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Patient and Family Involvement

Advising Patients About Patient Safety:

Current Initiatives Risk Shifting Responsibility

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The Institute of Medicine's landmark report *To Err Is Human* recommended that patients be viewed as members of their health care team and as actively involved in the process of care.[1] There are various ways in which patients and families could potentially contribute to their safety, but efforts to facilitate such contributions may raise important practical and ethical issues,[2] which have been little investigated to date. In the United States, federal agencies, national organizations concerned with health care quality, statewide safety coalitions, professional specialty associations, consumer groups, and health care providers have produced brochures and other materials advising patients what they can do to avoid errors and harms. In 2001, a federally funded review noted that these interventions "hold promise" but that "there is yet insufficient evidence of their effectiveness."[3] As the dissemination of safety advice becomes more widespread, it is increasingly important that questions are asked about the interventions' appropriateness and impact.

In this article, we identify a number of concerns about the development, content, and potential implications of currently distributed advice.

Methods

From September 2003 through August 2004, we examined several major campaigns that advise patients about safety in the context of professionally delivered health services. We developed a critique, drawing on published literature and a series of discussions with key informants with particular expertise and interest in patient involvement and patient safety issues.

Article-at-a-Glance

Background: Many health care providers now disseminate advisories telling patients what they can do to avoid errors and harms in their care.

Methods: The content of five leading safety advisories for patients was analyzed and a critique of their development, content, and impact was developed, drawing on published literature and 40 interviews with a diverse sample of 50 key informants.

Findings: Very little is known about the effects of the distribution of safety advisories to patients, but several grounds for concern were identified. There was a lack of attention to patients' perspectives during the development of advisory messages, and the advisories say little about what health care providers should do to ensure patient safety. Patients are given little practical support to carry out the recommended actions, and health professionals' responses may render their attempts to act to secure their own safety ineffective. Some messages suggest an inappropriate shifting of responsibility onto patients. Advice that involves checking on or challenging health professionals' actions appears to be particularly problematic for patients. Such behaviors conflict with the expectations many people have—and think health professionals have—of patients' roles.

Discussion: A serious commitment to optimizing patients' contributions to safe care requires a research-based understanding of patients' perspectives and more practical facilitation of patient involvement.

Table 1. Patient Advisories Reviewed

Developer	Agency for Healthcare Research and Quality (AHRQ)	Department of Health and Human Services (HHS) with the American Hospital Association and American Medical Association	Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)	National Patient Safety Foundation (NPSF)	NPSF
Title	20 Tips to Help Prevent Medical Errors	Five Steps to Safer Health Care	Speak Up: Help Prevent Errors in Your Care	Your Role in Making Health Care Safer	What You Can Do to Make Health Care Safer
Issue Date	February 2000	July 2003	March 2002	2002	2003
Format reviewed	Fact sheet	Fact sheet	Brochure	Brochure	Brochure
Citation (all last accessed Jul. 11, 2005)	Online at http://www.ahrq.gov/consumer/20tips.htm	Online at http://www.ahrq.gov/consumer/5steps.htm	Online at http://www.jcaho.org/general+public/gp+speak+up/	Available for purchase from http://www.mederrors.org/Merchant2/merchant.mv?Screen=CTGY&Store_Code=NO&Category_Code=BRO	Online at http://www.npsf.org/html/online_resources.html
Other formats and versions available	Version for parents: 20 Tips for Preventing Medical Errors in Children	Posters. Spanish-language and cartoon versions.	Versions focused on different health care settings (e.g., ambulatory care, long term care). Spanish-language versions.	Video.	The same brochure is also available as "You Can Help Improve Patient Safety."

There is no comprehensive catalogue of patient education resources relating to patient safety. We identified materials developed and disseminated at a national level by searching the Web sites of organizations known to be actively working for patient safety, including the National Patient Safety Foundation,[4] which had compiled a list of educational resources. We selected five advisories for a more detailed content analysis (Table 1, above) which were produced by high-profile national organizations and had been widely disseminated. The tips they contained had been further incorporated into advisories developed at state and local levels and were broadly representative of the general safety advice that health care providers give to patients.

Our sample of informants included people who were well-placed, by virtue of their position in key organizations, to provide information about specific patient-oriented safety initiatives, and persons from academic, clinical, consumer, and health care administrative backgrounds who had been actively promoting or researching patients' perspectives on and contributions to the safety and quality of health care. We conducted 40 interviews with 27 people from federal agencies and national organizations active in safety and quality improvement, 15 researchers and recognized leaders in patient involvement in health care safety and quality, and eight consumer advocates working on patient safety issues. The sample included eight people associated with the development and distribution of the five advisories selected for detailed study.

Semistructured interviews were conducted face to face or, in four cases, by telephone. Discussion focused on particular initiatives or studies in which informants were

Table 2. Information About Medical Errors in Selected Advisories

	AHRQ 20 Tips	HHS Five Steps	Joint Commission Speak Up	NPSF Your Role	NPSF You Can Help
What are medical errors? Why do they occur?	Medical errors: wrong plan or care not as planned. Mainly due to complexity of health care. Also occur if doctors and patients "have problems communicating."	No information.	No information.	No information.	Medical errors "often a result of a series of small failures that are individually not big enough to cause an accident, but combined can begin the process towards error."
Do all errors cause harm?	No information.	No information.	No information.	No information.	No information.
Are all poor outcomes due to errors?	No information.	No information.	No information.	No information.	No information.
Scale of safety problem	Medical errors a leading cause of death/injury. Up to 98,000 deaths in hospital/year. More than car accidents, AIDS, breast cancer.	Patient safety one of U.S.'s "most pressing health care challenges." Up to 98,000 deaths in hospital/year.	Institute of Medicine "identified the occurrence of medical errors as a serious problem in the health care system."	No information.	No information.
What is being done about the problem, by whom?	Government, purchasers, and providers "working together to make the U.S. health care system safer."	No information.	"Health care organizations across the country are working to make safety a priority."	Health professionals "committed to patient safety," "taking strong measures" to make care as safe as possible.	No information.

involved but also covered general issues relating to safety roles for patients and their families. All informants commented to some extent on the content and potential impact of the advisories. Interviews (30–120 minutes, depending in part on informant availability) were audiotaped and transcribed to facilitate thematic analysis, which followed a modified "framework" approach.[5]

Findings

Main Features of Safety Advice

The five advisories each have short introductory sections that outline the significance of health care errors and/or make general statements to the effect that providers are working hard to keep patients safe. They vary in the amount and type of background information they provide (Table 2, above), but none consider the nature of relationships between health care errors, harms, and otherwise poor outcomes; and none specify current safety-related standards.

The advisories are intended to tell people how they can contribute to ensuring their safety in health care and are optimistic about what patients can achieve (Table 3, page 486). Their main content is a list of tips, phrased as instructions. Several common themes are evident in terms

Table 3. Stated Aims and Claims about What Patients Can Achieve

	AHRQ 20 Tips	HHS Five Steps	Joint Commission Speak Up	NPSF Your Role	NPSF You Can Help
Purpose of advice	"This fact sheet tells you what you can do."	"This fact sheet tells you what you can do to get safer health care."	"This initiative provides simple advice on how you... can make your care a positive experience."	"Here are some hints that will help you be a part of the patient safety team..."	NPSF "suggests these steps to help make your health care experience safer:"
What can patients achieve?	"Help to prevent errors"	"Get safer health care"	"Play a vital role in making your care safe"	"Make a big difference in ensuring your own safety" In hospital: "Help ensure your safety"	"Ensure a safer experience with the health care system"

of the types of roles the advisories encourage patients to play and the mechanisms by which they appear to envisage that patients can avert errors and harms. For example, all urge patients to be well informed about their health care and encourage them to check that the treatments planned for them are delivered as planned. Yet they vary in terms of the emphasis they place on particular roles and the extent to which they explain the basis for their recommendations and to which they might imply that patients could be working with little professional support to "get around" the deficiencies of providers' systems (Table 4, pages 487–490). The emphasis is generally on actions patients should take to directly help ensure their own safety. The materials do not, for example, advise patients to report perceived errors in their care to ensure that they are not repeated for other patients.

Advisory Development

A number of factors prompted and influenced the production of safety advice for patients. The U.S. Agency for Healthcare Research and Quality (AHRQ) developed its *20 Tips to Help Prevent Medical Errors* as part of the early federal response to *To Err Is Human*, anticipating that in the wake of that report, questions would be asked about what patients could do about medical errors.[6,7] This advisory's developers and others talked in interviews about recognizing that there were things that patients could do—and were sometimes uniquely placed to do—to overcome factors associated with safety problems and to avoid and intercept potential errors in their own care. They sought to encourage patients' contributions to safety in the delivery of care but were concerned to avoid implying that safety problems were patients' fault or that their solution was patients' responsibility. They were keen to convey the message that all parties in health care had a role to play in ensuring patient safety: that it was, as one developer put it, "work for everybody."

The general belief that "an educated patient is likely to be the safest patient" was apparently widely shared, and the developers consistently sought to encourage patients to play more active roles in their health care. However, several admitted uncertainty about what forms of activation were appropriate and how the patients should be encouraged.

The advisories, written from a provider perspective, were drafted with relatively little input from patients. Although consumer advocates contributed to the development of some materials, there was little published research evidence that developers could draw on relating to public perceptions of health care safety, and no systematic attempts were made during the course of message development to ascertain patients' beliefs, concerns, and self-perceived information needs about health care safety and their own roles in promoting it.

Draft messages were tested by opportunistically sounding out colleagues and friends and, sometimes, consumer advocates and small samples of health professionals. Some messages were revised because of

Table 4. Safety Tips in Selected Advisories

	AHRQ 20 Tips	HHS Five Steps	Joint Commission Speak Up	NPSF Your Role	NPSF You Can Help
Format					
Number and organization of tips	20 numbered tips under 4 headings (medicines, hospital stays, surgery, other steps you can take).	5 main numbered tips, each with several related subtips.	7 main tips, each with at least 4 subtips. First letters of main tips form acronym SPEAK UP.	10 main tips, some with subtips in primary list. 3 further boxes of tips.	5 main tips, each with 1-5 subtips.
Form of tips	Instructions with up to 3 sentences of rationale, evidence, or action clarification.	Instructions.	Instructions. A few include rationales.	Instructions. A few include rationales.	Instructions. One includes action clarification.
*Themes**					
Select providers carefully	■ If you have a choice, choose a hospital at which many patients have the procedure or surgery you need. Research shows... patients tend to have better results ... in hospitals that have a great deal of experience with their condition.	■ Choose a doctor you feel comfortable talking to. ■ Talk to your doctor about which hospital is best for your needs. ■ Ask your doctor about which hospital has the best care and results for your condition if you have more than one hospital to choose from.	■ Ask your doctor about the specialized training and experience that qualifies him or her to treat your illness... ■ Use [a health care provider] that has [been evaluated] against established, state-of-the-art quality and safety standards, such as that provided by JCAHO	No tips recommending this.	■ Choose a doctor, clinic, pharmacy, and hospital experienced in the type of care you require.

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"political" considerations of their acceptability to the professional groups. We were surprised at the lack of formative testing of drafts of the advisories with patients. The most rigorous attempt to explore patients' responses to draft messages was apparently a series of focus groups of Medicare beneficiaries that were convened to help choose a subset of tips from *20 Tips* for inclusion in *Five Steps to Safer Health Care*.[8] These discussions centered on the question of which of the advocated actions people were most likely to take.

Several developers said they had lacked time and resources for more extensive testing. None of the five advisories was formally evaluated in practice before widespread distribution. Some informants compared the developmental process unfavorably with the more sophisticated approach that commercial entities take to message development for marketing purposes. One researcher, for example, lamented: "I don't think we've had nearly as much cleverness working on behalf of patient safety" as on direct-to-consumer advertising of pharmaceutical products. The lack of attention to patients' views would lead the development of these advisories to be judged poorly against current guidance for the production of information for patients.[9,10]

Table 4. Safety Tips in Selected Advisories *(continued)*

	AHRQ 20 Tips	HHS Five Steps	Joint Commission Speak Up	NPSF Your Role	NPSF You Can Help
Give health professionals information relevant to your care	■ Make sure that all of your doctors know about everything you are taking... ■ Make sure your doctor knows about any allergies and adverse reactions you have had ... ■ Make sure that all health professionals involved in your care have important health information about you. Do not assume that everyone knows everything they need to.	■ Keep / bring list of ALL medicines you take. ■ Tell [your doctor and pharmacist] about any drug allergies you have. ■ Tell the surgeon, anesthesiologist, and nurses about any allergies, bad reactions to anesthesia, and any medications you are taking.	■ Whenever you are going to receive a new medication, tell your doctors and nurses about any allergies you have or negative reactions you have had about medications... ■ Keep copies of your medical records from previous hospitalizations and share them with your health care team. This will give them a more complete picture of your health history.	■ Work with your doctors and nurses by providing complete information. If possible, write down and bring with you... ■ Answer all questions about your health as truthfully and completely as possible... ■ Report anything unusual to your doctor, such as any changes in your condition.	■ Keep track of your history. ■ Share your health history with your care team. ■ Share up-to-date information about your care with everyone who's treating you.
Encourage providers to adopt safety-promoting practices	■ If you are in a hospital, consider asking all health care workers who have direct contact with you whether they have washed their hands.	No tips recommending this.	■ Notice whether your caregivers have washed their hands... Don't be afraid to gently remind a doctor or nurse to do this. ■ Make sure your nurse or doctor confirms your identity, that is, checks your wristband or asks your name, before he or she administers any medication or treatment.	■ Ask everyone—caregivers and visitors—to wash their hands. Handwashing is the best way to fight the spread of infection. ■ Ask every person to identify himself or herself when they come into your room.	■ Discuss any concerns about your safety with your health care team.

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Dissemination of Materials and Support for Patient Roles

Four of the five advisories were developed for dissemination to general audiences via several possible routes and are freely available via the Internet. The developers generally rely on other organizations, particularly hospitals, to deliver the messages to current patients. Several consumer-led advocacy groups actively promulgate these and other tips, and many health care providers now distribute them via their Web sites, notice boards, brochure racks, in-patient admission packs and room cards, meal tray covers, and in-house television channels. However, our informants doubted whether many health professionals would regularly discuss the

Table 4. Safety Tips in Selected Advisories *(continued)*

	AHRQ 20 Tips	HHS Five Steps	Joint Commission Speak Up	NPSF Your Role	NPSF You Can Help
Check to ensure treatment is given as planned and care plans are followed through	■ When you pick up your medicine from the pharmacy, ask: Is this the medicine that my doctor prescribed?... ■ If you have a test, don't assume that no news is good news. Ask about the results.	■ Make sure your medicine is what the doctor ordered... ■ Ask the pharmacist about your medicine if it looks different than you expected. ■ Get the results of any test or procedure... Don't assume the results are fine if you do not get them when expected... Call your doctor and ask for your results...	■ Pay attention to the care you are receiving. Make sure you are getting the right treatment and medications by the right professionals. Don't assume anything... ■ Know what time of day you normally receive a medication. If it doesn't happen, bring this to the attention of your nurse or doctor. ■ If you do not recognize a medication, verify that it is for you. ■ ... read the contents of IV bags.	■ Before you go in for a procedure, ask to make sure they have the right patient and are doing the correct procedure. ■ Check that the medicine you are about to take matches [what you have written on your list of medications you will be receiving]. If the names differ or something doesn't seem right, call it to the attention of your doctor or nurse.	■ Pay attention. If something doesn't seem right, call it to the attention of your doctor or health care professional.
Be informed	■ Learn about your condition and treatments by asking your doctor and nurse and by using other reliable sources."	■ Ask questions and make sure you understand the answers.	■ Educate yourself about your diagnosis, the medical tests you are undergoing, and your treatment plan. ■ Write down important facts your doctor tells you so that you can look for additional information later. ■ Know who will be taking care of you, how long the treatment will last, and how you should feel. ■ Know what medications you take and why you take them...	■ The more you know the better your care will be... ■ Learn as much as you can about your illness, condition, treatment plans, and any tests you will be undergoing. Use the Internet, your local library, support groups, and information from your doctors.	■ Become a more informed health care consumer. ■ Research options and possible treatment plans. ■ Ask questions of our doctor, nurse, pharmacist, or benefits plan coordinator. ■ Make sure you understand the care and treatment you'll be receiving. Ask questions if you're not clear on your care.

continued

Table 4. Safety Tips in Selected Advisories *(continued)*

	AHRQ 20 Tips	HHS Five Steps	Joint Commission Speak Up	NPSF Your Role	NPSF You Can Help
Be involved	■ The single most important way you can help to prevent errors is to be an active member of your health care team.	■ Ask questions if you have doubts or concerns. ■ Make sure you understand what will happen if you need surgery.	■ Speak up if you have questions or concerns... ■ Participate in all decisions about your treatment. You are the center of the health care team.	■ By becoming involved and actively participating in your care, you will make a big difference in ensuring your own safety. ■ Talk to your doctors, nurses, and pharmacists.	■ Work with your doctor and other health care professionals as a team.
Bring personal support	■ Ask a family member or friend to be there with you... (someone who can help get things done and speak up for you if you can't).	■ Take a relative or friend with you to help you ask questions and understand the answers.	■ Ask [someone] to be your advocate. ■ Ask this person to stay with you, even overnight when you are hospitalized... [they] can help to make sure you get the right medications and treatments.	■ Ask a family member or friend to come with you to act as your advocate. It is easy to be overwhelmed by ... information, especially if you are ill. An advocate is someone you can trust to look after your welfare and help you ask important questions.	■ Involve a family member or friend in your care. They can accompany you on appointments or stay with you, help you ask questions, understand care instructions, and suggest your preferences.

* Only themes relating to professionally delivered care are presented here; that is, examples of tips aimed to promote safe self-care by patients are not included. Some advisories contain a number of tips that relate to the themes identified. The main recommendations are summarized, including partial quotations to illustrate the type of advice given relating to each theme.

tips with their patients or give them personal encouragement to follow their recommendations.

A lack of message reinforcement from health professionals and a more general lack of practical support from providers for the patient roles envisaged in the advisories are potentially critical shortcomings. The contexts in which advisories are disseminated could hinder patients' inclination and ability to act effectively, as the following informants (among others) suggested:

> We're providing consumers with information that is not well-founded or well-tested, and … the place they're supposed to be exercising that information is probably hostile to it, or at a minimum not able to receive it effectively. *(Consumer advocate)*

> Systems aren't set up to have you involved… You have to bully your way in to be a partner. And you're really not a partner, you're an imposition at that point. And patients feel that. *(Safety improvement specialist)*

Patient involvement does not appear among the main types of action that hospital executives are implementing to improve patient safety.[11] Several informants noted that, beyond distributing advice for patients, little was being done to support systems change or encourage health care professionals to facilitate greater or more effective involvement of patients in their own care—for the sake of safety or otherwise.

Possible Impacts on Patients and Patient-Doctor Relations

The information and tips contained in the advisories are potentially open to multiple interpretations of the kinds of errors and harms to which patients are susceptible,

whether or not they follow the recommended actions. There is currently little empirical evidence about the effects of the distribution of safety tips on patients' perceptions of their safety and their inclination to adopt the recommended behaviors.

Our informants varied in their opinions about the types of concern and forms and levels of vigilance that the advisories would and should tend to cultivate. For example, one person was concerned that "this kind of stuff can have the potential to make people nervous or paranoid," while another thought that it might (appropriately) "undermine people's trust [in their doctors], make them extremely skeptical." These different opinions about the potential effects of the advisories on patients' perceptions were not obviously distributed along either consumer/provider or organizational affiliation lines. They probably reflect a general lack of consensus about what constitutes an accurate appraisal of personal risk in relation to safety lapses, about which actions patients can effectively take for their own protection, and about the nature of relationships between patients' perceptions of safety, their adoption of behaviors intended to enhance their safety, their experiences of health care, and their health care outcomes.

Although the advisories aim to encourage patients to act to enhance their own safety, it is not clear to what extent patients would be willing and able to adopt the recommended behaviors to good effect, and there are grounds for concern that the distribution by hospitals of at least some of the messages contained in the advisories may have unwanted consequences.

The small amount of research that has explored patients' views on safety and responses to the advisory messages has tended to focus on patients' self-reported likelihood of acting on particular safety tips. It suggests that a proportion of people would try to follow the advice but that this would vary according to the clarity of the instructions and the types of action recommended.[8]

Advice that involves checking on or challenging health professionals' actions appears to be particularly problematic for patients. Such behaviors conflict with the expectations many people have—and think health professionals have—of patients' roles. Some people have personal or vicarious experience of health professionals responding negatively if they do adopt them, and some fear being labeled as "difficult" patients and subjected to recrimination.[12] Some health professionals have acknowledged that patients who adopt some of the behaviors recommended in safety advisories might tend to make health professionals less inclined to engage positively with them and thus inadvertently have a negative impact on the quality of their care.[13] Although a few advisories try to encourage patients to overcome these concerns, the general distribution of written "permission" from third parties may be insufficient to enable patients to overcome elements of health care culture that discourage effective adoption of such roles.

Several informants noted that patients will vary in their capacities to act to enhance their safety and that those who were socially disadvantaged would probably find it harder than most to follow the advice given in the tips. However, a few also noted from personal experience that some recommendations might not seem readily actionable even to well-educated people familiar with health care quality issues when they were seriously ill in a hospital. The sheer number of tips in some advisories could make it difficult for patients to follow all the advice in all consultations. This could make people feel overburdened or guilty. As one informant noted:

> [If you] didn't have time for them or you just didn't feel comfortable bringing them up, at the end of the day, this [advisory] says that you were bad. "Bad patient! Bad patient!" Because you didn't do it and [the advisory says] it's your job. *(Clinician/safety improvement specialist/advisory developer)*

A number of the actions that the tips encourage patients to adopt would require appropriate responses from health professionals if they were to be effective in averting errors and harms. For example, patients' and family members' vigilance in monitoring the delivery of planned care will be effective only if professionals are willing to check their actions when patients or family members ask questions or express concern about what they perceive to be potential errors. There are several anecdotal accounts of health professionals ignoring such questions and concerns and of patients being harmed despite their efforts.[13–15] Many people perceive that hospital staff often fail to respond adequately when patients seek professional attention for a complication in their care.[16]

The advisories' overall impact on rates of errors and harms is unknown. However, some of the actions that

patients are encouraged to undertake might not be well targeted to address important safety problems. For example, patients are often encouraged to check that the medicines they collect from pharmacies are the ones their doctor ordered. Such advice may help patients to intercept dispensing errors but will not protect them from the prescribing errors that recent research suggests are associated with far more adverse drug events in community settings.[17] A focus on actions that patients can fairly readily perform is understandable but could result in a distorted emphasis on relatively minor problems. Gaps in knowledge about the sources and distribution of safety problems currently make it difficult to prioritize recommendations to patients on the basis of their likely impact. The impact of the advisories on patients' health care experiences and outcomes more generally is also unknown.

Concerns About Shifting Responsibility

Several informants expressed concern that the advisories render policy makers and health care providers vulnerable to the suspicion that they are inappropriately shifting responsibility for the safety of professionally delivered health care onto patients. For example:

> The people who talk the most about patients taking responsibility for their own safety are people like pharmaceutical companies and physicians and others who are really still in denial about their own role. It's very convenient to say, 'Well, the patient's got to take some responsibility.' Who can be opposed to that? Of course they take some responsibility. But it's an agenda that particularly rankles me because I hear it coming from people who are really refusing to do what they ought to be doing. *(Clinician / safety improvement specialist)*

These concerns are most likely to arise when tips might imply patients may be the only ones working for their safety, when practical support for patients' involvement in the process of care is limited, and when there is little evidence of efforts to improve the safety of health care delivery systems.

Discussion

The development and distribution of advisories to help patients help ensure their own safety in health care was probably well intended and *might* help to reduce errors and harms, but the possibility remains that the advisories may be ineffective or even have unwanted consequences. Our analysis suggests several areas of concern regarding their development, content, and context of use.

We were particularly struck by the limited attention paid to patients' perspectives during advisory development. Early developers were faced with a dearth of research about what patients understand and think about safety and their potential roles in improving it. This makes it difficult to produce information and advice that "meets people where they are at," builds on popular understandings, corrects misunderstandings, addresses patients' self-perceived information needs, and stimulates appropriate beliefs and behaviors in relation to safety in health care. Unless advisory developers investigate how people understand and respond to draft versions of advisories, they can only guess the potential impacts of their information and advice.

A number of features of the general safety advisories that are currently in circulation may be suboptimal or potentially problematic. Several gaps in content suggest missed opportunities to increase public understanding of safety issues in health care. For example, none of the high-profile advisories that we reviewed outlined current safety standards or described what health care providers are doing to help ensure patients' safety. They thus tend to leave patients ignorant of policies and practices that could offer them some grounds for reassurance. None of the advisories explained that some adverse outcomes in health care are not preventable. They thus fail to correct the oft-lamented tendency for patients to equate poor outcomes with negligence and do nothing to address the problem that many lawsuits appear to stem from injuries that could not reasonably have been prevented.[18,19] Given the criticisms that have been made of news media coverage of patient safety issues,[20] which may be the main source of information about these issues for many patients, the broader educational (as opposed to merely instructional) potential of advisories perhaps warrants more careful consideration.

The appropriateness of advice is of course in part dependent on the context in which it is offered. Our informants expressed considerable uncertainty about the extent to which the messages contained in the advisories would be reinforced by the words and actions of health professionals and about the extent to which the

roles envisaged for patients would be supported by appropriate protocols and tools in clinical practice.

Advisory developers face something of a dilemma when they seek to encourage patients to work *with* health care providers to help ensure their safety even though health care providers do not routinely enable patients to work with them. If they communicate expectations that health professionals will support patients in particular ways, people may be disappointed when such support is not forthcoming and may become justifiably cynical about the "honesty" of the advice. If, however, developers phrase their advice to avoid suggesting that health professionals will encourage patients' involvement and imply instead that patients need to "work around" system deficiencies, they risk appearing to: (a) discredit the efforts of those health professionals who are striving to facilitate patient involvement and promote patient safety; (b) endorse a status quo of suboptimal facilitation of patient involvement and toleration of serious safety vulnerabilities in health care delivery; and (c) support a shift of responsibility for achieving involvement and safety in health care onto patients.

Any shift of responsibility for the safety of professionally delivered care onto patients has several worrying implications. First, it may tend to exacerbate existing social disparities in health care experiences and outcomes if uptake of safety advice is less effective among patients from less-advantaged groups. Second, it may tend to reduce the impetus for systems improvement. Third, it may increase patients' and families' tendencies to feel burdened by guilt as they agonize over whether they could have done more to prevent health care injuries,[21] as well as increase providers' tendency to deflect blame for such injuries to patients.[22] This latter tendency may eventually take on a legal dimension if providers who are sued for malpractice mount contributory negligence defenses arguing that a "reasonable patient" would have acted to prevent harm by following the safety advice.

The advisories that we reviewed focused on the roles that patients and family members could play in securing their own safety as they use health services. There have also been a few attempts to encourage and enable patients to contribute more generally to improvements to the safety of health care systems, including the campaign initiated by the Leapfrog Group[23] to encourage employees to use their health insurance well and "vote with their feet" for safer health care provision or explicitly challenge local providers to check that they are offering care consistent with certain standards.

Recommendations

We conclude with three main recommendations for future efforts to involve patients in ensuring their own safety and in the promotion of health care safety more generally.

First, there is a need for rigorous research and debate to tackle—with patients and health care professionals—the questions of what roles are appropriate for patients to play in efforts to enhance their safety and how health care providers should facilitate their contributions. It should be recognized that answers may vary across health care settings and between people from different social and cultural groups. Second, there is a need to critically examine and periodically review the information and advice that is given to patients about their safety in the context of professionally delivered health care. There is an urgent need for investigations of patients' interpretations of and responses to the advisories currently in circulation. Assessments of advisories should also take into account (1) evolving understandings of the epidemiology of health care errors and harms, (2) research evidence about the effectiveness of different safety promoting practices, (3) the development of safety standards and protocols, (4) research into patients' concerns and perceived information needs relating to their safety, and (5) research exploring the full range of possible effects of the distribution of the various advisory messages in different contexts. It may be worth considering tailoring information and advice to ensure that they more accurately reflect local safety problems and the adoption of safety-promoting practices.

However, our third recommendation is that the inherent limitations of giving advice to patients as an error- and harm-prevention strategy must be taken seriously. Efforts to increase patients' involvement to improve the safety of their care should include practical support for appropriate patient roles. Rather than rely on patients to remember to act to work around system deficiencies, systems should be designed to enable people to contribute appropriately by default. Attention also needs to be paid to health professionals' views about patient safety and patients' roles in securing it. Work is required to

ensure that patients' efforts to prevent errors and avert harms will be met by appropriate responses from their care providers.

The time is ripe for the development of a more substantial research and development infrastructure to support patients' involvement in promoting their safety in health care. Health care leaders need to work systematically with patients and front-line clinical staff to develop protocols and support mechanisms that will help realize the vision of health care systems that are safe and patient-centered.[24] J

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