Teaching Patients to Protect Themselves during Care Transitions
A Patient Safety Campaign

BY MARIE DOTSETH

Patient safety can be compromised at any time, but a disproportionate number of problems occur when patients are transitioning between care settings and care providers. Therefore, those trying to improve patient safety need to focus particular attention on times of transition. This article describes a public education campaign to change patients’ behaviors during those periods.

Threats to patient safety can occur any time, but a disproportionate number come up during care transitions such as when patients move from the hospital to home or from home to a nursing facility or when care is transferred from a patient’s primary care physician to a specialist.

During transitions, communication between the patient and/or caregiver and clinician or among clinicians can easily break down. As a result, the patient and/or caregiver may not understand the patient’s condition or may be confused about his or her treatment needs. In addition, an estimated 60% of medication errors, in which a patient takes the wrong medication or the wrong dose or the right medication at the wrong time, occur during times of transition.1 And about one in five (19%) patients has an adverse event following discharge from a hospital, with an estimated 61% of those events happening because of inadequate communication with the physician who is to provide follow-up care.2

These miscues can be costly on both a human and financial level. Failures of care coordination cost an estimated $35 billion per year. Overtreatment, which often results from lack of coordination, costs about $192 billion per year.3

Both clinicians and patients contribute to safety-related problems that occur during transitions. Clinicians may not share information with other clinicians. A study of referrals by 122 pediatricians in 34 states found that no information was sent to the specialist in 49% of cases, and the referring physician received feedback from the specialist only 55% of the time.4

Physicians also may not do a good job of sharing information with patients. According to a study by Boohaker, 75% of the time physicians don’t routinely contact patients about their test results, and 33% of the time they don’t notify patients of abnormal results.5

Patients contribute to the problem as well, as many do not follow clinical recommendations. A study from the Northeastern Ohio Network found 14% of patients never make recommended appointments with specialists.6 In addition, about 31% of prescriptions go unfilled.7 Finally, patients often don’t monitor or promptly address warning signs associated with their conditions.

Patients are uniquely positioned to improve communication between themselves and members of their health care team. After all, they have a comprehensive view of their own health and medical history: They know their symptoms and diagnoses, what tests they have had, the medications they are taking and treatments they have undergone, their preferences, and any complications they have experienced. If engaged in their own care, patients could help improve care coordination by sharing information about the medications they are taking, test results and their health histories with their physician and other providers.

Why Aren’t Patients More Engaged?
Members of the Minnesota Alliance for Patient Safety (MAPS), which is dedicated to improving patient safety across all care settings, and its partners recently wondered why patients weren’t doing more to coordinate their own care. So we asked them.

We hired a firm to conduct online conversions with a group of 100 patients from across the state who have chronic conditions including high blood pressure, heart disease, type 2 diabetes and high cholesterol. In online chat rooms that were open 24 hours a day over five days, participants were asked a number of questions, including these: What is your sense of the patient’s role in coordinating medical care? Why aren’t you more active in documenting and sharing medication lists and test results? What would you think if you were asked to take a more active role in coordinating your health care? Participants were
encouraged to share their thoughts with the facilitator as well as with each other.

Here are some things we learned from those discussions:

- **Patients perceive that little is expected of them.** When it comes to care coordination, many patients believe it’s not their job. They say they aren’t told to do more to coordinate their own care, so they believe doing more is unnecessary. They believe that their care management responsibilities are modest to nonexistent, particularly when it comes to gathering and sharing test results with members of their health care team.

- **Patients have a false sense of security.** Many patients feel “the health care system” is meeting every one of their care coordination needs, making patient-driven coordination unnecessary. Extensive marketing about the benefits of electronic medical records in care coordination as well as the traditional “trust your doctor” culture inform this conclusion.

- **Patients need specific instructions.** Another reason patients aren’t more engaged is because they aren’t sure what they can do. Simply encouraging them to “get more engaged” is not enough. Many patients in our focus group indicated that they are willing to do more to prevent safety problems, but they need clearly defined and articulated instructions about what to do.

- **Patients are drowning in information.** Yet another reason patients aren’t sufficiently engaged is because they don’t comprehend the information they receive about their condition or their discharge instructions. This shouldn’t be surprising, given that patients being discharged from the hospital are handed on average 70 pages of instructions.¹ Patients told us that they want jargon-free materials that they can quickly and easily read and understand.

### A Campaign to Engage Patients

Using grant funding from the Minnesota Hospital Association, we are incorporating what we learned from the focus group into a patient engagement campaign called You: Your Own Best Medicine (www.ownbestmedicine.mn). The goal of the campaign is to educate patients about how they can reduce their risk during care transitions. It uses best practices identified by a MAPS Advisory Committee.

As the name indicates, the campaign encourages patients to play a central role in their own care and help their health care team help them. This message is new for many patients who sometimes feel as if the health care system wants them to be compliant, rather participate in their care.

The centerpiece of the campaign is a brief to-do list with four tasks:

1. Maintain a medications list and continually share it with your health care team.
2. Collect and save test results and continually share them with your health care team.
3. Ask your caregiver about warning signs associated with your condition, monitor them and promptly act on any problems you may experience.
4. Promptly follow up on your health care team’s recommended next steps after each appointment or encounter.

These tasks are brief, clear and specific (the patients surveyed emphasized the importance of this). The list can be used to supplement the more detailed information providers are often required to give patients.

MAPS has created patient safety packets, which are currently being given to individuals at 11 sites (see box). The packets provide them with a pen and paper and a template for creating a medication list. They also include a bright red expandable folder with a label on it to encourage them to develop the new habit of keeping all of their test results in one place (Figure). In addition, the packets contain a refrigerator magnet and stickers reminding them of the items on the to-do list. In the coming months, MAPS will make available a smartphone app, which will send users reminders and help them keep their medication list, follow-up instructions and test results organized and readily available. MAPS also will launch a radio and print advertising campaign to educate the public about the importance of being engaged in your own health care.

The folders, pens, tablets, magnets, stickers and smartphone app not only are practical tools, they also send a message: “If my caregiver is taking the time to actually give me all of these tools, I guess my involvement is important and expected.”

### Patient Empowerment: Focus Needed

The Own Best Medicine campaign is very much in its infancy. Results from the test of the patient safety kits will be evaluated this fall. If the packets yield the desired...
results, they could be used by other health care providers in the future. Regardless of what we learn through our study, empowering patients to better understand and become involved in their care will continue to be a focus of MAPS. Both clinicians and patients play important roles in preventing expensive and tragic problems. We cannot ignore the need for patient engagement. MM

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REFERENCES