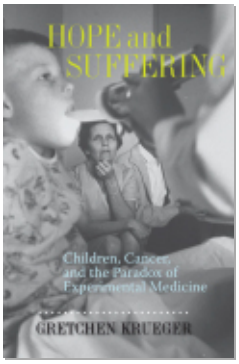
Hope and Suffering



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CHAPTER SIX

"The Truly Cured Child"

PROLONGED SURVIVAL AND THE LATE EFFECTS OF CANCER

During the 1970s, aggressive chemotherapeutic therapy led to a dramatic improvement in the long-term survival rates of children with leukemia and other common childhood cancers. Despite its name, acute lymphocytic leukemia, the most common type of childhood cancer, resembled a chronic illness for many young victims by the end of the decade and years to come. An essay by Amy Louise Timmons, an eleven-year-old girl with the disease, published in the *Journal of Pediatrics* and the *American Journal of Nursing* was one girl's plea for parents and health professionals to consider the period of healthy life enjoyed by many young patients.[1] In May 1974, Timmons had already lived nearly three years beyond her physician's initial prognosis and had remained an honor student, the president of her class, and a member of the Girl Scouts. She beseeched readers not to pity her; she had led an active, satisfying life despite her illness and believed that all children should be allowed to lead near-normal lives when they felt well. Timmons referred to an episode of the popular television program *The Waltons* in which a mother restricted her teenage son to his room after his leukemia diagnosis. Following the boy's appeals to be let out of the protection of their home, his mother finally relented and he rejoined his friends outside. Timmons acknowledged that treatment for leukemia caused children to experience infections, hair loss, nausea, and soreness at injection sites but informed readers that children often felt well enough to enjoy life. Only a month after composing this essay, Timmons spent a long day swimming at the beach and playing games with her family until very late in the evening. The next day, she entered a coma and died before she could be readmitted to the hospital. Combinations of chemotherapeutic agents and supportive therapy in leukemic children allowed Timmons and other children to live years after their initial diagnosis. And, building upon Burchenal's earlier claims, physicians tentatively suggested that permanent cures had been achieved in this set of patients.

In the 1970s, the history of pediatric cancers splintered into three separate narratives: illness and incurability, short- and long-term survival, and death and dying. Progress in treating and curing childhood cancers became the justification for increased cancer research funding, since gains in the five-year survival rates in many childhood cancers were often upheld as a predictor of future results in adult malignancies; however, the transformation of leukemia and other cancers from acute, invariably fatal diseases to nearly chronic conditions caused unforeseen challenges for physicians, allied health professionals, parents, and children. Surgery, radiation, and chemotherapy not only cured but also produced debilitating side effects such as recurring tumors and physical, mental, and learning disabilities. As child survivors lived longer, they faced discrimination among their friends, at school, by insurance companies, and in the workplace. For some, the manifestations of cancer often lasted long after childhood. For others, the late stages of their illness demanded a reconsideration and renegotiation of a "good" death.

Illness and Therapy

In the 1970s, longer survival for children with acute leukemia presented new challenges for medical professionals responsible for designing and administering combination chemotherapy regimens and managing the patient throughout all stages of disease. Chemotherapy protocols induced complete remissions in 90 percent of children with acute lymphocytic leukemia.[2] Even after a complete remission had been achieved, the child remained on chemotherapy from two to five years in an attempt to completely eradicate the leukemic cells and restore normal function.[3] Unfortunately, many children who experienced these prolonged periods of treatment eventually succumbed to a recurrence of leukemia in the central nervous system. Beginning in the 1970s, physicians ordered rigorous treatment including irradiation of the cranium and spinal axis, intrathecal administration of medication, or both to prevent the development of life-threatening disease in this physiological sanctuary.[4]

Many other medical interventions were required to maintain the health of leukemia patients in this tenuous state. Intensive antibiotic therapy was used during periods of immune system suppression. Despite these prophylactic efforts, 60 to 80 percent of deaths in children with leukemia treated at National Cancer Institute between 1965 and 1971 were caused by viral, fungal, or bacterial infections.[5] Chemotherapeutic drugs attacked both proliferating

leukemia cells and rapidly reproducing normal cells indeterminately, causing hair loss and ulceration of mucous membranes of the gastrointestinal tract from the mouth to the rectum. Transfusions of packed red blood cells helped children with anemia; transfusions of concentrated platelets aided those bleeding from inadequate production of these clotting tools. Frequent hospitalizations and supportive measures were required to stabilize young patients.

Despite these setbacks, treatment results compiled from the seventeen centers involved in research and treatment programs dedicated to childhood cancer centers reported a 50 percent five-year survival for children suffering from acute lymphocytic leukemia, a greater than 50 percent five-year survival for Wilm's tumor and soft tissue sarcomas (tumors in muscle, fat, or blood vessels), and an 89 percent five-year survival for Hodgkin's disease (cancer of the lymphatic system, part of the immune system).[6] Osteosarcoma and Ewing's sarcoma (bone cancer commonly found in the pelvis, thigh, or shin) also had rates near 50 percent but not at the five-year mark. Brain tumors and neuroblastoma were the only common childhood tumors with disease-free survival rates significantly lower than 50 percent.[7]

A single published source could not fully capture children's experiences with cancer, particularly because only about half of children had access to major cancer treatment centers or National Cancer Institute–related treatment research groups.[8] The following year, an American Cancer Society publication documented quantitative data based on participants in the End Results Group, a national program sponsored in part by the National Cancer Institute to evaluate the efficacy of cancer therapies.[9] In this report, data was submitted by more than 100 hospitals of varying types and sizes from different regions of the country. Thus, small community hospitals, larger general hospitals, and facilities affiliated with medical schools shared their data to provide a broader cross-section of children's outcomes. Based on this broader sample, only 5 percent of children with leukemia lived five years after diagnosis.[10]

What factors led to the disparities in survival rates reported in the two sources? Distinct patient populations were a major factor. Joseph Simone, a physician at St. Jude Children's Research Hospital in Memphis, Tennessee, a new center for the research of childhood cancers and other catastrophic diseases, described the admissions:

> Most of the children were from the mid- or Deep South, the area of the United States with the lowest per capita income, lowest hospitalization insurance cov-

> erage, the highest infant morality rate, and the shortest median life span. Since this hospital is the only pediatric medical center in the area that is completely free and open to all social, economic, and racial groups, it tends to attract low-income families and thus, many children with neglected health, advanced disease, and poor nutrition. All eligible children referred here are registered in the studies and included in the reports, regardless of their condition on admission. This includes children who receive little or no therapy, who die of overwhelming leukemia, infection, or hemorrhage shortly after admission.[11]

The particular mission and research guidelines that shaped hospitals like St. Jude attracted the sickest children.

Two inseparable, but sometimes contradictory, purposes for young patients—cancer trials and access to advanced care—continued to be touted as advantages of referrals to specialized institutions. In 1978, at the American Cancer Society–sponsored National Conference on the Care of the Child with Cancer, Giulio J. D'Angio, director of cancer centers at Philadelphia's Children's Hospital and the University of Pennsylvania, discussed cancer centers as sites of research collaborations between trained medical specialists in the field. He declared, "Highly coordinated battle plans now are drawn up by integrated staffs of surgeons, radiation therapists, and chemotherapists. Each move is plotted in advance and carried out with military precision."[12] They then pooled their results with other institutions involved in the national cooperative groups.

D'Angio and other specialists tirelessly promoted their principles and practices in order to gain wider support for their nascent field. In an opinion piece about the best medical care for the "hopeless" patient, Emil J. Freireich, chief of research hematology at M.D. Anderson Cancer Center, wrote, "I don't mean to put down the man in private practice," but described how clinical medicine differed. Adopting the rigorous language attributed to basic science, he characterized clinical medicine as objective and the results as reproducible. Clinical researchers not only prescribed treatment, they employed controls and analyzed outcomes data to apply the knowledge gained from one patient to another with the same disease. He stated, "As a result of clinical research, any doctor now can give leukemic children a two-drug combination—vincristine and prednisone—and produce remissions in about 85 percent of the cases. But every doctor shouldn't—he won't know what to do for an encore."[13] A single remission was only the first and most basic step of leukemia treatment. Freireich warned readers that only professionals in clin-

ical research centers had access to information about new discoveries from cooperative studies before they were published and could rapidly adjust the dosage or the method of drug administration if subsequent complications occurred.[14]

Freireich explicitly tried to dispel concerns that patients were treated as "guinea pigs," but his arguments suggested otherwise. He insisted that patients made the conscious choice to participate but acknowledged that drugs often made patients sicker than before. He mocked those who advised, "Let the patient die with dignity" and urged physicians to fight as long as the patient remained alive. Freireich said, "You give up when you can't get any blood into a vein. As long as she's breathing and her heart's beating, tend to her. You can't know what will happen."[15]

As pediatric cancer treatment became part of a culture of clinical experimentation in the United States in the 1950s and 1960s, the roles of physician, patient, and hospital ward had become intertwined with those of investigator, research subject, and laboratory.[16] Multiple factors contributed to this culture of investigation: the discovery and development of "miracle drugs" that used acute leukemia as a model; the increased role of cancer charities including child-focused organizations like the Jimmy Fund and the Leukemia Society of America; an influx of public funds into cancer research; links between government-sponsored research and industry; and a concentration of patients in specialized institutions such as comprehensive cancer centers.[17] Parents weighed the potential benefits of experimental cancer therapy to their children, but they also considered how to preserve quality of life and limit suffering when giving proxy consent.[18] The Declaration of Helsinki's *Recommendations Guiding Doctors in Clinical Research* (1964) and the American Medical Association's *Ethical Guidelines for Clinical Investigation* (1966) distinguished between clinical research for patient care and nontherapeutic clinical research designed to accumulate scientific knowledge, but gave parents the power to consent for both types of research on children. In 1970, in *Patient as Person,* Paul Ramsey departed from these earlier recommendations and advocated that children not serve as subjects of medical experimentation unless "other remedies having failed to relieve their grave illness, it is reasonable to believe that the administration of a drug as yet untested or insufficiently tested on human beings the performance of an untried operation, may further *the patient's own recovery.*"[19] According to Ramsey, the health of the child, not the advancement of medical knowledge or the advantages for future patients, made medical experimentation on children permissible.[20]

The bold warnings of physicians at a 1977 symposium on the social and ethical issues in cancer prevention and therapy indicate possible conflicts of interest encountered by physicians. One participant complained,

> By declaring a war against cancer, and amplifying such jargon, and by providing strong financial persuasion for investigators to conduct experiments on human cancer patients today for the sake of the patient of tomorrow, an operative climate has been created that erodes . . . physician-patient relationships.[21]

By combining therapy and investigation, the loyalty of the physician was divided between the patient, profession, and national research goals. Phase I, II, and III human cancer studies mandated by the National Cancer Institute required different types of deliberation. Phase I studies evaluated a drug's toxicity in order to establish a suitable dosage for an evaluation of the drug's therapeutic effect in a future patient. This type of study required frequent clinical and lab exams to monitor toxicity. Direct benefits for the patient were not the primary objective of the trial. Phase II and phase III clinical trial studies offered more therapeutic potential, yet toxicity risks remained.[22] Each phase of experimental cancer treatment held the possibility of short-term and lasting long-term side effects like permanent damage to vital organs, mental abnormalities, and cancer. While oncologists characterized the majority of side effects as "temporary, predictable, and manageable" if monitored carefully by skilled investigators, critics decried the risks posed by cancer experimentation and advocated for greater lay autonomy.[23]

In contrast to Ramsey's revisions and recommendations, the recollection of one mother demonstrated that parents' complex decision making process included the potential benefits for all children with leukemia and the preferences of their own child. She candidly confessed,

> There comes a time when there is a fine line between whether continued therapy is for the sake of research for future leukemics or whether it is truly best for the child at hand. Del and I felt much sooner than the physicians that the time had come, but it was more a feeling from the heart than from professional objectivity. Eric, unaware of the full circumstances and that the odds were against him no matter what, had wanted to go on with treatment for a longer period than we felt necessary. Maybe we should have been more open with him; that is something we will never know.[24]

The arguments from the social and ethical issues conference and from the mother of a child with cancer demonstrated that physicians had vested inter-

ests in promoting participation in clinical cancer research. Some parents, however, may have continued to give the professional, "objective" opinions given by doctors or the health of other children with leukemia priority over the emotional or intuitive sense of family members to protect their child from undue harm.

The aggressive treatment model was paired with "total care" programs at the National Cancer Institute–designated cancer centers organized in the 1970s. The centers originated from grant programs established by institute in the 1960s and 1970s to support multidisciplinary cancer research. As a result of the National Cancer Act of 1971, a cancer centers branch was established to fund develop new institutions, using Memorial Sloan-Kettering and M. D. Anderson as models. Two years later, a cancer center support grant defined two classes of cancer centers, including a "comprehensive" group that was charged with "conducting long-term, multidisciplinary cancer programs in biomedical research, clinical investigation, training, demonstration, and community oriented programs in detection, diagnosis, education, epidemiology, rehabilitation, and information exchange."[25] Like the program implemented by Farber at the Jimmy Fund Clinic in the 1950s these institutions also attempted to integrate the services of medical specialists with those provided by social workers, psychologists, nurses, and chaplains to confront both medical challenges and the "human side" of the cancer problem.[26] Although delivery of this complex model was—and is—difficult to execute for every family, it was singled out as an ideal for children and adults in the 1970s.

Treatment began with the affected child, but, in the words of one American Cancer Society writer, "The whole family actually becomes the patient."[27] Social workers assisted parents with the overwhelming financial burden of receiving extensive cancer care for their children at a facility located at a distance from their home. Duke University Medical Center joined the comprehensive cancer center network in 1972 and raised money to staff their new pediatric research unit with its own "total treatment team." Children from throughout the Southeast traveled to Duke, so transportation, lodging, and the financial hardships needed to be addressed for each family. The Duke medical system had a financial scale for determining each individual family's ability to pay, and outside sources assisted families with the costs. North Carolina's Crippled Children's Fund, state sources, community agencies, and local churches also assisted families in need. In addition, Duke hoped to build satellite clinics to help alleviate the rigors of travel.

At other cancer centers, Ronald McDonald Houses enabled parents to par-

ticipate in their child's care by providing inexpensive lodging for families of hospitalized children. In 1973, when his three-year-old daughter Kimberly was stricken with leukemia, Philadelphia Eagles football player Fred Hill recognized the lack of affordable housing for parents of hospitalized children.[28] During his daughter's three years of treatment, Hill and his wife often joined other parents in sleeping on hospital chairs and substituting vending machine snacks for proper meals. Hill worked with members of the staff in the pediatric oncology unit at the Children's Hospital of Philadelphia and the fast-food operator that lent its name to the project to build a place that acted as a "home away from home." With proceeds from the restaurant's green St. Patrick's Day shake, the first McDonald House was constructed in Philadelphia. And, with continued support, the facility was able to adjust its rates based on household income, thus enabling parents remain near their child without incurring prohibitive hotel charges or transportation costs.

Longer disease-free survival for many childhood cancer patients required greater emphasis on transitioning young cancer patients from hospital to home. By being involved in each step of their child's cancer care, parents became proficient in skills they would need to repeat at home. At Stanford Children's Hospital in Palo Alto, California, nurse-parent teams incorporated parents into their children's daily care. The parents lived at a hotel on the hospital property free of charge in exchange for helping to feed their child or administer injections. A representative from the program said, "The parents are a vital part of our program. They have the expertise in dealing with their child. They know them better than we do. Sometimes the doctors are even willing to admit that mother knows best."[29] Stanford staff also included cancer education for patients in their program, teaching children how to read and interpret blood counts for themselves. Proclaiming a 50 percent success rate in referral cases, they boasted that their cooperative approach had improved mortality rates and buoyed optimism in patients and parents involved in the program. Nurses acted as communication link between parents and the treatment team as the child transitioned from hospital care to regular outpatient clinic visits. This need for continuous nursing led to the professionalization of the pediatric oncology nurse specialist by the mid-1970s.[30]

Death and Dying

In the 1970s, many families suffered under the strain of caring for and losing a child at a time when children were championed—in the courts and the

media—as special, privileged members of the population that needed to be protected. As one researcher noted, "At this time in our history and consciousness, in this youth culture, children are not supposed to die."[31] In the *San Jose Mercury News,* an article titled "The Sad Wait at Ricky's House" told the story of five-year-old Ricky Pineda, a local boy in the final stages of acute leukemia. Over the course of his illness, Ricky had been hospitalized for spinal meningitis and survived four relapses, but doctors now predicted that the boy had only six months to live.[32]

Like many parents, Gloria and Richard Pineda bore the weight of their son's extended and ultimately fatal illness. A study at Stanford University Medical Center supervised by David M. Kaplan, director of clinical social work, had found that nearly half of thirty-nine families of leukemic children studied had experienced major social, marital, or psychiatric problems. In sum, eighteen couples had divorced or separated after the child's death, existing marital problems had been exacerbated in eleven couples, the surviving children experienced difficulty in fourteen families, drinking problems developed in fourteen families, and fourteen families experienced problems at work.[33] Based on these findings, Kaplan had called the average two- or three-year period of illness a time "a state of siege" when families were forced to come to terms with their child's impending death, meet unexpected medical expenses, and care for other children. Jordan R. Wilbur, head of the Department of Pediatric Oncology at Stanford's Children's Hospital, argued that the results no longer applied to cancer cases because the study had been conducted in a traditional pediatrics department, not the new comprehensive care program that had implemented the total care approach.[34] Wilbur confidently opined that Kaplan's findings would no longer apply.[35] Such organizational changes may have relieved some of the hardships endured by parents, but the demands and uncertainty of Ricky's illness strained the Pineda's marriage and prompted Richard to threaten divorce.

Ricky's case also reintroduced questions about the emotional health of young patients. During his illness, Ricky became curious about his impending death. He wondered aloud whether he would be buried, whether he could keep his favorite possessions, and whether his mother would accompany him to heaven, questions that revealed the boy's understanding and confusion about the meaning of death. His mother lamented, "It's so hard to tell your child about death, but children have a premonition."[36] Gloria chose her responses carefully, but it was important to her to remain truthful to her son. In the 1970s, physicians' preferences toward truth telling continued to vary

widely—some doctors advocated silence, others urged disclosure, and a third group thought that parents should make the final decision.

Investigators carefully listened to children's words and observed their behavior in order to gain insight about their understanding of illness and death and, consequently, what recommendations about truth telling were appropriate. By studying children's stories, researchers attempted to quantify children's anxiety about death.[37] Parents frequently insisted that their children did not know that they were suffering from a fatal illness, yet the researchers discovered that many children did comprehend that they were going to die, even if they had not been told directly. Many children who did not talk about their upcoming death (unlike Ricky Pineda) knew, however, that death was inevitable and deliberately concealed this information from their parents and the medical staff.[38] Myra Bluebond-Langner, the author of an influential book-length study, argued that the children's behavior reflected their socialization about death in America—that death should not be openly discussed. Bluebond-Langner urged parents and physicians to break the silence about death and dying and to be prepared for queries throughout the course of the child's illness.

Literature on truth telling published from the 1950s to the 1970s might have influenced the move toward more disclosure, but physicians' behavior also responded to social pressures that forced medical practitioners toward respecting greater patient autonomy.[39] By framing the model patient as one that was both autonomous and informed, supporters of the patients' rights movement attempted to empower patients and to restore their voice to the medical encounter.[40] Several components of this patient- or consumer-centered movement had a direct impact on the care of children with cancer, including the regulation of medical experimentation, wider acceptance of alternative medicine, and the new attention to death that gave patients and parents greater self-determination to reject life-extending medical care during the terminal phase of illness if they wished.[41]

Medical professionals' death anxiety and avoidance strategies continued to hinder interactions between physicians, parents, the young patient, and his or her siblings. In the 1960s, research by social workers and psychologists had begun to uncover this problem and design new strategies and solutions. At the end of the decade, Elisabeth Kübler-Ross published *On Death and Dying,* a best-selling book that implored readers to carefully consider and value the perspective of the terminally ill patient. Kübler-Ross described the account as "a new and challenging opportunity to refocus on the patient as a human be-

ing, to include him in dialogues, to learn from him the strengths and weaknesses of our hospital management of the patient."[42] By telling the stories of her patients and printing their own words, she sought to elevate the human above the medical technology surrounding modern death.[43] She criticized medical education that prioritized research and laboratory work over doctor-patient relations and recommended training for medical students that included psychosocial dynamics in the practice of medicine and curriculum on the care of the dying patient. Although the landmark volume focused almost exclusively on adult patients, its primary purpose, to transform patients into teachers of doctors, nurses, clergy, and their family members, also applied to her examination of children's voices in a later volume.[44]

Through *On Death and Dying,* a lecture tour, and an interview in *Life* magazine, Kübler-Ross's argument to restore agency to the sufferer, to replace technology with humanity, and to involve the patient in the process of death gained popular resonance. She became a leader in thanatology, a new field that studied concerns related to death.[45] The cover story of *Newsweek* in May 1978 described the "death-awareness movement" in America that reexamined taboos against death and revised the dehumanizing rituals identified in *The American Way of Death* a decade earlier.[46] On a national level, a panel of officials from the National Cancer Institute, the National Institute on Aging, and other federal agencies began to evaluate how research institutions dealt with dying. Famed cancer patients including Senator Hubert H. Humphrey discussed their illnesses publicly, making national appearances or recording their experiences in illness narratives. An article in *Time* the following month noted, "Once it becomes apparent that an illness is terminal, conventional medicine often seems unequipped, untrained and even unwilling to deal with death."[47]

The movement to modify the medicalization of death in America influenced the care of pediatric cancer patients. In a 1976 article published in the *Journal of Pediatrics,* the mother of a child with cancer recalled a movie that depicted a physician struggling to face his dying cancer patient. When he composed himself and walked into the room, the girl said to him, "I am not cancer, I am not leukemia, I am a person."[48] This dramatic episode suggested a need for physicians to reorient themselves from the disease to the patient and to better cope with the possibility of child death.

The desire to provide comfort, treat pain, and reduce the use of aggressive treatment during terminal illness contributed to the launch of the modern hospice movement.[49] In 1966, Florence Wald, a nursing educator at Yale Uni-

versity, had invited Kübler-Ross and Cecily Saunders to lecture about changes in the care of the terminally ill. The following year, Saunders founded Saint Christopher's Hospice in London. These key events helped initiate the first three American hospice projects, Connecticut Hospice in Branford, Connecticut, St. Luke's Hospice in New York City, and Hospice of Marin in California, and, by 1978, a National Hospice Organization had been formed to coordinate hospice facilities and speak on their behalf. The burgeoning American hospice movement reaffirmed Kübler-Ross's principles by relocating the place of death from the hospital or nursing home facilities to a hospice or home and reforming the manner of death to one that focused on aiding, not isolating, the patient. Nevertheless, the majority of hospice programs did not include pediatric patients in the 1970s because it was common for adults who were admitted to hospice to have cancer, to have a six-month prognosis, and to be looking toward palliation rather than cure. Children did not fit easily into this admission profile and the standard guidelines for care.

In the mid-1970s, a three-year, National Cancer Institute–sponsored study led by Ida Martinson, a registered nurse and director of research at the University of Minnesota School of Nursing, considered the viability of home care for terminally ill children, in particular those with cancer.[50] Martinson was aware of hospice programs that served adults and implored her colleagues, "For a dying child and his family, I believe an alternative is imperative—and now." She explained, "The hospital with all its technology and highly skilled personnel not only may not be essential in caring for the dying child, but it may well be an obstacle to the provision of appropriate care for such a patient."[51] By refocusing the emphasis from cure to comfort during the terminal stages of illness, she sought to minimize the suffering of young patients and their family members. At home, the child's treatment regimen could be simplified to include only the procedures needed to manage pain or other side effects. She had observed that most tests were futile by the end of life; they only traumatized the child further and added to the high costs of cancer treatment. The two primary goals of the project were to restore control over decision making to parents and their ill children and to limit the uncertainty of the final stages of cancer—areas that she believed medical professionals often handled improperly.[52]

In many ways, the University of Minnesota was an ideal location for Martinson's experimental "Home Care for the Dying Child" project. In Minnesota and the surrounding area, most pediatric cancer treatment involved partici-

pation in cooperative clinical trials and was administered at centrally located, major cancer treatment centers. Families residing in Minnesota, Wisconsin, and North Dakota repeatedly traveled as far as 400 miles to bring their children to centers in the Minneapolis–St. Paul metropolitan area. Martinson viewed hospitalization as a particularly traumatic experience for children and families because it forced parents to endure long commutes between hospital and home and often divided families between two locations. If parents felt that they could manage the death of their child at home, and the child expressed this wish, Martinson argued that death should take place at home—a place she associated with security, familiarity, and, she predicted, lower cost care.

Martinson refined her experimental model through firsthand experience with Eric Kulenkamp, a ten-year-old boy with acute leukemia.[53] Eric was in the final stages of his thirty-month illness and had expressed that he no longer wanted to go to the hospital for treatment. Previously, Eric had embraced the role of "professional patient," constantly asking about his condition and learning the routines of his treatment. Eric's mother, Doris, had been his partner in therapy. According to her own estimates, she had spent at least part of one out of every four days (more than 200 days total) with Eric in the hospital or at the outpatient clinic. Over the course of his illness, she had witnessed Eric undergo nearly 500 laboratory tests such as complete blood counts and regular platelet counts. Like Martinson, she had questioned whether this intense regimen was necessary when his health began failing. She suspected that her son was now just a part of a larger experiment. She later reflected: "Being subjects of research is not terribly comforting . . . I, and others, were a bit paranoid at times, wondering if what was done was actually for the sake of our loved one or for the sake of research. In reality, it is a combination of both."[54] After Eric voiced his last wishes, his parents agreed to participate in the home-care experiment with the hope that they could delay or, ideally, avoid further hospitalizations.

Under his parents' constant watch, Eric was able to remain at home. The public health nurse assigned to the case trained his parents to administer injections, watch for infections or bleeding in his mouth, and cope with common complications. He died at home in his own bed in the middle of the night just seventeen days, eight home visits, and five phone consultations after the initial meeting between Martinson and Eric's family. Satisfied that they had been able to provide adequate care for their son, Eric's mother, Doris, converted her diary entries from the time into an extended narrative. Martinson

and the public health nurse added their perspectives. The final product, titled *Eric,* suggested that facilitating children's death at home was a worthwhile project that should be pursued on a larger scale.

In *Meri,* another extended illness narrative, David Wetzel, Meri's father, shared his feelings about his ten-year-old daughter's illness and death from acute leukemia. Wetzel wrote that he and his wife had not thought beyond her cycles of relapse, treatment, and remission until relapse began to dominate the other phases. Wetzel wrote that at the time her home care began, "she had lived eight years with leukemia and we felt that she was suffering as much from her treatment as from the disease."[55] Meri experienced extreme bone pain from the proliferation of white blood cells in her bone marrow and she had rapidly moved from over-the-counter painkillers to Demerol, a potent prescription drug. After reading about the Kulenkamp's experience, they decided to care for Meri at home. They integrated her care into the pattern of their home life and successfully established a less confrontational relationship with her physicians, writing, "For the first time we felt like partners in her medical care."[56] Like many families, the labor to prevent and regulate Meri's worsening pain proved to be their biggest challenge as they tried to gauge the strength and dosage needed for relief and to persuasively communicate this to Martinson and the consulting physician. Martinson's presence and advice during Meri's illness, at her death and memorial service, and afterward helped the family cope and grieve. Martinson and other nurses in the project referred to themselves as "advocates for the dying" as they recognized that children's age and specific needs separated their experience from societal expectations of death.[57] Parent participants showed their support for "Home Care for the Dying Child" by recording their reactions with health professionals, dedicating memorial gifts to the research fund at the University of Minnesota School of Nursing, and, like Eric's mother and Meri's father, sharing their experiences.[58]

The project quickly gained institutional support from faculty members at the University of Minnesota. Physicians referred children aged five weeks to seventeen years old to the research team; the majority had forms of childhood cancer. By November 1977, Martinson's research team had worked with twenty-nine families, of which twenty children had died—seventeen at home and three in the hospital. Their involvement with the families averaged 32.5 days, with a range of 2 to 104 days and included professional services such as home visits, telephone calls, and accompanying families to clinic appointments for an estimated cost per child of $1,000. In contrast, Martinson's re-

view of comparable hospital charts showed that the average hospitalization for a child with cancer was 28.5 days with a cost of $4,480.[59]

Martinson's "Home Care for the Dying Child" project proved to be a partial success. Results showed that end-of-life care was less expensive and less invasive at home. Parents reported that providing care at home relieved their guilt that they could not or had not done enough for their dying child. Under this system, parents not only managed their child's medical care, but also were able to fulfill their child's unique requests for favorite foods, familiar toys, visits from playmates or favorite family members, or other special needs. Families were moved to record their positive experiences as participants in the project and testified that it was possible to facilitate a "good" death at home.

There were, however, also several major challenges. Expert nursing care was at the core of the project, yet when Martinson administered a statewide survey to assess the attitudes of Minnesota's registered nurses toward death and dying, she exposed a gulf between their attitude, education, and experience and the needs of her study. Nurses affirmed that alternative systems of nursing care for dying patients needed to be developed, but only 50 percent of respondents named "home" as the appropriate location for death. She also found that nurses had great difficulty coping with ill children; 61 percent reported feeling very uncomfortable when dealing with a dying child.[60]

At the time of Martinson's study, significant changes were occurring concerning the professionalization and practice of nursing. In 1974, a small cohort of nurses convened at a meeting of the Association for the Care of Children in Hospitals and decided to form a professional organization for subspecialists working in pediatric oncology. A year later, the Oncology Nursing Society was established and, in 1976, the Association of Pediatric Oncology was incorporated with a mission to support nurses involved in a rapidly changing field.[61] As the role of nurses evolved to one that required providing direct patient care, administering clinical trials and implementing research protocols, and working closely with young patients and families, this specialized group required a central association to link individuals who interested in the challenges posed by a rare set of diseases and, at times, tragic deaths. The need for a strong regional and national support system was evident in the challenges posed by Martinson's study.

At the same time, Martinson also encountered hostility from cancer specialists. She had received referrals from a number of physicians at the university and the surrounding region, but there was still profound ambivalence to

hospice care. Donald Pinkel, a pediatric oncologist at St. Jude, wrote, "For many families the death of a child is better conducted at home or in a community hospital."[62] One of his colleagues countered, "Not everyone needs a hospice," labeling such efforts "anti-therapy and anti-therapist."[63] At a time in late twentieth-century medicine when cancer medicine was focused on exhausting all options before abandoning hope for a cure, choosing to stop could be met with criticism from physicians. Significant work would have to be done if collaborations like those built at the University of Minnesota were to be implemented widely.

In 1983, Children's Hospice International was founded, and by 1985, 183 hospices had opened their doors to children. It soon became apparent, however, that there was a serious mismatch between the vision of Martinson and others and the realities of pediatric cancer treatment in the United States. One frustrated hospice organizer spoke for the entire community when he explained, "Everyone looks so hard for remission that the child [with cancer] might be dying while receiving aggressive therapy."[64] Few children in hospice care had cancer because it was difficult to accurately predict the life expectancy of children with cancer, and many parents were unwilling to halt treatment even if given only a slim chance of saving their child's life. The tendency, hospice workers remarked, was to treat to the end. A redesigned, more flexible choice was needed to successfully accommodate all children with cancer, their parents, physicians, and insurers.[65]

Child Advocacy and Survivorship

In the 1970s, issues of health, education, justice, poverty, and abuse and their relationship to the treatment of children became the basis for critical discussion and action in America. Stephen Hess, the chairman of the White House Conference on Children, stated, "The child—as far as our institutions and laws are concerned—is too often a forgotten American."[66] In *The Children's Rights Movement,* Beatrice and Ronald Gross urged each person to become a "child advocate" who would speak out for this voiceless population.[67] In the 1970s, parents became vocal advocates through a small, yet significant cluster of illness narratives and the creation of a new national organization devoted solely to childhood cancers and the families affected by this set of diseases.

This phenomenon explains in part why parents increasingly wrote cancer narratives in the 1970s. Parents of childhood cancer sufferers—like other par-

ents writing about hemophilia and cystic fibrosis—informed readers about the new course of these diseases.[68] By tracing their family's experiences during each stage of medical management from diagnosis, through their treatment decisions, to terminal care or possible long-term survival, the narratives acted as a comprehensive guide for other families facing cancer.[69] Ilana Löwy has suggested that cancer narratives commonly reflect the (sometimes reluctant) adherence of many cancer patients and their families to the oncologists' concepts and practices.[70] At the same time, accounts emphasized parents' involvement in managing their child's disease on their own terms. In some cases, they wrested control from health professionals and thought that their personal involvement in their child's care improved their child's hospitalization or healing process.[71] Barron Lerner has noted that a large collection of book-length illness narratives and breast cancer accounts in newspapers and popular magazines and on television served as powerful outlets for women to criticize and revolt against standard medical and surgical practices in the 1970s.[72] Childhood cancer narratives contained fewer overt criticisms of their child's care, but parents subtly interwove the personal and political in their published illness narratives as a way to participate in broader debates and public scrutiny toward medical care, the rights of children and other populations, and issues of death and dying that intersected in the experiences of all cancer patients and their families in the 1970s.[73]

Published in 1974, *Eric,* the story of a seventeen-year-old boy's experience with acute leukemia typifies childhood cancer narratives published in the 1970s and 1980s.[74] Many accounts highlighted the broad public awareness of cancer and the dread still associated with the disease. In the book's opening pages, Doris Lund, Eric's mother, described her poignant reaction to her son's diagnostic tests and diagnosis:

> I blanked out the words "bone marrow" instantly as if I'd never heard them before in all my life, as if I'd never read a single book or magazine article or watched a single TV drama which spelled out in the plainest possible terms exactly what a doctor was looking for when he ordered a bone marrow. After all, there was that perfect physical exam only twelve days before. . . .[75]

When the doctor called the next afternoon to schedule an appointment to share the diagnosis, Lund immediately replied, "You don't have to. I already know. Eric has leukemia."[76]

Eric, like most accounts, also detailed each step of the teenager's treatment. Massive doses of chemotherapeutic drugs were able to induce six consecutive

remissions. Eric, though, was unusually sensitive to the drugs, and severe side effects such as mouth ulcers and nosebleeds prevented physicians from administering the full doses. As Lund observed, his physicians walked a "tightrope," a careful balance between inducing remissions and preserving healthy tissues and their vital functions. After his first remission was obtained, Eric traveled to Memorial's outpatient clinic from his home in southwestern Connecticut for weekly blood tests and regular bone marrow exams. Through maintenance therapy, a course of drug therapy administered at home during remission to continue the healthy status, Eric remained in his first remission for more than a year.

Narratives also illustrated how patients procured experimental drugs when standard therapies had been exhausted. After Lund read about asparaginase, an experimental drug available in limited quantities, she approached Joseph Burchenal, director of clinical investigation at Sloan-Kettering, personally. According to Lund, Burchenal, stated bluntly, "There are six patients who ought to be getting asparaginase right now. I think that we have enough in that bottle for two."[77] After suffering relapses, Eric was given injections of vincristine and prednisone three times per day. To his mother's amazement, he also received asparaginase once each day as an outpatient at Memorial. Because of the experimental nature of the drug, he had to remain at the hospital all day so that staff members could identify, monitor, and record its side effects.

Physicians decided to hospitalize Eric after finding that the extreme nausea stimulated by the asparaginase made it impossible for Eric to ride home in the car after chemotherapy. He was housed in the clinical research facility, a separate service at Memorial designated only for research subjects. Despite carrying no major medical insurance, the Lund family had paid for Eric's doctor and hospital costs. Upon his admission to the clinical research facility, a federal grant given to hospitals investigating experimental drugs now paid for his treatment. Lund wrote that no one would be equipped to afford the new drugs or the intensive nursing care and special diets that were required during testing.

Parents emphasized the complications that accompanied the cycles of remission and relapse and their child's slow decline as periods of health became shorter and more difficult to maintain. During acute episodes, family and friends needed to donate adequate units of blood to address the demands of Eric's illness. A centrifuge separated plasma and platelets from whole blood through plasmapheresis, so the red blood cells were returned and the donor

could give again in only two to three days. Eric also developed a tumor behind his left eye that required pinpoint radiotherapy. Before his death, Eric suffered a severe crisis that resulted a four-day coma from infection and near organ failure.

Like most parents, Doris Lund had maintained hope that the next advances in chemotherapy would not only continue to prolong her son's life but provide a cure. As she and her son watched astronauts land on the moon, Lund had been amazed at the drama of the event:

> I thought, it was a miracle watching a miracle. It had taken billions of dollars to put those astronauts on the moon. It had taken millions in medical research to put Eric Lund, very much alive and well, in a Colorado tavern nearly two years after he was stricken with leukemia. Not too many years before, his life would have been over five or six weeks after diagnosis. Science had given him a gift of years. Because of that gift, Eric got to watch the greatest event of his time.[78]

Although she repeatedly professed her faith in science and denied that Eric would die, Lund and her family refused any life-saving interventions that may have prolonged his suffering. Only at the terminal stage of illness did parents accept the reality of their child's death. Using illness narratives, parents created a permanent record that preserved their child's ability to cope courageously with illness, gave lasting life to one cut painfully short, and served as a creative outlet to express grief.[79]

Childhood cancer narratives explored how illness altered their parent-child relationship and provided insight into the important influence of age on the sufferer's and the family's experience of illness.[80] Eric's age helped define the course of his disease, since young people over the age of twelve had poorer acute leukemia prognoses. His age also shaped his experience. As a seventeen-year-old, Eric wanted to contribute equally to the decisions regarding his care. He knew that he was seriously ill and factual information served to satisfy, not agitate him. Eric asked his mother for permission to manage his illness himself though private conversations with his doctor.[81] Eric became preoccupied with maintaining a positive attitude, fighting the disease, and staying out of the hospital as much as possible. During remissions, he returned to school for brief periods and was elected as captain of his collegiate soccer team. He began dating Mary Lou, his private duty nurse at Memorial, and gave her a copy of *On Death and Dying* as his death neared. During the last stage of his illness, he began to discuss how he wanted to die

and signed forms in order to donate his eyes. Lund thoroughly documented the events that unfolded throughout her son's illness, but she also captured her own struggles to protect him while according him the independence of a young man.

A final set of narratives was written to alert Americans of the mounting evidence about hazardous environmental toxins and their detrimental effects on child health. Heightened awareness of the direct effects of environmental pollutants such as DDT and dioxin on the health of plants, animals, and humans followed the publication of *Silent Spring* in 1962 and the establishment of the Environmental Protection Agency.[82] The first major epidemiological investigation of a childhood leukemia cluster occurred in Niles, Illinois, in 1963.[83] A cluster of thirteen leukemia cases during a four-year period in the town initially raised concerns. The children of Niles had little in common—they were of different ethnicities, their parents did not have similar occupations, and radiation levels in the town were not abnormally high. The only common factor was that all of the affected children resided in Niles and attended or had attended the same Roman Catholic primary school. Trained U.S. Public Health Service investigators from its Communicable Diseases Center in Atlanta conducted a house-to-house study in the town in order to directly link the cases to a common genetic, chemical, or infectious factor, but no conclusive link was found.[84] In the decades that followed, the Centers for Disease Control investigated dozens of other cases including sites in the Love Canal area of Buffalo, New York; residential neighborhoods in Woburn, Massachusetts; and a school in Rutherford, New Jersey.[85] In these three areas, parents suspected that improper disposal of toxic chemical waste were responsible for their children's cancers. Two mothers, Anne Anderson and Lois Marie Gibbs, led grassroots campaigns to accurately count and plot the number of ill in their communities and to persuade public health officials that industrial dumping threatened the health of all of the town's citizens—especially the youngest residents.[86]

The Anderson family of Anne, her husband Charles, and children Christine, Charles Jr., and Jimmy became the center of a controversy over the health risks of toxic chemicals dumped in Woburn, Massachusetts, an industrial suburb located eleven miles north of Boston. At age three, Jimmy had been diagnosed with acute leukemia. Under the supervision of John Truman, head of pediatric oncology at Massachusetts General Hospital, he was treated with an intense treatment regimen pioneered at St. Jude Hospital that included radiation of the skull and combination chemotherapy. Jimmy and his mother

traveled to Boston on nearly a daily basis for therapy and management of his short-term side effects. He also suffered permanent impairments such as a speech impediment, a learning disability, and a deficiency in fine motor control. At age seven, Jimmy relapsed. In *Cluster Mystery,* author Paula DiPerna wrote, "In this, the small boy's ordeal that was the life of Jimmy Anderson gradually became the chronicle of a town and a medical touchstone for a nation."[87]

Anderson kept an informal list of the cancer victims and their locations and recorded the cases on a pushpin map to vividly illustrate their number, location, and proximity to one another. Struck by her findings, she gathered a complete victim list by holding a city meeting. She found that between 1968 and 1979, twelve children from East Woburn were diagnosed with acute lymphocytic leukemia; six children lived close to one another in a geographical "cluster." Through FACE (For A Cleaner Environment), Anderson and other parents organized community meetings, distributed a newsletter, and tried to build critical connections between extensive toxic waste dumping, well contamination, and childhood leukemia.[88] On December 12, 1979, the headline "Child Leukemia Answer Sought" was the first public announcement of the cluster.[89] Throughout the case, a complicated relationship arose between expert scientific knowledge versus the public interest and the concerns of the individual.[90]

On May 22, 1979, wells G and H, two sources of water for Jimmy's home, were ordered closed immediately by the Department of Environmental Quality Engineering of the Environmental Protection Agency serving the state of Massachusetts because the water supply was contaminated with chemicals found to cause cancer in lab animals. As local newspaper articles unearthed details about illegal toxic waste dumping and hearings were held about the possible health effects of hazardous waste disposal, Anderson permitted reporters to interview Jimmy about the Woburn case. Patrick Toomey, another Woburn boy dying of cancer, spoke with Senator Kennedy about his experiences and the local situation.[91] On January 18, 1981, Jimmy died from a massive pulmonary hemorrhage caused by aplastic anemia, a side effect of chemotherapy. Jimmy and Patrick's deaths helped convince parents, other residents of Woburn, and those reading about the case in the *New York Times* and the *Washington Post* that the children's suffering was linked to improper toxic waste disposal by the Grace Corporation and Beatrice Foods. Based on a computer model of water distribution from the contaminated wells and the statistical disease evidence, eleven Woburn families filed a civil suit against the

corporation. In 1984, study results found a positive association between toxic waste and birth defects, stillbirths, and childhood leukemia. A verdict found that Grace had negligently dumped chemicals on its property, and the out-of-court settlement that followed captured national attention because it demonstrated corporate responsibility for proper toxic waste removal and the attendant physical and psychological health risks from improper disposal. Young victims such as Jimmy Anderson and Patrick Toomey, their families, and other community activists identified and acted against corporations and local, state, and federal officials for the remediation of toxic waste problems and the recognition that their actions had caused human suffering.

Long-Term Survivorship

In 1970, a new national childhood cancer foundation joined a long list of organizations such as the Jimmy Fund, the Leukemia Society of America, the Bright Star Foundation begun by the Bush family, and the Association for Brain Tumor Research that was established by two Chicago mothers concerned about research for inoperable tumors.[92] Although some were started by parents, others like St. Jude Children's Research Hospital and the American Lebanese Syrian Associated Charities, its fundraising arm, were launched by celebrities. Danny Thomas, a performer known for his role on the television program *Make Room for Daddy,* used his links to the entertainment industry to stage large-scale fundraising events to benefit an institution focused narrowly on the research and treatment of pediatric cancers.[93] In the past, like today, the dozens of nonprofit and for-profit groups for pediatric cancers were started on the local, national, and international level to help fill perceived voids in cancer services. Although few are linked directly, many shared a common origin—the premature illness or death of a loved young child from cancer.

In 1968, the daughter of Grace Ann Monaco was diagnosed with acute lymphoblastic leukemia. During her daughter's illness, Monaco met parents of other children in treatment at Children's National Medical Center in Washington, D.C., and witnessed how childhood cancer and the daily demands of treatment affected the entire family. Monaco founded Candlelighters in 1970 to create a network of peer support and information for patients and their families, a goal that resonates with the wishes expressed by parents who wrote the Gunthers in the 1940s and early 1950s. In the decades that followed, parents and patients had contact with others in outpatient clinic waiting areas or

in formal group meetings organized at individual research centers, but Candlelighters expanded communication beyond the institutional setting to local, regional, and national forums. Like parents of children with disabilities, members of Candlelighters sought to affect change in medical and social systems by gathering the voices of individual parents into a formal, specialized organization.[94]

By visiting children's hospitals across the country, Candlelighters' early members gained first-hand knowledge about the cancer-related concerns of children and met professionals willing to volunteer their time to help children. In 1970, the Childhood Cancer Ombudsman Program began organizing panels of volunteer doctors and lawyers willing to give free opinions on issues such as treatment choices, informed consent, employment discrimination against parents, education discrimination, and barriers to insurance. Candlelighters also promoted the need for more information about the proper nutrition for children with cancer. Children's size fluctuated at different points during treatment, but little was known about how to prevent these problems. Based, in part, on these efforts, the National Cancer Institute began a diet, cancer, and nutrition program that was first funded in 1974. The group also used their presence in Washington, D.C., to lobby legislators for access to pediatric clinical trials.

In 1978, Candlelighters convened "Maintaining a Normal Life," its first national gathering for sufferers, survivors, and parents of children with cancer. The number of childhood cancer groups associated with Candlelighters had increased from 3 to 100 groups in 47 states, Canada, and Europe, and approximately 400 adults, adolescents, and children from across North America participated in the conference. The National Cancer Institute's office of communications also recorded and published the conference proceedings so that they would be widely available.[95]

The conference program highlighted the growing challenges presented by cancer survivorship. Few of the invited speakers or sessions dealt directly with innovations in treatment regimens; rather, most were dedicated to issues related to the prolonged medical management of the disease and the long-term survival of children that characterized childhood cancers by the mid- to late 1970s. Jordan Wilbur described Stanford's ten-year history of completely integrating families into the daily activities of the oncology unit so that they could master skills such as dispensing oral or intravenous medication before the child returned home.[96] Other talks described the development of outpatient clinic services and the facilitation of children's reentry into "normal life"

at home and school during treatment. The provision of adequate supportive care at home was a crucial subject for parents caring for a child on a multiyear chemotherapy protocol.

Questions and comments from parents and teenage sufferers demonstrated that combining medical care and "normal" life posed many problems for families. Discussion focused on relations within the patients' family, practical problems including discipline, nutrition, cost, and home care, and the child's or teen's perception of illness and death. At each session, preselected panels composed of parents responded to the speakers' presentations and began a dialogue that often reflected tensions between expert advice and personal experience. A panel of ten teenagers with a variety of common childhood cancers also shared their frank responses. They expressed frustration yet resignation toward multiple relapses, the acute nausea that accompanied chemotherapy, their frequent absences from school and social life, and the stigmatization that followed amputation or hair loss. At the same time, however, each youth told of their overwhelming determination for continued life and revealed that they were not content to be viewed as passive recipients of care.[97] The teenagers willingly shared their opinions among this small circle of peers, but they also self-consciously sought to extend their influence beyond the panel to interested parents, physicians, and other readers of the conference proceedings.

As all childhood cancer survival rates slowly improved in the 1970s, "late effects" of therapy—delayed physiological and psychological consequences of their aggressive, repeated surgery, radiation, and drug treatment—first became apparent. Parents attending the conference session on the outlook for children who had completed treatment had many unanswered questions. After enduring a prolonged illness alongside their children, parents worried that their child's normal growth and development would be permanently retarded by the side effects of their life-saving treatment. Nevertheless, the presenter could not make definitive statements based on the limited data that was available. Investigation into late effects and the future for a growing number of childhood cancer survivors escalated into the twenty-first century.

During the 1970s, young acute leukemia sufferers like Amy Louise Timmons spent years cycling between periods of health and illness. Therapeutic breakthroughs in the form of effective chemotherapeutic agents and complex chemotherapy protocols had transformed the course of this disease from a rapid killer to a treatable illness with long-term survivors. By this decade,

comprehensive cancer centers became key sites for advanced childhood cancer treatment and many children spent years receiving regular outpatient care there after returning to home and school. Although care centered in the home enabled children to live in a familiar environment and reduced burdens of long-term hospitalization, it introduced new concerns related to maintaining daily family life while dealing with the side effects of toxic chemotherapeutic drugs and the unexpected exacerbations of leukemia. Illness narratives revealed young patients' courageous battles with illness while at the same time illuminating parents' struggle to care for their child while maintaining the family's home life. Parents gained additional responsibility as the primary caretakers of children with cancer: parents carefully monitored their children's health, questioned the use of experimental therapies in their ill and dying children, chose to supplement conventional care with alternative therapies, and dictated the terms of their children's deaths. As parent advocates, they participated in negotiations with professional health care providers and, sometimes, industrial polluters and the law. Despite numerous setbacks, guarded hope for a permanent cure united parents, physicians, and researchers.

At a 1977 conference on leukemias and lymphomas sponsored by the American Cancer Society and the National Cancer Institute, Joseph Simone, an oncologist at St. Jude, confidently stated, "It is no longer controversial to state that a significant proportion of children with acute lymphocytic leukemia can attain long-term, leukemia-free survival and, possibly, cure."[98] Simone reported that some of the young patients he treated at St. Jude had completed high school and college, married, and had children after regaining their health, but cures had not been achieved without a cost. As another speaker at the conference later noted, "The gratifying success of therapy permits the physician to divert some of his attention from cure to the consequences of the treatment he is giving."[99] The specter of late effects and their long-term consequences for children who had been cured of cancer through aggressive radiation and chemotherapy remained.