"Questions Are the Answer" to Improving Health Literacy and Patient Activation

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ABSTRACT

Low health literacy is a barrier to care and is linked to poorer health, higher rates of hospitalization and an increase in total health care costs.[1,2] Research suggests patient activation may help compensate for lower literacy skill, increasing comprehension among those with lower literacy.[3] Marshfield Clinic has been successful in using a set of tools developed by the Agency for Healthcare Research and Quality called "Questions Are the Answer."[4] Developed as a national consumer education campaign, these tools encourage patients to ask questions, access health information they can understand, and become more active partners in managing their care. This set of tools is incorporated into a community-based health literacy curriculum, promoted as agenda-setting tools for patients on the organization's public Web site, and used to improve information sharing between patients and providers.

PROJECT DESCRIPTION

As patients are expected to be more involved in their care, it becomes increasingly important to ensure that health information can be recalled, comprehended and then acted on correctly. While research suggests patient activation may help compensate for lower literacy skill, the question remains as to what interventions help improve patient activation.[3]

Patients with low activation share common characteristics with patients with low health literacy—they are more likely to report poor health status, and less likely to follow through on lifestyle changes and comply with treatment plans. Both groups are also less likely to ask questions (***Table 1***).

Improvements in awareness, comprehension, self management skills, and adherence to treatment can be achieved by improving patients' health literacy or by increasing their level of activation. Increasing patient activation, however, is often the easier path to take and may lead to faster, more effective results. In addition, there are validated, reliable tools that measure patient activation and are successful in predicting changes in self-care management skills and behaviors. The Patient Activation Measure (PAM) developed by Judith Hibbard (University of Oregon), for example, can be used to measure changes in patient activation and to tailor education and coaching to the individual needs of patients.[5,6]

Even simple initiatives, such as encouraging patients to ask questions and modeling what questions to ask, have been shown to improve patient activation by first raising awareness of the patient's role as a key member of his or her health care team, and second by encouraging meaningful exchanges of information between the patient and provider.

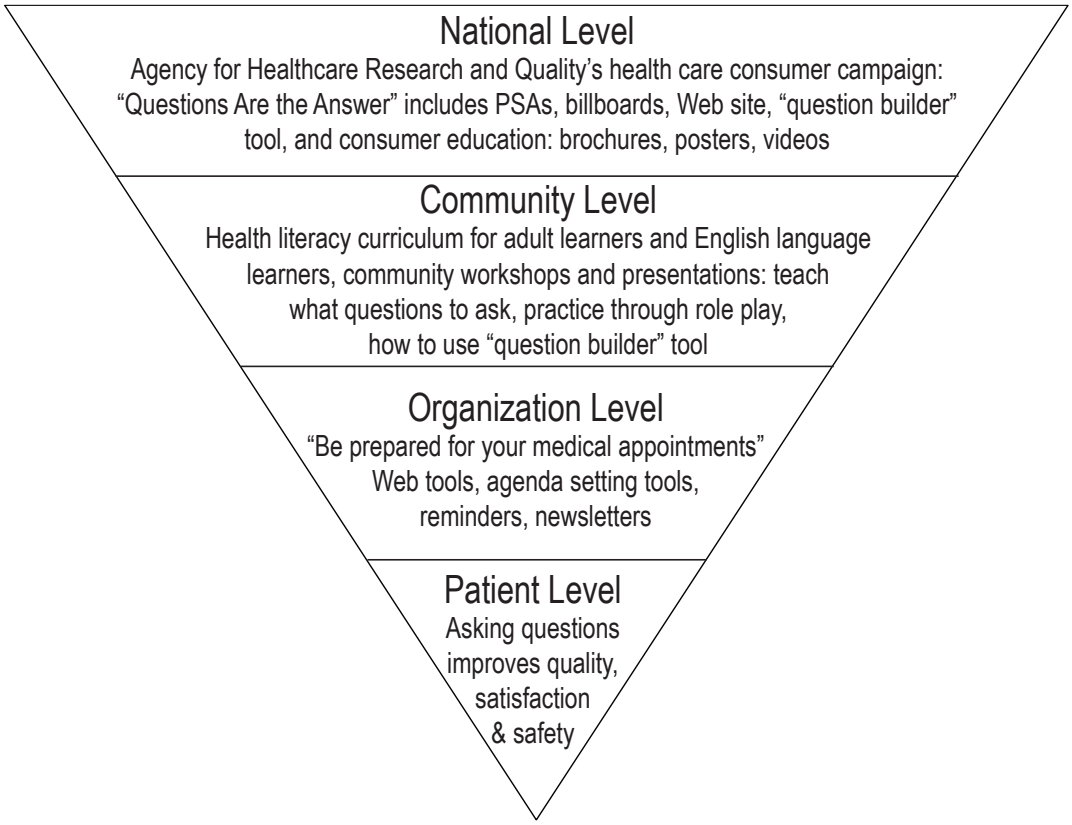
Research shows there are benefits to asking questions. There are also consequences for either not allowing time or not having a process for patients to ask questions, as well as in not providing answers to questions that are easy for patients to both understand and act upon. The consequences of not asking questions include an increased risk for errors, decreased adherence, lower levels of patient satisfaction, and increased feelings of anxiety, confusion and intimidation. On the contrary, the benefits of asking questions include increased understanding and adherence, higher levels of patient satisfaction, and building trust in the relationship between the patient and provider. Allowing and empowering patients to ask questions also increases patient involvement and improves patient-provider communication overall (***Table 2***).

The Agency for Healthcare Research and Quality (AHRQ) developed the tool "Questions Are the Answer" to promote the asking of questions as a positive health care consumer behavior and to encourage patients to be more active participants in their care. Marshfield Clinic has taken this national level consumer education campaign and incorporated it into initiatives at the community level (a health literacy curriculum used with adult learners and English language learners by the local technical college and county literacy councils), at the organizational level (as a series of proactive agenda-setting tools and resources available on the Internet and in patient education materials and newsletters), and at the patient level to improve one-to-one communication between a patient and a physician, and between a patient and a pharmacist (***Figure 1***).

"Questions Are the Answer" at the Community Level

In collaboration with Mid-State Technical College and the Literacy Council of Wood County, Marshfield Clinic assisted in the development of a health literacy curriculum for Adult Secondary Credit (ASC) classes, GED/HSED preparation, and English as a Second Language (ESL)

Figure 1: Integrating "Questions Are the Answer" on multiple levels



tutoring. "Questions Are the Answer" is featured in the unit "How to Talk to Health Care Professionals." Depending on the setting (one-on-one tutoring tailored to individual needs or classroom/workshop presentations tailored to the needs of a particular group), "Questions Are the Answer" is used in any of the following ways:

- Viewing the PSA videos, followed by discussion.
- Reviewing the "Questions Are the Answer" brochure.
- Demonstrating and practicing how to use the online question builder tool.
- Role playing exercises to practice asking questions.
- Discussion of the importance of asking questions, including the benefits of asking questions and the consequences of not having important information.

Mid-State Technical College piloted the health literacy curriculum through a series of classes and workshops with specific target groups including senior citizens, adult literacy learners, and English language learners. The goal is to make the curriculum widely available on CD ROM as well as downloadable through a Web site (this is part two of the project, and is expected to be completed by fall, 2009).

Mid-State Technical College conducts training sessions for volunteers from various community organizations and social service agencies who want to use the curriculum.

In addition to workshops and group classes, the curriculum is also used in one-to-one settings. According to the director of the Literacy Council of Wood County, "Our tutors are using pieces of the curriculum with their learners where it is of interest to their learners."

"Questions Are the Answer" at the Organization Level
Marshfield Clinic has incorporated information from the "Questions Are the Answer" Web site in the following ways:

- The list of questions, as well as accompanying materials including "Quick tips - When talking to your doctor," "Quick tips - When getting medical tests," and "Quick tips - When getting a prescription" have been imported into a Health and Wellness Library, available on the organization's public Web site. For example, on the page where patients can request an appointment, there is a web icon for "How to prepare for medical appointments." Clicking this icon takes visitors to a list of AHRQ tools including "Questions Are the Answer."

Table 1: Common characteristics of patients with low activation and low health literacy[1,7,8,9,10,11,12,13,14]

Patients with Low Activation:	Patients with Low Health Literacy:
■ are more likely to report unmet medical needs ■ have lower levels of preventive health behaviors and preventive care ■ are less likely to engage in self-management of health conditions ■ are less likely to follow through on lifestyle changes and comply with treatment plans ■ are more likely to have unmet prescription drug needs ■ are more likely to delay care ■ ***are less likely to ask questions***	■ are more likely to report poor health status ■ are less likely to obtain preventive health services ■ are twice as likely to be hospitalized ■ remain in the hospital more days per each admission ■ are less likely to comply with recommended treatment ■ are more likely to make medication errors ■ incur higher health care costs ■ ***are less likely to ask questions***

- This same information is regularly featured in patient newsletters.
- Materials are ordered from the AHRQ Web site, including "Questions Are the Answer" brochures and posters. Use of these materials is encourage throughout the organization.
- The "Questions Are the Answer" public service announcements are run on a closed-circuit television channel available in patient waiting areas.

"Questions Are the Answer" at the Patient Level

Marshfield Clinic has seen benefits at the patient level that correlate with benefits identified in existing research. Among the benefits are increased understanding, increased patient involvement, improved adherence to medication and treatment plans, and improved patient satisfaction. Encouraging and empowering patients to ask questions improves patient-provider communication, builds trust in the relationship, and demonstrates patient-centered care.

CHOOSING "QUESTIONS ARE THE ANSWER" OVER OTHER AVAILABLE TOOLS

"Questions Are the Answer" was chosen over similar tools (such as *Ask Me 3*) because it addresses both health literacy and patient activation. The tool encourages patients to ask both factual and challenging questions. Factual questions are more common and patients typically feel more comfortable asking these types of questions. Examples include: What are the side effects? When can I return to my normal activities? What's my main problem? Challenging questions, on the other hand, are less commonly asked, even though they are often on the minds of patients. Patients feel less comfortable asking these questions, often fearing they will "offend" their doctor or get labeled as a "difficult patient." Examples of challenging questions include: How many times have you performed this procedure/test? What is your success rate? Is this the only way to get a diagnosis? Is this procedure/test necessary? Challenging questions are often directly related to issues of quality and safety.

"Questions Are the Answer" also addresses both health literacy and patient activation in the following ways:

- Promotes pre-visit planning and agenda setting.
- Increases confidence to make decisions and use comparative information.
- Offers a broader framework and invitation for patients to take an active role in managing their heath and health care:
  - "Improving health care quality is a team effort."
  - "The single most important way you can stay healthy is to be an active member of your own health care team."
  - "You can improve your care and the care of your loved ones by taking an active role in your health care."[4]

Table 2: Question asking[15,16,17,18,19,20,21]

Benefits of Asking Questions:	Consequences of NOT Asking Questions:
■ Increases understanding	■ Increases risk for errors
■ Increases patient involvement	■ Limits information and patient involvement
■ Improves adherence	■ Decreases adherence
■ Improves satisfaction	■ Decreases satisfaction
■ Improves patient-provider communication	■ Increases opportunities for miscommunication
■ Demonstrates patient-centered care	■ Increases confusion and intimidation
■ Builds trust in relationship	■ Heightens unmet needs

Using the tools and resources developed by AHRQ, Marshfield Clinic is seeking to raise awareness among patients regarding the important role they play in the management of their health. AHRQ is promoting the message on a national level with public service announcements, billboards, and a Website that includes a "build your list of questions" tool. AHRQ conducts the research and makes the tools available to health care organizations and the consumers. Health care professionals have an obligation to help patients learn self-management skills and gain the confidence to take a more active role in their health and health care. Repeating the message multiple times, in multiple formats, makes the information more accessible. Adapting the message to meet the needs of a local community, a specific population of patients (i.e. people with diabetes), or a unique group such as English language learners, helps individual patients relate to the message and apply the tools and resources within the context of their individual or collective experiences.

Encouraging and empowering patients to ask questions is one small step in the process of patient activation. Research shows that activation begins with an awareness: the patient understands, "when all is said and done, I am the person responsible for taking care of my health," and "taking an active role in my own health care is the most important thing that affects my health." Once this awareness is present, the next phase of activation leads the patient through a series of small steps, including setting short-term, realistic, obtainable goals.[5,6,7]

Progress toward becoming more activated depends on a patient's level of confidence to be able to recognize signs and symptoms, to follow through on medical treatments, and confidence in being able to communicate with his or her doctor. Low confidence results from failure. For example, each attempt at communication that results in a negative outcome (confusion, shame, feeling rushed or that the doctor is "too busy" to answer questions) erodes confidence. On the other hand, small successes (such as asking a question and getting a helpful answer) build up confidence. Asking questions opens a dialogue with a physician or pharmacist and affirms the patient's role as an important member of the health care team. These small successes lead to bigger successes as the patient moves along the spectrum of increased activation.

IMPLICATIONS

Medical mistakes account for an estimated 44,000 to 98,000 deaths each year or a minimum of 120 deaths per day, according to the Institute of Medicine (IOM). That means that these mistakes lead to more deaths per year than motor vehicle accidents, breast cancer or AIDS. Research shows that consumers who get more involved with their health care can greatly improve the safety of their care, but patients are generally unaware of what to do to help prevent medical mistakes. Medical errors carry a high financial cost. The IOM estimates that medical errors cost the Nation approximately $37.6 billion each year; about $17 billion of those costs are associated with preventable errors. About half of the expenditures for preventable medical errors are for direct health care costs.[22]

The IOM report on Preventing Medical Errors concludes that one of the most effective ways to reduce medication errors is to move toward a model of health care where there is more of a partnership between the patients and the health care providers. In the past the nation's health care system has generally been paternalistic and provider-centric, and patients have not been expected to be involved in the process. Patients should understand more about their medications and take more responsibility for monitoring

those medications, while providers should take steps to educate, consult with, and listen to the patients.[22]

An important role in the prevention of medical errors rests with the patient. The Agency for Healthcare Research and Quality (AHRQ) reports that the single most important way the patient can help to prevent errors is to be an active member of their health care team. That means patients must take part in every decision about their health care. Research shows that patients who are more involved with their care tend to get better results.[4]

AHRQ has developed recommendations for the patient to use in managing their treatment and preventing medical errors, including:

- The patient should speak up if they have any questions or concerns. Patient have the right to question anyone who is involved with their care.
- The patient should learn about their condition and treatments by asking their doctor and nurse and by using other reliable sources.[4]

AHRQ also makes several recommendations regarding medication safety. Among them are several that include having the patient ask questions:

- The patient should ask for information about the medicines in terms that they can understand-both when the medicines are prescribed and when they receive them.
- When patients pick up their medicine from the pharmacy, they should ask if this is the medicine that the doctor prescribed. A study by the Massachusetts College of Pharmacy and Allied Health Sciences found that 88 percent of medicine errors involved the wrong drug or the wrong dose.
- The patient should always ask if they have any questions about the directions on the medicine labels.
- The patient should ask the pharmacist for the best device to measure liquid medicine. Research shows that many people do not understand the right way to measure liquid medicines.
- The patient should ask for written information about any possible side effects the medicine could cause. A study found that written information about medicines can help patients to recognize problem side effects and help them to communicate that information to their doctor or pharmacist.[4]

Encouraging and empowering patients to ask questions, and teaching them which questions are important to ask, is a small but powerful tool in reducing medical errors, adverse events, and lowering health care costs.

PROJECT RESULTS

Evaluation of an initiative using a tool like "Questions Are the Answer" can be challenging, mostly because there are few communication-based metrics to directly measure improvements in patient safety and quality. Marshfield Clinic uses patient satisfaction as one measure. On the patient satisfaction survey patients are able to provide feedback on whether or not their provider communicated clearly and answered their questions. We are beginning to identify areas for improvement and plan to develop interventions (including patient education and training for providers and staff) designed to improve communication, including encouraging patients to ask more questions. A pilot study is beginning in three Marshfield Clinic locations, and preliminary data will be available in the fall of 2010. Another research study at Marshfield Clinic will evaluate patient activation and its effect on the self-management behaviors of patients with asthma. Preliminary data, including pre- and post-test Patient Activation Measure (PAM) scores, will be available in the fall of 2010.

At this time, there is no evaluation data available for the health literacy curriculum. Mid-State Technical College and the Literacy Council of Wood County are in the process of collecting data during the second phase of the project. Through predictive modeling based on exiting research and evidence, however, we do expect results to show that our initiatives successfully increase levels of patient activation and in turn improve health outcomes for our patients and the communities we serve.

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