

Resilient Health Care through Patient Engagement

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Seeing healthcare from the patient and family perspective

With the great medical advances of the last century, such as antibiotics and vaccines, our populations are living much longer.¹⁾ Many acute illnesses and diseases that historically ended lives in infancy, childhood and midlife, are vanishing. More of us are living longer and enjoying better health far into advanced old age. Having benefited the young and middle aged, the resulting demographics feature much older populations who are seeking to prolong wellbeing while managing chronic disease and conditions.

This rapid medical revolution has fed a widespread expectation that medicine is “magic” . Medical interventions, especially those driven by perverse financial incentives to deliver new technologies and new drugs with inadequate trials, can mislead the vulnerable into believing that the latest treatment will banish all fear and prevent inevitable mortality.²⁾ In spite of remarkable ongoing medical research, hope may exceed any reasonable evidence of cure. The cost of excessive treatment free of evidence has led to major public campaigns to close those gaps. The goal is to identify what can prevent conditions that imperil health, what treatments are effective for patients “like me” , and what options are promoted for profit or preying on faint hope.

Grappling with over testing and over treatment, has led to important initiatives to help patients and families learn what they can do themselves to prevent and manage debilitating conditions often associated with old age. While the evidence may not support “cure” , there are often an abundance of useful and evidence-supported approaches to improve quality of life while preventing and managing symptoms. The evolution of healthcare’s movement beyond disease avoidance to wellness enhancement is also promoting prevention in early life and wellbeing at every age. For patients and families, this means continuing to take greater responsibility for our own health.³⁾

Much as we celebrate clinical advances, the consequences for medical support over longer lifespans has imposed new demands on patients and families. Patients may visit a doctor’s clinic for only a few hours in a year, but they spend 365 days every year living with the condition. There is no question that the patient and the family are more expert on symptoms, impact on activities of daily living, consequences of drugs and other therapies, change over time and needs. Developing services models for diagnosis, decision-making and treatment that respect the “expert patient” is a leading challenge for achieving efficient and effective care.⁴⁾

The traditional doctor-patient dyad is changing rapidly. No longer are optimal outcomes said to come from the obedient or “compliant”

patient in a hierarchical relationship with the healthcare professional. Increasingly, the patient, and perhaps with family as well, is an active participant in the care team. Ideally, the patient and family commit to contributing first person knowledge, learning how the research evidence informs their situation, appreciating their professional's clinical judgement, considering guidelines, weighing risk, and reflecting how care alternatives impact their own values and preferences. But even more important, the basis of the therapeutic relationship is trust. Developing reciprocal relationships of trust between professional carer and patient will support better understanding, commitment and reward to both the patient and to the provider of care. The strength of this trust can sustain better care through remarkable challenges to seamless and excellent care.

In the past, patients and families may most often have submitted to "indicated treatment" primarily as the result of a clinician's judgement as to what is best. Increasingly care planning and support are characterized by protracted deliberation and discussion in "shared decision-making" before care plans are agreed. As the resulting way forward is a co-production, the patient and family can benefit from greater certainty that they know they are understood, their priorities accepted, and that they have also participated in designing a plan to fit their needs. They also now share a personal stake in fulfilling what they have had a hand in creating. Compliance with treatment becomes a logical expression of self-determination. When unwellness erodes a sense of personal capacity, taking a personal role in care design can be a compelling achievement.

Self-management may create system expectations that patients and their families will willingly take on an unfamiliar and significant burden of treatment.⁵⁾ Care plans may require the patient to navigate and coordinate complex essential

relationships among members of a diverse team. If the system has failed to accomplish this, how might patients and families succeed? In spite of a team of healthcare professionals assigned to coach and help monitor a patient's self-management, the responsibility for the flow of accurate information and joined-up care may unduly rely on the patient and family. For some, successful self-management can be achieved with support from a care navigator, or peer mentors, or a clinical help line to solve problems. Emerging models of self-management through episodes of healthcare will transform primary medicine and all of the travel in and out of secondary and tertiary services.⁶⁾

What does Safer Care mean from the perspective of patients and families?

Safer care is seen as an adaptive and expanding criteria for every domain of care.⁷⁾ Innovation and expansion in the patient's new settings for care are already transforming the way professionals and administrators view demands for quality service in the full scope of practice, extending across all interprofessional relationships and encompassing transparent accountability. Old patient safety systems for identifying adverse events and tracking error in a standardized system view of patient "journeys" seem less relevant to this more dynamic self-directed experience for patients and families.

The consequences of adopting new methodologies for measuring what is safer care in micro, meso and macro system performance from a patient perspective are profound. Conventional outcome measures may make little sense when care planning is co-produced with patients. The need for new approaches, using new evaluation tools, is obvious. Excellence in healthcare must consider a broader environment where care delivery and its success are defined by the patient. New approaches for safer care and better patient experiences must originate from active

engagement of the patient and family.

Consider the interactions with healthcare from a patient perspective as “Patienthood” . The structure and dynamics lived by patients and families can be identified as a distinct complex adaptive system⁸⁾ that parallels and occasionally interacts with the co-existing complex adaptive system of healthcare.⁹⁾ This analytical model can help us better understand and respect patient skills. Consider the dilemmas even experienced healthcare workers face when navigating their own healthcare journeys as patients and family support. Respecting patienthood can also support the potential for achieving better care from collaborative participation in improvement by patients and family members.

Patients and families experience wellness, illness and treatment within a unique and personalized dynamic, referred to as patienthood here. A person becomes aware of symptoms, and triages their disruption to activities of daily living. When ignoring symptoms is no longer desirable or possible for any number of reasons, the patient and/or family may reach out to the healthcare system. But exactly how and when depends not only on what access is available, but also on the patient or family knowledge of medical services, needs met by those resources, past experience, and much more to inform this decision.

However, in spite of a certain reverence for medical expertise, the most part the patient’s lens on care reveals that most of healthcare occurs at home and in the community, with only occasional visits to clinics, treatment and specialist consultation. The dynamics of patienthood include support (or lack thereof) from family members and neighbours, economic stability, housing conditions and transportation availability. All of the social determinates of health play a role. Meanwhile, patient decisions are individual and unique. Patienthood includes not only avoiding ill

health, but also planning, nurturing and enjoying wellbeing.

When the healthcare system operates to serve its own needs rather than patient priorities in general, or for a particular patient in this moment, the quality of care will erode. Operational closures, service congestion, cumbersome record keeping, poor integration with all medical services, and many more characteristics of a system-centric healthcare point to a complex adaptive system that makes interactions with patienthood more difficult. Health quality and safety can suffer.

Encountering barriers to seamless care may have the effect of diverting or discouraging the patient, delaying treatment, influencing future care decisions, affecting the future decision-making of family and friends. Poor care spreads mistrust beyond the primary actors to influence many individuals far beyond. How else to create excellent care than by engaging those who know most what is needed?¹⁰⁾

If patients and families are participating in individual care planning and delivery, who and how do we evaluate care quality and safety? That is, when is care safer, and when is it less safe. When the patient plays a lead role in defining care goals, does the patient also share in accountability for achieving these goals? Clearly the concepts of quality and safety are changing.

Partnering with increasingly “expert” patients could ensure that healthcare systems and practitioners come to see care quality as defined by what matters to patients, and particularly for *this* patient. For patients with cognitive and other limitations, family members may engage actively in quality and safety assessment. Where there is no family to stand in, adaptive patient-centric approaches may prove to be appropriate and helpful for improvement.

Co-creating excellent care can lead to discovery of important priorities not otherwise apparent. Just as treatment decision-making is shared, so evaluation and assessment of care could be co-developed as integral to whole person planning for wellbeing. Patients and families can help to design methodologies and metrics that identify drivers for safer care and better patient and family experiences. That care interactions are individual and unique does not prevent higher level reporting, evaluation and improvement in collaboration with patients and families.¹⁰⁾

How can Patients and Families contribute to Safer Care through the Dimensions of Resilience?¹²⁾

Medicine and social norms need to support new understandings of the continuum of safety and care quality to keep pace with changing models of care. The characteristics of resilience outline a helpful perspective on how healthcare can succeed within complex dynamics such as the model of patienthood presented here.

How do patients experience “living well” with unique multiple chronic diseases and comorbidities? What does it mean if a patient chooses to opt out of care, even when the evidence suggests clinical benefit? What if the burdens of treatment outweigh a significant sense of quality of life? Can a patient’s own values and preferences override evidence and system assumptions about care quality? Will a patient’s healthcare team honour a patient’s decision without negative judgement, even if the outcome is “adverse”, or accelerates end of life? Can a patient change his or her mind?

New ways of thinking for self-management into old age also challenge conventional notions of the components of excellent care. As a society, what makes up well-being? Collectively, how will we

sustain strong social connections that allow us to find purpose and pleasure across our lifespan? Who will support us with assistance and affection as we decline towards frailty? Do we value freedom over paternalism such that each person may knowingly choose a risky care path, when autonomy and the pursuit of pleasures outweigh safety? Who decides? Who accounts for accidents and errors?

Resilience engineering offers some powerful concepts to satisfy the newly coined Quadruple Aim¹³⁾ of better outcomes, lower costs, improved patient experiences AND improved clinician experiences.¹⁴⁾ The best clinical care may only be achieved if the intrinsic rewards for truly caring return to the practitioner. This fourth aim, that of improved clinician experiences, offers a powerful force for sustaining safer care.

Equally, connecting up patients and families with the clinician’s experience of care can close the loop to validate an investment of empathy and excellence. Healthcare is all about relationships. When we commit fully to a value equation for care that matters to patients and families, we can sustain relationships of trust that reinforce the choice of a career in healthcare.^{15),16)}

Resilience engineering offers a plausible rationale for how relationships of trust support this value equation. The facets of collaboration emerge through partnering with patients and families for better care. Through these relationships we can better understand what makes care successful in mutual support, or hollow with expectations unmet, thereby exposing greater risk.

The ability to respond: *How ready is healthcare able to respond when something unexpected happens?* Do health care workers explore with patients and family members what safety means to them? What is the full range of safety precautions? Do healthcare workers respond effectively and

proactively to meet patient, family practitioner and public needs following harm, or the risk of harm, before harm's impact escalates?

The ability to monitor: *How well is the organization able to detect changes that may affect its operations?* Can patients freely inform providers when they feel safe, or vulnerable to harm? Would providers listen and react if patients experience a change? Are confident and trusting patients considered and assessed as a system goal? Do confident and trusting patients also experience better clinical outcomes that maximize value for care delivered?

The ability to anticipate: *How large an effort does the organization put into foreseeing what may happen in the future?* Are citizen-patient advisors embedded in improvement processes, planning and evaluation? Are patient peer counselors distributed throughout care settings to support patients and families, observe care effectiveness, detect change and play an early warning function for the impact of system stresses on clinical performance?

The ability to learn: *How well does the organization use opportunities to learn from what happened in the past?* Are patients and family members integrated

into safety reviews and system resilience scanning? Do patients and family members confidently provide specific, timely and detailed feedback to providers on drivers of care excellence as well as near-misses, harmful incidents and their impacts? Are patients and family members encouraged to propose innovations and improvements for secure and trustworthy care experiences?

By pursuing these four dimensions of resilience through collaboration with patients and families, better patient care returns better rewards for healthcare workers' investment in caring. With the current trajectory towards ever more specialized and fragmented care failing patients and families, change is needed. We do have alternatives to healthcare worker stress and "brittleness" that threatens the professions and the institutions of healthcare.¹⁷⁾ Recognizing the validity of patienthood and empowered patients as offering unparalleled expertise for safer healthcare will build on the very fundamentals that attract compassionate and skilled practitioners to this exemplary calling.