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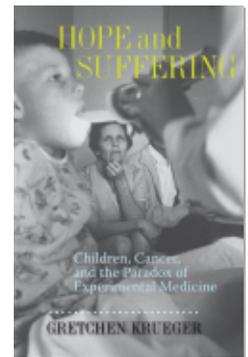
Hope and Suffering

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Introduction

In 1966, a *Life* magazine article by Will Bradbury titled “Two Views—the Lab, the Victim” illustrated the stark contrast between the promise of scientific research and the outlook for children diagnosed with acute lymphocytic leukemia (ALL), the most common pediatric cancer.¹ The story consisted of two separate, yet intertwining parts. A series of black-and-white photographs captured the story of Mike Parker, a ten-year-old boy who received urgent treatment at M. D. Anderson Cancer Center in Houston, Texas. Alongside the bleak pictures of Mike’s therapy and his parents’ anxious wait, vivid color photographs displayed the “all-out research assault” launched against the disease. The parallel layout pictured a life-and-death race. Although chemotherapy temporarily halted the progression of Mike’s disease, readers were left wondering whether the boy would survive until the next scientific breakthrough.

The Parkers’ story began in a fourth-grade classroom located sixty miles north of Abilene, Texas, where Mike had suddenly changed from being an eager student to a listless pupil. Soon thereafter, he began begging to stay home from school. After watching this unusual behavior for several days, Mike’s mother, Ella, called to make a doctor’s appointment for her son. The osteopathic physician diagnosed a common cold and prescribed vitamin and penicillin injections but did not suspect what was to come. A few weeks later, Ella had to rush her son to the hospital in the middle of the night with an uncontrollable nosebleed. A blood count the following morning revealed that Mike had ALL. He remained at the local hospital for six days before he was referred to M. D. Anderson for further treatment.²

The record of the boy’s admission to the specialized cancer hospital reveals the rapid advance of Mike’s disease. He had already lost sixteen pounds (a quarter of his total weight), leukemic cells had infiltrated and inflamed the bone coverings in his joints, his liver and spleen were enlarged, and tiny hemorrhages called petechiae partially obstructed his eyesight and dotted his legs. After noting this list of findings, the doctor tried to reassure the Parkers: “He’s

about average for a leukemic child. Not any worse.”³ Photographs captured the busy schedule of activities that began to govern his days: regular blood transfusions, chemotherapy treatments, bone marrow tests, and a strict mouth care regimen to help guard against bleeding gums and prevent dangerous infections. Mike’s mother moved into her son’s room to supervise his care while her husband returned home to work and look after their other two children. A bout of pneumonia caused a brief setback, but Mike successfully achieved his first remission after six weeks of continuous treatment. Despite his progress, a caption framing a photo of Mike returning home on a bus with his parents warned that the boy’s journey would not end here: “Doctors at Anderson know from sad experience that he will be back.”⁴

Despite the grim trajectory of Mike’s story, Bradbury described the scientific segments optimistically, suggesting that ongoing efforts to identify and test new chemotherapeutic agents and new virus research programs would soon reap benefits for young patients and families like the Parkers. A striking photo taken at the Sloan-Kettering Institute for Cancer Research in New York City showcased eight chemicals that had shown activity against ALL. One agent, mercaptopurine (6-MP), had been used in Mike’s case. In the background, cabinet-lined walls housed samples of the 28,000 chemicals screened for anticancer activity at the institution. Other images provided snapshots of the bench and animal experiments carried out as part of the Special Virus Leukemia Program, a “superplan” designed by the National Cancer Institute (NCI) to expedite leukemia-related virus research. As Mike received treatment at M. D. Anderson, investigators at NCI, Sloan-Kettering, City of Hope Hospital in Duarte, California, Roswell Park in Buffalo, New York, and dozens of other hospitals and research centers hoped to construct a viral hypothesis of leukemia and develop a vaccine against the dreaded disease.⁵

Mike Parker was only one of many young patients with cancer in the twentieth century caught in the uncertain space between hope and suffering. In 1930s, cancer had been redefined from a dread disease that struck only adults and the elderly to a rare but major killer of infants, children, and youth. By comparing the case records of young patients treated at the Memorial Hospital for Cancer and Allied Diseases in New York (now better known as Memorial Sloan Kettering), to extant medical literature and New York City vital statistics data, Harold Dargeon, a newly hired Sloan-Kettering pediatrician, determined that particular types of cancer disproportionately affected children while others predominated in later life. The small set of solid tumors



Mike Parker in the hospital. The *Life* photographer not only captured the details of the boy's busy hospital routine but also documented his parents' role in providing care. They looked on as his mouth was checked routinely for signs of infection. To protect his gums against bleeding and other complications, nurses recommended using a foaming toothpaste instead of a brush. Monitoring Mike's condition was a vital, constant part of his treatment. *Time*, November 18, 1966.

and cancers of the blood and related tissues most frequently observed in children from birth to fourteen years old were reclassified as “childhood cancers.”⁶ This research also led to another significant finding: mortality from cancer ranked second only to accidental death in the young. As mortality from common infectious diseases of children declined, cancer became a growing concern. The private institution established a host of child-centered programs and services during the late 1930s and 1940s in response to these startling observations. Families from the metropolitan area, across the country, and around the world began traveling to Memorial and, in later decades, other specialized cancer centers, for access to experimental therapies and enrollment in clinical trials. This fervent search for hope in the midst of suffering shaped gains in the knowledge about cancer, changes in practice and policy, and the interactions between parents and the medical professionals that began to govern the management of cancer in the young.

Attending to the complex negotiations between children, parents, medical professionals, and others involved in the care of pediatric patients and the treatment of childhood cancers, *Hope and Suffering* is a history of childhood cancers in twentieth-century America. But this story’s roots reach decades earlier. Beginning in the 1850s, philanthropists founded children’s hospitals in major American cities to provide a separate institutional home for the physical healing and moral education of young patients.⁷ Separate children’s wards were also established at general hospitals. By establishing hospital positions within these independent departments, gaining teaching appointments, and opening specialized private practices, physicians shaped a discrete specialty of pediatrics and became legitimate members of the medical community by the end of World War I.⁸ Pediatricians had solidified their authority by promoting well-child visits and precise routines of proper feeding, cleaning, and consumerism termed “scientific motherhood” that established the necessity for pediatricians’ expert advice in times of both sickness and health.⁹ This new pattern of medical supervision then expanded when experts in child guidance and specialists in adolescent medicine promoted the importance of identifying and studying the mental and physical issues of growth and development.¹⁰ Parental caretakers—usually mothers—played only an ancillary role in their child’s care.

By the 1930s, significant attention was devoted to maintaining and restoring the health of children—inside *and* outside the bounds of a doctor’s visit or the walls of a clinic. Public health reformers during the Progressive Era supported preventive measures against communicable diseases by ensuring

ample supplies of pure food, milk, and water, all of which contributed to declines in life-threatening infectious diseases such as measles, whooping cough, diphtheria, and scarlet fever.¹¹ As rates of infant and child mortality fell, fears shifted to other causes of death. It was at this time that Dargeon joined the staff at Memorial and uncovered cancer's profound impact on children's health. Soon thereafter, childhood cancer appeared in the hospital's publications, the pages of women's magazines, and in the wider public view.

Although it had been determined that different types of cancer struck children and adults, all cases inspired both fear and hope. Cancer alarmed laypersons because of its associations with pain, disfigurement, and inevitable death. Before the advent of chemotherapy, radiation and surgery were the only conventional therapies available to treat cancer, and, as the Parker's story dramatically illustrated, the development of chemical agents after World War II did not guarantee long-term survival. In *The Dread Disease*, James Patterson described the early activities of the American Society for the Control of Cancer, the predecessor of the American Cancer Society (ACS), as it began its fundraising and educational campaigns to promote awareness and early detection through the "Seven Warning Signals of Cancer."¹² *Dread Disease* included little discussion relative to the cancer society's attention toward young persons with cancer, but it joined several accounts that explored the complex interrelationships among the popular images and understanding of cancer, political activities related to directing and funding national cancer research programs, and the development and delivery of therapeutic modalities.¹³ Scholars have continued to pursue these themes, but through projects that are narrower in scope and transnational in perspective.

A growing body of scholarship has begun to evaluate the utilization of varied treatment modalities, prevention strategies, causal theories, and professional structures specific to different cancers and countries. Most important, this preliminary has revealed that a single, global model of cancer management and control did not and does not exist.¹⁴ It will require much additional research to understand each individual system as well as the entire network. Recent sociological inquiries into the organization of cooperative cancer groups in the United States such as the Acute Leukemia Group B (a child-centered program), however, contributed important groundwork to this story.¹⁵ In addition, complementary work on childhood cancers in the United Kingdom outlines another national structure and highlights possible points of contestation and cooperation between the United States and other countries.¹⁶ This book focuses on children (and families) in America and their

roles as part of a unique culture of clinical experimentation built around pediatric cancers in the mid- to late twentieth century in which the roles of physician, patient, and hospital became closely intertwined with those of the investigator, research subject, and laboratory.

Why focus on stories told by and about children with cancer? Historians of childhood have long recognized the ways by which children wield power as young subjects of national debates and political action.¹⁷ As Russell Viner and Janet Golden have argued, children have also played a vital part in shaping medical history. By listening for children's voices in the historical record and searching carefully for the faint imprints of their actions we can understand the channels by which children have negotiated or altered the practice of medicine and the policies governing care.¹⁸ By coauthoring illness narratives, creating comic books, composing diary entries and letters, and even participating in conferences, children critiqued hospital procedures, revealed their understanding of their diagnosis or prognosis, and detailed their complex negotiations with their caregivers.

Cancer institutions and organizations have also strategically used children to appeal to potential donors. Like young polio sufferers, children with cancer served as "poster children" to personify and personalize a menacing disease. Such materials played upon the twin realities of hope and suffering. As death rates fell overall, children's deaths from cancer became all the more heart-wrenching and disturbing. Young representatives poignantly illustrated the unnecessary loss of innocent victims to cancer; thereby undermining the child-centered model of the family and depriving the nation of future citizens. In contrast, poster children and children who made guest appearances on popular radio shows and in annual telethons also dramatized the hope and promise that a cure for all cancers was near. Through modern advertising and fundraising techniques, cancer—in adults and children—entered popular consciousness by the mid- to late twentieth century. Such materials add children's voices and faces to the dominant narrative—one that has given primacy to innovations in the medical management of childhood cancers.¹⁹

Childhood cancers must be understood as a disease that affects not only the child but also the entire family. By linking illness narratives and major "medical milestones" achieved in the laboratory, hospital, and outpatient clinic, *Hope and Suffering* reconstructs families' changing experience of disease from the 1930s through the late 1970s. Exploration of parents' involvement in their child's illness and their negotiation of the modern medical mar-

ketplace lends complexity to a history that is often told as a story of biomedical triumph by cancer organizations heralding statistics about improving survival rates, telethon hosts speaking with bald-headed children, physicians reporting the results of complex, multimodal treatment protocols, or pioneers in specialties such as pediatric oncology and hematology recounting the history of clinical research related to acute leukemia or other common childhood cancers. Top-down histories of pediatric cancers are valuable contributions to the field, but they miss half the story. Such accounts mask the lived experiences of the young patient and caregivers when confronted with a rare, but devastating disease. Correcting this omission is not only a matter of justice; it also attends to powerful forces that have remained relatively invisible in the historical record but have had an increasing role in shaping cancer treatment, policy, and funding in the United States.

Like breast cancer activists and celebrities, pediatric cancer patients and their families were not simply passive recipients of medical knowledge and care. Instead, they have been powerful arbiters of medical principles and practices.²⁰ Scholars who have studied childhood diseases, maternal and child welfare programs, and the medicalization of child health have argued that the image of distressed parents seeking treatment for a sick or dying child has social, emotional, and political power. *Death Be Not Proud*, a memoir of a teenage boy's illness and death from a brain tumor published in 1949, illustrated one couple's desperate search for experimental therapies at a time when multimodal treatment including surgery, radiation, and chemotherapy was first available for cancer. Thousands of letters sent from readers revealed that John Gunther, the author of the best-selling book, was not alone in this relentless pursuit; families from across the country had shared the Gunthers' experiences and identified with their pain. By establishing new organizations such as the Leukemia and Lymphoma Society of America (originally the DeVilliers Foundation), parents sponsored research programs for this unique group of cancers and, notably, memorialized their child. Parents also provided care at the bedside. The discovery of several effective chemotherapeutic agents, the rapid establishment of large-scale drug identification and screening programs, the design of combination drug protocols, the organization of a cooperative clinical trial structure, and the development of supportive therapies to control dangerous complications of cancer and its treatment led to longer survival times, especially for ALL. As many types of childhood cancer—and conditions such as juvenile diabetes, hemophilia, and cystic fibrosis—were transformed from acute, fatal illnesses to diseases

that responded favorably to long-term medical management, care shifted from the hospital to the outpatient clinic and home.²¹ The duties of parents expanded as they adopted primary responsibility for dispensing oral chemotherapy drugs, shuttling their child to frequent appointments, and closely monitoring the side effects of treatment.

From court proceedings to the bedside to Capitol Hill, integrating parents and other caregivers into the history of childhood cancer expands the boundaries of care and recognizes the participation of many more actors in the story of a disease. This approach uncovers the uncertainty not often expressed in top-down histories—that is, those written from the perspectives of institutions or experts—by showing that the hardships or suffering caused by an intractable disease or rigorous experimental therapies often tarnished the heady claims frequently repeated by journalists and investigators about cancer breakthroughs.

Drawing upon a wide range of published and unpublished sources, accounts of therapeutic innovation can be recast as nuanced histories of cooperation, skepticism, and resistance among patients, parents, and practitioners. Alongside excerpts from medical texts and conference proceedings, illness narratives offer detailed records of family's daily activities and their private concerns. Letters illustrate the diversity of patient and parent experience as they also illuminate common themes such as the availability of curative therapy, the merit of alternative treatments, decisions to pursue or halt therapy, or possible causes of cancer. Court records demonstrate intersections between cancer, child health, and the law. Newspaper and magazine articles, as well as fundraising and educational materials, document the stories of cancer sufferers; they also provided insight into prevailing messages about cancer, including those common to children. Campaigns often displayed childhood cancers to promote a standard slogan first promoted by the ACS that early detection and prompt treatment by orthodox physicians led to a cure, without addressing the peculiarities of this set of malignancies. These rich sources illustrate the paradox of hope and suffering that characterized pediatric cancers: childhood cancer research “breakthroughs” in clinical trial methods and drug development initiated early claims that a cure was near, but these high hopes were frustrated when sweeping cancer cures were not achieved quickly.

This book is organized chronologically in order to pair the dominant narrative of the history of childhood cancer—the transformation of acute leu-

kemia and other common childhood cancers from inevitable killers to curable cancers—with the personal experiences of young patients and their families. Each chapter opens with a family’s story, before expanding outward to consider several key themes that cross every decade: etiology, early detection, treatment, short- and long-term side effects, death and dying, and cure.

The first chapter begins in the 1930s, the decade in which physicians at Memorial Hospital for Cancer and Allied Diseases first recognized and classified cancers in children as a separate set of neoplasms and a leading cause of child mortality. Following this discovery, Memorial appointed a pediatrician, constructed additional treatment facilities, and launched a public relations campaign that featured the hospital’s youngest patients. Although the hospital’s child-centered initiatives garnered local attention, a series of controversial cancer cases heralded by front-page headlines made the American public more aware of certain childhood cancers and the lived experience of the dread disease. I examine the creation of “glioma babies”—young children diagnosed with retinoblastoma—and the role of the media in transforming private medical decisions into a public spectacle. In each case, when family members decided to withhold conventional cancer treatments, they were pressured to cede control of their child’s health to the state, physicians, ethics boards, or other authorities. With the proliferation of experts around the care of children and their particular medical problems, childhood cancers and those affected by the disease became the targets of increased scrutiny.

The second chapter is framed by the illness experience of “Jimmy,” a boy who traveled from his home in Maine to Boston to receive cancer treatment and became the first spokesperson for a new child-centered charity, named the “Jimmy Fund” in his honor. The images, voices, and stories of Jimmy and others personified and raised the public awareness of cancer in the young at a time when biomedical research efforts were receiving increased institutional interest and federal support. This chapter details the expansion of childhood cancer efforts at Memorial Hospital and other major research centers. By publicizing their youngest patients’ tragic stories, work on childhood cancer was promoted as a critical area of investigation and an area worthy of research dollars.

Chapter 3 probes John and Frances Gunther’s story about their son and his prolonged illness more deeply. Published in 1949, the best-selling memoir *Death Be Not Proud* offered a detailed record of Johnny Gunther’s illness and the Gunthers’ yearlong search to find treatments for his incurable brain tumor.²² The volume provided a narrow glimpse into one family’s life with can-

cer, while thousands of letters sent to Johnny's parents after the publication of the book and related magazine excerpts provided wide-ranging sources that exemplified the diversity of patient and parent experience in the late 1940s and early 1950s. The correspondence also revealed the silence surrounding childhood cancers and the manner in which the illness narrative bound together a diffuse community experiencing similar parental loss and grief. Parents sought this refuge at a time when discussion of child death (especially from cancer) was hushed and a cure was still unknown.

A single, lengthy letter written to John and Frances Gunther by Angela Burns, the mother of a daughter with ALL, serves as the basis of the fourth chapter. Burns enumerated the challenges posed by the side effects of toxic treatment, the rigors of making daily trips from their home to Boston, and her simultaneous praise and skepticism of chemotherapy.²³ By considering Burns's story alongside the development of a series of promising, yet only temporarily effective, highly toxic chemotherapeutic agents, the intertwined nature of medical science, the medical management of illness, and the family's role in caretaking is rendered in sharp relief.

Peter De Vries's novel *The Blood of the Lamb* provides the foundation for a chapter on patterns of remission, relapse, and child death caused by the introduction of new chemotherapeutic agents and rigorous combination regimens in the 1960s and 1970s.²⁴ The semifictional account of young Carol Wanderhope's illness and death from ALL in the early 1960s was based on the author's personal tragedy of losing his own ten-year-old daughter from the disease. Truth-telling debates, the repeated cycles of illness and wellness produced by newly developed chemotherapeutic agents, and the relocation of care from the hospital to the outpatient clinic and home are recorded and criticized in the novel.

In the 1960s and 1970s, investigators had begun to tentatively suggest that children with several types of childhood cancer—including ALL—could be labeled as "cured." Despite these advances, it remained a time of uncertainty. This final chapter examines a small cluster of cancer narratives that served as important vehicles for parents to share their varied experiences as they coped with illness and incurability, short- and long-term survival, and death and dying and sought to publicly appraise their child's medical care at a time when patient activism and parent advocacy on behalf of ill and disabled children was growing in strength.

At the end of this period, it was recognized that prolonged survival and cures had come at a price. Follow-up studies found that children often suf-

ferred lasting mental and physical disabilities from the toxic therapeutic regimens employed to kill cancer cells completely. Researchers now asked what it meant to be a “truly cured child,” and parents now faced another set of concerns regarding the long-term, healthy survival of their children. The epilogue briefly considers the concerns of physicians and parents as they face the continued challenges posed by childhood cancers, their treatment, and the anticipation of a cure.

By looking through the eyes of the children and families described on these pages we can gain greater insight into the management of adult cases. How are the two sets of cancers intertwined? During the past century, the popular interest created around children with cancer has educated Americans about new views of cancer and, at times, has spurred challenges to ideologies promoted by “experts” in the field. The aggressive, fast-growing nature of pediatric cancers has also advanced our scientific understanding of the basic biological mechanisms of the disease, suggested alternate models of cell growth and regulation, revealed unexpected etiological theories, and exposed the high price of immunosuppression exacted by chemotherapy. In addition, acute leukemia served as the basis for the first cooperative cancer clinical trials—a system now central to the evaluation of all treatment protocols and a vast transnational research network. This model has not only governed cancer research since the 1950s but has also led to the establishment of new medical specialties and professional structures in the hospital and clinic, including comprehensive care and hospice. It is clear that each facet of modern cancer care has been influenced by some of the littlest cancer patients—patients like Mike Parker. By looking both to the past and the present, we can note the agency of children and their caregivers in informing policy and practice and should use these insights to reshape our ideas not only about the best care of sick children, but the impact of modern biomedicine on our own health and wellness.