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A

THE LANGUAGE OF LOSS:
COMMUNICATION BETWEEN DYING CHILDREN AND THEIR PARENTS

by

MARGARET M. SPIER

A dissertation submitted to the Graduate Faculty in Psychology
in partial fulfillment of the requirements for the degree of Doctor
of Philosophy, The City University of New York.

1999

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This manuscript has been read and accepted for the Graduate Faculty in Psychology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

7/15/99
Date

David J. Bearison, Ph.D.
Chair of Examining Committee

7/28/99
Date

Joseph A. Glick, Ph.D.
Executive Officer

Steven B. Tuber, Ph.D.

Laurence J. Gould, Ph.D.

N. Mendie Cohn, Ph.D.

Linda Granowetter, M.D.

Supervisory Committee

THE CITY UNIVERSITY OF NEW YORK

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Abstract

The Language of Loss: Communication Between Dying Children and Their Parents

by

Margaret M. Spier

Adviser: Professor David J. Bearison

Since the 1970s there has been a movement to facilitate open communication regarding diagnosis, treatment, and prognosis with children who have cancer. Previous research findings have suggested that children as young as four may have an awareness of the serious nature of their disease. Offering discussion in an age-appropriate manner can help these children alleviate feelings of anxiety, depression, and isolation. Still, little is known about how open communication policies have affected parent/child discourse about death and dying.

The present study was a prospective, phenomenological exploration of communication between dying children and their parents. The objectives of the study were to capture the subjective experience of both children and parents and to examine barriers to communication.

A case study design, utilizing qualitative interviews and participant observation, was used. Six adolescents, who had a projected one year life expectancy estimated at less than 25%, and their parent(s), were recruited to participate in weekly interviews. Open-ended interviews were conducted over a period of time ranging from two to six months. Over the course of the study, four of the six children died.

Transcripts of all interviews were analyzed for thematic content. Analysis of the narratives indicates that: 1. Children with cancer do think about dying, and children who are dying are aware that they are doing so. The degree to which they

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want to express their thoughts and feelings about dying, however, varies considerably and is intricately connected with systems of psychological defense. 2. Patterns of communication and defense remain relatively stable over the course of the illness--and do not change markedly as death approaches. 3. Although communication about dying does occur, parents and children both engage in a form of mutual pretense regarding their emotional experiences. 4. Life-threatening illness continues to be accompanied by psychological isolation. However, the period of dying is not marked by the withdrawal of the dying child and/or his or her parent(s). 5. Issues related to the conception of self represent one of the major challenges for the sick and/or dying child.

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Love and death are the great gifts that are given to us. Most often they are passed on unopened.

Rainer Maria Rilke

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Acknowledgments

Saying good-bye is difficult. Having written these acknowledgments in fantasy so many times during the last few years, I now find that the joy and excitement that I had imagined are mingled with a sense of sadness. While the relationships I have made during these graduate school years will endure, this project, which has been such an integral part of my psychic life, is now finished. That this work has been such a deeply meaningful experience is due, in part, to the many people who shared in the process.

I was fortunate to have a dissertation committee in which every member made a significant contribution. Sometimes in life we find people whose thinking complements our own yet who also challenge us to move in new directions. David Bearison, the chair of the committee, has played such a role for me. It was David who suggested that I work not only with sick children but with those who were dying. Although I was initially panicked by the idea, he allowed me the time and space to discover that this work was exactly what I wanted to do, the place I most wanted to be. His passion and knowledge about the psychological aspects of death and dying have been inspiring. In addition, his interest in the writing was a delight. I relished the chance to talk about ideas but also to debate word choice, punctuation, and voice.

As the director of the clinical program, and one of my first professors, Steve Tuber has helped shaped my development as a clinician. His clinical acuity and thoughtfulness added enormously to my thinking about the cases reflected in this study. Throughout my graduate school career I have relied on Steve's belief in the value of this work. And Steve has the uncanny ability to find the precise word that captures an idea with which I am struggling. This gift allowed me to experience my own thinking with breathtaking clarity.

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It was in conversations with Larry Gould that the focus of the topic shifted from the experience of the dying child to that of parent/child dialogue. This more complex and clinically useful conceptualization enriched the project in ways both intellectual and emotional.

During my internship year at Kings County Hospital, I began conducting psychotherapy with dying adolescents. Mendie Cohn, the director of the internship, offered me an extra hour of supervision each week just for these cases. When I found myself overwhelmed by the emotional demands of this project, she once again volunteered her time to help me gain some perspective on the clinical material as well as to process my own feelings. Mendie's generosity and her capacity to hold my anger, confusion, and grief have made her not only a valued colleague but a true friend.

Linda Granowetter provided me with my first exposure to working with children with cancer. Her dedication to the psychological as well as physical care of children with cancer serves as a model to which all physicians should aspire. The entire committee created the atmosphere for an oral defense resonant with intellectual and personal meaning. I am thankful for the provision of what was one of the most satisfying experiences of my life.

Given the sensitive nature of the research interviews, I was initially concerned about gaining hospital review board approval. Linda Granowetter and Scott Miller not only championed the research but shared their medical expertise and their compassion. Scott's openness to my presence on the pediatric unit, and his including me in so many aspects of treatment, afforded me invaluable opportunities for learning. And his humor and easy friendship were much appreciated. I also thank Veronica Jones, Brenda Jenkins, Maureen Walsh, Laurel Whitaker, and Jennifer Caesar for offering their professional and personal insights and welcoming me into their community.

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Turning over my writing to someone else is like handing them my soul. I thank Didi Charney, Jeannie Blaustein, and Daniel Rothstein for the care they took with these pages. The readability of this work was greatly enhanced by the eagle editorial eye of Didi, my friend, neighbor, and copy editor nonpareil. Jeannie and Daniel also read the manuscript in draft form and provided the encouraging feedback that helped me look forward to the defense with eager anticipation.

While the dissertation is the final product of graduate school, it is the sustenance of family and friends throughout the years of study which provides the environment necessary to reach that goal. For many years my life has been graced by the warm presence of Renee Schlesinger. My dissertation group, Sophie Giovanola and Elisabeth Moss, created a place to vent, to expound, to share meals, and, ultimately, to succeed. I have been blessed with the friendship of Jeannie Blaustein, Sara Palmer, Carol Pepper, Melissa Ritter, and Daniel Rothstein. Rob Festinger has provided antic comic relief, incisive movie criticism, impassioned conversation about writing, and, above all, empathy. There is no life without music and I have treasured the companionship of Ken Rabb, my opera mate and fellow Handel aficionado. Bob Murray, friend and family for so many years, has been with me through my many metamorphoses: dancer, librarian, editor, triathlete, and graduate student. His steadfast belief in me has provided a constant base from which to venture. I would be lost without the love of my sisters Betsy Johnson and Jenny Hansen. They have supported me in ways both tangible and intangible throughout our adult lives. Betsy's unfailing good cheer has been a light in my life. And Jenny, so much like me and yet so different, continues to demonstrate the degree to which intimacy grows even with those we have known the longest. Greg Hansen has provided a second home for me and shown that a brother-in-law can be as close as a brother. Norma, Callie, and Martha Hansen made me a Hansen too. I have cherished their love and the many memories I have

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of "our" family. Finally, my grateful thanks to Esther Tooke, cousin and kindred spirit, who in seeing my mother in me provides me with a living link to her.

This dissertation was made possible by the children and parents who so willingly shared their love and pain with me. I am indebted to them for allowing me into their lives at such an intimate time. I will carry them with me always.

The dissertation topics we choose often reveal much about the deepest experiences of our lives. This dissertation about love and loss was motivated by the death of my parents almost thirty years ago. Through this work I have been connected to them in a special way over these last years. Not that this connection was always conscious and certainly not that it is the only way in which their presence was sustained. Yet I cannot help feeling that in completing this work I am in some way saying good-bye to them once again. If I am in any way sensitive to those who are about to lose that most precious of all gifts, life, it is because of both the love my mother and father gave me while they lived and the loss I have felt since they died. It is to their memory that this dissertation is dedicated.

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Introduction

> A story is told of the great Tibetan teacher Marpa, who lived on a farm with his family a thousand years ago. On the farm, there also lived many monks who came to study with this great teacher. One day Marpa's oldest son was killed. Marpa was grieving deeply when one of the monks came to him and said, "I don't understand. You teach us that all is an illusion. Yet you are crying. If all is an illusion, then why do you grieve so deeply?" Marpa replied, "Indeed, everything is an illusion. And the death of a child is the greatest of these illusions." (Levine, 1982, p. 87)

In late 20th-century America, as in Marpa's time, the death of a child causes special sorrow. Such a death has been called "one of the outrages of nature. . . . Instead of mastery, there is failure. Instead of growth, there is wasting. Instead of joy, there is grief" (Schowalter, 1970, p. 51). Waechter speaks of the "unfulfilled promise and destroyed hopes" that accompany the death of a child (1971, p. 1,168). In a society oriented toward achievement, autonomy, and the future, the death of a child reminds us of what has been missed rather than what has been accomplished, what will never be rather than what has already been.

I have found that many people have a visceral reaction to the topic of terminal illness in children. The response is a shudder, a look of horror, or an urgent desire to change the subject. Whether the reason for such discomfort is identification with the loss of one's own child, a sense of personal failure at not being able to protect children from fatal illness, identification with the child within us, or facing our own mortality, the result is retreat. What we cannot accept we have difficulty thinking of; what we cannot think of we cannot discuss. What remains is silence.

Currently, there is a growing movement to reawaken us to the needs of the dying, to increase both awareness and communication. The growing acceptance of

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hospice in the United States is but one sign of this desire to bring dignity and compassion to the process of dying, to focus on *living* even while dying.

But how did this conspiracy of silence evolve? Many factors converge to create the communication problems faced by terminally ill children and their parents. Yet these problems exist within the context of a more pervasive societal problem that is grounded in our fear of death. To gain a broader perspective on the specific difficulties faced by both parent and child, it will be useful to look at the evolution of Western civilization's denial of death.

The fear of death is, perhaps, our most private and primitive of fears. In his Pulitzer Prize-winning book, *The Denial of Death,* Ernest Becker (1973, p. 11) states: "Of all things that move man one of the principal ones is his terror of death." We worry about pain and suffering, about separation and loss, about facing what is unknown, about nonexistence. Some believe this fear is innate--that man always experienced such terror. If so, by what means has he sought mastery of it?

Phillipe Aries (1981) traces the progression of Western, particularly Christian, attitudes toward death in his masterful history *The Hour of Our Death.* He has found four psychological themes that govern our relationship with death: awareness of the individual, defense of society against untamed nature, belief in an afterlife, and belief in the existence of evil.

The tame death was the prevalent model throughout the Middle Ages. Death was common, ordinary, and expected. The dying person was aware of his or her imminent death and accepted such knowledge calmly, guided by ritual. Such ritual served as a defense system against the unpredictability and violence of nature. There were two characteristics of this death: the common acts of "the confession of sins, pardon of the survivors, pious dispositions on their behalf, the commendation of one's soul to God, the choice of burial" (p. 18); and the public

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aspect, as the dying person was surrounded by others. Death was frightening, yet it was accepted as a necessity. However, belief in an afterlife, death as the natural consequence of evil, and, for Christians, resurrection helped ease the sting of death. The unknown quality of the beyond brought relief, not anxiety, for eternity was imagined as an extension of life, a period of rest and waiting. Equally important was the location of the dying person in the center of an extended community--the belief that one's life was not unique but representative of a common destiny.

By the late Middle Ages, a subtle shift had begun. The rise of a monied class, which had increasing literacy, leisure time, and material comforts, created both a growing attachment to the pleasures of life and a reluctance to relinquish such goods at death. The belief in an immortal soul offered some consolation for the loss of life, but only if the soul could be guaranteed a place in paradise. The *artes moriendi*, treatises on dying well, appeared during the 1300s and were designed to guide the dying through a Last Judgment, which occurred at the hour of death. With the fate of the soul in the balance, the importance of the actual moment of death increased. Imbued with great drama, the deathbed was no longer commonplace. Physical death also took on new meaning, as now the soul was believed to depart directly for the beyond rather than remaining at rest with the body. The dead body became frightening and was covered with a shroud or hidden in a box. Already death had begun to lose its familiar quality.

During the Renaissance, the rise of a philosophy of dualism, with its emphasis on the separate but interacting qualities of body and soul as what is uniquely human, created a new metaphor for death: the sorrow of a broken friendship. The true pain of death came not in the final moments but in the ongoing realization that this important part of the self, the body, would be left behind. What then became

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essential in the 16th and 17th centuries was preparation for death throughout one's life.

Concurrent with this development was the increasing awareness of the self as individual and unique; the sense that what was lost at death was not just *a* life but *one's* life. As awareness of, and attachment to, the self increased, there was a newfound desire to perpetuate one's identity after death; the soul became the seat of personality. As Aries states: "The sense of one's own identity prevailed over submission to the collective destiny" (p. 605). Still, Aries posits that until the 18th century:

> Incredible as it may seem, human beings have never really known the fear of death. Of course, they were afraid to die; they felt sad about it, and they said so calmly. But this is precisely the point: Their anxiety never crossed the threshold into the unspeakable, the inexpressible. It was translated into soothing words and channeled into familiar rites. People paid attention to death. Death was a serious matter, not to be taken lightly, a dramatic moment in life, grave and formidable, but not so formidable that they were tempted to push it out of sight, run away from it and act as if it did not exist. (p. 405)

What occurred in the 18th century was a shift in man's relationship to nature and the beginning of what Aries describes as a "revolution of feeling." The age of science brought the promise of mastery over nature and a lessening of the rituals created to control its savagery. With this new sense of freedom, what had previously been the province of poets and artists--imagination--invaded daily life in ways that were conscious and expressed. One way imagination and feeling revealed themselves was in a common fear, that of being buried alive.

By the beginning of the 19th century, the environment was ripe for an increasingly conscious and shared fear of death. But before we discuss the current climate of denial, our relationship with death takes one more detour: the beautiful death.

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The fabric of society began to change as the value placed on autonomy, individuality, and privacy grew. Not only was there a change in the dimension of feeling, there was a change in the object of our emotions.

> In our former, traditional societies, affectivity was distributed among a greater number of individuals rather than limited to the members of the conjugal family. It was extended to ever-widening circles and diluted. . . . Beginning in the 18th century, affectivity was, from childhood, concentrated on a few individuals, who became exceptional, irreplaceable, and inseparable. (Aries, 1981, p. 472)

As the importance of those people central to our lives crescendoed, a new way of diminishing the fear of death evolved. Death became not the end of a relationship in this life but the promise of a reunion in the afterlife. The survivor experienced grief. However, it was a grief tempered by the possibility of everlasting union with loved objects after death. This romantic perception of death can be found in the works of both Emily and Charlotte Bronte.

In Emily's *Wuthering Heights,* Heathcliff and Cathy share a love that cannot be extinguished. She continues to come to him after her death in the form of a spirit, thereby soothing him. "A sudden sense of relief flowed from my heart through every limb. I relinquished my labour of agony, and turned consoled at once: unspeakably consoled" (Bronte, 1983, p. 321).

Charlotte describes the peaceful or beautiful death of this period in *Jane Eyre.* Young Helen Burns lies dying of consumption, yet says to Jane, "I am very happy Jane; and when you hear that I am dead, you must be sure and not grieve: there is nothing to grieve about. We all must die one day, and the illness which is removing me is not painful; it is gentle and gradual" (Bronte, 1942, p. 73).

This is the same romantic depiction of tuberculosis that Susan Sontag explicates in *Illness as Metaphor.* She describes the symbolism of TB as "the sign of a superior nature, as a becoming frailty," and as a "distortion" in the service of

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expressing "romantic attitudes about the self" (Sontag, 1977, p. 35). Aries believes this romantic upsurge, the idea of the dead or dying as beautiful, served another purpose: "This death is no longer death, it is an illusion of art. Death has started to hide. Death is concealing itself under the mask of beauty" (Aries, 1981, p. 473).

The dying were surrounded now not by an entire community but by a shrinking circle of family and friends. The family was in attendance to say good-bye, yet a new problem had developed: There was a reluctance regarding the warning of death. Aries attributes this holding back to a "love of the other, the fear of hurting him and depriving him of hope, the temptation to protect him by leaving him in ignorance of his imminent end. No one questions the idea that he ought to know, yet no one wants to do the dirty work himself" (p. 561). The dying person's awareness of death had not changed since the age of the tame death, when death gave warning of it's approach. What had changed was the reluctance of both the family and the dying person to publicly accept such signs. The beginning of a silencing of death would grow during the late 19th century and peak by the mid-20th century.

One can see this shift reflected in the literature of the period. Communication between the dying person and the family had deteriorated by the time Tolstoy wrote his short story "The Three Deaths" in 1859. The wife of a rich businessman is dying of tuberculosis. Although everyone in the family, including the servants, is aware of her condition, a carefully constructed illusion is created to avoid the truth. She is in the process of traveling to a southern climate to improve her health, a journey that is useless. Her husband refuses to tell her about her condition on the grounds that "to tell her about her own condition would kill her. . . . Come what may, I can't tell her that" (p. 46). Rather quickly, the journey is abandoned due to the woman's weakness, yet she continues to live in a world

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where the deception about her illness is maintained. Eventually, when a relative is enlisted to tell the dying woman the truth, we discover that she already knows: "Don't treat me like a child. . . . I know it all. I know I don't have long to live" (p. 51).

The isolation of the dying is even more complete by 1886 when Tolstoy writes his classic novella *The Death of Ivan Ilyich*. Here is a description of the fear and dread surrounding terminal illness that is recognizable today. The family and dying man not only fail to discuss his terminal condition, but they keep such knowledge away from themselves. It is as if the realization of impending death is too much to bear. Ilyich struggles with the meaning of his symptoms, but not until shortly before his death does he recognize, and accept, that he is dying. His family deny the fact for even longer. Absorbed in their own lives, they find his irritability and anxiety annoying, and leave him alone with his physical and psychological pain.

Ilyich turns to a succession of increasingly famous physicians for help. In fact, in this novella, the changing role of the physician vis-a-vis death is illustrated. Previously, the doctor's role was to herald the arrival of death and provide comfort and palliative care. In *The Death of Ivan Ilyich*, the doctor is now the person who can diagnose and, therefore, cure. To him Ivan entrusts his future, yet the doctor will disclose neither a clear diagnosis nor a prognosis. Abandoned by all but a faithful servant, who does not share the same distaste for the physical aspects of illness as the family does, Ilyich is left alone with his torment until his final hours: "During the last days of the isolation in which he lived, lying on the sofa with his face to the wall, isolation in the midst of a populous city among numerous friends and relatives, an isolation that could not have been greater anywhere, either in the depths of the sea or the bowels of the earth--during the last days of that terrible isolation, Ivan Ilyich lived only with memories of the past" (Tolstoy, 1981, p.

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122). Finally, three days before his death, the family acknowledges that Ilyich is dying. There is time for final farewells and for Ilyich to accept his imminent death: "He searched for his accustomed fear of death and could not find it. Where was death? What death? There was no fear because there was no death. Instead of death there was light" (p. 133).

There, in the late 19th century, is a death that presages our current attitudes: the isolation of the dying person, the concealment of death behind illness, and the indecency of death. The stage is set for the "hidden death, hidden because it is ugly and dirty" (Aries, 1981, p. 568).

At this time, advances in public health, medical science, and technology occurred, which led to the medicalization of death. Death became equated with disease, and the potential grew for controlling and curing disease. Once accepted as unfortunate but necessary, death now seemed unnatural--if not avoidable, at least capable of postponement. As Freud commented in 1915: "Our habit is to lay stress on the fortuitous causation of the death--accident, disease, infection . . . in this way we betray our endeavor to modify the significance of death from a necessity to an accident" (p. 305).

And with the new emphasis on hygiene came a distaste for death. "Our senses no longer tolerate the sights and smells that in the early nineteenth century were a part of daily life, along with suffering and illness" (Aries, 1981, p. 570). Modern treatment of disease also required technology available only in hospitals. From the mid-1900s on, many of the terminally ill would spend their final days in the hospital rather than at home, further distancing society from the presence of death. The burden of care had been transferred from the family to a professional staff. Today this trend continues; many of us are no longer present at the death of a loved one.

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Another essential change had occurred by the mid-20th century. When communities were smaller, there was a pause for each death. Death interrupted the flow of life, and time was taken to mark the break. But by the middle of this century, the loss of one member had a lessened impact on society's continuity, and the passing was not as public. Mourning became limited and private as society became less tolerant of public displays of emotion. Aries states: "The period of mourning is no longer marked by the silence of the bereaved amid a solicitous and indiscreet entourage, but by the silence of the entourage. The telephone does not ring. The bereaved is in quarantine" (p. 580). Painful, indecent, frightening: Death must be obliterated from consciousness.

Parallel with the rise of mass society came the rise of mass destruction, yet another reason to increase our psychological defenses. This attitude is captured by Freud (1950b) in "Thoughts on War and Death":

> We were of course prepared to maintain that death was the necessary outcome of life, that everyone owes a debt to Nature and must expect to pay the reckoning--in short, that death was natural, undeniable and unavoidable. In reality, however, we were accustomed to behave as if it were otherwise. We displayed an unmistakable tendency to "shelve" death, to eliminate it from life. (p. 304)

Freud attributed this denial in part to "the assertion that at bottom no one believes in his own death, or to put the same thing in another way, in the unconscious every one of us is convinced of his own immortality" (1950b, p. 305). Aries adds to this picture by contrasting phenomena before and after the 1800s:

> In the first place, all the available affection of each individual was not concentrated on a very small number of heads, as in the nuclear family, but was divided among a more extended group of relatives and friends. The death of one person, even one of the closest of this group, did not destroy one's whole emotional life; substitutions were still possible. Finally, death was never the complete surprise it became in the nineteenth century, before the spectacular advances in longevity. It was one of the risks of daily life. From childhood,

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> one more or less expected it. (p. 582)

Lengthening life span, advances in medicine and public health, technological developments, the loss of community, and the privatization of the self have all converged to create a world where death is no longer expected, viewed as natural, or made public. The invisibility of death only deepens our fear. While the removal of death from social discourse protects those of us who live on from facing our fear of death, it also increases the very mystery and unspeakableness that fuel our anxiety and despair.

This modern death impacts on society, but more important, it affects the individual. Isolated in the hospital, dependent on machines, cloaked in an atmosphere of silence, we are left alone with our fear. Kastenbaum (1977), a thanatologist who has worked for decades to bring issues of death and dying into public awareness states that "the paradox in much of our current treatment is that at the very moment we enhance attention to the patient's physiological needs, we isolate the patient psychologically and socially" (p. 7).

When Elisabeth Kübler-Ross began her groundbreaking seminars with the dying in the late 1960s, she had difficulty obtaining patients. The physicians she approached for permission to interview terminally ill patients looked at her with "stunned looks of disbelief" or abruptly changed the topic. One nurse "angrily asked in utter disbelief if I enjoyed telling a twenty-year-old man that he had a couple of weeks to live! She walked away before I could tell her more about our plans," yet, "when we finally had a patient he welcomed me with open arms. He invited me to sit down and it was obvious that he was eager to speak" (Kübler-Ross, 1969, p. 36).

Much has been written about the physician's sense of failure when a patient dies. In the instance just referred to, the staff were trying to protect the dying patient from an encounter that, apparently, was far more traumatic for them.

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Withholding disclosure and curtailing discussion about illness is one way to assuage the sense of failure for the physician--and to mediate anxiety and discomfort for family and friends. Yet, though we have moved far from the period of the *artes moriendi,* there is still a desire for dignity, for maintaining quality of life while dying. If we cannot be guaranteed a *good* death, perhaps we can at least be assured of experiencing *our* death, in whatever form that may take. In order to own the experience of dying, we must be aware that we are going to die. Kastenbaum (1977) writes:

> I find it perplexing that so many professional colleagues feel that truth and hope are mutually exclusive. Truth can be cold and cruel but it can also be gentle and merciful. Deceiving, disavowal, and raw confrontation are not the only options in speaking about death. If I were to act in light of what I know about psychology and responsibility I would follow the policy of first informing adult patients about their diagnosis and treatment plan and they would then decide what to tell the family. . . . The will, wishes, and integrity of the person would be *sine qua non* in any decision making about the patient. (p. 8)

Kastenbaum applies his comment specifically to adults. But what are the special problems faced when the terminally ill person is a child?

From the early Middle Ages through the 18th century, childhood death was common. Parents expected to lose one child or more to illness, as well as to the effects of poor sanitation and poverty. Children were also familiar with death, having witnessed many deaths in their community and their home; they, too, expected to die.

The changes that brought us to the modern, invisible death altered our relationship with childhood death. Children as a group benefited most substantially from medical and public health improvements. As childhood death became rarer, death became the province of the aged. Death in childhood came to

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seem unnatural and cruel so that "in middle-class circles in the 19th century the death of the child [had] become the least tolerable of all deaths" (Aries, 1981, p. 460).

New practices emerged to ease the pain of such deaths. In the 1800s, children were often buried in locked ornamental boxes rather than in sealed caskets. The sentimental consolation literature of this period frequently employs the death of a child to symbolize the overwhelming sadness of death as well as the projected blissful life after death, which made such a loss bearable.

Privatization, individualism, and the contracting of the family--from large and extended to small and nuclear--made each member of the family more important and strengthened the ties with one's child. The death of a child was equal to the death of the self.

The special value of children's lives is illustrated by David Sudnow (1967) in his ethnographic study, *Passing On*. Sudnow examined hospital culture surrounding the dying and the dead. He found that a child was perceived as having more "social value" and was more likely to receive immediate and prolonged treatment than a middle-aged or elderly person.

If it was intolerable for adults to accept that a child could die, it was even more difficult to imagine what the dying child faced. One way to eliminate this problem was to declare that children did not understand death. Thus, in a poem by Edna St. Vincent Millay written in the early 1900s: "Childhood is the kingdom where nobody dies. Nobody that matters, that is. . . . Childhood is the kingdom where nobody dies that matters--mothers and fathers don't die" (Millay, 1969, p. 203). In part, this attitude reflected a new emphasis on child development; the awareness that children were not just small adults but had different cognitive capacities. Developmental differences were also used in the service of protecting adults from an unbearable idea: that children could grieve.

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John Gunther's (1949) moving account of his adolescent son's death from a brain tumor, in *Death Be Not Proud*, reflects this protective stance. Gunther chronicles his son's illness from initial symptoms and diagnosis through repeated surgery and hospitalizations to his eventual death. Each page of the book is a testament to love and sorrow. While the family, the doctors, and John, Jr., himself are all aware of his prognosis, there are no conversations about death and dying. Such talks are alluded to in an afterword by John, Jr.'s mother, and it is possible that Gunther thought such revelations too intimate to share. What is most marked, however, is the pain of each family member and their efforts to hide such feelings from each other. There is a sense that acknowledging death and experiencing each other's sadness would be unbearable. What John Gunther gains succor from is "the unflinching fortitude and detachment with which [Johnny] rode through his ordeal to the end" (p. 3). Believing that children are not aware of their own death, or that they face death without fear, protects us from ever-deepening sorrow.

As we shall see in the following literature review, the belief that dying children are not aware of their terminal condition was not questioned until the late 1960s. Even today, while clinicians, researchers, and laymen have come to accept that many dying children *do* understand death and are aware of their conditions, there is a reluctance to openly discuss the issue.

Writing in 1999, a time when the rights of the dying are the focus of public debate, I find that it is still difficult for many to believe that talking about death and dying with those most immediately concerned can be beneficial. There is, of course, a crucial need to protect the dying from exploitation. And not all people who are dying choose to discuss their experiences. Still, the question remains: Whom are we protecting?

Unable to bear the idea of death, we try to deny its presence. The result of such denial is a curtailment of individual experience, in whatever form it may take.

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Feifel (1977) writes: "One cannot predict the significant concerns of every patient. Schematic stages--denial, anger, bargaining, depression, acceptance--are at best approximations, and at worst obstacles to individualization" (p. 120). The increasing boundedness and value of the self result in death becoming intolerable, feared, and, therefore, denied. Ironically, the means we employ to assuage our fear, e.g., by formulating predictable stages of dying, excludes our individual experience. (That we fear the process of dying is evidenced by our search for a theory that tells us how to die. One example of this desire for reassurance is the way Kübler-Ross's stage theory has been embraced as prescriptive rather than descriptive: the modern equivalent of the good death.)

The individual has been increasingly left out of discussions about death and dying. Psychological research studies that use large samples and objective measures further our knowledge about the experience of dying but also distance us from what is most intimate: the solitary voice of the dying person. Kastenbaum (1987-88) speaks of the death anxiety scale "assembly-line" research: "The average expectable study is not only easy to conduct, but also exposes the researcher to minimal risk. . . . The average expectable DA researcher [may say], 'I do not have to become personally involved with the respondents. Whew! I have enough needs and anxieties of my own--who wants their troubles too!'" (p. 399). The dying have much to share with us if we can calm our own fears long enough to listen.

This study represents such an attempt to listen to a group of people facing possible, if not probable, death. This group is perhaps the most difficult and painful to hear: children.

The literature on the psychology of children and adolescents with cancer is extensive. Awareness of death, loneliness and isolation, and the special problems engendered when developmental tasks conflict with regression in the face of

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illness are a few areas of research that will be reviewed in the next chapter. Little, however, has been written about the *process* of dying. One such study was Bluebond-Langner's (1978) ethnography of how children with cancer become aware of their prognoses. Commenting on the limitations of cross-sectional research, she states: "What children tell you about their view of death reflects their experiences, concerns, circumstances and self-concept at the time of the interview" (Bluebond-Langner, 1977, p. 52). Having a life-threatening illness is not a static experience but more like a journey down a river whose currents, thoughts and feelings, are deep and shifting. To capture the rich and varied landscape of this voyage requires that, given an invitation, one become a fellow passenger.

As the chance for curing many childhood cancers becomes greater, research on the problems of living with life-threatening illness and the repercussions of survival demand our attention. Yet children still die of cancer. How can we help these children--those who are dying, or who may die, and their parents?

Although pediatric cancers are rare, comprising just 2% of all malignancies, cancer is the second leading cause of death in children (Granowetter, 1994). While treatment advances have resulted in overall cure rates of 70%, (Granowetter, personal communication, 1997), a diagnosis of cancer still generates uncertainty about the future. Children with cancer think about dying:

> I thought like, when you get cancer you die because I just see like old people and when they have cancer, they die, so I was thinking, "Dag, what if I die." And then I found out that some people get chemo treatment and you can still die from cancer, so that blew me out right there, that for a while [I] couldn't put that down. I was thinking, I just wanted to tell them, "You gave me the chemo, and I could still die?" I just wanted to tell 'em, and I didn't know how. I just wanted to tell the doctor, like well, "Don't you know you're giving me chemo treatment and I could still die from cancer, that don't mean nothing." (Bearison, 1991, p. 134)

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For many children there is limited opportunity to share these thoughts.

In Bearison's (1991) collection of narratives by young cancer patients, the plea for communication emerges as one of four major themes. That this need is unmet is not surprising, given the societal taboo surrounding discussions about death and dying. Even the revolution in attitudes that occurred in the 1970s, and which led to open communication policies in pediatric medicine, has proven easier to adopt in theory than in practice. The tenacity of the problem points to underlying psychological mechanisms that are both complicated and entrenched.

In a culture where death and dying are shrouded in silence and denial, those individuals who are confronting the greatest of all human problems face a painful communication challenge. Yet if we view the process of dying as intimately connected to living, as a time of *growth*, it is necessary for us to develop a facilitative environment that surmounts this challenge. Without such sharing, we are left with isolation, guilt, and lost opportunities.

In my clinical work with fatally ill adolescents, I have experienced the intricate emotional negotiations that hold sway when communicating about dying. In a context of open discourse about the diagnosis of cancer and the possibility of death, parents and their children flow in and out of the capacity for shared dialogue; many never reach even this sporadic communication. For all of the knowledge we have gained conducting research and developing theory, we still have many questions about why ongoing openness is so elusive. Many children still die in isolation; many bereaved parents still regret missed chances for closeness.

Knowing that we will die is an essential part of what makes us human. Yet this human dimension has been marginalized in the research community. It is time to go back to the lived experience of the dying to search for clues about the struggle to communicate. Exploring the phenomenology of dying--with all of its

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idiosyncrasies, contradictions, and moments from the mundane to the transcendent--may illuminate the dark corners of our fears and generate hypotheses for further study.

I believe that children who are confronting possible death want to talk about their experiences but cannot always do so. They may fear abandonment if they express negative feelings. They want to protect people they love from feeling pain. In moments of denial, they may want to protect themselves from hearing distressing news. They may sense that those close to them are not open to such discussions.

I believe that parents of these children face similar problems. They do not want to acknowledge that their children might die. They dread relinquishing hopes for their children's future. They may feel guilty because they cannot save their children's lives. They fear causing pain to their children, and they fear that their own pain will be unbearable. In times of denial, they, too, want to protect themselves.

To enrich our understanding of the interplay of these, and other, barriers to communication, and to learn how to better facilitate dialogue and lessen isolation, requires entering the lives of those involved. This journey into the subjective experience of six adolescents facing possible death, and that of their parents, lies at the heart of this study.

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Literature Review

Awareness of Death

The prevailing philosophy in the first decades of this century was that children with cancer should be protected from disclosure of their diagnosis and prognosis. Central to this stance was the belief that children could not know they were dying because they lacked the intellectual ability to understand death. There was a corresponding assumption that children lacked the emotional capacity to cope with such knowledge; therefore, discussing their illness would only create unnecessary anxiety. These beliefs were based on what was known about the development of a death concept in healthy children.

In a classic study, Nagy (1948) traced the evolution of death fear in children. She proposed that children ages three to five deny death. They believe death is a temporary change and, unable to distinguish the external world from their internal world, cannot conceive of lifelessness. From ages five to nine children recognize death but regard it as a person; death is the "bogeyman." Only from the ninth year on do children achieve a realistic conception of death as a permanent biological process, both universal and inevitable. Nagy's work was influenced by her sample, Hungarian children who had experienced war, and has not been supported by subsequent research. She made a significant contribution, however, by introducing a developmental approach.

During the 1960s and 1970s, researchers following a Paigetian framework of cognitive development delineated four stages in the development of a death concept. Infants and toddlers in the sensorimotor period were thought to have no concept of death. During the preoperational period from ages two to seven, a time of magical thinking, death was believed to be reversible. When children reached the stage of concrete operations, ages seven to 11, they were aware that death is

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final, but it was not until the stage of formal operations, from age 12 on, that children reached a mature concept of death that includes the universality, irreversibility, nonfunctionality, and inevitability of death (Stevens, 1993). (Recent studies have shown that many children attain complete or nearly complete concepts of death between the ages of five and seven, and almost all have achieved complete concepts by eight or nine years of age. See Burbach & Peterson, 1986; Kane, 1979; O'Halloran & Altmaier, 1996; Speece & Brent, 1987; White, Elsom, & Prawat, 1978.)

This research guided beliefs about the sick child's awareness of death. Fatally ill children were said to face their illness with an air of "passive resignation and acceptance," rarely showing any overt concern about death (Richmond and Waisman, 1955). Easson (1970) states, "the child reacts to his own dying with the understanding and emotional strength of a child. . . . The three-year-old girl can run gaily to her visiting parents, proclaiming loudly and happily, 'Mommy, I got leukemia and a new dress' " (pp. 3, 13).

Other investigators also focused on cognitive and emotional developmental factors when concluding that sick children, especially those under the age of 10, were not aware of death (Knudson and Natterson, 1960; Natterson and Knudson, 1960). In a study of children on a pediatric cancer ward, Natterson and Knudson (1960) did find anxiety, depression, and withdrawal, but related these reactions to specific age-related fears. They posited that children under six suffered from separation anxiety, fear of abandonment, and loneliness. Children from the ages of six - 10 were found to fear medical procedures and bodily mutilation. Children older than 10 were acknowledged to have anxieties related to death. These findings were based on observations of children and their parents by physicians, nurses, the unit schoolteacher, the occupational therapist, and the social worker, who discussed their observations at a weekly meeting. Lack of awareness in

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children under 10 may be accounted for by these indirect techniques. Furthermore, by placing distress in an environmental context of separations from mother and traumatic procedures, rather than what such events might signify, i.e., that anxiety about abandonment and bodily integrity reflected fear about dying, Natterson and Knudson were able to conclude that there was neither awareness nor fear of death in children under 10.

Clinicians working with sick children found that their experience did not support this view and set out to explore the boundaries of awareness of death. Most of the studies conducted in the 1960s and 1970s suggested that children over 10 could be aware of, and anxious about, impending death, having either been told directly or gleaning the information in other ways (Solnit & Green, 1963; Easson, 1970; Spinetta, 1973).

To study awareness in a group of children ranging in age from nine to 20, Vernick and Karon (1965) conducted "life-space" interviews on a leukemia ward. Using the child's own questions as cues for opening a dialogue, they found that children did know about death and were concerned about their prognosis. Unlike Natterson and Knudson (1960), who reported that "even when a child died in the hospital most of the other children knew only that the child was no longer there" (p. 459), Vernick and Karon found that children did know about their condition and wanted to talk about it.

> The child's concerns and anxieties about his own welfare were most poignantly revealed in the question: "What happened to Johnny?" During the early phases of this program most of the staff would answer: "Oh, he went home." "He went to another hospital." "He went to another floor." These answers were designed to shield the child from the knowledge of his playmate's death. It soon became apparent, however, that while such answers always received a superficial acceptance, they were never believed by anyone in the age group under consideration! (p. 394)

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The idea that children were cognizant of their condition and eventual fate was beginning to surface. Morrissey (1963) reported that a three-and-a-half-year-old child in his study was judged to have experienced death anxiety. Spinetta (1974) reasoned that just because children do not speak overtly about death does not mean that they are not worried about the fatal nature of their illness.

Waechter (1971) used a projective test, composed of illness-related pictures, to tap fantasy expression about present and future body integrity and functioning in fatally ill children. Comparing children age six to 10 who were fatally ill with chronically ill children and those hospitalized for a brief illness, she found a higher degree of overtly expressed death themes and concerns in the terminally ill. The most striking finding of the study was the dichotomy between the child's awareness of his or her prognosis, as represented in the stories, and the parent's belief about the child's awareness. According to the parents, 63% of these children had not been told the nature of their illness.

Spinetta, Rigler, and Karon (1973) conducted a similar study with children in this age group and found that children with cancer had both a significantly greater preoccupation with threat to bodily integrity and greater anxiety than chronically ill children. Although the authors did not discover more overt expression of death themes, they, too, concluded that children with a life-threatening illness have anxiety about their prognosis even when shielded from such information by their parents.

To investigate how children acquire such knowledge, Bluebond-Langner (1978) undertook a longitudinal ethnographic study of children on a leukemia ward. She discovered that in addition to knowing their diagnosis and prognosis, children knew detailed information about medication, procedures, the conditions of other children on the ward, and whether a child had died.

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The children not only served as a peer network in conveying information but were adept at gathering new information. They hung out at the telephone area and listened to parent's conversations; they hovered around the door of the doctor's conference room; in short, they had numerous ways of finding out what their parents were trying so hard to hide.

Bluebond-Langner stressed that it is through the child's experience with his or her illness that awareness is gained. She suggested five stages in children's development of knowledge about the illness: 1. realization of the seriousness of the illness based on the family's reactions to the diagnosis; 2. learning, from personal experience, the side effects of treatment; 3. understanding the purpose of procedures and treatment; 4. becoming aware of the cycle of relapses and remissions as their medical condition deteriorates, but with no awareness that this process may result in death; 5. realization, through learning about the death of another child on the ward, that he or she could also die.

As the stages of acquisition of information progress from "it" is a serious illness to the realization that the disease has a terminal prognosis, there are accompanying changes in self-concept. These five stages are: 1. seriously ill; 2. seriously ill and will get better; 3. always ill and will get better; 4. always ill and will never get better; 5. dying. Bluebond-Langner's rich study did much to expand our understanding of the experience of the child who is fatally ill and, combined with the work of Waechter and Spinetta and his colleagues, provided the research base for the open communication policies that emerged in the 1980s (Martinson, 1994).

Still, Jay, Green, Johnson, Caldwell, and Nitschke (1987) reported that in a study of children's death concepts there was no evidence that children with cancer exhibit more advanced concepts of death than physically well children. One possible explanation for this finding is that the children were actively defending themselves from awareness of death. The researchers themselves state:

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> Perhaps admitting the possibility of their own death was too anxiety provoking, given the severity of their illness. Children in this study were asked, 'Will you die?'--which one might presume to be a more anxiety provoking question for children with a life-threatening illness than for healthy children. Further investigation with a less confrontive approach (projectives, stories using the third-person pronoun) might clarify whether children with cancer are actually aware of their own mortality, as the work by Spinetta and colleagues suggests. (p. 305)

This problem and other methodological issues will be discussed below.

From the 1960s to the present, theory about children's awareness of death has evolved from the commonly held tenet that only adolescents can anticipate their own death to the belief that some children as young as four or five know they are dying (Lansdown, 1994; Stillion & Wass, 1984). The fact that adolescents are generally acknowledged to understand death conceptually, and to be capable of knowing that they are dying, does not, however, mean that issues of survival are openly discussed with them (Binger, Albi, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Freidman, Chodoff, Mason, & Hamburg, 1963; Claflin & Barbarin, 1991).

Disease-Related Communication

Inherent in the protective strategy that grew from believing children were not aware of their condition was an assumption that if children were spared the "bad" news they wouldn't suffer from the stigma of living with cancer or experience emotional distress (Claflin & Barbarin, 1991). Solnit and Green (1963) write of an 11-year-old girl who discerned she was dying of leukemia by listening to others and by watching television and reading the newspaper. On learning of her awareness from a resident:

> the parents were initially shocked and distressed but finally relieved. Their realization that their daughter knew about her impending death was

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> experienced by the parents as permission to prepare themselves more explicitly for her death. While the child and parents were never able (and why should they be?) to discuss the child's questions they could review certain of their feelings and questions more freely with themselves and the doctors. (p. 224)

Vernick and Karon (1965) tell a similar story. A 16-year-old patient on their ward was not told his diagnosis until 12 hours before he died. The mother had found it hard to communicate throughout the six months her son had been sick and had used almost all her energy manipulating the environment to keep the diagnosis secret. Finally, he asked her if he had leukemia. When she replied yes, he turned to her in relief, saying that he had known it all along. The authors comment that the patient "had spent the last six months of his life denied the emotional strength that his mother could have provided if she had not been busy using all her energy to hide the diagnosis from him. . . . by the time an adequate mother-son relationship had been reestablished, his life was over" (p. 396).

In a study conducted by Chesler, Paris, and Barbarin (1986) the age of the child was directly related to the degree of information imparted by parents. Although parents of adolescents reported communicating more openly than parents of younger children, only 30% reported full disclosure. As this study was retrospective and asked only for the parent's assessment of communication patterns we cannot know whether the children would agree that even this percentage attained full disclosure.

Many children and adolescents come to know they are seriously ill through the altered emotional climate in their family (Bluebond-Langner, 1978; Claflin & Barbarin, 1991; Freud, 1952; Spinetta, Rigler, & Karon, 1973; Vernick & Karon, 1965; Waechter, 1971). Changes in the affective environment communicate a powerful nonverbal message to a child or adolescent who, at the same time, is thrust into the world of hospitals, tests, and treatments.

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Through a change in emotional climate adults may also intimate that certain topics cannot be talked about. "When [the] environment signals that certain subjects are not to be discussed and may be too painful for the adult to deal with in a manner which transmits some degree of strength, the child becomes mute, outwardly accepting the adult's benign words of falsehood but inwardly feeling abandoned" (Vernick & Karon, 1965). One adolescent girl sums this situation up poignantly: "They smile, act happy, and pretend I won't die soon, to make me happy!" (Kikuchi, 1972, p. 262).

Ethnographic studies have enhanced our understanding of the awareness contexts that govern dialogue about death and dying (Glaser & Strauss, 1965; Bluebond-Langner, 1978). In a longitudinal study of social interaction with the dying conducted at two city hospitals, Glaser and Strauss (1965) discovered four awareness contexts: closed communication; suspicion awareness; mutual pretense; and open communication. As they state, "the impact of each type of awareness context upon the interplay between patients and personnel is profound, for people guide their talk and actions according to who knows what and with what certainty" (p. 11).

Closed communication results when physicians and families take the "moral attitude" that a patient should not be told he or she is dying. Not aware of impending death, the patient continues to believe that recovery is possible while staff and family collude in hiding information. Through the 1960s many people died without ever being informed of their condition.

Suspicion awareness results when a patient who is not getting better, and who picks up on subtle social cues, begins to suspect he or she is dying and initiates strategies to learn the truth. A "contest for control" ensues which may or may not lead to open communication.

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When patient and staff both know that the patient is dying but pretend otherwise, a context of mutual pretense exists. Mutual pretense is described in terms of "ritual drama" and is achieved through following structured rules such as "dangerous topics should generally be avoided"; "talk is permissible as long as neither party breaks down"; "each actor should focus determinedly on appropriately safe topics"; and "when something happens or is said, that tends to expose the fiction that both parties are attempting to sustain, then each must pretend that nothing has gone awry" (pp. 72-73).

Bluebond-Langner (1978) describes the prevalence of mutual pretense on a pediatric leukemia ward. She found that children who knew they were dying hid this awareness from their parents if the parents signaled that such secrecy was preferred. Children would use distancing mechanisms such as refusal to talk, feigning sleep, or engaging in inaudible or superficial conversation. They would talk about future events they had little hope of experiencing, e.g., Christmas or their next birthday. Keeping up with their school work was another method of "pretending" that they were going to get better.

Bluebond-Langner contends that mutual pretense is not an artifact of a societal taboo about death and dying but is employed because it offers all involved " a way to fulfill the roles and responsibilities necessary for maintaining membership in the society, in the face of that which threatened the fulfillment of social obligations and continued membership" (p. 210). The role of the child includes consolidation of sexual identity; becoming socially responsible; and successfully negotiating school. "Socialization is by definition forward-looking, not a period of concluding or of summing up. . . . Dying children do not fit comfortably into such a view" (p. 213). Commenting on the similarities dying children bear to the elderly--"without futures, worried, often passive, unhappy, burdened with responsibilities for others and their feelings"--Bluebond-Langner maintains that "by practicing mutual

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pretense, these children keep the parent/child, doctor/patient relationship from breaking down . . . [giving] credence to the illusion of their normalcy, thereby allowing others to do what is expected of them" (p. 213).

What is expected of parents is that they will protect their children from harm. Yet these parents "saw themselves as powerless before the disease, the doctors, the machines used for treatment, and, most important, their children" (p. 215). For some parents protection meant shielding their children from knowledge of the prognosis.

Both of these investigations were conducted before the institution of open communication policies in the 1980s. In addition, Glaser and Strauss were studying adults. There have been no recent examinations of the intricacies of the mutual pretense context. Although one might assume that the current climate of disclosure would mitigate such deception, clinical experience attests to the fact that parents and children still engage in mutual pretense.

Why Is It So Hard To Talk?

Social roles and societal taboos about death and dying are but two strands in a complex process. Both parents and adolescents have particular responses to life-threatening illness that may further hinder communication.

The Parent

Vianello and Lucamante (1988) interviewed 30 pediatricians and 30 parents of healthy children about the possibility of dialogue between adults and children regarding death. In answer to the question "Who do you believe is the most suitable person to answer possible questions about death posed by a seriously ill child?" 56.7% of the pediatricians said they didn't know, while 30% of the parents wished to entrust this task to the doctors caring for sick children. Parents also

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proposed that "qualified people" such as social workers, psychologists, and nuns should intervene, thus delegating the responsibility to people outside the family environment. What are some of the problems involved in talking about death and dying that provoke this avoidance even in fantasy?

The emotional impact of having a child whose life is threatened by illness is massive. Parents may respond with intellectualization, irritability, depression, somatization, or frenzied activity (Binger et al., 1969; Bozeman, Orbach, & Sutherland, 1955). Shock, denial, anger, and guilt are other frequent reactions to this devastating news (Binger, 1984; Comaroff & Maguire, 1986; Friedman et al., 1963). The stability of the world of everyday reality is shattered. When the shock abates, many parents feel guilty for not getting treatment sooner, for not being better protectors. Friedman et al. (1963) suggest that parents may also feel they are being punished for past "sins" or blame themselves for not appreciating their child more. Guilt may last throughout the illness and oscillate with contradictory responses--repugnance, optimism, and despair--as the family tries to create meaning for their experience (Comaroff & Maguire, 1986). Such emotional experience is not fixed or reducible to dichotomous choices such as "to talk" or "not to talk" but follows the flux of internal and interpersonal life.

In 1955, investigators examining the adaptation of mothers who were threatened with the loss of their child through leukemia, at that time an invariably fatal disease, found "a constant oppressive awareness of the fatal outcome of leukemia . . . reflected in the content of [their] imaginative stories" (Orbach, Sutherland, & Bozeman, 1955, p. 20).

The TAT stories told by the mothers in this study were "saturated" with death and suicidal reactions to the loss of loved ones. Unhappiness, sorrow, acute despair, and intense loneliness were predominant, as were internal conflict and shifts in identification. The threatened loss was traumatic for these women. The

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authors speculated that losing a child reactivated earlier emotional attachments to parental figures. The stability achieved through repairing past conflict via the child now resurfaced and created instability in the mother. Guilt was seen not just as a failure to protect but also as the sequelae of the mother's developmental history. Guilt about causing the illness might then reflect unconscious hostility directed at the child as a means to compensate for the mother's unconscious fantasy of replacing her own mother.

The role of the child in the mother's intrapsychic life was found to play an important role in her reaction to the illness. If the child's role was reparative, e.g., to reverse past disappointments or fulfill incompleted goals or ambitions, the mother's response might include anger and rejection of the child, either in fantasy or feeling. Although the mothers in this study were struggling to integrate the approaching loss of their children, the internal conflict stimulated by such a threat could certainly impede mother/child dialogue.

The exquisitely etched sorrow relayed in the TAT stories presents another emotional strain that may disrupt communication. "She is blinded by tears and can hardly stagger through the door." "She feels very bad. She has had some news that she can hardly stand. It's more than she can bear." "This is despair. This woman looks like I feel every day when I leave the hospital" (p. 21-22). A mother may feel as if she is dying along with her child. Although this study examined only mothers, and was conducted over 40 years ago, many of the findings resonate with our deeply felt experiences of loss.

Fathers are also deeply affected. Becker (1983) relates the story of a man whose son had died:

> Took walks with wife through parks and other places where child had played, and spoke to each other often--"Here's the place where Dick had such a good time that day," etc. This was too much of a strain--it was terrific. I coined a phrase to express the state we had drifted into; we were "voluptuaries of grief."

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> We had no right to subject ourselves to that torture in the name of loyalty to the dead. (p. 201)

Emotions experienced during the dying process may include the same overwhelming and punishing sadness.

This father provides an evocative description of his grief, yet there have been few studies that explore the father's response to his child's illness. Townes, Wold, and Holmes (1974) compared parents reactions to the death of their child. They found that the fathers were more accepting of the loss after the child's death, while the mothers' mourning was intense throughout the illness and sustained after the death. Father's also reported fewer life changes following the child's death.

Many early papers describe the father as less involved in the care of the child, absented by the need to provide financially for the family or to take care of other children at home (Binger, 1969). In these instances fathers may have less time available to spend talking with their ill child. Kazak (1997) comments on the persistent belief in pediatric psychology that "you won't get the fathers" (p. 145) and points to the need to include these often neglected family members.

Experiences with illness, and beliefs about health and illness, have also been lacking in pediatric psychological research (Kazak, 1997). Each parent's history of illness-related experience and loss influence the way in which this current crisis is handled. Leyn (1986) tells of a stoic grandmother who was inconsolable after her adolescent granddaughter's death. This woman had a daughter who had died as an infant; a death that was not mourned until it was revived at the time of the new loss.

Much of the effort to protect children can be viewed in terms of adults protecting themselves from anxiety and grief (Binger, 1984; Buckingham, 1984; Graham-Pole, Wass, Eyberg, & Chu, 1984; Kazak, 1997; Leyn, 1976; Spinetta & Deasy-Spinetta, 1981; Vernick, 1973). Exploring how previous experiences with

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illness and loss contribute to these painful feelings, as well as to conflict, may further disentangle the complicated process of communication.

Misunderstandings abound when the subject of death and dying arises. Many people assume that when a discussion about death and dying is proposed a child will be cruelly treated or traumatized. These concerns are frequently a projection of the adult's own fears related to dying. As Vernick (1973) states, "on the whole we tend to decide for ourselves what the child needs to talk about purely on the basis of what we feel would be most comfortable for us to discuss with him. . . . The author has never recommended or even suggested that a child be told he is going to die. Such an interpretation is usually made by the adult who needs to protect himself from discussing, meaningfully, the subject of death and dying with the child" (p. 106, 118-119).

The intensity of emotions may be an issue here. Stone (1993) suggests that the traumatic stress encountered in terminal illness triggers overwhelming affect. In this view it is not the external event that is upsetting but the affective response to it. Parents and children may limit communication because they fear that their emotions will destroy them.

This fear reflects a primitive anxiety that predates object loss: a fear of annihilation that can be traced to the infants early and absolute dependence on the mother (Winnicott, 1965). It is possible that when faced with death, the ultimate annihilation, this early anxiety is stimulated and becomes unbearable. We have no descriptions from those on both sides of the dying process of why specific topics are avoided, or why topics are avoided at different times. Fear of overwhelming affect may account for the intermittent lapses into mutual pretense that occur even in open communication contexts.

The psychoanalytic perspective of early studies has been criticized for pathologizing mothers (Zevon, Tebbi, & Stern, 1987). This criticism may reflect a

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semantic shift. In early studies the term pathological was used to refer to a behavior that required outside help for resolution, even if that behavior was the normal response of a healthy person in a non-normal crisis situation (Spinetta, Deasy-Spinetta, McLaren, Kung, Schwartz, & Hartman, 1982). Guilt, anxiety, and conflict need not be viewed as abnormal. Although Binger et al. (1969) reported that in 50% of the families in their study at least one family member needed psychiatric help, this finding has not been validated by subsequent research (Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980; Zeltzer, Kellerman, Ellenberg, Dash & Rigler, 1980). Comaroff and Maguire (1986) stress that pain, confusion, distress, and the uncertainty of physical survival lead to persistent doubts that should not be viewed as " 'psychological maladjustments' or 'failure to cope'" (p. 108). Just as to talk or not to talk is not adequately portrayed in dichotomous terms, the question of adaptive vs. maladaptive response seems to miss the broader question. Whether regression in the face of traumatic stress is normal or abnormal obfuscates the issue of how parents and children can be helped to communicate in ways that are more satisfying for both. Few would question the agonizing difficulty in talking about such a serious matter as death and dying. Our efforts are better spent in addressing the complexities involved in such a process than in arguing about pathology vs. normalcy. In our culture very little about death and dying is normal.

Guilt, fear, sorrow, all may prove potent blocks for the parent who wishes to communicate with the sick child. What challenges face the adolescent?

The Adolescent

"Mad and muddled" is Winnicott's (1965) description of the storms of adolescence. During this tumultuous period that lasts from roughly ages 12 - 21,

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there are many developmental tasks to accomplish. Spinetta et al. (1982), using a theory developed by Havinghurst, outline eight of these tasks:

1. *Self-image:* Accepting one's physique and using the body effectively.
2. *Friendship*: Achieving new and more mature relations with age mates of both sexes.
3. *Sexual Identity:* Achieving a masculine or feminine role.
4. *Independence*: Achieving emotional independence of parents and other adults.
5. *Career and finances*: Preparing for an economic career.
6. *Marriage and Family:* Preparing for marriage and family life.
7. *Responsibility:* Desiring and achieving socially responsible behavior.
8. *Ideology and Values*: Acquiring a set of values and an ethical system as a guide to behavior--developing an ideology.

These tasks present specific challenges for the adolescent with cancer. Self-image can be taxed by the effects of treatment: hair loss, weight loss, and, possibly, amputation. Absence from school and peers may remove the adolescent from the normal social milieu, thus hampering friendships. Social isolation and the physical sequelae of treatment may affect opportunities to date. Schowalter (1970) describes the reaction of a 14-year-old girl after being moved from a single to a three-bed room:

> She became suddenly very agitated, told the pediatric interns she knew she was going to die, and asked to talk with a psychiatrist. Discussions with the girl uncovered the cause of her acute anxiety. The fifteen-year-old girl who occupied the bed next to hers had been hospitalized following a series of behavioral difficulties. . . . Helen overheard the doctors question the girl as to whether or not she had intercourse while she was gone. Helen had for years fantasized such adventures for herself but had rigidly suppressed the urges to carry them out with the self-promise that she would enjoy them when older. However, her sudden proximity to such actual happenings coupled with her

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> knowledge that now she would never experience them caused her to become overwhelmed by the limitations of her mortality. (p. 63)

Plans for the future--career, marriage, children--are also greatly affected by the threat of death and place the older adolescent out of synch with his or her peers.

Forging a self-identity and place in the world, a personal ideology by which to be defined and which to live, can be compromised when the sick adolescent may also be trying to find meaning for a life-threatening illness (Baum & Baum, 1989). This struggle for identity is linked to the struggle for independence and may have the greatest impact on the parent/child relationship.

In many ways the adolescent is reliving the rapprochement crisis of toddlerhood, trying to separate from the family while at the same time looking homeward for support and attention. This is a confusing time when defiant independence alternates with regression to dependence (Winnicott, 1965). The adolescent who is hospitalized or bedridden at home may feel these strivings are out of his or her control (Kellerman et al., 1980; Zeltzer et al., 1980). For instance, feeding, changing clothes, and bathing may all be managed by others.

Winnicott (1965) speaks of the adolescent as an isolate. He maintains that "this preservation of personal isolation is part of the search for identity and for the establishment of a personal technique for communicating which does not lead to violation of the central self" (p. 190). The sick or dying adolescent may not have the opportunity to create a private space for introspection and self-definition. Conversely, the adolescent may become too isolated if his or her parents react to the threat of death by withdrawing; thus necessitating an unwanted independence. This situation is equally troublesome, for the adolescent also needs to reconnect with the parent, communicating from a newly integrated position. As Winnicott states, "it is joy to be hidden but disaster not to be found" (p. 186).

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The problematic developmental tasks of this period may make the sick adolescent more vulnerable to shame, humiliation, and loss of self-esteem (Baum & Baum, 1989). The dying adolescent may also be more vulnerable to stress than the younger child.

In a study of the relationships among age, information disclosure, and children's psychological experience, Claflin and Barbarin (1991) discovered that compared to younger children, adolescents appraised more events in their life as stressful, e.g., unpleasant medical treatment, separation from family and friends, stigma, and worry about relapse. Adolescents also experienced a greater degree of stress from these events. The authors attribute these findings to the conflict between having a life-threatening illness and the developmental process. Children 14 years and older reported that their families babied them. They also were distressed by separation from school and peers, and many had given up their plans for the future. Having reached a stage where the autonomy of the wider adult world is beckoning only to be pushed back into dependence on the family, the adolescent may lash out in frustration and rage, or withdraw into stony silence.

It is important to remember that anger and withdrawal may be used to express fear, sadness, and loss of control. Language in such an emotionally charged situation is not always direct. Age can also influence the mode of communication.

Although abstract thinking has usually been attained by middle or late adolescence, communications about death and dying may be symbolic or indirect (Kübler-Ross, 1974, 1983). Concerns about dying may be communicated in play or through acts such as giving away possessions in preparation for death. Anxieties about dying might appear in dreams:

> Sometimes I have nightmares. Like, I remember when I first came here, you know, I was really scared, 'cause one night I woke up screaming, and I was in a cold sweat. 'Cause I dreamed that I was right there by the nurses' station, and this was like after it was, around one o'clock at night, in the morning. And it's

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> like there was nobody around, 'cause there's like two or three nurses running on the floor and they was all busy, and there was nobody there. And I remember, I was, I went to the nurses' station to get something and nobody was there, so I had a remote control car. So I was just there, waiting to see who would come. And nobody came, so I started driving around my little remote control car. Then I dreamed that I went to the edge, you know, to the corner of the nurses' station, right, and it's like, I drove it way down the hall. It's like I was trying to make the car come back, and it wouldn't come back. So I went after the car, went to get it, and then it's funny, 'cause I went around the corner, I saw the car, it was like, smashed to bits. And then it's like, some tall man, you know, I didn't even see his face, all I saw was a big huge body, with an axe. And I saw the guy sever my head and I woke up screaming that night. (Bearison, 1991, p. 34-35)

Abandonment, loss of control, aggression, anxiety about death, all make a vivid appearance in this dream.

Other indirect communications may be used. A child might simply state, "I'm not going to school anymore" or "I won't be here for your birthday." In times of great anxiety it may be easy for parents to miss such subtle cues. Adults, themselves, employ indirect or symbolic communication when hampered by anxiety or unconscious conflict and fantasy. And adults have a tendency to believe that by talking rationally and calmly their message will be comprehended, an often erroneous assumption (Adams-Greenly, 1984; Steward & Regalbuto, 1975).

Nonverbal communication must also be considered. Parents may not attempt to communicate with the adolescent who is comatose or unable to talk as the result of surgery or anergia. Vernick (1973) provides a powerful testament to the benefits of keeping communication channels open:

> Keith, an eighteen-year-old boy, became critically ill, and most of the time lay with his eyes closed giving only vague indications that he might be aware of his surroundings. No two-way communication was possible. However, whenever the writer was in the room he repeated over and over into the

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> patient's ear such brief statement as, "This is Joel," or "The sun is out." At the same time he would hold and squeeze Keith's hand. The boy responded to medication and this particular crisis ended. Later, Keith was asked what he could remember of the time when he was so sick. He had difficulty in recalling any specific verbal communication but said, "I remember your holding my hand. I could recognize your voice, I couldn't answer you. I could feel your voice. All this made me sure I was still alive." (p. 112)

Withdrawal does not necessarily mean an adolescent does not want to talk or is resigned to the inevitable.

Withdrawal, and other forms of negative communication, can serve many functions. Parents are not the only ones who try to protect. Children are acutely aware of the distress their parents are in and may use anger, banal chit-chat, or withdrawal to provide an excuse for the parents to leave:

> Myra: Jeffrey, why do you always yell at your mother?
> Jeffrey: Then she won't miss me when I'm gone.
> Myra [To Jeffrey's mother]: Why does Jeffrey always yell at you?
> Mother: Look Myra, he knows when I can't take it anymore in that room, and he knows that if he yells, I'll leave. He also knows that I'll come back. (Bluebond-Langner, 1989, p. 8).

Communication, verbal and nonverbal, serves many purposes; here, a son is trying to ease his mother's suffering and, at the same time, ensure that he will not be abandoned. How multifaceted and powerful are such dialogues. Still, the question lingers--why is such subterfuge necessary?

The Parent and Adolescent Together

Previous patterns of communication, ongoing problems and conflicts, and the family's history of, and attitudes toward, illness all affect the communication process. Patterns of defense may also influence what can be spoken about openly. Defense mechanisms are procedures the ego employs to avoid danger, anxiety, and unpleasure (Freud, 1950c). In the case of life-threatening illness, a stressful

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external event interacts with the internal world of both parent and child. Speaking to this phenomena, Steward (1993) quotes Anna Freud:

> . . . it is not the external danger, real and serious as it may be, which accounts for the traumatic value of an experience. Injections, loss of blood, surgical interventions, etc., are shown to remain manageable events unless they touch on and merge with id material which transforms them into experiences of being assaulted, emptied out, castrated or condemned . . . I believe in a sliding scale between external and internal threats and fears. (p. 185)

In response to the threat, specific defenses are set in motion to manage the crisis. Kübler-Ross (1969) used the language of defense in her stage theory of the psychological reaction to dying when she proposed that anger, denial, and bargaining were central to the process. Dying, however, is unique for each individual and the full range of defenses may be called into operation. (See Freud, 1966; Kernberg, 1994 for a list of defense mechanisms.) Issue has been taken with a model based on defense. It has been observed that dying is not a psychiatric illness but a normal process in human life (Corr, 1993). Yet, one does not have to pathologize dying to propose that in an effort to manage the anxiety engendered by the threat of death various defenses are used. One way of handling this debate is to reframe the conceptualization of such behavior from a defensive process to one of coping (Phipps, Fairclough, & Mulhern, 1995).

One model of coping used in studies of psychological adaptation in children with cancer is based on the tendency to approach or avoid information. Dimensions of information seeking behaviors by both adults and children have been labeled in several ways: approach/avoidance; monitor/blunter; repressor/sensitizer; leveler/sharpener (Byrne, 1964; Roth & Cohen, 1986; Santostefano, 1978; Smith, Ackerson, Blotcky, & Berkow, 1990). Although constructs utilized to reflect the tendency to approach, e.g., information seeking, vigilance, and monitoring, appear homogeneous, there has been some debate about

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avoidance behaviors (Phipps, Fairclough, & Mulhern, 1995). At the heart of the confusion is whether avoidant behaviors are conscious or unconscious processes, with blunting representing a conscious, effortful response to a stressor and repression occurring more outside of awareness (Phipps & Srivastava, 1997).

This line of research is being pursued in an effort to understand the low levels of depression and anxiety, and the high levels of defensiveness, found in the self-reports of children with cancer. Investigators are trying to discover whether repression is a contingent response to the stresses of the illness or reflective of a premorbid personality profile, and whether this style of defense creates an illusory picture of mental health (Phipps & Srivastava, 1997).

Where communication is concerned it may be more fruitful to consider the effects that differing styles of defense have on parent/child dialogue. Borrowing from the theory of affect attunement we might question how attunement of defenses affects communication. Affect attunement occurs when a parent reads the infant's feeling state, and provides a corresponding response. These attunements accomplish the intersubjective sharing of affect (Stern, 1985). As affect attunement, like defense, is believed to occur outside of awareness it provides an evocative metaphor for the deep connection that can keep communication, in whatever mode, open for the parent and dying adolescent.

Repression/sensitization scales have been thought to measure a subject's evaluation and private interpretation of emotionality (Lefcourt, 1966). Imagine the adolescent who is comfortable with expressing emotions, both positive and negative, who has a parent using avoidant defenses. This adolescent might suppress genuine feelings to avoid frustration or, perhaps, emotional distancing by the parent. Children who are more avoidant may shrink from a parent who not only seeks information but insists on sharing it with the child. Today there is an emphasis on pediatric patient education and patient participation in decision

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making. Although the philosophy guiding this policy is sound, involving children in their own care to enhance control and diminish anxiety, it can be pushed to extremes by parents who wish to avoid making painful choices regarding treatment (K. Woolverton, personal communication, June 1997). In such instances the communication of information may conflict with the adolescent's wish to be taken care of and protected.

Casting the discussion in terms of other defense mechanisms illuminates the degree to which parent and child may struggle to have a mutually satisfactory dialogue. One commonly noted consequence of illness is regression (Prugh, Staub, Sands, Kirschbaum, & Lenihan, 1953). For the parent who can tolerate a reversion to dependency and earlier modes of behavior, regression poses no problem. Regression may be less well tolerated in an adolescent, however, than in a younger child. The adolescent who wants to be babied may find communication blocked if the parent cannot accomodate such behavior. Intellectualization may clash with acting out, denial with an attempt at honest confrontation of death and dying.

It is expected that defenses will shift throughout the dying process, requiring ongoing work to keep communication open. The interplay of parent/ child defenses has not previously been studied and is an exciting area for exploration.

The Impact of Not Talking

The fatally-ill adolescent faces many stressors: separation from family and friends during hospitalization, pain and debilitation, and massive object loss. Failures of communication can add to this distress. The parent who tries to protect a child from the experience of death may only add distrust, confusion, and anxiety to an already difficult process (Buckingham, 1989; Graham-Pole et al., 1989).

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Turning to others, most notably peers, may lead to misconceptions, misunderstandings, and increased anxiety (Vernick & Karon, 1965).

Many researchers in the field of pediatric psychooncology have noted the increase in the child's anxiety that accompanies parental silence or pretense (Bluebond-Langner, 1978; Spinetta, 1974; Spinetta & Maloney, 1975; Spinetta, Rigler, & Karon, 1973; Vernick & Karon, 1965; Waechter, 1971). Open communication has been shown not only to lower stress and anxiety but also to enhance coping in both children and adults (Bluebond-Langner, 1978; Graham-Pole et al., 1989; Kaplan, Grobstein, & Smith, 1976; Kazak, 1997; Spinetta & Deasy-Spinetta, 1981; Spinetta & Maloney, 1978; Waechter, 1981).

Spinetta and Maloney (1978) conducted a study of the relationship between communication and coping in 16 leukemic children. They hypothesized that the child whose family reported open levels of communication about the illness would score as less defensive on a scale of defensiveness, express closeness to family members, express happiness with self, and feel free to express negative feelings within the family. Results indicated that level of family communication was related to coping strategies in the child. "Families in which levels of communication about the illness are high are those families in which the children (a) exhibit a nondefensive personal posture, (b) express a long-range close relationship with the parents, and (c) express a basic satisfaction with self. Freedom to express negative feelings was not significantly correlated with level of communication" (p. 1,541).

One drawback of the study was that level of communication was gauged only by the mother. Mothers were asked to relate how much the child knew about the illness, what kinds of questions the child asked, how the parents responded to the questions, what kinds of questions the siblings asked, and how the parents responded to the siblings questions. Addressing the limitations of the study in a

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later paper, Spinetta (1978) states, "further studies are called for to clarify whether, in fact, the mother's judgment of openness is a valid judgment of the true situation, whether there is a difference in communication patterns as the children go through subsequent relapses, and whether parents become more or less communicative regarding implications of the illness as the child nears death" (Spinetta, 1978, p. 46).

Kaplan, Grobstein, and Smith (1976) interviewed forty sets of parents three months after their child had died of leukemia and compared adaptive responses with coping classifications derived earlier in the child's treatment. These coping classifications were based on: (1) the ability of the parents to comprehend the nature of the disease; (2) the ability of the parents to communicate the seriousness of the illness to all members of the immediate family, including the patient; and (3) the ability of the parents to respond to the diagnosis with appropriate sadness without inhibiting the expression of these feelings in themselves or in any family member. Those families with the highest coping response had the fewest problems after their child's death, as measured by number of health problems, functional problems, marital problems, and sibling problems. Again, assessment of communication was based on the judgment of the parents.

A national study designed to examine issues of communication between parents, dying children, and their siblings was conducted by Graham-Pole et al. (1989). The investigators were interested in how much a child had been told about dying and his or her mood after these conversations. A 49-item questionnaire was sent to 408 chapters of the Compassionate Friends, an organization for bereaved parents. As few fathers responded, only information returned by mothers was analyzed. On average, the children were 12 or over when they died, and their death had been expected for more than four years. Death was the result of a range of illnesses, not just cancer. According to the mothers 66% of the children knew

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they were going to die, and those over 12 were significantly more likely to have talked about death. 58% of the mothers thought that talking about death and dying had been helpful and reported that their child's mood had been neutral to positive after such discussions. The dialogue was most helpful for the dying child if he or she was at home immediately before death, if there was extensive and specific discussion about death and dying, and when the parent was the major discussant. Mothers also benefited from these talks; recovery from bereavement was correlated with the mother having been the main discussant with the child about death. The authors comment that their sample was self-selected both by membership in the Compassionate Friends and by their decision to return the questionnaire. A further limitation is that retrospective judgments by mothers were the sole criteria for assessing levels of communication.

A briefly mentioned yet intriguing finding in this study was the emergence of a picture of "general acceptance and optimism among the dying children, with little sadness, anger, denial, or fear" (p. 477). Others who work with dying children have noted that children tend to die with greater softness and ease than adults, but little has been written about this phenomenon (D. J. Bearison, personal communication, June 1997; S. Levine, The Art of Dying Conference, April 1997).

These studies suggest that there is a close relationship between open discussion, positive emotions, and ability to cope among dying children and their parents. Communication can lead to a more meaningful relationship, increase family cohesion, and convey hope (Binger et al., 1969; Binger, 1984; Futterman & Hoffman, 1973; Shovelar & Perkel, 1990). Spinetta, Swarmer, and Sheposh (1981) discovered these same positive effects when they conducted a series of interviews with families whose child had died of a life-threatening illness.

> About half the families interviewed reported that they had talked freely and openly with their children about the impending death. None of the parents who

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> had spoken openly with their child believed that too much had been said; on the contrary, these parents thought that a higher level of closeness was achieved with the child than might have occurred otherwise. . . . The families whose children had died without open discussion of the illness or of the imminent death usually wished they had spoken more openly with their child. These parents reported feelings of incompleteness and nonresolution. (Spinetta & Deasy-Spinetta, 1981, p. 240-241)

Open communication appears to have an effect not only on coping but on the process of mourning. Parents in this study who talked freely with their child experienced less guilt and also felt closer to their child during the final illness. When discourse was not open, parents were left with a lack of closure, children with the isolation that can be the most devastating aspect of terminal illness.

One limitation of these studies is the reliance on retrospective reporting by only one member of the family, usually the mother. Such reporting is hampered by the passage of time, the difficulty in accurately remembering painful experiences, and the use of a single perspective. Other than Bluebond-Langner's (1978) work, there are no studies of communication between the dying child and the parent that utilize multiple perspectives.

Studies that have examined the agreement between parent/child ratings in the assessment of childhood depression, however, have found little correspondence (Ivens & Rehm, 1988; Kashani, Orvaschel, Burk, & Reid, 1985; Kazdin, French, Unis, & Esveldt-Dawson, 1983; Moretti, Fine, Haley, & Marriage, 1985). One hypothesis for such disparity is that it may be harder for parents to judge their child's internal feeling states than their behavior. Yet, Achenbach, McConaughy, and Howell (1987) also discovered significantly low correlations in child/parent reports in a meta-analysis of 119 studies of both behavioral and emotional problems. They suggest that rather than casting doubt on one or both informants such discrepancies point to the possibility that different informants validly

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contribute different information. Although these studies were focused on assessing psychopathology, it is likely that multiple perspectives on the communication process would also yield significant differences.

Parent and child functioning are interrelated in complicated ways and future research needs to consider the perceptions of both parties (Kazak, 1997). Speaking of the need for a more inclusive conceptual framework of dying that considers multiple, individual viewpoints, Kastenbaum and Thuell (1995) state: "none of the [existing] theories have explicated the role of perspective and values in the dying process" (p. 185).

The literature seems to suggest that the open communication approach has to be employed in every case (Van Dongen-Melman & Sanders-Woudstra, 1986). Yet forced communication can be destructive (Spinetta, 1978). Bluebond-Langner (1978) writes of a pediatric oncology nurse for whom the open approach was a cause celebre and who wreaked havoc in her determination to inform. We are reminded that the process of communication is complicated and influenced by a multitude of factors both conscious and unconscious. When a child or adolescent wants to talk the question is not *whether* to talk but rather *how* to talk? To help us in this difficult task it will be useful to examine the perceptions that both the child and the parent have of the interactional process.

Isolation

Perhaps the most pervasive result of the failure to communicate is the isolation, loneliness, and abandonment of the dying (Adams-Greenly, 1984; Binger et al., 1969; Bluebond-Langner, 1978; Fleischman et al., 1994; Spinetta & Maloney, 1975; Waechter, 1971; Wass & Stillion, 1988). As Koenig (1973) states, "Death is not always the main concern of the dying person. Dependency, isolation, pain, physical disfigurement, and fear of abandonment are among the issues that are

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sometimes as threatening, if not more so, than impending death" (p. 181). Many factors contribute to this physical and emotional abandonment.

Both cancer and terminal illness carry a tremendous stigma. In an investigation of stigma resulting from illness, Stahly (1988) designed a Stigma Inventory and had college students role play the status of "heart patient" or "cancer patient". Those in the cancer condition scored higher on fear of contagion, shame and embarrassment, diminished social networks, and reduced family cohesion, reflecting the student's perceptions of what it means to have cancer.

The terminally ill fared even worse. Stahly and Blackman (1985) report that terminally ill patients were among those scoring highest on the Stigma Inventory. Kalish (1966) asked college students to respond to a social distance scale evaluating 14 ethnic and nonethnic groups. More than a third of the sample would not willingly allow a dying person to live in the immediate neighborhood. Increased discomfort and personal distance stem from such stigmatization. If a patient responds to these difficulties with withdrawal or anger, social distance and isolation increase. Stahly (1988) comments that some patients deal with the anxiety and stigma by using denial or by channeling conversation into "safe" areas, thereby reducing physical isolation at the expense of emotional isolation.

Restriction of communication is one of the hallmarks of mutual pretense and isolation one of its consequences. Glaser and Strauss (1965) relate the effect on an adult: "One terminal patient told a close friend, who told us, that when her family and husband insisted on pretending that she would recover, she suffered from isolation, feeling as if she were trapped in cotton batting" (p. 77).

Illness itself contributes to this breach in interpersonal relations. As ego resources previously used to engage with others are drawn inward for additional strength, the sick adolescent's world constricts. His or her world may become no larger than the hospital room, the bed, or even the boundaries of the body. The

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healthy need empathy to traverse the distance created by illness. Anxiety or emotional pain may impede the empathic process and, again, prove fertile ground for mutual pretense:

> The worst phase of all was one in which patients, families, wives, and husbands did not talk or tell what they knew about the disease in order to "protect" each other. The result was an isolation of both parties and this was the most devastating experience of all. Each one "knew" but each one put all his efforts into trying to escape the inevitable. Of course they did not "escape" but only suffered greater turmoil in their isolation. (Solnit & Green, 1963, p. 226)

Binger et al. (1969) state, "older leukemic children attempted similarly to protect their parents: the children who were perhaps the loneliest of all were those who were aware of their diagnosis but at the same time recognized that their parents did not wish them to know" (p. 415).

Isolation may extend beyond the social circle; the dying child may also feel abandoned by hospital staff. Although the physician's sense of failure and subsequent abandonment of the dying is outside the scope of this review, a brief digression may illustrate the degree to which the dying child becomes isolated.

In a study of the social organization of terminal care in two pediatric hospitals, Doka (1982) found two patterns of care: the terminal pattern and the critical pattern. The patient in the terminal pattern, where death was considered certain, had less claim on staff time. "In most cases, aside from routine tasks such as checking vital signs and administering medication, there was little that staff did. While they might have offered a supportive role (i.e., attempting to offer some sort of emotional support and comfort), this task required time demands which often could not be worked in terms of the other demands on staff time" (p. 349). In addition, when a terminally ill patient took a turn for the worse the resulting demands on staff time had to be negotiated against the demands placed on the staff by patients believed to be better risks. "The result of these negotiations was that

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staff had a tendency to interact less with terminal cases" (p. 350). When treatment shifted to palliative care interaction decreased further. In contrast, the critical pattern, in which death is defined as possible but not inevitable, received high staff priority and intense interaction. Many of the critically ill were "specialed", meaning that a nurse was assigned solely to the care of that patient. Karon and Vernick (1968) suggest that lack of communication "leads to a progressive emotional disinvolvement of the staff from the child during the terminal phase of his illness--almost as if he were already a corpse" (p. 278). This social death can rob the dying child or adolescent of what is most meaningful in life.

The sick role also divests the adolescent of his or her common humanity: clothes are replaced by hospital gowns; school is forsaken; home becomes a depersonalized room in a hospital. In addition, the sick or dying child is given few opportunities for altruistic investment in others.

Jankofsky and Steucher (1983-84) write poignantly of these genuine acts of human communication and care. They maintain that the modern hospital environment, our social and cultural attitudes toward illness and death, and the emotional state of the patient and his or her family encourage a focusing on the self that inhibits acts of human kindness and tenderness. "Daily clinical experience with children and adolescents on a cancer ward confirmed time and again that the exclusion from the altruistic social process was a psychologically debilitating factor of magnitude during the entire period of terminal illness" (p. 343). A program initiated to provide growth opportunities for these terminally ill adolescents met with enthusiastic response. "The ones who were able to travel were sent on a two-week trip to a special education project to help teach and take care of handicapped Indian children. The combination of a nurturing role and the experience of being needed . . . provided strength and a changed outlook which stayed with them until their last conscious breath" (p. 346).

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Attig (1996) refers to the existential suffering that results from the severing of connections with wholes larger than ourselves as "soul pain." Cut off from that which brings value and meaning into their lives, the dying feel "a deep homesickness having little to do with physical location and everything to do with our longing for the embrace of those who share life with us and our yearning to feel at home in the world" (p. 21). Connecting with others through giving of the self is a potent communication that reduces this pain and humanizes the process of dying.

The isolation of the dying has been explained as a function of anticipatory mourning, described as a facilitating response in preparation for death. For the dying child, anticipatory mourning expresses grief over the coming separation from all those he or she loves, as well as from life itself. Withdrawal represents acceptance of death and a gradual decathexis of the object world (Abrams, 1966; Kübler-Ross, 1969; Martin, Martin, & Pierce, 1984)). For the parent this mourning is a way of gradually separating from the child when all hope has been relinquished. Withdrawal serves to cushion the parents against massive loss (Wiener, 1970). Interpretations of this process vary. Wiener (1970) suggests that symptoms of grief such as somatic distress; guilty self-blame; and irritability, impatience, and social withdrawal are evidence that "parents are prepared to accept the child's actual death with appropriate affect, composure, and even a sense of relief that the inevitable is finally over" (p. 95). He also believes that this process aids the final work of mourning which "may take several weeks or longer" (p. 97). Certainly, many people would argue that this grief can last a lifetime.

Easson (1970), who agrees that anticipatory mourning is adaptive, writes of the more tragic consequences of emotional withdrawal. The family who have completed their mourning too early may pay perfunctory visits, their conversation may be without spirit or true involvement. As a result the child becomes more

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isolated and alone, emotionally dead for the family while he or she is still physically alive.

It is possible that the physical and emotional withdrawal of the family are not reflective of anticipatory mourning but rather defensive maneuvers geared to protect the healthy from painful feelings of guilt, failure, helplessness, anger, or grief (Schoenberg, 1970). Writing about the transience of all loved objects, Freud (1950a) described two common responses to anticipated loss: despondency or rebellion. Yet Freud thought these reactions represented not acceptance, but a recoiling from the foretaste of mourning.

For the dying child or adolescent withdrawal may signify retreat in reaction to the family's avoidance; an indication of apathy, not serenity (Koenig, 1973). Bowlby (1960) described the response of healthy children of 15 to 30 months when they were hospitalized and, therefore, separated from their mothers. A predictable sequence of behavior with three phases--protest, despair, and detachment--was noted. Detachment, the counterpart of attachment, might account for the behavior of the dying. Rather than indicating a working through of grief related to future loss, or decathexis following acceptance of death, the detachment of the dying may be a response to abandonment in the present, as family and friends prematurely distance themselves.

Rando (1988) maintains that anticipatory grief does not involve a major decathexis from the dying individual but rather from the hopes, dreams, and expectations of a long-term future with that person. She believes that attempts to detach from someone who is not yet dead are misdirected and that the griever is faced with conflicting tasks: directing *increased* attention, energy, and behavior toward the patient during the illness while at the same time decathecting from the image of the patient as someone who will be present in the future.

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Results of a study of terminally-ill adults did not confirm the image of the dying person's withdrawal into self and away from others (Lieberman, 1966). Those subjects closest to death showed high interest in others and responsiveness to the environment. The author suggests that those approaching death do not simply disengage; they are interested in reaching out to others but feel hopeless about their ability to do so.

In a classic study, Spinetta, Rigler, and Karon (1974) used personal space as a measure of the dying child's sense of isolation. Personal space was conceptualized as mirroring the child's perception of growing psychological distance. They created a three-dimensional replica of a hospital room and had children aged six-10 place four dolls (nurse, doctor, mother, father) in the room where they "usually go," while creating a story about "his friend who was sick in the hospital." After making the first placement, children were told to place the dolls where they would most like them to be. Hospitalized children with leukemia were compared with children who had chronic but nonfatal illnesses. Of the 25 children in each group, 9 were newly diagnosed, while 16 were in the hospital for a subsequent admission for the same illness. When asked to place the dolls where they usually go, children with leukemia placed the dolls at a greater distance than the chronically ill children and this distance increased with number of hospitalizations. When asked to place the dolls where they would like them to be, children with leukemia placed them at a greater distance than chronically ill children but this distance did not increase with number of hospitalizations.

The investigators concluded that children who might not verbalize their feelings were expressing subtle fears that were real, painful, and related to the seriousness of their illness. They state that the parents of these children also reported a decrease in the intensity, frequency, and quality of physical and verbal

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contacts with their child. Finally, the authors raise many questions that have yet to be answered:

> Is the child somehow trying to prepare for his own death by separating himself from his parents? Or does he sense an embarrassment on the part of the adults to speak of the illness, and is he thus trying to protect the adult? Or is the child merely reflecting the reality of a situation in which he senses that the feelings of the adults, for whatever reason, are gradually being separated from him. (p. 755)

The fact that personal distance remained the same when children were asked where they would like the dolls to be, regardless of number of admissions, was not addressed. One hypothesis is that this placement reflects a wish for parents not to move further away but to at least remain where they are as the threat of death increases. That the dolls are not moved closer may be a compromise geared at protecting the parents from pain, or acknowledgment that parents do not wish to draw nearer.

In a similar study with children in outpatient treatment, Spinetta and Maloney (1975) did not find a difference in interpersonal distance between those with leukemia and chronically ill children. They hypothesize that the growing separation from family and staff seems to be related to hospitalization and nearness of death.

Raimbault, a French psychoanalyst who works with pediatric cancer patients, describes the clinical repercussions of the moral, affective, and psychological abandonment that result from a lack of meaningful interchange. "The child . . . left alone with his or her illness and personal drama is prey to an imaginative process, whereby the child is altogether a vehicle for aggressive, hostile feelings and a victim of this aggression and hostility. This conflict can only reinforce the child's sense of loneliness" (1991, p. 186). The child needs help in symbolizing his or her

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experience, a process which can seldom be achieved alone but which requires the help of others.

In a thoughtful and experience-near paper, Furman (1984) discusses withdrawal as quietude, a natural consequence of dying. She describes a boy whose silence was viewed as a neurotic reaction to the stresses of his illness. She found instead that as his pleasure in living functions ebbed, he had come to focus on avoiding pain and on protecting himself against excess stimulation, from within and without, in an effort to achieve inner equilibrium and peace. Furman states that the child senses death is near from signals within the body, including diminished pleasures in the functions of living such as eating or talking. The child then has a decreased wish to strive for these activities and instead focuses on conserving energy and coping with the sense of dying. Pleas for the child to play or talk may cause the child to withdraw because such intrusive demands are experienced as empathic failures. One is alone when one is not understood. Understanding what the dying child is experiencing and having the emotional strength to hold and contain the child's feelings reduce suffering and isolation. Shouldering this burden may, however, be too arduous a goal for parents who are, themselves, in pain.

This review points to the lack of empirical investigation of isolation in dying children. In addition, there is no previous work that validates the use of doll techniques in assessing withdrawal (Lewis, Horton, & Armstrong, 1981-82). There is a clear need for further exploration of this phenomenon.

Anticipatory grief is another complicated concept that has often been used with little rigor. Is detachment a necessary component of anticipatory mourning for the survivors or a defense against grief? What factors influence the withdrawal of the dying and what is the meaning of their detachment? Furthermore, as Alexander (1993) points out, we do not have substantive evidence that relatives, and the dying, grieve in advance or that such grieving is beneficial. A longitudinal

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methodology that taps the subjective experience of both the dying adolescent and the parent may help illuminate this process.

Methodological and Other Research Issues

In the evolution of research on death and dying, an increasing emphasis has been placed on the use of quantitative methods. Although quantitative studies have been useful in establishing death and dying as a subject of scientific inquiry, they have become increasingly removed from the context of clinical practice (Drotar, La Greca, Lemanke, & Kazak, 1995). There are other limitations.

In an effort to study distress in fatally ill children, and specifically the phasic process of protest, despair, and detachment in response to interrupted attachment, Lewis, Horton, and Armstrong (1981-82) used a variety of measures to assess specific areas of personality functioning. Anxiety, anger and aggression, denial, sadness and depression, reality contact, object relatedness, and interpersonal withdrawal were assessed using combinations of the following collection methods: a behavior rating scale filled out by parents; two types of ratings by a child psychiatrist following a brief interview with the child; an examiner-administered anxiety scale; a differential personality inventory to which the child responded; and a projective measure which yields an interpersonal distance score. The investigators found little inter-method agreement and concluded that the method of assessing distress in children has a great impact on the results. They also suggest that the subtle process of detachment may be lost to straightforward methods that don't include a relationship with the child.

Others have commented on the importance of developing rapport and an environment of trust with the child or adolescent. In a plea for more naturalistic studies Phipps-Yonas (1991) writes:

Consider for example Peters' (1991) finding that 58% of the 5 to 10-year-olds

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> who witnessed a staged theft stated incorrectly that the thief was not present in the live line-up they saw (i.e., most of his subjects made false nonidentifications). He went on, however, to report that among that group of presumably poor witnesses, over half later disclosed to their parents that they had failed to acknowledge the presence of the thief out of fear. . . . What would happen to those numbers in a meta-analysis? (p. 230)

These children feared retaliation, yet even when external threat is not an issue the value of establishing a relationship with a child in order to discover what he or she is feeling and thinking has intuitive appeal.

Similarly, in the study of awareness by Jay et al. (1987) discussed earlier in this review, the authors raise the issue of whether children in the study responded truthfully to the question "Will you die?" This confrontive approach may not only have evoked anxiety, as the authors suggest, but may also have ignored the importance an ongoing relationship plays in the communication of sensitive information. In such instances there are hidden realities that structured interviews and other quantitative tools do not tap.

Attention to process is also needed. Dying is not a monolithic event but entails fluctuations in awareness, mood, and thought (Feifel, 1974). There have been few studies that take into account the changes that may occur in the social and psychological environment during the dying process (Kastenbaum & Theull, 1995). The "snapshot" view provided by cross-sectional designs cannot capture how the ill child and his or her parents experience the progression of the illness, the threat, and the reality of death (Alexander, 1993; International Work Group on Death, Dying, and Bereavement, 1993; Kazak, 1997).

Finally, the experience of the dying person--adult, child, or adolescent--has not usually been included in accounts of communication (Schulz & Schlarb, 1988). The retrospective nature of most studies, and the reliance on one family member to describe events, not only obfuscates the perceptual differences of parent and child,

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it eliminates the subjective experience of the dying child (Davies, Reimer, Brown, & Martens, 1995). Two studies that do give voice to the dying child and adolescent (Bearison, 1991; Bluebond-Langner, 1978) capture not only the depth and richness of the child's world but also the nuances of psychological experience. Such studies provide valuable information for those involved in clinical practice.

Research Questions

There is much that we do know about communication during the dying process. Communication aids coping, lessens anxiety, alleviates isolation and guilt, and lends humanity and meaning to dying. We know that communication is hindered by attempts to spare others from pain, is influenced by both intra- and interpersonal factors, and is composed of a variety of modalities that require careful attention.

Previous research has in large part been responsible for our increased understanding of this multifaceted problem. But this research has been limited by use of retrospective reporting, lack of multiple perspectives, and methods that do not include a relationship with the child.

In addition, there are issues we want to learn more about: the contribution of illness and loss history; how the interplay of defenses affects communication; why specific topics are avoided, and why they are avoided at different times; and whether detachment represents acceptance, protection against excess stimulation, response to empathic failure, or reaction to a loss that has already occurred as caregivers withdraw.

To address methodological concerns and create an environment where many aspects of the communication process may emerge, this study will employ a descriptive, case study approach, using a longitudinal design and phenomenological orientation. Talking with, and listening to, adolescents and

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their parents over a period of time will allow a relationship to develop, capture fluctuations in thoughts and feelings as the illness progresses, provide multiple perspectives, and give voice to the lived experience of those most intimately connected to the dying process.

The questions underlying this exploration are:

1. How do adolescents and their parent(s) relate to their experiences of death and dying?
2. How do both the adolescent and parent(s) experience the communication process and how does communication change over time?
3. What can be openly expressed, what must be kept hidden (as revealed in conscious, unconscious, and symbolic communication), and why?
4. How do the adolescent and parent(s) express their need for relatedness and how do they prepare for death?
5. What is the unique voice that each family member uses to symbolize his or her experience?

Enriching our understanding of communication, a vital component of the dying process, by gaining more detailed information about these end-of-life issues will expand our theoretical base, generate questions for further research, and point to new interventions to help both children and their caregivers.

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Methodology

Qualitative Research

How does one learn from children what it is like to die, and from children and their parents what it is like to talk about it? Inherent in these questions are problems related to grasping the deep and personal meaning of such an experience; the fluctuating and complex characteristics of the process; and the sensitive nature of the subject. The phenomenological perspective embedded in qualitative research is uniquely suited to address these concerns.

Qualitative research is concerned with understanding phenomena from the actor's own viewpoint; it is an examination of how the world is experienced and has been called the "search for meaning" (Taylor & Bogdan, 1984). Taylor and Bogdan (1984) describe key aspects of the qualitative approach:

> 1. Qualitative research is inductive. Researchers develop concepts, insights, and understandings from patterns in the data, rather than collecting data to assess preconceived models, hypotheses, or theories.
> 2. In qualitative methodology the researcher looks at settings and people holistically; people, settings, or groups are not reduced to variables but are viewed as a whole.
> 3. Qualitative researchers are sensitive to their effects on the people they study.
> 4. Qualitative researchers try to understand people from their own frame of reference. Central to the phenomenological perspective . . . is experiencing reality as others experience it.
> 5. The qualitative researcher suspends or sets aside, his or her own beliefs, perspectives, and predispositions.
> 6. For the qualitative researcher, all perspectives are valuable. The researcher seeks not "truth" or "morality," but rather a detailed understanding of other people's perspectives.
> 7. Qualitative methods are humanistic. When we reduce people's words and acts to statistical equations, we lose sight of the human side of social life.

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> When we study people qualitatively we get to know them personally and get to know what they experience in their daily struggles. (pp. 5-7)

Qualitative methods lend themselves to research that aims at developing detailed descriptions, integrating multiple perspectives, describing processes, bridging intersubjectivities, and identifying variables and framing hypotheses for quantitative research (Weiss, 1994).

One does not, however, stand outside such an endeavor, especially when it entails an immersion in a subject as freighted with personal meaning as dying. Speaking of the "dogma of immaculate perception," Nietzsche stated, "everything of which we become conscious is arranged, simplified, schematized, interpreted through and through. . . . We never encounter facts (1968, p. 263-264). And, in fact, interpretation is a vital aspect of qualitative analysis.

Critical social theory speaks to the threats to objectivity created not only by history and culture but by the observer's influence on the process:

> Communicative experience originates in an interactive context in which at least two subjects are linked within the framework of a linguistically produced intersubjectivity of agreement on meanings that remain constant. In that framework the "observer" is just as much a participant as the "observed." (Habermas, 1988, p. 92)

Integrating critical theory into their work, many qualitative researchers actively attempt to examine their biases as well as the effects their participation has on the research process (Kidder & Fine, 1997). Such an attempt at self-examination was made throughout this study.

Design and Data Collection

The investigation utilized a case study design. Case studies have played a central role in clinical psychology and have been used to develop therapy techniques, to study rare phenomena, to illustrate methodological issues, and as a

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way to call attention to unmet clinical and research needs (Kazdin, 1992; LaGreca, Lemanek, Kazak, 1995).

Data was collected by use of the clinical method, an unstructured, open-ended interview that began with a general question and then followed the lead of the participant. This method allowed the adolescent and parent(s) to describe the experience in their own words and at their own pace. As Robert Coles (1990) remarks, "what a child may not show comprehension of in a formal . . . setting, in choosing among multiple choice alternatives, that child may well think about and talk about in his or her own manner and time" (p. 23). The clinical method allows one to remain in the psychological space of the participant rather than focusing on the predetermined interests of the interviewer, and, by doing so, respects the sensitive nature of the topic (Bearison, 1991). Of course, this investigation did have a focus and participants were told that I was trying to understand what it is like to have (have a child with) cancer, and that I was interested in learning how parents and children talk to each other about the experience. To a great extent, however, participants controlled the way the narratives unfolded. Many of the issues I wished to learn more about emerged spontaneously in these narrations, while new, and unexpected, topics surfaced over the course of the interviews.

The clinical method also allowed me the freedom to encourage a respondent to develop any response at length (Weiss, 1994). Probes that were used included: Can you tell me more about that?; What happened next?; What was that like for you?; Was there anyone else there when that was happening?; Did you talk to anybody about what was going on when that was happening?

Although qualitative interviews have been criticized for not providing widely generalizable findings, they capture the wide range of variation that exists in human experience and are responsible for much of what we know about the effects of crises in personal lives (Coles, 1990; Weiss, 1994). Not only do such narratives

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fill in the affective element in social science research, "they remind us that although the stories of all patients have common themes, the cancer experience itself remains unique for each patient" (McQuellon & Hurt, 1993, p. 106).

The reliability and internal validity of qualitative studies have also been called into question, yet methods to address these concerns are available. By coding the data in ways that allow another person to understand their derivation, and thus arrive at similar conclusions, consistency, or replicability, can be achieved (Rudestam & Newton, 1992). Internal validity can be ascertained through structural corroboration, that is, through prolonged engagement with participants, persistent observation, revising working hypotheses as more data become available, and clarifying tentative findings with participants (Rudestam & Newton, 1992).

An interview guide (see Appendix) that covered the following domains provided a loose structure for the interview:

1. Family composition (including demographic information)
2. Illness and loss history
3. History of current illness
4. Diagnosis
5. Communication
6. Isolation/Withdrawal
7. Thoughts and feelings about death and dying
8. Meaning of the illness

Participants

Six children participated in the study: two adolescent boys, ages 13 and 17; one pre-adolescent boy, age 11; and three adolescent girls, two of whom were 16, and one who was 17. Four mothers and one adult male friend participated in the parent

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component of the study. Parents ranged in age from 30 to 48. Three children were being raised by their mothers, one boy lived with his grandparents, and two children came from intact families. Two fathers were asked to participate. One father declined. The other father agreed initially, but never made himself available for meetings. The final composition of the dyads was: One 11-year-old boy and his mother; one 17-year-old boy and his mother (father declined); one 13-year-old boy and his adult male friend (grandmother declined but gave permission for child to participate); one 16-year-old girl (mother participated after the child's death); one 16-year-old girl whose mother was not interviewed but with whom I spoke when she visited her daughter; one 17-year-old girl and her mother. The fact that several parents consented to participate but then were not available for interviews highlights the ambivalence surrounding discourse about illness.

Participants were recruited from the Pediatric Hematology/Oncology divisions at two large urban teaching hospitals. While one of these hospitals serves a range of socio-economic groups, the hospital where most participants were recruited serves an extremely poor population, most with Medicaid or no health insurance.

Selected participants met the following criteria:

1. English-speaking male and female adolescents between the ages of 11 and 17 who had been diagnosed with cancer.
2. Parent(s) of the adolescent spoke English.
3. For the adolescent, a projected one-year survival rate estimated at less than 25%, as determined by the attending physician on the unit.

The criteria for inclusion in the research proposal specified adolescents between the age of 12 and 16, but due to the low number of eligible children and the difficulty in gaining consent from those children or parents who were eligible, that age range was revised. Two children who were approached stated that they did not want to participate. One of these children, a 13-year-old boy, stated that he

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did not want to talk about his illness. The other child, a 12-year-old girl, had recently come from the West Indies for treatment. She was having difficulty getting acclimated to her new surroundings, was separated from her mother, and was generally uncommunicative. She was referred for a psychiatric consultation.

In addition, the original design called for recruitment at only one hospital. To maximize the number of potential participants a second hospital site was added several months into the study.

Diagnostic categories included: Osteogenic Sarcoma (3); Renal Cell Carcinoma (1); Synovial Sarcoma (1); Acute Myeloid Leukemia (1). As almost all of the children had experienced a process of diagnosis, remission, and relapse, a short digression on the nature of cancer progression and treatment is in order.

Granowetter (1994) outlines the following stages in cancer treatment. After a child is diagnosed with cancer, treatment is started as soon as possible. The type of cancer a child has dictates treatment options. The children in this study had undergone one or more of the following treatments: surgery, amputation, radiation, and chemotherapy. The goal of initial treatment is to obtain a remission, a state where no disease is present. Further treatment to maintain remission follows. Relapse is the recurrence of disease during or after therapy. Relapse may mean that the original disease has returned or that it has metastasized to other areas of the body. Many cancers respond to treatment for relapse but death due to relapsed disease or as a consequence of therapy occurs in about 40% of all childhood cancer patients (Granowetter, 1994). When no further treatment options are available, palliative care is introduced. Palliative medicine includes management of pain and keeping a child physically comfortable. Palliative chemotherapy and radiation may also be used to halt the growth of existing tumors, thereby providing symptomatic relief.

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The adolescents who participated in this study were in varying stages of treatment: two were in palliative care; three were in active treatment; and one shifted from active treatment to palliation during the course of the study. Although a guarded, rather than a terminal, prognosis was used to select participants, four of the children died during the eleven-month data collection period.

Procedures

I was introduced to participants who met the selection criteria by the attending physician on each hematology/oncology service. The attending physician told prospective participants who I was, that I was doing a study on "what it is like to have cancer," and that I would explain further if they would like to talk to me. I then explained the study to interested patients and their parent(s), obtained written consent, and scheduled a first meeting. (See Appendix for Script and Consent Forms.)

Although an attempt was made to schedule interviews once a week over a four-month period, the unpredictability and strains of grave illness quickly proved such rigidity unworkable. A flexible schedule that met individual circumstances was then adopted. In some cases, I visited the sick child two or three times a week for two months; in other cases, interviews occurred once or twice a month over five or six months. Some parents, having initially agreed to the interviews, were reluctant to meet once the study began. In one such instance interviews were conducted after the death of a child, in another case no parent interviews were conducted.

While most interviews were tape-recorded, there were times when a child requested that the tape recorder not be used. I made detailed process notes immediately after these meetings. These notes included a reconstruction of the conversation that was as close to verbatim as possible. I also wrote notes of a

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more diaristic nature, recording my observations and reactions regarding interviews, life on the ward, and other occasions such as funerals.

Parents and children were seen separately. Interview material gathered from each participant was confidential. Neither children nor parents learned about the content of another person's interview. Exceptions to this policy were made when a child died. The first time this situation occurred the mother asked if she could listen to her daughter's last taped interview. After careful consideration, I made the decision to make a copy of the tape for her to keep. Reflecting on this mother's positive response to the tape, I decided to ask each parent whose child had died if they would like an edited tape. I tried to remain respectful of a child's confidentiality when making these tapes. I usually included snippets of conversation where a child had mentioned a parent, was engaged in play, or was discussing a neutral topic.

Most interviews lasted approximately 45 to 60 minutes, but they ranged from 10 minutes to three hours. Some children asked to draw pictures, and although not part of the original design, I then asked each child if he or she wished to draw. Interviews were conducted in hospital rooms, conference rooms, treatment rooms, visitor's lounges, parks, and in participants' homes.

In addition to talking to participants, I conducted a chart review, and when possible, spoke to the attending physician managing the case. Chart reviews provided information not otherwise available to me, e.g., full medical and treatment history. Talking to physicians was enlightening because I was kept abreast of a child's physical condition, learned more about the personal experience of the treating doctor, and was invited to attend important meetings with the child and/or family.

In the first interview, participants were reminded of the general focus of the investigation: "I am interested in learning about what it's been like for you/your

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child to have cancer, and what it's like to talk about it with your parent(s)/child." Participants were asked open-ended questions about their family composition, their previous experiences with illness and loss, and the history of this particular illness. I then followed-up on comments made by the participants. In subsequent interviews I began by asking, "What's been going on since I saw you last?" or I asked a child why he or she was in the hospital. In ongoing interviews, I also asked questions about topics raised in previous meetings.

Two paper and pencil measures (For adolescents: CSD Scale, Phipps & Srivastava, 1997; and How I Feel Questionnaire, Walker & Kaufman, 1984. For adults: Personal Reaction Inventory, Crowne & Marlowe, 1964; and Self-Evaluation Questionnaire, Chaplin, 1984) were in the original design. These scales were to be used to categorize participants into four defensive styles: Defensive high anxious; High anxious; Repressor; and Low anxious (Weinberger, Schwartz, & Davidson, 1979). These instruments were not to be used in a statistical analysis but as a guide for interpreting the narrative data. Once the study began, however, it became almost impossible to administer the measures in any consistent fashion. One young woman was much too weak to fill out the forms. Another died before she could take the tests. One boy was resistant. One parent would only participate in the study on an informal level. As a result, this aspect of the study was abandoned.

During the study, and at the conclusion of the investigation, participants were asked if they wished a referral for psychological counseling. No participants requested a referral. At the conclusion of the study, one sibling, although not a direct participant, was referred to his school guidance counselor for psychological support.

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Method of Data Interpretation

During the period that I was collecting data, I transcribed all audio-tapes for analysis. Analysis was an iterative process with transcripts being read regularly over the interview period; particular phenomena identified and assigned conceptual labels, or codes; and codes evolving and being refined as patterns and dissimilarities in the material emerged. In this way, I was able to identify thematic material throughout the data collection process. I then incorporated these themes into my inquiries. I also probed more extensively when participants raised these issues. As I was developing a coding system while I was still interviewing, I was able to ask participants to verify my interpretation of the material, thereby increasing validity.

I began the final analysis with a working list of 42 themes. After all of the material related to each theme was grouped together, some thematic codes were joined under a broader conceptual heading, some set aside, and some divided into subgroups. For example, anticipatory mourning was subsumed under the more inclusive heading of isolation; defense and coping was divided into subgroups by type of defense mechanism. Eventually, material was organized into eight major thematic categories, with subheadings under each primary theme. I then read the narratives in each category with an eye toward identifying the particular story they told.

Thematic material can be treated by means of either case- or issue-focused analysis (Weiss, 1994). Case-focused analysis captures the individual experience of participants within the context of their lives. Issue-focused analysis is concerned with what can be learned from all participants about a specific issue, event, or process. Over the course of interpreting the narratives, it became clear that key themes were embedded in the context of each particular parent/child relationship. For this reason, both case- and issue-focused material is presented.

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The case material, which provides the opportunity to develop a sense of each participant, appears in the next chapter, "Case Vignettes." This chapter is then followed by "The Illness Trajectory," a thematic presentation of the predominant issues raised by the children and their parents. The final chapter of the results section, "The Qualitative Interview with the Terminally Ill," describes the effects of the interview process on participants, hospital staff, and myself. For purposes of confidentiality, the names of all participants and physicians have been changed. Quotations have been left in the original language, unless to do so would impede understanding. In these instances, minor editorial changes were made.

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Case Vignettes

Anticipation

I think he ought to practice,
but he won't; he ought to get used to things.
It's death, I say; get ready.
But he goes on talking about life.
He liked it here, he had a good time.
You would, too, he says, if you'd relax.
I can't, I tell him, this is too much for me.
For me, too, he says, but so what. He's not dead yet.
I've lived by pretending what's coming is already here.
Anticipation--for me
that was the key. But he goes on eating peaches,
planning for spring, hooking the holes of his life
to the cleats of the future. It won't come,
everyone can see this. Death's
taking over the property. I look up,
and the sky's a huge blueprint
for an estate about to be built,
and I don't know the first thing about hammers
or nails. I roll him to the window
so he can see, but to him the sky is delight,
and the clouds are just puffs and white china dogs.

Charlie Smith

There are many responses to dying. The present study was conducted to explore the ways in which children faced the prospect of their own death and how they communicated about it with their parents. Over the course of the interview process, four of the six children who participated died. These children confronted not just the possibility of death but its certainty. While the narratives contained common themes, they also captured a process that was unique to each parent/child

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dyad. To anchor the themes in the context of the people whose lives they reflect, these individual stories will be told in six vignettes. These vignettes touch on such key issues as isolation, psychological defense, communicating about dying and death, and the circumstances surrounding the final days or hours of life. In the following chapter, which examines the central issues raised by this group of children and parents, these topics will be explored more fully and these individual stories will develop.

The Royces

I don't want to be rude and I don't want to hurt nobody's feelings.
Lillian Royce

To talk about it made it worse.
Mrs. Royce

Lillian was a soft-spoken, slightly built 16-year-old West Indian girl with light brown skin, delicate features, and a polite, serious air. She was diagnosed with a rare, and fatal, form of cancer when she was in the seventh grade. In our first meeting, she told me about the beginning of her illness: "I used to take dance and my mother used to feel my stomach. She felt something hard but we always thought it was a muscle. We were going to Disneyworld and my father said I had to get a check-up before we go. When I got this check-up, the doctor said he thought my liver was enlarged and he said take a sonogram. So we went to Disneyworld for the weekend, and when we came back, the doctor took the sonogram. They said there was a mass on my kidney and they didn't know what it was so they had to take a CAT scan. I took the CAT scan and they was, like, I have to have surgery immediately."

Lillian's parents were told that she would probably die within three years. Shortly after she was diagnosed, Lillian had surgery and was treated with

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chemotherapy. A year before our interviews began, Lillian had been given one month to live, one of a series of prognostic predictions that she would prove incorrect.

When I met Lillian, she was receiving palliative care: medication to relieve pain and radiation to slow the growth of her numerous tumors. Over the 10-week period that we met, Lillian went from living at home, with intermittent brief hospitalizations, to living in the hospital, with brief visits home. She spent the final two weeks of her life in the hospital. In our conversations over these final months, Lillian was preoccupied with conflicts in her family.

At the time of her diagnosis, Lillian lived with her mother, father, and younger brother; an older half-brother was living in the West Indies. Mrs. Royce was petite and seemed younger than her 38 years, more like Lillian's sister than her mother. She usually looked depressed and tired, her full mouth either set grimly or drooping in despair. Her voice was muted, and she avoided eye contact, which contributed to the sense that she was unapproachable.

Lillian described herself before she became sick as "mostly into school. I was in drama, dance, and I did performances." Her mother concurred. "All she did was school, play, and be happy, she was a happy child, she liked to play around the house, have fun, she had a lot of friends before she got sick." Lillian said she and her mother enjoyed "going to the bookstore or we go shopping, she'd do my hair and we'd go get my nails done, and I used to work in her store. I used to like doing that stuff, it was fun." But Lillian also described family conflicts: "My mother was always busy, I don't think she came to any of my performances but I understood, and then my dad didn't go to my graduation. He came the wrong date."

A year after Lillian was diagnosed, her father left the family. She said, "They were having their own personal problems, but then every time I'd say anything, he

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says like it's my fault. He said he couldn't take the pressure of me being sick." As a result of the friction between her parents, Lillian's father was unwilling to take care of her younger brother, thus limiting the time Mrs. Royce could spend at the hospital. Lillian's half-brother came from the West Indies at this time to help take care of both Lillian and her younger brother, but according to Lillian, this arrangement didn't work. "He helped for a while, and as soon as he started making friends and stuff, he stopped helping. Now when I'm in the hospital, my mother can't spend no time with me. She sees me like in the evening; she doesn't stay at night because she has to be at home. My older brother's not reliable, and then my younger brother will be there by himself."

Lillian's father was unable to cope with her illness, and she experienced him as insensitive. "He tells me I'm sick, it's not nice at all. I mean, I *know* I'm sick, you don't have to remind a person." Even though her father's visits were painful, Lillian wanted him to be a part of her life. "Cause I'm sick I should have both my parents," she explained. To maintain contact with her father and yet counter his hurtful comments, Lillian said she would "sit there and ignore him. I let him talk, cause if you say anything to him, he'll say nasty things to you, so I've learned to bite my tongue."

Mrs. Royce, struggling to take care of Lillian and her younger brother as well as attend to her business, was also having a difficult time. When Lillian was diagnosed, Mrs. Royce says she was "numb, I didn't cry, it's like I didn't believe. I figured Lillian would get over it. I didn't believe, I just stopped my mind from it." But now Mrs. Royce was all too aware that Lillian was dying. "I know she was going to die. I was told by the doctors. I was depressed, I was very sad by myself, I got to do things to get that off my mind. I go to the gym, try to do things that it was not constantly on my mind. I work, go to the gym. When I'm not at the hospital with her, I would do those things, just not to think about her being sick."

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Mrs. Royce tried to visit when possible, but she also wanted to forget that Lillian was dying and she avoided confronting the subject; in fact, she did not meet with me until shortly after Lillian's death. Mrs. Royce told me then: "She was just there suffering, that's the basic part of it, she was suffering a lot, and I couldn't, I couldn't bear to see her like that, and then to talk about it made it worse." Mrs. Royce was also angry at the lack of support she received from her husband and hurt by his abandonment of the family. Frequently, Lillian was caught in the middle.

Lillian observed: "My mother would come and say good evening, and he would ignore her, and if like he's here and she comes, he leaves, and he doesn't say anything to her. . . . My mother, she gets angry 'cause I still speak to him, but a whole bunch of people say I should still speak to him 'cause I'm sick--it's not time for me to have malice on anybody."

Ultimately, Lillian felt responsible for the many pressures in her family, saying, "If I wasn't sick, there wouldn't be so many problems in my house," and she began taking care of everyone else. She ignored her father's hurtful remarks: "Sometimes I just ignore him, not even talk to him and stuff, and when he comes, I just answer him and just watch TV, like I don't make conversation, I just answer, 'cause it's kind of rude when somebody's talking to you and you don't answer back. I wouldn't do that to nobody." She squelched her anger: "He said stuff that upset me and I didn't like it, just I don't want to be rude, and I don't want to hurt nobody's feelings so I just keep it to myself. Sometimes when I'm mad, I just write it down in my journal." Worried about burdening her mother, she tried to hide her pain. "If I'm in pain and if it's not bothering me much, I don't bother my mother about it. I try as hard as possible to like leave her alone, you know, she's upset, so I try to leave her alone." Even though Lillian preferred being at home, she stayed in the hospital. As she said, "It's scary for my mom when I'm at home."

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She tried valiantly to get better for her mother, saying, "You know, once I get better she'll feel . . . she won't be so sad anymore."

In the face of her massive physical deterioration, Lillian's insistence that she would get better was striking to everyone who knew her. Lillian weighed barely seventy pounds, and it seemed as if half of this weight was from tumors. She had brain tumors that changed the shape of her head and caused seizures. These tumors were being treated with radiation, which made her hair fall out. She had swollen, oozing tumors on her left shoulder and right breast. The tumor on her shoulder was so large that it stretched her skin until it was taut and shiny and radiated with heat. She had swelling in her groin and a tumor near her left knee. Her matchstick-thin legs were propped up on pillows to relieve the pain, and when a leg would fall from the pillows, she did not have the strength to lift it back up. Sometimes she lost sensation in her legs and did not even notice that one was dangling off the side of the bed. Her lungs were filled with mucus, which had to be suctioned in a painful procedure. Her breathing was shallow and labored, and her voice, barely a whisper, seemed to rattle when she spoke. Her skin grew dark and fragile, flaking off in your hand when you touched her. Her food intake decreased to an occasional thin slice of pound cake. Still, Lillian refused to acknowledge that she was dying.

Her mother described the meeting where Lillian was told that she would die from her disease. "She don't want to hear, and then [the doctor] said I'm sorry and they talk about the intubation [insertion of a breathing tube], if she would want them to intubate her, and she told them yes, and that was it, she didn't want to hear it, didn't want to hear nothing about her death, she said because it made her sad." After this meeting, Lillian said to me, "I'm not worried about myself because I feel that I'm going to get better. Everybody has to go through something and this is my thing to go through, but I'm worried about my mom."

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Many people who knew Lillian believe that it was her ferocious grip on life, what one nurse referred to as her "hanging-on strength," that enabled her to live as long as she did. It was clear that Lillian did not want to die, but it also seemed as if she couldn't face death until her family was united enough to support her. Describing how she would take care of her father if he were ill, she conveyed her own longing: "I would visit him every day, you know, I'd take care of him." She wanted her parents to get along so that they could both be there with her. She wanted her older brother to visit more. She wanted her father to be more understanding, and her mother to feel less pain.

Four days before she died, Lillian grew angry at something her father said. According to Mrs. Royce, Lillian "told him to leave and don't come back." Three days before she died, it was Mrs. Royce's birthday and Lillian urged her mother to "get dressed up and go out with friends" to celebrate. Two days before she died, Lillian was upset because she hadn't been strong enough to call her younger brother and wish him happy birthday. "I didn't want to be rude, didn't want to be rude." The day before she died, Lillian's mother found her in distress. "Lillian wasn't talking, she was like moaning so I said to her, are you in pain? She could hardly talk, she was groaning, so I asked her, do you want me to stay or do you want me to go and make dinner and bring dinner back for her? She told me yes, and while I was there they told me she couldn't breathe, they have to intubate her, and she was crying all that she can't breathe."

After being moved to the intensive care unit (ICU) and intubated, Lillian was approached by her doctor to discuss a do not resuscitate (DNR) order. When asked what measures she wanted the doctors to use to save her life, Lillian signaled for a piece of paper and wrote "DO EVERYTHING!" Lillian died the next morning. Her mother said, "She died about six o'clock. She couldn't breathe, and the machine couldn't do any more for her. At that point, Lillian was very sick.

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She was in a lot of pain, she was suffering, and dying, there was nothing the doctor could do, or that I could do, and I think that's the only relief from her pain and suffering, and I think for the past three years, when Lillian died, that's the best sleep she ever had."

James Wilson and Kevin Churchill

I don't want to die!
James Wilson

He allowed me to be like his dad . . . that was the way I guess it was meant to be.
Kevin Churchill

James was a 12-year-old Hispanic boy with a keen imagination and a hunger for interpersonal connection. James was medium height but long limbed, with coffee and cream coloring, warm dark eyes, and a shy, winsome smile. He was diagnosed with a cancer of the connective tissue in his right leg at the age of six and had had this leg amputated below the knee at that time. He recalled: "I was six. I was sick. I found out there was a bump in my leg. I couldn't straighten it out and my grandma took me to the doctor. They found out it was a tumor and I went to this other place and they stuck a needle in my leg to get some tissue out, and then they found out what it was and I had to stay in the hospital, a long time in the hospital." James said that he wasn't told what was wrong with him, but that he had been told he would have to have his leg amputated.

The cancer metastasized to James's lungs when he was 10, and he was in active chemotherapy treatment for almost two years. The cancer was progressing, however. When I met James, he was receiving palliative chemotherapy to keep the size of his lung tumor stable, and thus reduce his pain.

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James and his 13-year-old brother were raised by his grandparents, now both elderly and ill. His mother was a homeless substance user who had no contact with the family. James lived in the same apartment building as his father and many of his aunts, uncles, and cousins. James's grandmother declined participation in the study, saying that she didn't like thinking or talking about illness. She gave me permission to talk to James, if he wished, but stressed that she didn't want him to know he was dying, explaining, "I don't want him to be sad." Yet it was clear that James was sad and was eager for human contact. In our first interview, he talked about Heaven and said he worried about "when I die, where am I going to go?" (See Figures 1 and 2 for drawings of James's thoughts about this world and the "Heven" world.)

James's communication about dying was usually symbolic, expressed in dreams, drawings, or indirect language. One day, after learning that the chemotherapy he was receiving was not working, and that his tumor was growing, James shrouded himself from head to foot in his sheet. He gradually pulled the sheet down to reveal one eye, then another, then his nose. Finally, when his full face appeared, he said quietly that the meeting with the doctor had seemed "like a dream." He went on to say that his whole life seemed like a dream, "a bad dream," and then started asking me about cannibalism. He wanted to know what I would do if I was starving and I was with a dog--would I eat the dog? What would it feel like to face that choice? What would it be like to be eaten? Although it appeared that James was talking about how much we want to live, he also seemed to be telling me that he felt he was being eaten alive by his cancer. Another day, he wrote a poem:

Bird wants the sun for green growing nest
blue dolphin in black water
wild magic and eagle sea

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James explained to me that when Indians die, they want to be eagles.

James's grandmother came to visit daily and brought him food from home. He was very attached to her, although they rarely spoke. James said once that his grandmother took good care of him, making sure he went to the hospital even when he didn't want to. His father came to visit every few days, and they watched cartoons together but had little conversation. His grandfather, brother, and other family members did not visit James in the hospital.

Four months before James died, he met Kevin Churchill, an interpreter for the deaf who was interpreting for James's roommate. They struck up a friendship, and Kevin became a primary figure in James's life, almost a surrogate father. Kevin visited James often, and they made plans to go to the museum to see the dinosaurs and to go to the movies. Kevin tried to arrange for James to attend a camp for kids with cancer. He brought James toys to relieve the boredom of being in the hospital. Kevin talked to James about his illness, and James called him frequently, usually in the early morning when the pain was greatest.

James's family were wary of the outside world and had kept him isolated because of his illness. He did not go to school and, unlike most of the children I met, did not have a home tutor. Kevin said, "Maybe it was like they thought they had to protect him, so they kept him more isolated. James was sort of panicked with the thought of being sent away, and they would tell him things like if you don't do this, we're going to have you taken away, so because he internalized everything, I think he had more fear about all of that stuff--he'd be taken away if he didn't take his medicine or if he didn't get his shot."

James's friendship with Kevin created a rift in the Wilson household. The Wilsons did not like it when Kevin visited James at home. About six weeks before James died, Kevin suspected that James was being abused by an uncle and a report was made to the Administration for Children's Services (ACS). Angered,

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the Wilsons barred Kevin from visiting James either at home or in the hospital. Unable to return home until an investigation had been completed, James was kept in the hospital under an ACS hold. Miserable--and torn between his friend Kevin and his grandmother--James said, "I don't need nobody!" For a week, he would not talk to visitors or staff members. Eventually, when the abuse was not substantiated, James went home, the Wilsons relented, and Kevin was allowed to visit James when he was in the hospital. Still, a tense atmosphere lingered.

Perhaps as a result of his isolation, James sought out relationships with the hospital staff. Although he could be angry and withdrawn, James had a tenderness that drew people to him. One of his attending physicians, who rarely expressed his emotions, told me that when James died, it would break his heart. For his 13th birthday, I gave James a Beanie Baby that resembled a drawing he had made for me. He lavished love and care on the little animal. "It's like they're real, like they're alive," he said. "Unless it gets broken, it's like then they're dead. These are alive and they're happy." He told me that he was the stuffed animal's father and that his job was to take care of him. "I make sure no one breaks them, lets them get dirty. I wouldn't let anyone treat them bad." Noticing his animation, members of the staff then began to buy Beanie Babies for James, and he was given a poster on which he checked off all the animals he owned. He kept his growing collection in a bag by his bed and proudly took them out to show everyone.

Because Kevin was not a member of the immediate family, he did not know that James was dying, and there was no mechanism to inform him. James himself hinted at it when he told Kevin: "I won't get married and have children," and when he was reluctant to make plans for all but the immediate future.

James's looks had not altered appreciably, but as his cancer progressed he lost complete use of his legs and had difficulty breathing. He was treated with oxygen, which helped his breathing but made him feel tethered to his bed. Although he

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had integrated his amputation into his self-identity, he now began to speak of himself as "broken."

The staff knew that James had only a few weeks to live, but because James looked good and was actively engaged with him, Kevin still did not know. One night, a few weeks after James's 13th birthday, his grandmother and Kevin were visiting. Kevin and James were playing a board game, talking and laughing, when suddenly James began to cough up blood and gasp for air. Then, as Kevin describes it:

> The last thing that he did was grab my hand and squeezed it tight, and I almost thought is he trying to tell me I'm not weak? Like maybe he was just reaching to grab me because he was grabbing me, or was he saying I'm not ready to die, cause that's when he yelled out *I don't want to die!* He was absolutely strong and conscious right up to the moment he died. He wasn't like weak, and he wasn't fading or any of that; he was just what's going on? And get me more oxygen and get the nurse in here and what's happening? And then yelling *I don't want to die* and squeezing my hand. It was all this strength and then boom, gone, just in a flash.

After James died, there was a marked shift in the Wilson's' relationship with Kevin. They came to appreciate the support and care Kevin had provided James in his final months. James's grandparents and Kevin planned the visitation and funeral together. Kevin sang at the funeral and was a pallbearer. James was buried with all of his Beanie Babies. A month after the funeral, Kevin said, "I really just saw him as my son, that's how I saw him in my mind. Part of it was that he allowed me to be like his dad, he just allowed that from however we interacted, that was just what he allowed, so it all sort of came together that way--that was the way I guess it was meant to be."

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The Sahdis

I never really break down, I'm always up, so you can't expect no different ways from me.
Nickie Sahdi

She will live a hundred and more years.
Mrs. Sahdi

Nickie, a 16-year-old West Indian girl, had an infectiously cheerful approach to life and to her illness. Nickie had been on vacation, visiting relatives in the United States, when a pain she developed was diagnosed as osteosarcoma. "I came on vacation and my foot started to swell. Before, back home, they run a test, but it didn't say anything. They just said there was fluid under the knee, so I didn't bother with it. So I came up here for a holiday, and it started to swell bigger than before. I came to the doctor and, well, the doctor run the test and they said it looks like a tumor. . . . When they found out what it was, I started chemotherapy, and then later on in the year they amputated." Nickie's father came to stay with her when she was first diagnosed, and then her mother. By the time she had had her leg amputated several months later, the whole family had moved here from the West Indies.

After being in remission for six months, Nickie had a relapse. Her cancer had metastasized to her chest. During the period that we met, Nickie had surgery to remove the new tumor and was treated with a rigorous course of chemotherapy.

Nickie is the oldest child in her family. She has a sister and brother who are teenagers, and an infant brother. In addition, there are numerous aunts, uncles, and cousins who live near her.

Both Nickie's father and mother consented to participate in the study. Mr. Sahdi, a small, wiry man in his thirties, had initially seemed eager for the family to share their experiences. Mrs. Sahdi, a full-figured woman with long, silky, ebony-

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colored hair, an effervescent laugh, and a way of bringing the fresh air in with her when she entered a room, was more ambivalent. Over the six months that I met with Nickie, both her parents studiously avoided being interviewed. I did, however, talk to Nickie's mother when she was in Nickie's room visiting, and she seemed to share the same high spirits as her daughter. Sitting in the room with them was like being lifted aloft on peels of laughter and rapid, lilting speech that approached song. Nickie referred to these conversations as "talking stupidness."

This breezy style seemed deepseated and during the time we met, as Nickie went through relapse, surgery, and time in the ICU, her manner remained nonchalant. After she lost her hair to chemo, Nickie was pleased with her new short hairdo. She looked forward to meeting with the surgeons because they were "exciting," and she thought that anesthesia was "the greatest." Her approach to her illness was reflected in her comments: "It happened, it will go," and "I say I wouldn't die. If they say I'll die, too bad for them. I will not."

Nickie described her attitude to me: "I never really break down, you know, like some people break down. I'm always up, so you can't expect no different ways from me. Everybody who meets me always say I'm bright, my face is all bright, I'm always laughing." But she also talked about her boredom and loneliness in the hospital, and how she did sometimes think about dying. "I think about it, but I just think about it, I don't worry. I think I shouldn't worry because everything is going to be okay." Nickie also handed over her worry to her mother. "That's her job to think about it. I don't really bother with it, because I know that's their job to think about it."

Mrs. Sahdi was particularly close to Nickie, and she and Nickie reinforced each other's upbeat outlook. One day, shortly after Nickie's relapse, Mrs. Sahdi said, "She will live a hundred and more years. Nickie have the mind to get well, she don't think about it, she just thinking about the treatment, she don't think about it

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will come back, she no thinking of that. She think positive all times to herself and that's why I love her. If you ask her, she say, I'm fine, she don't say, I don't feel too good. That's why she'll get good and she'll look nice and pretty and she'll get a husband and make two kids for me and I'll help her."

During the time I met with the Sahdis, there seemed to be little room for sadness, fear, or anger. When our interviews ended, Nickie's doctors believed she would be cancer free. Five months later, Nickie's doctors discovered that her cancer had spread throughout her chest. She had surgery but the cancer was advanced and her condition terminal.

Nickie's parents were estranged during the last weeks of her life, and she tried to reconcile them. Her mother also had difficulty accepting that Nickie would die. At this time Nickie was in the ICU. Feeling the effects of family conflict and virtually abandoned emotionally by her family, Nickie withdrew into silence and sleep. Two weeks before Nickie's death, her physical condition deteriorated and her imminent death could no longer be denied. Mrs. Sahdi then began to spend as much time as possible with Nickie. They shared memories and laughed but they also talked about death. Nickie grew peaceful and calm. She drew closer to some members of the staff. One child life worker read her *Winnie the Pooh*. Nickie wouldn't let her read the last chapter, saying, "I don't know why, I just don't want to come to the last chapter."

The last day of her life Nickie woke up and told a nurse that she didn't want to die in the ICU and she didn't want to die alone. She was moved to a private room and Mrs. Sahdi came to the hospital and spent the day with her. A staff member who was present said that Nickie slipped quietly into death. Her peaceful last hours were spent with her mother, her doctor, her favorite nurse, and her teacher.

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The Anthonys

It's fun fun silly willy.
Joseph Anthony

That's the way it is, we all got to die.
Mrs. Anthony

Short and stocky, with a round face and mop of curly black hair, Joseph was a 10-year-old West Indian boy who had been diagnosed with acute myeloid leukemia when he was nine. Joseph remembered: "It started when my nose was bleeding for the whole day--from when I woke up till night, so my mother had to call a cab. She had to come home from work and take me to the hospital and then it stopped. Then they said I lost a lot of blood and had to stay, and the next day they would give me a blood transfusion. The next day, the doctors did a bone marrow, and that's when they found out I have cancer." After being treated with chemotherapy, Joseph had been in remission briefly but had relapsed shortly before we started meeting.

Joseph's parents were separated, and he lived with his mother, younger sister, and toddler brother. His mother, in her early thirties, was also short and compactly built, and had a soothing, resonant voice. Their apartment building housed a large and tight-knit family that included Joseph's grandmother, aunts, uncles, and numerous cousins. Although they had very little money, Mrs. Anthony worked only three days a week, so that she could spend more time with her children.

Joseph loved to play and make silly voices but he also had a quiet, serious manner that made him seem older than his years. His mother captured this quality in the following story:

> He is a very smart kid. At the age of five, he wanted to go to the laundry to wash his own clothes. I was sending my cousin to go wash his clothes, and Joseph said no, he insists he wanted to do it. So I said okay, let him do it, just

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> go with him and make sure he puts in the right amount of soap and everything. So she went with him. He put in the clothes, but he couldn't reach to put in the soap so she did the soap. When the clothes was finished, he wanted to take them out himself, put them in the dryer himself, put the money in, and the Laundromat that she was using they don't want kids to be messing, but somehow they allow him, and after that every week he would go to the laundry, they would put the soap in for him.

Joseph actively controlled the length of our meetings, holding up his fingers to tell me how many minutes we had left. One of his favorite lines, often repeated in a high, mad-scientist voice, was "That's fun fun silly willy." But he also spoke thoughtfully about his experiences. One night, as the hospital room darkened, he told me the history of his illness. Describing how he took care of his broviac, the central line for getting medication, he said, "You have to change the dressing, have to flush it, and it's not just like once a week, but like two or three times a week. That's a lot of work, it's like having a cat or a dog, you have to take care of it."

Joseph had always exhibited an interest in learning about his illness and talking about his treatment with his doctors, and Mrs. Anthony treated him as an equal in discussions about his condition. This decision was made right after Joseph was diagnosed. Mrs. Anthony said:

> I was crying that day, and they said he had to go for surgery, and he wanted to know why I was crying, and my sister tell him a lie and days later he asked me why I was crying, so I told him you have a very serious illness, that you can die. He said, why did they have to lie to me, why couldn't they just tell me the truth? So from that day I decide that I was going to tell him whatever, as long as it got to do with him. I said, you know what, I'm going to tell you the truth. Anything you want to know, you just ask me. As long as I know, I'll let you know. If I don't know, we'll ask the doctor together.

Mrs. Anthony was possessed of an almost preternatural calm and had a characteristic way of responding to Joseph's questions about death. "I'm not in fear. I'm not even in fear of Joseph dying, either. Like I tell him, we are all--I

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start with myself--I say we are all lucky to be alive. I'm lucky to be alive at 34, you're lucky to be alive at age 10 because they're kids who die at five and four. That's how it is, we all got to die. I tell them this all the time." Mrs. Anthony invoked this philosophy almost as a mantra, repeating it to all of her children.

Two months after his relapse, Joseph's condition worsened. His physicians, unable to provide further treatment, transferred him to a specialized cancer hospital. Over the next few weeks, Joseph began to lose weight. He no longer looked chubby, but he was puffy, a result of the medication he was taking. His hair, once so lush, fell out, lying in wisps on his pillow and T-shirt. He grew quiet, wasn't interested in playing, and became preoccupied with his pain. At the end of the month, with his cancer proliferating and no more treatment options available, Joseph returned home and was provided with hospice care. He died two weeks later, a day after his 11th birthday.

During his final weeks, Joseph initiated conversations about all of the events in his life. He and his mother spent hours together sharing memories of their trips to the West Indies and looking at all of the family photographs. Then Joseph asked for a birthday party. His mother said:

> I used to give him a party every year, from one until five years old, and at five, he said I don't like parties and he don't want any more parties, so I never give him one, and he told me this time that he wanted a party and told me I must invite this lady and another friend down the street, and I invited most of the family. He was laughing and talking with everybody, and after a while, he was lying in the chair and he was telling somebody thanks for coming, and then the pain started so he didn't want to eat any of the cake. After everybody went away, that's when we went to the bedroom, he got in bed, we talk awhile, and we said a prayer to take away the pain. I was up with him most of the night talking, and we pray together. The next day, I wanted to stay home but he said go to work. My mother was gonna be home, so he told me she'll be with him, she'll help him. My mother call me about 5 p.m. and told me he was in more pain. I just prepare and come right over, took a taxi and came. When I came

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> here, the paramedics was already here. I said Joseph, he was just getting ready to, his last words was Mommy, Mommy, please help me. That's what he said, and then he just breathed three or four times, I don't remember exactly, and that was it. The last one he did a big, deep breath, and then he let it out and then they took him out.

In retrospect, Mrs. Anthony thought that Joseph had sent her to work because "he probably didn't want me here to witness him dying. I guess he was just trying to protect me."

The Moores

As far as I'm concerned, nothing's wrong with me.
Derek Moore

I have to do what I have to do.
Mrs. Moore

Derek Moore was a tall 16-year-old African American boy, whose strapping good-looks and hip demeanor belied the seriousness of his illness. Derek was diagnosed with osteosarcoma shortly after his 10th birthday. He recalled:

> I was 10 or 11 and I was playing football. I got hit real hard and I said, my knee hurts. So, I went upstairs to my apartment and I showed my mother my knee. She put the heat pack on, the ice pack, and after a while the swelling got worse. So I went to the doctor and they took X rays. They said they didn't see anything. They said keep on doing what you're doing and the swelling will go down eventually. But the swelling just kept getting worse. I went back and they took X rays again and I guess they had some kind of specialist look at it and he told my mother. Well, they called us into Manhattan and they said they wanted to have some kind of sample, a tissue sample surgery. They thought it was bone cancer but they wasn't sure. They did the surgery and they found out it was bone cancer.

After having his right femur removed, Derek had a prosthetic metal rod and a plastic knee implanted and was treated with chemotherapy. Derek was in

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remission for almost five years. Right before his 16th birthday, Derek's doctors discovered that his cancer had metastasized to his lungs and lymph nodes. He began chemotherapy to halt the growth of the tumors with the eventual goal of removing them surgically.

When I met Derek, he was a year into this chemotherapy treatment. There had been little improvement in his condition. During the six months that we met, Derek's cancer showed no new growth, he had lung surgery, and started a new course of chemotherapy.

Derek lived in the suburbs with his mother, father, and eight-year-old brother. Derek's older brother was married and lived in the neighborhood with his wife and toddler son. Mrs. Moore, a large, self-possessed woman with a rich voice and throaty laugh, took a leave of absence from her job when Derek was diagnosed so that she could be with him during his treatment.

I asked Mr. Moore if he wanted to participate in the interview process but he politely declined. He did want to know, however, what I would do if Derek were to ask me if he was dying. His hesitancy to participate, and the worry in his question, seemed to reflect his own anxiety about discussing his son's possible death.

The specter of illness, and specifically lung disease, hung over the Moore family. Mrs. Moore's parents were both sick: "My mom has high blood pressure, sugar diabetes, emphysema, bronchial asthma. . . . My dad is recuperating from lung cancer. He had a portion of his lung removed a little over a year ago." In addition to caring for Derek, Mrs. Moore supervised her father's treatment: "I do a lot of the running back and forth with him now. I've scheduled the doctor's appointments and I let the doctors talk to me." Mrs. Moore was saddened by her father's illness and worried that his condition foreshadowed what lay ahead for Derek: "My dad would walk four or five miles a day. He would walk from his

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house to my house and you'd almost have to beat him in the head with a hammer to get to drive him back home, because he would want to walk back home. He's pretty sick right now. He doesn't want to let me know it, but I know it. I know breathing is a task for him. It doesn't seem to be a reflex like it is for you or I. He doesn't want to upset me, I know that, but that's why I go to the doctor with him now, because I need to know what's going on."

While Derek was in remission, Mr. Moore's mother died of cancer and his father had a fatal stroke. Mrs. Moore said, "My husband's mom was having a lot of headaches and they found an aneurysm behind her left eye. We put her in the hospital to have the aneurysm removed and in her post-op testing they found cancer on her lung. They attempted to remove the tumor and it was too late, it was in her stomach, it went to her brain. The good thing was that it wasn't a long, drawn out affair. She got sick in October and she passed in February."

After her father-in-law had his first stroke. Mrs. Moore said she and her husband "were in the process of arranging home care and putting him into rehab, so that he could learn to use his arm again." But while the Moore's were on a two-day trip to Nassau, Mr. Moore's father had another stroke and died before they could reach home.

Mrs. Moore described her husband's reaction to these deaths:

> Gordon gets lost in space every now and then. He was his mother's only child and they were very, very close. When he gets in his moods, you just have to back up and leave him alone. He'll disappear for hours, and I'll drive by the cemetery and I'll see him sitting there in his lawn chair. So I just leave him alone. I tell him, you've got to stop this. They're robbing people in the cemeteries now. He just says, what are they going to rob? My chair? Yeah, he takes his lawn chair and he sleeps, snoring, sitting right there at their grave. It makes him feel comfortable, so what are you going to do?

After his parents died, Mr. Moore became even more protective of Derek. As Mrs. Moore said, "He was like a big umbrella." Initially, Mrs. Moore held her

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husband responsible for Derek's cancer: "A lot of times . . . I would blame my husband's family because cancer is so rampant in his family. Our doctor would always tell me that there was no scientific proof that cancer was a hereditary gene. That's when I started understanding the break-up of the cell and what causes cancer. There's nothing hereditary about it but I used to say, I wonder if he got it from his dad, you know, if his dad passed this on to him, because so many people in his family had died, or are dying, of cancer." Mrs. Moore never shared these thoughts with her husband and they eventually dissipated: "I don't even go there anymore . . . it happened and we're dealing."

Dealing for Mrs. Moore meant seeking information about Derek's disease and treatment. She also kept a journal and prayed. Like her husband, Mrs. Moore was protective of Derek. She spent the night with him when he was hospitalized and accompanied him into the operating room when he had surgery.

For Mrs. Moore, Derek's diagnosis was the first step in a grueling journey. She recalled that when Derek first had knee trouble, "We called the doctor and they opened the office and she had a radiologist come in and they took X rays. About three days later, they called us and told us to take him to the hospital . . . and it's been hell ever since."

This image of hell was recurrent. One night, when we were talking in the hospital visitor's lounge, she said:

> I had a terrible nightmare the other night. My husband woke me up. He said I was, not screaming but, like, wanting to scream, and kicking. He made me wake up completely so I could tell him. It was the strangest thing. I was walking along a street, on a regular street, and then a big dark cave, and all of this smoke coming out of the cave. And these people were like dragging me into this cave, and I'm fighting them. I'm telling them I don't want to go in there. I don't want to go in there, you know. Nothing happened but he woke me up. He said, you never screamed but you were like really struggling to wake up. It was just the scariest thing. It was scary. It was scary. The first

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thing I thought about was like the cave to hell, but I just tried to leave it alone.

Yet even though death was a constant subtext, over the seven years of Derek's illness Mrs. Moore had learned to cope: "It got easier. I was just doing what I had to do, really just doing what I had to do. It didn't get harder, it might have gotten easier as I went along. It might have gotten easier. I really can't explain it any better than just that. I just did what I had to do."

Unlike his mother, Derek did not like to think or talk about his experience with cancer. He didn't remember much of his treatment for bone cancer and he shrugged off the news about the lung metastases. Derek was, in part, the cool adolescent, concerned with growing a mustache, buying clothes, hanging out with his friends, and meeting girls. He was also trying to wipe out sad and frightening thoughts. Of his metastases he said, "I think it's my left lung or something." His most frequent comments to me were "I don't care" or "it doesn't bother me."

One afternoon, when Derek was talking about how he liked to keep his feelings inside he said, "As far as I'm concerned, nothing's wrong with me." Yet Derek did, however briefly, hint at the memories he tried so hard to repress: "I loved my grandmother. I still do . . . I miss her. She had a brain tumor, and she didn't even know it. The doctors didn't even know it till it was too late. She was never in bed, and then she started staying in bed a lot, wasn't feeling good. And then they put her in the hospital. They didn't know what was wrong with her, so she just stayed in the hospital--and then it was too late. They said she died of brain cancer." On just one other occasion Derek talked about other troubling thoughts that he had--his grandparent's funerals and "other people becoming sick, like what I have, because it's a reality, you can't escape it because it's there, always, even when you daydream you've got to come back."

A month after our interviews ended, Derek had surgery on his lungs. The surgery went well and Derek's recovery was rapid. The last time I spoke with Mrs.

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Moore, she told me that Derek had had another surgery to replace the metal rod in his leg, but that they remained optimistic about the future.

The Harts

My mother, she's my heart and my soul, she understands what I'm going through.
Taisha Hart

She make me feel good, she's my heart, she's my joy, and that's my strength.
Mrs. Hart

Taisha was a mildly retarded African-American girl who celebrated her 17th birthday the week after our interviews began. Taisha was a large girl with a direct manner, and was quick to say whatever was on her mind. She had been diagnosed with osteosarcoma when she was 11. Taisha said:

> When I first got it I was 11. I was going to school and my foot had swollen real big. My teacher was, like, Taisha, why is your foot like that? You hurt your foot or something? I said, no, 'cause most of the time I was playing. When I came to school, I was dragging my foot and the teacher asked me why was I dragging my foot? I was telling her, I don't know. Then a few months later, I had a knot behind my leg and I went to my doctor. He said go to the hospital. It was raining, and my mother took me to the hospital and they said I have a mass behind my leg, look like a tumor. So they cut it off my leg. I had a bone marrow, CAT scan, echo, and all the other stuff. They took a piece of tissue and said it was cancer. So they transferred me to another hospital and they amputate my leg.

In the following years, Taisha had had three surgeries to remove tumors that had metastasized to her lungs. Five weeks after we began meeting, Taisha had an unexpected, and catastrophic, neurological event. She was taken to the hospital and admitted to the ICU. Her doctors believed that she was brain-dead. Mrs. Hart continued to meet with me during this time.

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Taisha lived with her mother and older sister. Mrs. Hart was an amply-built woman, with dark hair styled into a French twist. She wore dark glasses even indoors, which obfuscated her eyes and made her appear inscrutable. Taisha also had two half-sisters and two half-brothers who lived in the neighborhood. Her father lived in another state, having left the family years before. Taisha and her father did visit each other, and he was present during the last three weeks of her life.

Taisha and her mother shared a bond that was heightened by their experience of illness and loss. When Mrs. Hart was 17, her mother had died of cancer. As she recalled:

> I was there with her when she got really sick. She was in the hospital off and on, but she died when she was 41 and I was there, and I was just 17, and I never got over that. When I was 17, I didn't know nothing about cancer, you know, nobody mentioned cancer in the house, nobody talked about cancer. I heard them talking about what was wrong, but it was whispering.

Two years after Taisha was diagnosed, Mrs. Hart learned that she, too, had cancer; the same type that had killed her mother. After two years of treatment, including surgery and radiation, she had been in remission for two years.

Mrs. Hart was particularly close to her aunt Martha, who had cared for her after her mother died. Martha not only shared the same birthday as Taisha but she, too, had had a leg amputated and had been in a coma before her death several years earlier. Mrs. Hart remembered, "She was fine, and the next thing I know she was in the hospital, she went in a coma and she never woke up. I don't even know what she died from, and I never asked my sister because I don't want to know. She's at peace now. She went through a lot, too, she lost her leg like Taisha. They had to amputate--same leg, same birthday."

This convergence of illness was a central theme for the Harts over the course of our meetings. Shared illness had created an empathic bond, and the Harts

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frequently mirrored each other's comments. Taisha, explaining why she thought her mother was the one person who understood her, said, "*Nobody* understands what I'm going through right now. I love my mother. She's my heart and my soul. My mother understands how I feel because she's going through what I'm going through, and she understands how I feel."

When Taisha lay comatose, Mrs. Hart said, "She's a joy and she's special. She lights up my life. If you feel down, she'll say something out of the way and she'll make me grin. She'll say, what, Mommy--you don't want to smile? I say no, I want to smile. I said, you make me feel good. She's my heart, she's my joy, and that's my strength." Mrs. Hart also believed that illness had brought the pair closer together. "Maybe because what I had, what I went through and I feel she went through. I got the cancer and I feel the same like Taisha do. I can relate to her because I done have two surgeries to her three. If I have to have another surgery then I'll say we there, you three, I'm three."

For Mrs. Hart, this empathy blurred the boundaries between herself and Taisha. Speaking of getting Taisha's test results, she said, "We want to know if they could tell us today, we want to know what it say 'cause we got an appointment in two weeks but we want to know ahead of time, usually we want to know."

Taisha had a similar experience, feeling her mother's emotions as her own. A few days before her 17th birthday Taisha stopped eating. She attributed this loss of appetite to remembering her aunt's death and to a painful exchange she had had with her father. "I love my father and my father says sometimes that he don't love me and it hurts me inside." She would not share this information with her mother. "I don't want to hurt my mommy 'cause she gives me everything and when he hurts me I don't tell her because she gets real mad, and she gets hurt and angry, and it hurts me inside and I start to cry, it hurts me to see her hurt."

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In the absence of this information, Taisha's loss of appetite rekindled a memory of her mother for Mrs. Hart. "[My mother] kept losing a lot of weight, she must have had the cancer real bad, it must have been all through her body. Taisha not eating--it make me go back to the time with my mother. I mean, Taisha would eat three, four meals a day, she had a good appetite, that made me think about my mother, to go back to when I was 17, I'd rather not go back, I want to go forward to the future."

One week after this incident, Taisha was hospitalized briefly for hydration and I met with her for what would be our last interview. Taisha was preoccupied watching a movie about Jesus and spent the time reciting prayers and commenting on how much she missed being at home with her mother. She was discharged several days later and upon her arrival home suffered a seizure. Mrs. Hart said:

> She came home from the hospital, and the next thing I know she was going back out the door. She just came in the house and sit down on the couch. I thought she was playing. First she hugged me, she hugged me real hard. I said, Taisha, you're hugging me real, real hard. She said, Mommy, and she flopped down on the couch. I said, Taisha, what's wrong, you playing with Mommy? She didn't say nothing, so I decided to go over there and touch her. Her teeth were clutched together, and foam was coming out of her mouth. Quick, fast, I was calling the ambulance, and they worked on her in the ambulance for a long time. I couldn't even get off the chair and go to the window. I just dream about it, think about it, all I see is her coming in the door, sitting down, and going back out the door again.

Although the doctors believed Taisha was brain-dead, they did not inform Mrs. Hart and she shifted constantly in her assessment of Taisha's condition. One moment, she spoke as if Taisha was alive: "She's strong, she's strong, we been through too much for this to happen. Life gives you a lot to go on and you have to go on. She's a fighter, I think she's going to come out of this, I just feel it in my

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heart." In the next moment, she spoke as if Taisha was dead: "I think she's going through the light, to the tunnel, and she's seeing everybody she missed."

After Taisha had been in the ICU for five days, the doctors met with both of her parents to tell them that she was brain-dead. Although Mrs. Hart had overheard the staff commenting on Taisha's condition, she didn't ask them to elaborate. As she said, "I didn't ask them and they didn't volunteer to tell me, so I didn't ask." While Mrs. Hart had tried to remain open to talking with Taisha about their illnesses, she had a pattern of avoiding such communication with almost everyone else, especially physicians. Her frequent comment--you want to know but you don't want to know--evoked the silence surrounding her mother's death and her lack of curiosity about the cause of her aunt's death. After hearing that Taisha was brain-dead, Mrs. Hart walked out of the meeting. "If he had told me what exactly brain-dead was--but I didn't want to hear it. I could have asked him, but I didn't want to hear it. I could have asked him, but I didn't want to hear no more." Taisha died the next day.

In the end, Mrs. Hart's history of loss permeated her mourning. She fused Taisha's death with her mother's, flowing in and out of each experience in the same sentence: "It seemed the same when Taisha died as when my mother died, because I was there with my mother and I was 17. Taisha was 17 when she died, and I was the one who called the ambulance and they came, but I wasn't old enough to go in the ambulance, so I had to call my sister to come home from work . . . similar to Taisha, but Taisha walked into the house and she, you know, my mother was in the house, it's almost the same." Mrs. Hart was able to derive comfort from her belief that Taisha was now with her beloved aunt and her mother.

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The Illness Trajectory

The nature of the present study was both prospective and qualitative, and captured the subjective experience of people as they moved through a process. As varied and idiosyncratic as this process was, there were common elements: First, the issue of death hovered in the air, whether it was spoken about or avoided either consciously or unconsciously. Next, the difficulty in communicating about death and dying, the subtle hesitancies and stumbles, was ever-present. This awkwardness was shared by family, friends, and staff. Finally, the desire to protect those we love, and ourselves, from emotional pain pervaded thoughts, feelings, and actions. These overarching concerns appear throughout the following stories of the journey through life-threatening illness.

The narratives are organized into eight thematic sections, which address issues raised by both the children and their parents: Why me?; thoughts about dying and death; to talk or not to talk; defense and coping; child and parent interaction; emotional protection; isolation; and mourning the death of a child. Why me? was one of the questions that arose immediately after diagnosis. This section reveals the ways in which the participants thought about and attempted to resolve this question. In "Thoughts about Dying and Death," children and their parents elucidate the numerous ways in which death and dying were present in their psychic lives. The section "To Talk or Not to Talk" addresses the complex thinking behind decisions to discuss illness and dying. Then, the many methods that families used to manage the psychological stress of grave illness are explored in "Defense and Coping." "Child and Parent Interaction" traces the communication and behavior patterns of each child/parent dyad. In "Emotional Protection," the efforts of the children and their parents to shield each other from pain is discussed. Under the heading "Isolation," loneliness, withdrawal, and

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anticipatory mourning are examined. In the final section, "Mourning the Death of a Child," parents share their grief and the ways they searched for meaning after their children had died.

Why Me?

The period surrounding the diagnosis of cancer can be filled with shock, numbness, confusion, and disbelief. A previously healthy child has a swollen foot, a bump on the leg, or a lingering nosebleed that turns out to be a life-threatening disease. It takes time for the information to become real. Yet, almost from the beginning, one question surfaces--*Why me?* Mrs. Moore remembered struggling with this question early in her son Derek's illness:

> In the beginning, I said how did this happen to us, you know, what did I do in my life to deserve this happening to my child, you know, what have we done that this could possibly happen to us? I've been with my husband since I was a junior in high school. He was my high school sweetheart, and we got married and nobody's been wild and crazy, you know, I honor my parents, and there was just nothing to say this is what you did and God is punishing you for that.

Punishment emerges as a potent explanatory mechanism as people search to make sense of their experience. Mrs. Royce wondered whether she, her daughter Lillian, or even her parents, were somehow to blame:

> I always said I didn't do anything for me to go through this. I always think other people do bad things, and they're not suffering like I'm suffering and my daughter is suffering. My daughter is suffering and she didn't do nothing in this world. She never hate anyone, she didn't do anything bad or kill anybody. Why should she be suffering like this and people that do bad things don't suffer? I always say, I didn't do anything wrong. When I was growing up, my parents go to church. They were Christian. They didn't do anything that probably is falling on the third generation. All those things come into my mind.

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Nickie Sahdi had similar thoughts: "You think, why you, you never really done anything that bad, and all the people that are doing bad, they're not sick, only the people that's good get sick."

Issues related to communication arise at this early stage. Parents may mask their own feelings when answering their children's questions. Mrs. Anthony provided Joseph with this somewhat neutral answer:

> He say why did I have to get sick? I told him people don't ask to be sick, it's just that some people get sick, some people don't, some people live, some people die.

Yet, while she shields her son from these emotions, anger and a sense of injustice surface in her own thoughts:

> I ask why me many times. I even went so far as to think people eat from out of the garbage and nothing happen to them. People live in the streets, people make babies and they give them away, they throw them out in the garbage, and people who want theirs, you know, don't always have them.

Here, Taisha Hart repeats what her mother has told her:

> It's just something that happened to me. It could happen to anybody, it could happen to anybody. There are just things that happen to me in my life, just things that happen in life.

Mrs. Hart, who has cancer herself, doesn't have such a benign answer but struggles with a sense of guilt:

> I say why did it happen and why did she get cancer, and I say maybe it's from my genes and it went to her genes, genes pass on going back from generation to generation, I don't know, I don't know, I don't understand it.

These double communications are attempts at emotional protection, which continue throughout the child's illness.

Eventually, when no answer is forthcoming, questioning why the disease has occurred may gradually recede into the background, as it did for Nickie:

> Maybe in the early times I asked but not now, I don't really ask that question

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> now. When I got it, you know, you're really confused and terrified, but I don't really ask that question 'cause I grew accustomed to it, and you are asking a question that you can't afford to answer. I mean, nobody know why you, nobody can find the answer why. You ask a person about this, who's gonna answer, you can't find the answer. I don't know, but I don't think you can find the answer, scientists don't know, neither.

Mrs. Moore also found that she had stopped asking why:

> I would ask Pastor and even Pastor would say there's no why. Why? Because, you know, and God's not going to give you any more than you can bear, and I don't even ask why anymore, I just play the hand that's been dealt to me and try to do it to the very best of my ability. I stopped asking why. No answers. I don't get any answers from the doctors about why. I don't get any answers from God about why. So why am I beating my head against this wall and there's no answer to it, doesn't even come into my thoughts anymore.

Acknowledging the good things that had stemmed from Derek's illness, and developing a personal philosophy, helped silence the constant questioning for Mrs. Moore:

> Derek's illness brought us all a lot closer together--my husband and my sons and myself--brought us all a lot closer together. Derek didn't do this to himself. This is something that happened and only God knows the outcome of it. It's brought us all closer together. . . . I used to always say why, why, why, why, why? And I've come to the conclusion that there's no why. I mean, we are merely playing a role. Playing a role that's already planned out. Somebody knows how it started, and they know how it's going to end, and I'm just the puppet that they put in it to play this part and I'm fulfilling my role. I've done a lot of soul-searching since Derek got sick, and that's just my philosophy. I stopped asking why. I don't even say why anymore.

And if the question Why me? cannot be entirely eliminated, it may sometimes be answered in a way that lessens its urgency. The meaning that Derek found in his illness provided such an element of resolution for him:

> I was scared because, you know, a little kid going to surgeries and stuff. I was just mostly scared and not understanding why me. I still [ask that] to this day.

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> But something bad has to happen to every family, so I'm glad it's me. I'm the one who handles stress the best. . . . I feel I'm the one that can bring this family together, closer, even though we're already close, but I can bring them closer together.

Thoughts of Dying and Death

For some, thoughts of death also emerge at diagnosis. Talking about what happened when he first got sick, Joseph Anthony said:

> I was sad, really sad. I was crying a lot when it happened at first. I had to stay at the hospital and then my mother told me I got cancer. They said I'm lucky because I don't have it very bad. I cried a lot. I was very worried that I was going to die.

Joseph, who was nine years old when he was diagnosed, was the youngest child with whom I met and the only child who mentioned having thoughts of dying so early in his illness.

Mrs. Anthony had similar thoughts and describes the process by which they changed:

> When I first heard he has the cancer, the first thing that came to me is he's going to die, and it seemed as though he's going to die tomorrow. I was saying I don't want the doctor to tell me when he's going to die, if he's going to die tomorrow. I was thinking like that. I was very upset. Those feelings lasted for approximately a week. Then I told myself I had to pull myself together and be strong for him. I also tell myself it's not like he's dying today or tomorrow, you know, because that was my first impression.

In this instance, a mother's desire to protect and care for her son mobilizes her and pushes away frightening thoughts.

Even when these thoughts are not immediately present, most children and parents do come to think about death and dying. Sometimes the communication about dying is direct, as in the Anthonys' comments. But frequently the concern about dying is expressed symbolically.

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These thoughts may be revealed in the course of a medical interaction. When a nurse was clearing an air bubble in his IV, James Wilson said, "You took out my air--you took out the air. You see, they're killing me, they kill me!" While acts interpreted as aggressive may be experienced as if one is being killed, the rapidity with which death-related language bubbles to the surface is notable.

Thoughts of death arise quickly even in casual play. One morning, I was talking to Joseph Anthony in the doctor's conference room. Joseph was drawing on the blackboard, laughing and pretending to be a pirate, when he plopped himself down in the rather impressive chair at the head of the table and said, "The boss sits here." When I asked him what he would do if he were the boss, he replied, "I'd probably try not to make anybody die, try to make everybody do their best." He went on to say that he did sometimes think about dying when he came to the hospital and then told me this story:

> I saw this movie and they were doing surgery on this man and the man stopped breathing. Then he died. Then his wife took all his belongings, and the surgeon was going to get a lawsuit--like the man who died, his wife said that wouldn't be the right thing to do, 'cause her husband used to do the right thing and do a lot of good stuff for other people and she thought that wouldn't be the right thing to do. I just hope that won't happen to me.

In the midst of play, the concern about whether he would be well taken care of by his doctors, a fear of death, and the knowledge that even good people die are quickly triggered.

When these thoughts are too frightening to be allowed into consciousness, they may appear in dreams. Here, Taisha relates a battle for her very being:

> I have a dream that the devil's chasing me around the room. He try to get me, but I don't let him in my body. He has a sword, he's trying to get in my body, the devil, that makes me sad. He chases me around my room, he tries to get in my body, to take over my soul. I don't want to cry so I ask for God to help me. A good angel comes down and took the devil out.

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James Wilson drew a picture (Figure 3) as he told me the following dream:

> I was on the ceiling and then I heard my grandma talking wake up. I heard my grandma say wake up and the people in my dream said wake up, you have to come back, you have to go back. I woke up and I was in the same room and I was going to school, and my aunt, my cousin, and my brother say wake up, wake up, and I say I am awake, and I was like on the ceiling. I was floating but I saw my body on the bed, no, my body was on the bed but I wasn't in my body. They say wake up, wake up. I thought I was dead and I was crying, I was crying. I thought I was dead. I said I'm right here, and then I woke up. When I woke up, I thought it happened for real, wow! I test it out if it was for real. I went like that [pats his body] and then I knew it was just a dream.

After learning that her son Derek's cancer had metastasized to his lungs, Mrs. Moore said: "That was one of the first things that I asked [the doctors], was he getting ready to die? And they said, no, not right now, we're not going to tell you he's not going to but not right now, it's just not going to happen right now." Shortly after this meeting, she had the following dream:

> I had a dream the other night that he was in a casket, and it scared me so bad that I almost urinated on myself. I jumped up and ran to the bathroom and I peed. He was in a casket. I could see him, and I called my mother and she says well, that's not bad luck, that means when you have signs, when you see someone in a casket, that's not a sign of death, that's a sign of like getting better, you know, she says don't think he's getting ready to die. The strange thing is we had just gone to--my girlfriend had a 70th birthday celebration for her mom, it was a beautiful affair, it was formal, and my son had on a nice black suit and a beige shirt and beige and black shoes, and in the dream he had that suit on and that shirt I had just bought for him, and he was in a casket and I swear I almost peed in my bed it scared me so bad, it scared me. That was the worst, that was the worst, and then of course I go in his room and I look at him and he just looks at me and he goes, would you please go to bed, as I walk the floor all night, would you please go to bed and leave me alone. I said, okay, okay, I'm going.

For Mrs. Moore, signs that her son might die were everywhere. Speaking of the birth of her grandson, born at the time of Derek's relapse, she said:

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> I tell you it was amazing, the baby came out looks just like Derek. It was just so ironic. When he was born, everybody went he looks just like Derek. It kind of scared me because I thought maybe he was getting ready to die or something, 'cause the baby was his spitting image. It really scared me when we first saw him. My husband and I looked at each other, like, unbelievable, it was, like, can you believe this? I get a kick out of it now, but initially it was frightening--is he getting ready to die? Is [God] trying to replace him for us?

Both surgery and sleep, times when one is unconscious and out of control, can provoke fears of dying. Taisha commented:

> When I go in the operating room, I have second thoughts of going because I don't know when I could go, I could go. I could be here right now and just go. When I go to sleep I think about it. I wonder why do people die? My mother tell me another person is being born again, reborn, but it hurt me.

Pain also sparks thoughts of death. After surgery on her lungs, Nickie said:

> The worst part was when I do a surgery and the pain afterward and the nurses or Mom, they want you to get out of bed, you know those routines, and that's the worst part. You feel like you're gonna die. They want you to get up and you don't want to get up because you're in so much pain. You just want to die right there. My mom, when I had the tube, I had to come off the chair and I'm like I'm gonna die, I'm gonna die, because it's so much pain, so that's mostly the worst part, after every surgery when I have pain. I think of the worst there because the pain hurts so much, it's like you're really gonna die from the pain.

Of the 11 people with whom I spoke, only two never mentioned death; both were adolescents. For these children, the topic was too dangerous to be allowed into consciousness. Lillian Royce, who steadfastly avoided talking about death, did hint, on just one occasion, that she would not recover. Describing how she was told that she had cancer, she said, "They never used those words with me, and I was fine for a year, so I never thought I had it. I thought it was gone--and then when I really got sick I realized. I always knew, but because I never got sick, I never thought of it as anything. And then when I really got sick, I started realizing." She then began to cry and in a soft, sad voice that signaled her loss of

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hope said: "I always knew I had it and I knew I was going to be real sick, but I always thought I was going to get better."

The other adolescent who never mentioned death was Derek Moore. Although his avoidance of this topic was marked, his reluctance to discuss his illness was not uncommon.

To Talk or Not to Talk

In the psychological community, we assume that a dying child will be helped by sharing his or her thoughts and feelings. The literature reviewed in an earlier chapter is peppered with such assertions. But what do children themselves think about such communication?

Almost all of the children with whom I met wanted to talk--and seemed to enjoy our meetings. Hospitalization meant being separated from family and friends, painful procedures, lack of privacy, boredom, and loneliness. These feelings are forcefully illustrated by Nickie Sahdi's comment that she "felt more sad of coming back in the hospital than dying." Having someone new to talk to and play with provided a break in the hospital routine. In fact, James Wilson tried to extend each visit by insisting that we listen to the entire tape we had just recorded. Yet there was great ambivalence surrounding conversations about illness. For instance, Nickie said:

> I don't really talk, it helps without talking, I don't find talking helps. I don't have to really talk about it to feel good. You're supposed to feel good inside by yourself, no? Not just by hearing yourself. I don't know, maybe I'm different from all the other kids in the world. I don't like to talk about it, I don't like to talk about it. It happened, it will go. I don't like to talk about it.

This rather strong protestation masked an underlying anxiety:

> I just don't like talking about it. I don't know, I just don't like hearing about it, hearing about cancer and this stuff, I don't like to hear about it. It happened, it's

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> gonna go, according to which one you have it's gonna go. [Talking] just makes it bad for me. I guess like if somebody's talking about it, I just feel like getting up and just leaving because I don't want to hear about it. It makes it worse, for me it makes it worse, hearing all the [talk], saying it's that bad and this bad and all.

Although Nickie seemed to be protecting herself from uncomfortable feelings, an issue that will be explored in the next section, her comments raise issues about how adults communicate with sick children. Here, talking means listening to doctors relay bad news, not conversation focused on the needs of the child. Derek, who had a metal rod in his leg that produced a noticeable limp, had this to say about talking with adults:

> It's annoying because [adults] sit there and ask you questions for like 15 to 20 minutes. One person, young person ask you what happened, [you say] this, this happened. Oh, really, you all right now? Yes. And you keep moving on. Old people, they got to double-check, you know, even though they know they heard, they got to ask you the question again--a double question. I hate that.

Derek elaborated about how he would like to be asked about his illness:

> If we're sitting down talking for a while and then you, like, by the way what happened to your leg? I feel more comfortable like that. If you just come out like walking down the street and you see the way I'm walking, and you ask me what happened to your leg? I'm gonna lie to you, 'cause I don't know you from a hole in the wall. I never seen you before in my life. But if we sitting down and we talking for like a good 15, 20 [minutes] to half an hour and you ask me, by the way, what happened to your leg? I'll tell you because I know a little bit about you, you know a little bit about me.

Illustrating how extensive the sensitivity related to talking about cancer is, Derek also described rules for talking to kids his own age:

> When we sit there, when we sit around, it depends how they ask me. If they ask me all nice and courteous and like curious how they want to know, I will tell them, but if they ask all rude, like if they ask rude or impolite, I'll lie and say I ripped something. It depends. If I don't like you I'm gonna lie, 'cause some people get an attitude, so I lie to them. Knowing I won't ever see them

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> again, I can lie to them. Some people, the polite people, I tell the truth to. If you earn the truth, you get the truth.

Still, it was surprising that most children did not bring up their illness, or the threat of death, more frequently. Children gave different reasons for not wanting to talk about cancer. James grew increasingly quiet and withdrawn when telling me the history of his illness and then said simply, "Sometimes I don't feel like talking about it." Joseph said, "I don't like to talk about it a lot 'cause it makes me sad sometimes." When I asked Derek if he thought talking about his feelings was a way to help him deal with them, he quickly replied, "You have to deal with it yourself."

Derek was the other adolescent who never mentioned death. He also disliked discussing his illness: "I don't have much to say about being sick--parents usually want to talk about it. I just don't need to. I know everything I need to know." Derek had entered the study so that his mother would have someone with whom to talk. His parents did not know his reason for participating and had been surprised that he had agreed to meet with me. Mrs. Moore told me that when Derek was first diagnosed, the entire family had gone for counseling, but Derek told me that he had no memory of this event. Mrs. Moore worried because Derek rarely talked about his illness. "I wish he would go to counseling now. I really think he could benefit from it now, but like I said, if it's not something that he wants to do, he's not going. That's why we were so surprised when he said he would talk to you. He just floored everybody. It's so amazing to everyone involved that he said he would speak to you." When I asked Derek why his mother needed someone to talk to, and why she hadn't talked to him, he said, "I guess she didn't feel comfortable talking to me, probably because I'm the sick one." And when asked why he didn't initiate these conversations with her if he thought she needed

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someone to talk to, he said, "I figure if she wants to talk she'll talk. I'm the one who's sick, and I guess she doesn't feel comfortable talking to somebody like that."

Adolescents were not the only ones reluctant to talk about their experiences. Commenting on why she did not want to attend group meetings sponsored by the American Cancer Society, Mrs. Anthony said:

> I don't think that I want to be at the meetings, the meetings where people talk about it. I don't want to be in that. I just don't want to hear anybody else's sad story, much more tell about mine. I don't feel that I should have to sit down and listen to everybody's worst nightmare, so that's why I choose not to go. To see other people cry--I don't want to be a part of that. It's too sad to sit there and listen to all of that.

When I asked Mrs. Anthony if she had someone to talk to about her son Joseph's illness, she said, "I just have to deal with it, I don't usually talk to nobody." After Joseph died, I asked if she talked about him much with other people. She replied, "No, only if somebody asks about him. Other than that--no." She went on to say that when she did talk about him, "it don't make me feel any different, any better or any worse. . . . The situation remains the same. I don't usually go around talking about him unless somebody want to know something, other than that I won't tell a soul."

After Joseph's death, Mrs. Anthony continued to avoid the group meetings that she was invited to by both the hospital and the hospice organization.

> Well, they call me and they talk to me and sometimes, like this month, they have the lighting, a service, memorial service, and they light a candle, but I'm not going. I don't want to go. I don't want to be a part of it. It's just hard to be among sad people. It's very, very hard so I'd rather stay away from it.

And, despite the fact that she was always willing to be interviewed, her belief that talking was not helpful extended to our conversations. On one occasion, she said, "I talk to you because you ask. It don't make me feel any better or any worse."

Some parents worry that talking will burden others. Mrs. Moore said:

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> You're always so worried about burdening other people, you know, I just try and handle. I have a girlfriend I really can discuss just about anything with. When need be we discuss things, but basically I'm a private person and I handle it the best way I can, you know, you don't want to go to your parents because they're older and they worry about every little thing.

Speaking of her experience after her daughter's death, Mrs. Hart indicated that people really don't want to hear, that to talk is to risk becoming more upset, and that others will not be able to contain her feelings:

> I tell them I feel fine but I don't, just to keep them from saying things to me. I say I feel fine, and then they won't say no more, because when they ask me how're you feeling? I get really, I don't get angry, I just say, I feel fine, and that's it and they say something else. I want to tell them no, no, I'm not doing fine. I just lost my daughter! I mean, I lost my mother, and my grandfather, and my aunt, and a couple more relatives, but this was my child, and I was with her from the time she lost her leg in April of '91, and the time she had that operation on her lungs in October. No, I'm not fine, but I just say I'm fine, but what do I want to do, talk to you and talk to you and talk to you about how I feel? That's only going to make me more upset, and you may say now why'd I ask her that? Now I got her really upset.

In addition to feelings about whether talking to anyone was helpful, there were also specific responses to talking to me. Due to the nature of the interview process (i.e., preset meetings and a known focus of inquiry), the interviews themselves took on a specific meaning for some of the children. Thus, when I arrived, they knew it was time to talk about what it's like to be sick. For some children, this created a complicated and at times ambivalent relationship between us.

In the middle of one interview, Joseph asked what would happen if he pulled the microphone out of the tape recorder. When I told him that I wouldn't be able to hear what we were saying, he promptly pulled out the microphone and stated, "Me keep it." One day I visited James in Stepdown, a unit that is a step down from intensive care. He excitedly told me, "I had a dream and you were in it!"

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> I'm in the store and I'm naked. I'm running out of the store and you're coming out of the train station and you're bad, you want to get me, you want to take me away. You're in a suit, some kind of fancy suit, and you have a suitcase. And then I ran away, I ran away home.

In his dream, James stands before me naked and vulnerable, while I ascend from the bowels of the earth. Protected by my fancy suit, and distanced from him by my trappings, I am ready to take him away. As much as I bring companionship and the promise that he is not alone, I have also come to symbolize death, and thus am intertwined with his fears about dying.

Lillian felt the need to modulate our discussions. In a meeting after an interview where she had talked about painful family conflict, she said she didn't want the tape recorder on, because "I don't feel like I could do what we did the last time." She said that talking about her family would be too much for her, but then began to talk about her anger at her father.

Privacy was also an issue. Frequently, the children did not like being recorded when they were in Stepdown, an open unit with four beds and a constant influx of doctors and visitors. Lillian said she could talk if she knew the people in her room, but not if they were strangers. Sharing a room can actually increase isolation when you can't talk about what you want to because people are listening.

The decision to talk then hinged on many factors: privacy, the manner in which one is engaged by others, fear of being a burden, and/or the belief that others cannot tolerate such conversations. Perhaps most importantly, talking could be experienced as a catalyst for anxiety, sadness, and depression. *Not* talking about illness or death was but one way of keeping these uncomfortable emotions at bay.

Defense and Coping

Grave illness stimulates complex and painful thoughts and emotions that must be managed by the sick child and his or her parent(s). From the early stages of

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diagnosis and questioning why, through the rigors of treatment and the relief of remission, to the dismay of relapse and the inevitability of death, the family members must find ways of controlling both their internal and external environments. Clearly, the threats that the individual and his or her family have to cope with are enormous.

A sense of self and all of the markers that one identifies with normalcy can be radically shaken by life-threatening illness. The child must adapt to the foreign environment of the hospital, giving up familiar clothing and food. School is replaced by home tutoring. Some of the greatest challenges to self-identity are the physical changes that accompany cancer and cancer treatment.

Lillian had been ravaged by her illness. Yet integrating the changes in her body into her self-concept meant acknowledging the severity of her illness. As a result, Lillian had to protect herself from other people's reactions to her appearance. Recalling an earlier time in her illness, she said: "I used to go to the library a lot, but then I stopped going because I don't like people staring at me in the wheelchair." Near the end of her life, Lillian revealed the potential danger that lurked in every interaction, as well as the way her life had been restricted by other people's insensitivity:

> You know what upset me so much? This lady, she works at radiation, right. She saw me eating pizza. You know what she said to me? She didn't say hi or anything, how're you doing, she said, oh, my gosh, you're eating! I was so upset. Why would you say that to somebody? Oh, my gosh, you're eating! Like I don't eat food or something. I just don't understand. I mean, I don't sit there and starve myself, you know, so she was, like, the way she did it was, like, she was so surprised that I was eating food. I was mad. I know I'm kind of small and stuff, but it's not my fault. I'm self-conscious. I won't go nowhere 'cause people look and they stare and it's not nice.

Stigma continues to accompany cancer, and other people's remarks can be a cruel reminder that the physical self is in a state of transition. Taisha recalled her

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schoolmates reaction to her amputation: "My friends call me, oh, you're nothing, Taisha, you're nothing but a cripple and you ugly and you can't have a boyfriend. . . . I had a boyfriend, and he found out that I lost my leg and he dumped me. It made me mad."

Derek Moore, whose bone cancer had been treated by resecting his leg tumor and installing a metal rod in his leg, had had more surgeries than he could remember:

> I can't give you the numbers, but the first one was a tissue sample, the second one was installing the broviac, the third one was to transfer the leg bone to prosthesis, and I've had little minor surgeries of lengthening the prosthesis . . . and then I broke the prosthesis and they had to put a new one in 'cause it wouldn't lengthen no more. In eighth grade, I broke one, and they had to make a custom one that can go longer, and they had to get a bone graft because the bone in my thigh was thinning out. I think that was the last surgery on my leg, and then after that, I had a Portacath put in--that's a surgery to get it put in and taken out. I haven't had my lung surgery yet. I think I should have that at the end of this year.

For Derek, each leg surgery raised the possibility of amputation and the disruption of his body integrity:

> When I have surgery on my legs, the first thing I do is wake up, feel my leg, make sure it's there, make sure they didn't cut it off, decide they want to cut it off, look see who's around me, make sure there's a nurses' station somewhere in my sight. Then I guess I go back to sleep.

The emotional roller coaster precipitated by remission and relapse, and the uncertainty and dread aroused by tests are added strains. Mrs. Moore described the circumstances surrounding Derek's relapse:

> Derek was like a week away from five years in remission. It was just like, phew! We did it! You've got to go for tests, the farther you get in your remission the farther apart your tests become, but I always start my tests early. We went and we took the X ray at my doctor's office, and they called me and told me they saw something on the X ray. Of course, I told them that their

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> machines were inferior, and I'm so tired of going through this with them, and blah, blah, blah. I called Dr. Grant [Derek's pediatric oncologist], and she said bring him in. I wouldn't worry about it, their machines aren't like ours, probably just a shadow. So we brought him in, and we took tests, and we were waiting for Dr. Grant to come back--and when she turned the corner, I knew by the look on her face that it wasn't good news. She called us in and Gordon [Mr. Moore], and myself, and Derek, and Dr. Grant, and the social worker--she said I'm so sorry, it's back and it doesn't look good, and he just, well, first Derek punched a wall, and then we all just broke out. I do believe Dr. Grant was crying also because it was just the last thing any of us expected.

Mrs. Moore worried about what a relapse would mean for Derek and the family:

> Usually with this type of cancer, if it's going to come back, it comes back within the first two years. They had already told us, and I did my own studies, that with osteogenic sarcoma, if it comes back, it comes back in the lungs, and from the lungs it goes to the lymph nodes. And then they explained to us that cancer on a relapse usually comes back ready to fight, comes back stronger than it was the first time, but they would try to find something to work on it, and they tried numerous things that didn't work. He's got weakening of the heart muscles and the kidney, and it already did damage to the hearing, so I'm sure we're going to have to find a whole new regimen of drugs. I can't take much more of this. . . . I was scared, I was mad, I was more worried about Derek than anything--he had been doing so well, back in school. . . . It was just devastating, like somebody just snatched the rug right out from underneath you, falling in this deep black hole, and we had already dug ourselves out of that hole one time, and we all knew what was in front of us--and it was just devastating, devastating.

Mrs. Moore also talked about how her husband's response was complicated by his grief over his mother's death from cancer two years earlier, and his fear of becoming emotional:

> Gordon is just as frightened, or even more frightened, than I am. We watched his mom go through a terrible, terrible thing, and, you know, that's what he says to me sometimes--I can't believe God is gonna do this to me again. His mother was just a bundle of energy, just the sweetest, sweetest woman in the world, and she got sick and it just tore her up. I mean, from like October to

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> February, it just destroyed her, and they had her on life support, and when she came through, she told us don't do it again, don't you do that again, and then he had to be the one to sign the papers and it was very difficult, and Gordon just says, I can't believe God's gonna do this to me again. . . . I think he's just as frightened as I am, or even more so, but he thinks he's got to be this big rough, tough mountain and not let these emotions show. I tell him all the time it's cool to cry, sometimes it makes you feel better. I never do it in front of Derek but sometimes when you get finished it's like phew, that made me feel better--but it's very seldom that Gordon cries.

The counterpoint between life away from the hospital and life during treatment can make a relapse even harder to bear. Nickie Sahdi described the period surrounding her relapse in this way:

> They thought they saw something but it was benign, and they did a surgery to see if it was cancer, but it wasn't, so that was a relief right there. And then they continue the chemo afterward so--it was a germ, I forget the name of the germ. Then when I was finished with the year [of chemo], I went home--for good! But I come back every month for a checkup, and then, well, just last month I found out I have another tumor inside my chest. They took a biopsy, and found it. They took an X ray first and then they took a biopsy and it was more tumor inside my chest. I was sad because I was having so much fun being home and now I'm back here. I said, oh, my God, I got to go back in the hospital again, you know, I was like that, but I didn't cry, but I was like frustrated in a way 'cause I was just having fun--it was summer, too. It was nice, the few days off was nice, the few days off from the hospital, it was nice.

Relapse was not the only event that posed a threat. For Mrs. Hart, every meeting with Taisha's doctors stimulated anxiety about her own cancer. Mrs. Hart recalled the meeting the year before, when Taisha was told she might have a new lung tumor:

> If you say, Mrs. Hart you don't have no cancer, Taisha, you don't have no more cancer, then we'll just--we'll go throw a party and do things. But they never tell you that right then and there. They wait till something is wrong and then they tell you you got cancer again. And we all looking, tears getting ready to come to our eyes and we looking sad. Taisha started crying. I saw one tear come

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> and then I was just--I'm going in the bathroom for a minute, Taisha--and then I'm crying, and I would do a little screaming and come out.

The most casual remark by a neighbor could ignite Mrs. Hart's fears:

> Before I got sick, you could say how are you doing? I'd say fine, nice day, you know, whatever. Now that I've been sick and they say that to me, I'm thinking something is wrong. They saying how you feeling--and you go look in the mirror and say well, what's wrong, don't I look okay? One day, I asked [my neighbor] what, something wrong with me? I said I'll see you later and left. I try to cope with it. I try to deal with it, but it's hard. It's hard when someone says those words to me. I try to, I say I'm doing fine right quick 'cause if I don't answer right quick, I'm gonna say why you ask me, do I look all right? And I'm going to get very angry.

Even good news can be stressful. When the tumor that had metastasized to Derek's lungs and lymph nodes showed no new signs of growth, plans were made to operate. Mrs. Moore had been hopefully awaiting this decision:

> This is what we've been looking for for a year, and when they called us and told us that it could be done, I threw up. [I'm] so nervous, so scared, but I threw up that one time. Other than that, just like, you know, you get the feeling like if I eat, it's not going to stay down, and little anxiety attacks, you know, and it's something that we've been hoping and praying diligently for, but the thought of it is very scary. My dad had the same surgery, and I just keep saying to myself, you have to remember your dad is 69 and Derek is 16. My dad is hardheaded, he didn't do what he was supposed to after the surgery and he got very sick; he was in the hospital for almost two months. So I just keep saying to myself Derek is not going to do the things that Dad did, everything's going to work out okay, but it's just real scary. I'm tired of them cutting him, I know he's got to be tired of it.

Abandonment was one of the issues with which James had to contend. Kevin described conversations between James and his grandparents:

> They would say to him he'd be taken away if he didn't take his medicine, or we'll send you away, you'll be sent away. Then when I came into the picture, that was sort of brought up because he would say things like I'm just going to go with Kevin and they would say, well, if you leave the house, we'll have you

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> taken away. If I just showed up at the house and said, oh, I'm going to take James to McDonald's, they would be okay, they wouldn't say no. Then it got to where they did start saying no, no, James can't leave the house today, and they would tell James if you leave the house you'll be taken away, and during that time, James was calling me and getting upset.

James was also troubled by his own aggression. Amputation is certainly one of the most dramatic examples of the invasive nature of cancer treatment. But hospitalization is filled with procedures and interactions that can cause a child to feel attacked. Finger sticks, adjustments to the IV, temperature and blood pressure monitoring, toxic chemotherapy agents being pumped through the body, constant interruptions at all hours of the day and night--the number of acts that can be experienced as aggressive seems limitless. Anger is a common response to these attacks and is exacerbated by feelings of fear, frustration, and loss of control.

One day I walked into James's room and was met with a scowl. In response to my rather benign question--how're you doing?--he took all of my colored pencils and stabbed the sandwich in front of him until it resembled a porcupine. As we sat in silence, a nurse came in to change his chemo bag, a phlebotomist came to draw blood, he had two finger sticks to check his glucose level, and a phalanx of physicians swooped around him asking questions. Sullen silence was the response to all of these intrusions. When I asked James if he could put his feelings into words, I received another scowl. When I asked James if he could draw his feelings, he said, "I'll draw a picture of you." In this drawing (Figure 4), it seems that the shark with the treacherous teeth represents both his own aggression and the hostility that he feels is directed at him. He has placed me in a "garbage bag," tied at the top with a strong rope, to protect me from these destructive feelings. His next drawing (Figure 5) was of his "Uncle Hangry," a fierce and frightening representation. When I covered the initial H on the drawing and inquired if this

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was how James was feeling, I was greeted with the first smile of the day and a resounding "Yes!"

These are just a few examples of the concrete events that arouse painful emotions. Affect stirred by loss, pain, envy, traumatic procedures, conflict, aggression, social ostracism, guilt, and grief threaten the integration of the ego. A wide range of defense mechanisms and coping strategies were used to manage these stresses.

One of the primary ways both children and parents managed uncomfortable emotions was by keeping thoughts and feelings out of awareness, either through use of an unconscious defense mechanism or a conscious coping strategy.

While living with cancer is in itself stressful, the transitional moments in the illness created the greatest anxiety. These moments centered on markers such as hearing the diagnosis, beginning treatment, being faced with a traumatic procedure, being told about a relapse, or learning that no more treatment was available. Many people talked about being in an altered state of consciousness, or experiencing a sort of psychic numbing, at these times. This phenomenon was described in several ways, including being numb, having a blank mind, being in a fog, or feeling like a zombie. Repression, or as Derek Moore called it, a memory block, was another way of keeping painful thoughts and feelings out of conscious awareness.

Mrs. Moore recalled that when Derek was first diagnosed, "he was in a fog, he laid there and he let them poke him and probe him and do what they had to and he just didn't, he didn't store any of it. 'Cause even Dr. Grant says Derek, you don't remember that? He says no, I don't remember." Derek, himself, said, "I guess my mind blocked it out, all that pain or something, I don't know, just leave it alone." Mr. Moore had a similar reaction. Mrs. Moore said:

> Gordon was there, but he wasn't grasping what was going on around him.

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> He was there, not to say he wasn't there at the hospital physically. He was there physically, but as far as if you were to say to him do you know what's going on? Do you know what's wrong with your son? Do you know the name of his cancer? Do you know what kind of medicine he's getting? Do you know what his prognosis is? He couldn't have answered any of that.

Blocking out feelings was a fairly stable method of managing negative emotions for Derek. One day, he told me that the lowest moment of his life was when his grandparents died. When I asked what that was like for him, he replied, "I don't know. I blocked it out, blocked the pain out. I just block it out." He went on to say that he never had bad thoughts about himself--"They never pop in for a moment."

As mentioned previously, hearing the results of her own medical tests was particularly anxiety provoking for Mrs. Hart:

> When it's time to go to the hospital, I don't want to go by myself. I want someone to be there and be my tape recorder, because sometimes when the doctors tell me about tests, I'll sit there like I don't want to hear what he's going to say, and then my daughter's going to pick up when I like blank out. My mind just blanks, I don't know what he said. . . . I'm hearing little parts, but I'm just like a zombie.

This response was aroused by her apprehension that *any* news would be bad news. A meeting with Taisha's doctor prompted a similar reaction: "I'm standing there and they're talking to me and I don't want to hear what they're saying because they saying to me she gonna have another operation, or she gonna have to have more chemo. I don't want that. I don't want no more cancer." For Mrs. Hart, hearing bad news stimulated a fear that she would have "a nervous break," a total disintegration of self.

In addition to the dazed state many people described, people's experiences were also suffused with a dreamlike quality. When James heard that his lung tumor was growing and that his current chemotherapy was no longer effective, he said, "It's a

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dream, a bad dream. I woke up and I'm a baby. I dreamed 12 years. You're not here and I'm not here because I'm a baby. It was just a dream. I was dreaming. I was sleeping. Twelve years long of dreaming." When her daughter, Taisha, was lying comatose in the ICU, Mrs. Hart said, "It's not easy thinking about her. I don't see her around. I'm so used to seeing her in the house. You get up in the morning, looking around, maybe I'm in a dream or maybe I'm dreaming but it's real. She's not here." And after Taisha died, Mrs. Hart said, "Like I said, I couldn't feel her pain and she couldn't feel my pain, but it felt like I could. But that was something that I just dreamed, you know."

The senses, normally reliable conduits of information, were enlisted in a protective fashion. Several people commented that information "went in one ear and out the other" at stressful moments. As Mrs. Moore said, "Lately my brain's not even processing." This description of overloaded emotional circuits also caused people to mishear, in some instances actually compounding anxiety.

After the doctor told Mrs. Hart that Taisha's X rays did not show new tumor growth, she said, "She has something in the lung again, but it was thyroids. I think he said thyroids. I don't know how thyroids get in your lung. It's still there in her lungs. I may have misheard what he said . . . maybe I didn't want to hear what he was saying." This misunderstanding was caused, in part, by the doctor's use of medical language, as Mrs. Hart said, "he'll be running the mumbo jumbo." Still, when I asked Mrs. Hart why she hadn't asked the doctor for clarification, she replied, "I don't want to ask because he's gonna tell me something else is wrong with her." Taisha, who was not as anxious as her mother, was able to hear the news more directly: "He said it was a gland but it's not growing. He said it's real small and it's not cancer."

Not really hearing, or registering what is heard, also keeps unwelcome information at a preconscious level. Kevin Churchill had offered to send James to

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a specialized hospital. According to Kevin, James's father had responded, "No, James is terminal, there's nothing they can do for him." Kevin continued:

> That was probably three weeks before James died, so I mean I definitely was getting some messages like this is all pretty bad, so I did kind of know--but the grandmother had said no, James is going to be fine. . . . Later I did think, well, why didn't I just ask [the doctors] directly? I think that I just had taken in some information and totally had it wrong.

There were other ways of not knowing. Not putting thoughts and feelings into words was one of the ways Nickie coped with her illness. I asked her once how having cancer had changed her, and she replied, "It's a hard question because there's different things to put in it--it's hard to find words how it changed me." Nickie frequently said she couldn't put her experience into words, and it seemed as if articulating her experience would make it too real. Mrs. Moore described the same type of response to Derek's diagnosis: "I think it was a while before we actually said cancer. I know we didn't tell him that right away because the doctors were telling us that he was old enough to be told exactly what was going on and we were kind of, like, but he's just a baby and maybe this will go away next month. . . . If we don't tell him then maybe it isn't real."

Parents helped by holding thoughts and feelings too painful for children to admit into consciousness. Speaking about her thoughts of dying, Nickie Sahdi said quite matter-of-factly: "I don't really bother with it because I know that's [Mom's] job to think about it. That's her job to worry. It's not my job to worry. Her job is to worry about all her kids, everybody in her family, that's her job, being a mother. I do worry sometimes, but it's like she's worrying a little more than me. If I'm worrying 50, she's worrying 70. She's worrying way more. No matter when I worry, she's already ahead of me worrying."

Derek, responding to my question about the first time that he had been told he had cancer, said, "I'm not sure. I can't remember. My mother would know. She

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would know. I don't know." Derek often referred me to his mother for information about his early experiences with cancer.

Mrs. Hart hovered between wanting and not wanting to know. Her fear of losing Taisha created an ambivalence about meeting with doctors, which was evident almost every time we talked. On Taisha's 17th birthday, Mrs. Hart was worried because Taisha was not eating. They were also waiting to hear the results of Taisha's recent lung CAT scan. Woven throughout Mrs. Hart's conversation that day was an obsessional reworking of the situation:

> You get the nervous and scary feeling and thinking, oh, boy, they gonna tell you something when you get the test back. But I really don't want to know what the CAT scan says--if it's good I want to know, if it's bad . . . but you have to know. You say you don't want to know, but it's going to bug you if you don't know. . . . I think the worst. I think she'll have to go get chemo and get another operation. . . . I'm not thinking the worst because I think everything's going to be okay. It's just maybe she caught a cold, or arthritis, kids get arthritis, you know. So I'm thinking the worst, not the worst, but something better than that.

Mrs. Hart also struggled to not know what was already known. The day before Taisha died, I sat in the ICU with Mrs. Hart. We talked as she waited for Taisha's father to arrive for the meeting in which they were told that Taisha was brain-dead. Taisha had been comatose for seven days and had begun to make posturing movements with her arms, a sign that there was no activity above the brain stem. It seemed that Mrs. Hart knew, on some level, that Taisha would not recover but was afraid to make the loss real: "I'm afraid to go away and come back and she may not . . . I don't know." She hoped for a change in Taisha's condition: "Every time I wake up, I want to call. I pray that when I call this time, they'll say there's a change, her pressure's good, her fever is down, and she's breathing on her own. But it's not [sigh], it's not [sigh]. I just don't understand--it's not happening. . . . I don't understand why she's moving, but I think she's coming back. I know she's coming back. I know she's coming back. I don't want to think like that--she'll say

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don't think like that, Mommy, I'm coming back to see you." Again, Mrs. Hart's thoughts moved back and forth, as if trying to find a comfortable resting spot where none existed: "You're worried. You want to know, but then you don't want to know. But if it's good, I want to know; if it's bad, I don't want to know. I don't know if she's in pain. . . . Waiting, waiting to see what they gonna say is not real easy, you don't want to know. You want them to tell you something good, but I feel in my heart it's something good, but I don't know, I don't know."

In Lillian's case, it was emotions that weren't articulated or fully realized. One day, she told me that she and her mother thought that the way she was sick now was different than the way she had been sick initially. Although it seemed clear that they were referring to her increasing debilitation, when I asked what that meant to her, Lillian shrugged and in a flat voice said, "I don't know, I don't know, I don't feel any way." Another day, she told me about a friend she had made in the hospital who had died recently. When I asked how she felt about the death, her response was limited and bland: "Oh, you know, it made me sad, but she died, that's all, she just died."

In a similar vein, Mrs. Anthony split off her affect from her thoughts. In part, this was a conscious decision: "I tend to deal with it as though it's not a life-threatening disease, or as though it's a common sickness that can go away at any time. That's my way of dealing with it. When he goes to the clinic, we deal with it as though it's just a day, something we have to do, a routine." But in some instances, this casual manner disguised deeper feelings. Clinic visits can take 15 minutes or eight hours. Mrs. Anthony worked part-time and had a five-year-old daughter and 16-month-old son to care for, yet she said these visits weren't stressful. "Most of the time I come here, I just sit around and wait, waiting around. I only work three days, and so it's not really a hassle for me." But when I inquired further about what her days were like, she said, "Working, and taking

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care of the kids and coming to the hospital--some days are very busy, especially when I have other things to do. Like, for example, between today and tomorrow, I have to pick up my medical [exam] and take it to my job, and I have to come here today, then I don't know if I'll be able to go pick it up before four o'clock and take it back, and sometime Joseph come here, you never know if he have to stay."

At a more unconscious level, Mrs. Anthony's emotions seemed cut off from her calm words to Joseph that "we all got to die." It seemed as if these words were somehow disconnected from the fact that it was her son who was going to die. But after Joseph's death, she told me:

> Even though before I used to tell them we all have to die . . . I was afraid to die, in a sense, like I wouldn't want to die, but now it's as though if I'm to die tomorrow I wouldn't mind . . . but before I was, you know, I didn't want to die yet, just like Maya [her daughter], I told Maya we all have to die. She said no, I don't want to die . . . it was like that for me. I didn't want to die either.

Avoiding thoughts and feelings could also be a conscious decision. Nickie purposefully avoided attending meetings with the doctors:

> I don't listen to anything. I don't go to none of the talking. I just don't like it. I don't like sitting down and listening. I call it boring stuff. No matter it's about me, I just don't like to sit down and listen. Later on, I'll hear here and there.

I asked her how she felt when she did go to meetings, and she replied:

> I feel like I'm not in the conversation, you know, mostly they talk to Mom and Dad, they don't talk to me. When they're finished, they just ask me if I want to ask any questions, so why am I there? I'm just sitting there to hear, but I just don't like to sit down and hear what they got to say. They always repeat the same thing, and it sounds worse when you go sit down and hear what you have to go through than when you just go through it without knowing anything. Like I got a paper that says all the side effects on it and I felt I don't want to do this, you know, I'm scared to do it. But when I just go through it, what happens, happens. Now I don't like to go sit down in the meeting, hear what's going to happen and be scared.

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Mrs. Hart had a long history of avoiding information. Her mother had died in an atmosphere of "whispering" and secrecy. She had not inquired about the cause of her aunt's death, and she didn't press the doctors for information when she suspected that Taisha was brain-dead. She also said, "If you really want to know what's going on, I could go to the library and get the medical book . . . but I don't."

Mrs. Royce consciously avoided talking to people about Lillian:

> I didn't want to talk much about her sickness, and knowing that she was gonna, she was gonna die. I was scared, so I tried to avoid it most of the time. I know she's very sick and she was, like, too much for me--and then to talk to somebody again, it was like the sadness, it was very sad . . . and when I talk about her, I always cry . . . and get depressed, crying, and I was trying to avoid, avoid that.

And she specifically avoided talking to me:

> Basically we was going to talk about Lillian, and talking about her--I never liked to talk about her. It always, actually, I never really talked. If anybody should ask about my daughter, I wouldn't talk. I wouldn't tell anyone unless they asked me, and then if they asked me, I tell them I don't want to talk about it.

Finally, distraction techniques were used by many of the children in an effort to avoid anxiety. Here, Lillian talks about drowning out her thoughts:

> Tuesday night, I didn't get no sleep. I don't know why. I couldn't figure it out, anywhere I tried to sleep. You know how you fall asleep one minute and the next minute you're up, like you just forgot time? I tried everything--I turned on the radio, that wasn't working, so I put on my Walkman so the noise would drown me out, that didn't work, I was up the whole time. Sometimes when I think, I can't sleep.

Although Lillian denied having disturbing thoughts, she quickly recounted what sounded like a frightening event, having her tumors seep blood:

> I didn't think about anything--but every time I was sleeping, I was feeling something wetting me, and it was the bandages, the blood was going through. It was kind of late and I didn't want to bother my mother, but I kept on

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> bothering her, anyway, 'cause she had to get stuff for me, put on some more tape, some more gauze on it.

One day, Joseph told me, "I don't remember about bad things in the past . . . I just try to make it go away. . . . I think about other stuff, think about something good that happened, stuff like that." Derek said, "If it's a bad thought, it's going to stay in your head, but if you can beat it out of your mind, try to. Put it to the back of your mind and continue doing whatever you were doing, or get ready to do whatever you were doing." And Nickie used the following method to "erase" thoughts about dying:

> It's a question that pops in my mind, maybe not now, maybe not tomorrow, but at any time it just comes in--when you gonna die? It's not like you say I'm gonna think about that tomorrow. It just pops in. You don't know when it's gonna pop in, or when it's gonna pop out, it just comes--not like you're planning to think about it Saturday. . . . When it pops in, I try to erase it. Every time I think about it, I try to get rid of it, because I don't really want to think about it. But, you know, like, you have a dream, when you're sleeping, it's there, then you wake up and it's gone, but when you go back to sleep, you start dreaming about it again--it's like that. I think about it, and afterward I think about something else, all of a sudden it pops back in, and then I try to think about different things. I think about cars. . . . I'm just trying to erase that bad thought. I try to think about most things to get rid of it. My thought is I die when I die. I die when I die. I don't know when or how nor why.

In contrast to this avoidance, was the information seeking activity described by Mrs. Moore and Joseph Anthony. Although Joseph had repressed many memories surrounding his diagnosis, and consciously blocked out others, he also liked to be told the details of his treatment, gaining control where he could. "If they tell me the same day they're going to do it, it makes me scared. I just get shocks sometimes when they say I have to have something done." One thing that eliminated the "shock" was having the procedure explained--"I know that it's going to be done so I won't have to worry about it"--and being allowed a few days to

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process the information--"If I have to do it the same day they tell me, I get nervous. If they tell me a few days before, I get scared and it kind of goes away. . . . I can be more prepared to start. I can get my stuff ready, my clothes and things. I do things, I be going outside to play because, you know, next day I can't come outside." In fact, when I visited Joseph after his transfer to a new hospital and asked if he had any messages for the staff at his "home" hospital, he said, "Say hello to everybody, especially Dr. Ranji." When I inquired about this special hello, he told me that Dr. Ranji was his "favorite" doctor because "he's the one who tells me everything. He tells me everything, the others don't tell me squat. He tells me when I have to get this done, when I have to get that done, when I'm going home. He tells me everything."

Mrs. Anthony was well aware of the value of letting Joseph control his environment. "If he gets a day's notice that he has to come to the hospital and stay, it wouldn't be no problem, but when he have to stay, he act very angry and upset, so knowing prepares him, it puts him in a better mood, he's prepared, somehow in his mind or whatever, he's prepared."

Mrs. Moore described her characteristic style of maintaining internal equilibrium: "I have control of everything. I know what this one is doing at that time, and we all know that when we come in we have to do X, Y, Z. I know my house is in order." After Derek was diagnosed, she used these same organizing defenses to help manage her confusion:

> I have a journal because I couldn't remember the medical terms, the medicines and the doses, and what they were hoping it would do. So every time they told me something, I would jot it down and read it over that night, so that if anybody said what's your son taking, I could say he's taking methotrexate, X milligrams. I wanted to know what was going on. I didn't want to be lost, and so I started keeping a journal. I have what he took, how he felt that day, how I felt that day, who spent the night, who came to visit.

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But after seven years, the uncertainty of cancer was getting harder for her to bear, and her defenses were strained:

> Sometimes I just want to go in the room and close the door and say *leave me alone, world*! World, leave me alone. I don't think I would ever literally lose control of the situation but just to breathe lightly. Like last night, when I said my prayers, I was just telling God this is really getting to be too much, and I know that you don't place any more on my shoulders than I can bear, but I think I'm reaching that level now. I think it's starting to make me stumble, even if it's just a short reprieve, I need a breather. I feel out of control. I'm not controlling anything in my life anymore. I have *no* control over what's transpiring here. It's completely out of my hands and I'm not used to that. I'm used to having everything just right, but I have no control over what's going on, there's no control, not a good feeling, it's just frightening, it's just really frightening.

In a different way, Lillian may also have been trying to gain control by holding herself responsible for all of the problems in her family. Her guilt allowed her to hope: if she had created the problems, maybe she could make them go away. Lillian had no control over her illness, but perhaps she could effect a change in her family.

Much has been written about the use of denial by the terminally ill. Derek had a range of techniques for denying his condition. Minimization was central among these, as when he recalled learning he had relapsed: "When I found out, I was kind of shocked, but it didn't really bother me. It didn't bother me 'cause I thought I was fine. But they told me they found a spot on my [lung]--oh, well. . . . They told me the day before my birthday that I was sick again. So that bothered me because I was supposed to have a party that year. And I called the party off--that was the main thing that bothered me. I guess I'll have a party this year or something." He also said, "I don't think about the future. I don't care." And: "Stress, it don't bother me because I don't pay no attention to it." Derek also used the fact that his original bone cancer had been cured to distance himself from the

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reality of the cancer's metastasis to his lungs: "I had bone cancer. I don't mind talking about it, it was the past."

Perhaps the most cogent example of denial was that presented by Lillian Royce. Late one afternoon, about a month before she died, I visited Lillian in the Stepdown unit. She was in tremendous pain and struggling to hold her head up while doing some embroidery provided by the playroom staff. She told me that the playroom staff had offered her a summer job, playing with other kids who were hospitalized. Lillian hadn't quite decided whether to accept the job or not, as it only paid minimum wage, but thought she'd do it if she was feeling better. A few weeks later, she told me of her plans to be discharged from the hospital for Mother's Day so that she could go on a family outing. "My mother wants the whole family to go, but she thinks I won't be well enough to go . . . you know I think I could get better. I *will* get better by Mother's Day." The wish in these statements was palpable. (See Figure 6 for a drawing of another of Lillian's wishes.)

If a wish could be heard in these denials, it also resonated throughout Kevin Churchill's escape fantasy: "I just wanted to take James away from this all. We'll just get on a bus and we'll just go off and find every zoo we can go to."

Kevin's desire to shield James was, in part, a response to James's withdrawal, a reaction shared by several of the children. When James was faced with distressing memories, threats of abandonment, or current conflict, he would withdraw into himself, becoming silent and, at times, morose. Kevin said, "He would give up really easily because I think he was so used to not being able to either express himself or not being heard or to have it be effective, so his way a lot of times would be to just totally withdraw from it." James could also taunt and tease, engage and withdraw, until you felt just as uncomfortable internally as he must have.

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Hiding from the outside world was another way of trying to feel safe. Derek withdrew physically at the beginning of his illness: "When I got sick, I stayed in the house all the time . . . I was just in the house watching TV, that's what I'd do, sit there and look at TV and stuff."

Dangerous feelings were transformed in many ways. Lillian's anger at her father was turned into a preoccupation with "not being rude." She also rationalized his insensitivity by saying "he's just ignorant." Lillian, herself, was extremely sensitive to other people's feelings, almost as if she was projecting her own emotional pain into them as a way of more safely experiencing her own affect.

Mrs. Moore described how both she and Derek turned fear into anger. When Mrs. Moore first heard that Derek had cancer, she "went ballistic on everybody in the [doctor's office]. I told them they were incompetent because they've got my child's stuff mixed up with someone else's." When Derek was waiting for surgery to remove the tumors in his lungs, Mrs. Moore said: "He's been pretty mean and evil the past couple of days. He got sent to his room yesterday for quite a bit. He was losing all control--quiet and sullen, pissed off and angry. He never tears. I don't think I've seen Derek cry since the day he relapsed." And Mr. Moore used activity to manage his anxiety. Mrs. Moore said, "I think that's what keeps him sane. He's a very proud man. He doesn't want help from anybody, thinks he can take care of his family, so he works and they call him for overtime, and he gets up out of his bed and he goes in for overtime."

Strategies were also developed to ward off future danger. Both Nickie and Mrs. Hart had a scheme for protecting themselves: Don't plan. There was a superstitious flavor to their beliefs. Nickie had thought herself cured, only to be told she had relapsed and needed more surgery and chemotherapy. At the end of this treatment, she said, "To dream is a bad thing. You don't know when it's going

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to come true, and I don't plan. What happens, happens. Planning is not good." Mrs. Hart had similar thoughts while her daughter, Taisha, was dying:

> We was gonna do things. We had plans. Now the plans is--they broke again. Mother's Day is coming up. We had plans to go back and see [*Bring in Da Noise*]. Every time we plan something . . . maybe we shouldn't plan, we just do it, don't say nothing about it, just go. We plan and we plan and we plan all the time. I don't know. I'm not going to plan nothing no more.

For some people, there was an almost magical belief in the power of positive thinking. Nickie and her mother had an optimistic outlook that, for them, was central to managing the illness. So Nickie said, "I think I shouldn't worry, 'cause everything is going to be okay, that's my way of thinking," and "I never really break down. . . . I think positive--it helps me because like I said I don't break down. Thinking positive, [I] don't break down." And Mrs. Sahdi echoed Nickie: "She think positive at all times to herself. . . . She don't think about the chemo. If you ask her, she say I'm fine. She don't say I don't feel too good. She don't make herself [upset], and that's why she'll get good. . . . I know my child will be good. I never think negative neither."

Mrs. Hart recalled the advice she gave Taisha before lung surgery: "I told her all you got to do is don't have nothing bad on your mind, have good thoughts. Think about your nieces, your nephew, your cousins, you think about us. We're going to be waiting there for you, you don't think no bad thoughts, don't go with them bad thoughts, leave them out. Go with a positive mind, don't mess with the negatives." When Taisha was in the ICU, Mrs. Hart said, "I'm thinking positive with no negative." When I asked what would happen if a negative thought were to creep in, Mrs. Hart said that a negative thought might cause something bad to happen, a negative thought might come true.

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I met with Mrs. Moore one evening when Derek was hospitalized for chemotherapy to check the growth of his lung tumors. She talked in a slow, quiet voice about what would happen if she had a negative thought:

> That's when the nightmares come, because I do have them. And you have to tell yourself, you know, if I stay positive, positive thoughts bring [positive] things, and negative thoughts make it worse than it really has to be. . . . A negative thought is what if these tumors keep growing. A negative thought is Jesus, my baby's gonna die. A negative thought is suppose this chemo doesn't work and they don't have anything else to offer us. What do we do then? It's very scary--very, very scary. You try and push it into the back, [and] sometimes you can forget about it during the course of the day, but they come back at night. They come back at night and haunt the devil out of you. I do try and stay positive. It's difficult to always be positive . . . but you have to say we're gonna do this, we're gonna beat this. We did it once before, and we're gonna do it once again.

A controversial area in psychooncology research is whether certain personality traits increase the likelihood of getting cancer. Kevin worried that James's character, and his depressed feelings, actually caused his cancer. "I could see how James would fit a certain description of a type of person who would get cancer, because of the way that everything was--because of a certain sensitivity things were sort of held in, internalized. Everything seemed so internalized with him that I thought is that why a person like that gets cancer? I mean, on one side, he wasn't frightened, he was very much not afraid of things. On one hand, he would be very sort of bold about things, but in another way, he was very sort of frightened."

If all of these defense mechanisms and coping strategies were aimed at pushing painful thoughts and emotions away, there were also ways of keeping comforting ideas and feelings close at hand.

The resilience of the human spirit is remarkable; the sheer will to live seemed to inspire some children. Lillian Royce's unexpected longevity may have been due, in part, to the denial that allowed her to believe in her own future.

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Even though Derek Moore had once told me, "I don't think about the future. I don't care," he had plans to get his learner's permit and take driving lessons. Taisha told me about her plans to become a rap singer, and Mrs. Hart commented, "She wants to be a singer, a rapper, and I want her to have a good future, try to help her through her life." Taisha also had plans to attend college and then find a boyfriend. She said, "You always got to get your education first, go to college, and start to think about boys after that." James said, "When I get bigger, [Kevin and I] are going to go sky diving--and bungee jumping."

Mrs. Moore spoke of Derek's courage in the face of tremendous pain:

> A lot of times, Derek is very, very sick, and he won't sit down, he refuses. There are days when I bring him home from the hospital, and he should go in the house and take a shower and get in bed. He'll go in the house, and he'll take his shower, he'll change his clothes, and even if all he can do is make it to the front step, he will not go upstairs and get in that bed. He won't let this get him. And Dr. Grant says that's what keeps him going, that's what gives him strength--he just won't give in.

Hope can be sustaining. Joseph had been transferred to a specialized cancer hospital to receive an experimental treatment that might prolong his life. Joseph spent a month at this hospital, at the beginning of which his mother said, "They gonna give him something else, a different type of treatment. There's no guarantee that's it's going to work or not. I guess I'll let him stay here and see what it's like." Joseph told Mrs. Anthony that he wanted to go to the West Indies when he felt better. I asked what is was like for her to hear him plan for the future, and she responded, "It's like a kind of hope, by him, you know, saying he wants to go." At the end of the month, it became clear that there were no treatments available for Joseph and that death was inevitable. Mrs. Anthony still maintained hope. "[His death] is expected, you know, there's no way to prepare yourself for such, but, you know, we never know. . . . I mean, miracles do happen, so I just won't give up

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hope. If it comes to an end, well, I just have to accept it, there's nothing more I can do . . . but I just can't prepare myself for that." At this point, Mrs. Anthony decided to bring Joseph home to die. While she had previously clung to the hope that a new treatment could be found, she now accepted "there's nothing they can do." Her new hope was that Joseph would be comfortable during his last weeks of life. Hope seemed to cushion Mrs. Anthony during this final period, easing her through the transitions in Joseph's condition.

Almost everyone I met derived strength from their belief in God. Mrs. Anthony said:

> I pray for [Joseph] every single say, all day long. Coming [to the hospital] on the train, going home. At night, if I forget to say a prayer for him, my daughter will do it because since Joseph has been sick, it's been a year now, every night we say a prayer. Even if I'm not there, she would ask whoever is there to help her say a prayer for Joseph. Every night before she go to bed, she want to say this prayer for Joseph, and when she talks to him, she says, Joseph, you know we said your prayer last night. . . . We pray for him every day, every minute of the day, that's all we can do.

Mrs. Anthony prayed "for different things at different times. I'll ask Him to perform a miracle. I know miracles do happen sometimes. Nothing too much, but little things, like, I put Joseph's life in Your hands and You know what's best. Whatever is Your will I'll accept." Joseph's five-year-old sister prayed, "Gentle Jesus, please make Joseph better, so that he can come home and be with us as a family. Gentle Jesus, please take away his disease, his sickness. Thank you, gentle Jesus."

Lillian told me about arriving at the hospital in pain and asking God to ease her suffering:

> We came to the hospital. I was real sick. I had a fever and I needed blood. First, I told [the doctor] I need to lie down, I really need to lie down, I'm so tired. So he was, like, let's see if we can get you a bed just to lie down and you

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> could go home. But that's not how things work here--if you're outpatient, you can't have an inpatient bed or whatever. But I was so sick, I said I'd rather be admitted just for the day till I feel better. And right after I got the blood, I felt much better, and whatchamacallit--the [morphine], the pain went away, and I felt much better and stuff. I was planning to go home yesterday, but then suddenly my stomach started hurting me, like right here it was just hurting me like crazy, so they was, like, probably it's the tumor pressing on something--but I was, like, it wasn't here before.

Then Lillian was taken to radiation:

> I was feeling so sick and I didn't want to move and they said they would rush it through, but you know it was like the longest time I ever waited in my life. I was in so much pain. I hate when that happens. You're in so much pain, you just want things to happen so quick and it doesn't happen that way--you know, you have to wait, wait, wait--and I don't know why do you have to wait--I don't understand, even as long as I've been here and in pain and you still have to wait. . . . You can be in the worst pain ever and you just have to wait--I guess they have to do the rules and stuff, but I don't know.

I asked Lillian how she managed such a long wait, and she answered:

> I just cry, keep on crying, mostly I'm crying most of the time. Sometimes, like yesterday, I was trying so hard to breathe in and breathe out. A psychiatrist came, and he was, like, what you need to do is think about a happy place--but when you're in pain, you don't feel like talking about no happy place. I pray and I breathe in and out. I started just praying . . . sometimes it calms me down. The pain never goes away, you know. I try to think, thinking and praying. [I say] some psalms--the 23rd. I was teaching myself to sing the psalm, 41, I think. I just pray to God to stop the pain, to let me get better, and stuff like that. To stop the pain, and heal me, get well again, that the pain go away.

Although Nickie regretted that she was too weak to go to church, she found comfort in prayer: "Mom always says pray and God will answer your prayers, so we always pray. Praying to Him helps you stop thinking of things, you know He's gonna help you somehow, somehow He's gonna help you. I can't really explain how, but you feel you have confidence somehow."

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Mrs. Moore talked about her return to the church:

> I've been a faithful servant, but I hadn't been active in the church since I was 17 years old. I would say my prayers, I taught my kids to say their prayers and bless the table. The basic teachings of the Bible I was able to pass on to them, but as far as really being a religious family, we weren't. Even now, I wouldn't call myself a religious fanatic or anything like that, it just gives me comfort. I don't walk around thumping my Bible or anything like that, but the church just gives me comfort.

While others spoke about gaining strength from their personal relationships with God, Mrs. Moore also described the help she received from her church community:

> I'll come home from the hospital, and they'll have food in my refrigerator for me for a week. My little guy with his sports during the year, sometimes I'm stuck in the hospital and they come and pick him up for me. They take him to his games and wait for his games to be over. It's really comforting to know that I don't have to do this all by myself, you know. They help a lot.

Mrs. Moore began to cry as she shared one of her prayers with me:

> One of my prayers now is--I love my son to death, but I ask God now not to let him suffer. If You're going to make him better, make him better, and if it's time for him to come home to You, just come and get him. Don't make him suffer. That's what I ask now, because he's too young to suffer, too young. So that's my prayer now, just don't make him suffer, you know, if He doesn't make him better, let him enjoy five years, but don't let him linger and suffer, 'cause that, I think, would break me, yeah . . . that's it, and I don't cry often, I'm sorry.

Maintaining faith through such difficult times was not always possible. Mrs. Royce found her faith tested by Lillian's illness. As Lillian said, "She was angry at Him. She prayed for me to get better; it didn't happen. I just got worse."

A few weeks before Lillian died, she began receiving daily visits from members of the Pentecostal church and at one point told me, "The good thing that happened is my mother's born to God now." The closer Lillian came to death, however, the more conflictual these visits became. She complained one day:

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"Those two girls, they're constantly praying. I pray, yes, but not constantly, over, over, over. I don't like it, it's just too much." Yet she was torn because she appreciated their company: "Yesterday I was in a lot of pain and I had to wait for the pain medicine and Louise sat there and prayed and then she started singing--it was fun." Lillian allowed these visits to continue until she was on life support.

For Mrs. Royce, the return to a complete trust in God that Lillian spoke of was short-lived. After Lillian died, Mrs. Royce said:

> You know, you pray, you ask God to heal her, take away the sickness, that she not be sick again. You don't get no answer when you say it. What do you do? Why didn't You answer any prayers? You believe in Him, you do everything right and your prayer is not being answered. You start to go to church more. Little things that you would be doing, like going to parties, you stop. You start praying and reading your Bible, and there was no answer.

I asked Mrs. Royce if this experience had made her turn from God, and she replied:

> I'm going to be honest with you. I wouldn't say turn away from God, but I would say that I don't go to church anymore. I read my Bible and I pray at home, but sometime in the back of your mind, you're praying but, you know, if He didn't help you with Lillian it's hard for you to, you know, you're doing it but you're not doing it with a willing heart. You figure He's not going to answer your prayer because He didn't answer for Lillian. You will do it, but you're not doing it with that willing heart.

These were the many ways that both children and adults managed the physical and emotional turmoil precipitated by what was, in many cases, a terminal illness.

Living with a life-threatening illness is a complex process and people used more than one method to manage the stress. Yet, if an array of defenses and coping strategies were used, general coping styles were consistent over the course of the interviews, and, judging from people's recollections, seemed to have been stable from the onset of the illness. Thus, children and adults with a tendency to avoid painful thoughts and feelings did not shift to a more open style when they

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learned of a relapse or as death approached. For example, Derek had repressed the memories of his early illness, and met his relapse with a mixture of minimization and denial.

In the next section, we will see how these defenses influenced communication between children and parents. But before closing, several of the people with whom I met had advice on how to cope with life-threatening illness, which they wanted to share with those in similar circumstances.

Lillian Royce said, "Be strong. Don't be discouraged. Keep on thinking positive. Just don't give up, and keep positive thoughts. If you never started going to church, start going to church. You have to keep your faith." And Lillian had the following advice on what to say to visitors: "Never tell somebody to leave. Always say could you come back later, something like that."

Taisha's advice was: "Kids that have my problem, that's going through sickness, doesn't matter what your friends say, if they was really your friends, they don't mind what happened to you. . . . I couldn't do the things that other kids could do, but if I put my mind to it and really think I could do it, I could do it. Don't never give your hopes up because if you really put your mind to it, you can do it!"

Derek said, "Have fun with friends to take your mind off stress and just have a good time in life. Make sure everything [you] do in life is fun."

Joseph cautioned, "If you have a broviac and they tell you to take care of it, you have to take care of it very good. Don't leave it hanging out so it will get stuck to somewhere and when you're walking it will pull out. Always tape it up."

Nickie wanted to tell other children: "No matter how much you go through, sooner or later, it will be over, and you'll be back to as normal as you were. No matter how long it takes, soon it will all be over. It can't go on forever, it can't just go on forever."

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And one parent, Mrs. Moore, had the following advice for other parents: "Keep the faith. You have to keep the faith. You have to have faith. You have to have trust. That trust and faith, be it in your doctors, be it in your Superior Being, whoever that it is you praise, you've got to keep the faith, because if you don't, you'll just lose it. Keep the channels open for talk, because I find when I hold things in, it makes me feel so much worse. Have somebody to talk to, be it your spouse or a good friend. You just really need to be able to voice your fears."

Child and Parent Interaction

Communicating about the cancer experience is a process that begins at diagnosis and continues throughout the course of the illness. For many parents, the communication continues beyond death.

The sick and dying, however, are not divorced from the quotidian routines of life, or from developmental strivings, and communication encompasses a variety of topics. In many ways, the everyday nature of these pursuits reminds us that dying is inextricably connected to living.

Adolescent girls talked about getting their nails done; younger children talked about video games or plans to go to the toy store. People talked about the weather, the minutiae of home life, and, especially, food. Every child had his or her food brought from home when they were hospitalized. This provision of food not only maintained ties to a familiar place but also communicated love. In his poem "To Television," Robert Pinsky calls television the "escort of the dying and comfort of the sick," and every family also engaged in watching, and talking about, television programs.

Each parent/child dyad with whom I met was also dealing with illness-related issues. And each dyad had its own characteristic way of communicating and its own unique concerns.

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Derek and Mrs. Moore

Both Derek and Mrs. Moore reminisced about the early days of his illness. Mrs. Moore remembered telling Derek he had cancer:

> [The doctors] asked if we wanted them to tell him, but we told them that we would rather do it ourselves. We went in, and it was kind of difficult because he was 10 years old. No one in the family had ever had cancer. He didn't even know what cancer was. What I did was, I got some books from the library for his age group and I read them myself. And my dad, who draws good, we kind of, like, did diagram things, to try and show him what his cells were doing. But Derek didn't want to hear any of it. It went in this ear and came out that ear. From the time they found the tumor, he was on crutches. They wouldn't let him use the leg. They wouldn't let him go back to school. I can remember the first night, he was excited about spending the night in the hospital. Once he got that medicine, he told me to get his sneakers and get him out of there! . . . I think it was a while before we actually said *cancer*. I know we didn't tell him right away because the doctors were telling us that he was old enough to be told exactly what was going on. We were kind of, like, but he's just a baby and maybe this will go away next month. Now that I look back on it, it's crazy. I really do believe it was the doctors who pushed our hand and actually explained to Derek that he had cancer and what cancer was--and that's when we had my dad do the drawings and everything. They told us that he had to be told. That was the way they dealt with their patients. Derek was not a little baby. He was 10 years old and he needed to know what was going on in his life. I think they gave us two weeks to get it together.

Mrs. Moore also recalled that when Derek was first hospitalized, he only talked to the people with whom he felt safe: "He was totally 'mums the word.' He would speak only to his dad and myself in the hospital. He wouldn't talk to the doctors. He wouldn't talk to the nurses. They would say, can he talk? Does he have a problem that we don't know about? He would not speak to them. He would not acknowledge them. When they came into his room, he would turn his head."

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Although Derek did not remember much about the early days of his illness, he did remember that it was his mother who told him about the treatment. "[The doctors] told my mother the procedure and everything, and my mother told me. . . . A year of chemo and tests every so often to see if it was smaller. When it gets to the size that the surgeon feels comfortable with, he'll remove the bone and put a prosthetic rod in, a replacement. My mother told me all that. I didn't want to do it, but my mother said either I could do it or they could amputate my leg. I didn't want to have the surgery. I didn't want to have anything to do with it. I was around 10 or 11 then."

Mrs. Moore had similar memories: "He didn't ask any questions. I would say I think you should know X, Y, Z. I would explain to him all of his surgeries. He had so many surgeries. When they took the femur out, he was in surgery for 12 hours. What he knew, he knew because I'd say, tomorrow this is what's going to happen."

As Derek's illness progressed, Mrs. Moore developed a strategy for breaking news to him:

> When we're talking about changing a medication, we always involve Derek. I've been dealing with Dr. Grant for a long time, and they know me and they know what they can and cannot say in front of Derek. There are certain things I've already told them I'd like for you to discuss it with me and my husband before we discuss it with Derek. You have to let me get it together. You've got to let me get my thoughts, and get my knowledge, and then we'll pass it on to Derek. . . . He just takes it better from me than to have a room full of doctors in white coats standing around him. So most things Dr. Grant tells me first, and then she'll say, if you need me to be there with you, I'll be there with you when you tell him.

Mrs. Moore needed time to process the information, control her emotions, and prepare for Derek's response: "I have to come to grips with things. I just have to think about it. I do my little research. That's why they call me the little librarian.

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If he comes to me from a certain way, I want to know how I'm coming back at him."

During the time that we met, Mrs. Moore was concerned about Derek's moodiness and his continuing reluctance to talk. "I was trying to get him back into counseling, but he says he doesn't want to go and what's the point of wasting my money . . . but the way he treats his brother, sometimes he just treats him so mean and vicious." I asked Mrs. Moore if Derek ever talked to her about his anger, and she said, "Sometimes, not much. Dr. Grant says, first of all, 16-year-olds are hard to deal with healthy, never mind a 16-year-old with a terminal disease." Mrs. Moore was hesitant to discipline Derek; as she said, "He's been sick so long, he's had free rein on a lot of stuff." But she did try to control his behavior occasionally: "Sometimes he's just so out of control, you just have to tell him, you have to go to your room, and don't come down till somebody comes to get you. Then, when he's gone, you say, what is he in there thinking about? My husband goes to the door, and he's listening at the door. He says, he's okay, he's listening to TV." When I inquired if Mrs. Moore ever did go into Derek's room and ask what he was thinking, she replied, "No, because I'm supposed to be mad--I find the discipline thing so difficult."

The frustrations created by Derek's manner of communicating his fear and his aloof, adolescent attitude were captured in a comment Mrs. Moore made while Derek was undergoing chemotherapy to manage his lung metastases:

> He's very moody and snappish. Sometimes I just let him alone, but sometimes you have to say, Derek, this is no good. I'm not gonna have you walking around and storming and yelling and screaming. You're not going through this alone. Everybody in this family is going through this with you, and it's easier to talk. It's so much easier to talk and say, Mom, I'm scared, or whatever, instead of going around snapping everybody's head off. Of course, he listens and then gives me that "I'm retarded" look. Like, why are you trying to explain these things to me? You know I don't understand. You know that look they

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> give you.

During the six months that we met, Derek and his mother were actively engaged in a developmental tussle: Derek straining for independence and Mrs. Moore yearning to keep him close and, thereby, safe.

Speaking of his mother, Derek said, "I think 'cause she thinks I'm a little kid still, she's overprotecting me. . . . I was hanging out with my friends, but when they went out, I never went, because my mother would ask me a thousand questions and I didn't feel like answering, so I just, I didn't want to go anywhere." I inquired what questions his mother had asked. "A mother's questions, like where are you going? Who are you going with? What are you doing? What time are you gonna be back? I don't know! That's why we're going out, to not know when we're coming back."

Mrs. Moore's protective stance communicated concern but increased Derek's sense of being trapped. Mr. Moore's behavior also contributed to these feelings. Mr. Moore's mother died right before Derek's relapse. At this time, according to Mrs. Moore, "Gordon became more protective of everybody--myself and the kids. Every step we took, he was right there. You couldn't go to the mall without him jumping in the car, like afraid you were going to leave and not come back or something. . . . Derek would say, Mom, tell Daddy to let me breathe. Tell him to let me breathe."

Interestingly, Derek's fantasies about what he would do if he was home alone without his parents were similar to his weekend activities when he wasn't hospitalized:

> I'd wake up, take my shower, go downstairs, and have breakfast. I'd be on the phone planning with my friends on what we're gonna do for the day. By the time we finish planning what we're gonna do, I'd sit down and watch videos for two hours. Then I would go down the block and chill, hang out at my friend's house. Then, since my parents aren't coming home until the next day, I would

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stay out as long as I can, just hang out more.

The mere idea of being independent, of not having his parents around, was intoxicating for Derek. At 17, he was eager to break free. As he said, "I'm tired of being around them. I've been around them my whole life."

Derek and Mrs. Moore made strides in this area over the course of several months. First, Derek told Mrs. Moore that he didn't need her to spend the night with him. "I like to be in the hospital by myself. Especially at night, because they snore, and the room is crowded 'cause she gotta bring her clothes, she has to bring food, she gotta bring this, she gotta bring that. Go home, she's better off going home. . . . I told her to go home. One day I just decided to say go home."

Mrs. Moore described how difficult it was for her to leave:

> I know Derek can handle this here by himself. But maybe it's just the mom thing, like, nothing's going to go right unless I'm right there supervising everything. I was right here with him every night, every day. I didn't go home. I stayed right here. When he relapsed, I was staying for a little while, and then he decided he didn't need me to stay anymore. He just said he didn't need me to stay, so I said fine. I try and stay until he goes to sleep, because I don't like leaving him and I know he doesn't want me to leave. But he just wants to be this big boy now. So I let him make that decision, but it's very difficult. It would be easier for me if I could stay here. My heart wants to be here, but I know Derek's not a little boy anymore.

Mrs. Moore's presence had provided a sense of security for Derek, so that when he asked her to leave, he could trust she would be there the next day. As he said, "She came back the next morning! Bright and early."

Mrs. Moore, under pressure from her husband and oldest son, also allowed Derek more latitude with his friends, and he made his first trip into the city. He said, "I went out last weekend, on Halloween, and she didn't ask any questions!" Again, Mrs. Moore battled her own anxiety over the decision: "I let him go out. With all his sickness and everything, he's never been to the city without us. So we

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let him go out one night. They went to the movies, they went bowling, they went to a diner and ate, and they came home. I stayed up and I walked the floor. . . . It's difficult. It's difficult letting go of a healthy child. It was hard for me with my older son and it's 500 times harder with Derek."

While Derek was waiting for surgery to remove his lung tumors, Mrs. Moore had to return to work. Again, concern for his mother and a desire for autonomy stirred in Derek: "She's tired of being at home and I'm tired of her being home. She's tired of being home, so it's time for her to go back somewhere. We went away on vacation, that didn't help. She's been off for a year, that didn't help. So she's got to get back to work. I hope it helps her." Mrs. Moore reported the same story: "He's been telling me for the longest, you need to go to work. When I wake up in one of my tantrums and I start tearing apart the bedrooms, he says, you really need something to do, Ma, you need to go back to work. So, in my heart of hearts, I know he'll be okay." Although I never shared information with Derek or his mother about what each person had discussed with me, the Moores usually talked about the same issues within weeks of one another.

Derek's concern for his mother was also apparent in this comment Mrs. Moore made before the chemotherapy began to halt the growth of Derek's tumors: "I say how can you be somewhere enjoying yourself and this poor kid is fighting for his life. I know by last time, we were finished with everything by now. He had had his chemo. He had had his surgery. He was on his way back to school. And this time, we're nowhere near there. This is a pretty rough time. But he says, Mom, go somewhere, or I'll say, Derek, if that's [my friend] on the phone, tell her I'm not home, because I don't feel like being bothered. He says, I'm not telling her that, because if she's coming to get you, I want you to go out with her."

At the time of Derek's relapse, the communication pattern that was prevalent at his diagnosis reemerged. Derek said, "I thought it was a routine checkup. My

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parents told me like five minutes before I went in the room that they spotted something on the chest X ray. They didn't want me to worry about it. They told me like five, 10 minutes before I went in the room. . . . They were just looking out for my best interests, so I wouldn't walk around all bummed and bothering everybody, trying to hurt everybody, because I have a bad temper. When I do let off, I have a bad temper." Derek also recalled, "When they confirmed the tumor, it bothered me. I cried a little bit, but now I don't care. They told me after my surgery on my leg that there was a slim chance that I might get cancer again, but I never thought I would. But I did--so what?" Mrs. Moore remembered Derek hitting a wall, and then "nobody discussed it, for a while nobody discussed it." Now, one year into his treatment for the metastases, Mrs. Moore was concerned that Derek still did not discuss his illness:

> I don't get much feedback from him. I'm kind of like in the gray area with him. I don't know what he's thinking. It's like pulling teeth to get him to even discuss it now. When I suggested that we go to counseling, he said, I don't need counseling! My mom says you've got to remember he's getting older, and as they get older, they stop telling you everything, anyway. She says, you have to remember that he's sick and he probably doesn't want to worry you.

At the same time, Mrs. Moore worried about what she would say if Derek were to talk to her about dying:

> He's never asked me the question, am I getting ready to die? If he does, I don't know how I'm going to answer that--he's never asked me that. I've asked the doctors, but he's never asked me that, and I don't know how, I don't know what I'll say to him. I think about it a lot, and I still don't know what I'm going to say to him. I guess that will just be one of those as-the-moment-goes conversations.

Dying was a topic that the entire family shied away from. A friend Derek had made in the hospital died during Derek's initial treatment for bone cancer. The Moores made a conscious decision to withhold this information from Derek. Mrs.

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Moore recalled Derek's reaction when he heard about the death through other channels: "[He said], why did he have to die? Derek was very annoyed with us because we hadn't told him. He wanted to know what gave us the right not to tell him. How did we know that he didn't want to say good-bye to Ernesto? We felt that at the time he would be afraid to go ahead with what he had to be done with him."

Mrs. Moore did tell Derek: "You guys had completely different illnesses. You had this, Ernesto had that. When you came down with your diagnosis, Ernesto had already been sick for about three years. . . . Derek was sad and, phew, he hasn't mentioned Ernesto in years."

Throughout Derek's relapse, the Moores continued to avoid talking about death. As a result, Mrs. Moore was left alone with her fears:

> As far as now, we don't talk about death, specifically Derek dying. If I try and talk to my husband about it, he'll say, that's not gonna happen, that's not gonna happen, we're gonna get through this. If I mention it to my mother, she falls apart. My dad is just like my husband, you know, they're going to make him better again, just like they did before, and you shouldn't think negative--you know, they give you the whole song and dance. I think how scary it is for me. What will my life be like without him? I don't want him to suffer if he's got to go. Sometimes I just shake myself out of it.

Mrs. Moore did try to broach the topic with Derek once, while he was still in remission:

> It must have been when my father-in-law passed away. . . . I think when Pop passed and everybody was really sad, and I was saying, well, tomorrow's not promised to any of us. We're all put here to die. You come and you go. And Derek, it wasn't even like it was directed at him and his illness. It was just something he did not choose to discuss. . . . He said *I don't want to talk about that!* I don't want to discuss this. I don't want to discuss this anymore. I said, you don't have to. There's really nothing that you have to discuss Derek. It's just a fact of life. We're all put here to die. Nobody lives here for ever and ever.

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After a year of chemo, with no new tumors, and the existing tumors exhibiting no new growth, Derek was scheduled for lung surgery. Around this time, Mrs. Moore noticed a change in Derek's willingness to talk about his cancer. "Just recently, he has started to show an interest in what his medications are and what they'll do, because before that he wasn't interested. He didn't wish to discuss it or anything. But I'll say, like, maybe [in the last few months] he's taken more of an interest in the names of the drugs, what the next step will be if this doesn't work."

Mrs. Moore speculated about Derek's new openness: "I think he can no longer ignore or deny that he's a sick young man. There's no more denying it now. He wants to know what's going on, whereas before he was a little boy and he just left everything in his mommy's hands. I tell him to the best of my ability. That's all I can do." She also commented on Derek's compassionate behavior to other sick teenagers: "I see Derek is a bit more open now. Like the young man he's sharing a room with is newly diagnosed. I hear him giving Danny encouraging words. You know, you feel bad today, man, but tomorrow you'll be feeling better, believe me, I know. He's really coming out about it now, because before he would never have said that to him."

Derek was not actively dying during the time that we met, and so it is impossible to know how he and his mother will communicate if he becomes sicker. Based on their closeness and general way of communicating, Mrs. Moore believed that Derek would talk to her when he needed to. Her hope seemed justified based on this story that she told me: "I spoke to Dr. Grant about it and she says, well, I really don't think there's anything for you to worry about. You've got a really good relationship with your son, and when he gets to the point where he wants to talk about it, I'm sure he'll come to you and he'll talk to you about it. . . . So I just leave him alone and the door's always open. He knows he can talk to me about anything." She continued with a hearty laugh, "I had my mom

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laughing last night on the telephone. I called and said, Ma, Derek just came in my room and told me that his butt was itching. So I told him, well, scratch it, Derek. But, Ma, [he says], would you mind taking a look at it 'cause I feel something. And he pulled down his pants. I mean, not all the way off, but enough to show me his cheek. I said, it looks like maybe you were sitting on a pebble or something like that. I said, but take your bath, and put some lotion on it, and it will be fine. My mother says, I tell you, you and your children."

James Wilson and Kevin Churchill

For Kevin and James, a conversation about cancer was one of their first interactions. Kevin recalled the day he and James met:

> As soon as we started talking, I said, what happened? He talked very openly that he had leg cancer when he was six years old, that they amputated the leg. He talked about the amputation. He said it was very painful. Talking to him about it, he didn't seem like the amputation had caused him a lot of fear. After he had it done, he seemed to quickly rebound. He told me that he would run and play, and with his prosthetic limb he could ride a bike. He could climb fences. He could climb trees. He seemed not bitter. He didn't seem self-conscious about having his leg amputated. He seemed very accepting of it. That same day, he also told me that he had cancer in his lungs. So we did talk about his having cancer, that it was cancer in his lungs. He didn't know an awful lot about it.

James's father spent time with him, but they did not often talk. Kevin described one such visit: "James said to him, oh, I'm hungry. So his father brought him Twinkies, Ding Dongs, but James couldn't eat them, he was diabetic. James said, I can't eat that. Then his father said, oh, okay, and he proceeded to open up the Ding Dong and eat the Ding Dong. His father put a cartoon on TV. He was laughing and eating his Ding Dong and Twinkie, and James was just sort of sitting there. It was always like that, pretty much every time I'd see him. He'd come, and

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he'd stay a long time . . . but there didn't seem to be much communication between them."

Kevin seemed to fill a communicative void for James. On the day they met, Kevin remembered James asking, will you be my friend? Kevin felt an "immediate bond" with James and believed James reciprocated: "I think I wasn't in any way threatening to him. He would say things about my being silly or my being goofy. He would say, why'd you make that goofy face? He would respond to me not like I was an adult and he was a little kid."

Kevin said he and James talked about "everything, but nothing. We would talk about stuff James wanted to do. Stuff about his writing, about painting, things he enjoyed creatively." Kevin urged James to make friends on the unit: "I said, the next time you feel bored, you have to go find a kid in the hospital who looks more bored than you, and you have to go bring them a piece of paper and draw them a picture. I knew he wanted me to come over as much as I could, but even that was only a couple of hours a day. So I kept thinking that there was some way to get him more involved with other kids."

Kevin talked about how James would turn to him when in pain: "A lot of times he called me about four, five a.m. with pain issues. His head hurts, his stomach hurts. I would try to get a hold of the nurses, or we would just try to talk and get through it. We'd talk about other things and see if we could get him through whatever that particular pain was. Some of it seemed like pain that wasn't going to go away immediately." But it also seemed that James just wanted to make a connection when he called Kevin. He'd tell Kevin about "the stuff he was doing in the hospital or who he spoke to that day. . . . I talked to James every day, two, three times a day."

James also talked to Kevin about the conflict in his family. Kevin said, "James told me so much stuff. His grandmother didn't like the fact that he told me stuff

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and she would even tell him, you shouldn't tell him everything, you shouldn't tell him what's going on at home. And, luckily, James never stopped telling me stuff. I tried to make it clear to him that he didn't have to keep any of this stuff in."

Kevin's friendship with James created even more conflict: "His grandmother would say things like his father can take him to the park. But his father *didn't* take him to the park. There was this kind of sense that the father should be doing these things, but he wasn't."

James would retreat into silence when he was upset; he felt powerless to effect change in his life. A month before he died, James was having trouble breathing. He had been told that his lung tumor was growing, but Kevin believed he wanted to know more. James would become passive when the doctors came to exam him. He told Kevin, "No one's going to listen to me, anyway. It doesn't matter, no one will listen." Kevin coached James on how to communicate: "Sometimes the doctor would come in, and he would just lie and watch TV and they would do whatever. I would try to explain there are certain words you have to use, and you have to ask questions in a certain way. If someone doesn't answer you, then you have the right to pound on the table and say, excuse me, I asked you a question . . . but I think he had given up on the whole process of getting information."

James was not going to pound on the table; in fact, he was frightened of direct confrontation. He was afraid of destroying the connections he *did* have. James worried that he would be abandoned by his family, and that his family would separate him from Kevin.

Around the time that James was growing weaker, he was being kept in the hospital while the Administration for Children's Services (ACS) investigated charges that he was being physically abused by an uncle. During this period, the Wilsons barred Kevin from visiting James, but James sent Kevin a letter:

He wrote me a note, a very, very terrible note saying, I hate my life. I have a

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> terrible life. I'm terrible. I'm miserable. He wrote, I want everything to get better. I have no love in me. I have no love left. I think he just had an emotional shutdown. He just couldn't deal anymore with this stuff. He was saying he's a bad person and he doesn't want to be a good person anymore. A day later, he called and by that time he'd gone through the anger and was more sad. He told me how sad he was, and that he didn't want to be mean, but that he felt like all of the goodness in him had been taken out and that he didn't have any goodness left.

James's self-hatred was coupled with a growing sense that he was no longer physically strong. Kevin said:

> The image of himself had seemed very strong, but this stuff with the lungs, that sickness and pain--he would talk about feeling broken and that he's never going to get better. He would say, I feel broken. It wasn't because he felt broken emotionally. It was always like he would be really frustrated when the strength of his hand got weaker. I made an issue once about how strong his grip was, so that kind of became a little thing for him about how he was strong. He would squeeze my hand and I would say, owww. Later, when he couldn't do that, when he knew he wasn't as strong, he would get very frustrated.

Kevin said that James "couldn't verbalize what was going on," but James did have many symbolic ways of communicating. He voiced his fears in his dreams and limned his destructive feelings in his drawings. He spoke metaphorically. He conveyed his emotional pain through his behavior, withdrawing into himself in sadness and defeat, or eliminating dangerous feelings by creating them in other people.

James may have felt this subterfuge was necessary, given his grandmother's fierce determination to shelter him from what he already knew. Kevin tried to talk James's grandmother into allowing James to go to a camp for children with cancer: "I said, I really think that this would be a great thing for James. It's not going to cost you anything, it's totally free, they'll pick him up at the house. She said, no, no, no, James can't go to that. So I said, but he'll be with other kids who have

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cancer and he won't feel so alone, like he's the only person that has this thing. She said, no, no, no, I don't want him to be with other kids. I want him to forget that he has cancer."

When James talked to Kevin about dying, he also communicated indirectly. Kevin said, "One time, the first time we discussed his getting older and getting married and having kids, he was adamant, no! I'm not getting married. I'm not having kids." Sometimes Kevin, who was guarding himself from loss, missed these indirect messages: "I would be fine with whatever he wanted to say, but I would never pursue it. I mean, part of me felt, well, he's very sick and he's got lung cancer, and I knew lung cancer's one of the more fatal ones, but . . ."

When James was being held in the hospital by ACS, he hinted to Kevin that he was dying: "The times we did talk about his possibly dying, James would say things like, well, I may not be around for that. When all this stuff was happening in his family, he said to me, I'm afraid. And I kept on saying, it's gonna work out, it's gonna work out. And he said, I'm afraid I'm not gonna be here by the time it works out. I'm not gonna be here."

Kevin tried to respond to James's fears: "At that point, we started discussing about not being here, what that meant, and I said, I might not be here, either. I said, I might leave the hospital tonight and go and get hit by a truck or something." Kevin also said, "I didn't get a sense that it was something he wanted to pursue and discuss, because I guess I didn't see it as imminent. I mean, I did try to let him know from the very beginning, from the first time I met him, that it was perfectly okay, more than okay, to talk about his cancer. I would just say, how'd you get your leg cut off, just very bluntly with him, so that it wasn't like a tabooish type of thing."

Kevin and James never did discuss death directly. And James's wish to live fueled Kevin's own fantasies. "I was talking about going to Europe, and I was

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going to get him email. I said, I'm going there to sing and he said, oh, they want you to sing! I said, I have to go audition for these houses, but hopefully I'll make enough money, [so] as soon as I make enough money, you can come watch me sing, wherever in the world. Really, he said. Like where? I said, France or Italy or Germany, or even Los Angeles. He said, well, what about my shots? What about my medicine? I said, we can get a nurse who can make sure you get your shots and all that. Again, that was in a couple of years. He was actually looking at the options."

Kevin held two different beliefs at the same time. He imagined this future relationship with James, while realizing that James was saying he was going to die. Kevin said, "James seemed pretty clear that he was not going to be around to a certain age. If he came up with that on his own, or from what he had gleaned from other people, and what had been happening, and maybe other kids he'd seen, or whether at some point something was said to him . . . I don't think we ever discussed something very far in the future."

Kevin received James's penultimate communication. It was early evening and James was visiting with his grandmother and Kevin. Suddenly, James began to bleed from his mouth. Within minutes he was dead. Kevin said, "The last thing he did was reach back and grab my hand . . . the last thing he did is grab my hand and squeeze it tight." Their earlier games of strength left Kevin questioning the meaning of this gesture: "Maybe he was just reaching to grab me because he was just grabbing me, or was he trying to tell me I'm not weak?" In his last moments, James cried out his final words to his grandmother and Kevin: "I don't want to die!"

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Taisha and Mrs. Hart

Taisha Hart and her mother talked about many things--TV shows, boys, food. Mrs. Hart valued their talks: "She probably told me everything. Sometimes I wish she wouldn't, but she do. I say, I'm your mother. I'm here for you no matter what. Good times, bad times. Anything you want to ask me, I'll try my best to answer the best way I can. I will tell you the truth about it in my way of saying it."

But talking about cancer was difficult for Mrs. Hart. These conversations made her anxious about her own illness. As she said, "Taisha's always talking about her illness and why this is happening. I say, I'm sick, too, Taisha, we both sick, but we in remission." Mrs. Hart's efforts to reassure Taisha often failed: "She's going to talk and talk. I say, stop talking to me. I'm starting to get angry. I'm starting to get upset, and I have to go in the bathroom and pretend like I'm doing something. I tell her go in and turn on the VCR, watch a movie or something, just to get her mind off it. Try and stay positive. You don't want to think about it till we go back and let the doctors tell us what's going on. . . . She talks about it, and I tell her don't talk about it because you could be making yourself sick by talking about it, you could be willing sickness in you."

Like many parents, Mrs. Hart tried to get Taisha's mind off her illness by supplying her with material objects: "For somebody to have sickness since they were 11, and now she's 16--she didn't have much of a real good life, so I try to make her happy by giving her videos and super Nintendos and a computer. All this stuff to keep her from thinking about cancer." She tried to distract Taisha by changing the subject: "I listen to her talk and I say, I'm going in the kitchen for a minute. You want a sandwich or something to eat? Anything just to stop her from thinking about it."

It pained Mrs. Hart to hear Taisha mourn the loss of her leg: "Every two months, she'd get the blues. She'll get all angry, and she'll talk about her leg. I'll

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just sit there and listen to her. I'll say, I don't want to hear her talking like this. There's something we gotta do to stop her from being blue, gray, whatever you call the colors you feel now." Yet, despite her anxiety, Mrs. Hart did listen to Taisha, and she tried to help her adjust: "When she got the prosthesis, she'd walk with a limp. People would stop and look at her. She'd say, why you looking at me? You got a problem? I said, Taisha, we gonna get in trouble. Somebody gonna poke you and try to hurt you. Mommy will step in there and help you, but you can't be snapping at people because they looking at you. People are not blind. They see something wrong with your leg and if they ask you, you tell them you lost your leg through cancer. It's no crime. It's a disease. Don't be ashamed, tell the truth. . . . I'm gonna be there beside you. I ain't letting nobody hurt you."

And Mrs. Hart *was* beside Taisha. "When she first had her leg amputated, I was in the hospital with her for a month and a half. She was 11 years old. She didn't need me, but that was my baby. She was there in the hospital, and I never left her. I would feel bad if I left her. It was my responsibility. I was the mother, and I had to do my job. I would sit there and look out the window and say, I'm going home today, but nope. They brought me clothes every day. I was living here. She'd talk to you all day long. She liked everybody, but she didn't want to be in here. I felt safe here with her, knowing she was safe here. I was protecting her. [I was there] if she needed to cry on my shoulder. I was there to help her try to solve her problems or make her feel calm."

Taisha internalized Mrs. Hart's messages. One afternoon she told me, "My ma, she strengthened me up. She strengthened me to believe that I could be anything. Even though I don't have my leg, I believe I can do it. If I couldn't, I try and try until I get it."

Taisha's father visited her shortly before her 17th birthday. Taisha was upset by some cruel remarks he had made but wouldn't tell her mother. Mrs. Hart

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sensed that something was wrong with Taisha, and was frustrated that Taisha wasn't talking about the problem. "It makes me feel like I ain't doing my job. As a parent, she's supposed to talk to me, no matter what. I tell her always I'm there. Talk to me if you're having pain, if you're having problems." But Taisha didn't want her mother to be upset. They never discussed the incident, and Taisha died three weeks later.

The seizure that left Taisha brain-dead was sudden and unexpected. The Harts had no opportunity to talk while Taisha was dying. They had, however, talked about death since the early stages of Taisha's illness. Mrs. Hart said, "It was constantly on her mind. She always mentioned it. Maybe I'm going to die now that I got this cancer. I said, no, you ain't going to die. You going to be around a long time. I always joked, but it was on her mind and it was on my mind. But I tried to cheer her up, and I did cheer her up."

Mrs. Hart tried to allay Taisha's fears about dying: "The teenagers would say to her, you have cancer? You may die. It hurts her, and she comes to me crying and stuff. I tell her, they don't know that. They're not God. Doctors don't even know for certain. They give you a time, you may outlive that time. They're not certain. We not giving up no matter what life gives us. We ain't giving up. We going to keep trucking on, talking, whatever. I tell her, don't worry about that 'cause you ain't gonna die no time soon. I say, you a strong person. And she just keep on. I mean, she's just like a flower, she blossoms as time goes on."

From the beginning, Mrs. Hart had tried to avoid confronting the possibility that Taisha might die. "I was planning on reading about every sickness when she got cancer and I never did. I didn't know what it was going to tell me, like that word was going to be there--death. After so many years, she's going to die. And I never asked the doctor that, neither. When I found out that she had bone cancer, I

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never asked him. I didn't want to know. . . . I never approached them and asked them. It was in my expression, but they never told me and so I let it go."

Still, Mrs. Hart tried to respond to Taisha's communications about death: "When my youngest brother died, she started talking about if she ever died to cremate her and don't spend a whole lot of money on the funeral. I thought she was joking. I said, no. I said, if you die, I want to come and see you and put flowers on your [grave]. I know you like flowers. And say hello and tell her what we did, even though you're not going to say nothing back to me. I said, that's the way I want to remember you by, coming to you and sitting down, and putting flowers around you and saying things, all them things we said to each other."

But for Mrs. Hart, the undercurrent of fear was always there: "Taisha always express it, she always come out and tell you what's on her mind. . . . I just try to respond the best way I could without getting real upset, you know, why's she asking me this, maybe she knows something and she's not telling me."

As Taisha lay brain-dead in the ICU, Mrs. Hart continued to communicate with her: "I touch her all over. She loves the rain, it's raining. I told her it's raining outside. She hear me talking. She know I'm there. I'm always going to be there, close by. I can't spend the night. She don't know I'm not spending the night, but I come every day and stay till closing. . . . I'm going to show happiness and talk about things that she did, you know, make her feel better, make her strengthen her body up."

A month after Taisha died, as Mrs. Hart talked about her plans to go to the cemetery, it was as if she was still carrying on a familiar conversation: "Soon we gonna go visit her. We going to see her, but in another way. She going to be laying there sleeping. She can't talk to us like she usually do. You couldn't get no words out if she starts talking, she going to talk until you say, okay, I'm looking at the TV now."

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Almost a year after Taisha's death, on what would have been her 18th birthday, I spoke to Mrs. Hart. She was going to the cemetery to put flowers on Taisha's grave and to talk to her. Mrs. Hart told me that she still talks to Taisha every day, but that she "doesn't get an answer." She went on to say, "That's not like Taisha, because she always had an answer. But I guess she's hearing me and *is* answering. I just can't hear it."

Nickie and Mrs. Sahdi

Nickie Sahdi learned she had cancer from her father. "The doctors told my dad that it looks like a tumor. They have to run some tests and see exactly what it is. They run the tests, and it was a tumor. Dad told me. You know, I didn't take it that hard. I didn't, like, break down and cry. I can't remember exactly what he said. I don't know how he took it. He has a kind of way--he keeps things inside. He hides it. I can't tell if he's sad or happy . . . I suppose he was, well, sad."

Nickie learned she would have her leg amputated from her mother: "My mom told me. My parents came in a meeting to the hospital, and they found out from the doctors and then they came home. I didn't cry. Mom cried. Dad cried. But I didn't cry. When I came out of surgery, well, Mom was there and Dad was there. They were crying, but I wasn't crying. I say, I don't want to cry, so I didn't cry at all, and they cried. They cry, they crying, and I'm telling them not to cry. I am telling them not to cry. I didn't cry at all. For nothing I didn't cry."

Nickie, reticent about letting "scary" thoughts or feelings into her awareness, did sometimes talk to her mother about her illness. After her relapse, Nickie had a thoracotomy to remove a tumor on her lung. Complications after the surgery necessitated a second surgery to reposition a drain, and Nickie said that then she was frightened. "They had to go back and fix the tube. I was scared. If they had to take the stitches out, it would hurt. It's already so sore." Nickie shared her fear

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with her mother, but as she was quick to point out, this emotional expression was unavoidable: "It really just showed because I told them I was scared. It's out loud, it's not like the two of us just sit down. I told everybody I'm scared."

Nickie and her mother had a way of handling discussions about her illness: "Sometimes Mom says [the feeling] out loud. She'll ask how I was feeling and she's telling me how I was feeling. You know, like you'll tell someone, I know how you're feeling. Well, she'll start off like that. And when she start off like that, I say, yeah, it was painful. It was this, it was that. So that's how the conversations are. You know, make the conversation a little longer."

But most of the time, Nickie and her brothers and sisters liked to "talk stupidness" with their mother: "We talk about a long time ago. How we were afraid to tell her when we make mistakes, children-like. We tell her when we make cake and didn't tell her. We tell her all sort of stuff and she say, yeah, that's why you guys didn't tell me! Because if we tell her when we was small, she would spank us. Now we're big so she can't."

For Nickie, not talking about her thoughts and feelings was a way to protect both her mother and herself from sadness or anxiety: "Sometimes I don't really ask for nothing. What I have, I keep it until I'm ready to tell her, or when I want to tell her. I don't tell her just anything. Sometimes I just say, later on, and then I forget. I end up forgetting and forgetting."

Nickie said that she didn't talk about dying with her parents. But the issue did arise when her parents argued: "My mom cries every time Dad say something about it. She don't like to hear it. Sometime he'll say I'm gonna die. Sometime they might argue. She says, don't say that. She's not gonna die, and if she dies, she's not gonna die in your hands. She means I'm not gonna die around him, his care. That's the only time it really comes up. They don't argue much, but when

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they do argue, everything stirs up at once. That's the only time they say about dying. . . . It doesn't really bother me. It's my life, and I don't really take them on."

When Nickie and her mother were together, the room was filled with chatter and laughter; their way of dealing with the stresses of Nickie's illness were well attuned. Mr. Sahdi's style was different and did not have the same enlivening effect.

When Nickie was first hospitalized, Mr. Sahdi stayed with her every night for a month. But when she was getting her final chemotherapy treatment after her relapse, she said, "I don't like him to come. When he comes, it's not exciting. Somehow it's not exciting. You can't talk to him, and he's always leaving the room--not on purpose--he always says, I have to talk to this one, have to talk to that one. So it's like what the hell you come for? You see Mom, sometimes when she's cleaning up and ready to go home, we talk about this, we talk about that, she never leaves the room. Most of the time, we talk, we joke about something. It feels different, real different." This excitement, coupled with the holding function Mrs. Sahdi provided for Nickie's feelings, kept conversations about death and dying in abeyance but seemed to allow Nickie to remain optimistic about her future.

Lillian and Mrs. Royce

Lillian Royce rarely talked about her illness. Her mother recalled that when Lillian was diagnosed at age 13, "the doctor told me and her father and they told Lillian. They said renal cell carcinoma. It's rare, the cancer she had is rare, it's mostly for older people." The doctors told Mr. and Mrs. Royce that Lillian would probably die within three years, and urged them to share this information with her: "They said she would die in the space of three years. . . . The doctors want me to tell her that she's going to die, and I tell them that I couldn't do that, 'cause I know

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she don't want to know. She always think she's going to get better. The doctor told me it's not fair for her not to know. So they asked me if I would want them to tell her. I tell them no."

Whether Lillian would have wished to know her prognosis or not, it seemed clear that she didn't want to talk about being sick. Mrs. Royce said, "She always said she gonna get better. She never want to die. I tried to talk to her about it, but she never want to hear about that. She told me that she didn't want to talk about nothing about her sickness. . . . She don't want anyone to be sorry for her. She don't want to be treated special. She wanted to be like a regular person. But it was hard to do with her: She's sick and she didn't want to talk about her sickness, never."

Lillian's father did talk to her about her illness, but in ways that threatened her self-representation. Mr. Royce made Lillian feel damaged. As a result, their conversations were usually one-sided: "I don't even like talking to him about me, 'cause he says stupid stuff. One time, when I was in for a transfusion, he said that probably getting somebody else's blood would help me. I don't know where he got that from. What are you talking about? Me getting somebody else's blood, 'cause like my blood is contaminated or something. He said my blood has cancer in it, but that's just the same as saying you're contaminated with cancer, and somebody else's blood, which is healthy--I know there's nothing wrong with my blood."

Mr. Royce also complained to Lillian about Mrs. Royce: "He talks mostly about my mother. What she's doing. What boyfriend she has in the house. Stupid stuff. Something's wrong with him. He's always complaining about himself, how his life is so hard. He's real spiteful. He does spiteful things to my mother."

Lillian did not discuss these conflicts with her mother. Mrs. Royce said, "She didn't want her father to talk anything bad about me. She hates that, it upset her. But he always did. And she never want to tell me because she said it will upset

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me." Several days before her death, Lillian had her last conversation with her father. Mrs. Royce heard about the talk from Mr. Royce: "Her father told me that she told him to leave and don't come back, because he was telling her things that she don't want to hear. He's telling her that she's sick, that she's gonna die."

Lillian was extremely protective of her mother. She worried about how her mother would pay the family bills, about the long hours Mrs. Royce worked, about Mrs. Royce having to single-handedly take care of both her and her younger brother, and about her mother's sadness. Mrs. Royce said that Lillian "always wanted to talk about me. If I tell her to talk about her, she'd want to talk about my day. What did I do? You know, about whatever. I might have had a problem paying a bill, she always wanted to talk about that. She always wanted to help. . . . She always wanted to talk to me, but it's just about me. She never really want to talk about herself."

Lillian said that she had always been able to talk to her mother. "We always go shopping, and she'd do my hair and get my nails done. She used to have a beauty supply store, and I used to sit there in the summertime and if somebody wanted to buy something, I would go behind the cash register. I used to like doing that stuff. It was fun."

Mrs. Royce's time at the hospital was limited by several factors. She received no help with child care from her husband and thus frequently had to leave the hospital to be at home with her 10-year-old son. She had full responsibility for her business and the family's finances. But she also was depressed by Lillian's illness and felt powerless to ease Lillian's pain. Ever watchful of her mother's feelings, Lillian was upset by what she experienced as malicious gossip. Mrs. Royce said, "In the end, she didn't like nobody to talk about me. She would tell me [the nurses] keep on asking, did your mother visit? She said she don't like that. I had it

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hard. I have to be working. I get really depressed. I didn't even want to get up. I was so depressed about Lillian."

Lillian was often in severe pain, which hampered communication. Although Lillian may not have wanted to talk about her approaching death, she did want to be with people. Her actions sometimes conveyed a different message: "One day I was feeling so sick, my mother tried to kiss me and I said, leave me alone, I don't feel well. And she felt bad. I push everybody away from me 'cause I feel so sick. When I'm sick, I just want somebody to be around, you know, so I'm not alone. Somebody who's just talking and I'm listening to them, while I'm waiting for the pain pills to work. Sometimes I'm not in the mood to talk. I just want to sit there and listen."

Ultimately, Mrs. Royce agreed that the doctors could talk to Lillian about her condition. Twelve days before Lillian died, there was a meeting at her bedside. Mrs. Royce said, "When she was in the hospital this last time, I tell the doctors they can tell her. They did it while I was there, sitting down with my son. The doctor was there and he tell her that, he didn't tell her that she's going to die, he just said, do you know that one day what you have--it may take your life. She tell him she don't want to hear, she didn't want to hear. They talk about the intubation and if she would want them to intubate her, and she told them yes. That was it. She didn't want to hear it, didn't want to hear about it, didn't want to hear nothing about death. She said because it made her sad. She wanted me to be happy, said she wanted me to have a boyfriend."

At this time, Mrs. Royce tried to engage Lillian in conversation: "I told her I'm not scared to die because we all have to go one day, and she didn't want to hear. She never answered. I could see that she didn't want to talk about that."

In her last days, Lillian and her mother seemed to move between an unspoken awareness that she was dying and a hope that she would live. They reminisced

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about a trip the family had taken early in her illness and acknowledged that "back in those days when we thought I was sick, I wasn't that sick compared to now." Yet they also made plans for Lillian to go on a new diet consisting exclusively of fresh fruits and vegetables.

Lillian spent the last two days of her life in the ICU. As she was intubated, her last communications were written. Lillian told the doctors that she wanted them to "*do everything*" to prolong her life. Her final note to her mother concerned her younger brother. Mrs. Royce said, "It was Roger's birthday, and I know she was very sad. The last [thing] she wrote on a piece of paper, tell Roger happy birthday. She was concerned about other people. She didn't concern about other things. She didn't concern most about her sickness. I don't know why, she was just worried about other things."

Joseph and Mrs. Anthony

In contrast to the Royces, Mrs. Anthony and Joseph talked about the possibility of death from the onset of his illness. Mrs. Anthony was two weeks away from the scheduled delivery date of her third child when she took Joseph to the hospital because of an uncontrollable nosebleed. She gave birth that same day. The next day, she checked herself out of the hospital and went to visit Joseph: "I was crying. He asked my sister why I was crying. One of my sister's said I was crying because the baby was still in the hospital. The next day he found out that that was a lie, and he was very, very upset. . . . He found out because he ask me the next day why was I crying. So I told him . . . I said, because I found out that you have a serious illness, that you can die."

Joseph recalled: "I was crying a lot when it happened at first. I had to stay at the hospital and then my mother told me I got leukemia. . . . I was very worried

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that I was going to die." Joseph turned to his mother to ease his fears: "I talked to my mother. It helped. I don't worry about that anymore."

As part of his initial treatment, Joseph had a broviac surgically placed in his leg. The procedure was painful, and afterward Joseph was lethargic and reluctant to get out of bed. Mrs. Anthony negotiated with Joseph: "He didn't want to walk, talk, or anything of the sort. I tell him he have to walk, if he stay in bed he'll never walk again. I would tell him things like that, and he said, okay, I'll try it, not today, but tomorrow, that's what he said. So I said, okay, you have all day today in bed, but tomorrow, first thing, get out of bed, and if you don't walk you'll never go home, the doctors won't let you go home unless you walk. So the next day I got him out of bed, and he complained a lot about here hurts and there hurts. I even had to force him to eat because he wasn't eating, because his mind was bent on going home. I said, if you want to go home you have to eat--and he went home." Mrs. Anthony added, "We talked, and he said to me, I don't want to die, that's what he said. I told him I didn't want him to die, either. I said to him also, I said, we all must die sometime. It may not be today, but we all have to die. I don't know if that meant anything to him. He didn't say anything. He just listened."

Joseph was vague about this last part of the conversation, but otherwise his memories were similar:

> When I woke up from surgery, I was in a little pain in my left leg. Then the next day, I tried to walk on that leg, but I couldn't walk on it. Later, my mother told me to just try to walk on it, and she took me walking around. The next day, they put in another broviac. They was going to put it in my neck, but something was wrong up there, so they put it in my leg. I was in a lot of pain, like a week. The same night when they put it in, I had to get chemotherapy. I was thinking I wouldn't come out of the hospital for, like, a long while, and lots of things. I thought I wasn't even going to use that leg no more. I told my mother. She told me, don't worry about it and you're going to walk around, try to walk on the leg. [Then] I felt a little better."

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Even at this initial stage of his treatment, Mrs. Anthony involved Joseph in decision making about his care:

> The doctors wanted to put a central line in his neck. So I sat down with Joseph and I said, Joseph, we have to put in another line, and they want to put it in your neck. He said, no, I don't want it up here. He say he wanted it in the leg. So I told the surgeon, and I insist they put it in the leg. Joseph's doctor call me on the phone and said, I think it would be a better idea to put it in the neck. I discuss that with Joseph. He was crying. He said, no, no, no. He said, I want it in the leg. I said, you take full responsibility if they put it in the leg and they have to move it and put it somewhere else. He said, yes. So I insisted they put it in the leg. Because that's his body. He's not stupid, you know, so I let him be a part of what's going on in his life. If he doesn't want me to sign something, and I feel to myself he's right, I go with that."

Mrs. Anthony's belief in open communication with Joseph--with all of her children--predated his illness:

> If he was sad, it would bother me, and we would talk about it, you know, [I'd ask] what make you sad? We talk about anything, we can talk about anything. If something is wrong, he can come to me without me screaming or yelling, because that would cause him not to say a word. If my kids did something wrong, or they broke a glass, they would come to me and say, I did this. I would say, it can be replaced. When I was growing up, we wouldn't tell our parents that we broke a dish. They would be screaming. I guess I would say that if you treat children with respect, they'll treat you with respect. That's just my way.

Joseph was in remission for only two months. When he relapsed, he again shared his fears with his mother: "I wish they had got rid of all the leukemia, but they had to wait and see if it's going to come back--and it did. They said they were going to give me another chemotherapy. My mother said they got rid of it by giving it to me [before], and they're going to get rid of it again. I believe it."

But chemotherapy did not halt the progression of Joseph's disease. Two months after he learned about his relapse, Joseph's condition worsened. He said, "The

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doctors said they was going to do the bone marrow to see how much bad cells I had. The nurses took too long to [give me] the platelets, 'cause I had to get platelets, too, so Dr. Ranji decided to get bloods drawn. And when he saw it, there was bad cells in my blood. So they didn't need to do the bone marrow. And Dr. Curtis said there is nothing more they can do over here. They told me that I had to come to another hospital, 'cause they can't give me the medicine."

Joseph was to be transferred to a research hospital for an experimental treatment. Distraught at having to leave familiar surroundings, he told his mother that he was sad, and that he didn't want to transfer to a new hospital. He said that she responded by asking him if he wanted to die. He said no. He was transferred to the new hospital.

Mrs. Anthony didn't remember this conversation in quite the same way: "I think Joseph mentioned about coming to the new hospital. I think he mentioned it. So he knew we were coming, because I told him and he said he already knew." Foremost in Mrs. Anthony's mind was Joseph's disappointment when what was supposed to be a quick blood test at the new hospital turned into a two-week stay: "As usual, you know, he wasn't too thrilled. We came here not with the intention of him having a fever and having to stay. He was very, very angry that he had to stay. And after a couple of hours, he calmed down."

Due to certain characteristics of Joseph's disease, he was ineligible for the experimental protocol. Joseph's condition deteriorated, and several weeks after his transfer, his doctors met with Mrs. Anthony:

> They said that the treatment that they used, they expected that to work and it didn't. That there, you know, there's nothing more that they can do for him. They did sit down and they talk, we talked. They told me first. Then I told them to go tell Joseph. The first thing he said was, am I going to die? So they said, yes, it was a possibility. He was crying. I said, I told you before we all die. We must die. And live we may, I said, but doctors don't always be right.

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> So don't get yourself all worked up over whatever, and he calmed down. I came back the next day. I said, were you thinking about what the doctors said? He said, a little. Then every day I ask him, so he said, I'm not thinking about that. I stopped asking him. I asked him for like three days in a row, because I wanted to know whether he was focused on thinking about that. He said, no, so I stopped asking him about that. Then I would come and say, what you have on your mind? Tell me what's going on. What are you thinking? He might say, I was thinking I just want to go home. I was thinking why do I have to get sick? I said, are you worried? He said no. I don't think he's thinking about it. He's thinking about going home. I told him if he get better, I'll send him to the West Indies with my mother. I said, if you're well enough to go, I'll send you . . . so we'll just see.

Shortly after this meeting, Joseph returned home to die. During his final two weeks, he and his mother had many conversations: "One night he was talking about things that we did, places we went. Since he's been home, he said he can't believe this, another summer and he can't get to different places, like Great Adventure. He said if he live, he wanted to do something or go someplace. I don't remember exactly." Mrs. Anthony wanted to ask Joseph if he was afraid of dying, but hesitated:

> Sometime I ask him, what are you thinking? He says, what I would be doing if I wasn't sick. . . . I wanted to ask him if he's scared about dying. My mother doesn't want me to. I don't want him to be worried about anything, so I took her advice. I would love to ask him that. I just want to know what he's feeling and what he's thinking. I suspect he's thinking. You know, sometimes he sit there and he's just as quiet as ever. I think maybe he's thinking about something, so I would ask him, are you worried about anything? He would say, not really. I don't know if he's scared and he's not saying. I just keep on trying to get in and see what he is thinking, 'cause sometimes, like I say, he 's quiet, very quiet, and other times he's talking a lot. He knows everybody have to die, 'cause I always tell him that. So I would love to know if he's thinking about it, if he's scared. I'll probably wait until he's in one of those talking moods.

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Mrs. Anthony never did ask Joseph this question directly. When he was in a talking mood, Joseph and his mother stayed up into the early hours of the morning: "Joseph was always reminding me about different stuff that happened, places we went, and one night I was really scared because I actually thought he was gonna die that night. He was reminding me of every single place he went. When he went to the West Indies, when he went to Great Adventure. He remind me about a lot of things that I didn't even remember. I said, why is he telling me all this? When he fell asleep, I couldn't go to sleep 'cause I was just wondering why he was telling me, and every minute I was checking him to see if anything was wrong."

Joseph and his mother discussed the various services that were offered by the hospice organization: "He said he wanted somebody to come out with the organ or whatever, and they play music. He said he wanted somebody else to come out and tell him Bible stories."

And Joseph and Mrs. Anthony talked about dying:

> I tried to comfort him. We talked about death a lot. I guess he knew he was going to die from the way he felt. 'Cause one day he asked me why is his stomach hurting so much. I have to tell him because the leukemia was spreading and that was the cause of him having so much pain. He asked the question, what kind of people go to Heaven? And then we end up talking about killers and thieves, and I said, those kind of people don't go to Heaven. I say, have you ever killed anybody? And, you know, we were talking just normal, and eventually I end up telling him that he will go to Heaven because he hasn't done those crimes and things. I told him he'll go to Heaven and he would be happy and he wouldn't be in no kind of pain.

Two days before he died, Joseph and Mrs. Anthony reviewed his life: "We went over all his pictures from when he was baby until now. We were going through all these pictures, and he was looking at them. . . . I think he knew he was gonna die, that he wanted to see those baby pictures and remind me of different things that was happening."

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Joseph requested that his mother give him a party for his 11th birthday. Joseph went with Mrs. Anthony to pick out the cake, and they planned the guest list together. On Joseph's birthday, he asked to go to church. Because he was in so much pain, Mrs. Anthony "let the church come to him. A member of the church came and sang to him. Because of the pain, I asked the church to come to him and they came, on the day of his birthday."

Joseph visited with all of his friends and family at the party, thanked them all for coming, and said good-bye. He was in pain and got into bed with his mother: "After everybody leave, he say, why was he having all this pain in his stomach. I asked him if he wanted to go to the doctor. He said no. I told him, it's because the leukemia's spreading. I told him to say a prayer and ask God to deliver you from your pain, and basically we hold hands. He was on and off in pain, and we were up until about three. He wanted to go to the bathroom, and he don't want to use the bedpan, so I have to walk with him."

The next day, Mrs. Anthony wanted to stay home from work, but Joseph urged her to go. She talked to him on the telephone throughout the day. Joseph told her that he was in pain but that he didn't want to go to the hospital. A worker from the hospice came to play the guitar and sing to Joseph. In the evening, Mrs. Anthony received a call from her mother asking her to come home. Joseph was in more pain. Mrs. Anthony reached the house just in time to hear Joseph's last words: "Mommy, Mommy, please help me."

As these narratives show, communication styles, like patterns of defense, appeared to remain relatively stable over time. Still, regardless of whether illness, death, and dying were openly discussed or not, one aspect of experience was routinely concealed: Emotion.

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Emotional Protection

Every child, at some point, talked to his or her parents about physical pain. James called Kevin in the middle of the night when he was in severe pain. Although Lillian tried to hide her pain, she would eventually ask her mother for help. Joseph and his mother prayed that his abdominal pain would pass. Emotional pain was revealed far less readily.

Physical pain may have been more immediate and less capable of transformation or suppression than emotional pain. Or, perhaps, there was a more direct path for resolving physical pain. Kevin said, "If James was anxious, I just felt hopeless, helpless. Maybe that's why the [physical] pain had a certain, you know, you could do something about it. I could get a hold of the nurse and stand there and wait until they called the doctor. And then they would come and give the medication, and you knew that would take care of that. If there were things that you couldn't do anything about, then you would just kind of feel that helplessness."

Emotional pain had a different quality than physical pain. Mrs. Hart said, "Taisha had pains from the surgery and stuff, but the pain that's inside, I think that's the worst. The way she feels the pain emotionally." Mrs. Moore described the all-encompassing nature of emotional pain: "Physical pain hurts here [pointing to a specific spot on her body]. Emotional pain hurts from your head to your toes. Your kidneys, your heart, everything hurts from emotional pain. Physical pain can be controlled a lot easier than emotional pain. Physical pain you can take a Tylenol with codeine. Emotional pain, you kind of brush it to the side and it goes away for a little while, and when it comes back, it comes back trifold. It's three times worse than it was when it left. I think you carry emotional pain longer than you carry physical pain."

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That it was their own child who was experiencing this emotional pain was unbearable for the parents. Mrs. Royce said, "You're the one that bring your child for nine months. That's your child. You see her growing up until a certain age and then . . . it's really hard, it's just--that's your child." Mrs. Hart also felt that the special physical connection between a mother and child added to the suffering: "We're separate, but I'm the mommy that carried her for nine months and gave birth to her. I can't feel her pain but I try like crazy to."

A child's vulnerability and dependence increased the sense of impotence that parents felt. Kevin said, "I think with children, they're looking to you, like, do something, and when you can't do anything, then you just feel, it's not like a failure, it's like I want him to know that if I could do something that I would do it."

Emotional pain was spoken of as if it was contagious. Mrs. Moore expressed this belief when she said, "I told Gordon, when you go in there with Derek, you can't go in there with [a sad] face. He's going to pull strength from us, and if you're walking around crying and in a funk all the time, it's going to rub off on him." Mrs. Hart described this empathic emotional communication: "When Taisha's sad, I'm sad. When she hurt, I hurt. I, like, feel her pain."

Although Mrs. Moore laughingly related this story of shared affect, the underlying fear can be discerned:

> I can remember when Derek had his first major surgery, when they took his femur out. He's got this humongous scar. It was sewn on the inside and stapled on the outside. Every time they would come to take the staples out, Derek would say, no, no, not now. . . . So finally, this one day the doctor came in and said, okay, Derek, we have to do this today. So now Derek's crying, I'm crying, and the doctor's popping the staples. And Derek, maybe he was about 11, and he's saying to him, you get the hell off of me. I mean, I'm not even hearing him cursing. I'm just crying and he's crying, and the nurses are running down the hallway to see what they're doing to poor little Derek, and it was just the most dramatic thing. As soon as the doctor popped the last one, he stood

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> there and he looked at the two of us, he was a nice guy, he was very young, and he really had a good rapport with Derek, but he just looked at us and he chuckled. He said, look at you two, mother and son. Wait till I tell your husband on you. But Derek was so scared and I was so scared for him. He's screaming and crying, and I'm crying and tears, and it was just a mess, it was just a mess.

It was not just that it was difficult to see someone you loved in pain, there was a belief that sharing feelings would create an escalating spiral of suffering that could not be endured. Mrs. Royce described how Lillian, in one of her last gestures, tried to halt this cycle: "Lillian never wanted to cry. It made her sad when I cry. When I go to see her and I start to cry, she always tell me not to cry. That's the last thing she said to me before she died. I was crying and she wasn't able to talk, and she made a hand motion not to cry."

There was a sense that affect was overwhelming, and that to give in to it would mean to lose all control. Mrs. Moore said, "I'm always wound up like a clock. Like, if somebody just lets it out, you just go out of control."

Mrs. Hart described her efforts to maintain equilibrium: "I don't want to cry. Taisha will get emotional. She'll come over and we'll hug, and we'll both be crying and crying. But I got so much inside of me, if I let it out, I think I'll be like a faucet. You can't turn me off. I wouldn't never stop crying. I would just keep crying, and crying, and crying . . . and so I just do a little bit of crying and try to hold so much in."

Reining in violent emotions was not always possible. After Taisha's catastrophic seizure, Mrs. Hart voiced the agony that fed her efforts to suppress her feelings: "Let that guard down--once you let that guard down, that's it. I think I let it down when I saw her go back out through that door. I was hysterical. I'm just, my child's gone. No, no! Don't take her! She just got here! She hugged me,

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Mommy, and then you're going out with her. No, no, don't take my child! I yelled and screamed and say, no, don't take my child back again, she just got here."

Mrs. Anthony described holding back her tears in an effort to buoy Joseph: "I feel like crying many times, many times. But I have to be strong for Joseph." It seemed that she was also trying to keep herself from disintegrating. When I asked if she cried when she wasn't with Joseph, she said, "No. Then I wouldn't be able to control myself when I'm in front of him." When I asked Mrs. Anthony how she was able to carry on, she replied, "Just as usual. I can't give up. Sometimes you feel like screaming. Some nights you just feel like screaming. But I can't give up."

Emotions seemed dangerous; their expression might lead to breakdown. Mrs. Moore said, "Let that guard down, once you let that guard down, that's it. Then there'd be nobody who had all their senses about them. Then he'd be out there by himself. Got to keep my senses." Mrs. Hart explained why she hadn't allowed Taisha to attend her uncle's funeral: "I cry. I try to hide it but sometimes I cry. And she'll cry, she get real emotional. When I lost my baby brother, they was close and she took it real hard. We couldn't go to the funeral. I think for some reason if she went she'd be in the hospital, because she get very upset."

Speaking of James, Kevin said, "I didn't want him to be anxious. I didn't want him to be anxious about anything. I guess I just wanted him to be as happy as I felt he deserved to be. I just wanted him to be happy." The desire to shield children from anxiety and sadness seemed elemental, and almost every parent talked about his or her efforts to hide those feelings.

Mrs. Moore worried that expressing emotions would unravel Derek: "Get it together, because Derek's going to react off of how we're acting. And we can't go in there like that 'cause he's waiting to see how we are. If we're falling apart at the seams, he's definitely going to fall apart at the seams. So there you are, right back

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to protecting Derek. Get yourself together for him. Kind of like putting on a mask."

Mrs. Hart tried to pretend, however unsuccessfully, that she wasn't upset: "I'd go in the bathroom and I'd cry, and I'd come out and Taisha would see my eyes red, and she'd say, what's the matter, Mommy? You was crying? And I say, no, I just had something in my eye and I was rubbing it. But I was crying, she knows, we was that close."

Mrs. Anthony said, "I didn't want Joseph being upset. I spend most of whatever time I had with him. Talking to him, getting to know how he feel and, you know, try to make him comfortable. It was important to me not to make him upset, so why would anybody want to cry in front of their kid and make them more depressed?"

If affect was contagious and couldn't be survived, then it must be suppressed. Emotional communication went underground. Mrs. Anthony and Joseph had already had one emotion-laden misunderstanding when he saw her crying after his diagnosis. She was determined never to cry again: "I have never walked in the hospital room crying. Joseph never seen me cry. Going to his bedside and crying. I have to be strong for him. If I cry in front of Joseph, he would want to know what I'm crying for. He would start crying also and get himself all worked up and excited. I don't want that for him. I don't want him being upset and worried over me being upset, because that's exactly what's going to happen."

Joseph's father was present when the doctors told Mrs. Anthony that Joseph was dying. Mrs. Anthony encouraged him to subdue his emotions in front of Joseph: "When the doctor told me the news about Joseph, his father was there. The father was crying and he came in the room crying. So when he came in the room, I walk out of the room and he walk out behind me. I tell him, I don't want to see you cry in front of Joseph. You want to cry, don't cry in front of Joseph.

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Joseph said, why is he crying? Go find out why he is crying. So I walked out of the room, and then I turn back. I said, he's all the way to the elevator. When he comes back, maybe you can ask him why he's crying. He never did." Mrs. Anthony explained, "I just don't want Joseph being upset, because he gets worried and everything. I just want him to be as pleasant as always."

The degree to which Mrs. Anthony tried to protect Joseph and herself from what she envisioned as emotional collapse was revealed in a comment she made soon after she heard Joseph was dying: "I cry once in a while but not very often. Like, for instance, the day when the doctor told me the news, I did shed a few tears and I just wipe them away. They said he wanted me, so I washed my face and I went directly to him. He didn't know I was crying. Since then, I haven't shed another tear."

Mrs. Anthony and Joseph also discussed whether they would tell anyone else in the family that he was dying: "When we found out he was going to die, I said, do you want me to tell it to everybody? I think he said he didn't . . . I don't think he answered. I don't remember him answering. I said, well, between you and I, I don't want to see everybody coming crying and saying how sorry they are. So he said, okay, we won't tell anybody. I didn't even tell my mother. I never repeat anything that the doctors say to anybody. But, you know, between me and Joseph, we talked about it. He agreed that he wasn't gonna tell anybody, it would stay between us, and he never told anybody."

When I visited Joseph during the last two weeks of his life, he was in too much pain to speak to me. I don't know how he felt about not talking to other members of his family about his condition. I did talk to his grandmother, however, and she knew that Joseph was dying. One afternoon at the hospital, she said to me, "I don't understand why there is nothing they can do for him." Mrs. Anthony suspected that her mother knew by "instinct."

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Mrs. Anthony's almost militant stance against expressing sadness seemed to be a way of containing herself that enabled her to function. For after Joseph died, she said:

> I'm glad in a sense that I didn't [tell anyone], because it was worse after he died and everybody came to say how sorry they were. It was worse. It was worse. I find it terrible. I was hurting more by hearing everybody say how sorry they were. I felt like running, going away, don't want to listen to anybody say anymore, I'm sorry. I was disgusted and everything else. I wish I could put everybody out and just close the door and stay by myself instead of having to hear I'm sorry, I'm sorry. One person came in after the other to say I'm sorry. It got to the point where I wasn't answering my phone. At the time when we decided not to tell, I didn't know the effect that those words would have on me. I just didn't want anybody coming and crying in front of Joseph, to make him feel upset. I didn't know that's the way I would feel after he died and someone tell *me* that they were sorry. I was just protecting Joseph.

Still, children knew their parents were in emotional pain and they, in turn, tried to protect them. Taisha wouldn't tell her mother about the upsetting comments her father made. She said, "I don't want to see her hurt, because it hurts me to see her hurt." Derek thought that his mother needed someone to talk to about her feelings and so volunteered for this study when he himself had no desire to talk about his illness.

Children felt their parent's emotional pain and wanted to eliminate it. Derek told me that because of his illness, his family had "cracked down." He went on to explain: "They cried. Showing emotions. Hugging, kissing, showing their emotions toward me, how much they care and stuff. They're saying I'm hurt, too, that they're feeling my pain, too. But they really don't feel my pain, 'cause my pain is much greater than theirs. I just don't show it 'cause I don't want other people to be sad and hurt. I just hide it and stuff." I asked Derek what would happen if he did reveal his feelings, and he answered, "They'd be sad and stuff, and it's not necessary. Make them feel sad for me." And just as Derek's parents

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felt the need to keep him from feeling sad, he reciprocated: "I'm going to have to be the one to cheer them back up so it's just a waste of time, might as well keep it inside."

Unlike most of the other parents, Mrs. Sahdi was affectively demonstrative, both in her joy and her sorrow. After Nickie fainted after arriving home from the hospital one day, Mrs. Sahdi had a dramatic reaction. Nickie said, "She crying all the time and she can't talk, and Dad had to come. She was scared because no matter how sick I was in the hospital, that never happened." Nickie returned to the hospital, where she learned she had low blood pressure. On her arrival home, she was met by her frantic mother: "If it happen again, Mom will be like, oh, she'll die. . . . Anything happens to anyone, she'll die. She said she don't know how she'll live. So, you know, you're expecting that she'll go crazy."

Nickie didn't cry after she had her leg amputated. Reflecting on this lack of expression, she said, "I don't know, maybe I didn't want to upset my mom too much. 'Cause when she starts to cry, she cries right through the day. She don't stop. Maybe it was that. Trying not to upset her so she wouldn't cry more and more." Nickie went on to say that it was more painful for her to see her mother upset than to lose her own leg: "Seeing her cry made me want to cry, but I didn't want to cry--because of her. I didn't want to cry that much. Just because I saw her cry, I wanted to cry. But I didn't cry. If I did cry, she would think I'm crying because of the leg. You know, she'd have cried more and more. But it would be because of her." She explained her feelings in this way: "You just don't like to see somebody that you love crying. It's like she already has enough to deal with. It's just a feeling you have. You don't like to see that person upset, crying."

Surely, the ultimate protection was Joseph sending his mother to work on the day that he died. Mrs. Anthony remembered that morning: "I really wanted to stay home that day, but he said, you go to work. I know that he didn't want me

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here. Most of the time when I say I'll stay home today, I'll call in sick, he'll say okay. And I would stay home. But he specifically said no. He said, go to work. He probably didn't want me here to witness him dying. I guess he was just trying to protect me."

Pain so extreme requires surcease. If parents thought they could not endure their own emotional pain, or their despair at being powerless to stop their child's physical and emotional pain, there was a way to fantasize about being in control. Almost every parent wished to trade places with his or her child.

Mrs. Royce spoke of the unnaturalness of outliving her child: "Most of the time, you expect you should go before your child, and probably you could deal with it more than her. I would tell her, I'm so sorry you have to go through this. I wish it was me. It was so painful to see her suffering. I would say to her, I wish I could give you my life."

Kevin wept as he said, "It's just there's nothing that can be done. So you want them to somehow know that you would do anything. If I could have somehow, like, just immediately switched places with him, I would do that in a second. If there was some way to put everything on hold for two seconds and say, okay, God, just let me die and let him go on, like if the agreement is, okay, he can live for the next 30 years, then I would have done that. I wouldn't even have to think about it. It's like wanting to tell them you love them."

Mrs. Moore said, "I remember when I was a young lady, in my twenties, and I can remember my mom saying things to me, like when you would go through something traumatic, and my mom would say, if I could take your pain I would, because I can't stand to see my children hurting. You know, it would touch your heart, but you'd just say, oh, that's the mother thing. But it's just so true. If I could take it and make him all better, I would in a second. As I'm sitting here talking to you, if it could go from him to me, I'd take it in a second. It's just the hardest thing

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to see them suffer and there's nothing you can do, absolutely nothing but be there, that's all I can do." It was difficult for parents to feel that there was comfort in just being there.

Given the impossibility of making such a magical switch, parents did not have to consider its effect on their surviving children. Their wishes expressed a pain so keen that they would give their lives to bring about its end. But children felt their parent's pain just as deeply; they would not accept the fantasied offer. Derek said he was glad he was the one who was sick because he was the only member of his family strong enough to bear the pain. Lillian's life revolved around sheltering her mother from sadness. And Joseph, quite simply, refused his mother's suggested sacrifice:

> Every day I used to tell him I wish I could take it away from him. It was as though I was feeling his pain, too. It was very frustrating, in that I can't help him. Sometime I wish, I said, it should have been me instead of him. . . . I remember once I told Joseph, I wish it was me than him, instead of him being sick and going through all this pain. He said he didn't want it to be me. I said, why? He said--I don't remember exactly what he said--but what he meant is he wouldn't want to see me in pain. 'Cause I usually tell him I wish I could take away his pain for him, but I can't--and that's what he said.

Isolation

Long-term illness begets isolation. Breaks in social and psychological connection can begin as soon as cancer is diagnosed. Lengthy hospitalizations remove children not only from their families but from their friends and all of the landmarks of childhood and adolescence. Every child talked about school. Taisha missed math class. James wanted to study science. Nickie said that one of the primary ways her illness had changed her was that she could no longer go to school. Speaking of Joseph, Mrs. Anthony said, "Sometimes he insists he wants to go to school. I say, you want to go to school, and you can fall in the street. You

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can go to school and fall in your class. He said, I don't like to be out of school. He always liked going to school. He was never late, not even once, for school."

When Derek's doctors told him that he could finally have his lung surgery, the hope of returning to school eclipsed his anxiety. Mrs. Moore said, "I told him that when we go to the doctor on Monday, if his schedule allows it, there's a very good possibility that he'll say surgery Thursday morning. How do you feel about that? He was like, nah, nah, nah, not yet. Later, he came back and he said, I was in my room looking through my autograph books from school. He said, if he says Thursday or Friday, I'm ready. He says, I'm ready to do this and get this over with. I want to spend my senior year in school with my friends, and I want to go to my prom with my girlfriend. I think he misses the camaraderie and the horseplay."

Some children were isolated by stigmatization. Taisha was rejected by some of her friends after she got cancer and had her leg amputated. Lillian was also deserted by her friends. Mrs. Royce said, "Lillian had a lot of friends before she got sick. After she got sick, there was nobody around for her. Only one friend was always there for her, she was there till the end. The [others] never called, they never said anything." Although Mrs. Anthony said Lillian "was sad" about this loss of friendship, she also said, "I don't think she wanted them to come around, because she was sick." Lillian adamantly refused to identify with her sickness. As a result, some of her isolation was self-imposed; she avoided interactions with anyone who reminded her that she was sick.

Parent's protective behavior could limit peer relationships. Rather than submit to Mrs. Moore's anxious questions, Derek sometimes refrained from joining his friends. Mrs. Hart limited Taisha's activities, rarely letting her leave the block. Nickie spoke jealously of her younger sister's freedom and of her own plans to one day "go to the movies without someone trailing me." This restriction was

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particularly hard for older teenagers who were trying to establish independent identities.

Some children were more isolated than others. James's grandparents tried to seal him off from the world after he became sick. Not only was James deprived of the chance to go to school, he didn't have a home tutor. Kevin said, "I knew that James needed more contact with people. But I realized his grandmother was not going to let him out of this isolation that he's in. The grandmother just sort of worked it out so that the tutor wouldn't come. I mean, the grandmother knew that unless she called the tutor, he wouldn't know if James was back from the hospital. Then if the tutor happened to call, she would tell him that James wasn't feeling good."

James's grandmother's dictum against speaking about cancer with James isolated him even further; there was no one in his family with whom to share his experience. In addition, his father and grandmother were his only family visitors. Kevin said, "The grandfather had never come, and no one else in the family had ever come [to the hospital]. None of the other siblings had come, siblings or aunts or uncles."

Like most people, James hated being in the hospital. One spring afternoon when I visited him, he complained that there was nothing to do. When I asked what he wanted to do, he laughed and said, "I want to get out of here, that's one. I want to get out of here, that's two. I want to get out of here, that's three. After I get out of here, I'll go home and then my friend Kevin can take me out to places, and we can have fun."

Hospitalization was one of the most isolating aspects of sickness. Lillian said: "I get real lonely in the hospital. Not at home, 'cause there's always somebody there at home, no matter what, mostly there's always somebody there. I get lonely in the hospital, real lonely. Like, if I'm in the room here by myself and I don't talk

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to nobody, and like Wednesday I didn't have no phone, no TV. I was just, you know, bored. Nothing to do. I try to sleep, but I couldn't sleep. It's good when you know people here and they'll talk to you once in a while. They'll stop in and talk to you. The nurses I know, and some parents come and they'll sit here and talk to me, and when that happens, I feel much better."

Parents and other family members can't be at the hospital all the time, and their visits were eagerly anticipated. I asked Nickie what she did all day. Without missing a beat, she replied, "Nothing. Just wait for Mom." Nickie had her mother's subway trip timed to the minute: "Sometimes I call my mother 'cause it's so boring. I time when she'll get home. She'll reach home in about an hour, so I time her and when she gets home, I call her. I ask, did Mom reach home?" Nickie frequently couched her loneliness in terms of boredom: "When somebody leaves, it gets boring all of a sudden. Television is there, but television is not nothing like talking to somebody. Maybe talking some fun little thing. The television is there, but it can't talk back to you. You can watch it, it be funny, but you want to talk, maybe laugh. You want to talk to someone."

Derek and Nickie's parents were often with them in the hospital. The sustenance provided by their parents' presence was the flip side of the developmental clash created by their overprotectiveness. Nickie said that her parents had helped her the most by "just being there." Derek used the same words when I asked him how his parents had helped him throughout his illness: "Just being there . . . I always have somebody here. I'm here by myself during the day, but that's okay, that's only for, like, three hours. As soon as I wake up, my mother's usually here. She leaves around two to get my brother, and then my father's here around six, seven, and he stays until around 11. I've never been without my parents or my older brother, so I really wouldn't know how it would

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feel without, like, both of my parents or my brother being there, or my grandparents being there."

In contrast, Lillian's older brother rarely visited her:

> He's not nice anymore. I mean, I've been here almost four weeks. I think he came two, three times. And two of the times, no, three of the times, my mother forced him to come. So he really didn't want to come. It makes me feel sad. Like he don't want to see me. I mean, Roger always comes, always happy to come here. I mean, he even came after school. My mother doesn't like that. She don't want him to be taking the bus by himself, but he'll try. He'll come and he'll call me, and he's, like, what do you want me to buy you? And that's Roger. Roger's only 10 years old, so you know.

Near the end of her life, I asked Lillian if there was something she would like people to be doing. She sighed, "I'd probably like my older brother to come more. That's the only thing. I'd ask my older brother to come more."

Parents, too, could suffer from feelings of isolation and loneliness. Although Mrs. Moore felt that she was "crumbling" when Derek was first diagnosed, she had to quickly rally. She said there was no one for her "to lean on," and that she was "basically standing by myself."

Mrs. Royce had the same experience when Lillian was dying: "I was just on my own, and it was very hard. It was so hard. How I didn't get sick, it was so hard to not, it was just me alone." Aware of the strain on her mother, Lillian tried to relinquish her own emotional comfort: "My mom spent the night last night. It was good. My mother had to pay somebody to watch my little brother. I felt bad. I told her, you don't have to come. Then, you know, those little recliners, not so comfortable. I told her she didn't have to come. I don't want her to not sleep good. She has to work."

Mrs. Royce believed that Lillian was trying to separate when she made these gestures: "I think she was trying to let go. That's what she was trying to do. It was hard for me. . . . When I go to see her, it was not the right time. She always

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tell me I'm too early. I go in the morning, I'm too early. If I go later, it was, why do you come so late, come back tomorrow. If I try to hug and kiss her, she would complain that I'm hurting her. . . . She would call me sometime and say, you don't have to come today. I'd tell her I will come, and she would say, go to the gym, go do something, or on my birthday she say, you don't have to come, go have fun."

A staff member told me that Lillian was telling her mother and a friend not to visit. I asked Lillian about the meaning of this seeming rebuff, and she replied, "I was sleeping and I feel bad if I'm sleeping and they're just sitting there. So I would just rather they would come back. I said, can you come back later, 'cause I feel bad if I'm sleeping and they're just sitting there."

In the last weeks of her life, Lillian was torn between the wish to take care of her mother and her need for companionship. Contributing to the problem was her desire for privacy. Like most people, Lillian sometimes wanted to be alone. One day, I found her lying in bed brooding. When I inquired how she felt, she said, "I'm not sad. I just want to be alone and all these people keep coming to visit. It's bothering me. If I'm not feeling good, some people bother me. Those religious women come every day. I had to tell them not to come on Sunday." Lillian really had very little control over her environment. Visitors came on their schedule and talked about what they wanted. In addition, Lillian was grappling with excruciating pain, which made almost any kind of communication difficult.

Lillian felt internal pressure to entertain her visitors: "I feel I should be up, but I'm so tired I can't be up." And she persisted in her attempts to comply: "I try as hard as I can to stay up, you know, and then I eventually fall asleep. Sometimes people come when I get the morphine, and I fall asleep on them. I try real hard to talk to you, everybody, and I might fall asleep, but I try."

I accompanied Lillian to one of her radiation treatments the week before she died. She was in so much pain that she could barely speak. The radiation staff,

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who were very fond of Lillian, hovered en masse around her bed, talking and asking questions. Lillian snapped back in response. Later, she felt terrible: "I was upset, 'cause when they moved me my leg was hurting me, and they kept bothering me. So I was, like, not snotty but fed up. I was saying to a couple of them that I was in a lot of pain. You know, when you're in pain and you don't want to talk to people constantly talking to you. It's just that sometimes you gotta, you know, if you know somebody's in pain, you don't bother them. I'll talk to you, but I don't constantly want to talk and talk. I'm in pain at the moment. I don't feel well. They constantly still talking. So, you know, that upset me. That's why I apologized." Lillian had to be pushed to the limits of her endurance before she would speak up for her own needs. In this instance, the radiation staff interpreted Lillian's shortness as a "hypersensitivity" that indicated she was nearing death.

Lillian's predicament highlights the importance of being sensitive to the needs of the sick and dying. Lillian didn't want to be alone, she just wanted to be quiet. Lillian said she enjoyed just "listening to what other people do." Her deep desire for personal connection and dignity at the end of her life was reflected in this advice she had for visitors: "Talk to the person, and if they don't feel like talking at the moment, don't take it personal. . . . I would tell them, come visit the person. At least if you're family. Come visit them, and talk to them. Don't treat them like they're sick."

Mrs. Hart didn't have a chance to have a dialogue with Taisha as she lay dying, but she was with her, touching her and talking to her. And although Kevin did not know that James was dying, his visits increased at the end of James's life, and he brought James even more gifts than usual.

After Mrs. Anthony learned that Joseph was dying, she orchestrated constant companionship for him. Joseph's primary hospital was not far from their home, and Mrs. Anthony was able to visit once or twice a day. The new hospital was

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over an hour away. Mrs. Anthony remained at the hospital all day when she was not working. But, with two young children at home, she could not spend the night. She arranged for Joseph's father or his grandmother to sleep in his room: "I am so far away and if there's as much people as can come to visit him, I think it would be better for him. I did it because of Joseph. I think he need as many visitors as he can get. To cheer him up."

Mrs. Anthony, always eager to keep Joseph from feeling anxious or sad, explained why she thought it was important for Joseph to have visitors: "He's much--instead of lying down in the bed and sleeping all day--he's much livelier. 'Cause when he sees me once a day, after I leave he's just to bed, you know, he don't even try to make it to the playroom."

Joseph did seem happier when he had company. Before his final discharge from the hospital, I spent a Saturday afternoon with him. His throat hurt too much for him to talk, so we sat and watched videos. His grandmother was expected at dinnertime, but she was late arriving. Each time I thought about leaving, I asked Joseph if he wanted me to stay a little longer. Each time I asked, he looked at me imploringly and vigorously nodded his assent.

Joseph was not isolated when he was dying. He and his mother spent many days together in his last weeks. He had visitors from the hospice staff. The day he died, Joseph was with his grandmother, his sister, and his brother. In his final hour he was surrounded by other family members. Mrs. Anthony said, "Everybody was here with him. My sisters, my brother, and two other friends were here." Despite Joseph's attempt to spare her pain, Mrs. Anthony was also there for Joseph to appeal to for help one last time. Mrs. Anthony regretted that she had not been able to spend even more time with Joseph: "I wish I could be with him for a longer period of time than what I can. I try to do the best I can." When I asked Mrs.

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Anthony if she or Joseph had withdrawn from each other at the end of his life, she said, "No. As a matter of fact, I think we were maybe closer than ever."

Mourning the Death of a Child

The grief that a parent felt after his or her child died found many forms of expression. The rupture was followed by disbelief, a loss of bearings, deep distress, and in some cases depression. Parents strove to maintain the relationship with their dead child through fantasies of reunion, by keeping the child's presence alive in imagination, and by picturing the child living on in Heaven.

Mrs. Anthony said, "At first when Joseph died, I felt like my world has come to an end." Mrs. Anthony had various somatic responses including sharp pains in her chest and an inability to eat. In addition, she was unable to sleep: "I can't go to sleep. Everybody thinks it's because I'm thinking about Joseph, but that's not it. I mean, there are times when I do think about him, but before I go to sleep, I'm not thinking about him. I just can't go to sleep."

Mrs. Anthony told me that she once more questioned why Joseph had to die: "I did ask somebody, and they explained, they said, that's how God wanted it." When I asked if this answer was sufficient, Mrs. Anthony said, "Not really. But I have no control over it. I got to accept whatever. It makes no sense asking. It's already happened, and you realize that it still don't make no sense to keep on wondering why."

Mrs. Anthony feared her daughter and toddler son might die: "Now, for the first time, I'm afraid of losing the other two. I think about if they get sick, the same kind of sickness. It could happen."

In her yearning to be with Joseph again, Mrs. Anthony was willing, albeit in fantasy, to no longer insulate him from pain: "Seeing him in pain, it was as though I was carrying his pain. Even though I wasn't the one hurting, in a sense I was,

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because I was feeling his pain. And when he died, I guess after he died, I felt that a little more. Somebody asked me, would I rather have him here and in pain than to let him go, and I said, yes, I'd rather have him. I guess that's selfish, but that's how I feel."

Mrs. Anthony realized that her measured comments to Joseph that everyone has to die covered her own fear of death: "Even though I used to tell him we all have to die, I was afraid to die. I didn't want to die. But now I don't care if I die tomorrow. I'm not afraid to die tomorrow." Mrs. Anthony said that her feelings about death reflected both a longing to be reunited with Joseph and a newfound understanding that dying was not such a frightening experience.

Mrs. Royce also expressed a wish to be reunited with Lillian: "I want to go where she is . . . then I think Roger needs me." For Mrs. Royce, Lillian's death was "the hardest thing. I get depressed. I get sad. All these thing when Lillian died. It's like I'm lost. I didn't know where I'm at. Now I'm trying to take it one day at a time, but it will never erase from my mind."

In an effort to alter reality, and undo her guilt over not protecting Taisha from death, Mrs. Hart imagined a different outcome: "I want to turn that day back she went in the hospital. I would be with her. Then, if anything was wrong, I would have asked her and maybe, maybe, maybe she'd still be here." Mrs. Hart wanted to escape from what were now painful memories of Taisha, but thoughts of their traumatic final interaction intruded: "It's painful sitting up there in that apartment when she isn't there. The memories are here. I'm thinking about moving, but I don't have the money, so I have to stay here. I want to get out. It's good memories except the last time I saw her. She came into that apartment and she went back out in the ambulance, and I keep seeing that over and over. I can't get that out of my mind. I just sit there and they just come through. I don't know if I'm losing it."

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Just as the initial diagnosis of cancer took time to filter into consciousness, so did a child's death. Parents cushioned the loss by imagining that their child was still alive. Two weeks after Taisha died, Mrs. Hart had an appointment at the hospital with the social worker. She was anxious about revisiting the place where she and Taisha had spent so much time, and decided to pretend that Taisha "was at home."

Several weeks after Joseph's death, Mrs. Anthony said, "I still don't believe that Joseph's not coming back. I don't know, somehow I don't believe. Even though I know he's dead and he's not coming back, that feeling is still lurking around." Four months later, her thoughts were the same: "It's still hard to believe that he's not coming back, that's for sure."

Mrs. Royce said, "It's so hard going in Lillian's room and she's not there. And the fact is always in my mind that she's not died. She went away." Mrs. Royce tried to avoid reminders that Lillian was dead: "I'll go to the cemetery but I don't like going there. I'm trying to, like, she's away, like she's at college or on vacation or something. Going to the cemetery lets me see that she's dead, so I try not to go there."

When I spoke to Mrs. Anthony eight months after Joseph's death, she said that she, too, avoided going to the cemetery. Mrs. Anthony said that she hadn't been to the cemetery since Joseph's funeral, that, in fact, she "didn't know where it is."

Mrs. Hart, on the other hand, found visits to Taisha's grave a way to maintain contact:

> She was my joy. She was my life. But life goes on. Gonna miss her, but we gonna go to the cemetery to see her on her birthdays, Christmas, whatever. If the weather's hot, we gonna see her. We gonna see her on everybody's birthday. We gonna take her flowers. We gonna be there with her. Now I have to get the money for the tombstone and then we gonna visit her. It rained out there, and I said, we gonna have to wear boots to go see you, Isha. All this mud--I'm

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> laughing with her, I know she's laughing. We gonna visit her most every holiday. We going to get some flowers and put it on. I know they got a little cross but we want a tombstone, and they so expensive, they want so much for it. I'm going to get her one if I have to save or whatever, I'm going to get her one. So we going to see her but in another way, she going to be laying there sleeping."

Children's clothes and belongings took on special meaning. These objects were an embodiment of the child and the thought of removing them presaged pain. Mrs. Hart purged her apartment of some items: "Taisha had a stuffed lion and we always throw it around. We angry, we throw it, or we'd punch it or hit or something. I got rid of it." Other items were harder to relinquish: "I have to look through all those old things that Taisha got. That's a lot of birthday cards. I kept everything. I even kept her hair when she lost her hair the first time from the chemo. I still have that. I didn't go in and look through the drawers and the chest and everything. I don't know what I'm going to do with them."

Four months after Joseph's death, Mrs. Anthony still had all of Joseph's possessions just the way he had left them: "I didn't give away any of his clothes or anything, 'cause I feel like giving it away is like putting him out. That's how I feel, so I just leave everything like that. Everything is just the same way. His clothes, he leave his shoes under the bed, his sneakers and his sandals is under my bed, and the rest of his stuff is over in his room."

Parents longed to know where their children were and how they were feeling. Both Mrs. Royce and Mrs. Anthony were disappointed that they hadn't been visited in their dreams by their children. Mrs. Anthony said, "I guess Joseph's happy. I never dreamed him since he died. My mother never dreamed him. A lot of people dream about him, but I never did. I think he's okay, because I didn't dream him or anything. If I dream about him, I would know whether he's happy or unhappy. That's my belief."

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Mrs. Royce held a similar view: "I think Lillian's at peace and she's very happy. She never dreamed me. I thought she would come in my dreams. She never did that. I was told that if you're still mourning, she's not going to come in your dreams because she don't want you to be sad. I was telling one of my friends that. She asked me, did your daughter dream you as yet? I said no. So she said, if you're still in mourning for her, she's not going to dream you, because she don't want you to be sad."

If Mrs. Royce did not dream about Lillian, she found other ways of keeping her daughter's essence alive: "Most of the time, I feel she's right around. I think sometimes she, sometimes, like, I heard her voice. I don't know if it's my imagination or not, because she was here and I'm used to having her here."

Envisioning their children in Heaven and surrounded by other dead loved ones also brought a measure of peace. Mrs. Hart said, "Taisha's happy. I think she's happy where she at. There's a lot of people that she missed. She always talk about my aunt, my little brother, cousins, my nephew. I think they go up to Heaven and everybody that they lost is up there. And they's just talking about old times and telling everybody what's going on down here. Maybe I'm just imagining, but that's what I hear, that's what I believe. I'd tell her, you gonna meet my mother. If I'm wrong, then I'm wrong, but I think that's where everybody's gonna meet. No matter what you did wrong, there's only one place you gonna go and that's Heaven."

After Derek's relapse, Mrs. Moore gave some thought to the afterlife: "I just recently started thinking about that. I don't have an answer because I have no idea. I'm doing a lot of reading [and watching television]. . . . From everything that I read and I've seen, it seems to be a comforting sensation. From what I've read and what I see, like, the bright, soothing lights and the smooth music and seeing those

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you haven't seen. That doesn't seem frightening to me. But I don't really have an answer because I don't know that."

Mrs. Royce pictured Lillian in Heaven: "She was a good person. She was very nice. You'll never find a nicer person than Lillian. I think Heaven is a beautiful place. It's, like, I think it's peace. A place where you're happy. Everywhere people."

Regret haunted some parents. Mrs. Royce, in particular, voiced her concerns: "I regret it. I still talk about it. I feel that I should spend more time with my daughter. And because my husband was not around, he take that time from my daughter. Because of the bills and I want to keep my family together, I didn't get much time to spend with her. I would like to spend a little more time with Lillian." Mrs. Royce also regretted that she and Lillian hadn't discussed her death: "She didn't want to talk about it. I wish that she did sometimes. You know, at least say something. Then probably we could be more open and prepared."

Mrs. Hart also rued the loss of preparation: "I thought maybe a person gets really sick and then you know it's going to happen. The doctor tell you this is going to happen. But, no, it wasn't. It was a shock. Even people who had seen Taisha the week before, the day before. It was a shock. People was devastated."

Mrs. Anthony didn't believe that there *was* a way to prepare for such tragedy: "I don't think anybody could be prepared for a person's death, especially a child, their child. I wouldn't know how to be prepared. Even though you knew he was gonna die, but still . . . couldn't, couldn't prepare. I don't think anybody could prepare themselves."

Although Mrs. Anthony had not been able to prepare herself emotionally for Joseph's death, she was satisfied with her behavior: "I don't have any regrets, meaning in the way we live. 'Cause we go places, get to do a lot of things together. I mean, if I was the type of person that just go to work and just save

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every penny and just come home and he get to go no place, I would be very upset right now, 'cause I would say I think we should have done this or we should have been here. I can't say that. I can't sit here and say that right now. . . . I think we did a lot. He went places. He went to the West Indies probably every year. You know, we went to different places, so it's not like I regret anything. I did what I could at the time." She also had no regrets about their communication: "I pretty much tell Joseph everything I wanted to tell him. I have no regrets, none at all, in a sense because of the way we lived."

Kevin was glad that he had always answered James's telephone calls, no matter how late at night they came: "The whole time that I knew James, I never--and there were many times that I would be in bed, totally asleep, and think, oh, God, and then know that he was going to say, oh, hi! Now, I don't have any angst about it. I don't have any guilt about the fact that there were times that I didn't not pick up the phone. I knew at the time that that just wasn't right. With other people, but somehow with him it just wasn't right. He really trusted in me as his friend and so I couldn't."

Sometimes remorse over words not spoken more accurately reflected the ache of never being able to speak those words again. Mrs. Hart regretted not having a chance to tell Taisha: "I love you and I know you're strong. You wanted to do the thing with the talent, the music and everything. We love you. You got a lot of people here that loves you." When I commented that Mrs. Hart *had* said these things to Taisha and that, in some respects, listening to her was a lot like listening to Taisha, she chuckled and replied, "Yeah, she heard them over and over again."

Finding meaning in an otherwise incomprehensible event had helped the Moores when Derek was diagnosed. Both Derek and his mother believed that his cancer had brought the family closer together. Mrs. Moore also thought Derek was "unique. He's my special boy. That's what my mom says all the time. He's

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with us for a reason. Every now and then, God picks out a person and Derek's one of them. He's still here with us for a reason. I said, Mom, why is he here with us? She said, it's not for us to know. When we're supposed to know, we'll know."

For many parents, this same search for meaning continued after their child had died. Mrs. Hart mused, "I think Taisha's going to be my guardian angel. She said she was going to be my guardian angel all the time. There's a reason this happened. Maybe she is going to be my guardian angel, 'cause I say, I don't have no guardian angel. She said, Mommy, I'm going to be your guardian angel. I don't know what reason she said that. I was only joking with her, but she said, I'm going to be your guardian angel, Mommy. I said, oh, Taisha, you always my guardian angel."

Reflecting on Lillian's curtailed life, Mrs. Royce said, "Sometime I think probably that's her destiny. That's her destiny to be here for a short time. She was a good person and probably that's her destiny. Some people don't live long, some live long. That's the only solution I come to is it's her destiny. It's what's supposed to be happening. She do her time and probably that's what God wants to happen."

Kevin had no religious creed to help assuage his grief: "I'm so agnostic, not atheist, but so agnostic, and have been for so long. My answer to everything is I don't know, I just don't know. It was rough during James's death because I would see people who would come, some of the preachers and the priests and things like that, and I would think, well, they believe what they're saying and if they do believe, that must be nice. Because I just don't believe. My whole attitude is I don't know. It's a nice thought that there's something that happens afterward, nice thought that you sort of stay who you are. And if it doesn't happen, then that's pretty bleak. I would have liked to know what James's conception of it was, to know what he thinks is gonna happen on the other side."

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After James's death, Kevin mourned the separation: "I couldn't accept the detachment. I couldn't accept that he was gone and that I had no idea where. At one point, I was just tossing with this and turning. . . . I was immobilized in the sense that I was just obsessed with, how am I gonna find James? How am I gonna get ahold of James? I've gotta get ahold of James somehow."

As we sat on a park bench one fall afternoon, Kevin told me how finding purpose had aided him in containing his sorrow:

> I finally made a decision which really kind of resolved everything in a way. Resolved a certain angst that I had. I just thought for the rest of my life I will, I'm open. I will always look for James. I will always look for James for the rest of my life. If somehow he's gone somewhere, I don't ever want him to think that I forgot him. Or maybe he's like right around. I don't want him to think that I'm not trying to sense him, like that I've just forgotten about him and gone on. I could see how people totally get wrapped up in taking all their money and giving it to mediums and people they somehow think could talk to people. I could see how you could get totally sucked into that because you so want some contact.

Kevin was interrupted when a squirrel vigorously flung an acorn in our direction. He continued:

> So I thought, okay, I will just make a commitment to myself that the rest of my life I will always look for James. If it means just always listening to someone who talks about something to do with the afterlife, just to see if there's something that makes sense in it. If it just always means being open to whatever religion has to say, or if it just means being open to, like, when the squirrel threw the little nut down, for a second, I think, oh, James. I just keep it open that it's a possibility that James pushed a little acorn so that it fell. I just keep that open. And as soon as I did that, it really gave me a tremendous amount of calm. And then, if, say, I die and somehow come into contact with him again, I guess part of it is that he knows that he's still in my mind, he's still in my heart. He knows that I'm still searching for him.

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Summary

Organizing the course of terminal illness into discrete subject categories fragments a complex and multifaceted human experience. A fuller portrait requires the integration of many elements. How well parent and child defenses and communication were attuned, relations with hospital staff, and support from friends are but a few of the factors that influence the process of dying.

Lillian's illness had exacerbated already existing family conflicts, and her dying was colored by her relationship with her father. When Mr. Royce left the family, Lillian was burdened with a sense of responsibility and guilt. His cruel remarks and virtual abandonment of her mother filled her with rage, which she dared not express. Lillian did not want to sever the connection with her father and she continued to hope he would change.

For the last two weeks of her life, Lillian was the sole occupant of a semiprivate room. She had been moved from the Stepdown unit because she no longer required that intense level of care. Lillian said that she didn't like being alone in this room at the end of the hall, but insurance would not pay for Stepdown unless it was medically indicated.

Lillian was cut off from her friends as a result of both their retreat and her own reluctance to be with others now that she was sick. She did receive daily visits from the two women connected with the Pentecostal church. And she had visits from many staff members, including daily visits from one radiation technician. Some of these visits were trials for Lillian. She grew increasingly irritated by visitors who touched her without ever having asked her permission, who commented on her gradual loss of hair, or who carried on conversations as if she wasn't there.

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Lillian's denial of her impending death was frustrating for many around her. Her physicians were reluctant to use all-out measures to revive her, but her refusal to talk about her death made it impossible to adequately discuss a DNR order.

Lillian's denial was also difficult for her mother. From the beginning of Lillian's illness, Mrs. Royce had avoided thinking or talking about death. She asked the doctors to tell Lillian her diagnosis and requested that they refrain from discussing the prognosis. Mrs. Royce, however, was not in denial. She knew that Lillian was dying. At the very end of Lillian's life, Mrs. Royce wanted to have an open discussion with Lillian about the situation, but Lillian would not participate. For Mrs. Royce, who was also isolated and without family in the area, her inability to spend more time with Lillian--and this misattunement of defenses--created lingering regrets after Lillian died.

Lillian spent her last two days in the intensive care unit. When she died, early in the morning, she was alone.

James was also faced with family conflict during the last months of his life. The allegations of physical abuse made him a virtual prisoner in the hospital while an investigation was under way.

Kevin's entry into James's life also created conflict as he threatened the family's attempts to isolate James from the outside world. Already cut off from normal social encounters with friends and at school, James despaired when Kevin was not allowed to visit.

James was an old-timer at the hospital, however, and he had friends among the staff. In addition, several medical students rotating through the unit took a shine to James and frequently played with him. James attended the schoolroom on the unit and had a close relationship with one of his teachers. And until the last week of his life, he spent as much time as possible in the playroom.

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James's grandmother had tried to eliminate all discussion about illness and death from James's life. But James wanted to communicate his thoughts and feelings about dying. He told Kevin in indirect ways. He told me through his dreams and his drawings. In the end, a psychiatrist, called in for a consultation when James was so angry and uncommunicative, spoke directly with James about death. James complained that no one was talking to him about his death. Yet it seemed he also tried to shield the people he didn't want to hurt, like Kevin, from such straightforward discussions.

After the abuse charges were dropped, the turmoil that existed a month before James's death quieted. He was busily engaged in building his Beanie Baby family. Although he was weak, he was talkative. Visits with Kevin were restored. James was moved from Stepdown to a semi-private room that he shared with a boy his age with whom he talked and played. James died with the two people he loved most, his grandmother and Kevin.

Taisha and Mrs. Hart differed in their approach to their illnesses. Taisha wanted to talk about her anxiety and her anger, and she could be irrepressible once she began to share her feelings. Mrs. Hart wanted to reduce her anxiety by avoiding prolonged, affectively charged discussions. Yet Mrs. Hart valued open communication, and she and Taisha talked about many aspects of the illness.

Taisha and Mrs. Hart talked about stigma, about believing in yourself, about family members who had died, and about death. Mrs. Hart was watchful of Taisha's safety, yet encouraged her to learn how to ride a bicycle after she got her prosthesis.

Taisha and Mrs. Hart felt connected through their own illnesses as well as those of Mrs. Hart's mother, aunt, and brother. This family history of illness, especially cancer, brought Mrs. Hart and Taisha closer together, enabling an enhanced form of empathy.

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Taisha was seldom alone when she was in the hospital. Being gregarious and outspoken, Taisha managed to have a steady stream of friends and staff coming to her room. When Taisha was hospitalized, Mrs. Hart visited during the day. When her mother was not at the hospital, Taisha kept in contact by telephone. The few days that Taisha was in the hospital before her seizure, her older sister had spent the nights with her.

Taisha's death was a reminder that even in long-term, chronic illness, the unexpected can happen. Mrs. Hart and Taisha had no opportunity to talk during Taisha's last week of life. Still, Taisha was visited in the ICU daily by family and friends. After her death, Mrs. Hart did what she had told Taisha she would--she went to visit her grave, bring her flowers, and continue to talk to her.

Both Nickie and Mrs. Sahdi had an irrepressibly optimistic attitude toward illness and hospitalization. For Nickie, this approach was present at diagnosis and continued through amputation and relapse.

Mrs. Sahdi, too, pictured the future as promising and was convinced that Nickie would survive cancer. They did differ, however, in their expression of emotion. Mrs. Sahdi was free with her laughter and with her tears. Nickie preferred only to laugh. It seemed that part of Nickie's reluctance to cry was an attempt to keep her mother from getting more upset. But it also seemed that Nickie did not experience the same degree of fear or sadness as did her mother.

Nickie explained why she was not as concerned as her mother was one day when we were talking about dying: "Because we're kids, we don't really study about it, but the people that are big, they study more of it. We just know it's cancer and it's bad, but we don't worry about it every day. We may worry once a week or once a month but we don't worry every day. A big person, when they have it, they study what they gonna do if they have children, what they gonna do if

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they have a business. They have it more tough than us. We don't really have any business to worry about. The parents got to worry."

Given the extent to which only happy feelings were given full expression by Nickie, it is notable that she was able to discuss death and dying with me. Even if such discussions often focused on her lack of worry, she did give voice to her thoughts and feelings. Children who tried to keep thoughts of death and dying out of consciousness were unable to talk in this manner.

In addition to her mother's daily visits, Nickie's father, sister, and brother visited regularly. These visits could not compare, however, to the delight she felt when her mother arrived. Their mutual creation of pleasure bolstered Nickie, and allowed her to persevere through the ups and downs of treatment.

Derek was one of the children who rarely discussed his illness. He never talked about death. Derek had repressed most of his memories of diagnosis and treatment. When he relapsed, Derek continued to keep illness-related thoughts and feelings out of consciousness, either by minimizing or denying his condition. His feelings were communicated through angry outbursts or actions.

Mrs. Moore's coping style was just the opposite. Her take-charge, get-all-the-information behavior helped her control an otherwise uncontrollable situation. Mrs. Moore was frustrated and concerned that Derek did not communicate more directly about his thoughts and feelings. But she also believed that he was not ready for such discussions and tried not to push him. And she herself was worried about what she would actually say if Derek did broach the topic of death.

Derek had enormous support throughout his illness. When he was in remission Derek attended junior high school and developed deep, stable friendships. Derek's friends took pains to include him in all of their activities. If they were on bicycles, they walked them because Derek could not ride. When they played baseball, they

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gave Derek a position that didn't require running. Derek was popular, and when he was hospitalized, he spent most of his time on the telephone with his friends.

Mrs. Moore had felt that she was standing alone when Derek was first diagnosed, but after his relapse she demanded--and received--the support of her husband and friends. The entire family was also aided by the community. After Derek's relapse, the high school had a fund-raiser to help pay for some of his medical expenses. The church community also provided support by taking care of Derek's younger brother and supplying cooked meals when Mrs. Moore was spending long hours at the hospital.

Like James, Derek had had a long illness, and both he and his mother referred to the hospital staff as family. Nurses would stop by to chat when they heard Derek was in the hospital, and he had numerous visitors and phone calls.

Even though Derek had relapsed and was going through painful chemotherapy treatment, the developmental push toward independence seemed to be the most critical problem for him. With his family in the background providing constant support, his concentration centered on living as normal a teenage life as possible.

Joseph and his mother developed a pattern at the beginning of his illness that lasted through his final weeks. From the time that Joseph was diagnosed, Mrs. Anthony decided that Joseph would be told the truth about his condition. Joseph was told his diagnosis; he was included in discussions about his treatment; he was told about his relapse and when no more treatment was available. Finally, he was told that he was dying. Joseph was the only child with whom I met whose parent had urged that medical news be communicated so unambiguously.

Joseph had been instrumental in developing this open policy when he had demanded to know why his mother was crying the day he was diagnosed. And his information-seeking behavior, for example, calling the American Cancer Society

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for information about leukemia, not only helped him control his environment but reinforced his mother's decision.

This open communication--and desire to know--did not mean that Joseph was not upset by such news. Each time Joseph faced a downturn in his treatment, he became sad and anxious. And each time, he turned to his mother for comfort and reassurance. Mrs. Anthony seemed to have split off her own feelings in an effort to maintain equilibrium. This isolation of affect allowed her to respond to Joseph's physical and emotional pain. In turn, Joseph was soothed by her enveloping calm.

Mrs. Anthony's family helped her carry some of the pain. Joseph was especially close to his grandmother, who lived downstairs. Mrs. Anthony's mother also helped by taking Joseph to the hospital on days when Mrs. Anthony had to work. Mrs. Anthony's sister and brother lived in the same building and also shouldered some of the responsibility for Joseph's care.

Mrs. Anthony had strong beliefs about how Joseph should spend his final weeks. Mrs. Anthony was so intent on providing companionship for Joseph that she asked her estranged husband to spend the night at the hospital when she had to return home to care for their young children. She decided that Joseph should die at home with the support of hospice.

Joseph's dying was a time of special closeness for him and his mother. They sat up at night reminiscing and looking at pictures. They talked and giggled. They planned his last birthday party.

Mrs. Anthony was plagued with doubt about Joseph's emotional state but hesitated to ask him if he was thinking about dying. Yet his life review, his farewell party, and his questions about Heaven were all ways of communicating about dying. Mrs. Anthony acknowledged the power of these communications when she said, "I won't say that Joseph was happy, but he was comfortable, he didn't fight it."

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Always an intensely private person, Mrs. Anthony faced her grief as she had Joseph's illness. She didn't talk about her feelings with others. Neither did she talk about Joseph. But Mrs. Anthony was no longer able to mute her own pain, and she did now acknowledge her suffering. Still, Mrs. Anthony had no regrets about her relationship with Joseph or their communication during his illness.

The ways in which people communicate about their experiences of illness, dying, and grief encompass a wide terrain. The participants in this study communicated through what was said and what was left unspoken, through their actions and interactions, and through the expression of emotion. In these communications they conveyed the doubt, fear, anger, sadness, optimism, loneliness, hopelessness, anxiety, faith, grief, hope, and love which shaped the world in which they lived, and the world in which some of them died. They show us that even in the universality of death and loss lies the singular.

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The Qualitative Interview with the Terminally Ill

By nature, qualitative research involves subjectivity and ambiguity. Setting forth with no structured hypothesis to test and no strict rules for engagement was truly a journey into the unknown. The open-ended nature of the inquiry--and the degree to which one becomes involved with participants--created numerous possibilities and numerous challenges.

Although I was not conducting psychotherapy, I was aware that a series of qualitative interviews might serve as an intervention. I could not, however, anticipate the extent to which the interviews would have an impact on the participants, the hospital staff, and me.

The interview process tapped a range of experiences: Nickie and Joseph both worried that talking to me meant they were crazy. In fact, one day Joseph bluntly inquired, "Are you talking to me because I'm a psycho?" But Joseph also seemed to think there was some benefit in being able to share his thoughts and feelings. He even urged me to talk to James, saying, "he needs your help."

Nickie had not articulated for herself the impact cancer was having on her life. The process of talking helped her crystallize the experience. For instance, when I asked if she ever wondered why she had developed cancer, she paused, reflected, and then spoke with great fervor for 30 minutes. In one of our last meetings, Nickie said, "The questions you ask fall into place for talking about. Before this, I thought about them but never really came up with an actual answer."

Lillian told me, a week before she died, "I like talking to you. I always knew I was going to like talking to you. I feel [if] you talk, you feel better."

Mrs. Royce agreed that Lillian had found talking useful. Speaking of Lillian, she commented, "Most of the time, she said she was too sick to talk. Then she say that when she start to talk, that it was good. I would say, is Margaret coming

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today? And she'd say yes. I said, do you want to talk to her? And she'd say, it will help me feel a little better."

James was delighted with the open-ended nature of the interviews. In our very last meeting, he started talking about how his roommate had "a good family. His father comes, spends the night in the chair, his brother comes--they help him." When I asked how he felt about his own family, he said, "My grandma is good. She makes me come to the hospital when I don't feel good. I think about all the things that happen here--chemo, throwing up, operations--and I don't want to come. But you need to come to get better." Then he smiled broadly and said, "This was a great talk . . . it isn't planned or anything. I just talk about what I want, just whatever I want to talk about!"

For some parents, sharing grief was helpful. Mrs. Royce, who had so studiously avoided me while Lillian was alive, spoke freely with me after Lillian's death. She wept throughout most of our first meeting. Before I left, I asked how it had been talking to me, and she replied, "I feel better because I can't talk to everybody about this. I can talk to you, and I know I won't hear it back on the street. I feel good because at least somebody's there to listen . . . not everybody gonna sit and listen."

On my next visit, I asked Mrs. Royce how she was doing, and she said, "A lot better. Probably it's because I talked to you about it. A lot of things was on my mind. Explaining it to someone, and you listening, it helped me feel . . . ease, not like I forgot my daughter but that it brought . . . relief . . . speaking to you what was on my mind, because I couldn't say it to anyone else. It was a relief."

A month after Taisha died, I met with Mrs. Hart at one of Taisha's favorite spots, the carousel at their neighborhood park. It was a warm spring day, and Mrs. Hart reflected on how Taisha would have loved to have been there. Mrs. Hart had been ambivalent about our meeting, reluctant to stir up painful feelings. But as we

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parted, she said, "I feel good, really good. I was down not to come but then I say I promised, I said I'm coming so I'm coming, 'cause I would have called you ahead of time and told you I wasn't coming, but it was Thursday and I wasn't going to cancel out. I was thinking about not coming to talk about it. But I feel good, and she know I feel good."

The intervention extended beyond the power of talking. I found myself in the unexpected position of being one of the last people to have had meaningful communications with a dying child. Parents wanted to know: What was she thinking? How was he feeling?

After Taisha died, Mrs. Hart asked if she could hear the interview Taisha and I had taped just a few days before her seizure. I struggled with issues of confidentiality, but after listening to the tape, I decided to make a copy for Mrs. Hart. Mrs. Hart didn't have any videotapes of Taisha or any recordings of her voice. She told me, "The tape you gave me, I listened to it . . . it made me sad but I listened to it, 'cause I listened to what she said--and it sounded like she was happy."

Mrs. Royce, Kevin Churchill, and Mrs. Anthony also said that they would like tapes, and I made edited compilations for them all. On the tape I made for Kevin, James talked at length about his Beanie Baby collection and mentioned each animal that Kevin had given him.

Lillian was often in too much pain, or too sedated, to talk. She asked me once if I would stroke her forehead. After that day, whenever she was unable to talk, I would ask if she wanted me to rub her head. I learned how to adjust my touch as her disease progressed. One day, Lillian asked me where I had learned such a soothing touch, and I told her: "From you." When verbal communication was no longer possible, there was still a way to maintain a connection. This interaction, unexpectedly, turned into an opportunity to model behavior. One night, I visited

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when Mrs. Royce was with Lillian. Lillian asked me to rub her head, and I did. The three of us discussed how good it feels to have someone touch you. Two days later, Lillian told me that her mother had started to rub her head whenever she came to visit.

Interviews with children who are so sick, and with parents who are under enormous stress, are complicated. Illness does not follow a schedule. Thus, flexibility became my primary operating rule. I might arrive for an interview to find that a child had been taken to surgery, had been unexpectedly discharged, or was in too much pain to talk. I also came to realize, quite quickly, that my time with some participants would be short.

As I spent so much time on the pediatric ward, my research became equal parts qualitative interviewing and participant observation. One learns a lot about the experience of being gravely ill when conducting research in this manner. The immersion into the world of the sick and dying is felt down to your bones. I sat in while procedures were performed, IV pumps fixed, doctors made rounds, bad news was delivered, and parents visited. To my surprise, children asked me to accompany them to radiation or the operating room. I began to experience the anxiety of not knowing whether a child would be alive from one day to the next. I witnessed how poorly physical pain is managed.

Hospice provided Joseph with a PCA (patient-administered analgesia) pump. This pump ostensibly allowed him to administer a boost of morphine whenever his pain intensified. The pump rarely worked, however, and each time it failed, a nurse would have to come to the house to fix it. As it took hours for the nurse to arrive, Joseph was frequently in pain. James also had a PCA. I was with him when the doctor explained how to use it. James wasn't able to follow the instructions. He would hit the pump over and over, not realizing there was a lockout period, which prevented an accidental overdose. When James didn't

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receive the medication, he panicked. Both Kevin and I coached him on how to use the pump. Eventually, he mastered its use. One afternoon, Lillian was almost begging for a shot to quell the throbbing pain in her shoulder. There wasn't a physician's order for prn (as needed) morphine, and she had to wait for a resident to arrive before her pain was alleviated. And Lillian was conflicted about the pain medication. She wanted relief from her pain, but she didn't like being sedated; she "didn't want to miss anything."

I learned about endless waiting. One day, Mrs. Anthony couldn't pick Joseph up after a blood transfusion, and I volunteered to accompany him home. Our four-hour wait for the ambulette was but a small taste of the frustration that the Anthonys experienced on a regular basis.

The value of patience and the solace that is provided merely by sitting quietly with someone were brought home to me. Sometimes when a child was too sick to talk, we watched television or I read aloud to him or her. Sometimes I just sat. I found that over the course of several hours, we would have sporadic, meaningful communication. The desire to be heard was shown in the many ways people struggled to still communicate--words were murmured, moaned, written.

I came to appreciate, again and again, how difficult it is to talk about death and dying. In fact, my own awkwardness and uncertainty were visceral reminders of how threatening such conversations can be. My reluctance to tell Kevin that James was dying was based on the fact that it was not my place to do so, but his remark to me about how he came to suspect James might be dying revealed that we communicate as much by the *way* we say things as by *what* we say. Kevin told me, "I only got two things that were said to me. One was the thing you said, which I kind of had to read into the lines. I remember going home to my roommate and telling him what you said. I said it wasn't what you said, it's how you, you kind of stumbled a little. You said, well, I'm here interviewing kids, and

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I think you were going to say who are dying, and then you went, who are really sick, and I knew, I could tell by the way you said it, wait a minute, he's not just a kid in the hospital sick, she's coming and doing this and he's really sick. And then one of the ladies in the playroom said to me one time, you know James is very, very sick--that was all."

My presence on the unit had an impact on the staff. Attending physicians wanted to know if a particular patient was talking to me about death. The pain management team wanted me to make chart notes about a child's psychological state. At the end of the summer, the staff, reeling from so many deaths in such a short period, asked me to lead a process group. The meeting highlighted the diversity of concerns. Some people wanted to remember each child and process the loss; others were concerned about how to talk about death and dying with patients and their parents. One pediatric resident talked about feeling out of control when a child was dying, and many staff members talked about the strain of working with parents who were angry, confused, or unable to make wrenching decisions about their child's care.

I became an active component in the communication process, serving as an information conduit. Taisha's final hospitalization was not in the hospital in which I was conducting research but in a neighboring hospital. Each time I visited Taisha, I gave a report to the "home team" on her condition. Similarly, when Joseph was transferred to the research hospital, I carried notes and photographs to him from the home hospital and relayed his messages back. I also passed greetings back and forth between parents and hospital staff after a child had died and the hospital was no longer part of the daily routine.

It is perhaps easier, or safer, for us to talk about our involvement with research participants in terms of intervention or the therapeutic nature of qualitative interviews. But conceptualizing our impact only in professional terms obscures

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the very real human element that exists when people share such an intimate time. I became involved in people's lives in ways I could not have foreseen. I spent time with Joseph at his home when he was dying. I celebrated three of the children's birthdays with them. And I attended four funerals. Funerals offered not only a way to grieve, and to say a final good-bye, but an opportunity to find comfort in the fellowship of staff members who were also mourning.

I remember being surprised by Mrs. Royce's enthusiastic greeting when I called her a month after Lillian died. Each time I call, I am met with the same warmth. I realize now that I am connected to Lillian in an important way for Mrs. Royce. I knew Lillian, I remind her of Lillian, and I shared a crucial period of their lives together. It seems that when I call, Lillian is palpably alive.

A year after Taisha died, I called to say hello to Mrs. Hart. It would have been Taisha's 18th birthday, and Mrs. Hart and I reminisced about Taisha's excitement at turning 17--independence seemed just around the corner! Mrs. Hart remembered that I had brought a little cake for Taisha the year before, and she described how they had shared it on their way home. In the remembrance of this small gesture, that day sprang to life.

The participants in this study had an enormous impact on me. It was a privilege to be allowed into their lives. I remember how one afternoon, as I was setting up some drawing paper, James sidled next to me and, at first tentatively, and then with growing courage, laid his head on my shoulder. I have the picture of Simba the lion that Joseph made for me right before he died. The mystery of some events stays with me. One of the child life staff went into James's room immediately after he died. On her entry, a sudden gust of wind swept through the room, shutting the window behind as it exited. She said, "It seemed to me it was James." The day of James's funeral, a nurse, a member of the child life staff, and I discovered that we had all woken up at 3 a.m. the night before. After an hour of

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tossing and turning, each of us had decided to get up. And then we had all had the same thought--James!

I formed a closer bond with some children than with others--in particular, James and Lillian. I do not know how my feelings influenced the interviews. I suspect that my attachment to these children was greater because they expressed a greater need for connection. Derek, who had so much support from his family, did not desire the same kind of involvement.

At times, I questioned the nature of my involvement. The countertransference issues that exist when working with the dying--rescue fantasies, overinvolvement, guilt, relief, intense attachment, and loss--do need to be explored. Supervision was of enormous value in this respect. And I was helped by my therapist's wise counsel that I was not conducting psychoanalysis with these children. Finally, I was always sobered by wondering how I would feel if I left at this moment, with this act undone or these words unspoken, and never saw this or that child again.

Ethical guidelines do not help one deal with every situation. What do you do when a parent wants to be interviewed but to do so means taking him or her away from a crying child? What are the limits of the search for knowledge--does one ask a parent for an interview while he or she is sitting in the ICU waiting to hear from the doctor that his or her child is, in effect, already dead? How does one make peace with the fact that one's own intellectual interest coincides with such unbearable pain? At one point in the study, a physician began to refer to me as the angel of death. I could understand this epithet as a sign of his own anxiety, and also as "data" about the pervasive unease with which death and dying fills us. It was still disturbing. And on my way to meet the last child recruited into the study, I had the disquieting thought that if a child was being introduced to me, it meant that he or she was dying.

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I knew that I began this study with biases: I believed that talking helps, that having thoughts and feelings heard, validated, and held is transformative. I came to discover assumptions of which I had not been aware.

I had planned to conduct most of the interviews in participants' homes. I reasoned that this arrangement would be the most convenient for people under such constant pressure, and who were, perhaps, eager to escape the confines of the hospital. Some participants did welcome me into their homes. But arriving for a scheduled meeting to obtain written consent, and having the door slammed in my face, was a rather rude awakening to my naive assumption that I was being considerate. I realized that I had never thought through the implications of a home visit. No one would ever tell me exactly why they preferred meeting in more neutral territory. I can only speculate about the differences in race or class, or the fact that as a putative member of the hospital staff, my visiting the house was seen as an intrusion.

I did hold to one bias. I once heard someone say that a good death is a death in character. The central belief that guided my behavior throughout this study was just that. After Lillian died, one of her physicians commented that she needn't have died such a painful death. The subtext was that if Lillian had given up sooner, her physical suffering would have been lessened. But who can really decide what is best for any one person? Whatever we wish for those we know, those we love, and for ourselves, it is the right of the individual to choose how he or she wants to die. In this choice is dignity.

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Discussion

> We have been given two ears and but a single mouth, in order that we may hear more and talk less.
>
> Zeno

In the introduction to this study, I wrote that life-threatening illness is not a static experience but a journey down a river whose currents are deep and shifting. The sweep of that journey, as detailed in these narratives, has been broad. These narrators have told stories that span from the early days of illness through the final hours of life, and, for the survivors, on to bereavement. In doing so, they have delineated not just the ebb and flow of the illness experience but the psychological atmosphere in which we die or watch our loved ones die. In their stories, they point to the difficulties we face when communicating about death and dying. But they also demonstrate our ability to transcend our fears.

Discussion of Findings

The present study represents a first step toward exploring the communication process between dying children and their parents as it unfolded. But the scope of the investigation was not restricted to this one theme. Woven throughout the narratives are five key issues, which will be elaborated on in the following discussion: 1. Children with cancer do think about dying, and children who are dying are aware that they are doing so. The degree to which they want to express their thoughts and feelings about dying, however, varies considerably and is intricately connected with systems of psychological defense. 2. Patterns of communication and defense remain relatively stable over the course of the illness--and do not change markedly as death approaches. 3. Although communication

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about dying does occur, parents and children both engage in a form of mutual pretense regarding their emotional experiences. 4. Life-threatening illness continues to be accompanied by psychological isolation. However, the period of dying is not marked by the withdrawal of the dying child and/or his or her parent(s). 5. Issues related to the conception of self represent one of the major challenges for the sick and dying child.

1. *Communicating about Death and Dying*

Almost every child in this study indicated that he or she thought about death and dying. One boy worried about whether he would go to Heaven. One girl wondered when she would die. Another child told her mother that she wanted to be cremated. The youngest child interviewed stated that he thought about dying from the day he was diagnosed.

The fact that death-related language or imagery surfaced frequently in dreams or play, or in the context of even the most innocuous medical procedure reveals that thoughts about death and dying are often just below the surface, waiting to be expressed.

Most children, however, also indicated that they really didn't like to talk, or even think, about their illness or the possibility that they might die. Two older adolescents, one of whom was close to death, never raised the subject. In light of the previous research findings discussed below--which indicate that children do want to talk about death and dying--this finding is surprising.

Many investigators have commented that seriously ill children wish to speak about their fears, concerns, and ideas about death and dying (Bluebond-Langner, 1978; Raimbault, 1991; Spinetta, 1978; Spinetta & Deasy-Spinetta, 1981; Spinetta & Maloney, 1978; Vernick, 1973). Adults have not always provided an opportunity for children to have such open discussions. Parents in this study *were*

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sometimes reluctant to share their thoughts and feelings with others. Their hesitancy to talk with other adults stemmed from a belief that they would be burdening others, or that others could not tolerate or contain such intense emotion. Yet the primary reason both children and parents offered for not talking about illness experiences was that to do so would increase feelings of anxiety, sadness, and depression.

One mother stated that "to talk about it made it worse." Another mother was concerned that her son never talked about his illness, yet feared the day he would ask her, am I going to die? And one mother refused to attend support group meetings because she didn't want to sit and listen to "everybody's worst nightmare." Children spoke of "erasing" thoughts about death or "thinking about other things." One adolescent girl steadfastly denied the reality of her own imminent death, and one boy said of his cancer that "it don't bother me." Although it is usually adults who have been described as reluctant to initiate discussions about death and dying, it is interesting to note that the parents of these last two children did try to broach the topic of death. Due to their children's defenses, these attempts were not successful.

The reluctance to talk or think about death and dying did not mean that dying was not to be discussed, but confirmed that timing was crucial. Kübler-Ross (1974) states: "Patients cannot talk about dying when it is convenient for us! Usually in the middle of the night when it is dark and quiet and all their defenses are down, it suddenly hits them that they are dying. Then they should have a friend who walks in, sits down and listens to them" (p. 23). Sometimes it was in the aftermath of hearing bad news or undergoing a difficult procedure that children did want to talk about dying. At other times, the topic arose seemingly out of the blue. A child, referring to a dream, might say, "I thought I was dead," only to have repressed the dream a week later. The importance of being there when the child

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wished to talk was verified in these instances. Methodological issues related to timing may also have influenced these findings and will be discussed below.

If the question of *when* to talk is important, so is the issue of *what* to talk about. Elisabeth Kübler-Ross (1969) writes: "The most meaningful help that we can give any relative, child or adult, is to share his feelings before the event of death and allow him to work through his feelings, whether they are rational or irrational (p. 25). These feelings, however, may not be directly related to dying. Absence of communication about death and dying did not mean that the children interviewed did not have pressing problems that they wanted to discuss. Koening (1973) maintains that death is not always the main focus of the dying person. Isolation, pain, physical disfigurement, and fear of abandonment may be more immediate concerns. Certainly, these topics were raised by almost every child. In addition, some children were preoccupied with family conflict. Relatively little has been written about the experience of the child who is dying in the midst of a chaotic family environment. Two of the children in this study were trying to deal with verbally abusive fathers. Another was trying to cope with an investigation into charges that his uncle had physically abused him. These problems demanded immediate attention and left little psychic energy for reflecting on death and dying. One of these children also seemed to sense that the conflict in her family precluded her parents' ability to support her through her time of dying.

Communication about death and dying may also be limited by the desire to maintain a relationship. One child relied on symbolic and indirect communication almost exclusively, and his communications were frequently missed. Yet this same child spoke about his impending death quite directly with a psychiatrist who was called in for consultation. Some authors have noted that communication with a stranger is perceived as nonthreatening (Nimrocks, Webb, & Connell 1987; Pearce & Sharpe, 1973). In this case, the child's efforts to maintain an existing

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relationship--and spare emotional pain--may have necessitated finding a neutral party to engage in the direct communication he really desired.

Previous studies have relied solely on retrospective reporting by mothers to assess communication (Spinetta, 1978). In the present study, dual perspectives were obtained. While both children and parents in the present investigation relied on memory to depict their experiences prior to the interviews, the degree to which a child's and a parent's story meshed was remarkable. Frequently told stories have a life of their own, and it is possible that children had heard about the incidents surrounding their illness often enough to influence their own perceptions of these events. Yet children and parents also corroborated each other's current narratives, lending support to the accuracy of the recollections.

Not one child said that he or she wanted to talk with his or her parents more about dying. And while some parents wished their children would be more communicative, they did not push such interactions. In two dyads, relatively open communication about death and dying had been practiced since the beginning of the illness. In these cases, both the parent and the child described these discussions. Open communication served to bolster hope and optimism, and lessened the extent to which parents suffered from regret after a child died, supporting the findings of previous investigators (Shovelar & Perkel, 1990; Spinetta, Swarmer, & Sheposh, 1981). Honest communication also seemed to enhance both psychological comfort and self-esteem.

Cancer and the effects of treatment can lead to a sense of shame. After one girl had her leg amputated, she was subject to such taunts as "you're nothing but a cripple." It was through supportive conversations with her mother about the pain inflicted by this cruelty that this girl was able to internalize a different message--that having cancer was not a reason for shame. Another child, troubled by conflicts in his family, and by a loss of physical strength, began to say that he was

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"bad" and that he had no love left in him. His family was not open to dialogue about his illness or family strife. With few outlets for discussing such problems, this boy was left with feelings of shame and self-hatred.

It is also interesting to note that, contrary to previously published research, it was the youngest children who talked more openly or more frequently about death (Claflin & Barbarin, 1991). And the child who was told most unequivocally about his relapse and terminal condition was the youngest child who participated in the present study. In the latter instance, parental response to the illness greatly influenced the level of information that was shared. Open communication was adopted early in the illness and was the result of both the child's articulated wish to be included in discussions about his illness and his mother's belief that her son not only had the capacity to handle such dialogue but that he deserved to be treated with respect. Open communication can occur only with the agreement of *both* parties in the dialogue, as illustrated by this example.

A question that has been posed about families dealing with life-threatening illness is whether communication patterns change as the child goes through relapse or as he or she nears death (Spinetta, 1978). For the participants in this study, communication patterns remained consistent over the course of the illness and did not change dramatically as death approached. A child who communicated symbolically continued to do so up until death. A child who never talked about her illness maintained this silence until she died. The child and parent mentioned above, who communicated most openly about death and dying, did so from the day of diagnosis through the last days of the child's life. In fact, the only factor that appeared to influence whether death and dying could be openly discussed at the end of life was the degree to which such communication had been possible from the start. This same stability was reflected in patterns of defense and coping.

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2. *Defense, Coping, and Communication*

Styles of defense and coping are integrally connected to communication. One cannot discuss death with a parent who is unwilling to engage the topic, or with a child who denies that he or she is gravely ill. The type of defense employed greatly affected communication.

The ways in which children and parents coped with the strains of life-threatening illness were numerous and varied. The use of increased avoidant coping has been demonstrated in children who have life-threatening illness (Phipps et al., 1995). These defenses protect the ego from the overwhelming power of the stressor (Roth & Cohen, 1986). In this study, many of the children and their parents did rely on avoidant defenses. But although participants could be categorized by a primary style of defense, e.g., approach or avoidance (Byrne, 1964; Roth & Cohen, 1986; Santostefano, 1978; Smith, Ackerson, Blotcky, & Berkow, 1990), these constructs do not do justice to the ways in which different types of defense were used to serve different purposes. Thus, while repression might be used to keep painful memories about diagnosis or early treatment out of consciousness, information-seeking strategies might be employed when they offered the opportunity for immediate control over the external environment. For example, one child who had almost no memories of the first years of his illness was hypervigilant about his IV. He felt powerless to work through early, traumatic memories, but taking care of problems with his IV *before* they occurred provided him with a sense of control.

Similarly, one mother actively sought information about her son's illness and treatment. Gaining knowledge helped her monitor his condition and treatment. But to continue functioning required that she deny the emotional impact of his illness. As a result, she isolated affect from cognition. As others have noted, approach and avoidance are not mutually exclusive (Roth & Cohen, 1986).

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Consideration must be given to both the range of defenses used and the degree to which they can allow for effective functioning.

In this analysis, what was perhaps more notable was the stability of defense strategies over time. Many of these children had had cancer for years. As both they and their parents described their coping responses over this lengthy period of time, patterns emerged. While other aspects of the cancer experience have been described in terms of stages (Cohen, 1995; Hinds & Martin, 1988), defense showed no such linear progression. Defenses were fluid, coming to the fore at critical moments and then receding into established patterns. So, for instance, at diagnosis many people described a break with reality. This break was captured in language such as being in a "fog" or feeling like a "zombie." The same language was used to describe the response to relapse and the aftermath of a child's death.

Perceptual difficulties were another frequent response to critical setbacks. Information went "in one ear and out the other"; people declared they were unable to "process anything." Misperceptions occurred. People heard the wrong information or did not fully register what was being communicated. Many of these same responses have been seen in children who have experienced psychic trauma (Terr, 1979).

One child's response to hearing of his relapse was "to punch a wall." This same explosive anger arose when he was waiting for the results of crucial tests. After each emotional outburst, he would return to his standard I-don't-care and it-doesn't bother-me mode of operating. His mother, when faced with bad news or any significant development, leapt into action, corralling facts and organizing her resources. Another child's behavior pattern was the same at relapse as it had been at diagnosis. After his initial fear and sadness, he turned to his mother and was soothed by her reassuring words and manner.

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Although defenses remained relatively stable from diagnosis to death, their effect on communication changed over time. Until one young woman was actually dying, her denial meshed well with her mother's avoidance. The mother, however, was not in denial; her avoidance was a conscious strategy, which she was able to overcome when it appeared that time with her daughter would be short. She gingerly approached the topic by telling her daughter that "we all must die," but her daughter's denial represented an insurmountable roadblock. Their inability to talk about death left this mother with no chance to prepare and caused her lingering regret.

Other mismatched defenses did not have such a negative impact. One child's repression and denial caused his mother some anxiety. Yet her action-oriented coping skills allowed him to rely on her to manage his care. He was also able to utilize her as a container for both his cognitive and emotional experiences. In this instance, the only critical issue was how to help the mother manage her concerns about her son's reluctance to talk about his illness.

Types of defense also affected communication. Those children who denied the reality of their illness were unable to talk about death and dying. Children who used more conscious distraction techniques were able to allow thoughts and feelings about dying into consciousness and to talk about them, however sporadically.

The children who used repression and denial may have experienced illness as more traumatic and less capable of integration. Unconscious avoidant processes may then have been necessary to manage threatening aspects of their disease. Denial and repression are not in themselves problematic. Roth and Cohen (1986) state that when there is no possibility of changing the situation or of emotional assimilation of the threat, approach can lead to worrying, which is both time-consuming and nonproductive. The exclusive reliance on these defenses,

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however, may thwart the process by which working through and integration might occur.

Styles of defense can reinforce isolation. One child in this study did restrict her activities in an effort to keep threatening cognitions and affects out of awareness.

All of the children who participated in this study knew that they had cancer. Some had been told that they would die. One child had been told her disease "would one day take her life." She also had been told that her treatment was palliative. Still, she believed that radiation would cure her and that she would be well again. This example raises the issue of the impact of both individual and family dynamics on communication. It is likely that this child's inability to confront her disease influenced her doctor's ability to talk more straightforwardly. Interestingly, the dyad that exhibited the most open communication also had the most direct communication with physicians.

Defense then has a significant impact on what can be allowed into consciousness and, therefore, into dialogue. But open communication entails more than verbal exchanges. Kaplan, Grobstein, and Smith (1976) found that the ability of parents to respond to the diagnosis of cancer with appropriate sadness--without inhibiting the expression of these feelings in themselves or other family members--was important for successful coping. Yet almost all participants in this study related their attempts to limit the expression of emotion.

3. *Emotional Pretense*

One of the prevailing communication problems in the middle decades of this century was mutual pretense (Bluebond-Langner, 1978; Glaser & Strauss, 1965). Open communication policies regarding diagnosis and prognosis were developed to stem just this problem. The current study illustrates that bad news is still difficult to impart. Doctors do not always communicate directly. Parents who are

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trying to sustain hope may hamper open discussions about death and dying. Still, in this study, only one parent--in this case, a grandparent--tried to pretend that her grandson would get well. If communication about diagnosis and prognosis has improved, however, emotional pretense is still ubiquitous.

Emotions related to the process of illness and dying were depicted as dangerous and overwhelming. There was a concomitant belief that expression of emotion would lead to collapse. Parents, in particular, voiced the fear that expressing any of their sorrow would end in a total loss of control. As a result, parents suppressed their emotions in an effort to protect themselves and their children. Instead of manipulating the environment to keep the diagnosis secret (Vernick & Karon, 1965), parents now manipulated it to keep *feelings* secret. Yet even when parents hid their feelings, children sensed their distress and, in turn, concealed their own feelings.

Both parents and children described an empathic connection that caused them to feel each other's pain as their own. Mother-child boundaries have been shown to be subject to merger when a child is chronically ill (Seiffge-Krenke, 1997). These permeable boundaries may make it difficult to determine whose pain is whose. Although many people acknowledged that one cannot really feel another's pain, this realization was purely intellectual. On an experiential level, the suffering caused seemed unbearable. Emotional pain seemed less capable of resolution than physical pain. Concealing or suppressing emotions offered a way of halting the escalating suffering. But the very fact that emotions had to be hidden may have made them appear more dangerous.

Not only did the fear of overwhelming affect curtail the expression of emotions, it hindered full dialogue. One mother could talk about death with her dying son but was unable to ask him if he was afraid. Another mother was convinced that

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talking about her daughter's death would lead to unsurvivable sadness; therefore, she avoided all interactions where the topic might surface.

Parents indicated that they needed to suppress their feelings, or "put on a mask," to remain strong for their children. Controlling painful emotions also shielded parents from a feared disintegration of the ego. Yet there is a difference between being strong and acting as if you are not sad.

Children need to feel protected and cared for by their parents. The challenge for parents is to provide this sense of containment while still remaining emotionally available to the affective experience of the sick or dying child. Open communication about diagnosis, treatment, and prognosis delivers the facts of the situation. But simply conveying the news addresses only part of the communication problem. For full communication to occur, *all* parties must be able to integrate that information, sense that one's subjective experience can be tolerated, and believe that emotional pain can be both shared and survived.

The ability to contain emotions enables parents and children to function in a time of uncertainty. But when emotions must be continually suppressed, there is a risk of psychological isolation.

4. *Isolation and Anticipatory Mourning*

Chronic, life-threatening illness propels both the sick child and his or her parents from "the secure world of the known, the familiar, and the predictable to a normless world of ambiguous boundaries, unclear rules, probabilistic predictions, and sinister possibilities" (Cohen, 1993, p. 83). This rupture with the world of everyday reality may also create a sense of psychological isolation.

Mothers in this study described this isolation in numerous ways: "I was just on my own," "It was just me alone," and "I was basically standing by myself." For

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mothers, this isolation was often exacerbated by the fact that they were the primary caretakers of both the sick child and his or her siblings.

Children were isolated by stigma, the break with normal routines such as school, and the reduction in peer interaction. But the separation entailed by hospitalization presented the greatest problem. Every child spoke of being "lonely" and "bored" when hospitalized. They complained there was "nothing to do" and counted the minutes until discharge.

In an analysis of drawings by children with leukemia, Clunies-Ross and Lansdown (1988) found that 50% of the children depicted themselves as alone in the hospital. The investigators comment: "Although many children do spend some time in cubicles, none is isolated; they have a parent, teacher, or play specialist with them for much of the time. . . . In this context it is particularly worrying that children may perceive themselves as alone; it possibly indicates that a degree of psychological isolation is felt even when, in actual fact, the children have ample company" (Clunies-Ross & Lansdown, 1988). The children in the present investigation also had frequent social interaction. Yet while schoolrooms, playrooms, and the fact that hospital staff came to seem "like members of the family" helped relieved some loneliness, they could not counter the effects of separation from home, family, and friends. Children wished to be at home. If they could not be at home, they wanted a parent to be with them most of the time. Since constant companionship was virtually impossible, children did feel isolated. The isolation these children experienced may also have been the result of the shrunken worldview and egocentricity that accompany illness, and may not have been due to a lack of meaningful communication (Brody, 1987). Isolation continues to be one of the greatest challenges in the psychological care of the sick and/or dying child.

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At the same time, most of the children in this study felt connected to, and sustained by, their parents. Parents were said to impart "strength," "excitement," or the ability to make one "feel better." Children said that parents helped "just by being there." The degree of interaction did not change as a child neared death.

In contrast to previously published reports, (Abrams, 1966; Martin, Martin, & Pierce, 1984; Spinetta, Rigler, & Karon, 1974), children did not withdraw from their parents as they were dying. The one child who did seem to withdraw from her mother expressed a desire to protect her mother from sorrow. She did not withdraw from other people and, in fact, voiced a wish for visits from other family members.

Parents also demonstrated a desire to be with their children during illness and as death neared. Again, in the one instance where withdrawal occurred, it did not appear to be a way of preparing for death, but rather a means to avoid reality. And this withdrawal was not confined to the final months of the child's life but, rather, was the continuation of an ongoing pattern of self-protection. This withdrawal was a defensive maneuver, not a facilitative working through of anticipated loss.

These cases challenge the assumption that withdrawal, or a period of anticipatory mourning, by the dying and the survivor(s) is a necessary or even desirable process. For the dying child, withdrawal may be a response to severe pain and the soporific effects of analgesia. The wish for privacy may also be misinterpreted as withdrawal. In general, dying children desire companionship and continuing connection with those whom they love. When a parent is able to acknowledge the presence of death, and provide sustained support and interpersonal connection, the child may find the energy to relate to loved ones and enjoy some activities (Furman, 1984). This continuity of cathexis not only eases the suffering of the dying child, but reduces the amount of regret experienced by the surviving parent(s).

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Anticipatory mourning is a well-established phenomenon in the literature on death, dying, and bereavement. Withdrawal by the dying has been said to represent the acceptance of death and a gradual decathexis of the object world (Abrams, 1966; Kübler-Ross, 1969; Martin, Martin, & Pierce, 1984). Both physical and psychological withdrawal have been said to shield the surviving family members from massive object loss (Easson, 1970; Wiener, 1970). Anticipatory grief has been described as a common, and adaptive, response to the impending death of a child.

But anticipatory mourning has also been noted to serve a defensive function. Sourkes states: "In a self-protective move against loss and further pain, the family seems to 'leave before being left.' Such disengagement may be seen in a family's general emotional withdrawal from the patient, or it may take specific forms. Psychotherapy can help a family stay at, or return to, the level of thought ('I wish I could just leave all this grief behind') rather than translate the wish into action" (1982, p. 72).

Given the degree to which anticipatory mourning is said to occur, we would expect to see various aspects of distancing, from physical withdrawal to linguistic disengagement, among the participants in the present investigation. That such withdrawal was not evident, except when it was used as a defense against loss, raises questions about the prevalence of anticipatory mourning as well as whether it is primarily adaptive in nature.

I would like to offer a different perspective: Many parents are able to remain physically and psychologically present while their children are dying. It is not that these parents feel the anticipated loss any less sharply. Rather, they believe so strongly that their children should not be abandoned during this critical period that they push through their grief. Many parents also want to spend as much time as

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they can with their children, knowing that this contact will soon no longer be possible.

At the same time, dying children do not wish to withdraw from their parents in preparation for death. One of the most pressing concerns for the dying is the fear of being abandoned. The effort to keep people near may become even more important than talking about dying.

Three weeks before one boy died, I had to leave town unexpectedly. I went to the hospital to tell him that I was leaving and to let him know when I would return. During my absence, he asked to see the attending physician, whom he'd never asked for before. When the physician arrived at his bedside, the boy simply wanted to know when I was coming back. On my return, he told me that I was to visit whenever I wanted and to stay as long as I could. The last words he spoke to me were: "You'll come see me again, won't you?" While I was away, this boy had been referred for a psychiatric consultation. He told the psychiatrist that he was angry because no one was talking to him about dying. Yet in his last conversations with me, he didn't seem to want to talk about dying. What was most urgent was that he be assured of my continuing presence.

In a classic study, Spinetta, Rigler, and Karon (1974) found that children with leukemia placed four dolls (nurse, doctor, mother, father) at a greater distance than chronically ill children when asked where these people "usually go." The distance of the figures increased with the number of hospitalizations. The authors noted that this placement mirrored the child's perception of a growing psychological distance. When asked to place the dolls where they would like them to be, children with leukemia placed them at a greater distance than did chronically ill children, but this distance did not increase with number of hospitalizations. I speculate that these figures were not moved farther away because children do not want their parents to withdraw. That the dolls were not moved closer represents a

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compromise formation geared toward protecting parents from emotional pain. The prevalence with which emotions were concealed by participants in the present study points to this desire to protect.

Seeking and creating intersubjective union with another is a primary developmental task (Stern, 1985). I would argue that the urge to share one's thoughts and feelings with another does not dissipate as death approaches. Although almost all parents with whom I talked wished that they had been more prepared for their children's death, most did not know if such preparation was truly possible. Preparation, or a facilitative working through of grief before the loss, may be a chimera--holding out the promise of a tempered grief, which is not only illusory but which isolates the dying.

5. *Sickness, Dying, and the Self*

Illness has been described as an ontological assault, which affects our very being (Pelligrino, 1979; Pelligrino & Thomasma, 1971). As Freud stated, "The ego is first and foremost a bodily ego" (1960, p. 20). In illness, the integration of mind and body may be sundered. At the very least, the body takes on a primacy in our conscious and unconscious lives that does not exist when we are healthy. For some of the children in this study, changes in self-representation were at the core of the illness experience.

Many children had had limbs amputated. While most had integrated the amputation into their body concept, surgery and the consequences of progressing illness presented ongoing threats to body integrity. In addition, changes in the body challenged previously formed concepts of the self.

Most psychological writing fails to include descriptions of the physical aspects of dying. When such information is provided, it is usually presented in distancing

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medical terminology. But it is the failing body that in many cases threatens the ego most forcefully--and most persistently.

One child's frequent refrain was "I don't like to be treated like I'm sick. . . . I want to be treated like a regular person." While this comment probably reflected a perceived shift in social interactions, it also conveyed the threat that illness posed to an established self-representation. Another child, no longer able to walk or to breathe without supplemental oxygen, began to describe himself as "broken." These children were having trouble incorporating these ruptures in self at an intrapsychic level, which resulted in emotional distress.

Bluebond-Langner (1978) has suggested a five-stage theory to explain the changes in self-concept that accompany a child's progressive awareness of the seriousness of his or her illness. The last two stages are: always ill and will never get better; and dying. Although the youngest child in this study had reached these stages, one of the oldest had not. In fact, most of the children had not moved past the second stage--seriously ill and will get better--even though they had been ill for many years and had relapsed at least once. These children demonstrate that there are always exceptions to theory. In addition, awareness is not a monolithic construct but is subject to the fluctuations of emotional life. Thus, awareness that one is dying and hope that one may recover can occur simultaneously or alternate in a more fluid manner. Self-concept in relation to illness and death may have more plasticity than a stage theory allows. Lansdown and Goldman (1988) acknowledge that while there is no agreement on whether all children reach these last two stages, the possibility that even children as young as three or four years may attain them must be considered.

It is also important to tease out the influence of social and psychological factors. Bluebond-Langner (1978) maintains that talking about school is a way for dying children to pretend that they will get better. This pretense allows children to

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fulfill their social role, thereby letting parents fulfill theirs as well. But school represents more than just a social role. School experiences also provide opportunities for both consolidation of self-representation and the ongoing development of the self. Relationships with peers, the ability to learn, competence, curiosity, and altruism may be added to already existing conceptions of the self. Defining the self is a lifelong pursuit, and illness robbed these children of some of the mechanisms that facilitate this process.

The merger that occurs as a result of shared emotional pain may also affect self-and object representations. In some cases, these changing representations may provide a sense of comfort. For the adolescent embarking on a period of self-discovery and individuation, this merger may deter an already difficult process.

Dying brings to the fore a fundamental question--Who am I? The self struggles for definition when all of the external signs of identity are gone. The dying child might wonder what remains of *me* when I can no longer go to school, ride a bike, play with friends? The diminishment of these multiple social roles strips away identity, leaving the child to define the essential aspects of being that remain.

The adolescent is in the process of self-discovery and the search for a place in the beckoning world of adulthood. The dying child faces a more elemental process of discovery, that of defining the core self. Stern (1985) posits that there are four components of the core self: self-agency, self-coherence, self-affectivity, and self-history.

Self-agency is the experience of a sense of volition or having control over self-generated action. Self-coherence entails being a nonfragmented physical whole with boundaries. Self-affectivity involves experiencing patterned inner qualities of feelings that belong with other experiences of self. Self-history is a sense of continuity with one's past. The integration of these four components generates an organizing subjective perspective. This subjective self counters what Stern refers

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to as "cosmic loneliness" by allowing us to achieve intersubjectivity with another (p. 7). But even these basic experiences are tenuous when one is dying. Self-coherence is especially fragile given the disruption of the physical self caused by grave illness. Self-agency is also at risk when one has so little control over the physical, social, and psychological environments. Perhaps one of the greatest challenges we face is helping children find that deeper part of being that remains when all else has changed. In this way, the process of dying need not be equated with the death of identity but can be viewed as a final developmental stage.

Other Findings

In addition to exploring the world of the dying child, the narratives collected in this study captured the subjective experience of mothers. While the mothers relied on memory to describe their reactions to diagnosis and the initial phases of treatment, their experiences were consistent with previous findings. The shock, disbelief, and disruption that accompany the diagnosis of life-threatening illness have been much documented (Binger, 1984; Comaroff & Maguire, 1986; Friedman et al., 1963).

After the initial shock abated, most mothers tried to maintain control of the situation. "I've got to do what I've got to do" was the modus operandi of many of these mothers. Managing their child's illness became a part of the daily routine.

After the death of a child, mothers said they felt as if they were "lost" or that their "world had come to an end." The physical presence of a child was missed the most, and attempts were made to maintain the relationship by imagining the child in Heaven. Grief responses included an inability to eat and/or sleep, and there was a newfound fear for the safety and health of surviving children. Most mothers did not have regrets about their behavior during their children's illnesses and found solace in happy memories. Finally, mothers seemed to find comfort when

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professionals showed even small signs of human caring. These findings are supported by a recent prospective investigation by the International Work Group on Death, Dying, and Bereavement. Qualitative interviews conducted with mothers in five countries whose children had died of cancer reveal almost exactly the same results (Davies et al., 1998).

This convergence of findings points to the universality of the mourning experience. The mothers in the current study were West Indian and African-American. Yet the only cultural differences that surfaced in the narratives concerned the desire by the West Indian mothers to have their children appear in dreams after they died.

Issues related to palliative care also emerged. Belasco (1996) describes three stages of illness: the initial phase, where intervention is aimed at cure; the transition period, when illness progresses from curable to incurable; and the final phase, where the illness is recognized to be irreversible or terminal. She states: "If we would look at the transition phase as a time of living with disease and the terminal phase as living with hope of quality time, we would be less reluctant to have frank but gentle conversations with the ill child and his family about disease progression" (p. 3).

The results of the present study indicate that palliative care is not always demarcated so clearly. Of the three children receiving palliative care, only one seemed to be aware that treatment no longer centered on cure. Some of this confusion stemmed from individual factors, such as one child's denial of her impending death. That these treatments were usually based in the hospital and not the home also contributed to the problem. And as palliation can include chemotherapy and radiation, interventions also used in active treatment, the issue became even more complicated. Yet the vague manner in which physicians

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communicated the news was the most compelling explanation for this misunderstanding.

This kind of fuzzy communication is often a response to a physician's own sense of ambivalence and failure when cure is no longer available (Appleton, 1996; Khaneja & Milrod, 1998). The physician's attachment to a patient, and consequent desire to "soften" the news, also adds to the problem. Continued attention to this issue is essential if we are to enhance a child's ability to both understand and discuss his or her condition.

More holistic approaches to caring for the dying are a hallmark of hospice (Moore, 1997). The mission of hospice is to treat the physical, psychological, and spiritual components of the terminally ill person. Healing touch is one of the many therapies employed with the dying. Given the positive response to touch demonstrated by several children in this study, the power of touch should not be overlooked. Such physical contact maintains an interpersonal connection and is an anodyne to loneliness and isolation. The use of therapeutic massage has also been shown to decrease levels of the stress hormone cortisol and to reduce pain in children with rheumatoid arthritis (Field et al., 1997). And the effects of therapeutic touch on the regulation of blood oxygen in preterm infants have been so positive that minimal touch policies for preterm infants have become standard protocol in many hospitals across the nation (Scafidi, Field, Schanberg, & Bauer, 1990).

Hospice also facilitates caring for a dying child at home, which has been shown to improve the quality of life for both the dying child and the family (Fleischman et al., 1994; Martinson, 1993). It is notable that the one child in the present study who received hospice care did seem to have the fullest experience while dying. This child was soothed by the familiar people, smells, sounds, and objects that

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surrounded him. And being at home provided an opportunity for him and his mother to share a period of special closeness.

Limitations of the Study

The goal of the present study was to describe the communication process between dying children and their parents. In addition, this investigation hoped to represent the subjective experience of dying children as they progressed to the end of life, and of their parents as they kept them company. The qualitative method employed was uniquely suited to both of these research goals. There were, however, limitations to what could be achieved.

The most significant problem arose from the very nature of the research design. I did not want to raise the issue of death and dying unless a child indicated that this topic was on his or her mind. But in the process of informed consent, all children learned that I was there to talk about what it is like to be sick. I therefore became associated with a subject that, in some instances, a child wanted to avoid. Rather than being accepted as a benign figure, I was viewed with ambivalence.

When talking to children about death and dying, or about any sensitive matter, timing is of the essence. Although I tried to remain as flexible as possible, interviews were scheduled and did have time limits. As a result, I was not always present when a child wished to discuss these matters. In retrospect, I believe I would have learned more about children's thoughts and feelings had I been a more constant presence on the unit and had I not been known to have such a focused area of inquiry. Weeks spent in play or conversation with a child might have created a more trusting and open environment for dialogue.

Children were sometimes reluctant to have an interview taped. I used a small tape recorder and lapel microphones to record the interviews. This equipment was visible to staff and visitors. Some children were self-conscious about this setup

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and asked not to have an interview recorded. Although I wrote process notes after these meetings, they are not as accurate as tape recordings. More discreet taping equipment might have eliminated this problem.

The parent component of this study was almost exclusively composed of mothers. The two fathers who might have participated did not wish to do so. While fathers did not participate in the interviews, they were not absent from the narratives. Given the enormous impact these fathers had on their children, their input would have been valuable.

The sequelae of terminal illness also affected the interview process. Pain, sedation, and life support equipment sometimes made conversation virtually impossible as a child grew closer to death.

Finally, while capturing the depth of human experience, qualitative methods utilize small samples. Such was the case in this study. However, the families recruited at the primary research site were representative of the population served on that unit. These families also comprised all but two of the families who were eligible for the study. And given the focus of the investigation, it is perhaps fortunate that the number of eligible participants was so small.

Clinical Implications

Dying is a natural and universal process. These narratives, however, remind us of the unique ways in which people respond to that process. A perspective that considers individual needs, personalities, coping styles, histories of illness and loss, and other individual factors is well suited to facilitate the delivery of psychological services. As Rainey (1988) states: "It is not death per se we need to ponder so much as the interaction between situational factors (e.g., constraints imposed by the patient's disease, social factors inherent in the treatment setting,

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etc.) and individual factors. . . . The situation may be extraordinary, but it is populated with quite ordinary folks" (p. 147).

Although dialogue about death and dying has improved since the advent of open communication policies, many children and parents still have difficulty expressing and sharing their emotions. Exploring the fantasies surrounding such open expression may facilitate at least some sharing of emotions. If mutual expression of emotions remains too threatening, the safety of the therapeutic relationship may at least provide children and parents an outlet for releasing painful feelings. In this setting, parents and children may also learn that affect need not be overwhelming and destructive, but can be survived.

Matters related specifically to death and dying are not the only concerns of the dying child and his or her family. Stressful situations often give rise to conflict. This conflict may be due to illness-related family pressures or it may be internally driven. While the resolution of family conflict is a common therapeutic focus, less attention has been paid to intrapsychic conflict. Raimbault (1991) writes about the conflict created when a child feels both the victim of aggression and a vehicle for hostile feelings. Several children in this study were having problems with their own aggression. The defense mechanisms they employed to manage the conflict were of long-standing and not particularly effective. Attention to experiences that predate the illness can provide a way to work through some of this conflict and create a more flexible defense system.

Sick and dying children may also require help integrating changes in self-representation. As previously discussed, the body changes associated with severe illness and dying may precipitate problems with self-esteem, body integrity, and the most fundamental representations of self. The dying child is also confronted with basic existential questions about being and meaning. The therapeutic

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relationship provides not only the opportunity for integrating changes in self-concept, but an environment in which the core self may be discovered.

Psychologists are also in a position to help physicians and other hospital staff who work with dying children. Disease-related information is still frequently poorly communicated. Staff need help in understanding how individual factors influence communication. For example, one mother in this study wanted to hear a quick report: Is it cancer or not? Another mother wanted detailed information about her son's disease and treatment. One child wanted to be involved in making decisions about his treatment. Another child didn't even want to be told the side effects of upcoming chemotherapy. By helping hospital staff understand these varying needs, we can facilitate more mutually satisfying interactions.

Psychologists must continue to help physicians understand how their *own* responses to death and dying affect their ability to communicate effectively. While medical schools have added courses on communicating about death and dying to their curriculums, much work remains to be done in this area. In addition to these formal didactics, small groups where staff can explore and process their reactions to this stressful work are needed. Group work can facilitate ongoing attention to how anxiety and defenses hinder honest discourse. This more intimate environment can also help staff cope with the cycles of attachment and loss that occur when working with the dying, thus reducing psychological withdrawal.

Finally, we need to consider that even when people do not reach out for our services, they may still desire our help. One mother in this study reported that she found talking made her feel "no better and no worse," both while her son was dying and after his death. Yet, without prompting, this same mother told me the story of the day that her son died over and over. It seemed that without being aware of it, she *did* need to tell the story. As therapists, we must remain mindful

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of the service that we offer just by staying in contact with family members after a child has died.

Closing Comments

Death may be the end of life, but the process of dying does not mark the end of living. As these children have shown, dying does not occur in some separate realm of experience but is entwined with the flow of daily existence. That flow allowed these children to focus on what was most immediate at any given moment--family conflict, friendship, pain, play, loneliness, or wondering what was for dinner.

Some psychologists have remarked that dying children, in contrast to dying adults, exhibit a general sense of acceptance and optimism with little expression of anger, denial, sadness, or fear (Graham-Pole et al., 1989). Children have also been said to die with greater softness and ease (Levine, The Art of Dying Conference, April 1997). Children do seem to live their lives more in the moment than adults. This engagement with the present imparts a different tone to the period of dying. Children also still exist within the cocoon of parental protection, which may ease their fears and sadness. And yet the dying words of these children--"Do everything," "I don't want to die," and "Mommy, please help me"--forcefully convey the anguish of dying.

At a conference I attended called The Art of Dying, panelists commented that children do not struggle with death in the same manner as adults. A mother whose six-year-old daughter had died of cancer got up and angrily addressed the room: "You all talk about acceptance. My daughter did not want to die!" A physician once asked me what deeper meaning lay beneath one child's denial of her impending death. I remember thinking, what is deeper than our desire to live?

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Acceptance of death seems like a wonderful goal. Dignity while dying is what all of us would choose. The mission of hospice--quality of life instead of quantity of life--has intuitive appeal. But if we opt for quantity, if we never achieve acceptance, have we failed? Speaking not of a good death but an appropriate one, Rainey (1988) states: "A death is appropriate if it is consistent with what a person has been, with what is meaningful and important to him or her, and if it maintains important relationships" (p. 146). An appropriate death is not necessarily a peaceful death. What this study reveals most emphatically is that children die unresolved. They die longing for closer family connections; they die suddenly and unexpectedly; they die wanting to live.

Corr (1993) believes that "we cannot be or become effective providers of care unless we listen actively to those who are coping with dying and identify with them their own needs. This is so basic as to be almost obvious, if one did not know that is practiced far less frequently than it is preached" (p. 75). Dying is not just physically messy, it is psychologically messy. In order to listen to the dying, we must work on tolerating the discomfort this situation produces.

In some ways, dying is like being newborn. You are dependent on others to feed and bathe you. You lose the external trappings of selfhood. You may not have the power to walk or even talk. To support a person at the end of life may require something akin to the primary maternal preoccupation of which Winnicott (1965) speaks. This does not mean that we should infantilize the dying, but that when entering and leaving life, the focus needs to remain on the person making the transition.

This type of empathic listening necessitates an identification with the dying person. The fear and pain engendered by this identification are the primary reasons we find the task so difficult. We are also hampered by the belief that in a matter of such import we are not allowed to make mistakes. Yet we do not need to

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say things perfectly; we just need to try. If we take the risk, the rewards are great. As Carl Rogers once said, "I fall far short of achieving real communication--person-to-person--all the time, but moving in this direction makes life for me a warm, exciting, upsetting, troubling, satisfying, enriching, and above all worthwhile adventure" (in Attig, 1995, p. 13). For the dying child, this sensitive attunement may offer something greater than acceptance; it may affirm his or her value as a human being and provide the reassurance that he or she is not alone.

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My first wish is I wish for World peace. No more crime. No more murder
My Second Wish is I wish no Suffering. No more pain. No more disease.
My Third Wish is I wish I will be rich. So I can help lessfortunate people
And get people off the street

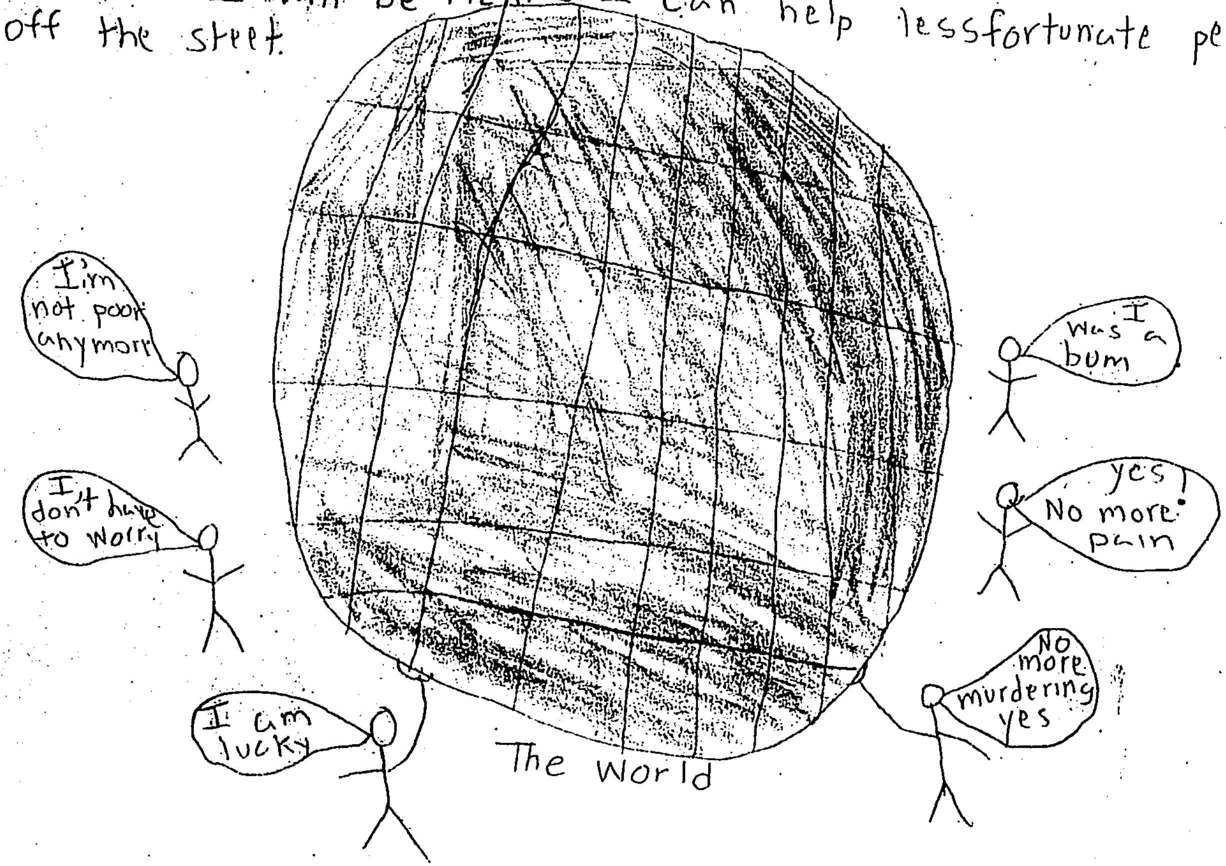

Figure 1. No More Pain

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I wish for my ~~fourth~~ wish that they will be tw
World. One for good people and bad
people. They are two world. If
you do bad you go down below
the clouds in the world of Evil.
And the people will suffer
for eternity in the Evil
world. If you do good you will
go above the clouds in to th
If you go to the World of Heven.
heven world you
will live for eternity
peace. And you will And you will have
finally meet the
man up stairs.

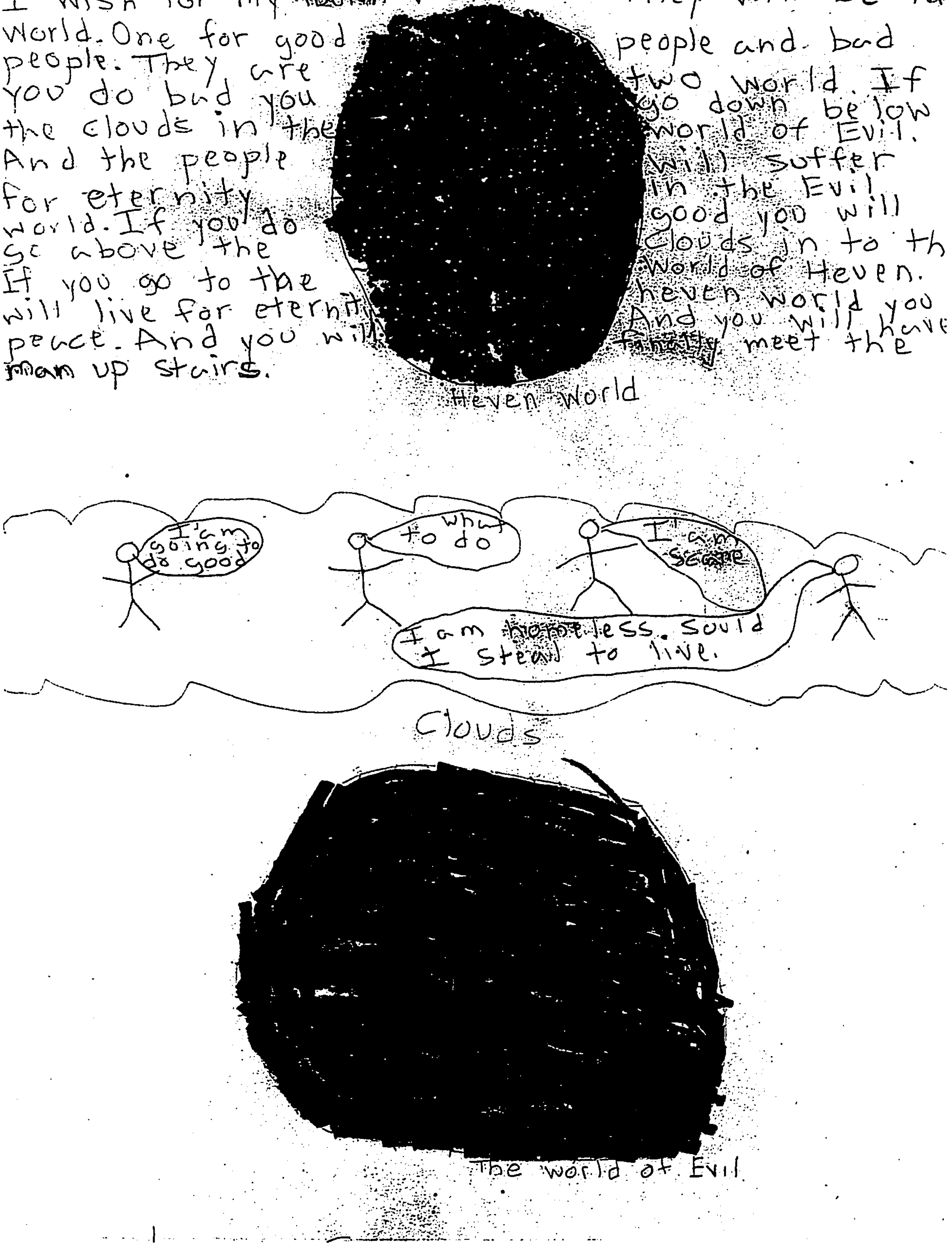

Figure 2. The Two Worlds: I Hope I Go to Heaven

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Figure 3. I Dreamed I Was Dead

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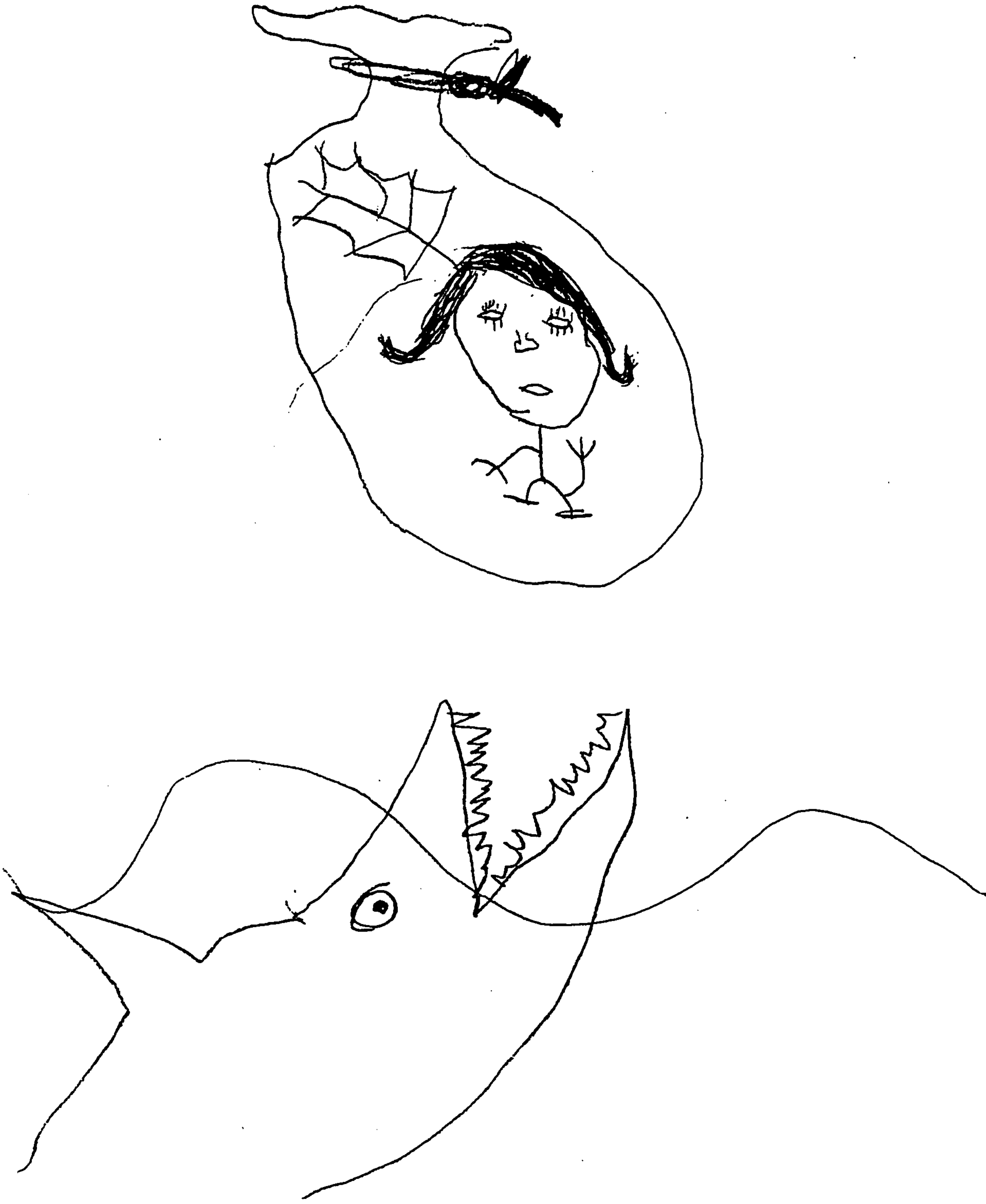

Figure 4. The Shark

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Figure 5. Uncle Hangry

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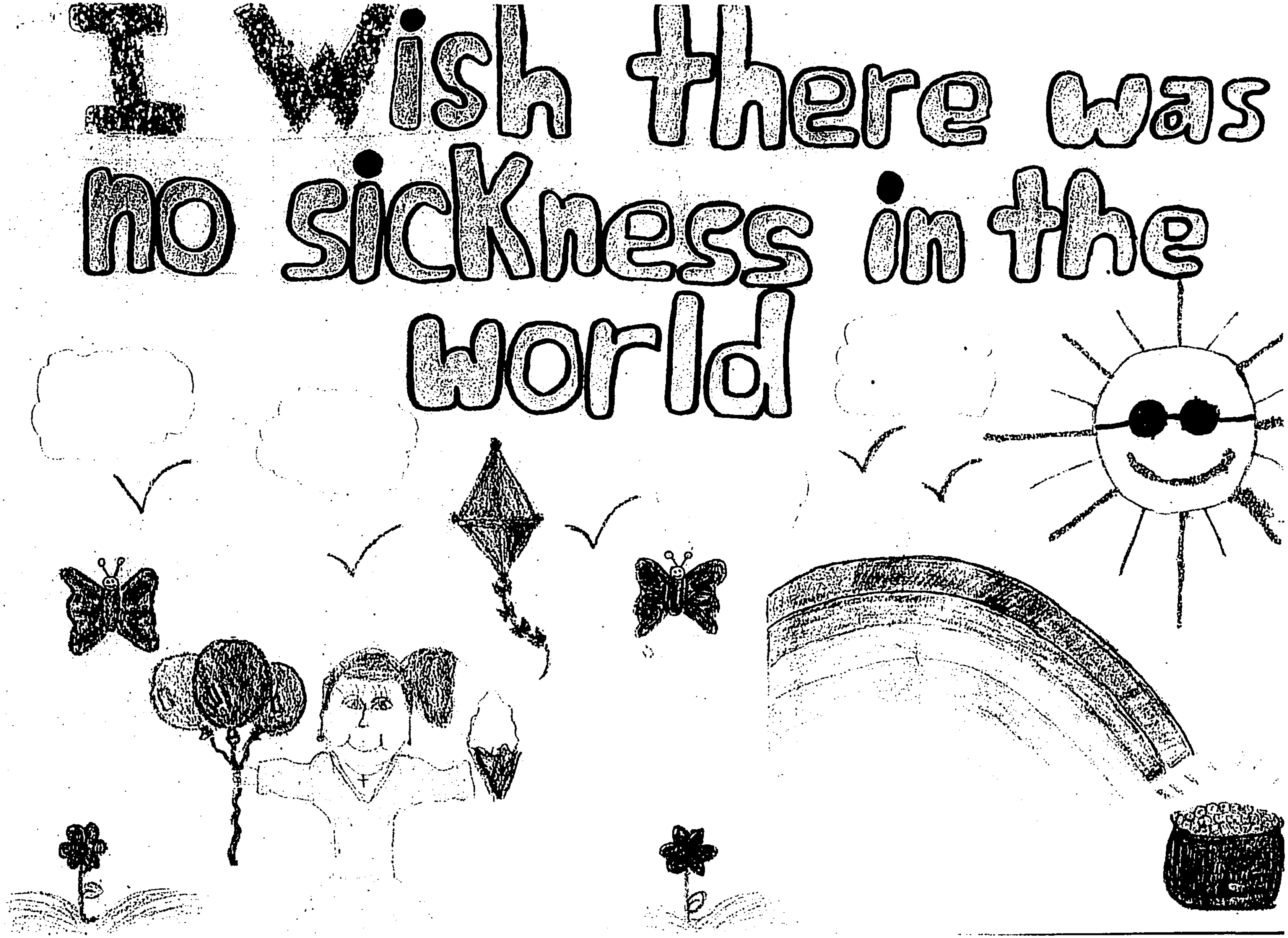

Figure 6. A Wish

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Approved: December 15, 1997
Expires : December 16, 1998.

INFORMED CONSENT

SUNY HEALTH SCIENCE CENTER AT BROOKLYN

A Study to Examine Psychological Factors Influencing Communication Between Adolescents with Cancer and Their Parents

Patients Name:______________________________

I/my child am being asked to participate in a clinical research study. In order to decide whether or not I wish to participate in this research study, it is important that I understand its benefits and risks so that I will be able to make an informed decision whether to participate or not. My doctor and the co-investigator of the study will answer any questions I might have about the form and the study.

Purpose of the Study:
The purpose of this study is to describe the manner in which adolescents who have cancer and their parents communicate with each other about the illness experience. Exploring the communication process will promote greater understanding of the difficulties both adolescents and their parents encounter when talking about illness-related issues, as well as provide information about how communication changes over time. Such information will facilitate staff's ability to help families adjust to the ongoing emotional stresses associated with having cancer.

Procedures:
Adolescents diagnosed with cancer between the ages of 12 and 19 years and their parents will be seen individually approximately once a week for a period of four months by Margaret Spier, the co-investigator, to discuss issues and ask questions related to parent/child communication about the illness experience. Ms. Spier is a doctoral candidate in Clinical Psychology at CUNY. Four patient/parent groups will be seen over the course of the study. During the interview I/my child will be asked some general questions, e.g., what has it been like for you being sick (for you having your child be sick). Interviews will last approximately 45 minutes and will be tape recorded. Written transcripts will be made from the tapes. I/my child may listen to the tape(s) and may request that any portion not be used. Ms. Spier is the only person who will hear the tapes or read the transcripts although she may share some of the information with the professor at her University who is supervising her work. Adolescents, mothers, and/or fathers will be interviewed separately and interview content will remain confidential for each participant. The place of interview will vary according to the health status of the patient and may (with permission) include participant's homes as well as the hospital. At selected points during the study, participants will fill out a brief questionnaire about coping responses. These questionnaires take approximately 10-20 minutes to complete. Both I/my child will be asked individually if we would like to participate and told there will be no consequences if we choose not to. An individual interview may be terminated at any time with no consequences and I/my child may withdraw from the study at any time with no consequences.

Risks and Discomforts:
There are no known risks associated with this study although I/my child may experience mild anxiety when talking about the illness experience.

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Alternative Therapy:

Participants may derive the benefits associated with talking about a stressful experience but they will not be receiving psychotherapy. Any participant requesting psychological treatment will be referred to an appropriate agency. Any participant who desires to continue in psychological counseling at the conclusion of the study will also be referred to an appropriate agency.

Exclusions:

Participants must speak English

Benefits of Participation:

Compensation for Medical Treatment:

If I/my child suffer any adverse experience resulting directly from participation in this study only emergency medical care will be provided. No other form of compensation is available. The investigator should be notified immediately of any new conditions or injury which may develop during the course of this study.

Confidentiality:

In this study, notations will be made of my/my child's age, gender, and other facts. These details will be identified by number and stored in a locked file kept by Ms. Spier, as will all tapes and transcripts made from the tapes, and will be seen only by the investigator or co-investigator and members of the Institutional Review Board. At the end of the study all tapes will be erased. I/my child will not be identified personally in any reports from this study and every effort will be made to keep identity and medical information confidential.

I/my child am free to withdraw consent and discontinue participation in this study at any time. Such discontinuance will not affect my/my child's regular medical treatment or medical care in any way.

For additional information I may contact Dr. Miller at (718) 270-1692 or Ms. Spier at (212) 877-7725.

For information regarding my/my child's rights as a research subject I may contact the Executive Director of University Hospital of Brooklyn at (718) 270-2401.

		Signature of Witness	Date
Signature of Parent(s) or Legal Guardian	Date		
Patient Assent (if a minor)	Date	Signature of Investigator	Date

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MOUNT SINAI SCHOOL OF MEDICINE
CONSENT FOR RESEARCH

GCO #

GCO PAGE 7

PART I - RESEARCH PARTICIPANT INFORMATION SHEET:

A. PURPOSE OF THE STUDY:

You and your child are being asked to participate in a research study. The purpose of this study is to describe the way adolescents who have cancer and their parents talk to each other about the illness in order to increase understanding of the difficulties you and your child encounter when talking about illness-related issues. You and your child qualify for participation in this study because your adolescent child has been diagnosed with cancer, speaks English, and is between 12-16 years of age.

B. DESCRIPTION OF THE RESEARCH:

You and your child will be seen individually approximately once a week for a period of about four months by Margaret Spier, the co-investigator, to discuss issues related to the illness experience. Ms. Spier is a doctoral candidate in Clinical Psychology at CUNY. During the interview you and your child will be asked some general questions, for example: what has it been like for you being sick? (what has it been like having a child who is sick?) Interviews will last approximately 45 minutes and will be tape recorded. Written transcripts will be made from the tapes. You and your child may listen to the tape(s) and may request that any portion not be used. Ms. Spier is the only person who will hear the tapes or read the transcripts although she may share some information with the Professor at her University who is supervising her work. Patients, mothers, and/or fathers will be interviewed separately and interview content will remain confidential for each participant. The place of the interview will vary according to the health status of the patient and may include participant's homes (with permission) as well as the hospital. At a selected point during the study, you and your child will fill out a brief questionnaire about coping responses. These questions ask some questions about how you describe yourself, like "I worry too much," and also about things you may do or feel, like "Do you like to share with others?" These questionnaires take approximately 10-20 minutes to complete. Both you and your child will be asked individually if you would like to participate and told there will be no consequences if you choose not to. You and your child may end the interview at any time. You and your child may derive the benefits associated with talking about a stressful experience but you and your child will not be receiving psychotherapy. If you and your child request psychological treatment, you and your child will be referred to an appropriate therapist.

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From three to ten patients will be enrolled in this study.

C. COSTS/REIMBURSEMENTS:

There are no costs or reimbursements involved in this study. You and your child will not be paid for participation in this study.

D. POTENTIAL RISKS AND DISCOMFORTS:

There are no known risks associated with this study although you and your child may experience anxiety when talking about the illness experience. If you and/or /your child feels anxious or uncomfortable at any time, you and/or your child may end the interview.

E. POTENTIAL BENEFITS:

You and your child may feel less anxious, less sad or depressed or less alone by talking about their experiences. You and your child may feel positive knowing that you and your child's story will be told. You and your child may help other teenagers with cancer and their families. However, there is no direct benefit to you and your child from participating.

F. ALTERNATIVES TO PARTICIPATION (where applicable):

The alternative is not to participate.

G. TERMINATION OF PARTICIPATION (where applicable):

You and your child is free to withdraw consent and stop participation in this study at any time.

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MOUNT SINAI SCHOOL OF MEDICINE

CONSENT FOR RESEARCH

GCO #

GCO PAGE 7

PART II.A. - RESEARCH PARTICIPANT INFORMATION SHEET FOR VOLUNTARY PARTICIPANT WHO WILL NOT DERIVE DIRECT BENEFIT FROM THIS RESEARCH (continued):

Participation in this study is voluntary. You will suffer no penalty nor loss of any benefits to which you are otherwise entitled should you decide not to participate. Withdrawal from this research study will not affect your ability to receive medical care available at Mt. Sinai Medical Center.

Significant new findings developed during the course of the research study which might be reasonably expected to affect your willingness to continue to participate in the research study will be provided to you.

Your identity as a participant in this research study will remain confidential with respect to any publication of the results of this study. Your medical record in connection with this study will be kept confidential to the extent permitted by law. Furthermore, your medical record may be reviewed by government agencies or agency sponsoring this research in accordance with applicable laws and regulations.

In the event of injury resulting from participation in the research study, short term hospitalization and professional attention, if these are required, will be provided at Mt. Sinai Medical Center at no cost to you. Financial compensation from Mt. Sinai is not available. If you believe you have suffered an injury related to this research study or have any questions at any time about this research study or your rights as a participant in this study you should contact Dr. at telephone (2416031.00). If you still have additional questions, you may discuss them with a member of the Institutional Review Board (the body overseeing research at Mt. Sinai School of Medicine) at telephone number 241-8673. A signed copy of the consent form will be given to you.

PART II.B - AUTHORIZATION OF VOLUNTARY PARTICIPANT WHO IS NOT EXPECTED TO OBTAIN ANY DIRECT BENEFIT

Participant: ______________________________
(Print Name) (Unit #)

1.a. I hereby volunteer to participate in a research program under the supervision of Dr. Granowetter and his/her associates at Mt. Sinai School of Medicine and the Mt. Sinai Hospital which will involve the following conditions, drugs or procedures:

conversations with Ms. Spier

1.b. I also agree that the following body fluids and tissues may be sampled for research analyses and related purposes (include volume and frequency of each):

NONE

2. I acknowledge that I have read, or had explained to me in a language I understand, the attached Research Participant Information Sheet and that Dr. Granowetter has explained to me the nature and purpose of these studies, including the extent, if any, to which they are experimental, the possible attendant discomforts, symptoms, side effects and risks reasonably to be expected, and the possible complications, if any, which may arise from both known and unknown causes as a result of these studies. I have had the opportunity to ask any questions I had with respect to such drugs, devices or procedures and all questions I asked were answered to my satisfaction.

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CONSENT FOR RESEARCH

GCO #

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PART II.B. continued

3. I understand that these studies are not intended to be of any direct therapeutic benefit to me and I voluntarily accept the risks and discomforts associated with these studies.

4. I understand that, in order to provide the data by which to measure the effectiveness of these studies, Dr. Granowetter and his/her associates may carry out certain routine preliminary diagnostic procedures which have been fully described and explained to me. Should these indicate any abnormality, my participation in the aforementioned studies may be terminated. I am unaware of any preexisting medical or emotional problem which would make it unwise for me to participate in these studies.

5. I understand that I am free to withdraw this authorization and discontinue participation in these studies at any time. The consequences and risks, if any, of such withdrawal during the course of the studies have been explained to me. I understand that such withdrawal will not affect my ability to receive any medical care made necessary by the performance of such studies.

6. I grant this consent as a voluntary contribution in the interest of medical research.

7. I confirm that I have read the foregoing authorization and that all blanks or statements requiring completion were properly completed before I signed.

Patient/Surrogate: ______________________________ Date: ______________
(Signature)

Name: ______________________________
(Print Name)

Relationship: ______________________________
[illegible]

8. I confirm that I have accurately translated and/or read the information to the subject:

Witness: ______________________________
(Signature)

Name: ______________________________
(Print Name)

Address: ______________________________
Number and Street City State Zip Code

I have fully explained to the above volunteer the nature and purpose of the above-mentioned research program (including the fact that the studies will not result in any direct therapeutic benefit and the extent, if any, to which the studies are experimental), the possible complications which may arise from both known and unknown causes as a result thereof and the consequences and risks, if any, if the volunteer decides to discontinue participation. I believe that he/she understands the nature, purposes, and risks of these studies. I have also offered to answer any questions relating to these studies and have fully and completely answered all such questions.

____
(Signature of Principal Investigator) (Date)

____
(Print Name) (Title)

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GCO Version 1.1

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Principal Investigator: Margaret Spier
Project Title: Psychological Factors Influencing Communication Between Adolescents with Cancer and Their Parents

Script for addressing subjects (adolescent and parent) orally:

Scott Miller, M.D. will tell prospective participants that Margaret Spier, a Ph.D. student in Clinical Psychology at CUNY, is conducting a research study about how adolescents with cancer and their parents communicate about the illness experience. If they are interested he will give them my telephone number and I will arrange a meeting to explain the study and obtain written consent.

At this meeting I will explain the study in this way:

Hello, my name is Margaret Spier. As Dr. Miller told you I am a doctoral student in Clinical Psychology at CUNY and I am conducting a study of how adolescents who have cancer and their parents communicate about their experiences with the illness. I'm interested in finding out what it has been like for you to have this illness (for you to have a child with this illness).

If you choose to be in the study, I will meet with you once a week over a four-month period. When we meet I will interview you for about 45 minutes to an hour. I will also interview your (child/father/mother) for the same amount of time. I'll meet with you in a place that is convenient for you--at your house if that's okay, at the hospital if you (your child) are (is) hospitalized and you both say it's okay, or at an office. I'll be asking you some very general questions, mostly I want to learn about what it has been like for you to be sick (for you to have a child who is sick). I'm interested in what you've been thinking about and what you've been feeling, anything you want to tell me. If you get tired, or you want to stop for any reason, we will stop the interview. If you want to drop out of the study at any time you can do that. There will be no consequences if you do stop an interview or withdraw from the study, and your (your child's) medical treatment won't be affected. Anything you say in the interview will be confidential, except if you are at danger of hurting yourself or someone else that will not be confidential. What you (your child/your parents) say(s) will also be confidential.

I will be tape recording our interviews and then transcribing the tapes. You will get an ID number so your name won't be on the tapes or transcripts, and I will keep the tapes and transcripts in a locked file at my house. The only people who will hear the tapes are the professor who is supervising my work and me. If you want to hear the tape you can, and you can ask that it not be used. When the study is finished the tapes will be erased Also your name and identity will not be used in any publications that result from this study. In any publications I'll identify you with a made-up name and any identifying characteristics about you won't be mentioned.

There's a slight possibility that you or (your parents/child) may feel some mild anxiety. If that happens we will talk about it--if you want to get psychological

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counseling at any time I will refer you to an agency. At the end of the study, if you want, I can also refer you to an agency for psychological counseling.

Sometimes people also feel better when they talk about their experience and that may happen to you.

There is no direct benefit to you for being in this study. You do get a chance to talk about your experience and you may get some satisfaction from knowing that you may help other adolescents/parents who will go through this experience.

At three times in the study I will also have you answer two questionnaires. Each one takes about 10-20 minutes to fill out. These questionnaires ask some questions about how you describe yourself, like "I worry too much" and also about things you might do or feel, like "Do you like to share with others?"

Why don't you read the consent form and then you can ask me any questions you have.

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Interview Guide

This interview guide serves two purposes. In the initial interviews open ended questions about family composition, illness and loss history, history of the current illness, and events surrounding the diagnosis will be asked (#1-4). In subsequent interviews, the remaining subject areas will serve as a listening frame for the interviewer; these are areas for further exploration if they arise. The adolescents and parents who participate in this study will be actively involved with the illness, and while areas of interest have been established, they must bend to what participants decide is most important in their lives. The balance between predetermined areas of inquiry and the emergent nature of the clinical method is delicate. Material related to domains 5-9 is expected to emerge in clinical interviews based on the general question "What's it been like since I saw you last?" One could say that these areas represent the melody for which the investigator listens with a "third ear".

1. Family composition
    Demographic information (age, race, marital status, education, occupation)
    Who is in your family; can you describe them for me?

2. Illness and loss history
    Has anyone else in the family had cancer?
    What other illnesses has the family experienced?
    What are their beliefs and feelings about illness?
    What losses (deaths) has the family experienced (who, when, what happened?)

3. History of current illness
    Can you tell me everything you remember about when you first got sick?
    What was that experience like for you?

4. Diagnosis
    How were you told about your/your child's illness?
    What was that experience like for you?
    How did you deal with your feelings?

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Do you think there was anything you weren't told?
How do parent/child think the other handled the information?

5. Communication with parent (Communication with child)
   What has been discussed over the past week
   Are there topics that have been avoided--why

6. Perspective on parents' thoughts and feelings (Perspective on child's thoughts/feelings)
   What do parent and child imagine each other are thinking and feeling

7. Isolation/Withdrawal
   How much time have parent and child spent together
   Do parent and child have different perceptions of closeness
   Does parent accompany child to hospital, stay overnight, stay during treatment

8. Thoughts and feelings about dying/death
   If these were discussed together what was the mood, what was said, how did each party think the other responded, how is death imagined, relevant dreams

9. Defenses
   Do parent or child discuss ways in which they are coping with or avoiding aspects of the illness

10. Meaning of the illness
    Causes of illness, fears about illness, what does it mean to have cancer

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Reference List

Abrams, R. D. (1966). The patient with cancer--his changing pattern of communication. *New England Journal of Medicine, 274,* 317-322.

Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin, 2,* 213-232.

Adams-Greenly, M. (1984). Helping children communicate about serious illness and death. *Journal of Psychosocial Oncology, 2* (2), 61-72.

Alexander, D. A. (1993). Psychological/social research. In D. Doyle, G. W. C. Hanks, & N. McDonald (Eds.), *Oxford textbook of palliative medicine* (pp. 92-96). New York: Oxford University Press.

Appleton, M. (1996). Hospice medicine: A different perspective. *American Journal of Hospice and Palliative Care, 13* (1), 7-9, 49.

Aries, P. (1981). *The hour of our death.* New York: Oxford University Press.

Attig, T. (1996). Beyond pain: The existential suffering of children. *Journal of Palliative Care, 12* (3), 20-23.

Baum, B. J., & Baum, E. S. (1989). Psychosocial challenges of childhood cancer. *Journal of Psychosocial Oncology, 7* (4), 119-129.

Bearison, D. J. (1991). *"They never want to tell you": Children talk about cancer.* Cambridge, MA: Harvard University Press.

Becker, E. (1973). *The denial of death.* New York: The Free Press.

Becker, H. (1983). The sorrow of bereavement. In H. M. Ruttenbeek (Ed.), *The interpretation of death* (pp. 195-216). New York: Jason Aronson.

Belasco, J. B. (1996). *Palliative care in pediatrics.* Unpublished manuscript, Children's Hospital of Philadelphia, Department of Pediatrics, Philadelphia.

Binger. C. M. (1984). Psychosocial intervention with the child cancer patient and his family. *Psychosomatics, 25,* 899-902.

Binger, C. M., Ablin, A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and family. *The New England Journal of Medicine, 280,* 414-418.

Bluebond-Langner, M. (1978). *The private worlds of dying children.* Princeton, NJ: Princeton University Press.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

_____. (1989) Worlds of dying children and their well siblings. *Death Studies, 13,* 1-16.

Bowlby, J. (1960). Separation anxiety. *International Journal of Psycho-Analysis, 41,* 89-113.

Bozeman, M. F., Orbach, C. E., & Sutherland, A. M. (1955). The adaptation of mothers to the threatened loss of their children through leukemia: Part I. *Cancer, 8,* 1-19.

Brody, H. (1987). *Stories of sickness.* New Haven, CT: Yale University Press.

Bronte, C. (1848) *Jane Eyre* (3rd ed.). New York: The Heritage Press.

Bronte, E. (1847). *Wuthering Heights.* New York: Penguin Books.

Burbach, D. J., & Peterson, L. (1986). Children's concepts of physical illness: A review and critique of the cognitive-developmental literature. *Health Psychology, 5* (3), 307-325.

Byrne, D. (1964). Repression-sensitization as a dimension of personality. In B. A. Maher (Ed.), *Progress in experimental personality research* (Vol. 1, pp. 169-220). New York: Academic Press.

Chaplin, W. F. (1984). State-trait anxiety inventory. In D. J. Keyser & R. C. Sweetland (Eds.), *Test critiques: Volume 1* (pp. 626-632). Kansas City, MO: Test Corporation of America.

Chesler, M. A., Paris, J., & Barbarin, O. A. (1986). "Telling" the child with cancer: Parental choices to share information with ill children. *Journal of Pediatric Psychology, 11* (4), 497-516.

Claflin, C. J., & Barbarin, O. A. (1990). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology, 16,* 169-191.

Clunies-Ross, C., & Lansdown, R. (1988). Concepts of death, illness and isolation found in children with leukemia. *Child: Care, Health and Development, 14,* 373-386.

Cohen, M. H. (1995). The stages of the prediagnostic period in chronic, life-threatening childhood illness: A process analysis. *Research in Nursing and Health, 18,* 39-48.

Coles, R. (1990) *The spiritual life of children.* Boston: Houghton Mifflin.

Comaroff, J., & Maguire, P. (1986). Ambiguity and the search for meaning: Childhood leukaemia in the modern clinical context. In P. Conrad & R. Kern

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(Eds.), *The sociology of health and illness: Critical perspectives* (pp. 100-109). New York: St. Martins Press.

Corr, C. A. (1993). Coping with dying: Lessons that we should and should not learn from the work of Elisabeth Kűbler-Ross. *Death Studies, 17,* 69-83.

Crowne, D. P., & Marlowe, D. (1964). *The approval motive.* New York: John Wiley & Sons.

Davies, B., Deveau, E., deVeber, B., Howell, D., Martinson, I., Papdatou, D., Pask, E., & Stevens. M. (1998). Experiences of mothers in five countries whose child died of cancer. *Cancer Nursing, 21* (5), 301-311.

Davies, B., Reimer, J. C., Brown, P., & Martens, N. (1995). Challenges of conducting research in palliative care. *Omega, 31* (4), 263-273.

Doka, K. J. (1982) The social organization of terminal care in two pediatric hospitals. *Omega, 12,* 345-354.

Drotar, D., La Greca, A. M., Lemanek, K., & Kazak, A. (1995). Case reports in pediatric psychology: Uses and guidelines for authors and reviewers. *Journal of Pediatric Psychology, 20* (5), 549-565.

Easson, W. M. (1970). *The dying child: The management of the child or adolescent who is dying.* Springfield, IL: Charles C. Thomas.

Feifel, H. (1974). Psychology and the death-awareness movement. *Journal of Clinical Child Psychology, Summer,* 6-7.

Field, T. M., Seligman, S., Krasnegor, J., Sunshine, W., Rivas-Chacon, R., Schanberg, S., & Kuhn, C. (1997). Juvenile rheumatoid arthritis: Benefits from massage therapy. *Journal of Pediatric Psychology, 22,* (5), 607-617.

Fleischman, A. R., Nolan, K., Dubler, N. N., Epstein, M. F., Gerben, M. A., Jellinek, M. S., Litt, I. F., Miles, M. S., Oppenheimer, S., Shaw, A., van Eys, J., & Vaughan, V. C. (1994). Caring for gravely ill children. *Pediatrics, 94* (4), 433-439.

Freud, A. (1966). *The writings of Anna Freud, Volume II: The ego and the mechanisms of defense.* (Rev. ed.) New York: International Universities Press.

Freud, S. (1950a). On transience. In J. Strachey (Ed.), *Collected papers* (Vol. 5, pp. 79-82). New York: Basic Books. (Original work published 1915)

_____ (1950b). Thoughts for the times on war and death. In J. Strachey (Ed.), *Collected papers* (Vol. 4, pp. 288-317). New York: Basic Books. (Original work published 1915)

_____. (1950c). Analysis terminable and interminable. In J. Strachey (Ed.),

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Collected papers (Vol. 5, pp. 316-357). New York: Basic Books. (Original work published 1937)

_____. (1960). *The Ego and the Id.* New York: W. W. Norton.

Friedman, S. B., Chodoff, P., Mason, J. W., & Hamburg, D. A. (1963). Behavioral observations on parents anticipating the death of a child. *Pediatrics, 32,* 610-624.

Furman, E. (1984). Helping children cope with dying. *Journal of Child Psychotherapy, 10* (2), 151-157.

Futterman, E. H., & Hoffman, I. (1973). Crisis and adaptation in the families of fatally ill children. In E. J. Anthony & C. Koupernik (Eds.), *The child in his family (Vol. 2): The impact of disease and death* (pp. 127-143). New York: John Wiley and Sons.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying.* Chicago: Aldine Publishing.

Graham-Pole, J., Wass, H., Eyberg, S., & Chu, L. (1989). Communicating with dying children and their siblings: A retrospective analysis. *Death Studies, 13,* 465-483.

Granowetter, L. (1994). Pediatric oncology: A medical overview. In D. J. Bearison & R. K. Mulhern (Eds.), *Pediatric psychooncology* (pp. 9-34). New York: Oxford University Press.

Gunther, J. (1949). *Death be not proud.* New York: Harper & Row.

Habermas, J. (1989). *On the logic of the social sciences.* (S. W. Nicholson & J. A. Stark, Trans.). Cambridge, MA: The MIT Press. (Original work published in 1967)

Hinds, P. S., & Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. *Nursing research, 37,* 336-340.

International Work Group on Death, Dying, and Bereavement. (1993). Palliative care for children. *Death Studies, 17,* 277-280.

Ivens, C., & Rehm, L. P. (1988). Assessment of childhood depression: Correspondence between reports by child, mother, and father. *Journal of the American Academy of Child and Adolescent Psychiatry, 27,* 738-741.

Jankofsky, K. P., & Stuecher, U. H. (1982-83). Altruism: Reflections on a neglected aspect in death studies. *Omega, 14* (4), 335-353.

Jay, S. M., Green, V., Johnson, S., Caldwell, S., & Nitschke, R. (1987). Differences in death concepts between children with cancer and physically

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

healthy children. *Journal of Clinical Child Psychology, 16* (4), 301-306.

Kalish, R. A. (1966). Social distance and the dying. *Community Mental Health Journal, 2* (2), 152-155.

Kane, B. (1979). Children's concepts of death. *The Journal of Genetic Psychology, 134,* 141-153.

Kaplan, D. M., Grobstein, R., & Smith, A. (1976). Predicting the impact of severe illness in families. *Health and Social Work, 1,* 71-82.

Karon, M., & Vernick, J. (1968). An approach to the emotional support of fatally ill children. *Clinical Pediatrics, 7* (5), 274-280.

Kashani, J. H., Orvaschel, H., Burk, J. P., & Reid, J. C. (1985). Informant variance: The issue of parent--child disagreement. *Journal of the American Academy of Child and Adolescent Psychiatry, 24,* 437-441.

Kastenbaum, R. (1987-88). Theory, research, and application: Some critical issues for thanatology. *Omega, 18,* 397-410.

Kastenbaum, R., & Thuell, S. (1995). Cookies baking, coffee brewing: Toward a contextual theory of dying. *Omega, 31* (3), 175-187.

Kazak, A. E. (1997). A contextual family/systems approach to pediatric psychology: Introduction to the special issue. *Journal of Pediatric Psychology, 22* (2), 141-148.

Kazdin, A. E. (1992). *Research design in clinical psychology* (2nd ed.). Needham Heights, MA: Allyn & Bacon.

Kazdin, A. E., French, N. H., Unis, A. S., & Esveldt-Dawson, K. (1983). Assessment of childhood depression: Correspondence of child and parent ratings. *Journal of the American Academy of Child and Adolescent Psychiatry, 22,* 157-164.

Kellerman, J., Zeltzer, L., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. *The Journal of Pediatrics, 97* (1), 126-131.

Kernberg, P. F. (1994). Mechanisms of defense: Development and research perspectives. *Bulletin of the Menninger Clinic, 58* (1), 55-87.

Khaneja, S., & Milrod, B. (1998). Educational needs among pediatricians regarding caring for terminally ill children. *Archives of Pediatric and Adolescent Medicine, 152,* 909-914.

Kidder, L. H., & Fine, M. (1997). Qualitative inquiry in psychology: A radical tradition. In D. Fox & I. Prilleltensky (Eds.), *Critical psychology: An*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

introduction (pp. 34-50). London: Sage Publications.

Kikuchi, J. (1972). A leukemic adolescent's verbalizations about dying. *Maternal Child Nursing Journal, 1,* 259-264.

Koenig, R. (1973). Dying vs. well-being. *Omega, 4* (3), 181-194.

Koocher, G. P. (1974). Talking with children about death. *American Journal of Orthopsychiatry, 44* (3), 404-411.

Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy, and their own families.* New York: Simon and Schuster.

________. (1979). The languages of dying. *Journal of Clinical Child Psychology, Summer,* 22-24.

________. (1983). *On children and death.* New York: Macmillan Publishing.

Lansdown, R. (1994). Communicating with children. In A. Goldman (Ed.), *Care of the dying child* (pp. 93-106). New York: Oxford University Press.

Lansdown, R., & Goldman, A. (1988). Annotation: The psychological care of children with malignant disease. *Journal of Child Psychology, Psychiatry & Allied Disciplines, 29* (5), 555-567.

Lefcourt, H. M. (1966). Repression-sensitization: A measure of the evaluation of emotional expression. *Journal of Consulting Psychology, 30* (5), 444-449.

Levine, S. (1982). *Who dies? An investigation of conscious living and conscious dying.* New York: Doubleday.

Lewis, S., Horton, F. T., & Armstrong, S. (1981-82). Distress in fatally and chronically ill children: Methodological note. *Omega, 12* (4), 293-306.

Leyn, R. M. (1976). Terminally ill children and their families: A study of the variety of responses to fatal illness. *Maternal Child Nursing, 5* (3), 179-188.

Lieberman, M. A. (1966). Observations on death and dying. *Gerontologist, 6,* 70-72, 125.

McQuellon, R. P., & Hurt, G. (1993). The healing power of cancer stories. *Journal of Psychosocial Oncology, 11* (4), 95-108.

Martin, D., Martin, M., & Pierce, L. (1984). The dying child: Understanding developmental processes for parents and therapists. *Journal of Child and Adolescent Psychotherapy, 1* (2), 107-110.

Martinson, I. (1993). A home care program. In A. Armstrong-Dailey & S. Z.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Goltzer (Eds.), *Hospice care for children* (pp. 231-247). New York: Oxford University Press.

Martinson, I. M., & Papadatou, D. (1994). Care of the dying child and the bereaved. In D. J. Bearison. & R. K. Mulhern (Eds.), *Pediatric psychooncology: Psychological perspectives on children with cancer* (pp. 193-214). New York: Oxford University Press.

Moretti, M. A., Fine, S., Haley, G., & Marriage, K. (1985). Childhood and adolescent depression: Child-report versus parent-child report information. *Journal of the Academy of Child and Adolescent Psychiatry, 24,* 298-302.

Nagy, M. (1948). The child's theories concerning death. *Journal of Genetic Psychology, 73,* 3-27.

Nietzsche, F. (1968). *The will to power.* (W. Kaufman & R. J. Hollindale, Trans.). New York: Vintage.

Nimrocks, M. J. A., Webb, L., & Connell, J. R. (1987). Communication and the terminally ill: A theoretical model. *Death Studies, 11,* 323-344.

O'Halloran, C. M., & Altmaier, E. M. (1996). Awareness of death among children: Does a life-threatening illness alter the process of discovery? *Journal of Counseling & Development, 74,* 259-262.

Orbach, C. E., Sutherland, A. M., & Bozeman, M. F. (1955). The adaptation of mothers to the threatened loss of their children through leukemia: Part II. *Cancer, 8,* 20-33.

Pearce, W. B., & Sharp, S. M. (1973). Self-disclosing communication. *Journal of Communication, 23,* 409-425.

Pelligrino, E. D. (1979). Toward a reconstruction of medical morality: The primacy of the act of profession and the fact of illness. *Journal of Medicine and Philosophy, 4,* 32-56.

Pelligrino, E. D. & Thomasma, D. C. (1981). *A philosophical basis of medical practice.* New York: Oxford University Press.

Phipps, S., Fairclough, D., & Mulhern, R. K. (1995). Avoidant coping in children with cancer. *Journal of Pediatric Psychology, 20* (2), 217-232.

Phipps, S., & Srivastava, D. K. (1997). Repressive adaptation in children with cancer. *Health Psychology, 16* (6), 1-8.

Phipps-Yonas, S. (1993). A case example of clinically relevant research: Commentary on Steward. In C. A. Nelson (Ed.), *Memory and affect in development: The Minnesota Symposia on Child Psychology* (Vol. 26, pp. 227-235). Hillsdale, NJ: Lawrence Erlbaum.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Prugh, D. G., Staub, E. M., Sands, H. H., Kirschbaum, R. M., & Lenihan, E. A. (1953). A study of the emotional reactions of children and families to hospitalization and illness. *American Journal of Orthopsychiatry, 23,* 70-106.

Raimbault, G. (1991). The seriously ill child: Management of family and medical surroundings. In D. Papadatou & C. Papadatos (Eds.), *Children and death* (pp. 177-187). New York: Hemisphere Publishing.

Rainey, L. C. (1988). The experience of dying. In H. Wass, F. M. Berardo, & R. A. Neimeyer (Eds.), *Dying: Facing the facts* (pp. 137-157). New York: Hemisphere Publishing.

Rando, T. A. (1988). Anticipatory grief: The term is a misnomer but the phenomenon exists. *Journal of Palliative Care, 4,* 70-73.

Roth, S., & Cohen, L. J. (1986). Approach, avoidance, and coping with stress. *American Psychologist, 41,* 813-819.

Rudestam, K. E., & Newton, R. R. (1992). *Surviving your dissertation: A comprehensive guide to content and process.* Newbury Park, CA: Sage Publications.

St. Vincent Millay, E. (1981). *Collected lyrics of Edna St. Vincent Millay.* New York: Harper & Row. (Original work published 1917)

Santostefano, S. (1978). *A biodevelopmental approach to clinical child psychology: Cognitive controls and cognitive control therapy.* New York: John Wiley & Sons.

Scafidi, F. A., Field, T. M., Schanberg, S. M., & Bauer, C. R. (1990). Massage stimulates growth in preterm infants. *Infant Behavior and Development, 13* (2), 167-188.

Schoenberg, B. (1970). Management of the dying patient. In B. Schoenberg, A. C. Carr, D. Peretz, & A. H. Kutscher (Eds.), *Loss and grief: Psychological management in medical practice* (pp. 238-260). New York: Columbia University Press.

Showalter, J. E. (1970). The child's reaction to his own terminal illness. In B. Schoenberg, A. C. Carr, D. Peretz, & A. H. Kutscher (Eds.), *Loss and grief: Psychological management in medical practice* (pp. 51-69). New York: Columbia University Press.

Schulz, R., & Schlarb, J. (1987-88). Two decades of research on dying: What do we know about the patient? *Omega, 18* (4), 299-317.

Seiffge-Krenke, I. (1997). One body for two: The problem of boundaries between chronically ill adolescents and their mothers. *The Psychoanalytic Study*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

of the Child, 52, 340-355.

Shovelar, G. P., & Perkel, R. (1990). Family systems intervention and physical illness. *General Hospital Psychiatry, 12,* 363-372.

Smith, K. E., Ackerson, J. P., Blotcky, A. D., & Berkow, R. (1990). Preferred coping styles of pediatric cancer patients during invasive medical procedures. *Journal of Psychosocial Oncology, 8* (4), 59-70.

Solnit, A. J., & Green, M. (1963). The pediatric management of the dying child: Part II. The child's reaction to the fear of dying. In A. J. Solnit & S. A. Provence (Eds.), *Modern perspectives in child development* (pp. 217-228). New York: International Universities Press.

Sourkes, B. M. (1982). *The deepening shade: Psychological aspects of life-threatening illness.* Pittsburgh, PA: University of Pittsburgh Press.

Speece, M. W., & Brent, S. B. (1987). Children's understanding of death: A review of three components of a death concept. In T. Krulik, B. Holaday, & I. A. Martinson (Eds.), *The child and family facing life-threatening illness: A tribute to Eugenia Waechter* (pp. 74-95). Philadelphia: J. B. Lippincott.

Spinetta, J. J. (1974). The dying child's awareness of death: A review. *Psychological Bulletin, 81* (4), 256-260.

Spinetta, J. J. (1978) Communication patterns in families dealing with life-threatening illness. In O. J. Z. Sahler (Ed.), *The child and death* (pp. 43-51). St. Louis, MO: C. V. Mosby.

Spinetta, J. J., & Deasy-Spinetta, P. (1981). Talking with children who have a life-threatening illness. In J. J. Spinetta & P. Deasy-Spinetta (Eds.), *Living with childhood cancer* (pp. 234-252). St. Louis, MO: C. V. Mosby.

Spinetta, J. J., Deasy-Spinetta, P., McLaren, H. H., Kung, F. H., Schwartz, D. B., & Hartman, G. A. (1982). The adolescent's psychosocial response to cancer. In C. K. Tebbi (Ed.), *Major topics in pediatric and adolescent oncology* (pp. 312-346). Boston: G. K. Hall.

Spinetta, J. J., & Maloney, L. J. (1975). Death anxiety in the outpatient leukemic child. *Pediatrics, 56,* 1034-1037.

Spinetta, J. J., & Maloney, L. J. (1978). The child with cancer: Patterns of communication and denial. *Journal of Consulting and Clinical Psychology, 6,* 1540-1541.

Spinetta, J. J., Rigler, D., & Karon, M. (1974). Personal space as a measure of a dying child's sense of isolation. *Journal of Consulting and Clinical Psychology, 42,* 751-756.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Spinetta, J. J., Swarner, J. A., & Sheposh, J. P. (1981). Effective parental coping following the death of a child from cancer. *Journal of Pediatric Psychology, 6,* 251-263.

Stahly, G. B. (1988). Psychosocial aspects of the stigma of cancer: An overview. *Journal of Psychosocial Oncology, 6* (3-4), 3-27.

Stern, D. N. (1985). *The interpersonal world of the infant: A view from psychoanalysis and developmental psychology.* New York: Basic Books.

Stevens, M. M. (1993). Psychological adaptation of the dying child. In D. Doyle, G. W. C. Hanks, & N. McDonald (Eds.), *Oxford textbook of palliative medicine* (pp. 699-707). New York: Oxford University Press.

Steward, M. S. (1993). Understanding children's memories of medical procedures: "He didn't touch me and it didn't hurt!" In C. A. Nelson (Ed.), *Memory and affect in development: The Minnesota Symposia on Child Psychology* (Vol. 26, pp. 171-225). Hillsdale, NJ: Lawrence Erlbaum.

Steward, M., & Regalbuto, G. (1975). Do doctors know what children know? *American Journal of Orthopsychiatry, 45* (1), 146-149.

Stillion, J., & Wass, H. (1984). Children and death. In E. S. Shneidman, (Ed.), *Death: Current perspectives* (pp. 225-247). Palo Alto, CA: Mayfield Publishing.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage Publications.

Sudnow, D. (1967). *Passing On.* Englewood Cliffs, NJ: Prentice-Hall, Inc.

Taylor, S. J. & Bogdan, R. (1984). *Introduction to qualitative research methods* (2nd ed.). New York: John Wiley & Sons.

Terr, L. (1979). The children of Chowchilla: A study of psychic trauma. *The Psychoanalytic Study of the Child, 34,* 547-632.

Tolstoy, L. (1981). *The death of Ivan Ilyich.* New York: Bantam Books. (Original work published 1886)

______. (1991). "Three deaths". In M. R. Katz (Ed.), *Tolstoy's short fiction.* New York: W. W. Norton. (Original work published 1859)

Townes, B. D., Wold, D. A., & Holmes, T. H. (1974). Parental adjustment to childhood leukemia. *Journal of Psychosomatic Research, 18,* 9-14.

Van Dongen-Melman, J. E. W., & Sanders-Woudstra, J. A. R. (1986). Psychosocial aspects of childhood cancer: A review of the literature. *Journal of Child Psychology and Psychiatry, 27* (2), 145-180.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Vernick, J. (1973). Meaningful communication with the fatally ill child. In E. Anthony & C. Koupernik (Eds.), *The child in his family (Vol. 2): The impact of disease and death* (pp. 105-119). New York: John Wiley and Sons.

Vernick, J., & Karon, M. (1965). Who's afraid of death on a leukemia ward? *American Journal of Diseases of Childhood, 109*, 393-397.

Vianello, R., & Lucamente, M. (1988). Children's understanding of death according to parents and pediatricians. *Journal of Genetic Psychology, 149*, 305-316.

Waechter, E. H. (1971). Children's awareness of fatal illness. *American Journal of Nursing, 71*, 1168-1172.

Walker, C. E., & Kaufman, K. (1984). State-trait anxiety inventory for children. In D. J. Keyser & R. C. Sweetland (Eds.), *Test critiques: Volume 1* (pp. 633-640). Kansas City, MO: Test Corporation of America.

Wass, H., & Stillon, J. (1988). Death in the lives of children and adolescents. In H. Wass, F. M. Berardo, & R. A. Neimeyer (Eds.), *Dying: Facing the facts* (pp. 201-227). New York: Hemisphere Publishing.

Weinberger, D. A., Schwartz, G. E., & Davidson, R. J. (1979). Low-anxious, high-anxious, and repressive coping styles: Psychometric patterns and behavioral and physiological responses to stress. *Journal of Abnormal Psychology, 88* (4), 369-380.

Weiss, R. S. (1994). *Learning from strangers: The art and method of qualitative interview studies.* New York: The Free Press.

White, E., Elsom, B., & Prawat, R. (1978). Children's conceptions of death. *Child Development, 49*, 307-310.

Wiener, J. M. (1970). Reaction of the family to the fatal illness of a child. In B. Schoenberg, A. C. Carr, D. Peretz, & A. H. Kutscher (Eds.), *Loss and grief: Psychological management in medical practice* (pp. 87-101). New York: Columbia University Press.

Winnicott, D. W. (1965). *The maturational process and the facilitating environment: Studies in the theory of emotional development.* Madison, CT: International Universities Press.

Zeltzer, L., Kellerman, J., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychological effects of illness in adolescence. II. Impact of illness in adolescents--crucial issues and coping styles. *The Journal of Pediatrics, 97* (1), 132-138.

Zevon, M. A., Tebbi, C. K., & Stern, M. (1987). In C. K. Tebbi (Ed.), *Major*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

topics in adolescent oncology (pp. 325-349). Mount Kisco, NY: Futura Publishing.

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