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At MGH, striking a critical balance

Tough calls as doctors ration proton therapy

By Raja Mishra, Globe Staff, 12/26/2003

The device towered above 6-year-old Sean Baker, its giant rotating metal gurney enveloping him, its particle accelerator poised to drill a high-energy beam into the cancer lodged within his head and spine.

"In we go, into the big microwave," said his father, Lance Baker, looking on.

In being chosen for treatment at the proton therapy center at Massachusetts General Hospital, Sean Baker had won a lottery of sorts. Proton therapy attacks cancer with more precision and less damage than normal radiation, but only three of these devices exist in the United States, and the demand for them far outstrips their capacity to deliver it.

Two years old and stretched to capacity, the $50 million machine at Mass. General dramatically embodies the conflict at the heart of modern high-tech medicine: The device is powerfully effective, but so costly and rare that the hospital is forced to ration its availability. Because insurance often covers only part of the hospital's operating costs, Mass. General allocates some of its limited slots to wealthy foreign patients who can pay the full, $4,000-per-session price for the treatment.

The hospital does not keep statistics on the number of patients rejected, but Dr. Nancy J.Tarbell, Mass. General's pediatric oncology chief, estimated that about one-third of pediatric applicants were refused. The number rejected is even higher at times when there's an unexpected flood of requests.

"I had to turn away more kids than I took this summer," she said. "It's heartbreaking."

Proton therapy harmlessly eliminates localized tumors wedged near sensitive organs, where traditional radiation kills the surrounding tissue as well. It is especially useful for treating brain tumors, sparing nearby sensory organs. Children are also good candidates for the therapy, because radiation often leads to stunted growth and mental retardation, as well as increasing lifetime cancer risks.

Since opening in November 2001, the machine at Mass. General has attracted referrals from around the world, treating more than 540 patients, about one-quarter of them children. In the next week or two the hospital plans to open a new bed in the proton department, effectively doubling its capacity.

But the need, experts say, is far greater. Tens of thousands of US patients currently treated with radiation could benefit from proton therapy.

Faced with that reality, doctors at Mass. General administer a high-stakes rationing system that mirrors the choices made by physicians throughout the medical system. Organ transplants are the classic rationing case, but doctors weigh similar decisions about who should receive home kidney dialysis units, a powerful and expensive anti-sepsis drug, heart assist devices for cardiac patients, and numerous other innovations.

The gatekeepers At Mass. General, the decision about who gets access to the proton machine begins on Tuesday mornings, when a committee of doctors meets over coffee. In one recent session, attended by a Globe reporter, a mix of physicians and nurses considered the medical record of a 3-year-old girl from New York with a brain tumor. There was a wrinkle: She'd been treated earlier with methotrexate, a chemotherapy drug known to reduce the effectiveness of radiation therapy, and possibly protons.

Tarbell, noting this, added: "All her doctors love her. They attacked me, saying please treat her, please."

"Do we open this door, though?" asked Dr. Thomas F. DeLaney, proton therapy medical director. "We won't be able to say no to these patients in the future."

They decide to give a tentative yes for treatment in March, concluding that protons would probably work despite the methotrexate.

In another case, a 3-year-old from the Philadelphia area was rejected. Her tumor type did not fit the scientific criteria for experiments ongoing at the proton center. Moreover, previous research indicated that proton therapy cure rates for her tumor type were slightly lower than those of other candidate patients. It was a hard call, but Tarbell said no.

She says there are no rigid rules, but her staff tries to select patients who will benefit most and also provide useful scientific data. They had quickly approved Sean Baker, who began treatment two weeks ago: Protons worked well on his tumor type, which Mass. General also happened to be studying, and radiation directed at his brain and spine would have put him at risk for developmental damage, hearing loss, and future cancers.

But beyond science and need, finances also factor into the doctors' decisions. The proton center made a small profit last year, according to hospital officials, who would not disclose specific figures. The hospital charges about $4,000 for each proton treatment. Medicaid, which insures many of the center's poor patients, pays only about 40 percent of the price tag, or about $1,600 per session. Many other patients are uninsured; those from Massachusetts are covered by the state's free care pool, while the federal government pays a fraction of the cost for out-of-state cases. The facility balances these out with wealthy patients from abroad, who account for a "fair amount" of its cases, DeLaney said. The center's first pediatric case, in 2001, came from China.

Overall, most patients are American, about evenly split between Massachusetts residents and those from out of state.

"If the hospital loses money on some patients, how do you make it up? There's no hard and fast rules," said DeLaney.

Medical ethicists said this sort of medical rationing involves considerable ambiguity.

"As long as you have some balance, and you're not discriminating against groups based on age or ability to pay, it's good. There's no magic formula . . . but it must be really hard with kids," said Boston University medical ethicist George Annas.

From atoms to tumors The proton therapy program's origins date to 1946, when Cornell physicist Robert Wilson published research indicating protons could help cancer patients. The proton beams came from a cyclotron, a device that until then had been used only by particle physicists to split atoms.

At the time, radiation therapy was already in wide use. But as radiation enters and exits the body, it damages healthy cells, causing often severe side effects. Protons enter the body without harm and, if aimed correctly, can deliver a sudden energy spike at tumor sites, then dissipate. No healthy tissue is damaged.

Over the last decade, computerized X-ray imaging has given doctors detailed portraits of the human body's interior, providing the first precise targeting maps for proton beams.

In 1990, Loma Linda University in California, near a well-known particle accelerator lab, opened the nation's first proton therapy center. Mass. General, using $25 million in federal government grants and $25 million in charitable contributions, opened the second.

The proton facility at Mass. General has operated with two beds, one dedicated only to eye cases. The primary bed handles 22 half-hour treatment slots daily. The number of sessions required for patients varies: Small eye tumors require only four or five sessions, while dense brain tumors may need up to 20. The number of daily sessions required increases with the size of a tumor and the number of sensitive organs around it.

Sean Baker's treatments are covered by MassHealth, the state's health insurance program for poor families. His mother, Wendy Baker, 36, brings him every day from Mashpee on Cape Cod, a four-hour commute. His treatments, which started last month, will last until late January.

As he rolled around the proton center's waiting room on a recent morning, knocking toy trucks around, his mother smiled and told him: "You're a lucky kid."

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