



Prescriptions for Excellence in Health Care Newsletter Supplement

A collaboration between Jefferson School of Population
Health and Eli Lilly and Company

Volume 1

Issue 8 *Prescription for Excellence in Health Care* # 8
Spring 2010

Article 4

Spring 2010

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Recommended Citation

Joshi, Maulik DrPH (2010) "Practical Ideas for Patient and Family Engagement in Health Care," *Prescriptions for Excellence in Health Care Newsletter Supplement*: Vol. 1 : Iss. 8 , Article 4.

Available at: <http://jdc.jefferson.edu/pehc/vol1/iss8/4>

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Prescriptions for Excellence in HEALTH CARE

A COLLABORATION BETWEEN JEFFERSON SCHOOL OF POPULATION HEALTH AND LILLY USA, LLC

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Practical Ideas for Patient and Family Engagement in Health Care

By *Maulik Joshi, DrPH*

A few years ago, my then 7-year-old daughter was hospitalized for asthma complications. When my wife walked into the hospital room and saw our daughter's medical chart on a cart by the door, she began to look through it, trying to understand the information. A nurse walking by told my wife that she could not look at the chart. She whisked it away to the nurses' station. Although we noticed medical charts outside of other patient rooms, we never saw our daughter's chart again.

As clinicians stood outside our daughter's room discussing her case before discharge, my wife and I felt like outsiders. We wanted to know what we could do to control our daughter's asthma so she would not return to the hospital. But our conversations with the medical team left us without answers to our questions. Every conversation ended with a practitioner telling us to call the outpatient clinic and make an appointment with the pediatric pulmonologist.

Did we receive outstanding care at this hospital? Yes. How was the staff? Heroic. Could the system have better engaged us in our daughter's care for a better health outcome? Absolutely!

The National Priorities Partnership (NPP) has identified patient and family

engagement in health care as 1 of its 6 National Priorities - "...to make health care safer, more patient-centered, affordable, and effective."¹ Patients and their families want to become more involved in managing their health care and making decisions about treatment and procedures. Research has shown that engaged patients help achieve better health outcomes, lower service utilization, and lower costs.²

The NPP set 3 goals to engage patients and families:

- All patients will be asked for feedback about their experience of care, and this information will be used by health care organizations and their staff to improve care.
- All patients will have access to tools and support systems that enable them to effectively navigate and manage their care.
- All patients will have access to information and assistance that enables them to make informed decisions about their treatment options.¹

The NPP also emphasizes shared decision making as an important underlying goal in health care — calling for it to be "the norm for most diagnostic and treatment processes."¹

To help achieve these goals, I offer the following practical suggestions for involving patients and families in their health care. I believe that these ideas have merit and are worth testing as a means for achieving our overall aim.

Involve patients and families in the design and redesign of care.

Asking patients for feedback typically means distributing patient satisfaction questionnaires, but it also can include hands-on involvement for patients. For example, hospitals and health systems could include patients and families on care improvement teams and advisory councils. Such involvement gives patients formal opportunities to participate more directly in the design and redesign of processes, and their involvement and feedback helps to accelerate the pace of improvement.

Engage patients and families in the care process.

Two years ago, the Agency for Healthcare Research and Quality and the Ad Council launched a patient involvement campaign with a Web site called "Questions Are the Answer" (<http://www.ahrq.gov/questionsaretheanswer/>). The site features a "question builder" that helps patients prepare a list of questions for medical appointments. The message to patients is clear: get more involved in your health care.

(continued on page 2)

Hospitals and health systems can engage patients in the care process by including them and their families in multidisciplinary daily patient rounds. A study by Rosen et al compared and evaluated conventional rounds with family-centered multidisciplinary rounds in an inpatient pediatric ward. After family-centered rounds, the staff reported better understanding of patients' medical plans, better ability to help the families, and a greater sense of teamwork.³

Scheduling liberal visiting hours is another way to engage families. A research trial showed a positive clinical impact with a more flexible and open visiting policy in the intensive care unit.⁴ By participating in the care process through rounds or hospital visits and being prepared for appointments, patients and families have direct access to tools and support systems that help them manage their care.

Provide patients and families with easily accessible, meaningful, and understandable information.

Hospitals and health systems can begin by giving patients full and easy access to their personal health records. Ross and Lin reviewed outcomes from several studies in which patients were permitted access to their health records. They concluded that giving patients such access showed “modest improvements in doctor-patient communication, adherence, patient empowerment, and patient education.”⁵

Along with access to health records, providing customized educational materials for each patient is important. Customized materials are written in the patient's preferred language and at an appropriate reading level. Ease of reading is very important. NPP cites a recent study that found that over 75% of patients discharged from emergency departments do not understand the information or instructions they receive. More alarming, a majority of these patients *do not realize* that they lack understanding.⁶

In addition to providing understandable information, accommodating each patient's language preferences and cultural needs ensures that the hospital or health system is providing patient-centered care.

Address needs of patients and families with limited English proficiency (LEP).

A national study conducted by the Health Research & Educational Trust found that 80% of hospitals encounter LEP patients “frequently,” defined as at least monthly and often weekly or daily. Surveyed hospitals identified over 30 languages they had encountered, from Spanish (encountered by 93% of the hospitals) to Tagalog and Thai (encountered by 21% and 20% of the hospitals, respectively).⁷

Strategies to address the needs of LEP patients and families include: establishing a centralized program or department to coordinate language services; implementing remote or telephonic interpretation; hiring trained medical interpreters in high-volume languages and bilingual staff members with training in medical interpretation; providing training to clinicians on how to access and work with interpreters; and designating more positions—particularly clinical positions—as bilingual.

Transparency is an additional goal when engaging patients and families. Many hospitals and health systems currently report clinical outcomes including comparative costs and quality information. As a result, many health care consumers are gathering information before seeking medical treatment. Hospitals and health systems must ensure that the information they provide is relevant and useful. In a recent article on “patient-centeredness,” Berwick suggested that hospitals “extend transparency to all aspects of care, including science, costs, outcomes, processes, and errors.”⁸

Conclusion:

During my daughter's hospital stay, my wife and I wanted to become more engaged in the care process. Participating in rounds, having access to her health record, or sharing in decision making would have made us feel less like outsiders and more like active participants in her care. Many hospitals and health systems are doing more and doing better at engaging patients and families in the care process. The journey continues.

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