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Rebalancing the patient experience: 20 years of a pendulum swing

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Abstract

This essay looks back at two decades of the patient experience movement. The evolution of patient experience includes moving from a belief system in which patients and families are solely the recipients of care to a model in which patients and families are co-designing treatment plans, systems and policies. This evolution has taken time and continues to evolve to this day. As the pendulum swings, we see that we have made great progress and, simultaneously, found ourselves with all new challenges to overcome.

Keywords

Patient experience, patient experience movement, resiliency, workplace violence, end of life, partnership

*There been times that I thought I couldn't last for long
But now I think I'm able to carry on
It's been a long, a long time coming
But I know a change gon' come, oh yes it will*

--Sam Cooke

As a person with cystic fibrosis who has received 2 double lung transplants, I have spent a large amount of time in hospitals, emergency rooms and out-patient clinics. It's for this reason that, when I learned I had gotten the job as a patient advocate in a major medical center, I felt confident that I would do well. It seemed that there would not be any situation that I might encounter in this role that I had not encountered in my personal life as a patient. What I discovered was that a lot had changed during my lifetime as a patient, particularly in the last 10 years. While I was only minimally aware of how these changes impacted my patient experience, I would soon become acutely aware of how they impacted the experience of those working in healthcare.

A Brief Look at History of the Patient Experience Movement

In 1992, The Institute of Patient and Family Centered Care established the 4 guiding principles for PFCC as dignity and respect, information sharing, participation and collaboration. In 2001, the Institute of Medicine defined Patient and Family Engagement as "Providing care that is respectful of, and responsive to, individual patient preferences, needs, and values; and ensuring that patient values guide all clinical decisions." In 2007, The Beryl Institute released the definition of patient experience as "The sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care."

Through each of these definitions we can see an evolution of the movement. First, we must establish the basic needs of those who are vulnerable during their time of illness or injury. Next, we must operationalize the need for patients to have control over their medical destiny. Today, we understand that the patient experience is a result of all healthcare experiences in a person's history combined with the culture of the organization where they find themselves receiving care. For much of the past ten years, this movement has been focused solely on moving the spotlight of importance off of the physician's perspective and putting that spotlight squarely on the patient's preferences, values and goals. Despite how long these efforts have been underway, in many organizations, improving the patient experience is seen as "the soft stuff" and, for a variety of reasons, not yet fully embraced.

The Change in Experience is Here

As a patient advocate, I witnessed the change in how patients experience care through the complaints I received. For example, elderly patients called me to their bedside to complain that the nurse failed to bring them a basin to wash their face in the morning. Assistance with daily hygiene was an expectation of the older generation and, when that expectation was not met, they did not feel properly cared for. That was not a complaint I ever received from a person under 80 years of age. In fact, I would venture to guess, younger patients didn't even know that assistance with personal hygiene each morning was at one time a common practice for hospital bedside nurses. In contrast, younger patients called me more often to report times in which they were not involved in shared decision making or when they generally did not feel they were treated with respect.

The patterns of complaints and grievances I received reflected our history. Over time, as medicine evolved past holding cold cloths on the forehead and providing whisky for pain, the complexity of the procedures and technology managed to push aside some of the core elements of health care. The geniuses of the patient experience movement came from a need to return to some of the practices that made us feel cared for, that made us feel like human beings being cared for by human beings. By the time we, collectively, realized this need for human connection in healthcare the pendulum had swung so far that connection had been trained out of the professional experience. As a result, even the concept of connecting to patients had become viewed as a liability rather than a necessity. Over 20 years into the patient experience movement, we are now seeing more and more nursing and medical schools recognizing that medical training is the root of the patient experience and, therefore, it is time to redesign the way we train our future healthcare providers.

Dr. Rana Adwish writes in her astounding autobiography, “In Shock,” of a physician who becomes critically ill and evaluates her medical training; “I thought about the training system we are all a part of. A system that had evolved over decades with norms, patterns and expectations that were so persuasive that residents in geographically diverse programs had nearly identical experiences.” She goes on to say “We were trained to value efficiency over cultivating a relationship through trust and disclosure. We weren’t trained to value the patient’s story.”¹

It’s professionals like Dr. Adwish and Dr. Atul Gawande that are leading conversations around professional training and sensitivity to the patient/family experience that serves to strengthen the efforts of organizations like The Beryl Institute and The Institute for Healthcare Improvement.

The New Challenges We Face

Who cares for the care providers?

This necessary focus on the patient experience has brought with it new challenges. These have only been compounded by the efforts to hold healthcare organizations accountable to the patient experience through value based purchasing. As we see the numbers of medical student suicides on the rise, reports of physician burnout at epidemic numbers and the struggles with nursing retention², we have to take a deep breath and own up to the fact that some of our efforts may have pushed the pendulum too far. We must acknowledge that while we struggled in the dark to improve the patient experience, in some cases, we abandoned our care for the care providers. We have to accept that we sometimes focus on metrics more than supporting the needs of those who work with patients every day. We have to bravely move forward in improving the patient experience while

also shedding light on the areas that have become confusing and overwhelming in the context of patient satisfaction.

Safety protocols/regulations meet patient satisfaction

Bed alarms are annoying. Patients who desire independence and have some mobility will often complain about them and many turn them off with or without the consent of their care team. This is clearly a safety risk. In the context of “patient satisfaction” this type of situation is both confusing and common for our modern healthcare professional. We want our patients to be “activated” and “empowered.” We want to honor their preferences and allow them to have autonomy over their own body and care plans. We also want to keep them safe and, despite their own self-perception, patients who deem themselves capable of walking on their own fall and get seriously injured all the time. This list of “wants” is a series of contradictions and leads itself to a place in which care providers are between a rock and a hard place. Satisfaction or safety? Personal autonomy or professional experience? When is a patient empowered and when are they lacking the information or insight to make good decision? How do we support our patients, families and professionals in sifting through these nuances?

Violence in the workplace

Working in healthcare is extremely challenging for a variety of reasons. If personal safety is uncertain, however, these challenges may simply become unbearable. Patients and families physically threatening or actively assaulting nurses or other care providers is, sadly, not a unique story. Patients or families saying emotionally abusive things to healthcare professionals, in some settings, is fairly routine. At what point do we place the emotional needs of those who work in healthcare over those who are receiving the care? At what point do we excuse bad behavior out of compassion for the fear, pain or grief a patient or family member may be experiencing? How do we help healthcare professionals who have been verbally or physically assaulted process their own trauma in order to restore their emotional well-being and sense of security?

Family Driven Care at the End of Life

Along with the patient experience movement, the efforts to get families to discuss end of life wishes long before a person becomes gravely ill has been going on for decades. While there has been some amount of improvement, there remains a high degree of confusion about what we mean by “healthcare power of attorney” and “living will.” Combined with our general societal aversion to talking about end of life, it is common for families to make end of life decisions for patients who are not alert and oriented based on very little concrete information about what the patient’s wishes might have been. It is also not uncommon for those decisions to lean toward invasive care at end of life despite low probability of recovery or even

improvement. For those who work in healthcare this can be both exhausting and disturbing. How do we support the care providers who are being told by the next of kin to carry out treatment plans that feel more like torture than good medicine? How do we help our care providers know when to draw the line, if there is one? How do we give our care providers the tools they need to effectively communicate with a patient's loved one through a thick layer of grief?

Moving Forward

Genuine partnership includes mutual respect for the opinion, expertise and experience of our partner, even if we are in disagreement. Partnership includes the willingness to speak honestly in the interest of finding understanding, common ground and a path forward.

Partnership does not include disregarding the partner's opinion, expertise and experience when it does not match our own. It means listening during times of confusion and conflict. It means laying out the primary motivations for each partner such as a provider's primary focus of safety while a patient's primary focus may be on independence.

Leadership must ensure that bedside providers have the tools they need to communicate risks effectively and, when a patient chooses to ignore those risks, there must be an avenue to ensure the patient has the right to assume responsibility. While making a patient sign a document stating they understand the risks they take and are acting against medical advice can seem off-putting or even divisive, these documents can be executed in the spirit of partnership and recognition of a person's right to make their own decisions despite regulations or protocols. When these documents and conversations are paired in the context of the partnership characteristics named above, they can actually be a relief for all parties.

Violence against healthcare professional cannot be tolerated. Leadership must support those at the bedside by ensuring that patients and families who attempt violence or threaten violence are swiftly spoken to and made to understand the consequences of their actions/future actions. Strong measures must be taken to ensure that the patient or family member has an appropriate level of supervision from an officer of the law so that the healthcare professional feels both safe in continuing to care for patients while also clearly drawing a line between the role of healthcare professional and peace keeper. It is most important that staff see that, while we may not be able to control the behavior of patients and families, we can control how we respond to violence in the workplace.

Family driven care in conflict with professional values inherently requires a fine balance. While professionals

must never impose their medical will on patients and families, they usually carry with them far more context for the medical choices being laid before grieving family members. The impact on the family experience during these moments is obviously significant as end of life is something we never forget. What is often overlooked, however, is the recipe for burnout these situations hold for those caring for patients at end of life. It is not hard to imagine that this conflict would contribute to the three symptoms of burnout; depersonalization, emotional exhaustion and a sense of inefficacy. A significant amount of suffering could be avoided if time and training was encouraged by leadership, insurance models and other reimbursement models. If providers are not given the skills and space to discuss end of life before the crisis, we will continue to see these painful dynamics over and over again.

Conclusion

A partnership is an arrangement where parties, known as partners, agree to cooperate to advance their mutual interests. In the healthcare space, the mutual interest is primarily to restore health and/or provide comfort from pain and other kinds of physical suffering.

If we are truly striving for genuine or authentic partnerships between patients, families and healthcare providers, we must insist that the principles apply to *all* of the parties. As we continue on the patient experience journey, we look ahead and discover that we can let go of some of our practices while simultaneously innovating new ones. At the bottom of it all however, we now can see clearly that one truth will remain as we forge ahead: we can only change healthcare by committing to improving the experience for everyone engaged.

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