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David A. Fleming, MD 315 Clark Hall Columbia, MO 65211

Ethical Issues: Engaging Patients

The Institute for Ethics at the American Medical Association initiated the Ethical Force Program in 1997.ⁱ The purpose of E Force is to develop performance measures for ethical behavior and practices that can be useful throughout the health care system. To date an assessment tool measuring ethical behavior in privacy and confidentiality, and guidelines for ensuring fairness in health care coverage decisions, have been produced. The most recent work in progress addresses patient-centered communication for vulnerable populations, which encounters multiple layers of obligation for organizations and individual health care providers to ensure effective communication to patients. These concerns are summarized.

Organizations should help staff to engage all patients, including those from vulnerable populations, through quality interpersonal communication that effectively elicits health needs, beliefs, and expectations; builds trust; and conveys information that is understandable and empowering.

In *Crossing the Quality Chasm*, the Institute of Medicine recommended that the health care system make deliberate efforts to give patients more control over their own health care.ⁱⁱ The report noted that "systems must be designed to serve the needs of patients, and to ensure that they are fully informed, retain control and participate in care delivery whenever possible, and receive care that is respectful of their values and preferences." Health care systems that effectively integrate the needs and values of patients and helps patients feel confident in their participation require robust communication infrastructures.

Research has shown that good interpersonal communication between patients and their health care practitioners is a critical determinant of patient satisfaction, patient loyalty, adherence to treatments, and overall positive health outcomes.ⁱⁱⁱ For patients with varying levels of health literacy, whose primary language is not English, or who may come from a range of racial and ethnic backgrounds, failure to receive health information in ways that they can understand and adhere to may be a significant barrier to becoming engaged in their health care and receiving high quality care. Without effective communication and information exchange practitioners and patients are missing an integral linkage, which is critical to bridging the potential gap between patient and health professional views of medical conditions and health care treatments.^{iv} It is also important for organizations and providers to communicate with patients in a way that is understandable and not alienating. For example, to become engaged in their own health

care patients need accurate information about their health that they can understand and use, they should be encouraged to participate in making decisions and setting goals for their health care, they need to learn what to do at home to care for themselves and their families, and they should be encouraged to ask questions and learn about preventive measures and tests, treatments, or other services they may need.^v

Patient engagement hinges on trust. While a lack of trust may prompt patients to question their physicians' decisions, research has shown that patients who trust their physicians benefit from an improved therapeutic bond that results in better healing.^{vi} Trust is a foundational element of the medical profession and maintaining trust should be a focal point of physician practices, hospitals, and the health care system overall. Because of personal or other first hand experience with family members, patients may have either elevated or diminished levels of trust.^{vii} Organizations should ensure that staff recognizes the role of trust in patient engagement and the importance of good communication to building a trusting relationship. Barriers to communication created by cultural differences and gaps in health literacy often augment the fear and vulnerability fear created by illness and collectively may act as a negative driving force in the relationships we have with patients. Assuring patients' ability to understand what we do and say should remain constant in our collective efforts in caring for and treating patients, especially those that are most vulnerable.

ⁱ http://www.ama-assn.org/ama/pub/category/3592.html

ⁱⁱ IOM 2001 Crossing the Quality Chasm

ⁱⁱⁱ IOM 2002, Safran et al. 2001, Gordon et al. 1995, Stewart 1995, Roter and Hall 1993, Kaplan et al. 1989, Clark 1999

^{iv} 2003

^v Laine 1996, RWJF 2004

^{vi} Safran 1998, Thom and Campbell 1997

^{vii} Boulware 2002, Hauser 1997, Blackhall 1999, Yuen 1998, Siminoff 1999, Gamble 1997, Freedman 1998, Minniefield 2001