Child Cancer Survivor: Kids Deserve Better Treatments | Opinion

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By Gillian Bomi Okimoto
High School Student and Cancer Survivor

In December 2017, when I was 11, I was diagnosed with osteosarcoma, a rare bone cancer. I was one of the lucky ones—the tumor in my right femur had not spread to other parts of my body. My doctor assured me that my treatment would be as straightforward as it could be.

At the time, I was relieved. I finished nine rounds of chemotherapy in 2018 and had the last of nine surgeries in 2022. It wasn't until this year that I learned that my "straightforward" treatment protocol hadn't been updated in decades. It has been 40 years since osteosarcoma got a new drug for treatment.

When I discovered this, I felt nothing but anger. I'd lost two friends to the very same disease—two brave young women who had battled for years. I was lucky to keep my leg after everything that had happened, but several of my friends have lost their limbs.

This could have been avoidable if adults would just learn to play by the same rules kids are taught—to share.

There's a plethora of roadblocks in the way of research and it's even tougher for pediatric cancer. Only 4 percent of federal cancer research funding is dedicated to childhood cancer, despite it being one of the leading causes of death by disease for children. Children's cancers also behave differently than adult cancers, oftentimes being more aggressive.

The lack of funding is largely due to the fact that children are more likely to get rare diseases. It's more than just money. Gathering data to find a cure is a major challenge for rare illnesses like osteosarcoma. Cases are scarce, and willing research participants are even scarcer.

Let's do the math: there are about 1,000 people diagnosed with osteosarcoma every year. In contrast, more than 200,000 cases of lung cancer and 240,000 cases of breast cancer are diagnosed every year. Big data can only be proven powerful when dealing with large quantities of information.

More common diseases have treatments updated regularly—for example, both breast and lung cancer have had new treatment drugs approved by the FDA this year. That's not the case for diseases like osteosarcoma.

To make matters worse, in the United States, most cancer research opportunities are only presented to patients being treated at large academic hospitals. Many cancer patients in the United States are treated at community hospitals, where research is not often being administered.

"Patient volume is so important in order to analyze trends and see patterns," explained Christina Ip-Toma, the director of scientific programs at MIB Agents, an organization dedicated to osteosarcoma research and education. Her job fosters collaborations within the community to advance research for improved treatments and outcomes.

"In reality with diseases like osteosarcoma, you have 10 patients participating in a study and 10 participating in another study," she says. "We could have had 100 patients in a study, but instead we have 10 participating in 10 different studies and none of that data is connected."

There are some solutions in place. Count Me In, a nonprofit organization of the Broad Institute of MIT and Harvard, partners with patients to conduct research. The patient-reported data is placed into public depositories for the global research community—combining the clinical, genomic, molecular, and personal data without sharing any identifying information.

"We specifically try to look for a disease space that is under-researched," says Beena Thomas, Clinical Data Manager for Count Me In. Count Me In currently has projects dedicated to rare cancers such as osteosarcoma and leiomyosarcoma (muscle cancer), as well as pediatric brain tumors and metastatic breast cancer, and is open to anyone who has ever been diagnosed with any type of cancer.

"There's so much support the patient needs," says Thomas. "There's language barriers, patient trust, patient burden. I honestly cannot imagine going through something as difficult as any type of cancer and thinking about research at the same time. Even in remission, it's such a really hard, emotional journey for the patient. So, what are the ways that we're actively making research as accessible as possible to everybody?"

Ip-Toma also emphasized the need to ease patients' burdens. "For example, 'I want to share my medical records, but there's 10 places I can choose to send it to.' It's just complicated—which one's better? Where will it have the most impact?"

Sharing data internationally would be ideal to increase patient volume, yet it leads to other roadblocks. Many research institutions are unable to share already-rare data with others even within the United States.

In contrast, places such as Canada or the United Kingdom have universal health care systems, which makes data sharing easier. "In Canada, you have to go to a cancer center to receive care," said Noorshifa Arssath, a project coordinator at Count Me In. "So, we're only pulling data from participants from maybe five to 10 hospitals or institutions because those are the only places you can receive care." This means data sets are compatible on a

nationwide scale—but incompatible across systems. This becomes an even bigger problem when attempting to share data with the U.S., which has non-standardized health care systems.

There are other institutions like Count Me In. For example, Project:EveryChild aims to maintain a registry for childhood cancers, including a biobank for tumors, DNA, and clinical data. Another organization, Pattern.org, is dedicated to rare diseases and shares fresh tissue samples with researchers directly after surgery.

But such patient-driven data centers are not the solution.

"The research is being done, but at different institutions with repeated efforts," Arssath says. "[At conferences] various researchers would go up on stage and present similar studies. Being able to come together as a research community as opposed to siloed research efforts would make a difference in cancer discovery in general."

So, children's cancers are aggressive and underfunded. There's very little research done for rare pediatric cancers—there are few patients that can participate in research to begin with, and those patients are spread thin.

The true solution is coordinated data sharing between institutions and internationally—but with the current system, it's close to impossible.

Having a universal database for every illness would solve all the issues with data sharing. It would allow patients an easy experience when participating in research and would allow great strides to create better treatments for all types of diseases.

Kids are told to share their toys while teens are scorned for oversharing. But, for the sake of those battling cancer, please scrape all our data and make it big.

Gillian Bomi Okimoto is a New York City high school senior. She is a cancer survivor and is an advocate for improved pediatric cancer research and education, particularly for rare diseases.

The views expressed in this article are the writer's own.

About the writer

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