

# Conference Summaries

Research & Policy Forum 2010 • January 28, 2009 • Washington, D.C.

## Securing a Change for the Future

**Jeffrey Belkora, PhD**

*Jeffrey Belkora, PhD, the director of decision services at the University of California-San Francisco Breast Care Center, described the organization's innovative decision support program. Alexandra Teng joined Dr. Belkora to discuss her experience providing decision support to patients with breast cancer.*

### Introduction

- Dr. Belkora began by describing the patient journey through cancer treatment decisions: The patient receives a frightening diagnosis that triggers many emotions including fear of mortality. While reeling from this emotional shock, the patient is propelled into a series of visits to surgeons, medical oncologists, and other specialists. At each visit the patient learns of treatment options, which may engender additional fears. In this context, it can be very challenging for a patient to remain informed and engaged.
- According to Dr. Belkora, research has identified three effective strategies for informing and involving patients:
  - Use of decision aids;
  - Creating lists of questions; and
  - Providing summary notes and recordings.
- Breast Care Center staff works to integrate these strategies into the patient journey without increasing the burden on the patient. According to Dr. Belkora, their solution is to employ premedical trainees to support shared decision making.

### The Premedical Trainee Program

- The premedical trainee program, which began in 2002 and has graduated 37 trainees, involves a collaborative arrangement in which college graduates spend a "gap year" between college and medical school working for the Breast Care Center. They spent 80 percent of their time working with faculty members on research projects. The remaining time the trainees support the shared decision making process within the center.
- Alexandra Teng, a current premedical trainee, explained the decision support process at the Breast Care Center by describing the experience of a recent patient, whom she called "Anna."
  - Anna made an appointment with one of the center's oncologists; Anna's name automatically was placed on Ms. Teng's call list.
  - Ms. Teng called Anna to offer her a decision aid. On the basis of their conversation, she sent Anna the DVD about hormone therapy. She asked that Anna begin thinking about questions specific to her situation.
  - After Anna viewed the DVD, Ms. Teng spoke with her by telephone. She helped Anna create a list of questions and concerns, and organized them to ensure that all key points were included. Ms. Teng emailed the list to the physician.
  - Ms. Teng accompanied Anna to the appointment with the consultant, taking notes on a laptop computer and recording the consultation. Because the physician was cognizant of Anna's desire to be given a lot of factual information—a preference that Ms. Teng elicited when she helped craft the list of questions—the communication was more effective than it might have been otherwise.

- Anna left the consultation with a patient-oriented summary and a CD recording of the discussion.
- Anna later sent Ms. Teng an email that said, "I cannot imagine having my questions, fears, and concerns being addressed and answered if it wasn't for you. You're going to be a wonderful, caring doctor in the future."
- Ms. Teng concluded by commenting that a unique aspect of the program is it provides clinical exposure in which the trainees "shadow" patients rather than doctors. The trainees see the clinical experience through the patient's eyes and learn the importance of eliciting and addressing patients' questions and concerns as part of their clinical care.

### Provider and Patient Response

- According to Dr. Belkora, the four surgeons and eight oncologists who collaborate with the Breast Care Center are very pleased with the program. They report that patients who have received decision support ask better questions and begin the consultation at a higher level of understanding than those who have not accessed the program.
- Patients also report a high level of satisfaction with the program. A recent evaluation of more than 1,000 patients found that 96 percent would recommend the use of decision aids; the median satisfaction score was 10 out of 10; and the proportion of knowledge questions answered correctly was higher after viewing a decision aid (81 percent compared with 50 percent correct before viewing). The majority of patients (97 percent) reported that they "participated in their treatment choices as much as they wanted to."
- Dr. Belkora addressed the potential concern that a program such as theirs might be difficult to replicate at other sites. He believes that many features of the program can be reproduced elsewhere, including:
  - The use of a relatively inexpensive resource to leverage a more expensive one. The cost of the premedical trainees' time is much less than that of medical professionals; the decision support provided by the trainees maximizes the value of the consultant's time, with the added benefit of providing clinical experience for the trainees.
  - The strategic use of resources to avoid "overshooting the need." The premedical trainees are trained to complete certain specific tasks that facilitate shared decision making; they are not employed to provide medical advice.
  - Looking for the win-win situation. The program provides significant advantages for all concerned: patients, trainees, physicians, and faculty members.
  - Combining high tech with high touch. The program relies on a combination of technology (e.g., use of DVDs, email, telephone calls, and voice recorders) and interpersonal connection (the intergenerational bonding and optimistic atmosphere that results when young people are given the opportunity to serve others).
- Dr. Belkora expressed the hope that similar programs could be launched nationally, perhaps comparable in scope to the Peace Corps or Teach for America.
- His group is currently working with the regional cancer support community to craft a program that would employ trainees in medicine, nursing, social work, and mental health to deliver shared decision making.

### Dr. Belkora concluded with a patient quote:

"Decision and consultation service was fantastic. Made me feel so well-prepared. This is how medicine should work...Having the booklet info available online was terrific. This was exactly the material [statistics] I was looking for all over the web, but having a hard time finding in a consolidated format that made sense...The consultation with doctor was superb...Everything was very proactive."