Fox Chase Cancer Center’s ‘Education Intervention’ Helps Patients Fight Fatigue, Improves Their Care Experience

By Audrey Doyle

An “education intervention” designed to improve communication about fatigue in cancer patients has helped clinicians in the Radiation Oncology department at Philadelphia’s Fox Chase Cancer Center provide clear, concise information to patients and families about this common, often distressing side effect of radiation therapy. Proof of the intervention’s success can be seen in the facility’s skyrocketing performance on the related communication measure of the Outpatient Oncology patient experience survey.

The most common side effect of cancer and cancer therapies, fatigue can have significant physical, emotional, psychological and social consequences for patients, yet many patients feel underprepared to cope with it. The Fox Chase Radiation Oncology team realized this was the case with their patients when they reviewed the Outpatient Oncology survey results for Q2 2017. The facility was in the 24th percentile among other NCI cancer centers for its performance on the survey item “Management of radiation therapy side effects was explained.” Patients’ survey comments were equally disheartening. “We were really struggling with this,” said Erin Longstreth-Papsun, Radiation Oncology clinical nurse manager. “We needed to find better ways to educate patients about cancer-related fatigue.”

To do that, the Radiation Oncology team conducted an “education intervention” to improve their method of teaching patients about treatment-related fatigue and fatigue-fighting strategies. Their efforts paid off. In just over a year, Fox Chase’s ranking rose from the 24th to the 83rd percentile. In addition, the number of patients who experienced fatigue during radiation treatment dropped 7%.

“Cancer-related fatigue is more intense than everyday fatigue, and for many patients it can be their most distressing symptom, but there are ways to manage it,” said Longstreth-Papsun. “The key for us was to identify what was driving our patients’ negative perceptions about the education they were receiving, and then to develop the right educational material and give it to them at the right time. Now that we’ve done that, we’re providing a better care experience for our patients and improving their quality of life.”

Timing Is Everything

Fox Chase Cancer Center was formed in 1974 through the union of the American Oncologic Hospital and the Institute for Cancer Research, and became an NCI-designated cancer center that same year. An affiliate of Temple University Health System, Fox Chase also serves as the cancer program for Temple University.

Prior to the intervention, Fox Chase’s Radiation Oncology nurses educated patients on treatment-related fatigue at their new-patient consult by describing the condition and offering a document outlining basic facts and suggestions for management. Then, during patients’ weekly on-treatment visits, they’d be assessed for treatment-related side effects, and if they complained of fatigue, they’d be reeducated on fatigue-fighting strategies.

These efforts weren’t working, however. Although nurses discussed treatment-related fatigue during new-patient consults, patients weren’t retaining the information. “Usually they’re newly diagnosed and have visited with a few other disciplines prior to their radiation oncology consult,” Longstreth-Papsun said. “We surmised that by the time they saw us, they were feeling so overwhelmed that they weren’t processing our conversation.”
Moreover, because radiation has a cumulative effect on one's system, most patients don’t start experiencing side effects until a few weeks into treatment. Therefore, patients weren’t reeducated on fatigue-fighting strategies at their first few on-treatment visits because they hadn’t begun to experience fatigue yet. As a result, patients perceived that they’d received no education on fatigue or fatigue-fighting strategies until their third or fourth on-treatment visit, when the effects of radiation had accumulated and they were already suffering.

Exacerbating the situation was the fact that the staff were underutilizing the facility’s fatigue education and management material. Because each patient can experience fatigue differently, Fox Chase suggests many different fatigue-fighting strategies—from taking short naps and getting a good night’s sleep, to avoiding caffeine and following a healthy diet that’s high in protein, to staying hydrated and reducing stress and discomfort. The facility suggested those strategies through nearly a dozen hard-copy handouts, including two documents that explained fatigue and several more that covered ways to fight fatigue through exercise, energy conservation and task prioritization, and relaxation techniques. In addition, the Physical Therapy department had developed their own educational material for PT patients.

“There was a ton of paper, and the nurses didn’t think their patients would want or read it all—they thought it would be too burdensome,” Longstreth-Papsun said. “So most nurses were giving patients only one handout on cancer-related fatigue, and they were giving it to them at a time when they were very overwhelmed and stressed, so it was getting lost in the shuffle.” In addition, the nursing staff were unaware of all the treatment-related programs at Fox Chase that can help patients cope with fatigue, including reiki and yoga classes, stress management programs, disease-specific support groups, and a cancer-related fatigue and exercise program offered through PT. “Each department was developing their own programs and they weren’t doing a great job letting others know about them,” Longstreth-Papsun said. “Our nurses weren’t suggesting the programs to patients, because they didn’t know they existed. Until I started looking into what we offer, I didn’t know they existed either.”

An Education Intervention

The upshot of this was a perception among patients that they hadn’t been properly educated on fatigue as a side effect of treatment, and this was affecting their care experience.

To rectify the situation, the Radiation Oncology team began by reviewing the latest National Comprehensive Cancer Network (NCCN) Guidelines®, a set of strategies detailing the management decisions and interventions that currently apply to 97% of cancers affecting patients in the United States, to better understand current data on cancer-related fatigue as well as prevention and education practices. Longstreth-Papsun also studied recently published scholarly articles and other literature on the subject.

Then they reviewed their education process and the facility's Outpatient Oncology survey results and determined that the best time to educate patients on fatigue as a side effect of radiation is during their first on-treatment visit. At this point, Longstreth-Papsun explained, patients typically feel a bit more at ease with their diagnosis and their mindset is more conducive to retaining and processing the information. Plus, because they're not experiencing side effects from treatment yet, it's possible they can apply what they learn at that time to decrease the amount of fatigue they end up experiencing, or prevent some of it from occurring altogether.

Next, the team reviewed the existing educational documents and condensed them into one easy-to-read trifold color handout, which was reviewed and subsequently approved by Fox Chase’s Patient Education Committee, a team comprising nurses, clinical specialists, librarians, health educators, pharmacists, researchers, and members of the facility’s Patient and Family Advisory Committee.

In addition to describing what cancer-related fatigue is, the new handout explains when patients should be concerned and who they should talk to, and includes a fatigue scale so that they can rate their level of fatigue from 1 to 10. The handout also discusses the importance of exercise, as maintaining a level of activity during treatment can be very effective in fighting cancer-related fatigue. “That was the most important thing we learned from the NCCN Guidelines and literature,” Longstreth-Papsun said. “Most people believe that if you feel tired, you should rest. Although rest is important, it can be counterproductive if you don’t balance it with activity.” To that end, the team decided to provide patients with an activity log where patients would be able to record their daily activity and periods when they were most and least tired, and which they’d be able to bring to their weekly on-treatment visits so that the team can advise them on different strategies if their fatigue was particularly bad the previous week.
The new handout was presented to the nursing staff at their monthly staff meeting, and expectations for its use were discussed at that time. In addition, the staff were given specific terminology to use during patients’ first on-treatment visit—for instance, referring to fatigue as “cancer-related fatigue” and describing it as a “side effect of treatment.” They were also instructed to discuss the activity log during this visit so that patients would be sure to track their activity and fatigue throughout their treatment.

To gain insight on patients’ perceptions of how their fatigue was managed, the team developed a questionnaire that they distributed for two months pre-intervention and six months post-intervention. The questionnaire asked patients how satisfied they were with how the radiation staff managed their fatigue, whether they felt fatigued while on treatment and whether they received verbal and printed education.

According to Longstreth-Papsun, of the 72 pre-intervention respondents, 61% said they were Very Satisfied, 31% said they were Satisfied and 8% said they were Not Satisfied with the way staff managed their fatigue. Of the 172 post-intervention respondents, 81% said they were Very Satisfied, 19% said they were Satisfied and 0% said they were Not Satisfied. In addition, 96% of patients post-intervention reported they had received verbal and printed education vs. 90% pre-intervention, and there was a 7% decrease in the number of patients who experienced fatigue while on treatment.

“We also reviewed our referrals database, and in the first three months post-intervention, Radiation Oncology had a 45% increase in ambulatory PT referrals, which is great because it shows physician support,” Longstreth-Papsun noted.

In addition to the new handout and activity log, each patient also now receives at their initial consult a four-page resource guide that lists all the support tools and programs available both at Fox Chase and within the community. Staff also now assess patients’ level of moral distress at their first visit and throughout treatment. “Fatigue plays a big role in that, because if a patient is tired, their level of moral distress goes way up. If this happens, we know to talk in more detail with them about the support tools and programs in the resource guide,” Longstreth-Papsun said.

Cancer treatment—radiation therapy, chemotherapy, immunotherapy, surgery, bone marrow transplant—saps patients of their energy and can leave them feeling physically, emotionally and cognitively exhausted. “Although cancer-related fatigue can significantly affect a person’s ability to enjoy life, many patients assume nothing can be done about it, so they don’t mention it to their care team,” Longstreth-Papsun said.

“But there are ways to limit cancer-related fatigue,” she concluded. “By educating patients on fatigue at a time in their treatment when they’re best able to process and retain the information, we’re helping them manage this side effect of treatment so they can have a better quality of life.”