Early-stage breast cancer

Research tools reveal outcomes for women’s quality of life
When women learn that they have an early form of breast cancer called DCIS (ductal carcinoma in situ), they often consider 2 surgical treatment options: removal of the breast, called mastectomy, or removal of the tumor and tissue around it, referred to as a lumpectomy.

However, little has been known about how DCIS affects the patients. What did it cost them in terms of lost work and medical expenses? How did it affect their employment, relationships, and overall quality of life?

A study team at the Kaiser Permanente Southern California Department of Research & Evaluation decided to find out. The team was led by Research Scientist Aniket Kawatkar, PhD, MS, who focuses on health care economics and compares the effectiveness of treatment options.

Initial findings answer treatment question
Some of the first findings in 2016 showed that among women at KPSC, there was no difference in breast cancer recurrence and progression between the women who chose mastectomy and those who chose lumpectomy. This answered one of the biggest questions in women’s minds when they receive the DCIS diagnosis, as well as in the minds of their physicians when recommending treatment. The research has been presented at conferences and was submitted for publication in 2017.

Why women chose the more invasive mastectomy over the less invasive and less expensive lumpectomy was another question.

"Is it fear of progression? Is it because their friend or sister had a successful mastectomy?" Dr. Kawatkar asked. "If we can understand the decision-making process of our patients, we can help Kaiser Permanente come up with a better treatment plan."

Health economics research improves value
Health economics research focuses on improving the value of medical care. Typically, researchers analyze the patterns of use for health care services and medications, the costs, and the outcomes for patients and clinicians.

"Kaiser Permanente strives to deliver high-quality, affordable health care," said Steven Jacobsen, MD, PhD, the senior director of research for the Department of Research & Evaluation. "By considering the economics as well as the outcomes, we can evaluate opportunities we have to reduce costs without sacrificing quality."

Interest in treatment options began early
Dr. Kawatkar’s interest in the economics of breast cancer began in graduate school at the University of Southern California, where he researched treatment options for women with metastatic breast cancer. Metastatic breast cancer is cancer that has spread beyond the breast to other organs in the body. It is the most advanced form of breast cancer.

In that study, Dr. Kawatkar created a model to determine the cost effectiveness for 2 different chemotherapy regimens for breast cancer while factoring in quality of life and longevity.

“The question was, what is the trade-off between going for additional rounds of chemo versus the quantity of life and quality of life?” Dr. Kawatkar said. “A life lived by a cancer patient is not the same as a life lived by a healthy patient.”

After he joined the Department of Research & Evaluation, he learned the nonprofit research funding agency Patient-Centered Outcomes Research Institute had an interest in DCIS, which can be a precursor to metastatic breast cancer. He applied. Based on the reviewers’ comments, Dr. Kawatkar realized his application would have a better chance of funding if he conducted a pilot study first. So, this work began. Not only have the results been gratifying, but “now that we have this cohort, we will apply again,” he said.

Treatment can prevent cancer progression
DCIS is a form of breast cancer in which abnormal cells are contained within a woman’s milk ducts. It is noninvasive, but without treatment the abnormal cells may progress to invasive breast cancer. Surgery, with or without radiation therapy, is typically recommended to treat DCIS. With treatment, the prognosis is excellent.
“One of the key questions to look at when a woman has DCIS is, what are her treatment options?” Dr. Kawatkar said. “It’s not malignant. The cancer is still in the ductal cells, but it can spread.”

The more aggressive mastectomy procedure costs the patient more in terms of lost time at work for recuperation. Patients also may face additional surgery for reconstruction and a higher risk of infection. Concern over the cancer spreading, though, can lead some women to choose mastectomy over lumpectomy.

To evaluate the effectiveness of lumpectomy versus mastectomy, biostatistician Lewei Duan, MS, applied Instrumental Variables, a statistical approach used to estimate causal relationships. It is popular in economics research but not often used in health research.

This approach allowed Duan to better determine the causal effect of surgical type on probability of cancer recurrence and progression.

“To use a method such as Instrumental Variables was a very exciting experience for me,” Duan said. “We were able to obtain a consistent estimate for a causal relationship in a clinical setting.”

Creating a survey to capture decision-making
Research Associate Janet Mora Márquez did much of the work to create the survey. Her job involved finding questions that had been validated by previous research to show they were effective.

Tools included statistical models and surveys
Dr. Kawatkar and his team began the research by developing the cohort with information from the Kaiser Permanente Cancer Registry, the Kaiser Permanente HealthConnect electronic health record, and an online survey. The team sent out 3,092 surveys to female KPSC patients diagnosed with DCIS between 1998 and 2014. About 1,400 women filled out the surveys and returned them—even though there were 70 to 100 questions per survey. Nearly 1,000 women completed the entire survey.
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— Lewei Duan, MS

“We did a lot of research to try to understand what questions would best capture the kind of information we wanted,” Mora Márquez said. “The focus was on questions that dealt with the women’s quality of life after their diagnosis and treatment.”

One of the more unusual parts of the survey was including a Decisional Conflict Scale to measure perceptions of decision uncertainty, clarity of values, and decisiveness in decision-making, said Cecilia Portugal, MPH, a senior research project manager.

“One of the questions we looked at was how informed the members felt they were when they made the decision,” Portugal said. “Another looked at how clear and certain they were about the decision they made.”

A major finding was that women under 50 years of age with DCIS reported more decisional conflict about their treatment than older women.

Portugal made 2 poster presentations in 2016 on the differences in decisional conflict about treatment of DCIS by age, race, and ethnicity: one at a cancer conference at the Kaiser Permanente Los Angeles Medical Center, and one at the annual meeting of the American Public Health Association in Denver.

Survey gets positive response from patients

Research Associate Erika Estrada managed patient outreach: contacting the members and following up if they had issues on the survey. The day after the survey was emailed, Estrada arrived to work to find 30 messages on her phone.

“Women were leaving messages about how they would do anything they could to help,” she said. “They appreciated the type of care they received and the opportunity to share their experience.”

When Estrada talked with the women, she heard a strong, clear message that the breast cancer survivors wanted to help others facing the same situation. She and other team members talked to several hundred people on the phone and answered many emails.

Portugal was one of the team members involved in follow-up calls to patients.

“I didn’t talk to one person who was unhappy with their cancer care at Kaiser Permanente,” Portugal said. “They told me, ‘I had the best breast cancer care’ and ‘I had such a great doctor and the nurses were wonderful.’ People were really happy with their care.”

Researchers provide answers for patients

Providing answers that could help women and physicians was gratifying, Duan said.

“Our research can help patients decide what choice to make regarding DCIS. They can make a more informed decision regarding their body and body image. That’s something that could affect their quality of life,” Duan said. “Kaiser Permanente wants people to have a good quality of life. And that doesn’t have to cost more.”