

Chicago, said her center has been doing IORT with an Intrabeam for nearly a year and has treated about 50 patients so far. “We don’t have a strict protocol,” she said, “but we tend to use it on women in their 60s who have relatively small, invasive [ductal] cancers.”

“Patients love it,” said Hansen. But it’s frustrating for those who find out later, from the final pathology report, that they have a positive node or involved margins. In such cases the patient undergoes WBI, and the IORT is treated as a boost.

Memorial Sloan–Kettering Cancer Center has its own IORT protocol using a high-dose-rate afterloader that technicians wheel into a special shielded operating room. Beryl McCormick, M.D., chief of external-beam radiotherapy, said the center has 60 patients in a phase I/II feasibility study. Although the study has completed enrollment, she said, the center continues to offer the technology to older

women with low-risk breast cancer. “But we do only a few cases a year,” she said, because getting time in the operating room is so difficult.

#### Tentative Uptake

McCormick does not see IORT becoming widespread in the U.S. because the technology is expensive and the difficult logistics of having a radiation oncologist on call to the operating room.

Alphonse Taghian, M.D., chief of breast radiation oncology at Massachusetts General Hospital, has the same concern. He agrees that patients will demand shorter treatments, but he does not believe IORT is the answer.

Although the Intrabeam device is not expensive, he said, “operating room time is expensive, and it takes a long time [about half an hour] to get the dose delivered.” Another problem he sees

with IORT in general is that, to be eligible, patients need to have clean margins, negative lymph nodes, and no high-risk markers. “We need to wait for the final pathology report to say we’re comfortable that [a given patient] is a good candidate,” he said.

Taghian said the TARGIT trial “proved the principle that partial-breast irradiation is equivalent to WBI in the short term.” What remains to be seen is which of the 10 or more APBI techniques will become dominant.

“It’s like a horse race,” said Taghian, and he, like McCormick, is betting on a type of external-beam radiation called 3D conformal that can be given in 10 sessions over 1–2 weeks. “It’s simple,” he said. “It’s not invasive, it can be taught in community hospitals, and it’s at least 30% cheaper than 6 weeks of radiation.”

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## The Plight of Childhood Cancers for Families

By Kurt Ullman

They are among the most frightening words a parent can hear: “Your child has cancer.” Those words are repeated 12,000 times every year in the U.S. Even though around 75% of children go into remission with treatment, the diagnosis is traumatic for children and parents alike.

Vickie Sardi-Brown recalls the trauma of learning about her son’s diagnosis in July 2008. “It is important to understand that one day our son Matthew was an active 6-year-old going to day camp,” she said. “One day he came home complaining of arm pain. Two weeks later he couldn’t move the arm, and soon after that we got the diagnosis of osteosarcoma.”

Unlike treatments for other childhood illnesses, cancer treatment moves quickly. It is not unusual for a child to be diagnosed one day, hospitalized for surgery the

next, and getting chemotherapy soon thereafter.

“The speed can be incredibly disorienting,” said Kenneth Mitten, a social worker in the department of patient care at St. Jude Children’s Hospital in Memphis, Tenn. “Within 24–36 hours, [parents] are wading through

information on treatment protocols, learning the definition of new terms, and still trying to come to grips with the fact that their child has cancer.”

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Because they often involve intrusive, painful procedures, the treatments themselves usually add to parents’ stress. To cope, the child may exhibit behaviors and emotions unfamiliar to the parent.

“When the child gets angry with them during the course of treatment, parents feel they are doing something wrong,” said Bernadette Mazurek Melnyk, Ph.D., R.N., dean of the College of Nursing at Ohio State University in Columbus. “They were used to parenting



Kenneth Mitten

a healthy child, and suddenly they have one who is not only ill but also reacting in ways they aren't familiar with. This adds to their feelings of anxiety."

Families often must travel to treatment centers, because most childhood cancers are treated at academic medical centers, according to Anita Nirenberg, professor of clinical nursing at Hunter-Bellevue School of Nursing at the City University of New York. "This means that if you don't live in a major urban area, you may have to travel great distances."

Financing both the treatments and the travel can devastate families, especially because often, one parent will quit his or her job to care for the child. And although the Family and Medical Leave Act allows an employee to take up to 12 weeks off to address family health issues, such leave is typically unpaid.

### Changing Family Dynamics

Family members often negotiate new roles with the onset of childhood cancer. For example, the father may stay at home to care for siblings while trying to maintain outside employment, whereas the mother stays at the hospital.

Other children in the family may resent the changing dynamics. "So much attention goes to the ill child that you often see acting out as other children are confused by and anxious about changes in their family and as they try to get attention for themselves," noted Melnyk. "There is also a grieving process over the loss of a sibling who was also a friend."

Siblings may become anxious or depressed; their grades may slip, or they may start fights for attention.

If the family already had problems, dealing with a seriously ill child will only exacerbate those, said Mitten. "If the parents couldn't be in the same room before coming to the hospital, they seldom change," said Mitten. "To be put into the pressure cooker, to be unmoored geographically, to have a child needing your constant attention is by itself jarring. But then we toss in the day-to-day family dynamics on top of that."

Another complication is that family members process the child's illness differently. "Families do not always go through the process at the same time or speed," said Melnyk. "This dyssynchrony makes the road tougher since they do not experience the same emotions at the same time."

The Browns agreed. "When something happens to a couple, one is supposed to support the other," said Brown. "In this situation both are crippled. That means very fundamental needs of a relationship are not being met."

### Help Available

Most cancer centers have programs to help families cope with the immediate stressors of childhood cancer as well as the long-term effects.

"The cancer center at Georgetown University Hospital immediately assigned us a nurse practitioner as case manager and a social worker," said Sardi-Brown, who also has a doctorate in mental health counseling. "They did much of the heavy lifting with bills, making sure we were preapproved when insurance required it, and serving as an advocate for Mattie and us throughout the 15 months of treatment."

In many hospitals, child life specialists help the child be a child. They help with schoolwork and coordinate treatment to lessen waiting time. Most important to the Browns is that they allowed Mattie time to play.

"Kids in a hospital are surrounded by adults doing adult things," said Brown. "The child life specialist focuses on addressing the psychosocial needs of the child. They educated, empowered, and normalized a very unnatural process for Mattie through therapeutic and recreational play."

The support system within the hospital can be a bridge to help in the general community. The Ronald McDonald House and similar charities offer no-cost housing if needed, and parents often bond with one another while there.

Philanthropic organizations help with non-treatment-related expenses. Many sponsor community-based family-to-family mentoring programs to help with questions that only someone who has already gone through the process can truly answer. Such

programs can be found through the hospital's social workers or by searching for the specific type of cancer the child has.

"It takes a village," noted Nirenberg. "The child is the star of the team, but parent, health care providers, nonprofits, and the communities play vital parts in the process."

Friends and neighbors can be an overlooked resource for taking some pressure off the family.

"I often ask parents if they have a bulldog in the family to stand at the front gate and guard them," said Mitten. "Usually someone says, 'That sounds a lot like Aunt Frieda,' and she becomes the conduit of information. Friends also want to do something to help."

Families may also turn to their own inner resources. The Browns started a blog about Mattie. The writing helped them to not only process what was happening but also communicate to people who wanted to help.

"Because neither of us had family in the area, the friends and community members we met through the blog became 'Team Mattie' and were instrumental in supporting us," said Sardi-Brown. "In fact, some of the people who were bringing meals to the hospital, buying toys for Mattie, and even raising money were people we never met before. I honestly don't know how we would have made it through without their help."

That community is an anchor through the cancer experience, and losing that when a child dies only adds to the sense of loss, the Browns said.

"When Mattie was diagnosed, we lost a healthy and bright child with all the prospects that came with it," said Brown. "When we went to the hospital, we lost our regular lives. After Mattie died, we lost the hospital and the only community we had known over the last 15 months."

"As a parent, your life revolves around your child. Most of your social activities have soccer games, school functions, or play dates at their center. When a child gets sick, a whole other universe opens up that only a few people can truly understand and appreciate. Now suddenly all of this is gone."