

The  
Private  
Worlds  
of  
Dying  
Children

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## CHAPTER ONE

### Children as Actors

A child lies in bed, a white sheet drawn taut under his chin, staring out through the slightly open doorway. Outside, a doctor informs the parents, in hushed tones, that their child has leukemia. Questions race through their minds: "What am I going to do? What does it all mean? Will he die? What am I going to tell him?"

The physician's answer to this last question will depend upon his beliefs about the thoughts and feelings of young children. These beliefs are informed by what is to date a rather small and diverse literature on awareness and coping in terminally ill children.<sup>1</sup> The contributors are generally the physicians themselves, social workers, and psychologists, whose concern about what to tell a dying child led to an examination of the behavior of these children.

Noting the failure of terminally ill children to ask questions about their illness, some researchers believe that such children do not know the gravity of their condition.<sup>2</sup> Some feel that no good would be served by telling the children; in fact, it would probably make them more depressed and anxious.

Others interpret the children's silence differently. They attribute the lack of questioning not to an ignorance of the condition, but to the children's perceiving that adults are reluctant to talk about it.<sup>3</sup> But these researchers fail to understand the complex relation of these two factors, and this

<sup>1</sup> For a review of literature on awareness, communication, and coping in terminally ill children, see Bluebond-Langner 1975:1-16.

<sup>2</sup> See Agranoff and Mauer 1965, and Richmond and Waisman 1955.

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then leads them to one-sided solutions. For example, they suggest that groups led by health care professionals be formed so that children can talk freely about their condition with their parents and the physician.

There is a third group of physicians who advocate neither silence nor disclosure.<sup>4</sup> They start from the premise that children, in contrast to adults, have rather limited linguistic, intellectual, and emotional capacities. Children under ten are not capable of understanding their condition as adults do,<sup>5</sup> therefore the notions of "seriously ill" or "dying" just do not have the same import for them. Without clarifying in what way the children view their conditions, these authors go on to recommend that disclosure of information be left to the discretion of the parents and physician.

The literature is, I believe, inconclusive, and its recommendations problematic. It is not clear whether the children know, and if they know, what the precise nature of their knowledge then is, or how they come by it. Much of the problem, I submit, lies with the theories and methods these authors employed. Implicit in all of the work discussed is a view of children and their socialization common to both structural- and psychological-functionalism.

Socialization studies conducted from the structural- or psychological-functionalists' viewpoint tend to focus on situations in which the child is the patient and the caretaker is the agent.<sup>6</sup> For the most part these study child-rearing by the society's adult members. Other areas of childhood (e.g., peer relations, play, even the child's manipulation of the adults under study) are neglected. The understanding of and approach to childhood socialization that result are not

<sup>4</sup> See Kliman 1968, Natterson and Knudson 1960, Morrissey 1965, Solnit and Green 1959, 1963.

<sup>5</sup> For a full discussion of the problems inherent in these assumptions, see Bluebond-Langner 1977.

<sup>6</sup> See Elkin 1960, Aberle and Naegele 1968, Brim 1966, Maccoby 1968a and b, Kaplan 1961, Kardiner 1945, Linton 1945, Mead 1928, 1929, Mead 1970, Richards 1970, and Whiting and Child 1953.

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very different from the layman's. Attention is directed to the same areas of behavior that parents focus on. Traditionally oriented researchers concentrate on education, child-rearing, sexual identity, goals, internalization of norms and values; in brief, what is necessary for competent performance as an adult, according to their definition of adulthood.

In such studies, children are defined in terms of what they will become; childhood is viewed in terms of its bearing on future activities and status. Adults hold up a preexisting image to children, and measure them according to that standard, yet the children's definition of themselves and their world remains unexplored.

Critics of this approach argue that the very area of study, socialization, is neglected. Socialization is a negotiated two-way process involving the self and others over time (cf. Mead 1970, Blumer 1969). It is not simply "putting in" information at one end, and "getting out" a finished product, the adult, at the other (Inkeles 1968:77). Research that proceeds from a view of children as recipients of action from an external agent, or an internal force beyond their control, that approaches them in terms of an image to which they are being reared to conform, loses sight of the dynamic and functional character that marks socialization and, in fact, all interaction. As Denzin (1973:7-8) writes of structural-functionalist and psychological-functionalist approaches, "[they] fail to grasp the shifting, unfolding, creative aspects of all human behavior."

Finally, in their failure to respect children and their world, these studies do not comprehend the child's role in the initiation and maintenance of social order, to which adults respond with things like child-rearing practices. Researchers in structural- or psychological-functionalism mistake for socialization one of the many interactional strategies used when dealing with children. Child-rearing is only one aspect of interaction between parents and children, let alone of socialization. How children initiate such actions,

their responses to the action taken, its consequences for the parents' or children's succeeding act, and for the parents' view of themselves and of the children—these are some elements ignored by traditional studies. As Inkeles (1968:103) points out, "All 'views' and 'perspectives' are inherently one-sided."

Whatever the merits of these general criticisms, the view and approach common to structural- and psychological-functional perspectives is unsuitable for studying terminally ill children.<sup>7</sup>

How can one use a model that presumes a future, that presupposes adulthood, for children who will never reach adulthood, particularly when everyone associated with these children is acutely and painfully aware of the fact? Leukemic children's knowledge of their condition colors their entire world view (see chapters two, three, and four).

The consequences of using the traditional model can be seen in the work of physicians, psychologists, and sociologists who have studied dying children's understanding of their terminal condition and prognosis. Richmond and Waisman (1955), and Solnit and Green (1963), for example, though studying such children, based their conclusions on the observed interactions between parent and child and doctor and child. Since the children did not ask adults about their condition, researchers assumed that the children either did not know, or were not interested in finding out, about their condition. Children would indicate their awareness, felt the researchers, by discussing it with adults, as many older children did. These investigators did not entertain the possibility that perhaps the children obtained information

<sup>7</sup> Considerations of space and continuity preclude further discussion of this model, but the reasoning behind such criticism and the ensuing choice of an alternative perspective is more apparent in the work of the symbolic interactionists and ethnomethodologists who study children when one sees what problems are solved there that could not have been solved using the perspective common to structural- and psychological-functionalism.

from other sources; or that they were in fact expressing awareness, but in a symbolic way that adults did not understand; or that by not talking about their condition, the children were observing social taboos, and attempting to save others' face (chapters six and seven).

These alternatives do not occur to one who fails to see children as willful, purposeful individuals capable of creating their own world, as well as acting in the world others create for them. Had the researchers entertained such a view, they would have sought out and investigated those possibilities by studying the children's peer-group interaction, their use of symbolic expression in art and play, and their knowledge of cultural norms and values, before concluding that only some older children become aware of their prognosis. They would also have formulated the problem of acquisition of information differently. It would not have been looked at as a simple process of learning from adults. We must employ an alternative view and approach; this may be found in the more recent work on childhood socialization done by those who share the symbolic-interactionist or ethnomethodological perspective.<sup>8</sup> Both of these rest on the premise that children possess a self, and are, therefore, purposeful, willful individuals capable of organizing their own behavior toward others. Children are able, as Denzin (1973:9) states, "to take one another's roles, present definitions of self, construct elaborate games and manipulate adults into desired directions." They can initiate and sustain prolonged interaction (e.g., play) without adult intervention; they can also participate in worlds that adults create for them, and initiate action in those situations.

Possessing a self, children can interpret the behavior of others and act on the basis of their own interpretations (cf.

<sup>8</sup> For examples see Denzin 1970-1973, Joffee 1973, Speier 1970, Cicourel 1970, and most recently the contributors to Dreitzel 1973. Dreitzel's book appeared after I wrote the first drafts of this work. While many of my ideas appear there, I was not aware of his work until I had completed my own.

Mead 1970 and Blumer 1969).<sup>9</sup> For example, Faith (age three) interpreted the hospital as a threatening place. Those associated with it, identifiable by their uniforms, inflicted pain. Whenever anyone in white approached Faith, she dove under the covers. Jeffrey (age five), like Faith, saw the hospital in terms of "us" and "them." He made his primary cut (major category division) on the basis of those in uniform vs. those not in uniform. He later moved to a more behaviorally based interpretation—those who took orders and spoke only when spoken to versus those who came and went when they pleased, sometimes with and sometimes without explanation, a practice usually reserved for adults. On the basis of these interpretations, Jeffrey refrained from questioning the medical staff about his condition and assumed a supplicant position (see play, below, Act 1).

Interpretations of the self, others, and objects are made in the course of interaction.<sup>10</sup>

The meanings of such things [self, others, objects] is derived from, or arises out of, the social interaction that one has with one's fellows. (Blumer 1969:2)

The interpretations become available through action and are the basis for consequent action. For example, a five-year-old boy interprets his mother's crying as indicating that he is very sick. "See my mommy's red nose, that's from me. Everybody cries when they see me. I'm pretty sick." He also notes that he is getting more presents than his sister. "I get more presents than when I had my tonsils out. My sister gets the same." Finally, he has been behaving in

<sup>9</sup> "Interpret" is used here and throughout not in the sense of giving meaning to something recondite, but as giving *any* meaning, the basic act that all language-users must perform.

<sup>10</sup> According to Blumer (1969:10), "an object is anything that can be indicated." There are three categories of objects: physical (e.g., drugs, bone marrows, lab results); social (e.g., mother, doctor, anthropologist); and abstract (e.g., illness, the word *sick*, death, taboos). In this chapter, I refer to social objects as "others."

ways that are ordinarily cause for reprimand and finds that he is not reprimanded. In fact, he is rewarded. Following his interpretation of others' behavior toward him, he sees himself as very ill, and he forges a line of action in accord with such a view. He acts the sick role and claims his right on the basis that he is truly ill. For example, Beth, snatching a toy from her sister, said, "Gimme that, I'm the sick one, not you."<sup>11</sup>

In arriving at a certain self-image, children interpret not only the behavior of others toward them, but also their own behavior toward other objects. For example, Scott (age five and a half), seeing his mother crying after the doctor told her that Scott would need a bone marrow (a diagnostic aspiration of the marrow), and knowing that the bone marrow was not expected (it was not four weeks since the last one), deduced from his mother's behavior that he was not doing well, and that unexpected bone marrows are not a good sign. His behavior after leaving the doctor's office indicates he did not interpret his mother's tears as concern over the pain of the procedure. He chose to postpone his lunch until he heard the results of the bone marrow. "The worst part is waiting for the results," he said (see play, below, Act II, Scenes 5 and 7).

Children are capable of choosing behavior so as to affect the way others see them. Children who know they are dying but wish to conceal this knowledge from their parents can, by doing some of the things that normal children do, momentarily change their parents' view (see chapter five).

A form of behavior common among terminally ill children, "exhibition of wounds" (see chapter four), underlines how children try to affect not only the way others see them, but also how they see themselves. By showing where and how they have been poked and prodded, children present themselves to others as sick and find their self-image con-

<sup>11</sup> This kind of interpretation and consequent action is also seen in normal children when they are sick. Children often play sick because they know that rules will be relaxed and they may get more attention.

firmed. This is further evidenced by the fact that once children internalize this view of self, they no longer use this strategy, except when meeting someone for the first time and wanting, for any number of reasons, to affect the stranger's view of them (see chapter four).

This use of behavior can also extend to affecting others' actions. For example, by crying in the face of a procedure in the terminal phases of the disease, the child may change the nurse's view of him ("He's ready to die") as well as her behavior (she will not administer the drug).

The children's interpretation of themselves, others, and objects, and the consequent action taken varies with the social, physical, and temporal settings. A child's failure to discuss his or her prognosis in the presence of adults, compared to open discussion in the presence of other children, is one illustration of the effect of social setting. Since the children interpret death as an inappropriate topic of conversation with adults (evidenced by the adults' reactions when children try to discuss it), and as an appropriate topic with other children (evidenced by their willingness to offer information and answer questions), they refrain from discussing the subject in the presence of adults, but pursue it with peers. This is also true of sex discussions among normal children. Leukemic children often discussed their condition in the place children often go to discuss sex—the bathroom, where adults cannot hear them. Looked at another way, then, we can say that children's pretense in one social setting and their candor in another indicates their ability to make judgments about a situation and to act appropriately.

The role of physical setting in the interpretation of self was shown in the different way children viewed themselves in the clinic, as opposed to in the hospital. Regardless of whether the children were sicker when they came to the clinic than they had ever been when hospitalized, they saw themselves and were seen by others as being in better health than when they had been hospitalized. The hospital was

"where people go to die." There was a feeling among the parents, children, and staff that no matter how sick children might be, if they were not in the hospital, they were not going to die. This interpretation of the self had consequences for people's actions in both settings. For example, parents and children could separate far more easily in the clinic than in the hospital.

As discussed in detail in chapter four, terminally ill children's view of themselves, others, and objects also changed over time. They first defined themselves as well, then, by degrees, as ill, seriously ill and will get better, always ill and will get better, always ill and will never really get better, and, finally, as dying, with noticeable changes in their behavior at each stage. The children's view of nurses ("others") changed from all nurses are threatening all of the time, to all nurses are threatening some of the time, to some nurses are threatening some of the time, to nurses are not threatening at all. They acted toward each on the basis of these definitions. For example, those whom they viewed as nonthreatening, "on their side," they tried to solicit help from to get out of medical procedures. "I bet if Elsa were here she wouldn't let them do this to me." It should be noted that this shift in view of certain nurses from threateners to protectors or nurturers came at about the time that children ceased to see their mothers as the authorities, protectors, and nurturers, and began to see them as the ones to be protected or whose authority could be disobeyed (see chapter six).

Similarly, children's interpretation of the illness ("abstract object") changed from acute to chronic to fatal. Even the definition of concrete objects, like drugs, changed from healing agents to just something that prolongs life; from always effective, to effective some of the time, to not really effective at all. Children's behavior changed accordingly, from passive acceptance of the drugs to refusal to take them. "They don't do nothin' anyway."

The children's view of time itself changed (see chapter

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four). It was no longer, as it is for most other children, endless. It became finite, marked by relapses and remissions. One consequence of this changed view was that the children no longer spoke of the future. Above all, time was not to be wasted.

The following points can be made about children, based on this research:

1. They are willful, purposeful creatures who possess selves.
2. They interpret their behavior and act on the basis of their interpretations.
3. They interpret their own self-images.
4. They interpret the behavior of others to obtain a view of themselves, others, and objects.
5. They are capable of initiating behavior so as to affect the view others have of them and that they have of themselves.
6. They are capable of initiating behavior to affect the behavior of others toward them.
7. Any meaning that children attach to themselves, others, and objects varies with respect to the physical, social, and temporal settings in which they find themselves.
8. Children can move from one social world to another and act appropriately in each world.

It is not true, then, that a child's view of himself is "x" and therefore he does "y"; or a child sees her mother as "z" and therefore she does "b"; or a child's view of a certain object is "f" and he therefore acts towards it with "g." Each interpretation of self, others, and objects varies with the physical, social, and temporal settings in which it occurs, and with the individuals' views of themselves and their relation to the society of which they are members. These interpretations and consequent actions become available to us through participant-observation. To duplicate this process, the data are presented in the form of a play.

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"The World of Jeffrey Andrews" (chapter two) was written to give a sense of the everyday life of terminally ill children, their emotions and thoughts at each step of a finite journey from diagnosis to death. It recreates the dramatic, living quality of that which is taken apart, analyzed, and used to illuminate theoretical issues in succeeding chapters. To construct the play, I went through my field notes (a combination of taped transcriptions and recorded observations) and wrote a play for each child from these. Then I assembled them to form the composite play, "The World of Jeffrey Andrews." In this way I could include a sufficiently wide range of characters and experience to sustain a broad analysis. Preserving the anonymity of a few individuals who might have been recognizable was also facilitated by the composite characterization.

Often, I created a single character from two different children. However, one can also separate the two children without doing violence to characters or my conclusions, because the children were not combined to make an ideal type. Similarly, in other cases several characters were created from a single child, since using the same name more than once would have made it easy for others to recognize the child. Age, sex, and circumstances have been altered when necessary to protect a child's or adult's identity. Dialect has been removed altogether for the same reason. I have tried to present the information without compromising scientific validity, while preserving the anonymity of informants.

Being terminally ill, living with dying, is an extended process, and the acts reflect the length of the various aspects of the disease. The longest act, Act iv, deals with a series of relapses and remissions, as this is the longest aspect of the process in actual time and the patients' view. Act v, the death, is the shortest. The five acts also reflect the five stages of the socialization process. Each act represents what occurs at a stage in the process that is discussed from a more theoretical perspective in chapter four. To replicate as closely as possible the data-sorting process, the data taken from

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the dialogues in the plays and necessary for the analysis in chapters four through seven is presented in chapter three. In brief, the play immerses one in the fieldwork experience; analysis begins in the succeeding chapters.

## CHAPTER TWO

### The World of Jeffrey Andrews

#### PERSONAE

(In order of appearance)

JEFFREY ANDREWS: *Five-year-old boy with leukemia\**  
MRS. ANDREWS: *Mother of JEFFREY ANDREWS*  
MR. ANDREWS: *Father of JEFFREY ANDREWS*  
NURSE RICHARDS: *R.N. on pediatric ward*  
NURSE STEVENS: *R.N. on pediatric ward*  
RECEPTIONIST ON PEDIATRIC WARD\*\*  
"DR." SID COLE: *Third-year medical student*

("Heme Team")

DR. ABRAMS: *Chairman of the department of pediatrics, and hematologist*  
DR. ELLIS: *Pediatrician, hematology fellow*  
DR. WESSON: *Pediatrician, hematologist*  
DR. WESSLEY: *Pediatric hematologist/director of pediatric oncology clinic*  
DR. CELLARS: *Pediatrician, hematology fellow*  
STUDENT AIDE\*\*  
TV MAN\*\*  
DR. ESTERSON: *Resident in pediatrics*  
DR. MC PHEARSON: *Intern in pediatrics*  
FAITH WELDER: *Three-year-old girl with leukemia\**  
MRS. WELDER: *Mother of FAITH*

\* Age when the character first appears in the play.

\*\* When no name is given, it indicates that neither the children nor the parents ever learned that person's name, who then remained nameless throughout the course of the illness.



mouth and held it there on top of his tongue. He remembered what Charlotte had told him—that the sac was waterproof and strong. It felt funny on his tongue and made him drool a bit. And of course he couldn't say anything. But as he was being shoved into the crate, he looked up at Charlotte and gave her a wink. She knew he was saying good-bye in the only way he could. And she knew her children were safe.

'Good-bye!' she whispered. Then she summoned all her strength and waved one of her front legs at him.

She never moved again. Next day, as the Ferris wheel was being taken apart and the race horses were being loaded into vans and the entertainers were packing up their belongings and driving away in their trailers, Charlotte died. The Fair Grounds were soon deserted. The sheds and buildings were empty and forlorn. The infield was littered with bottles and trash. Nobody, of the hundreds of people that had visited the Fair knew that a gray spider had played the most important part of all. No one was with her when she died." (*Closes the book.*)

JEFFREY: (*Dozes off.*)

MYRA: (*Places the book by his bed, leaves him a note on the end of the bed.*)

(*MYRA leaves the room.*)

Later that afternoon, at 5:15 p.m., JEFFREY ANDREWS died.

### CHAPTER THREE

## What Terminally Ill Children Know about Their World

All of the leukemic children whom I studied faced death with a great deal of understanding about the world of the seriously ill and their place in it. They knew the institution and the disease as well as any lay adult. This chapter delineates the range of the children's knowledge of the hospital structure, personnel, disease treatment, process, and prognosis at the time of death. Particular attention is given to areas of knowledge that had been foreign to the children before they were diagnosed. How this knowledge was acquired, its role in shaping behavior, world-view, and self-concept is discussed in the following chapters.

### I. THE HOSPITAL'S PHYSICAL PLANT

None of the children involved in the study had ever been hospitalized for a serious illness or injury prior to their hospitalization for diagnosis. A few had been hospitalized for minor surgery (e.g., tonsilectomies, hernia repairs) before they were three years old. Although many of the children lived in the city where the hospital was located, none had visited it; the majority had not even heard of it. It was also virtually unknown to the children from the surrounding tristate area. One twelve-year-old boy from the southern part of the state did remark that he thought he had heard "people back home" talk about it as "the place where you go to die."

For the most part, the leukemic children lived in relative isolation from the rest of the ward. At times this was for

medical reasons (e.g., reverse isolation or wound isolation), and at other times it was for personal reasons (e.g., their parents did not want them to leave their rooms or be visited by other patients). But this isolation did not seem to be a barrier to the children's rapid acquisition of information about the hospital order. What follows is an account of the children's knowledge of the covert and overt functions of various rooms, of written and unwritten rules, and of hospital regulations and procedures.

### *Pediatric Department*

All the children knew that the pediatric department was one of several departments in the hospital. Commonly referred to as "peds," the department utilized the top three floors of the hospital. One floor was for the pediatricians' research activities; they did not normally see patients here. Two floors were for in-patient care. Of these two in-patient floors, one was for children aged five and above, and the other for newborns and children less than five years old. The children differentiated the two groups in terms of "kids who don't wet the bed" or "don't wear diapers" as opposed to "kids who do." Most of the children I studied had never stayed on the fourteenth floor, reserved for the younger children. Those who had, when describing the fourteenth floor, said that when there was not enough room on thirteen, older children were sent to fourteen. None spoke of thirteen as also serving for the overflow from fourteen. During the period in which I conducted my study, thirteen had never served for the overflow.

The layout of a hospital floor is easy to understand. By observing the equipment, one can discern the probable function of any room; however, such observations may not indicate what the room is really used for, or its other functions.

The children were well aware of the multiple purposes hospital rooms served in addition to their designated functions as: treatment room, lab, conference or doctors' room,

kitchen, supply room, medicine room, "O.T." (the occupational therapist's office and adjoining playroom); school-room or playroom, nurses' station or "desk" (as the nurses' station was often called).

The treatment room, next to the nurses' station, served not only for diagnostic procedures, but also as a medical supply and examining room. The children did not expect to be taken to the treatment room for routine procedures like cultures and blood tests (CBCs), or for major surgery. It was for things somewhere in between, like bone marrows, spinal taps, or lumbar punctures, which were carried out in the treatment room, unless the patient was in reverse isolation. If one of these procedures was done in their own rooms, the children knew that the supplies came from the treatment room. Although leukemic children were examined, even on first admission, in their own rooms, they knew that other patients were usually first examined in the treatment room. Some of the children mentioned that the treatment room was also used by doctors from other floors (e.g., surgeons) when they had a patient on thirteen and "they wanted to look at him" or "to change the bandage or something." Such occasions usually involved "a lot of people."

Many of the children commented on how it seemed that "if the doctor doesn't want your mother around, he takes you in the treatment room." Some doctors did remark that they preferred carrying out procedures in the treatment room, because it was easier to keep the parents out and the children were easier to manage. Or, as one intern remarked, "If you take them in there you don't have to ask the parents to leave. It's a lot easier without them."

The results of diagnostic procedures on hematology patients were analyzed in the lab on the thirteenth floor. The only lab on thirteen, it technically belonged to pediatric hematology, and was not used by other services. The children, all hematology patients, did not make this distinction. Instead, they often spoke of the lab as "Roberta's lab." Roberta was the laboratory technologist assigned to pedi-

atric hematology, and was there all day. The children knew that the hematologists often gathered in the lab after lunch to discuss the results of various tests. Often the children would be seen milling about the area "waiting for their doctor."<sup>1</sup>

The conference room or doctors' room, or office, as it was often called, was the scene of formal and informal meetings among the physicians. Rounds were held there, doctors from other services reported there when they came on the floor, cases were charted, and doctors relaxed there. The children's awareness of the kinds of information discussed in the doctors' room was revealed by the lengths to which they would go to glean the information. One child went so far as to plant a tape recorder in the conference room.

The children and their parents did not enter the doctors' room without being asked, but they would often call to a doctor from the doorway. On weekends and in the late evenings, this unwritten rule was relaxed. Interestingly, the children observed this rule when I was in the doctors' office and they wanted to speak with me. Usually, if children wanted my attention, even when I was in the middle of a conversation, they would walk right up to me and start talking. When in bed, they would call to me or send someone to get me. But when I was in the doctors' office, writing up my notes or talking to one of the physicians, the children acted towards me as they did towards the physicians present. At such times, I believe, the children were observing the rules of the room, rather than treating me as a physician. On other occasions, even when I was in the company of the physicians, children treated me differently than they did the latter.

The children also commented that the nurses "can't just go in there." While there was no such written rule, nurses did not enter the conference room without a specific reason. Generally they stopped by only to consult a doctor or to look

<sup>1</sup> "Their doctor" was always one of the hematologists. They never referred to a resident or an intern as "their doctor."

for charts. They never went in on a break to socialize among themselves, and rarely to socialize with the physicians. Such fraternization as did take place occurred only in the evening and involved residents, interns, and medical students, not attending staff. Fraternization with the attending staff was rare.

The kitchen was to the nursing staff what the conference or doctors' room was to the physicians. It was the place where the nurses made rounds (passing information on to the next shift, also known as "report"), held case conferences, met with the staff psychiatrist, and took their breaks. On the evening shift, many nurses ate their dinner in the kitchen. At one time, the kitchen was used to prepare food for the pediatric service; its only current food-related function is to serve as a storage area for snacks sent up from the kitchen and for food children want to save. To the children, the conversations that took place in the kitchen were more important than any food-related activity. In their descriptions of the kitchen, food aspects were relatively minor.

The children knew that the kitchen was "off limits," and they followed the same procedure as in the doctors' room, calling to the nurses from the doorway. As with the doctors' room, rules were relaxed in the evening. At report time, the children often listened in around the kitchen doorway. They were especially interested in "who was on" and who would be "their nurse." Being invited into the kitchen during the slow evening hours and on weekends was one of their particular pleasures. The kitchen was a good place to talk to the nurses, the children thought. Many held lengthy conversations with the nurses in the kitchen and from the hallway.

The supply room was another room whose name did not suggest its major function. During the day shift, it was used as a lounge by the nurses' aides, the woman in charge of supplies, and the housekeeping staff. The R.N.s, however, never took breaks in the supply room, and the L.P.N.s rarely did. The children revealed their awareness of the utilization

of this area when discussing the whereabouts of a particular person at any given moment.

The medicine room was also a nurses' area. The children agreed that it was where the nurses went to get the medicines ready. They were dispensed in small cups with water, or in an injection into the I.V. tubing, the I.V. bottle, etc., from larger bottles kept in the medicine room. The medicines either came up in the shoot from the pharmacy or were already in inventory on the floor. Some children also mentioned that "the nurses go in there [the medicine room] to talk private . . . to other nurses and to doctors they like." While this was not necessarily the case, many of the conversations held in the medicine room were not drug-related. The doctors rarely walked into the medicine room.

"O.T." was the children's name for the office and room next to it used by the occupational therapy staff and students assigned to pediatrics. The office was used by the pediatric occupational therapist and her students, and later in the year by one assistant, for conferences, storage, and socializing. Even though many of the leukemic children had never been to the playroom next to the office, they knew that it was used for group occupational therapy sessions and for testing. They were also aware that many of the things that came down on "the cart" to clinic on Monday morning came from that room and from the O.T. office.

Whenever the occupational therapist or her students were there, the children were allowed to go to O.T. They could also go to O.T. for scheduled play periods, or to borrow games and arts-and-crafts materials. Realizing that no other hospital personnel had access to the room, they usually just walked away if they found it closed. When they did ask staff for games, or crayons and paper, they did not expect them to go to the O.T. room, but thought they would get them from the "desk."

Across the hall from O.T. was the schoolroom, set aside by the hospital for use by the teacher sent by the city board of education. The room had a blackboard, a piano, and a

locked floor-to-ceiling cabinet for storing books and other instructional materials. During school hours, the teacher met with the ambulatory children in small groups according to age. Other patients were seen in their rooms.

Many of the children referred to the schoolroom as "the playroom." They would often wander down to the schoolroom in the evening to play the piano and just "mess around." This was especially true when a group of veteran patients of about the same age were hospitalized together. They knew that they were not supposed to be there unsupervised, but if there was a nurse available to check on them and they did not cause too much trouble, they would be allowed to stay.

Many of the nonleukemic children mentioned that the schoolroom was used by parents "to cry in" when their child died. If a class was in session, word would be sent ahead to the teacher and the class would be dismissed. If class had not already started, it would be canceled or postponed. During these times, the schoolroom was strictly off limits and the children knew it.

The parents would wait in the schoolroom for the nurses to collect the child's belongings and prepare the child to be seen by the parents before being wrapped for the morgue. The hematologist or the resident met with the parents there to answer any questions and to ask for permission to do an autopsy. Sometimes a chaplain was present. Nurses often went in and out to dispense medication to the parents and to offer sympathy.

The schoolroom served several other functions. It was used as a dining room twice a day for the ambulatory patients, as an entertainment room where civic and military groups came to perform for the children, and as a nursing-staff party room for the staff Christmas party, and nurses' baby showers, special birthdays, and farewell parties. On rare occasions, it was used by parents staying overnight. The children, ambulatory and nonambulatory, knew when the room was being used for any of the above purposes.

The centrally located nurses' station, or as it was more commonly known, "the desk," was the hub of all activity, as the children were well aware. All doctors and other hospital personnel stopped there when they arrived on the floor. It was the first place the children had to go when they arrived and the last place they had to stop before they could go home. Calls came in and out constantly; announcements over the floor loudspeaker were made there; charts were kept at the desk. To the children, the desk was the place where they could always find someone. They knew that if certain individuals were there and it was not too hectic, they could wander about the area and even sit on the desks. They often said that it was not permitted, but "they let us." They quickly scattered when those who might object entered the area.

There were also two definable areas that served important functions: the area around the two pay-phones and the area near the elevator. Each area was named after its central object. The open telephone booths, where patients and their relatives made and received calls, were located opposite the desk. There were no phones in the rooms, and the phones at the nurses' station were for hospital business only, although the children were sometimes permitted to use these during off-hours to call home. During the day, they knew they had to use the pay-phones, and nonleukemic children would often "hang around" and share each other's calls. For the majority of the leukemic children, this was a rare activity and their knowledge of it was mostly hearsay. They knew that their parents spent most of their time out of the room around the phones and at the elevators. When children wanted their mothers, they would often ask someone to check at the phones and the elevator. They described the elevators as the place "where the parents go to smoke." Nonleukemic children often lingered near the elevator pretending to wait for O.T. to open. When I asked one nine-year-old hematology patient, who knew that O.T. was closed,

why she was standing around the elevators, she said, "I know what I'm doing." Later she told a leukemic child whose mother she had seen seated at the elevator that the mother would have to leave the hospital earlier than she had promised.

### *Clinic*

None of the children involved in the study had ever been to the pediatric oncology clinic prior to their first visit following discharge from the hospital after diagnosis. Many of the children had never been in any clinic situation. On Monday mornings, the children went to clinic. If a holiday occurred on Monday, they reported on Wednesday afternoon to the pediatric hematology clinic.

The children referred to the pediatric oncology clinic simply as "clinic." Only some of the children knew the full name. Two children who had been patients for more than five years used an older designation, tumor clinic.

The children differentiated between the pediatric oncology clinic, the pediatric clinic, the pediatric hematology clinic, and the adult oncology clinic. The pediatric oncology clinic was for "other children like us, who have the same thing," and it met on the third floor. The "regular children's clinic" met on the first floor. The "Wednesday afternoon clinic is for kids with different blood diseases." The adult oncology clinic was for "adults with the same thing." It met on Monday afternoons in the tumor clinic. The children, waiting for the results of their bone marrows, sat with the adult oncology patients who were waiting for that clinic to open.

Although the children knew that the clinic was part of the hospital, they tended to describe it separately. In part, this was because going to the hospital as an in-patient was very different from being a clinic out-patient (see chapters one and four). The clinic included a waiting-room area, with a women's bathroom and reception desk for patients sched-

uled to see the radiologist; treatment and examination room area; a reception desk for patients scheduled to see the hematologists; and a conference room.

A reception desk was located in the waiting room to the right as one entered the clinic. All the children knew that this was not the desk to which they were to report, but very few knew that it was for radiology patients or individuals receiving radiation therapy. This latter group had to report first to the hematology reception desk, at the opposite end of the clinic.

The waiting room was divided in half by a wooden lattice-work divider. On one side of the divider, tables were set up for children in the playgroup to use. This was not a formal group. Children came and went, participating in activities as they chose. The small furniture marked this as a gathering place for children; on the opposite side of the divider, full-size chairs set up in rows within a "U" of chairs along three walls marked that side as a gathering place for adults.

The "O.T. cart" that was brought down by the occupational therapist was placed at the end of the divider. The children knew that they could take the games, toys, and art supplies from the cart and play with them anywhere in the clinic. They knew that things usually had to be put back on the cart by noon, but that they could retain one thing to play with if it was returned before they left the clinic for the day.

The children were well aware of the various activities besides toileting that went on in the women's bathroom, located on the "adult" side of the waiting room. Older girls held meetings there about the disease, various drugs, and what was happening to other children. When adults entered the bathroom, the girls ceased conversation and often left. Boys revealed their awareness of what happened in the bathroom by their tendency to gather, clutching a toy, near the bathroom entryway.<sup>2</sup>

<sup>2</sup> See Act IV, Scene 11, of "The World of Jeffrey Andrews."

The children also knew what kind of information was exchanged by parents in treatment rooms and in the conference room when children were not there. The children's awareness was evident in the lengths to which they would go to obtain such information. They would often hide behind office doors and try to listen. Andy (a six-year-old boy) for example, became quite fidgety when his parents went to talk to the doctor without him. He stopped playing and said, "I think I better go get weighed [the scales were located across from the treatment rooms]." I responded, "You already got weighed." Getting up from his chair, Andy replied, "Well, I'll go check again." He went down the hall, creeping against the wall so as not to be seen, and stepped to the side of the scale to listen.

The children would also wander in and out of parents' meetings in the conference room. When I heard one five-year-old girl call the meeting "the P.T.A.," I asked her what the P.T.A. was, thinking that perhaps she did not know the subject of these meetings. She told me that it was "where the parents go to talk about what's wrong with you." Children knew they were talked about over coffee, and they would eavesdrop on conversations in the waiting room; this was almost as much a reason to delay separating as was emotional anxiety.

The children did not describe the reception desk where they checked in and out as a hub of activity, as they did the desk on the floor. The reception desk was simply where one handed in the card, retrieved the card, and received a Tootsie Pop. In the clinic, the most active area was between the treatment rooms and the hallway where medicines were drawn up.

Other places in the hospital that, although part of the clinic process, were not located there, were no mystery either. The children knew that no matter how sick they were, they had to stop and get a blood test on the first floor before going up to the clinic. They also knew that they could not see the doctor until he or she had received the results of the blood test. They knew that the medicines

came either from the first-floor pharmacy or from the doctors' refrigerator on the twelfth floor. If medicines were to come from the pharmacy, the parent had to wait for them.

X-rays for the clinic and X-rays for the hospital were taken in the same place. The difference was, children in clinic waited with their mothers, children in the hospital waited with the nurse, or an X-ray technician came up to the room.

Most children could tell how to get from the clinic to the cafeteria to the phone booth, and to other floors. This was no easy matter, as the halls were a maze with many dead-ends, and not all the elevators went to all floors.

#### *Other Places in the Hospital*

The children also knew the location of the gift shop, vending room, blood bank and emergency room. They would often ask permission to go to the gift shop or vending room, but rarely asked to be taken any other place. They never mentioned the blood bank unless asked about it. Conversation about the emergency room was infrequent, except in regard to admission, or transfusion as an out-patient.

## 2. HOSPITAL PERSONNEL

The children were in basic agreement that the staff ranked from top to bottom as follows: hematologists, residents, interns, nurses, and medical students. Some children put medical students above nurses. Children who made distinctions among various types of nurses put the medical students below the R.N.s, but above the L.P.N.s, nurses' aides, and housekeepers. But the children were quick to perceive that placement was not always so clear-cut. For example, nurses who technically ranked below doctors could sometimes talk doctors out of things. Sometimes the residents went against the hematologists' decisions.

The children differentiated among the allied professions—occupational therapists, lab technologists, and teachers—

but judged them equal to the nurses. Some children also mentioned a certain social worker when discussing this category of personnel, but those who had had no contact with her did not mention her. A very few children mentioned the dietician, who was also included in this equivalent, but different from nursing, category.

The children did not place the TV man, the ward clerk, leaders of the parents' group, or me, anywhere in the hierarchical structure. Unlike any of the above, we never wore uniforms or even lab coats, nor did we perform any medical services. Hospital personnel who were never mentioned by the children included the chaplains, secretarial help, and physical therapists.

The children pointed out to me that each group was identifiable by its duties and time and modes of appearance. None of the children were incorrect in their accounts of the social organization. What varied was the completeness of their descriptions, the degree of detailed information that they gave me.

#### *Pediatric Hematologists*

The pediatric hematologists, known as the "heme team," were identifiable by the long white coats they wore over their street clothes. They made rounds every morning. On Monday afternoons, however, they were led about by the head of pediatrics, also a hematologist. I often asked the children how they knew the man who came on rounds on Monday afternoon was a hematologist. After all, he did not treat any of them in clinic. He was not one of their own or their peers' doctors. Several said that their family physician had sent them to this hospital because of this man. Others said as much or that he did not go on the other rounds. Some children commented that on Tuesday mornings he occasionally went to a few rooms with the residents, interns, and medical students.

Only a few children were aware of the ranking within the heme team. They knew that Dr. Ellis and Dr. Cellars were

not as high as Dr. Wesson or Dr. Wessley, but they did not know why. Many did not know where to place Dr. Wesson, probably because he had so few patients, only one of whom was hospitalized during the study. Many of the children were aware of research projects that the doctors were involved in, as well as the other types of blood diseases that they treated.

The children identified the hematologists as "their doctors." Everyone saw "their doctor" in the clinic as well as in the hospital, and usually had the same doctor throughout the course of the illness. Hematologists "make all the decisions. Everybody has to do what they say." When a resident or an intern came in to do a procedure and the children had not been told about it in advance, they would often ask if the hematologist told the resident that he could do it. When it came to asking about going home, the children asked the hematologists first.

The residents and the interns were well aware of the children's feelings and would often refuse to do a bone marrow on them. "Why should I do the scut work? Let one of them." The children often heard the residents saying such things, or arguing with the parents about a particular procedure. They could often succeed at stalling a procedure by putting up a fuss in front of the resident.

This attitude toward residents, as opposed to attending staff, was not as prevalent among inexperienced nonleukemic patients. It was even less prevalent among inexperienced nonhematology patients. They were more willing to put the resident at the top. Also, nonleukemic patients generally knew more about the ranks and role of residents, interns, and medical students than leukemic patients. In part, this was because they had more dealings with them over a longer period of time than the leukemics did; they were seen by the residents more than by the "attending men" (which included the hematologists). Much of the nonleukemics' knowledge of residents was based on observa-

tion of behavior, and the residents and interns did more for these children than they did for the leukemics.

### *Residents*

The children were quick to point out that the residents were younger than the hematologists and some mentioned that they were older than the interns. But that was not the only thing that distinguished them from the hematologists and interns. Like the "attendings," the residents wore lab coats over their street clothes most of the time. But sometimes, when they were on duty all night, they wore what the interns did—scrub suits, or as one child described them, "white pajamas." Female residents who worked in the nursery or who were on at night wore scrub dresses and lab coats. But no matter how old they looked or what they wore, the residents had blue name tags and the interns had green name tags. One resident continued to wear his green name tag from internship days. When this was pointed out, many of the children just said, "He didn't get his new one yet." In many cases the children had seen him "move up." "Move-up day" (July 1) was noticed by many of the more experienced patients.

According to the children, the residents could do "almost anything" the hematologists could do. The qualification stemmed from the fact, previously mentioned, that the children often heard the hematologists tell the residents what to do.

The children knew that the residents ran the floor and that if they wanted medicine at night for pain, they were dependent on them. When they were admitted to the hospital, the resident did the history and physical before the hematologist did. The residents made rounds with the interns, medical students and, on some mornings, with an attending physician. When they made these rounds, the charts clanked along on a metal structure that looked like a laundry-basket frame. In the afternoon, they made rounds



without looking at patients. A few children noted correctly which residents ranked higher than others.

#### *Interns*

The younger children did not consistently distinguish interns from residents, as the older or more experienced patients did. For that matter, neither did many of the parents. The male interns wore white scrub pants, shirts, ties, and short white jackets. The female interns wore white skirts, blouses and short white jackets. The "whites" were provided by the hospital.

None of the children knew that the interns were assigned to particular residents. While some noticed that their blood cultures were always taken by the same intern, and that that intern accompanied the resident who came in to do the bone marrows and spinal taps, and even mentioned the coincidence, none of them ever spoke of interns being assigned to residents.

Some of the children remarked that the interns started I.V.s more often than did residents and medical students. All the children knew who would probably come in to restart their I.V.s, but only the more experienced knew that the intern was sent only if the veins were hard to find. Otherwise a medical student would be sent. The hematologists often left word that no medical students were to try to start I.V.s. A few of the children would tell the medical student who came in start an I.V. that they wanted a certain intern to do it. When the medical student would ask why, the children would usually tell him that the intern was better, even though they had no way of knowing whether this was really so. The intern was, however, a "real doctor"; medical students were not.

#### *Medical Students*

Although the children referred to residents and interns as "Dr." So-and-So, they referred to medical students by their first names. They would often laugh when a medical

student was paged with the title "doctor," saying, "He's not a real doctor yet." When I asked one eight-year-old girl why they called him doctor, she replied, "So the patients don't get shook."<sup>8</sup> I believe she was right, especially about some of the other floors, where the medical students did a great deal of the routine work.

To the children, the only differences between the medical students and the nurses were their dress and their ability to start I.V.s. The medical students wore street clothes and short white jackets. There was one male medical student who worked part time as a nurses' aide and wore a scrub suit. The children did not consider him a nurse. All the nurses were female. The children never confused female medical students with nurses, nor did they, like many adults, confuse female doctors with nurses. They acknowledged the mixing of sexes.

#### *Nursing Staff*

Few nurses wore caps, but most wore colored uniforms, the idea being to appear less imposing to children, especially the younger ones. This was never the case. Even a newly admitted child could tell the difference between a woman in a yellow dress and a woman in a yellow uniform. The child reacted to the uniform, regardless of its color. It was not simply a reaction to strangers; when a stranger in street clothes appeared, the child did not cry.

Many of the children were aware of the conflicts that existed between the nursing staff and the physicians. A few called my attention to the fact that the nurses always addressed the doctors, and sometimes the medical students, as "doctor"; yet the doctors addressed the nurses by their first or last names. The children also liked to tell stories of romances between staff members. Their accuracy was often uncanny. Much of this behavior came out only in the eve-

<sup>8</sup> Duff and Hollingshead (1968:478) found this kind of reasoning on the part of some of the hospital administrators where they did their research.

ning, when the hospital was left to the residents, interns, and medical students.

All the children knew that the nurses worked in shifts, and that they were the only staff members to do so. As discussed earlier, they knew when and where the shifts reported to each other, and would often be around to listen.

Children who could distinguish R.N.s from L.P.N.s from nurses' aides did so on the basis of the nurses' responsibilities. Most frequently, the distinction made was that all the R.N.s, but only some of the L.P.N.s, and none of the nurses' aides, could "pass meds." The children who did not make these distinctions abstractly could, however, tell which individuals did what. All nursing personnel could take temperatures; however, the L.P.N.s usually took temperatures at the same time as blood pressures. The nurses' aides helped bathe the children, passed out snacks, and often kept the children company.

When the children mentioned nurses' aides, they often mentioned the housekeeping staff too. The one housekeeping person that they singled out was the "supply lady." "She's in charge of the linen and gives you stuff like old syringes to play with." This woman kept the floor stocked and often gave the children bits and pieces of medical supplies to play with. They often talked about her distinctive dress. She wore a scrub suit or dress with a hospital gown on backwards. Some of the children also singled out the man who washed the rooms. They talked about how he did not seem to like to clean the isolation rooms and grudgingly put on a mask and gown. Very few of the children mentioned the woman who cleaned the beds. In the context of describing the housekeeping staff and nurses' aides, some of the children mentioned the kitchen help. "They come up with the trays." The children talked about how they failed to get the food up to the rooms hot and did not remove trays promptly.

The student nurses performed many of the same tasks as

the nurses' aides and L.P.N.s. Although the children could not necessarily distinguish licensed R.N.s from licensed L.P.N.s, they could distinguish student R.N.s from student L.P.N.s, probably due to the difference in uniforms; also, they got to know the student R.N.s better than the student L.P.N.s. The student L.P.N.s came on the floor as a group accompanied by their instructor, and stayed for only part of the morning, perhaps for only one day. The student R.N.s came up for longer periods of time, without an instructor, and often worked on the floors on weekends and in the evening to earn extra money.

#### *Other Hospital Personnel*

As noted earlier, the children distinguished between non-nursing personnel, but classified such members with the nursing staff—the schoolteacher, the "O.T. (occupational therapist)," the lab technician, and the social workers.

The children under five did not mention the schoolteacher, as they had no contact with her. The older children did and knew when and where she worked. They felt that she could not really make them do anything. Since the leukemic children were often in reverse isolation, she would usually come to their rooms to give them a lesson. They often refused to let her come in, sometimes rejecting school and school work as a way of saying "I'm dying."

All the children were quite familiar with the role of the O.T. and her students on the thirteenth floor and in the clinic. They were not as aware of her activities off the floor and outside the clinic, including lecturing to occupational therapy students, testing children, and participating in FATIS (Family Adaption to Terminal Illness) meetings. And they did not know that, like the doctors, she wrote reports in the charts after play sessions.

All the children spoke about Roberta, the lab technician. Although they knew that she did all the hematology patients' bone marrows in the hospital and in the clinic, they

did not know that she did not do other patients'. The children knew that when Roberta came to the clinic, it was for a bone marrow. CBCs (blood tests) were always done before clinic by her or reported through her to the hematologists.

The social worker on the floor was unknown to the majority of the leukemic children. She was not involved with any of the hematology patients. She did see two of the parents, however, and tried to become involved with one of the children. The child, however, wanted no part of her, feeling that she asked too many questions, smiled too often, and stayed in the room too long. The children did not know that the woman had been a nurse. She was addressed as "Sister," which they mentioned more than the fact that she was a social worker. The children noted she wore a lab coat over street clothes, not a habit.

Another social worker, Miss Green, was mentioned only by the children she served. They said that she sometimes gave them toys and came to talk to them. Only one child added that she helped to get his parents transportation money.

While the TV man was not spoken of as part of the structure, he was a very important person to the children. They knew when he came and how much money they had to give him for daily or weekly TV service. Children over six knew that the TV man did not give credit. If a child did not have the money when he came to collect, the TV was taken out. Recall that in the play, Tom was quite concerned that Myra get the money to the TV man before he left for the day.

The ward clerk was more familiar to the ambulatory patients, especially those whose mothers did not stay at the hospital all day. These children would often go to her and ask for things to do. She would let them paste things in the charts, staple forms, count materials, etc. For the child of nine who could read, this was a sought-after position. They also went to the ward clerk for permission to use the ward phones during the day if they did not have money, "dimes."

## 3. OTHER PATIENTS

While the leukemic children lived in relative isolation from the rest of the patients on the floor, they did know something about them. What they knew, however, was limited to what "the regulars" (this included the "sicklers" and the "hemophiliacs") would tell them about these other children, since the leukemics were for the most part confined to their rooms. The "regulars" were the major carriers of ward news and gossip.

The leukemics knew the most, of course, about the other leukemic children. Even on the rare occasions when they were placed in rooms with nonleukemic children, they still tended to know more about the other leukemic children on the floor than about their own nonleukemic roommates.

All the children could distinguish between leukemic and nonleukemic patients. "They [the leukemic patients] come to Monday clinic." "We [leukemic patients] all have the same blood disease. You know Greta, she comes [to the hospital] all the time. Well, she has a blood disease [sickle cell disease] too, but she goes to another clinic."

They constantly called attention to what was happening to other children, drawing parallels or distinctions.

CHILD: Is Gene getting vincristine again?

MYRA: Yes, I think so.

CHILD: When I had vincristine the second time I lost my hair. (*Pause.*) Gene gets his hair back real fast, I wish I did.

CHILD: Jeffrey can't walk. I bet he's in relapse.

MYRA: You think it's relapse.

CHILD: Well, it could be he's weak, but he's weak because he's in relapse.

The children always knew who else was in the hospital from the clinic, why they were there, and the protocol that they were on: "Jeffrey's in his first relapse"; "Tom has a lot

of relapses"; "Esther's in isolation"; "Jeffrey's getting platelets to stop his bleeding" (further examples are in the play).

Most striking, in light of what others have said (Richmond and Waisman 1955:43, Natterson and Knudson 1960:20), is that the children did know who was alive and who was dead.

TOM: Jennifer died last night. I have the same thing, don't I?

NURSE: But they are giving you different medicines.

TOM: What happens when they run out?

NURSE: Well, maybe they will find more before then.

MARIA: I'm going to play with Luis [a child who died six months earlier] in heaven.

ANDY: I knew Maria died. I saw the cart come for her. They told everyone to go in their rooms.

Even the children who were isolated tended to know a great deal about other children's conditions, often more than the respective parents knew. Mary Costin was not permitted to play with or speak to other children in the clinic or in the hospital. Her door was kept closed and her mother kept a watchful eye over her and those who spoke to her. Her statements, however, revealed that she was well aware of what was happening to other children and was continually trying to gather more information: "Gene gets his hair back real fast, I wish I did"; "You know Ellen, she's the one with the scars on her legs"; "Is Rachel going to be coming here? I was like her when I started coming"; "Did Alan get blood for his anemia part? He looked pale"; "Did Jeffrey go up? I thought so. He brought his stuff."

One day when several of the leukemic children were hospitalized, Mrs. Turner, who had recently lost her own son, came to visit them and brought gifts. When she came into Mary's room she greeted Mary and Mrs. Costin by name. Mrs. Costin said that she was sorry, but that she did not remember Mrs. Turner's name. At that point Mary

chimed in, "That's Richard's mother. I remember Richard. He died last summer."

In general, though, the leukemic children knew very little about other leukemics beyond their experiences as fellow sufferers. They knew almost nothing about each other's lives outside the hospital or clinic, except through disease-related conversations. A child might know that another had been to Disney World or to the zoo, but also that the child got sick there; or that another child liked to go fishing, but also knew that the child could not go any more.

Knowledge about other children's personal lives was also affected by the parents' relationship to each other. At one point during my study, a great deal of visiting was going on between several leukemic families. The children got to know one another and the siblings of the other children. They spoke relatively little, however, about the knowledge they acquired from these outside contacts, unless it was disease-related.

#### 4. THE DISEASE: TREATMENT, PROCESS, AND PROGNOSIS

Not all the children knew the name of their disease, acute lymphocytic leukemia. Of those who did, very few ever referred to it by name. Not knowing the name of the disease was no barrier to learning as much as any lay adult about it, and its treatment, process, and prognosis.

All the children knew that chemotherapy was the common mode of treatment. "They give you medicines to make you better." The children had a great deal of technical information about the drugs used in treatment—the purposes for which the drugs were given, their side effects, when and how the drugs should be given, their efficacy at various points in the illness, and how long the drugs' effects lasted. The children divided the drugs into two categories according to purpose. One category consisted of the maintenance and induction drugs (e.g., vincristine, methotrexate, and

cytoxan), the drugs used to treat the disease, or in the words of one child, "that made the sick blood go out and good blood grow in." The other major category consisted of antibiotics and pain medications, the drugs used to treat the problems resulting from the disease or in reaction to drug treatment. The children never confused these two categories by ever supposing that the antibiotics helped their leukemia or that the antileukemic agents cured an infection.

ANDY: (*Pointing to red stain on I.V. board*) Do you know what this is?

MYRA: No.

ANDY: Guess.

MYRA: Is it gentomycin? [*an antibiotic*].

ANDY: No. It's not an antibiotic.

MYRA: Is it keffin? [*an antibiotic*].

ANDY: I said it's not an antibiotic.

MYRA: I give up.

LISA: It's for my blood.

MYRA: Is it vincristine?

LISA: No. I had that already. It's daunomycin.

This certainty about the uses of different drugs was true even of children who could not rattle off all their names. They would distinguish blood medicines from pain medicines when asked what a particular drug was for.

The children were well aware of the extremely toxic side effects of many of the drugs and were especially concerned with those that altered their physical appearance. They knew, for example, that prednisone created mood swings and weight gain: "Prednisone makes me eat like a pig and act like a brat"; "It's [*prednisone*] like a tapeworm." They were conscious of the alopecia that resulted from cytoxan.

CHILD: Don't! [*in response to someone stroking his hair*]. I'm getting cytoxan.

CHILD: (*When other children were discussing what they needed for their Halloween costumes*) I needed a wig for Halloween.

O.T.: What were you?

CHILD: No! I was getting cytoxan.

Stomach and mouth ulcers that they got from methotrexate were another frequent topic. Many children also remarked that the drugs themselves sometimes created problems requiring as much treatment as the disease: "There's blood in my pee from the cytoxan and they can't stop it. Maybe the platelets will help." Some even knew that some drugs were so toxic that one could die from the drugs as easily as from the disease: "I'm going to die soon. They are trying to help my blood, but it's [*the medicine*] making my liver bad."

The children realized that before any drug could be administered, a procedure had to be performed to determine the type and the amount of the drug to be given. Before a new antileukemic drug (e.g., induction drug) could be administered, for example, there would have to be a bone marrow. At the end of four weeks, there would be another bone marrow, and in most cases another new drug (e.g., maintenance drug) would be started.

PETER: (*Shaping pieces of clay into balls that resembled pills*) I take ten of these (*pointing to the already finished balls*) each day, but today they are going to change my medicine.

JENNIFER: (*Looking up from the animal she was molding*) They have to do a bone marrow first.

PETER: How do you know?

JENNIFER: You'll see. Then they wait four weeks and give you another bone marrow and another medicine until that one stops working and then they start again.

The children often spoke about what was involved in a bone-marrow aspiration, and were very anxious in the face

of it. It was not uncommon to see children pulling out their hair, running from the clinic (legs riddled with pain), pretending to be in great shape, or to hear children making inappropriate jokes about how bone marrows tickled, and then screaming wildly before, during, and after being injected, on hearing that they were scheduled for a bone marrow. But it was also clear that the procedure itself did not bother them, as the anxiety continued (often to an even greater degree) after the procedure was completed; the children were more anxious about the results. This could only be if the children had some grasp of the significance of the procedures. In fact, the children knew not only the bearing these had on their hospitalization, but also the meaning of the laboratory results. Children would, for example, refuse to go to lunch until they had heard the results of the bone marrow.<sup>4</sup>

NURSE: Does it bother you to have a bone marrow?

TED:<sup>5</sup> No. It's waiting for the results.

NURSE: Does it hurt?

TED: No! All you feel is the press. They make it red and use a needle to take it out. Oh, yeah, they numb it first.

MYRA: What's happening?

SCOTT:<sup>6</sup> Not good.

MYRA: What do you mean not good?

SCOTT: (*Putting head in MYRA's lap*) I have to have a bone marrow. Dr. Wessley said it's not good. I think Mommy's in there crying.

<sup>4</sup> When bone marrows were given in the clinic, the results were not ready until after 1 p.m. The doctors always suggested that patients and their parents go to lunch in the interim, rather than remain in the waiting room.

<sup>5</sup> This eight-year-old boy ran out of the clinic whenever he was told he was going to have a bone marrow.

<sup>6</sup> This five-and-a-half-year-old boy claimed shots and bone marrows "tickled." He cried more after the procedure, while waiting for the results, than before and during it.

The children knew not only that an unexpected bone marrow was not a good sign, but also why it was not a good sign. First, it was an indication of a change in their condition, and changes were not usually for the better. More often than not, it was an indication that the drug they were on was no longer working and a new drug would have to be started. And of course, that drug might not work as well as the one they already failed on: "The yellow medicine was supposed to last two years, but it only lasted seven weeks. Now I have the red medicine, but it won't last as long as the yellow was supposed to." Second, the results usually indicated relapse or the onset of "bad times." It would be four weeks before the doctors could tell if a remission had been attained, at which point a new medicine would be started and with it the hope of a more lasting remission—"a good time."

JEFFREY: What's a relapse?

JENNIFER: That's a bad time. There are good times and bad times. It's usually when the medicines aren't working and your body is sick again.

JEFFREY: Oh, I guess I'm in a bad time still.

JENNIFER: How do you know? Did you get a bone marrow?

JEFFREY: No, I just had one.

JENNIFER: But not this week.

JEFFREY: No.

JENNIFER: Are they going to give you another one?

JEFFREY: No. It's not even three weeks.

JENNIFER: Do you have the same medicine? I mean did they give you the same stuff as last time?

JEFFREY: Yeah. I'm pretty sure.

JENNIFER: Well, that means you haven't gotten a remission yet from what they are giving you. The medicine isn't working yet. So you're still in relapse.

The children knew that the disease was a series of relapses and remissions, of "good times and bad times,"

against a backdrop of bone pain, headaches that did not go away with aspirin, hemorrhaging that never seemed to stop, constant weakness, anemia, and infections that required hospitalization. Just as the treatment of the disease was determined by a bone marrow, the treatment of any of these related sicknesses was determined by special tests and procedures. When they complained of bone pain, they had X-rays as well as bone marrows.<sup>7</sup> When they complained of headaches, they had spinal taps or lumbar punctures.<sup>8</sup> When they were exhausted and pale, they were given blood. When they were infected, they came into the hospital, were placed in reverse isolation, had cultures taken, and were given their antibiotics intravenously. And whether they complained of anything specific or not, when they felt well and when they did not feel well, they were given "CBCs" (blood tests), to assess changes in the disease.

All the children knew that a low platelet count indicated bleeding or the onset of relapse. Many knew that a low hemoglobin was often an indicator of secondary anemia. Many also knew that a high white count or the presence of immature white cells or leukemic cells indicated that the disease was going out of control. There was, however, only one child who could recognize all of these blood factors under a microscope.

The CBC was necessary not only for establishing the status of the disease, but also for determining the course of treatment. For example, transfusions were indicated for low platelet counts as well as for secondary anemia. The children knew, however, that there were two different types of transfusions, platelet and whole blood; which one was used depended on a variety of factors determined through exam-

<sup>7</sup> The X-rays were used to identify possible disease infiltrate to the bone or to palliate pain.

<sup>8</sup> Through these tests the doctor could discern whether or not there was leukemic infiltrate to the brain (referred to as C.N.S. involvement). If there was, the child received skull irradiation and/or a course of intrathecal methotrexate (an antileukemic drug injected in the spine).

ination of the CBC. Platelet transfusions were indicated when the platelet count was low. "They are going to give me platelets today to try to stop the bleeding." Whole blood transfusions were given for secondary anemia, indicated by a low hemoglobin: "I got blood for my anemia part." Even when a blood transfusion was for both anemia and the hemorrhaging that resulted from low platelets, the children distinguished one purpose from another. A five-year-old Spanish-American child put a hand puppet up to the I.V. tube, which had the blood flowing through it.

MARIA: (*Makes drinking sound for puppet*).

MYRA: Is he going to drink the blood?

MARIA: Oh, damn blood. I cannot drink the blood.<sup>9</sup>

MYRA: You cannot drink it?

MARIA: No. (*Pause*) I want to eat this (*points to potato chip*).

MYRA: You want to eat this? (*Holds potato chip up to puppet's mouth.*)

MARIA: Mmm. Mmm. (*Puppet and child shake head no*) I want the other blood.

MYRA: Which?

MARIA: The one that's over there. (*Points to the blood in the bag, as opposed to blood in mouth.*)

MYRA: This one?

MARIA: Yeah. (*Puts cookie in the puppet's mouth.*) A blood cookie. I want a blood cookie.

MYRA: The puppet wants a blood cookie.

MARIA: Yeah. He's not bleeding no more.

MYRA: All better.

MARIA: No, he tired. Needs more cookie.

MYRA: Here.

<sup>9</sup> The child identifies herself with the puppet, and speaks through the puppet. In the first part of the conversation she reiterates the doctor's instruction not to swallow the blood clots that formed in her mouth as a result of the low platelet count. In the second part of the conversation she shows her awareness of the need for blood transfusions for relief of the "tired feeling" that results from the anemia.

The transfusions, like the bone marrows, created anxiety unrelated to the pain of the procedure.<sup>10</sup> The children often worried about getting allergic reactions to transfusions, because then the blood would have to be stopped, and they felt that they needed it fast. For example, when a character was dying on TV, a few children suggested giving him a transfusion; "It made me well." Many felt that getting new blood was the key to making them better, and that since transfused blood was new, it should make them better. After all, they invariably felt better and people told them that they looked better after a transfusion.

Not only did the drugs and the disease impede platelet function and production, they also hampered immuno function. The children were often immuno-suppressed and, as a result, easy targets for infection. They talked about how easily they became infected and what they had to go through to be treated. In most cases, they had to be hospitalized, placed in reverse isolation, and cultured, before treatment could even begin.

JEFFREY: They took cultures today from my I.V.

NURSE: Do you know what a culture is?

JEFFREY: Yeah. Germs grow on it and then they give you antibiotics to fight the germs.

NURSE: Do they culture other things?

JEFFREY: Yeah. My throat. They tried to culture my stink, but I didn't let them do it.

Once treatment had been started, however, they still were not free to leave, even if the leukemia was under control or their blood had improved. Going home hinged on the infection being cured: "I cover my finger or I'll get an infection, then a fever and then an I.V. and then I don't go home."

CHILD: I'll be getting out in a while.

MYRA: That's good.

<sup>10</sup> Transfusions are relatively painless.

CHILD: If everything goes well I mean. (Pause.) If my things keep and I don't get a temperature. I mean if the medicine works. It's fighting the infection so it helps if I don't have a temperature. It stayed and it's staying down, that's good.

The series of relapses and remissions, of good times and bad times, of periods at home and periods in the hospital for transfusions, infections, and hemorrhaging, did come to an end—in death. All of the leukemics that I studied knew their prognosis. All knew that they were dying before death was imminent. They did not, however, all express their awareness in the same way. Some children said directly, "I am going to die," or "I'm going to die soon. They are trying to help my blood, but it's (the medications) making my liver bad." Other children were less direct. They talked about never going back to school, of not being around for someone's birthday, or of burying dolls that they said looked the way they used to look. All of these forms of expression are indications that the children knew they were dying.

The leukemic children acquired a great deal of information about the hospital, staff, rules and procedures; about the disease, its treatment, process and prognosis, before they died. The fact that they managed to acquire so much information was even more remarkable because they learned in a situation in which the parents and the staff unconsciously conspired to keep them in painless ignorance. In the next chapter, I explain how the children managed to acquire various kinds of information, the differences in children's knowledge, and the effects particular kinds of information had on self-concept and behavior.