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

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The success of the intervention relies on the interior condition of the intervener.
—William O’Brien, 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. 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 model and is explicitly set forth as a central theme in nearly every national health care reform initiative today. 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. 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. Although increasingly featured as a component in children’s health care quality measurement and improvement processes, the majority of studies, measures, strategies, and frameworks for patient engagement focus on adult health care. 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.

Even as evidence grows regarding the positive impact of proactively engaging and activating patients and families, recent Agency for Healthcare Research Quality reports 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 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, 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. 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, 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.

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. For example, both the pediatrics-focused Practicing Safety initiative and
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

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