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Patient Activation and Engagement

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Increasingly, practices involved in Patient-Centered Medical Home understand that patient “activation” and “engagement” are critical to the success of the medical home model of care. The concepts discussed in this article were first published in *Health Affairs* in February, 2013.

The first step in patient-centered healthcare is “activation,” which appears to involve four stages

1. Believing the patient role is important,
2. Patients having the confidence and knowledge necessary to take action,
3. Patients actually taking action to maintain and improve one's health, and
4. Patients staying the course even under stress.

According to *Health Affairs*, “Patient activation refers to a patient’s knowledge, skills, ability and willingness to manage his or her own care.” In 2008, the Institute for Healthcare Improvement defined the “Triple Aim,” two of which elements are improved healthcare outcomes and decreasing the cost of care. A growing body of evidence demonstrates that patients who are more actively involved in their health care, experience better health outcomes and incur lower costs.

The step beyond “activation” is “patient engagement.” “Activation” addresses a patient’s preparation and ability to be involved in their own care; “engagement” is a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly. “Activation” is the preparation or empowerment to obtain excellent healthcare, whereas “engagement” occurs when the patient actually participates in their care.

“Activation” involves learning and knowledge; “engagement” involves action and application. Patient engagement is one strategy to achieve the “triple aim” of improved health outcomes, better patient care, and lower costs. Both “activation” and “engagement” involved “health literacy” or a true understanding of their medical conditions. Modern health care is complex, and many patients struggle to obtain, process, communicate, and understand even basic health information and services. Traditionally, healthcare was actively delivered by providers to patients who passively received that care.

The desires and needs of patients were not often given consideration. And, beyond the scheduling of tests, procedures and appointments, practitioners often failed to provide

patients with the information they need in order to be “activated” and to be “engaged” in their own care. And even when patients do receive detailed information, they can be overwhelmed or lack confidence in their own choices.

The 2001 Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, called for reforms to achieve a "patient-centered" health care system. The report envisioned a system that provides care that is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Out of this recognition, in part, the field of patient engagement has emerged.

Shared Decision Making

This is a concept which is alien to traditional medicine as historically practitioners diagnoses and prescribed a treatment program and patients were expected to comply with the practitioners’ plan. Shared Decision Making is the first level of engagement, i.e., “patients and providers together considering the patient's condition, treatment options, the medical evidence behind the treatment options, the benefits and risks of treatment, and patients,, preferences, and then arrive at and execute a treatment plan. “

Health Affairs included the following illustration of “patient engagement through shared decision making.” “For example, although one patient with knee pain may wish to have knee replacement surgery, another may worry about the risks that the surgery may not completely relieve pain or restore mobility and may choose to forgo it in favor of managing the pain with medication and weight loss. In such cases, there are multiple, reasonable treatment options, each with their own risks and benefits, and the „correct“ path forward should be guided by a patient's unique needs and circumstances.”

According to *Health Affairs*, shared decision making involves several essential elements:

1. First, providers and patients must recognize that a decision is required.
2. Next, they must have at their disposal, and understand, the best available evidence.
3. Finally, they must incorporate the patient's preferences into treatment decisions.

Many studies have shown that patients who are "activated," that is, patients who have the skills, ability, and willingness to manage their own health and health care, experience better health outcomes at lower costs compared to less activated patients. In an effort to quantify levels of patient engagement, Judith Hibbard of the University of Oregon developed a "patient activation measure," a validated survey that scores the degree to which someone sees himself or herself as a manager of his or her health and care.

Conversation Ready

The “Conversation Ready” program is a grassroots public campaign that encourages people to think about how they want to spend their last days and to have open and honest discussions with their families and health care providers. By having these important conversations before a crisis

occurs, patients can consider and clearly communicate their wishes and forestall situations in which those decisions are made by others and not fully aware.

These conversations, initiated by Maureen Bisognano, president and CEO, IHI, and IHI colleagues, are an effort to make certain that the nation's health systems and providers have the skills to elicit and receive patients' and families' views about end-of-life care, document them, and carry them out. Ten "pioneer" health care organizations working with the institute have committed to being "Conversation Ready" within one year and to developing replicable and scalable models of change that others can adopt as well.

Patient Engagement Factors

A patient's degree of engagement may be affected by such factors as cultural differences, sex, age, and education, among others. As a result, specific competencies, such as language skills or an awareness and understanding of religious beliefs, may be required on the part of clinicians and delivery systems to effectively engage patients with diverse cultural backgrounds and socioeconomic status.

There are well-known limitations to human decision-making skills and the ability to maintain attention that serve as barriers to patient engagement. They argue that there may be better ways to influence patients' decision making, such as through "choice architecture," in which decisions to be made are structured so as to "nudge" a patient toward a particular choice. Most participants were unwilling to consider costs and generally resisted the less expensive inferior options.

A number of factors that lead patients to ignore cost have been identified. These factors include:

1. Patients' preference for care they perceive to be the best, regardless of expense;
2. An inclination to equate cost with quality;
3. Inexperience in considering trade-offs among cost and quality;
4. Disregard for costs borne by insurers or society as a whole; and
5. The impulse to act in one's own self-interest even though resources are limited.

Three main barriers to implementing shared decision making have been identified:

1. Overworked physicians,
2. Insufficient provider training, and
3. Clinical information systems that failed to track patients throughout the decision-making process.

Researchers note that payment reforms and incentives may be needed for shared decision making to take hold.