

Patients learn to share in health care decisions

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By Joe Fahy, Pittsburgh Post-Gazette

After her mother died of breast cancer in 1979, Chris Vitko suspected that she, too, might someday develop the disease.

So when those fears were realized late last year, Ms. Vitko, 48, of the North Side, had some idea of the cancer surgery she wanted.

She modified those plans, however, after participating in an Allegheny General Hospital program that helps breast cancer patients learn more about their treatment options.

Modeled after initiatives used by the Center for Shared Decision Making at the Dartmouth-Hitchcock Medical Center, Allegheny General's program offers counseling, educational videos and other information to selected patients soon after they are diagnosed. The goal is to help them become better informed about their options and collaborate more effectively when they meet with their surgeons to discuss a treatment plan.

While the program is limited to certain patients with noninvasive and early stage invasive breast cancer, the hospital hopes to expand it to other breast cancer patients, said Dr. Thomas Julian, assistant director of the Allegheny Breast Care Center.

Proponents believe that shared decision making between patients and their physicians may especially help when patients have more than one viable treatment option.

Many patients with early stage breast cancer, for example, could have either a mastectomy or a combination of radiation and lumpectomy. Both treatments offer comparable rates of survival.

Breast cancer patients also can face other treatment decisions related to chemotherapy, genetic testing or reconstructive surgery.

Providing unbiased information on the range of options available "makes a huge amount of sense," said Dr. Robert Smith, director of cancer screening for the American Cancer Society.



Tony Tye, Post-Gazette

Chris Vitko, right, of the North Side, who has breast cancer, meets with her oncologist, Dr. Larisa Greenberg, at Allegheny General Hospital.

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Shared decision making "gives patients control," said Dr. Julian, "and that's important in a process that says you're no longer in control of what's going on in your body because a cancer has developed."

More than 60 women have participated in Allegheny General's program, which began last year with funding from Highmark and a Boston-based nonprofit, the Foundation for Informed Medical Decision Making.

Before they meet with a surgeon to discuss a treatment plan, patients in the hospital's program complete a questionnaire that assesses how far along they are in making a treatment decision and whether they know the options available, including the risks and benefits of each. Then they watch a video that discusses those options.

Though women can find information on their cancer from the Internet or other sources, the videos are particularly helpful because they address the patient's specific type of cancer, said Harriet Gudenburr, who coordinates the program with another nurse, Marianne Jeffries.

The videos are regularly updated, and every effort is made to present unbiased information, said George Bennett, chief executive officer of Health Dialog, the Boston-based company that produces the videos using information from the Foundation for Informed Medical Decision Making.

"If you are well informed and you know the different things that you can do about your sickness, it makes it a lot easier for you and you won't feel afraid," said one breast cancer survivor featured on the video that Chris Vitko watched.

Once they finish the video, patients answer additional survey questions that assess what they learned and whether the video prepared them to make a treatment decision. Patients also can contact the nurse coordinators of the program if they are having trouble making a choice.

Based on the survey responses, the patient's surgeon receives a written summary indicating how well the patient understood the information presented. The document also mentions the surgery the patient appears to be considering and whether the choice is being made without pressure from others.

Having the summary "makes for an easier dialogue" when surgeons meet with patients, Dr. Julian said, noting that it can otherwise be difficult, in some cases, to determine what treatment a patient might prefer.

"There are still some patients who say, 'Whatever you think,' but that's becoming less of a standard approach," he said. "Patients want to have control, and that's appropriate."

The hospital's survey data also are being used for a research project, funded by the Foundation for Informed Medical Decision Making, that involves more than 20 breast cancer centers around the nation.

Magee-Womens Hospital also makes informational videos available to patients, said Dr. Gretchen Ahrendt, director of surgical breast services. Though patients typically view the videos after they meet with a surgeon, seeing them ahead of time "probably is a more optimal way to start the discussion with the patient," she said.

Health Dialog's Bennett noted that the informational videos have been available for years for a number of health conditions.

Patients who are more actively involved in their care tend to be more satisfied with their treatment, he said. Quality of care may be improved and costs may go down.

For Chris Vitko, a routine mammogram in August quickly led to a diagnosis of cancer in her left breast.

The news left her shocked and in tears, but she quickly began planning what she would do to recover her health.

"I have too many people to watch growing up," she said, noting she has four children and five grandchildren. "You just have to put things in the Lord's hands, and in perspective."

She had always told herself that she would have a mastectomy if she developed breast cancer, and thought she would prefer a prosthesis rather than reconstructive surgery.

She also had genetic testing, which could have led to even more surgery, but the tests were inconclusive.

After watching the video several times, alone and with family members, Ms. Vitko decided she still wanted to have her cancerous breast removed. She had the surgery, along with the removal of some lymph nodes, in late October.

Rather than a prosthesis, though, she opted for breast reconstruction. She also has had follow-up chemotherapy.

Strong support from her husband, Tony, and the rest of her family has been a big help, she said. She also has been pleased with both the medical care she has received and her treatment decisions.

Statements made by several patients on the video influenced her choices.

"They all made different decisions," she said, "but they were so true, and felt so strong in their beliefs, that you couldn't help coming away from that feeling like, 'I have a right to do this.' "

