:1320-8. doi:10.1016/j.pec.2015.04.017
19. Institute of Medicine. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America.* The National Academies Press; 2013. doi:10.17226/13444
20. Commission TJ. *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.* The Joint Commission, <https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/health-equity/roadmapforhospitalsfinalversion727.pdf?db=web&hash=AC3AC4BED1D973713C2CA6B2E5ACD01B> (accessed April 30, 2020).
21. Clay AM, Parsh B. Patient- and family-centered care: it's not just for pediatrics anymore. *AMA J Ethics.* 2016; 18:40-44. doi: 10.1001/journalofethics.2016.18.1.medu3-1601
22. Needham BR. The truth about patient experience: what we can learn from Other industries, and how three Ps can improve health outcomes, strengthen brands, and delight customers. *J Health Mana.* 2012;57:255-63. doi:10.1097/00115514201207000-00006
23. Acar M. Do we need a new word for patients? What's in a name, after all? *BMJ.* 1999;319:1437. doi:10.1136/bmj.319.7222.1436a
24. Shale S. Patient experience as an indicator of clinical quality in emergency care. *Clin Govern Int J.* 2013;18:285-92. doi:10.1108/CGIJ-03-2012-0008

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