Patient Narratives Bridge Gap in Doctor-Patient Communication

By Susan Jenks

It is often said that we tell ourselves stories in order to live—and for some patients that may be literally the case.

Unscripted patient narratives, in which patients talk about their healthcare experiences with cancer and other life-changing illnesses, have emerged as one method to overcome communication barriers that often arise between doctors and patients.

“The surest route to failure lies in deciding what patients need to know without asking them,” said Gregory Makoul, Ph.D., senior vice president for innovation at Saint Francis Hospital and Medical Center in Hartford, Conn., and the keynote speaker at a conference last May entitled “Cancer, Culture & Literacy,” in Clearwater Beach, Fla. The two-and-a-half day conference was sponsored by the Moffitt Cancer Center.

Listening to patients and engaging them in health decisions, while seemingly intuitive, is “no trivial matter,” Makoul stressed, showing a video clip of patient narratives that was part of a project first started at Northwestern University, where Makoul served as director of the university’s Feinberg School of Medicine until recently. “We give patients a video camera and tell them to tell their stories. We did not instruct them and never asked them about medicine or how they feel about their doctors.”

What ultimately emerged from the project was the Communication Assessment Tool, known as CAT, which is being funded by the American Board of Medical Specialties. CAT is also a response to several blistering critiques of doctors’ bedside manners that patients voiced throughout the project. One young woman in a video, vigorously chopping onions in her kitchen, expressed exasperation at her physician’s tendency to treat her questions as stupid. “Doctors don’t know everything, do they?” she asked angrily. Another patient in a video chastised her doctor for treating her as the “disease.”

Although CAT was originally designed simply to elicit patient preferences, it has evolved into much more, tailored for measuring patient feedback in emergency rooms, for example, as well as a training tool for medical students, Makoul said. CAT also includes different measures of how well patients understand what their doctors are telling them.

Patients consistently scored three of 14 items the lowest: how well doctors involved patients in care decisions, how well patients understood the medical information provided and how often doctors actually encouraged patients to ask questions.

Addressing patients’ concerns means physicians need to go beyond simple stereotypes of cultural competence—including language barriers—to a more general appreciation for what patients fear most about their illnesses, Makoul said, adding that he also suggested a plain language communication style that all patients can understand.

“There are all these variations in cancer (types), but we keep hearing the same stories over and over again,” McMullin said—from the comic memoir, “Cancer Vixen,” to Miriam Engelberg’s “Cancer Made Me a Shallower Person.”

Perhaps surprisingly, most of these stories are filled with hope, she said, but “Before you get to hope, you have to talk about the experience first—the struggles these families and individuals endure,” McMullin said. She added that in academia, there’s a big push to study medical narratives told in this way. A professor at Penn State offers a course on comics in medicine, a top on which there have been several conferences. A website called “Graphic Medicine” explores the usage of comics in medicine through blogs, podcasts and articles: http://www.graphicmedicine.org/

“We’re talking about other ways of communicating. It isn’t explicitly educational—in many ways, it’s just storytelling,” McMullin said. But the hope is these stories will provide a window through which patients and providers can gain a better understanding of each other.

Comics and Cancer Stories

Medical anthropologist Juliet McMullin, Ph.D., an associate professor in the department of anthropology at the University of California at Riverside, spoke about a low-tech vehicle for cancer messages that also relies on patient narratives. Instead of videos, patients use graphic novels and comic books to talk about cancer, often relying on visual images to tell their stories.

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“Friending” Your Physician?

Physicians have also turned to simpler forms of social media such as Facebook, Twitter and even text messaging to communicate with patients.

According to Abby Prestin, Ph.D., a postdoctoral fellow in the Health Communications and Informatics Research Branch at the National Cancer Institute, harnessing social media for vital health messages is cheap, convenient and most importantly,
interative. Data from the Pew Internet and American Life Project in 2011 found that between 69% and 75% of adults use social media. But usage skews young, with only 33% of people over age 65 engaging in social networking sites such as Facebook or Friendster.

Given that the elderly face the greatest health risks, to improve health outcomes researchers eventually may need to use proxies, such as children or grandchildren, to reach this population, Prestin said.

“New initiatives are under way, but we’re still learning how to optimize social media, as well as how to measure success.”

**Does Social Media Work?**

As in clinical medicine, researchers crafting health messages for the public have begun looking for evidence-based proof that their messages actually work.

In August, the Centers for Disease Control and Prevention rolled out a new program with that precise goal called “MessageWorks.”

“MessageWorks addresses a long-standing need for translating what research has been shown to be the most effective,” said Matthew Schnupp, a registered nurse and contractor with the Atlanta-based federal agency. “It’s a good starting point for collaborating and centralizing message development.”

Schnupp described the Web-based tool as one that allows the health community to assess an existing message or create a new one according to 10 specific demographic characteristics, such as age, gender and race. It also scores any message, based on the user’s assessment of variables, and provides recommendations to improve it.

“MessageWorks is a tool, which is not meant to replace community resources,” Schnupp told the audience, “but addresses key issues,” such as whether a message embodies the messenger’s intent and whether people will act on a health message after receiving it to improve their health.

The CDC’s division of cancer prevention and control and the Oak Ridge Institute for Science and Education created the messaging tool, following an extensive literature review between 1961 and 2006, and the identification of an empirical model. The model was then validated by a panel of 15 experts drawn from academia, private and government sectors. All had extensive experience with message development, health and social marketing, and health communications campaigns.

MessageWorks is free and user-friendly, Schnupp told the audience. “Viewed through expert eyes, it’s ready for you professionals to bring to your communities.”

For more information on MessageWorks, go to www.healthcommworks.com

**PDQ (Physician Data Query)** is the National Cancer Institute’s source of comprehensive cancer information. It contains peer-reviewed, evidence-based cancer information summaries on treatment, supportive care, screening, prevention, genetics, and complementary and alternative medicine. The summaries are regularly updated by six editorial boards. The following PDQ summaries were recently updated:


The PDQ Breast Cancer Treatment summary was recently updated to include pertuzumab, a monoclonal antibody approved by the FDA in June 2012 for use in combination with trastuzumab and docetaxel for the treatment of patients with HER2-positive metastatic breast cancer who have not received prior anti-HER2 therapy or chemotherapy. The phase III CLEOPATRA [NCT00567190] trial assessed the efficacy and safety of pertuzumab plus trastuzumab plus docetaxel versus placebo plus trastuzumab plus docetaxel, in the first-line HER2+ metastatic setting. The median PFS was 12.4 months in the control group versus 18.5 months in the pertuzumab group (HR, 0.62; 95% CI, 0.51–0.75; P <.001). Final OS results are pending. The toxicity profile was similar in both treatment groups with no increase in cardiac toxic effects seen in the pertuzumab combination arm. To review the summary, please use the following link: http://www.cancer.gov/cancertopics/pdq/treatment/breast/healthprofessional/page10/AllPages#Section_821


The PDQ Breast Cancer Treatment summary was recently updated to state that, based on the results of several clinical trials that have studied ovarian ablation and chemotherapy, the weight of the evidence suggests that ovarian ablation should not be routinely added to systemic therapy with chemotherapy and/or tamoxifen in premenopausal women with early-stage invasive breast cancer. In addition, ovarian ablation alone should not be routinely used as an alternative to any other systemic therapy in these women. Further results of research studies prospectively evaluating the role of adjuvant ovarian ablation are awaited. To review the summary, please use the following link: http://www.cancer.gov/cancertopics/pdq/treatment/breast/healthprofessional/page10/AllPages#Section_821


The PDQ Prostate Cancer Screening summary was recently updated with prostate