

The owners have a right to be heard: Patient voice in design and performance improvement

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Abstract

The Canadian taxpayer is an owner of the healthcare system and the owners have a right to be heard. This article encourages leaders both formal and informal to create cultures that promote ASKING questions to test assumptions held, LISTENING to hear the patient voice, and TALKING with patients and families to create new conversations and narratives. Looking at the label, “healthcare system” what’s your contribution to creating health, how will you dedicate yourself to caring about the healthcare consumer and care provider, and what will be your role in creating a new and improved system? An implied question at the foundation of the article is this: Is the difference between managing and leading a difference of empathy?

Introduction

In 1904, pioneering Canadian physician Dr. William Osler wrote,¹ “It is much more important to know what type of patient has a disease than what sort of disease the patient has.” If it was important at the turn of the 20th century to advise physicians to see, listen to, and treat patients as individuals, it is even more important today.

A hundred and ten years later (2014) in the article, *It’s All About Me: The Personalization of Health Systems*, Snowden and team had this to say:

... traditionally health teams have been the key decision-makers in most health systems and consumers are the patient who is viewed largely as the recipient of care. Although many health systems aspire to deliver patient-centred care, health professionals primarily focus on making choices for, and occasionally, with the patient ... the traditional health systems in many countries could be characterized as patriarchal: health system leaders determine the allocation of resources to deliver health services and health providers teams determine the best treatment and therapy options for the patient populations served.²

Discussion

Patients have preferences, values, and histories that need to be acknowledged and respected. They also have families, live in communities, and contribute to society.

The system of tomorrow needs to see whole patients, recognize their place within their family and community, and link them to the resources they need for maintaining their health, regardless of whether those are within or outside of the formal health system.

Given our increased understanding of disease complexity, the pace of new drug development, the proliferation of new medical technologies, and the demands of ever-changing clinical protocols, it is not difficult to understand why our health system is focused on the treatment of disease rather than the treatment of patients as unique individuals. Given the combination of

multiple health system conditions and challenges, it should be no surprise that patients often feel dissatisfied with their experience of treatment within our healthcare system.

A case for change

First, a concrete call for change cited in the article *It’s All About Me* . . . , we can gauge how well we are doing in our delivery of healthcare if we consider how many people stick to their treatment plan.² As many as half the people who are initiated on a medication are not still taking it within a year. This is a real indictment of the system. We have lost the connection with the people we treat because the plans we make are not perceived by them to be for them.

A second example, according to a recent (2013) study from the prestigious *Journal of Patient Safety*, 4 times as many people now die from preventable error, as many as 440,000 a year. Preventable errors, now claims the third spot in the United States, are the leading cause of death. When I talk to our Patients For Patient Safety Members, a common theme in their personal story and experience is this: “the providers did not listen to me or my family.”¹⁰

A third example relates to our most important asset, our people. A recent study from Truven Health Analytics, formerly the Healthcare business of Thomas Reuters, reports that hospital employees are less healthy than the general workforce and cost more in healthcare spending. They found hospital employees are more likely to be diagnosed with chronic conditions like asthma, obesity, and depression and were 5% more likely hospitalized. These workers spent 9% more in healthcare costs than the general public. What impact does an unhealthy workforce have on health system design, performance improvement and transitions of care?¹¹

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What's wrong with this picture? An alarming paradox, a healthcare industry that purports to care for people but ends up being third in the United States in terms of creating unexpected deaths and has a workforce that is less healthy than the general workforce. Given the 2013 US study previously referenced, what would the Canadian picture look like? What does your photo look like?

Often the images painted don't always mirror the reality in which patients and providers find themselves. Like photographers, healthcare leaders at all levels make choices. They choose what to focus on within their personal frame. Time to focus on the difference between what is reported and what patients experience every day.¹³ Silence, unawareness, indifference to variation, and complacency are the greatest enemies of improvement.

Back to the title of this article . . . Owners have a right to be heard. As Margaret Wheatley³ said, "When a system is failing or performing poorly, the components must come together to learn more about itself, from itself." Expanding our view of health services to encompass a more multidisciplinary, community-based model is one way to help support the treatment of whole patients.

A personal experience with patient safety and quality

This may be little more than common sense, but there is nothing like a little unplanned field work to confirm the importance of the patient voice and experience in the design, operation, and performance of the healthcare system. I didn't think part of my orientation would be to inadvertently spend my first 5 days as the Chief Executive Officer (CEO) of the Canadian Patient Safety Institute in a hospital. This was my first time ever as a patient and it was an eye opener.¹² I got to see and feel firsthand the complexity of a hospital system: a busy emergency room, people on stretchers in hallways waiting for a bed, 13 hours in my case, confined quarters, equipment and supplies stacked everywhere, multiple tests, and the tireless efforts of frontline providers.

In a room partitioned only by curtains, privacy and at times dignity go out the window. It is interesting that a government rightly obsessed with privacy on so many levels institutionalizes an astonishing lack of patient privacy in its own facilities. As a small consolation, the absence of privacy makes equally violated bedfellows.

I and my roommate were sick and would have rather have been somewhere else. I was in a large teaching hospital in a big city where the chance of running into anyone I knew was minimal. I wondered what it would be like to be in a hospital in a small town where the fact that everyone knows everyone else is both a community-building virtue and a privacy-challenging limitation.

In any event, there we were, and I found it extremely difficult to distance myself from the agony, obstacles, and progress of those around me. Our difficulties and illnesses became common knowledge as did our treatment and progress. I began to observe the activity inside my room: I was part patient, part amateur medical anthropologist, and part informal counsellor. I watched and listened to the care provided to those around me.

For many, understanding patient safety from the patient's perspective is critical to achieving success in their own organizations. I urge all senior decision-makers, planners, policy-makers, theory experts, tool kit designers, and anyone who wants to make a difference in healthcare to spend time on the wards, have conversations, and see and feel what it is really like.

During my hospital stay, I lived the gap between the theory and practice of *patient empowerment*. I was a relatively informed patient, but I found it difficult to ask safety related questions. I wanted people to wash their hands but did not want to annoy while I was vulnerable and needed their care. I was in no position to take my business elsewhere. What haunted me the most was how my vulnerability stripped me of my autonomy, my power. I was on my back and helpless.

Any economist who persists in believing that healthcare is a market product just like any other has not spent any time as a patient. You give up your body and power to an institution and a team of strangers. They have all of the technical knowledge and you are scared. The last thing you are is a shopper and bargaining agent.

There is nothing new in what I experienced—it is the reality of being a patient in a system that struggles to get things right. Perfection is unattainable, but we will never approach perfection *unless we commit to settling for nothing less*.

A challenge for all

We are all servants to those we are here to serve. Our healthcare system embodies the highest order and purpose—to foster life, health, and well-being through knowledge and service at each stage in the cycle of life.

The challenge for all is to lead, manage, guide, and coach others through a patient experience transformational process that includes the patient voice in design and performance improvement. This goes much deeper than tinkering with structure and adopting the right rhetoric, like patient-centred care. It is a sustained effort to embed value, quality, and safety as a defining imperative *that permeates both individual behaviour and organizational culture*.

Within our context, within our organizations we have all the gifts (intelligence, experience, and know how) we need to move forward. Every individual, including patient and family, has the capacity to contribute to healthcare transformation. Every individual who is part of the healthcare system carries the seeds of success: skills, talents, potentialities, and enthusiasm. Unfortunately for many frontline care providers and patients, the same seeds also contain too many intellectual, emotional, and systemic barriers. Leaders both formal and informal—all of us—need to take action and nurture the growth of those seeds that will allow for a patient centred system.

Far too often, organizational culture with its customs, traditions, and practices play out in day-to-day power and political relationships. In the book *Learning in Relationships* by Ron Short the following observations are offered:⁴

- The current relationship and behaviour patterns you and your colleagues have were created by all of you. You are all active, card-carrying members who help maintain

them. It is far easier to see the other's behaviour than to notice how your behaviour invites the other's behaviour and thus co-creates the pattern.

- When you understand relationships, you will shift from managing others to managing yourself with others.
- The critical path to learning begins with the ability to think differently.
- Reality is made up of interconnecting and overlapping circles but we see and act and respond in straight lines.
- Transformation begins when one person leans in to listen.

Patient engagement is not an add on

Patient engagement is not an item to be checked off a list, rather, it is a vital process that must be built into the everyday operation of our healthcare system. It cannot be an add-on to what we do, but must be embedded in our practice as healthcare providers.

From a system perspective our biggest, yet least visible challenge is that often we think the world is outside of us. MIT's Wanda Orlokowski⁵ puts it this way, social systems and the structural properties of these social systems are not "out there," independent of us but they are created every day through our thinking and through our actions.

In her 2012 report *Measuring What Matters*, Anne Snowden found that Canadian values (what consumers of healthcare value in their healthcare system, such as patient engagement and partnership with healthcare providers) do not match the standard dashboard of organizational metrics (eg, costs, medication errors, and mortality rates).⁶ That which is measured gets done. Yet "there is no link between costs and outcomes of healthcare, such as quality of life, collaborative partnerships with providers, or community empowerment. Thus, there are no direct incentive models or performance measures to account for health system outcomes that align with the values of health, wellness, or quality of life for Canadians."

MIT's Peter Senge⁷ was asked a penetrating question, "Are the basic fundamentals for sound leadership the same and are we just responding to a different world, or are the fundamentals shifting?" He responded: "For me the fundamentals start with a set of deep capacities with which few in leadership positions today could claim to have developed: systems intelligence, building partnerships across boundaries, and openness of mind, heart, and will." To develop such capacities requires a life-long commitment to grow as a human being in ways not well understood in contemporary culture. Yet, in other ways, these are the foundations for leadership that have been understood for a very long time. Unfortunately, this ancient knowledge has been largely lost in the modern era.

In the essay *Implementing Leadership in Healthcare* by Saul et al.,⁸ they offer 5 guiding transformational principles.

Clarity of purpose

What is needed is a clear, compelling purpose that reflects our nation's core health values. This purpose should reflect

functionally integrated system across the continuum of care and be built to achieve its intended outcomes for the people of Canada.

Alignment of effort

Ministers, boards and CEOs, clinicians, frontline leaders, patients, and families need to work together to develop a shared vision for the future and to define the roles each must play toward achieving that vision.

Credibility of leadership

Authentic, credible leaders champion and orchestrate change, by taking action and "walking the talk." Leaders must model the behaviours and values they wish others to emulate (eg, building relationships, establishing partnerships and building teams, walking the halls, and showing empathy).

Integrity in the organization

Successful leaders value and encourage diversity and different points of view. People need to know that their voice counts and feel free to state opinions that may not be shared by everyone.

Accountability for performance

Leaders are accountable for organizational and system performance, but true system performance is achieved only through collective accountability for outcomes.

There is an opportunity before us to reform healthcare in Canada to achieve its purpose of improving health outcomes and to do it better than any other system in the world. The skills, power, and passion required to meet this challenge *today* are present in abundance so let us begin.

The call to action is nicely captured by Saul et al.⁹ in an essay titled *Advancing the Art of Healthcare through Shared Leadership and Cultural Transformation*. They suggest a 3-legged foundation consisting of the patient voice, practitioner ears, and organizational support.

- First, the patient must be at the centre of every interaction within the healthcare system and recognized as a unique and whole individual, extending beyond the boundaries of the shift or room within which care is provided. Relationships among everyone involved in a healthcare event—including the patient, her family members, and all care providers—form the backbone of the healthcare experience. Prioritizing these relationships and listening carefully to the patient voice allows us to tip the scales to achieve a better balance between the art and science of healthcare.
- Second, everyone in the healthcare system must share the responsibility for listening and watching for threats to quality and patient safety and for the authority for taking action to make changes. The eyes, ears, and hearts of frontline care providers and middle managers must be fully trained on the target of improving the patient experience if progress in this area is to ever be made.

- Third, and perhaps most importantly, improving the patient experience requires a change in culture. This change must be embraced by and reflected in the actions of everyone within the system. Furthermore, everyone must understand the fundamental truth that change is an ongoing and healthy process. All organizations undergo constant change, but healthcare organizations that embrace the patient voice, encourage shared leadership, and seek to build trust rather than apportioning blame are bound to evolve in a patient-centric direction.

Conclusion

My professional and personal experience with patient safety allowed me to see clearly what it really takes to transform our patient safety culture into a culture we all can be proud of.

1. Context is everything—while the capacity to change exists in every individual and every organization, it must align with the organizational history, sense of urgency, readiness for change, culture, and degrees of leadership commitment.
2. Denial is our greatest threat—there is a gap between the quality and patient safety outcomes we see on paper and what patients and providers experience. Silence, unawareness, indifference, and complacency are the greatest enemies of improvement.
3. It is all about relationships—honest and open relationships between all involved in care together with a culture that supports healthy interactions and is rooted in true values are the sources to achieve excellence.

Let's ensure that we:

ASK questions to test assumptions held,
LISTEN to hear not counter, and
TALK to create a new conversation and narrative.

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