

Engaging Families (and Ourselves) in Quality Improvement: An Optimistic and Developmental Perspective

Christina D. Bethell, PhD, MBA, MPH

From the Department of Pediatrics, School of Medicine, Oregon Health and Science University, Portland, Ore
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The success of the intervention relies on the interior condition of the intervener.

—William O'Brian, past CEO, Hanover Insurance Company

Unleashing the potential of engaged patients and families to catalyze improvements in health care quality, safety, outcomes, and efficiency has been emphasized by health care leaders, researchers, and advocacy organizations for well over a decade.^{1–3} Since 2000, patient and family engagement at all levels has been a pillar in the Maternal and Child Health Bureau's (MCHB) legislatively required "systems of service" performance monitoring model⁴ and is explicitly set forth as a central theme in nearly every national health care reform initiative today.^{5–9} Championing a transformational brand of patient engagement, these initiatives urge fundamental shifts in system structures, patient care processes, and the culture of care and point to the importance of simultaneously engaging and activating patients and families in policy, research, health care governance, and services design and delivery.¹⁰ Cross-cutting to engagement at each level is continuous and intentional communication regarding patient and consumer needs, goals, and capacities and the ability of systems, care teams, and policies to remain flexible, adaptable, and responsive to the information that arises through this type of transparent communication.

Engaging and activating patients has been associated with reductions in safety errors, improved adherence to treatment plans, fewer appointment no-shows, better self-care behaviors, reductions in repeat procedures and hospitalizations, better care coordination, greater trust, reduced health care costs, and other benefits.^{11–13} Although increasingly featured as a component in children's health care quality measurement and improvement processes,¹⁴ the majority of studies, measures, strategies, and frameworks for patient engagement focus on adult health care.^{10–13,15} This presents the pediatric community with a tremendous opportunity to learn from and build on these methods to address the many unique factors essential to promoting the healthy

development of children and meeting the often complex needs of America's growing population of children with chronic conditions and special health care needs.¹⁶

Even as evidence grows regarding the positive impact of proactively engaging and activating patients and families, recent Agency for Healthcare Research Quality reports^{10,15} and similar reviews point to the fact that doing so is still in early stages of development. While evolving, we possess neither an agreed-upon lexicon to define engagement^{17,18} nor well-defined strategies or professional training and implementation models to sustainably and effectively engage families. Importantly, we also lack standardized measurement tools to evaluate a family's existing level, potential, and requirements for engagement and to monitor the success of efforts to move families along a trajectory to optimize engagement and activation.

Given the predictable failure of change efforts that work against the predominant paradigm and culture in any health care system,¹⁹ particularly alarming are studies documenting that many clinicians and health care leaders do not report holding core beliefs, knowledge, skills, and/or resources needed to embrace patient engagement.^{20,21} Rather than meet the innovation challenge engagement presents, many report being stalled by worries that engaging and activating patients will reveal needs and expectations that cannot be met,^{22,23} especially in the fiscally stressed and hurried context of the still-dominant episodic, acute-care model where mindful communication to address even immediate needs can be difficult, leaving little attention to establish a partnership with and engage patients and families around more holistic and longer-term health needs and goals. At best, such engagement is focused on medication use adherence and shared decision making around medical events such as surgery.^{10,24}

Pursuing the brand of patient activation and engagement reflected in prominent reform efforts today not only requires clinicians, teams, and the organizations they operate within to do things differently. Rather, as noted in studies evaluating the Primary Care Medical Home model, we are also called to *be* different.²⁵ For example, both the pediatrics-focused Practicing Safety initiative²⁶ and

the Joint Commission's High Reliability Organization's (HRO) model^{7,27} to transform the quality and safety of health care in the United States emphasize the practical importance of self-reflection, mindfulness, and personal development to navigate the inherently complex, relationship-centered processes of engaging patients and each other in improving the quality and safety of health care. The HRO model defines a series of essential personal- and team-level attributes that, taken together, are summarized as collective mindfulness.²⁸ Engaging this presence effect²⁹ requires clinicians, teams, and leaders to prioritize highly personal tasks to 1) continuously improve real time self-reflection and mindful, transparent communication skills, including the capacity to perceive and inductively respond to the tacit knowledge essential to partnership-based care³⁰; 2) make assessment and nonreactive reflection on performance a habit; and 3) to proactively shift patient and care team relationships from paternalism to mutuality.

Despite challenges, there is cause for optimism. First, the high level of focus on engagement may indicate that the nation is in fact on the cusp of a developmental leap, having now wrestled with and learned from efforts thus far. In pediatrics, while still rare, promising strategies are emerging to employ family engagement not only *in* QI processes, but also *as* the primary QI intervention, including the use of personal technologies, such as the patient-driven previsit planning and self-care tools recently recognized in AcademyHealth's 2012 Relevant Evidence to Advance Care and Health challenge. Finally, inspiring optimism is today's more supportive policy environment that seeks to align financial incentives with our values to partner with families and promote health—values that drew many into pediatrics to begin with.

Many articles in this journal issue rightfully focus on quantitative methods and the “what” and “how” of QI. Adding to these, research suggests an equal focus on the “we” and the “who” of QI—and developing excellence in the relational abilities and intrapersonal capacities essential to engaging families. Doing so may be the key to making our “what and how” QI methods come alive and may very well be the key ingredient to woo the elusive development leap in QI we are all searching for. This brief scan suggests we adopt a developmental perspective in our work to engage patients and families. Doing so adds an appropriate seriousness to the task. It prevents us from underestimating the fundamental shift represented by moving to a culture of partnership for providers, patients, and organizations; challenges us to map milestones and trajectories; and ensures that we objectively assess where we stand—individually, and as members of teams and organizations.

As we map the developmental landscape for effectively engaging patients and families and meet the related challenges, we are also likely to find that authentically engaging families and patients at all levels draws us into closer alignment with already deeply held values, aspirations, instincts, and goals to promote and improve health and health care. In this way, patient and family engagement

engages us in turn—and, I expect, will contribute to the creation of greater joy among the pediatric health care community as well as among the children, youth, and families we serve.

REFERENCES

- Berwick DM. Disseminating innovations in health care. *JAMA*. 2003; 289:1969–1975.
- Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington DC: National Academies Press; 2001.
- Wagner EH, Austin BT, David C, et al. Improving chronic illness care: translating evidence into action. *Health Aff (Milwood)*. 2001; 20:64–78.
- Strickland BB, van Dyck PC, Kogan MD, et al. Assessing and ensuring a comprehensive system of services for children with special health care needs: a public health approach. *Am J Public Health*. 2011;101:224–231.
- Patient Protection and Affordable Care Act, Pub. L. No. 111–148 [S] 10307. Available at: <http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>. Accessed November 12, 2012.
- Ahier B. Stage 2 meaningful use: patient engagement and HIE. Government Health IT, August 31, 2012. Available at: <http://www.govhealthit.com/blog/stage-2-meaningful-use-patient-engagement-and-hie>. Accessed November 7, 2012.
- Chassin MR, Loeb JM. The ongoing quality improvement journey: next stop, high reliability. *Health Aff (Milwood)*. 2011;30: 559–568.
- US Department of Health and Human Services. National strategy for health care quality in America, 2012.
- Agency of Healthcare Research and Quality. The patient-centered medical home: strategies to put patients at the center of primary care. February 2011. Available at: http://www.pcmh.ahrq.gov/portal/server.pt/gateway/PTARGS_0_12547_955661_0_0_18/. Accessed November 12, 2012. Publication No. AHRQ 11–0029.
- Maurer M, Dardess P, Carman KL, et al. *Guide to Patient and Family Engagement: Environmental Scan Report*. Rockville, MD: Agency for Healthcare Research and Quality. Available at: <http://www.ahrq.gov/qual/ptfamilyscan/ptfamilyscan.pdf>; 2012. Accessed November 12, 2013. AHRQ Publication 12-0042-EF.
- Hibbard JH. Engaging health care consumers to improve the quality of care. *Med Care*. 2003;41(1 suppl):161–170.
- Hibbard JH, Greene J, Overton V. Patients with lower activation associated with higher costs; delivery systems should know their patients' “scores.”. *Health Aff (Milwood)*. 2013;32:216–222.
- Hibbard JH, Mahoney ER, Stock R, et al. Do increases in patient activation result in improved self-management behaviors? *Health Serv Res*. 2007;42:1443–1463.
- Aquino E, Bristol TE, Crowe V, et al. Powerful partnerships: a handbook for families and providers to improve care. National Initiative for Children's Healthcare Improvement. Available at: <http://www.nichq.org/documents/powerful%20partnerships.pdf>. Accessed November 7, 2012.
- Agency for Healthcare Research and Quality. *Guide to Patient and Family Engagement in Hospital Quality and Safety*. Rockville, MD: Agency for Healthcare Research and Quality; June 2013.
- Bethell CD, Kogan MD, Strickland BB, et al. A national and state profile of leading health problems and health care quality for US children: key insurance disparities and across-state variations. *Acad Pediatr*. 2011;11(3 Suppl):S22–S33.
- Coulter A, Safran D, Wasson JH. On the language and content of patient engagement. *J Ambul Care Manage*. 2012;35:78–79.
- National eHealth Collaborative (NeHC). Patient engagement stakeholder survey results. Available at: <http://www.nationalehealth.org/ckfinder/userfiles/files/2012%20NeHC%20Stakeholder%20Survey%20Results%20FINAL.pdf>. Accessed November 7, 2012.
- Best A, Greenhalgh T, Lewis S, et al. Large-system transformation in health care: a realist review. *Milbank Q*. 2012;90:421–456.

20. Hibbard JH, Collins PA, Mahoney E, et al. The development and testing of a measure assessing clinician beliefs about patient self-management. *Health Expect*. 2010;13:65–72.
21. Sweet M. Busting some myths about consumer and community engagement in health decision-making. November 16, 2012. Available at: http://blogs.crikey.com.au/croakey/2012/11/16/busting-some-myths-about-consumer-and-community-engagement-in-health-decision-making/?wmp_switcher=mobile. Accessed November 16, 2012.
22. Hibbard JH, Lorig K. The dos and don'ts of patient engagement in busy office practices. *J Ambul Care Manage*. 2012;35:129–132.
23. Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care*. 2011;23:510–515.
24. Improve Adherence and Enhance Patient Engagement World Congress Conference. Available at: <http://www.worldcongress.com/events/PB13001/index.cfm?confCode=PB13001>. Accessed November 22, 2012.
25. Berenson RA, Hommons T, Gans DN, et al. A house is not a home: keeping patients at the center of practice redesign. *Health Aff (Millwood)*. 2008;27:1219–1230.
26. Stroebel CK, McDaniel RR, Crabtree BF, et al. How complexity science can inform a reflective process for improvement in primary care practices. *Jt Comm J Qual Patient Saf*. 2005;31:438–446.
27. The 2012 Fifth International High Reliability Conference Proceedings. Available at: <http://www.jointcommission.org/highreliability.aspx>. Accessed November 7, 2012.
28. Mindfulness centered quality improvement in pediatrics: a dialogue. November 9, 2012. Available at: <http://www.thepresenceeffect.org>. Accessed November 16, 2012.
29. Epstein RM, Street RL Jr. The values and value of patient-centered care. *Ann Fam Med*. 2011;9:100–103.
30. The 2012 Relevant Evidence to Advance Care and Health (REACH) challenge enabling access to relevant, timely, and useful information to improve health and health care. Available at: <http://www.academyhealth.org/Training/Training.cfm?ItemNumber=7098>. Accessed November 7, 2012.