Chapter 50. Other Practices Related to Patient Participation

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Background

A number of practices and resources aim to facilitate the role of patients as their own safety advocates. These practices are not intended to shift the burden of monitoring medical error to patients. Rather, they encourage patients to share responsibility for their own safety. Although these types of interventions hold promise for enhanced patient safety, there is yet insufficient evidence of their effectiveness. Therefore, this chapter is a brief, general survey of practices related to patient participation; there are few practices that have been studied with sufficient rigor to merit a full evidence-based review. This chapter explicitly excludes consumer report cards, since such tools presently are more relevant to health care quality than patient safety.[1,2] There is a substantial literature on the patient's role in quality improvement related to specific diseases - eg, self-management and general education for patients with certain chronic diseases such as asthma,[3-5] diabetes,[6-8] and rheumatoid arthritis,[9-12] as well preoperative educational and preparation programs for patients undergoing cardiac surgery. [13] This literature was not reviewed in detail, both because it falls outside our definition of patient safety practices (Chapter 1) by virtue of its disease specificity, and because the volume of material was overwhelming given the time allocated for the production of this Report. There are obvious additional opportunities to promote patient involvement in helping protect their own safety drawn from the disease-specific experiences of the past, and this should be the subject of further exposition and analysis.

Patient Education Materials Regarding Patient Safety

Books, Web sites and consumer group publications abound with health care and medical information for patients.[14] The goal of these resources is to enable consumers to arm themselves with the knowledge to protect themselves. Health care providers may wish to distribute such materials to patients to alert them of the possible problem of medical error, and encourage those that would like to take appropriate action.

The Agency for Healthcare Research and Quality[15] produces a 5-page "Patient Fact Sheet" on preventing medical errors. This fact sheet educates patients on the problem of medical error, and provides 20 tips patients may follow to avoid medical error, ranging from properly measuring liquid medications to ensuring health care employees have washed their hands.

Proprietary educational materials have also been developed. For instance, DoctorQuality, Inc., a quality management company that provides products and services to health care consumers, purchasers, and providers, has developed online and offline tools that providers and patients can use to improve care,[16] including patient safety workbooks and quality guides for a variety of diagnoses and surgical procedures. The books describe the key events that patients should anticipate at each step of diagnosis and treatment, identify high-risk points in the treatment plan where mistakes are more likely occur,[14] and provide tips as to how to avert common errors.

Patients may also find resources in the popular literature. In *Lerner's Consumer Guide to Health Care*, the authors coach readers on questions to ask their physicians and ways to avoid

medical mistakes.[17] Dr. Robert Arnot's book, *The Best Medicine*,[18] educates patients about specific procedures (eg, coronary artery bypass surgery, cesarean section, hysterectomy, and carotid endarterectomy). Potential complications of each of these procedures are described, and volumes, average lengths of stay, and complication rates of major hospitals are presented.

Health information on the Web has increased patients' desire for medical information and raised significant issues regarding patient safety and the manner in which patients approach their doctors for information.[19] A recent study revealed that many physicians believe that Web resources can distance patients from physicians and have an adverse effect on patient safety. Specifically, there is concern that patients can receive and believe misinformation, or read of treatments and procedures unfamiliar to physicians, and in both instances lower their trust in physician recommendations.[20] Other physicians see the Web as a positive development in patient safety because when patients approach their doctors prepared with questions, office visits run more smoothly, and the physician's counsel may be better received.[20]

Similar issues surround the topic of direct-to-consumer (DTC) marketing by pharmaceutical companies.[21] In 1997 the Food and Drug Administration relaxed restrictions on television and advertising for prescription medication. Drug companies responded with an explosion of marketing in all forms of media. DTC advertising may stimulate discussion between patients and their doctors about treatment options, but it also drives patients to demand newer and costlier medications, when less expensive treatments might be effective.[22] When doctors resist, 46% of patients try to persuade them to change the original recommendation and another 24% attempt to obtain the requested drugs from another physician.[22] These sort of interactions erode the physician-patient relationship and may jeopardize safety by promoting polypharmacy.

Practices to Improve Non-compliance

Compliance with medical advice is widely discussed in the literature and non-compliance with treatment may result in adverse drug events.[23] The frequency of non-compliance is higher than many health care professionals realize.[24] Non-compliance may arise from misunderstandings regarding instructions for drug use, self-care, or other factors. In addition, some of these misunderstandings may arise from remediable factors, such as language barriers[25] or low health literacy.[26,27] Simple solutions, such as using a trained interpreter instead of a family member or untrained volunteer, and providing self-care and other literature in multiple languages and bilingual versions may improve patient understanding. Other interventions, such as patient education publications, have been proposed to reduce adverse drug events due to non-compliance.[28]

Access to Medical Records

Although patient access to their own medical records is regulated in some states, these statutes differ across the United States.[29] Some states mandate certain levels of access for patients; others limit access or allow the provider to deem access appropriate or inappropriate. Other countries, such as Britain, have passed legislation requiring that providers allow patients to have complete access to their medical records.[30] Some argue that access to medical records may encourage patients to take a more active role in their own health care, allow patients to become better informed about their care, and increase rapport. Others argue that staff may modify medical records due to concerns about offending the patient, and will be diverted by the time needed to explain information contained in the records. Finally, still others express concern that patients may be unnecessarily worried by what they read.[30] No studies in the United States have

analyzed these competing views, and therefore it is not clear whether cultural norms reported in studies from other countries are applicable here, and whether allowing patients to review their own charts will have the intended effect of reducing errors.

Comment

With the growing level of consumerism in health care,[31] patients may wish to take a more active role in reducing their chance of experiencing a medical error. However, the research regarding the ways in which providers can facilitate this role for patients who desire it is lacking. More research is needed on the efficacy of these interventions regarding medical error reduction and on patients' willingness and ability to use them.

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