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Women Experience More Side Effects from Pelvic Radiation than Realized

Women who have undergone standard radiation therapy have reported pain, diarrhea and fecal incontinence.

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Women undergoing radiation therapy for cervical or uterine cancer have a much higher incidence of serious side effects than previously realized, according to results from a new clinical trial. This information may help women and their clinicians more accurately weigh the potential benefits versus harms of adjuvant therapy, said the trial's leaders.

The study used the PRO-CTCAE™, a system that patients can use to report side effects they are experiencing during treatment. Developed by NCI, the PRO-CTCAE captures 78 common side effects of cancer treatment that are amenable to self-reporting—that is, that cause symptoms patients can recognize, rather than those that can only be picked up by medical tests. It allows patients to report the frequency and severity of side effects and the degree to which these side effects interfere with their everyday activities.

In the study, published February 19 in the Journal of Clinical Oncology, women who received radiation to the pelvic region reported side effects much more often using an online version of the PRO-CTCAE than they did during conversations with their providers, who recorded patients' side effects in the clinician version of the system, called the Common Terminology Criteria for Adverse Events (CTCAE). For example, the rate of fecal incontinence captured with the PRO-CTCAE was 15 times higher than that captured by clinicians.

“The issue isn't really about one reporting system versus another, since both PRO-CTCAE and CTCAE are designed to capture adverse events that occur with a given cancer therapy," said Sandra Mitchell, PhD, CRNP, of NCI's Division of Cancer Control and Population Sciences, who directed the development of PRO-CTCAE but was not involved with the study.

"What this study shows is PRO-CTCAE captures important information about patients' symptoms and could be used to improve communication between the patient and the clinician doing the grading,” Mitchell said.

“There are some symptoms that patients are just not going to bring up easily in discussions with their doctors,” said Anamaria Yeung, MD, of the University of Florida, who led the study. “And in that case, the clinician is going to assume that they don't have those symptoms.”

Armed with more information about what side effects patients experience with a given treatment, clinicians can more accurately prepare patients in advance and, in some cases, offer preemptive supportive care, explained Mitchell.

“If they know what’s normal, what’s not, and what will get better over time, that can promote greater trust and reduce fear on people’s part about the symptoms that they are experiencing,” Mitchell said.

Personal Risk‒Benefit Calculations

After surgery for cervical or uterine cancer, some women at high risk of their cancer returning may also have radiation therapy to the pelvic region. The decision to have radiation therapy is often very personal, explained Yeung, and requires a woman to balance concerns about potential harms of treatment with the risk of cancer recurrence.

“What I always tell patients when I’m counseling them about this scenario is: ‘Giving you radiation will reduce the chance of your cancer recurring. But it has its own chance of doing bad things to you. So this is a decision that you have to make; a risk–benefit analysis,’” Yeung said. But patients need to know what the risks of side effects really are to make an informed choice, she added.

To better understand the difficulties that are actually experienced by patients having pelvic radiation, Yeung and her colleagues carried out a clinical trial in which they randomly assigned more than 250 women at high risk of uterine or cervical cancer recurrence to receive intensity-modulated radiation therapy (IMRT) or standard radiation therapy to the pelvis.

The trial’s main goal was to compare patient-reported gastrointestinal side effects in the two groups during treatment, which lasted for 5 weeks. A secondary goal was to compare patient-reported side effects with clinician-reported side effects during treatment and at regular intervals for up to 5 years after treatment.

The researchers used the PRO-CTCAE system to track the participants’ experiences with several potential side effects of radiation to the pelvic region, including pain in the abdomen, diarrhea, and fecal incontinence. Health care providers were asked to capture information about the same side effects using CTCAE during follow-up visits at approximately the same intervals. Data were available for 234 patients.

Large Discrepancies in Reporting

According to the data collected from both the clinicians and from the patients by direct self-report, women who had IMRT experienced less pain, diarrhea, and fecal incontinence during treatment than women who underwent standard radiation therapy. The differences between groups shrank or disappeared over about 6 weeks to 3 years, depending on the symptom.

But at all timepoints, the differences between symptoms reported by the women and by their clinicians differed substantially. Whereas 36% of women overall had abdominal pain at some point as reported by their clinicians using CTCAE, the PRO-CTCAE system recorded that 80% of women experienced any abdominal pain and 70% experienced pain that interfered at least somewhat with their normal activities.

The rate of diarrhea was 75% by clinician report and 87% by patient report. But for severe diarrhea, the discrepancy was much greater: less than 3% by clinician report and 43% by patient report. The rate of fecal incontinence reported by clinicians was 3% but was directly reported by more than 50% of patients.

Yeung, herself a radiation oncologist, had no idea that this was what her patients have been experiencing.

“I didn’t realize that there was such a high rate of fecal incontinence in these patients, so it was not my habit to ask specifically about it on a regular basis,” she said. “But if clinicians know that this is a common side effect, they’ll [be] more likely to ask about it.”

Giving patients a way to report symptoms in private, on their own terms, also provides a way for clinicians to start hard conversations about symptoms that can be perceived as shameful, explained Mitchell.

“If I see something like sexual symptoms on a [patient report], I’ll just say: ‘I noticed that you reported that. Is that something you’d like to talk about with me or someone else here?’” she said. “That way the patients don’t have to raise the issues themselves, and the clinician can offer an entrance to the conversation.”

Jump-Starting Better Communication

The medical team will always have an important role in documenting the side effects from cancer treatments, explained Yeung. In addition to symptoms, the clinician version of the CTCAE captures abnormalities found on laboratory tests and objective measurements of observable side effects, like a skin reaction at an injection site. Such things can’t be evaluated and graded by patients themselves.

And while patient reports may more accurately describe some symptoms, what to do about those symptoms during treatment needs to be handled with honest and open communication between patients and their clinical team, taking the patient’s goals for care into account, explained Mitchell.

To be fully open about the side effects they’re experiencing, patients need to know that the information they supply won’t be used to make decisions about their care without their input, she said.

“I’ve had patients say to me: ‘If I think my chemotherapy [dose] is going to be reduced because I report severe fatigue, I’m not going to report severe fatigue,’” she continued. “Patient-reported outcomes [should] enhance communication and shared decision making. Nobody should feel like they’ve got to constrain their honesty because they’re afraid of how the information will get used.”

Those conversations will be different based on individual patients’ goals for care, said Yeung.

“Every patient is going to be coming from a different place in terms of how important quality of life is for them versus reducing their risk of recurrence. I think information like [what we gathered in this study] gives patients the ability they need to be a more involved participant in the decision-making process.”

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