Linda Goulet first encountered “shared decision making” when she came to Massachusetts General Hospital for advice about treating her stage III bladder cancer. Michael L. Blute, MD, chief of Urology, had assembled a team of top medical experts to discuss her case, but she quickly discovered that her own opinions were considered critical.

SHARED DECISIONS

MGH patients are helping to chart the course of their care

By S.M. Nichols
“This was the beautiful thing,” says Linda, who brought her partner and a nurse friend along for advice and support. “They talked to us. They talked to each other. They asked us questions, and they asked each other questions.”

With shared decision making, patients and their doctors carefully consider scientific evidence as well as a patient’s own preferences before jointly making a treatment decision. Although patients with a cancer diagnosis may face particularly complicated treatment options, the process can benefit patients suffering from conditions ranging from depression to diabetes.

Shared decision making not only ensures patients are fully informed of all available treatment options and the benefits and drawbacks of each, but also enables patients and doctors to develop a health-care plan that best aligns with the patient’s lifestyle, values and goals.

“For many, and I would argue, most things in medicine, there’s more than one reasonable option,” says Michael J. Barry, MD, medical director of Mass General’s Stoeckle Center for Primary Care Innovation. “Someone with a bad hip could decide to have a hip replacement. They might also decide to manage it conservatively with medications, physical therapy or exercise. There’s real choice.”

Dr. Barry began researching medical decision making at Massachusetts General in 1983 under the tutelage of Albert G. Mulley, Jr. MD, MPP, then chief of the MGH General Medicine Division. In partnership with outside researchers, he and Dr. Mulley conducted seminal research on the role of patient preferences in treatment. One of their most recognized national studies involved patients treated for prostate disease. Dr. Blute, then at the Mayo Clinic, was a participating clinician.

From Research to Practice

Today, the MGH Health Decision Sciences Center builds on their pioneering research to improve the quality of decisions made by patients and healthcare providers about medical testing and treatment.

In addition to research, one of the center’s main goals is to make shared decision making a part of routine care.

“Mass General has become one of the leaders in the implementation of shared decision making,” says Karen Sepucha, PhD, the center’s director. “We have worked over the past 10 years with all the adult primary care practices affiliated with Mass General and all have adopted it. We are now expanding to specialties like cardiology and orthopaedics.”

The center provides training to help physicians develop the skills necessary for successful shared decision making. Physicians learn how best to convey medical information, how to elicit a patient’s preferences, values and goals, and how to communicate the probability of a given outcome.

In addition to training, the center distributes decision aids that physicians prescribe to patients. Although these tools address many types of decisions and come in all forms—from web-based, risk calculators to printed handouts—the most comprehensive is a set of DVD programs on common medical conditions. The DVDs, with accompanying booklets, provide detailed information on the condition, its treatment options and testimonials from patients.

Matching Patients and Treatments

Leigh Simmons, MD, an MGH internal medicine physician and center staff member, considers the DVD programs invaluable for both the impact of the patient testimonials and for prompting patients to ask questions they might not have otherwise. She prescribed one for a patient recently diagnosed with diabetes.

“What was most compelling for him was hearing other patients talk about how they took control of their diet and lost weight and how it helped them avoid medication,” says Dr. Simmons, who prescribes a decision aid program once a day on average. “He found it very inspiring, and he had some very insightful questions about whether he needed medication or could try losing weight. That preparation enabled us to make a plan.”

Developing Innovation Decision Aids

The Health Decision Sciences Center has a catalog of 40 programs on topics such as “Early-Stage Breast Cancer: Choosing your Surgery” and “Heart Tests: Learning About Your Choices.” The DVD programs are produced by Health Dialog with annual editorial review and input from the Informed Medical Decisions Foundation, an independent nonprofit headed by Dr. Barry.

The center also develops innovative decision aids. A clear and simple medical decision worksheet uses a “frequently asked questions” format to present treatment options and includes questions for the patient to complete. These worksheets not only facilitate discussions between physicians and patients, but also reveal relevant information about a patient’s preferences.

“The point of shared decision making is figuring out how to match the right person with the right treatment.”

Karen Sepucha, PhD
same treatment,” Dr. Sepucha says. “Two patients with the same symptom burden might look at the same medically appropriate options and choose completely different paths. We help people choose the one that’s right for them.”

**Patient and Provider Satisfaction**

Over the past three years, the center has surveyed patients of MGH-affiliated primary care practices who have received decision aids. The results speak for themselves: 86 percent responded it was “very or extremely” important to receive these programs and 70 percent found them “very or extremely” useful in helping them prepare to talk to their doctor.

“Our patients are more satisfied with their visit and more satisfied with their decision,” Dr. Simmons says. “A patient benefit not as easily measured is how these decision aids help future decision making even where no decision aid is available. You’ve already set the stage for an equal partnership, and the patient will feel comfortable raising concerns.”

In addition, an international research group’s review of randomized trials of decisions aids and their effects on decision making, published in 2014, reflects the center’s positive results and reports some data that could impact medical costs.

“This review shows that patients are more knowledgeable,” Dr. Barry says. “They understand the risks better. They’re less conflicted about their decision and they’re less likely to be on the fence. In many areas, there was about a 20 percent reduction in elective surgical rates.”

MGH healthcare providers register just as much enthusiasm for shared decision making as their patients. Ninety percent surveyed said decision aids help them provide better care.

An Informed Choice

Sitting across from a team of physicians she had never met before, Linda Goulet was facing a decision that could save her life but could dramatically alter how she lived it. The avid golfer knew cystectomy, the removal of the bladder, was the standard treatment for stage II bladder cancer, her recently diagnosed condition.

However, at Linda’s meeting with the multidisciplinary team at Massachusetts General Hospital Cancer Center, she was learning more about her choices. The team—Philip J. Saylor, MD, medical oncologist, Anthony Zeitman, MD, radiation oncologist, and Dr. Blute, chief of Urology—were discussing treatment options, their associated risks and benefits, and probable outcomes. Linda, in turn, was expressing her hope to save her bladder, if possible, and avoid the use of a drainage appliance for the rest of her life.

Unfortunately for Linda, her advanced disease presented her with difficult decisions. However, the Mass General Cancer Center’s multidisciplinary team has 20 years of practice helping patients like her.

“A diagnosis of bladder cancer leads to a tremendous amount of shared decision making,” says Dr. Blute, an expert in bladder-sparing surgeries and one of the few surgeons in the country who perform neobladder reconstruction (removing the bladder and creating a new one using a piece of intestine). “It’s a very complex disease with a lot of variables.

Understanding the Patient’s Goals

“When they do make their decision, they’re pretty confident they’ve made the right choice. They’ve had the benefit of a thoughtful discussion with experts in each area and the experts understood their goals” During the discussion, the team presented Linda with two treatment options, either a cystectomy upfront or a course of chemotherapy in advance of the surgery to increase her chances of long-term survival and shrink the tumors in her bladder. Dr. Blute also determined that Linda was an excellent candidate for a neobladder, which would meet her objective to maintain as normal function as possible.

Linda chose to undergo chemotherapy and responded so well Dr. Blute was able to perform the neobladder reconstruction last May. More than satisfied with her decision, Linda is already back on the links.

“I feel like it’s a miracle that I feel so good and that it’s working so well,” she says.

To support shared decision making initiatives at Mass General, please contact Amy Fontanella at afontanella@partners.org or 617-724-6426. To support urology care and research at Mass General, please contact Heidi Bergmeyer at hbergmeyer@partners.org or 617-643-7160.

**MOREINFO**

"Patients appreciate the single-session discussion. When they do make their decision, they’re pretty confident they’ve made the right choice."

Michael L. Blute, MD