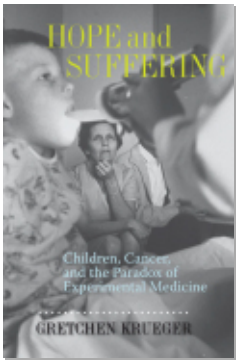
# Hope and Suffering

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# "Who's Afraid of Death on the Leukemia Ward?"

## REMISSION, RELAPSE, AND CHILD DEATH IN THE 1960S AND 1970S

In 1961, Peter De Vries, a prolific writer and contributor to the *New Yorker,* published *The Blood of the Lamb,* a novel that documented the tragic illness and death of a young girl from acute leukemia.[1] In the first half of the book, Don Wanderhope, the book's protagonist, recounted the sickness and suffering of close family members and friends. After this long series of events, his eleven-year-old daughter, Carol, was diagnosed with acute leukemia. The second half of the novel offered an exacting description of his daughter's illness and Wanderhope's own inner struggle to comprehend a disease he termed "the Slaughter of Innocents" against his beliefs about religion and medical science. *The Blood of the Lamb* drew criticism for its radical departure from the author's comedic style, a style that was defined by its wise use of its puns and malapropisms. De Vries's quick wit and dark humor allowed him to make biting evaluations of the contemporary American scene and the absurdities of modern life. This unusual voice caught the attention of critics and readers alike. The dark tone and heartrending plot of *The Blood of the Lamb* led the reviewer from the magazine *Commonweal* to write, "The grief of Mr. De Vries's hero is agonizingly real, as real as life."[2] Another predicted, "Those who have laughed with him in the past and during this book will not begrudge him their tears."[3] Far from a purely fictional account, De Vries had based the book closely on autobiographical events and used the writing process to cope with the tragic death of his ten-year-old daughter, Emily, from acute leukemia.

Close parallels existed between the events described in *The Blood of the Lamb* and patients' experience of acute leukemia in the 1960s. Despite improvements in the survival rates of children with retinoblastoma, Wilm's tumor, and other common childhood tumors, leukemia remained a frustrating

enigma. Chemotherapeutic agents delayed, but did not deny, death early in this decade, and longer survival through chemical means brought a list of benefits and challenges to physicians, parents, and children: complicated multidrug treatment regimens, severe physical side effects, and the inevitability of death once experimental chemotherapeutic options had been exhausted. Children relapsed when cells became resistant to a chemotherapeutic agent and the bone marrow again became packed with diseased cells. Physicians administered another drug, if available, but if the limited treatment alternatives had been exhausted, the child died. The new pattern of illness fostered debates among medical professionals at conferences and in medical journals as the coordination between hospital, outpatient, and home care was negotiated. This chapter explores the contests that erupted over each phase of treatment but also attempts to capture the personal, variable component of disease experience, specifically acute leukemia in the 1960s.

## *The Blood of the Lamb*

De Vries's family life and local community became the basis for many of his writings.[4] In 1956, his daughter Emily was pictured with her father on the dust jacket of *Comfort Me with Apples* and the novel was dedicated "To Emily With Love."[5] She died shortly after, on September 19, 1960. De Vries's own stay at a church-sponsored tuberculosis sanatorium in Denver, his father's debilitating mental illness, Emily's premature death, and his own experiences during her illness served as the basis for the events in *The Blood of the Lamb.*[6] Although Carol's birth did not take place until the book's halfway point, De Vries's biographer J. H. Bowden argued, "It is her death—impending and then actual—which informs the book, shapes it."[7] Wanderhope's character provided readers with an intimate exploration of two themes: Carol's diagnosis, illness, and death and his intense theological inquiry into the limits of humanity, God and religion, and scientific medicine. Though not an exact description of De Vries's experiences with Emily's death, the biographical similarities were striking. In a 1967 manuscript documenting the history of the Department of Pediatrics at Memorial Hospital for Cancer and Allied Diseases, pediatrician Harold Dargeon wrote, "Although, we did not consciously contribute to the book published by the well-known author Peter De Vries, his own experiences at the hospital are a matter of record in the volume entitled *Blood of the Lamb.*"[8] "As would be expected," his bibliographer noted, "this disaster needed to be organized and exorcised fictionally by De Vries."[9]

De Vries's work, in the form of published poems, novels, essays, plays, and reviews, reached wide audiences through a variety of noted literary publications and anthologies. A lengthy summary of *The Blood of the Lamb* was reprinted by *Reader's Digest* Condensed Books and titled "Carol."[10] This abbreviated edition was translated into eight languages, and the original book was reprinted as a "Popular Library" volume. Despite the fictionalized nature of the personalities and events in De Vries's personal experiences, *Carol* provided readers with a provocative character and a substantial window through which one could gain insight into the deep impact of acute leukemia on the child and family in the 1960s.

## Recommendations and Reality

Like many children with acute leukemia, Carol was not immediately diagnosed with the disease. She first fell ill with a mild fever and recurrent back pain. A prescription of antibiotics failed to relieve Carol's common flulike symptoms, and she was admitted to the hospital for x-rays, blood tests, and a throat culture. Doctors detected and treated a streptococcus infection, but a second episode of fatigue, fever, and aches prompted her physician to order another blood test and a bone marrow aspiration. The pathology report established a definitive diagnosis of acute leukemia.

A flurry of popular articles written about childhood cancers in the 1960s in *Family Circle, Reader's Digest, Good Housekeeping,* and other publications repeated the messages promoted by earlier articles alerting parents to common cancer sites in children, warning them about suspicious symptoms, promoting early detection, urging them to promptly seek physicians' counsel, and updating readers about advances in treatment.[11] They also began promoting yearly physical exams for preschool-age children as vital tools for prompt tumor detection and treatment.[12] In *Health,* a publication of the American Osteopathic Association, the author noted that children experienced a high cancer rate during this period that coincided with a gap in medical care that occurred between the first-year checkups and the required school entrance medical exams. "During the first year of life," Stewart wrote, "infants keep regular doctor appointments, by and large, transported back and forth by conscientious modern mothers who are properly respectful of the widely publicized diphtheria-whooping cough-tetanus and polio immunizations."[13] In *Reader's Digest,* a distressing story urged parents with a family history of the eye tumor retinoblastoma to watch closely for physical signs

of the disease such as a white speck in the eye or an unusual widening of the pupil.[14] Studies of twins and the tumor's incidence had proven that retinoblastoma was caused, in large part, by heredity. The article described how one watchful mother detected the growing tumor in each of her three children and saved the lives of two of them through her vigilance. Unlike the Vasko and Colan cases, new technology allowed physicians to pinpoint the small tumor with radiation and preserve the affected eye. With early detection and new treatment methods, the cure rate for retinoblastoma had improved from a fatal outlook to a 90 percent cure rate by 1964.[15] The message of joint responsibility by the child's mother and pediatrician for cancer detection continued into the 1960s, but it focused on treatable childhood tumors. Reports virtually ignored acute leukemia because without curative agents, early detection did not equal longer survival. Instead, articles that included information on acute leukemia outlined incremental steps made in chemotherapy research.

## Chemotherapy and Miraculous Cures

In 1963, *Cosmopolitan* magazine featured a special report on cancer in children that vividly extolled the progress in the treatment of acute leukemia and other common childhood cancers. Notably, it also recounted parents' concerns about cancer causation and informed readers that the number of such inquiries had risen sharply. Many parents who brought their children to the Children's Cancer Research Foundation wondered whether the fallout from nuclear testing had contributed to their child's cancer, fearing that fission products of uranium and plutonium like strontium-90 and uranium-131 had tainted their family's milk and food. They had heard the message that isotopes could lodge in children's developing tissues and slowly accumulate over time, wreaking genetic damage and causing cancers, as these dire warnings had been disseminated through a number of highly visible means: congressional hearings, popular magazine articles, and boycotts, protests, and advertisements sponsored by Women Strike for Peace and the National Committee for a Sane Nuclear Policy, a peace organization cochaired by pediatrician Benjamin Spock.[16] Now, with few concrete answers as to why their child was sick with a rare, fast-growing disease, they searched for a plausible explanation; however, two major factors—a variable delay between radiation exposure and diagnosis of the disease and uncertainty about "safe" levels of radiation in children—made it difficult to definitively make a cause-and-effect relationship. Thus, the article focused primarily on a more optimistic angle.

Highlighting Farber, the Children's Cancer Research Foundation, and the "developing science of chemotherapy," the article acknowledged the dreaded nature of common childhood cancers but boasted of Farber's ability to cure cancer through new chemotherapeutic agents.[17] Wilms's tumor, in particular, responded dramatically to chemotherapy. In medical lectures, Farber showed a slide of a boy at age two and a half with Wilms's tumor and pulmonary metastases. He began, "Considering the size of the tumor and the presence of cancer in the lungs, the doctor treating this boy regarded an operation as contraindicated, and told the parents the outlook was hopeless."[18] He went on to contrast this fatalistic attitude with the approach toward the boy's condition at the Children's Cancer Research Foundation: the boy was immediately scheduled for radiotherapy appointment and given the antibiotic actinomycin D. "In a few weeks," Farber claimed, "his lungs were clear of cancer, and the tumor had reduced in size to the point where surgery was possible."[19] The next slide showed the boy at age seven with no evidence of cancer. New treatments for Wilm's tumor had transformed its cure rate from 20 to 40 percent with surgery and postoperative radiotherapy to 80 percent when the antibiotic actinomycin D was added. Farber assumed that a similar radical improvement would take place for acute leukemia sufferers in the near future. As in the late 1940s and 1950s, Farber sought "not only to prolong life, but to prolong good life" as long as possible in the event that a new, effective drug was discovered.[20]

Official American Cancer Society publications reinforced this optimism. In *The Truth about Cancer,* Charles S. Cameron, former medical and scientific director of the American Cancer Society, mimicked the dramatic, perhaps exaggerated style in newspaper and popular magazine articles to bring attention to potential power of chemotherapeutic agents against acute leukemia. Cameron told of the suffering of a leukemic child who was brought to the hospital on Labor Day. He characterized the young girl as "pale, drawn, distressed by constant bleeding from gums and nose, and with a prodigiously swollen tummy, unable to eat or even to walk, facing, by standards of five years ago, a few more weeks of increasing misery and ebbing life."[21] Drawing upon the biblical story of Christ's miraculous resurrection from the tomb, Cameron framed his story as a medical miracle produced by chemical compounds. He described the young girl's remission: "I have seen the same child Easter Sunday afternoon, gathering the newly blossomed daffodils in her mother's garden, jumping rope with her friends, to all outward appearances a healthy, happy child."[22] This pair of observations convinced him that something "ex-

citing and important has happened" in cancer chemotherapy research and that the experiences of this little girl indicated "only the beginning."[23] As a promoter of the American Cancer Society message of hope, Cameron used the story to assure readers that the advent of additional drugs held the potential to deliver more consistent, prolonged results that would ensure a rebirth for terminally ill cancer sufferers. De Vries's novel also used religious imagery but used it to deliver a different lesson. The symbolism and language signified the death of an innocent child from acute leukemia and, perhaps, the sacrifice of one child to improve the health of other sufferers. Through the thoughts and voice of Don Wanderhope, sections of the novel exposed a father's considerable wariness about experimental cancer treatment, his daughter's suffering, and the utility of continuing the aggressive treatment.

In *Blood of the Lamb,* Dr. Cameron, the Wanderhope's family physician, visited their home in Westchester County to deliver the grave diagnosis personally. He advised Wanderhope to take Carol to Westminster Hospital in New York City for access to the "world's leading authorities," extensive scientific research laboratories, and medical treatment facilities dedicated solely to cancer on childhood cancer.[24] Westminster was modeled after Memorial Hospital, the location of Emily De Vries's acute leukemia treatment. In response to Wanderhope's uninformed queries about possible treatments or cures, Cameron admonished,

> My dear boy, where have you been the last ten years? There are first of all the steroids—cortisone and ACTH—which give a quick remission. The minute she's pulled back to normal with those, Dr. Scoville will switch her to the first of the long-range drugs, some of which he's helped develop himself. If they should wear off, there's—but let's cross those bridges when we come to them.[25]

Such a series of chemotherapeutic agents typified the therapy for acute leukemia therapy in the 1960s. By administering effective drugs sequentially, gradually shorter remissions were linked with the goal of extending the child's life as long as possible. The physician not only made reassuring predictions about the length of Carol's remission but also imparted genuine hope for a cure in the near future, saying, "They're working on it day and night, and they're bound to get it soon."[26] After the diagnosis, Carol's care immediately shifted from Dr. Cameron to the specialized cancer center, where she could receive advanced treatment based on late-breaking research results.

At Westminster, Dr. Scoville, a pediatrician and specialist in childhood cancers, reiterated Cameron's enthusiasm for the potential of chemothera-

peutic agents to prolong and, perhaps save, Carol's life. He began by examining her and ordering another battery of laboratory tests to confirm her previous diagnosis. At a private meeting between Scoville and Wanderhope, he admitted that her condition was worsening but listed the possible chemotherapeutic agents that induced or maintained temporary, complete remissions in acute leukemia patients: steroids, methotrexate (a less toxic form of aminopterin), 6-mercaptopurine, and other experimental agents. Although he was intentionally evasive about Carol's chances for a permanent cure, he stated,

> Chemotherapy—drugs—is the scent we're on now, and it's only a few years ago we didn't have anything at all. It's quite a game of wits we're playing with this beast. The 6-MP, for example, breaks the cells up nutritionally by giving them counterfeit doses of the purine they like to gorge themselves on. I hope we'll have some other pranks to play on him soon, and if there are, you may be sure the clinic downstairs will be the first to try them out. There's nothing hot at the moment, but who knows? It's an exciting chase, though I can't expect you to look at it that way at the moment.[27]

For Scoville, the discovery and testing of chemotherapeutic agents was a professional challenge, a kind of intellectual game. Wanderhope appreciated the function of research hospitals, but he was also keenly interested in practical, available chemical agents that could be applied in his daughter's case. Scoville provided hope for acute leukemia patients in the form of scientific and medical discoveries but recognized that he could actually only promise a long series of medical tests, temporary remissions, and an uncertain future for Wanderhope and his daughter.

Scoville represented a member of the small cohort of physicians involved in Leukemia Group B, one of the most successful of the ten collaborative clinical research groups sponsored by the Cancer Chemotherapy National Service Center. Leukemia Group B organized clinical trials and evaluated the activity of cytotoxic drugs, modified chemotherapeutic protocols for children, and managed the dangerous side effects of drugs. As a consequence, they significantly increased the one-year survival rate of acute lymphocytic leukemia.[28] Children survived longer but invariably relapsed and died. In his conversation with Carol's father, Scoville optimistically portrayed the ongoing search for new agents by researchers and steered Wanderhope toward the promise of further chemical breakthroughs for his daughter.

By the early 1960s, Leukemia Group B became a part of a broad cooperative program organized to test chemotherapeutic agents against cancer in clinical settings. New funds, appointments, and a special task force suggested the political importance attached to the development of new chemotherapies. In his analysis of national medical and cancer research policies, Stephen Strickland described the testimony from experts such as Farber that persuaded Congress of the great promise of cancer chemotherapy. He wrote, "In proposing $24 million above the House recommendation for the National Cancer Institute in 1960, the Senate appropriations subcommittee indicated that the chemotherapy program was one area where it wished to see increased activity."[29] In 1960, two leaders in chemotherapy research moved from the Cancer Chemotherapy National Service Center to leading National Cancer Institute posts; Kenneth Endicott became National Cancer Institute's director and C. Gordon Zubrod became the institution's scientific director. In spring of 1962, Zubrod created the Acute Leukemia Task Force, a special group directed "to engineer a cure" of acute leukemia. Drawing upon management principles used by IBM to direct particular projects, the task force used the industrial model "because the problem of the cure of ALL [acute lymphocytic leukemia] was seen as a technical one: five efficient drugs existed already, and researchers were convinced that it would be possible to design drug protocols that would kill all of the residual malignant cells and prevent relapses."[30]

In 1964, a review article by Joseph H. Burchenal of the Sloan-Kettering Institute for Cancer Research and Memorial Hospital summarized the "present armamentarium" of five different classes of chemotherapeutic agents available to treat acute leukemia in children and adults.[31] Between 1948 and the early 1960s, aminopterin (methotrexate), prednisone, 6-MP, cytoxan, and vincristine were shown to be effective against acute leukemia in children. Patient records at Memorial Hospital through 1963 show that children treated with the nitrogen mustards alone in 1946–1947 survived an average of two months, whereas those treated with the full set of agents in the early 1960s survived an average of thirteen months from the start of treatment. In the mid-1960s, preliminary studies demonstrated that the new agents cytosine arabinoside and daunomycin were also active against experimental tumors, childhood leukemias, and forms of adult leukemia.[32] Treated in 1960, Carol Wanderhope did not have recourse to the complete "armamentarium" of agents or combination protocols, but she did receive steroids, 6-MP, methotrexate, and an unnamed, experimental drug. New chemotherapeutic treat-

ments for acute leukemia and other common childhood tumors again raised hopes for a cure, but deaths continued to be more common than cures in this set of cancers.

One branch of the Acute Leukemia Task Force focused on modifying dosage schedules to maximize efficacy while minimizing toxicity. M. C. Li, a National Cancer Institute researcher, had demonstrated that an equally effective, but less toxic form of aminopterin named methotrexate cured choriocarcinoma, a rare reproductive cancer. Choriocarcinoma studies in the L1210 mouse leukemia model showed that methotrexate showed more activity when administered intermittently than with the daily doses given in standard treatment.[33] As a result of this work, Leukemia Group B developed a similar dosing pattern in humans in order to lengthen remissions. Their clinical experiments compared the standard oral daily dose with intravenous administration, an intermittent schedule, and massive doses. Researchers also launched the first quantitative "adjuvant" study to probe whether administering an active agent during complete remission lengthened the period before relapse significantly.[34] This practice, termed adjuvant therapy, became the focus of many cancer research programs.

Investigators rigorously compared the administration of single agents or drug sequences to combination therapy protocols. Combination or cyclic therapy seemed to prevent the problems of drug resistance.[35] Based on encouraging results in the L1210 mouse leukemia model, Emil Frei III and Emil J. Freireich predicted that if two chemotherapeutic agents were administered simultaneously patients could respond to either. The researchers used a three-arm design to test whether they should give methotrexate, 6-MP, or both and to quantify the difference between using a single agent or two agents simultaneously. The combination produced a synergistic effect—the number of children in remission equaled the expected rate for both individual agents. If the researcher maintained the full doses, the combination improved the complete remission rate from 20 to 90 percent.[36] Clinical investigations also demonstrated that the best agents for inducing remissions differed from those that were most effective for treatment during remission: vincristine and prednisone were the optimal combination for inducing rapid, complete remissions, but 6-MP and methotrexate substantially lengthened remissions.[37] On the basis of these results, the National Cancer Institute researchers designed the VAMP protocol (vincristine, aminoptherin, 6-mercaptopurine, and prednisone) to measure the activity of four antileukemic agents given simultane-

ously.[38] After three cycles of VAMP, they stopped treatment to observe its effect on human patients. Calculations based on cell kinetics—a method to predict total cell death mathematically—had predicted a cure. Although "cures" could not be declared immediately, within six months researchers were confident that VAMP was inducing longer remissions than had been observed previously.[39]

National Cancer Institute researchers modified VAMP by creating a new two-cycle drug regimen known by the acronym BIKE (from "bi-cycle") that was initiated after remission was achieved. The physicians used vincristine and prednisone simultaneously to induce remission and then administered a full dose of methotrexate and 6-MP. Then the first two agents were resumed. The next study combined VAMP and BIKE into POMP (prednisone, vincristine [oncovin], methotrexate, 6-MP [purinethol]) which used the same agents as BIKE, but treated patients longer and used higher drug doses.[40] Based on this series of key studies, researchers discovered that the most effective treatment regimen was not continuous low-dose therapy, but an intermittent schedule of aggressive treatment even after all evidence of leukemia had disappeared. This plan induced remissions very quickly, caused less cell toxicity, and allowed for normal cell recovery. New experimental agents and this series of protocols introduced a rapid rise of the multidrug, multicycle regimens that were continually modified and accepted as the standard treatment for acute leukemia and many other cancers found in children and adults from this point forward.

## "*Everything Was Fine*"

Children like Carol Wanderhope who responded positively to chemotherapy entered a cyclical pattern of treatment, remission, and relapse that ended when the supply of effective agents was exhausted and the child died. After discussing Carol's diagnosis, Scoville led Wanderhope and his daughter to the outpatient clinic, the site of Carol's physical exams and procedures once her condition stabilized. Regular bone marrow aspirations would help physicians chart her condition and detect remissions, relapses, and infections while she lived at home. The family also relied on the clinic during unexpected crises. Scoville warned Don Wanderhope that the disease would destroy his daughter's platelets and hinder her blood's ability to clot properly. He supplied him with cotton packing to plug her nostrils during a nosebleed, but be-

fore her next scheduled visit, Carol, her father, and the family housekeeper traveled to the clinic for urgent aid when the bleeding became uncontrollable.[41]

The novel chronicled the repeat hospitalizations one young girl required for the management of her disease. After the nosebleed had been stopped, Carol was readmitted to the hospital for a transfusion and a dose of cortisone to induce her first remission more quickly—the first of many emergency visits. She was housed in the Children's Pavilion—a separate place for children described by her father as, "a bedlam of colliding tricycles, bouncing balls, and shouts for nurses and the volunteer workers known as Bluejays, so named for the color of the uniforms in which they bustled about on non-medical errands," at the time of his first visit.[42] Although he dismissed the lively Bluejays as frivolous society women, Wanderhope credited them with contributing to the prevailing attitude that "Everything Was Fine" despite the presence of children with amputated limbs and massive bleeding.[43] A few days later, Scoville was unable to palpate Carol's spleen, a sign that her platelet count had improved through the cortisone treatment, and Carol returned home.

Wanderhope depended on Scoville's advice and Carol's regular outpatient visits to properly monitor her condition. As Carol cycled through a sequence of chemotherapeutic agents, she experienced side effects that signaled the activity of her treatment and, consequently, fluctuations in the severity of the leukemia. The steroid therapy increased Carol's appetite and required her to strictly adhere to a low-salt diet to prevent high blood pressure. She gained a significant amount of weight and became self-conscious both about her new body shape and the way her friends viewed the dramatic change.[44] At her next visit to the clinic, Carol was given 6-MP to help maintain her remission. The first doses of 6-MP raised concerns about a new set of side effects, including mouth sores, vomiting, and diarrhea that indicated the drug's toxicity. Wanderhope reported to Scoville that Carol's gums were painful and inflamed, but he dismissed the father's concerns, saying that it was best if she could remain on the "edge of toxicity" while maintaining a solid remission. Once a sternal puncture, a procedure to sample bone marrow, demonstrated that Carol had stabilized on the 6-MP, she was given a three-week interval before her next appointment. Six months after starting 6-MP therapy, Carol developed resistance to the drug, but she quickly responded to the next drug, methotrexate. After only three months on the new drug, though, Carol complained of chronic headaches and problems with her eyes.

The symptoms suggested that treatments had controlled the leukemia in

her blood system, but cells had continued to proliferate in the meninges, an area of the central nervous system where the drugs could not penetrate and a sanctuary for leukemic cells formed. Children like Carol, who experienced long remissions, risked the development of meningeal leukemia because layers of leukemic cells lined the membranes to constrict the movement of spinal fluid. Patients experienced headaches and changes in their vital signs as a result of the added spinal pressure, but they remained systemically in remission. Physicians used a lumbar puncture to detect leukemic cells in the spinal fluid and intrathecal injections to transfer massive doses of methotrexate directly into the space surrounding the spinal cord. This improved children's symptoms for a relatively brief period before relapse occurred.[45]

As Carol's body became resistant to methotrexate, she was hospitalized again for severe bleeding. Wanderhope described the uncomfortable cotton packing that extended from her nose into her throat to stop the blood flow. Carol bore obvious physical signs of her constant, invasive medical treatment, including scars on her hands from intravenous and transfusion needles and on her breast from a marrow aspiration. Using religious symbolism to compare his innocent daughter's suffering to that of the crucified Christ, Wanderhope referred to her injuries as "stigmata." The bleeding, open "stigmata" designated Carol as a sacrifice to the disease and to the goals of medical research. Her father felt helpless as he became a bystander to the unfolding events.

## *Debating Cancer Centers*

Like Emily De Vries and Carol in *The Blood of the Lamb,* many children were immediately referred to cancer centers by their pediatricians.[46] Despite the promotion of these centers by cancer specialists, proceedings from a one-day conference "Care of the Child with Cancer" illustrated the benefits and possible drawbacks of the facilities.[47] The November 1966 meeting was sponsored by the Association for Ambulatory Pediatric Services, an organization for directors of pediatric outpatient departments interested in promoting improved care, teaching, and research in pediatric ambulatory facilities, and the Children's Cancer Study Group A, physicians engaged in the cooperative clinical trials of chemotherapeutic agents under the direction of the National Cancer Institute. Participants critically evaluated the proper role of their home institutions. In addition to internal review and assessment, one convener noted, "We have much conviction but little knowledge about the feel-

ings of the medical consumers and the health professionals outside medical centers."[48]

Most of the participants agreed that specialized centers were the optimal site for treating childhood cancer patients, though there was dissention. Specialists like John R. Hartmann, director of the hematology and oncology division at the Children's Orthopedic Hospital and Medical Center in Seattle and chairman of the Children's Cancer Study Group A argued vehemently that it was worthwhile for pediatricians to refer their cancer patients to specialized cancer centers for advanced care, despite the debilitating effects of the treatment and the absence of permanent cures. His supporters argued that centers contained a multidisciplinary team who all contributed to the care of the patient and his family. But some challenged the utility of the center by suggesting that that the centers geographically isolated cancer patients and often divided the family between home and the institution. One participant used the term "fatherectomy" to describe the separation between the ill child and the mother from the father.[49] Another participant countered that parents felt more secure when their child was treated in a center with other children with leukemia or cancer, saying, "Many, many parents have said to me, 'I am glad I came to this center because here I feel the security of all the doctors interested in the field.'"[50]

Addressing these concerns, however, was futile if local pediatricians did not refer their patients to centers. Without a standardized system, care was provided in a variety of settings using different approaches. Charles J. A. Schulte of the U.S. Public Health Service said, "Less than a third of children who have leukemia are cared for by large institutions devoted to the care of patients with malignant diseases or by physicians involved in large cooperative studies."[51] The discussion regarding the proper relationship between the pediatrician and the cancer specialist exposed the emerging tensions between the two groups of physicians. One participant presented the views of a general pediatrician as, "How can I get rid of this patient? Nobody likes doctors who take care of dying kids; how can I unload this patient?"[52] Another reported that he had observed an attending physician bypass leukemia patients during rounds, explaining, "Well, it's a hematology patient."[53] Hartmann confirmed, "No one wants to take care of dying children by preference. Most of us have been hematologists (specialists in blood disorders) and have gotten into the field of oncology (cancer specialists) because of the therapeutic effects of chemotherapeutic agents, especially in children with leukemia."[54]

In short, Hartmann saw the new set of specialists as having a more positive, active orientation toward the treatment of this set of diseases.

The 1960s were a decade of transition for the patient with cancer and for the professional at the bedside. Many critics of chemotherapy remained. Surgeons and radiotherapists defended the traditional cancer treatments that they could offer, while others actively criticized the limited efficacy and harsh side effects of chemical therapies. In this setting, hematologists and a nascent group, medical oncologists, vied for control over this new treatment modality.[55] When they learned that chemical agents had induced temporary remissions in the leukemias and lymphomas, some hematologists began to refocus their work from problems of classical hematology—like the anemias and coagulations—to cancers of the blood and related tissues. Simultaneously, a small group of internists became interested in the application of chemical therapies to common solid tumors, like those of the breast, but when demonstrable gains in the treatment of solid tumors proved to be limited, they extended their reach to include all cancers. In their early organizational meetings, those promoting medical oncology defined the burgeoning medical subspecialty as devoted to the "total management" of all patients with cancer. They accepted full responsibility over coordinating surgical or radiation treatment, administering chemotherapy, rendering supportive care if complications occurred, and tracking patients from their initial diagnosis through cure or end-of-life care. The two professional groups staked a claim over the same patient population: the "unwanted patient" was now a contested patient.

Through a series of heated internal discussions and cross-disciplinary debates, each group defined its identity, training requirements, and targeted patients. Like cardiologists, both groups pursued (and gained) subspecialty status by building alliances with the American Board of Internal Medicine. It was hematologists, though, who perceived that they were gradually losing status to the emerging group. Medical oncologists (first unified under the banner of the American Society of Clinical Oncology in 1964) then compounded these concerns by initially proposing a plan that ensured complete separation between the two groups. After further consideration, they approved a compromise that recognized the value of joint training and certification in hematology-oncology. This specialist was uniquely prepared to cope with the challenges posed by a child diagnosed with leukemia now that multiple agents could be offered.

While the involvement of a specialist was key, the "best" case was described

as a cooperative partnership that formed when the primary physician continued treating the child with cancer under a center's direction. Denman Hammond, the head of the Division of Hematology at the Children's Hospital of Los Angeles, said that all of his patients were referred to the center, so there was always a primary physician involved in the case (although sometimes at great distance). He stated,

> We, in talking to the parents, make it very clear to them in the first interview that we are happy to try to give them complete care for leukemia but that the family physician is very important to them. We would hope that the child would be in remission for 80 or 90% of the course of leukemia. During this time, the child is going to have colds and infections with other pediatric problems they may have otherwise; and, appropriately, the family physician is the one who should take care of these problems.[56]

In this case, hematologists or oncologists acted as consultants who saw well patients every month or two and sick children during relapse or terminal care. A lack of regular communication and inadequate education were cited as two obstacles to maintaining a good working relationship between the primary physician and the specialist. One participant complained that there was an attitude conveyed by specialists that community physicians did not know enough about this "field of expertise" and that they should not be treating the patients. Hartmann suggested that by implementing an elective two- or three-month rotation for second-year pediatric residents to introduce them to protocol studies and available drugs, it would enable physicians at cancer centers to work with experienced physicians in outlying communities (though not always the referring doctor).[57]

Participants presented two studies, based on the Children's Hospital of Los Angeles and the Pacific Northwest Children's Cancer Center in Seattle, as evidence of the advantages conferred in specialized cancer centers. Data collected from the Children's Hospital of Los Angeles documented shifts in the location of patient care, specifically in the proportion of time that a leukemic child spent in the hospital during the course of his or her disease. "Prior to 1953, when we had no cooperative programs nor much in the way of chemotherapy," Hammond recalled, "the course of leukemia in children was rather short. The records indicated that about 30% of the course, from diagnosis to death, was spent as an inpatient in a hospital."[58] In the next period, 1953 to 1957, patients received more chemotherapy and transfusions. Median survival time increased to about a year, but the children spent only about 13 percent

of their illness in the hospital. In the most recent period, 1957 to 1963, median survival improved to about a year and a half, but the period of hospitalization dropped to 4.1 percent.[59] As the duration of the disease lengthened, there was a shift from treatment in the inpatient wards for the duration of the disease to ambulatory care during acute exacerbations.

The Pacific Northwest Children's Cancer Center, a referral service for children with malignant diseases from the Seattle metropolitan area and Alaska, also established outpatient clinics and many affiliated services to provide care. The hematology and oncology clinic had grown from one small room to a four-room outpatient clinic with four physicians to manage the intravenous medication, bone marrows, and blood transfusions previously provided by the hospital inpatient service.[60] Medical care was provided through a weekly tumor clinic, a daily hematology-oncology clinic, and a 24-hour a day on-call physician. An ambulatory transfusion clinic was conducted each morning, afternoon, and evening for children to receive transfusions, plasma, or platelets in an effort to keep children out of the hospital as much as possible. Children who needed to be admitted to the hospital for longer than six to eight hours to evaluate signs of toxicity or relapse and make major changes in therapy were admitted on a one-day service. However, the charges were reduced to a half to a third of the usual inpatient charge through a special arrangement with an insurance carrier. The National Cancer Institute also provided limited travel funds and support for children using outpatient services as part of cooperative protocol studies.

Finally, participants debated whether enrollment in cooperative studies constituted the best treatment for every child. Some offered that cooperative studies added to the knowledge of the disease through research and potentially contributed to the welfare of other leukemic children. They also provided solace for parents, since they could now view their child's life as ultimately purposeful, as helping another through their suffering. Despite these efforts, concerns arose regarding the conduct of the cooperative studies and their risk to the individual patient. At the National Cancer Institute, one major investigator received repeated criticism from his colleagues for not following proper FDA animal and toxicity trials before testing the experimental regimens on children.[61] Possible abuse was a major concern from inside and outside the medical profession. Also, the VAMP-type protocols required National Cancer Institute researchers to readmit children in complete remission to the hospital for additional experimental chemotherapeutic treatment cycles. These additional cycles—given to children who felt healthy—made

them feel extremely ill. While parental permission was required before submitting children to these risks, few had refused the experimental treatments at National Institutes of Health.[62] At the 1966 conference, Hartmann challenged his colleagues, "Is it morally and ethically right to treat a child who is in a terminal state of his disease with these compounds?"[63] He urged his listeners to weigh several factors when making their decision: the short remission gained by the patient, the patient's quality of life, and the benefits for other young sufferers. He insisted, "We must often and always reflect on whether or not this is the right thing to do. There is no other way to find out whether such agents are effective, but we must also look upon the child and the family group as individuals."[64] In the 1960s, the availability of increasingly complex, aggressive chemotherapy at a limited number of cancer centers and the life-threatening side effects that often accompanied combination treatment required physicians to carefully consider a calculus that weighed their scientific goals against those of each child and family coping with cancer and, at times, to rigorously defend their decisions.

## Death and Dying

In *Blood of the Lamb,* Wanderhope attempted to preserve many of the family's normal daily routines while accommodating the constant demands of his daughter's illness and treatment. Carol and her father continued to read, listen to music, and drink hot chocolate late in the evening before bed, but there were also perceptible changes around the house. Silence stifled any discussion of Carol's illness. At the time of Carol's diagnosis, Scoville had implied that a measure of privacy—perhaps even secrecy—about the disease was desirable, suggesting the name of a tutor who could aid Carol in her schoolwork who "won't talk" or "even ask any questions."[65] Later, he recommended that Wanderhope tell Carol that she had anemia because, "That's part of it, after all."[66] Wanderhope and the family's housekeeper, Mrs. Brodhag, were careful to hide the truth about the illness from the eleven-year-old girl, but he found it difficult not to spoil his daughter.[67] He showered Carol with gifts on her twelfth birthday, buying her a bicycle, half a dozen dresses, shoes, ballet leotards, books, jewelry, a doll, and an expensive tape recorder. Brodhag admonished him to limit the number of presents he purchased and to be less obvious about recording her piano playing. One evening, Wanderhope found Carol watching a documentary on cancer on television. The program showed Carol's physician, Dr. Scoville, examining a young boy in the pediatric cancer

clinic. The narrator announced, "The most fruitful source of study, and the best variation of the disease in which to try out certain new remedies, is that form in which it cruises in the bloodstreams of children under the name . . . "[68] Her father quickly diverted her attention away from the television program. Despite mounting evidence that suggested otherwise, Wanderhope and Brodhag tried to adopt the approach of the Children's Pavilion at home—to maintain the attitude that "Everything Was Fine."

Medical innovations had created a young patient population that included more children with chronic, prolonged, and fatal illnesses; however, only a few studies systematically investigated truth telling or death and dying in children before the late 1950s and 1960s. Truth telling to adult cancer patients was also under intense scrutiny at this time. In 1962, Lemuel Bowden, a physician at Memorial Hospital, editorialized, "It is absurd for a physician who has spent many years studying the science and practicing the art of medicine to discuss the diagnosis, methods of treatment, and the probable results of therapy in detail with a patient who, at best, can bring only rudimentary comprehension to the problem at hand."[69] For Bowden, news about incurable cancers should not be delivered to the patient, but sweeping changes in accepted practice and policy were already underway. A study published a decade later revealed that whereas 90 percent of doctors had not discussed diagnoses with patients in 1962, 90 percent reported that they now had adopted a frank approach.[70]

A similar debate played out in medical and psychosocial journals over truth telling to children of all ages and stages of development. In the 1950s, child psychologists Morris Green and Albert Solnit advocated open communication between the child, physician, and parent but did not favor truth telling in all cases.[71] Green cautioned physicians to carefully consider a child's age and developmental stage and noted, "A concept of death does not become established in most children until just before puberty or early in puberty."[72] Based on his own clinical experience, he found that children with fatal illness did not directly ask if they were going to die, but inevitably sensed what was happening to them or in their family. Green advocated an individualized approach to truth telling but also recommended that children's queries never be completely evaded.

In 1965, Joel Vernick, supervisor of the social work department at the National Cancer Institute Clinical Center, and Myron Karon, chief pediatrician of the medical branch of the National Cancer Institute, added their analysis to the growing body of medical literature. Their article about telling leukemic

children the truth about their disease—"Who's Afraid of Death on a Leukemia Ward?"—departed significantly from a number of previous authors who had recommended that diagnoses be kept from the child to protect them from unneeded anxiety.[73] Vernick and Karon gathered information from fifty-one children from nine to twenty years old who were hospitalized for acute leukemia at the National Cancer Institute. They collected data using "life space" interviews that enabled workers to focus on the actual events that concerned the child, such as an intravenous infusion or a pill.[74] They also organized weekly group sessions so that parents had a forum in which they could discuss their concerns with the senior staff—members of the staff who formulated long-term research goals, but were also interested in each individual child's case. Vernick and Karon found that these meetings usually began with medical matters but moved to emotional topics.

The authors concluded that the central question was "not whether to talk to the child about his serious concerns, but how to talk to him."[75] Lies temporarily deceived the child, but they also raised a child's anxiety and caused serious behavioral problems. The result was often irreparable damage to the parent-child relationship. In addition, the authors discovered that the sudden absence of the child and his or her name plate outside the room, the removal of equipment including the oxygen tent, the disconnection of the respirator, or the transfer of a child to a separate room in the middle of the night served as clear nonverbal cues to children that a death had occurred on the floor. Straightforward yet age-appropriate discussions with the children were needed.

The medical staff at the National Cancer Institute changed its policies in order to address issues of truth telling and death. Following a death, the first staff member to see other children discussed the event directly. To comfort other children, the staff member emphasized that the child who died was very ill (unlike others on the floor). "With the cooperation of the parents," Vernick and Karon wrote, "every child over the age of 9, and in some instances those even younger were told the diagnosis of their illness as soon as the presence of the disease had been verified."[76] Older patients, they suggested, should be informed about procedures or the course of treatment not for legal consent but to gain cooperation and understanding. Although the amount of shared information varied depending on the child's age, the authors emphasized open communication between physicians and other allied health workers on the cancer floor, parents, patients, and their siblings to abolish secrecy and invite dialogue about disease and death.[77] Karon and Vernick concluded that

the care of the fatally ill child was perceived as one of the most difficult tasks faced by physicians, because they were not properly trained for it in a medical curriculum focused on curing illness, not preparing for death and dying.

In September 1965, the editors of the *American Journal of the Diseases of Children* solicited a response to the Vernick and Karon article from Joseph H. Agranoff and Alvin M. Mauer, physicians from the Children's Hospital in Cincinnati, Ohio, who wrote, "only discussion and controversy can ultimately lead to progress."[78] Contesting the conclusion that older children with leukemia could and should be told the truth, the Cincinnati doctors suggested that the children in the original study were a special population not representative of all pediatric cancer patients. They pointed out that the children treated at the National Cancer Institute were hospitalized for relatively long periods of time on a special study ward reserved for children with acute leukemia. Children attended school in separate facilities provided by the National Institutes of Health and, when it was deemed medically permissible, children participated in weekly activities and outings in the Washington, D.C., area like swimming, trips to the zoo or museums, and White House tours.[79] Under these circumstances, children closely identified with other dying children, which made it nearly impossible to conceal the nature of acute leukemia.

Unlike the National Cancer Institute, children at the Cincinnati Children's Hospital were admitted to a general medical ward that contained patients with a variety of illness. Children with leukemia spent as much time as possible at home, were only admitted to the hospital during an acute phase of their illness, and made return visits to a hematology clinic—not a special leukemia or cancer clinic where they would only be exposed to other children who shared their diagnosis. Thus, deaths on the general ward were uncommon and children did not receive the same exposure to illness and death. Few children asked about their illnesses. They worried that applying Vernick and Karon's recommendations to children treated outside of the National Cancer Institute environment would increase anxiety and encourage families to rely on information about acute leukemia from sources outside the hospital. Agranoff and Mauer argued that their system at the Children's Hospital represented the prevailing care for children with acute leukemia and that this model dictated different policies. While agreeing that Vernick and Karon persuasively argued their position, the authors called for additional information gathering so that informed decisions could be made about the management of the child with leukemia cared for in the general medical center.[80]

In their rebuttal to the Cincinnati doctors' comments, Vernick and Karon

noted that similar concerns had hindered investigations about truth telling in the past. They acknowledged that their ward was not typical but claimed children's anxieties and perception of their environment were universal. It might be even more important to openly share information in a general ward, they argued, because such an environment deprived children of the opportunity to communicate easily with others suffering from the same disease.[81]

Despite this counterargument, Agranoff and Mauer's views resonated with other physicians. Henry F. Lee, a physician in the Chestnut Hill Pediatric Group in Philadelphia, wrote that his experience in a children's medical center and in the pediatric service of several general hospitals taught him that older children, except, perhaps, those treated in a specialized leukemia ward, should not be told the name or nature of their diagnosis. Lee wrote that most of his leukemia patients had been satisfied with his false or partial diagnoses. He told patients that they suffered from "an unusual form of arthritis" or a "big spleen," so they would be spared frightening articles or conversations about acute leukemia.[82] In his own practice, Lee preferred to keep the child at home as much as possible and to minimize medical interventions, saying, "I am certain that my recent leukemia patients are far *happier* than those I cared for earlier when driven by more need within myself to achieve a 'university-hospital-type' workup and therapy."[83] He nevertheless acknowledged that his community hospital approach was ill suited to making advances in the disease. Like the Cincinnati physicians, Lee agreed that the approach described by Vernick and Karon should not be applied to all settings. Alfred Hamady, a physician from Battle Creek, Michigan, agreed with many of Lee's arguments. He recognized the value of truth telling but gave precedence to ensuring the quality of the child's final days. He also expressed skepticism that the methods were widely applicable. "Most of the advice [about what to tell child with leukemia] is coming from 'large' centers in the form of generalizations based on 'controlled studies,' 'statistics,' and the like. How can the subject of impending death, as it relates to a child, be anything but a personal and intimate matter? How can controlled studies and statistics take into account the close, hour-to-hour relationship between the young patient, his playmate, his parents, and the attending physician?"[84] Instead, Hamady preferred that no standard practice for truth telling be established but, rather, that each case should be considered individually based on information exchanged through late-night phone calls from parents to physicians, from the child's teacher, home visits, and other conversations. He maintained that pre-

serving the positive aspects of the child's remaining life was at the foundation of his recommendations.[85]

The exchange printed in the pages of the *American Journal of the Diseases of Children* again demonstrated the vast ideological differences that existed among National Cancer Institute physician-researchers, physicians at specialized children's hospitals, and community doctors. Representatives from each group argued that their disparate treatment methods, aims, and outcomes necessitated a different truth-telling policy from the one recommended by Vernick and Karon and pitted the results of the National Cancer Institute study against personal experience, anecdotal evidence, and familiar practices. A single path did not prevail in the 1960s, but it was increasingly clear that parents had vital responsibilities and burdens as caretakers at all stages of treatment or disease.

Studies on the relationship between physicians, parents, and physicians generated standardized guidelines for cancer care in the 1960s.[86] In his research, Stanford Friedman, senior instructor in pediatrics and psychiatry at the University of Rochester Medical Center, charted modifications in parental behavior toward acute leukemia and the threat of death as the face of the disease changed from the 1940s through the 1960s.[87] Friedman found that most parents seemed to suspect the seriousness of diagnosis before hearing it from the physician and hypothesized, "This probably reflects the relative sophistication of the general population regarding medical matters, particularly about diseases that are associated with various fund drives."[88] Parents also combed newspapers, magazines, and medical texts for answers to their questions, especially about etiology. To remedy any misinformation or confusion from other sources, he urged physicians to distribute the National Cancer Institute publication "Childhood Leukemia: A Pamphlet for Parents" as a dependable source.[89] Pamphlets, however, could not possibly prepare parents for the challenges that arose.

By systematically studying behavior and physical indicators of stress, Friedman and his team monitored forty-six parents of children with fatal, neoplastic disease (primarily leukemia) while the children were being treated at the National Cancer Institute. They quantified parents' responses to events during their child's illness in order to determine the primary stressors. For example, as chemotherapeutic regimens began to reliably induce lengthy remissions—a long period when their children were apparently restored to health—parents remained in denial longer. A child's first medical relapse of-

ten represented the first time his parents were confronted with the reality of his disease. The sudden downturn provided a powerful visible reminder that the child suffered from a critical illness, and parents commonly experienced a major crisis at the time of this event. The longer life produced by chemotherapeutic agents also lessened parents' grief at the time of death by giving them more time for anticipatory grief. However, Friedman advised physicians to contact parents in the months after a child's death to provide an opportunity to discuss the illness and death again.

Friedman also drew more general conclusions. Weekly interviews, ward observations by the psychiatrists and nurses, and data from a regular parental discussion group revealed that the parents—classified as mostly lower and middle income, predominantly white and Protestant, and from both urban and rural locations—maintained relationships, preserved their own personalities, and carried out necessary tasks during their child's period of illness. Significantly, the authors detected an overall pattern of coping strategies, defenses, and searches for meaning in their child's illness and death that illustrated a common "natural history" or sequence of adaptational techniques employed by the group that allowed hospital staff to implement additional services like support groups or individual counseling for the parents of children cared for in leukemia wards or clinics.

Studies by Friedman and others suggested certain behavioral patterns among parents of leukemic children at the National Cancer Institute, but characters in *The Blood of the Lamb* illustrated the myriad variations possible in parents' approach to the disease. De Vries created a vocal mother in his novel, an obese woman clad in a rumpled housedress who chain-smoked cigarettes as she paced the halls of the children's cancer ward. A short, darkly comedic monologue suggested her lack of understanding about the disease:

> "Boy, dis place," she said. "When me and my little girl come in here, she di'n't have nuttin' but leukemia. Now she's got ammonia." I listened, unbelieving. "Ammonia. Dat's serious. She's in a oxygen tent, and I can't smoke there. It's a tough break for her because, like I say, at first she di'n't have nuttin' but a touch of leukemia. I don't believe I ever hear of dat before. What is it?"[90]

The woman's daughter died of pneumonia soon afterwards. Other parents in the book clearly understood the stages of acute leukemia and became grief-stricken as their children's lives neared their ends. Wanderhope watched one father's frustration escalate into a physical struggle with a cancer specialist after he received the news that all of the therapeutic options had been ex-

hausted in his child's care.[91] A third parent, a mother who had seemed outwardly staid to the other parents visiting the ward, unexpectedly confided her worries to Wanderhope in the middle of the night as they rested near their children's bedsides. Mistaking Wanderhope's late-night laughter for stifled cries of despair, she divulged that the demands of her daughter's illness had rendered communication with her husband nearly impossible. She welcomed the opportunity to talk to another parent on the ward who could fully understand and relate to her concerns.[92]

The reader could gain insight into Wanderhope's personal experience of his daughter's illness through two intertwined themes—his depiction of Scoville and medical science, more generally, and his inner debates about religion. From Carol's diagnosis to her death, Wanderhope viewed medicine with both respect and skepticism. At times, Wanderhope gained optimism from Scoville's inexorable scientific curiosity, his single-minded dedication to his profession, and his aggressive approach toward the medical management of acute leukemia. At the end of Carol's first hospital stay, De Vries depicted Scoville as virtually superhuman. Wanderhope noted,

> When I saw him enter the ward on the third afternoon he looked sixty years old, rumpled and unshaven, scarcely able to hold the dispatch case he was dragging in one hand. He had flown to five cities in a series of research conferences, with a dash to Washington to bludgeon loose some funds for an experimental drug costing fifteen thousand dollars a pound, and he had not slept in a bed, he told us cheerfully at the foot of Carol's, for thirty-six hours.[93]

But Scoville's positive outlook was tempered by cynicism from parents who had already seen their child alternate between remission and relapse. In the early stages of Carol's illness, as Scoville lauded the chemotherapeutic agents developed during the past ten years, one father noted, "So death by leukemia is now a local instead of an express. Same run, only a few more stops. But that's medicine, the art of prolonging disease."[94] As his daughter's condition worsened, Wanderhope adopted some of this rhetoric. He likened the doctors' white coats to "butcher's coats" and said that they were worn as they "merely hounded the culprit from organ to organ till nothing remained over which to practice their art: the art of prolonging sickness."[95] As Carol alternated between relapse and remission, sickness and health, the hospital and home, Wanderhope's hope only wavered intermittently, but his faith in a benevolent God and the miraculous power of St. Jude, the saint of hopeless causes, completely faltered.

In *The Blood of the Lamb,* a final burst of rigorous, experimental treatment

marked the final phase of Carol's cancer therapy. After Carol became resistant to methotrexate, Scoville prescribed a second course of steroids. Because steroids were less effective when administered the second time, he supplemented them with an experimental drug that had induced shown short-term activity in preliminary cooperative clinical trial results. Before her next marrow count, the drugs had begun to successfully kill Carol's most quickly replicating cells. Thus, she began losing her hair (alopecia) and contracted an infection when her healthy white cell count fell. She received broad-spectrum antibiotics and was readmitted to the hospital as a precaution, but, fortunately, a bone marrow test showed that she had again achieved a full remission. On his way to the hospital to celebrate the remission with Carol, Wanderhope briefly stopped into a church near the hospital, a routine that he had developed during his daughter's illness. In the pews of the church, another parent informed him that an infection had swept the ward and that half of the children had been placed in oxygen tents and on antibiotics to guard them against the threat. Wanderhope rushed to the children's ward with hope that his daughter had been spared from the outbreak. Tragically, the infection had already ravaged Carol's vulnerable system and covered her lower body in discolorations from the blood poisoning. Unable to treat the rampant infection, Scoville advised the grieving father to allow him to halt all life-saving measures and use morphine to lessen the child's pain. Carol died within hours.

*The Blood of the Lamb* reflected the experiences of Emily and Peter De Vries through the lenses of Carol and Don Wanderhope. Although the novel was a fictionalized account of the DeVries's experiences, the two well-developed characters provided valuable insight into patient and family experiences during a critical decade of incremental developments in acute leukemia research and therapy. This was especially valuable for a period in which few parents spoke publicly about their experiences in an extended form. The novel and the conference proceedings from "Care of the Child with Cancer" offered two complementary sources for analyzing changes in medicine that contributed to a growing distance and distrust between the physician and the patient in the 1960s and 1970s. The Wanderhopes received Carol's diagnosis at a home visit from their family physician, a rarity in the 1960s. After this point, she was regularly treated in a specialized hospital away from her home. Wanderhope initially respected Scoville's expertise and welcomed the inclusion of experimental therapies in his daughter's care. During Carol's last crisis, though, Wanderhope questioned the promises of medical science and his religious

faith. He referred to leukemia as the "Slaughter of the Innocents" and asked, "Who creates a perfect blossom to crush it? Children dying in this building, mice in the next."[96] Parents labored under the struggles presented by acute leukemia—its devastating effect on their child's health, its ability to erode hope at a time of incomplete cures, its threat to the stability of marriage and family, and its fundamental challenges to their beliefs and values.

At the time of Carol's death, chemotherapeutic agents prolonged children's lives, but "cures" of acute leukemia were viewed as miracles. In a well-publicized example, *Life* magazine published a two-page story on Mother Elizabeth Ann Bayley Seton, the first native-born American likely to achieve sainthood.[97] After Seton's conversion to Catholicism in 1805, she founded the Sisters of Charity, America's first society of nuns, and aided in the establishment of the United States parochial school system. In 1963, two American cardinals, members of the Daughters of Charity, and thousands of other religious pilgrims traveled to St. Peter's Basilica in Rome for a ceremony that recognized two cancer cures "as the direct and miraculous result of prayers to her."[98] One of the cured cancer sufferers was fifteen-year-old Ann O'Neil, a leukemia survivor who traveled to Rome from Baltimore, Maryland, to observe the beatification proceedings. A study published in 1951, one year before O'Neil's diagnosis, reported that only three of 150 child and adult patients with acute leukemia at Memorial survived more than a year, and all died within fourteen months.[99]

By the mid-1960s, the few acute leukemia survivors were no longer only those healed by "spontaneous cures" or religious miracles. In 1964, Burchenal was able to present dozens of cases of long-term acute leukemia survivors (children and adults) who had been off therapy for at least a year and were living with no evidence of disease.[100] Burchenal gathered these cases by surveying hematologists from around the world and recording the data in the Acute Leukemia Long-term Survival Registry of the Acute Leukemia Task Force. Although he estimated that they represented only between 0.1 and 1 percent of all cases, the statistics provided solid evidence that long-term survival was possible by combining chemotherapeutic agents and providing adequate supportive therapy.[101] Burchenal boldly predicted that these results suggested the eventual control of acute leukemia, a childhood killer. News of long-term survival in acute leukemia supported the proposed goals of the "War on Cancer"—a large, federally funded program against cancer declared in 1971 that targeted the rapid elucidation of effective therapies and cures for the dread disease.