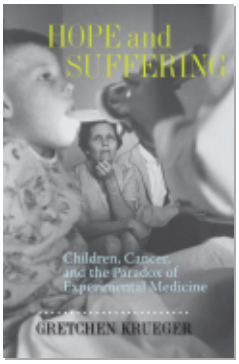
Hope and Suffering



Published by Johns Hopkins University Press

Hope and Suffering: Children, Cancer, and the Paradox of Experimental Medicine.
Baltimore: Johns Hopkins University Press, 2008.
Project MUSE., https://muse.jhu.edu/.

Conclusion

In October 1939, metropolitan newspapers reported that surgeons at Memorial Hospital had amputated the right leg of eight-year-old Dorothy Lewis in order to remove a malignant bone tumor completely.[1] Cancer specialists had advised her father that radical surgery held the only hope of completely removing the growth and predicted that Dorothy would survive only a year without the operation. Despite this dire prognosis, the girl's father, William Lewis, a laborer for the Queens Parks Department, repeatedly refused to permit the potentially life-saving operation, admitting, "I couldn't stand Dorothy's being a cripple."[2] Instead, he permitted his daughter to undergo weekly radiation therapy. Not long after her diagnosis, newspaper articles about Dorothy and the physician-parent dispute prompted readers from around the world to send letters to the Lewises' Brooklyn home to offer their support or to challenge the father's stance regarding his daughter's treatment.[3] When treatments failed to shrink the tumor or provide lasting symptomatic relief, Lewis allowed the amputation. After her surgery, physicians cautiously labeled Dorothy's condition "satisfactory" and reported that they believed the tumor had not spread to other parts of her body.[4] This announcement concluded the yearlong debate.

Thirty-four years later, Edward M. Kennedy, Jr., complained to his father that his lower leg was painful and swollen. The twelve-year-old, known as Teddy, was the son of Edward Kennedy, the chairman of the Senate Subcommittee on Health and Scientific Research. Their family physician initially dismissed Teddy's symptoms and recommended that he soak the leg in Epsom salts, but a second examination and biopsy by George Hyatt, a professor of surgery at Georgetown University Hospital, revealed a tumor. Hyatt recommended prompt amputation to prevent the rare, fast-growing cancer of the cartilage from spreading. Only four days after his diagnosis, Teddy underwent an hour-long operation to amputate his leg above the knee and to form a stump for attaching a prosthetic device. Brief articles in the *New York Times* updated readers on Teddy's treatment regimen, his release from the hospital

and continued treatment every three weeks, his first ski trip after the surgery, and his correspondence with a penpal who was also an amputee. Teddy also received thousands of letters and telegrams wishing him a speedy recovery.[5]

After surgery, Teddy participated in a study at the Dana-Farber Cancer Center (previously the Jimmy Fund Clinic) that investigated the role of adjuvant chemotherapy in children with osteogenic sarcoma who had been treated with immediate amputation.[6] A pair of articles published in the *New England Journal of Medicine* reported that by adding chemotherapy to surgical intervention, clinicians could defer or prevent the onset of lung metastases. Research at the cancer center found that relapse was deferred with the administration of methotrexate and citrovorum factor.[7] To prevent dangerous side effects such as anemia, nausea, mouth ulcers, and impaired organ function caused by the methotrexate, the effective but toxic dose was followed by a massive dose of citrovorum factor; this combination allowed methotrexate to selectively target the tumor by sparing the normal cells that were "rescued" with the citrovorum factor antidote. As part of the study, Teddy stayed at the cancer center for six-hour continuous intravenous infusions of methotrexate in which he received up to 100 times the standard dose of the drug. Two hours later, the administration of citrovorum factor began and continued up to six days by oral dose. When the methotrexate level in blood had declined satisfactorily, he was allowed to return home for his body to recover. Citrovorum factor allowed researchers to continue this treatment for long periods of time without inducing life-threatening side effects in the young patients. Only two patients of the twenty-person study group developed lung metastases. Teddy was cured.

Immediate amputation may have prolonged Dorothy Lewis's life, but it did not guarantee a cure. The radiotherapy that temporarily stalled the tumor's growth and the delay before her surgery may have assured—not caused—a virtually inevitable death from lung metastases. It was not until the 1970s that chemical agents and the principle of citrovorum factor rescue—a protocol developed through acute leukemia and adjuvant chemotherapy research programs in the 1950s—had improved the chances of a long-term survival or cure for Teddy and other children with osteogenic sarcoma. However, it also extended the demands and duration of medical treatment for the young patient and his or her family.[8] The marked changes in the prognosis of bone cancer was reported in the medical literature and summarized in the popular press, but the newspaper articles that described Dorothy's and Teddy's

cases vividly depicted and personalized new innovations. The stories of two children—one from a working-class family of five and one from a wealthy and politically powerful family—showed the contested nature of diagnosis and treatment that characterized many childhood cases from this entire period.

Both cases raise important questions about childhood cancer that this book has only begun to probe. Why did the specialists at Memorial allow Dorothy's father to delay her critical operation for more than nine months? Did this response indicate the degree of parents' influence at the child's bedside or physicians' uncertainty regarding treatment for bone cancers? Can it be traced to attitudes about physical disability, especially in children? It is difficult to know the answers based on the information given in the popular press, but Dorothy's physicians did appear guardedly hopeful about her recovery. Teddy Kennedy underwent surgery and was immediately enrolled in a clinical trial focused on a related but different cancer. His diagnosis may have been uncertain initially, but he may have also gained access to the experimental Dana-Farber study through his father's political connections and activities in shaping health legislation.

Why were these stories in the news? Teddy's story made the news, in part, because of the Kennedy's notoriety. But why did Dorothy Lewis's plight garner such sustained attention? The stories of individual cancer patients were often featured in the newspaper for a specific purpose such as soliciting donations for cancer hospitals or emphasizing the need for blood donors. In many cases, however, they seem to serve only as dramatic public interest stories. The series of articles and thousands of letters readers to Dorothy and Teddy attest to readers' fascination with the progress and outcome of children's cancer stories. Cancer, publicized as "the child killer," elicited a level of attention unmatched by many other childhood illnesses in the mid- to late twentieth century.

Dorothy Lewis and Teddy Kennedy joined "Jimmy," Johnny Gunther, and many others whose faces and chronicles were strategically used to raise awareness and funds for cancer research. *The Story of Teddy,* a movie about Teddy's illness, was aired on television. In a follow-up article after her surgery, Lewis was photographed while seated in a chair with her two favorite dolls. In the text, the reporter wrote that Dorothy had showed off her skill with crutches and hopped about the room, but the published newspaper photo masked her disability.[9] Like the youthful images and heartrending testimonials of Amer-

ican Cancer Society poster children, photos of Dorothy posed with her toys and Teddy on a ski trip emphasized the promise of improving survival rates and restoring children to full, healthy citizenship.

Abbreviated stories of sickness featured in popular articles, fundraising materials, and letters, as well as book-length narratives made the patient and the family—not the disease—the primary actors. By tracing changes in cancer awareness, research, and treatment through the pages of *Death Be Not Proud,* Angela Burns's letter, *The Blood of the Lamb, Eric,* and the cluster of illness narratives written in the 1970s and 1980s, we gain a more nuanced understanding of the toll cancer exacted from individual pediatric patients and their families. By valuing both medical accounts and stories of sickness, we approach a balanced knowledge of the changing course of many childhood cancers from the late 1930s through the 1970s.

A more complex image of childhood cancer research and treatment survival emerges by listening to children's and parents' own words. Only a portion of afflicted children received the first new chemotherapeutic agents popularly lauded as miracles because access often depended on proximity to a cancer center or the availability of adequate funds and transportation. Experimental therapies—especially those directed toward acute leukemia—promised new but, perhaps, false hope for children who had exhausted all other treatments. Chemotherapeutic agents threatened the health of the patient with intolerable, toxic side effects. In addition, they provided brief respites from the disease; a period of remission that prolonged children's lives from weeks to months to years but did not result in cures. This new pattern of disease challenged patients and families who returned to their normal daily activities but remained continually threatened with the unexpected exacerbations of an incurable disease.

Stories of individual sufferers also highlighted the communal aspect of cancer care. As concepts such as "total care" and "comprehensive cancer care" imply, the child was only one participant in the complex medical management that began to govern pediatric cancer treatment in the United States in the 1950s and 1960s. The child's local pediatrician or family physician, cancer specialists such as oncologists and hematologists, nurses, social workers, recreational therapists, and teachers were all a part of his or her multifaceted care—especially as cancer prognoses improved and children lived with the disease. Parents also played a prominent role in their children's treatment and became increasingly responsible for the daily demands of their children's illness after pediatric cancer care shifted to outpatient clinics and the home.

These duties tested marital relationships and placed burdens on families, yet parents also gained more time with and proximity to their children over the course of their illness and during their final days. Such concerns persisted as the number of pediatric patients treated in clinical trials continued to expand. According to the National Cancer Institute's figures, currently 55 to 65 percent of children in the United States who are diagnosed with cancer by or before the age of fourteen years enter a National Cancer Institute–sponsored clinical trial, as compared to 2 percent of adults.[10]

In their writing, parents not only illuminated the promise and limitations of cancer treatment, they also suggested the universal challenges posed by all catastrophic illnesses. In 1975, Robert and Suzanne Massie, parents of an eighteen-year-old boy with hemophilia, wrote, "The details of this struggle are personal, but the story itself is not unique. Every family with a handicapped or chronically ill child shares the same problems: lack of money, isolation from the community of the healthy, prejudice, misunderstanding in the schools, loneliness, boredom, depression."[11] They hoped that their account would impart strength to families faced with similar medical challenges and help readers who were unfamiliar with hemophilia better understand the disease. The Massies, like other parents and health activists in the 1970s, also used the book as a forum for voicing criticisms about the medical establishment: "Many parents felt trapped and silenced by the expertise and routine imposed by the clinic rules and accepted treatment."[12] Unlike the Massies and many adult cancer victims, most parents of young cancer sufferers expressed their disapproval in a less overt manner, however, most self-consciously depicted their child's cancer treatment as a series of negotiations between themselves, physicians, and allied health personnel. Denying or questioning experimental therapies, using alternative remedies, or providing terminal care at home all challenged medical authority over cancer care in children.

The end point of this history, the late 1970s, does not denote a definitive conclusion to the history of childhood cancer. New challenges faced professionals and parents responsible for children with cancer who were involved in long-term treatment plans or returned to home or school.[13] The establishment of specialized cancer camps, such as the Hole in the Wall Gang sponsored by actor and philanthropist Paul Newman, helped children find peer support in others who had cancer experiences and would not question their demanding treatment needs or hair loss.

Dramatic images and narratives about children with cancer and their families continue to attract attention at the local and national levels.[14] Alexandra

Scott, an eight-year-old girl who had been diagnosed with a neuroblastoma at infancy, died in August 2004. Years earlier, she and her family had started Alex's Lemonade Stand to raise money for pediatric cancer research and, specifically, for the two institutions who contributed to her care: Connecticut Children's Medical Center and Children's Hospital of Philadelphia. Widespread news coverage and appearances on popular television talk shows such as the *Oprah Winfrey Show* and the *Today Show* had rapidly disseminated her story to local and national audiences, and by the time of her death Alex and many other young volunteers had raised nearly $1 million through the construction of lemonade stands in all fifty states, Canada, and France.[15] The obituary by the Associated Press retold Alex's heroic story and included a photograph of the girl tending her drink stand, a simple wooden structure covered with handmade, rainbow-colored signs that asked for a fifty-cent donation and informed customers that the profits would benefit pediatric cancer research.[16] Framed by the stand, Alex sported a wide grin and a cocked hat that partially covered her bald head, a familiar marker for cancer. The jarring dissonance between a neighborhood lemonade stand—a common summertime activity for children—and the serious purpose of Alex's sales drew wide attention to her, the threat of childhood cancers, and the ongoing need for further research.

Alongside biomedical innovations like bone marrow transplantation and the identification of specific genetic and molecular markers of disease, pediatric oncologists have began to plot and study troubling patterns of "late adverse effects" among patients cured of cancer during childhood. New obstacles including secondary tumors and mental or physical impairment diminished the elation toward the promise and potential of cure. Since the late 1970s and early 1980s, pediatric patients, parents, and physicians have asked a series of new questions: Can survivors bear children? Do radiation treatments suppress bone growth or have permanent, deleterious effects on vital organs? Does chemotherapy's neurotoxicity cause motor dysfunction or learning problems? Are aggressive, lengthy chemotherapy regimens responsible for the occurrence of secondary cancers? Sites and systems of long-term follow-up care, new mechanisms for record keeping, and clinical research in this area has potential not only to answer these troubling questions but also to extend a child's "patient" status throughout his or her lifetime.

While child-focused efforts such as the Jimmy Fund and St. Jude's telethons continue to the present, the patient rights movement empowered adults with cancer (and their supporters) to share their personal experiences

and critique their care.[17] An increasingly competitive, crowded field of health fundraising, marketing, and advocacy has refocused some attention away from children and rare childhood cancers and toward common adult cancers like those of the breast and colon that have responded well to adjuvant chemical and hormonal therapies.[18] While children's faces and tragic stories continue to garner particular attention and spur community action around individual sufferers, the term "poster child" has expanded widely to include spokespersons of all ages. The American public now not only expects that all children survive to adulthood; twenty-first-century health consumers expect scientific medicine to effectively prevent, manage, and, hopefully, eradicate chronic diseases like cancer throughout the human lifespan. It is our challenge to care for the young patients, survivors, and families who continue to struggle with this rare set of diseases in ways that honor their voices and best address their needs.

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