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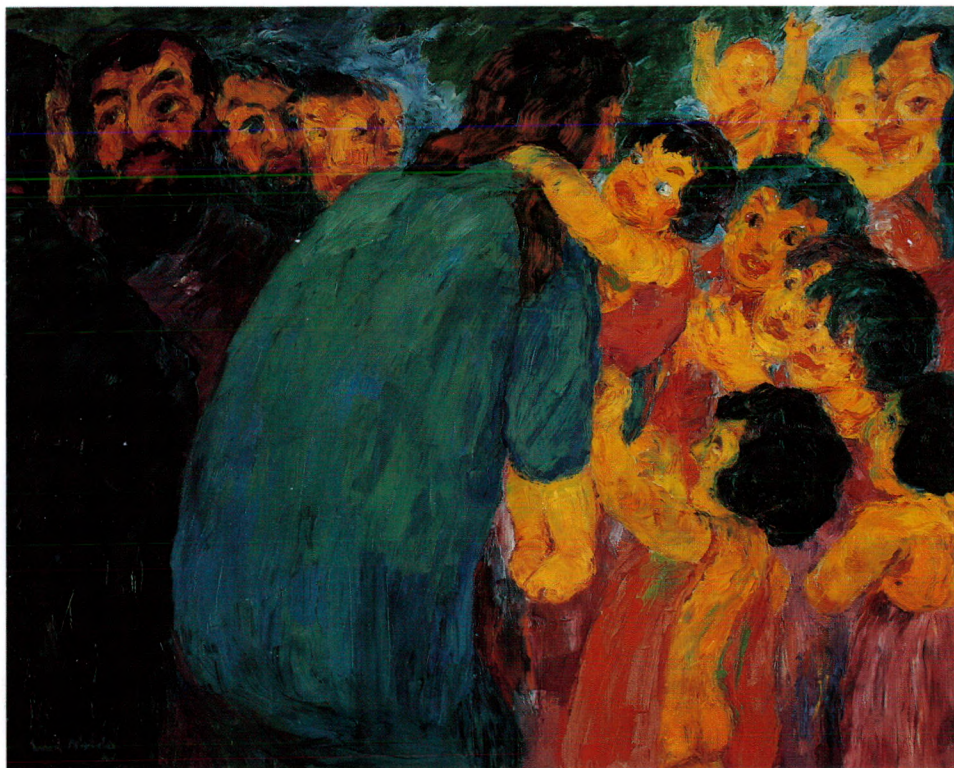
Second opinion: Health, Faith, and Ethics, 1993, V18 N4, April

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S E C O N D O P I N I O N

HEALTH • FAITH • ETHICS



FOCUS ON CHILDREN: Mister Rogers • Illness and Play • The Dying Child • Robert Coles Interview

A publication of the Park Ridge Center for the Study of Health, Faith, and Ethics

COVER

Christ among the Children. Oil on canvas by Emil Nolde (Emil Hansen), 1910.

The Museum of Modern Art, New York. Gift of Dr. W. R. Valentiner.

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S E C O N D
O P I N I O N

HEALTH • FAITH • ETHICS



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The Park Ridge Center exists to explore the relationships among health, faith, and ethics. In its programs of research, publishing, and education, the Center gives special attention to the bearing of religious beliefs on questions that confront people as they search for health and encounter illness. It also seeks to contribute to ethical reflection on a wide range of health-related issues. In this work the Center collaborates with representatives from diverse cultures, religious communities, health care fields, and academic disciplines and disseminates its findings to professionals and others interested in health, religion, and ethics.

Second Opinion, as its name implies, recognizes that the complexities of modern health care make it increasingly difficult to find the single “correct” action, thought, or method. Each situation is open to a variety of apparently legitimate and appropriate interpretations and applications. But such confrontations with ambiguity need not lead to discouragement. They can instead elicit greater research, discussion, and thought.

By inviting contributions from a wide range of perspectives, *Second Opinion* stimulates interdisciplinary conversations between members of fields relating to health, faith, and ethics. While other publications deal with one or two of these concerns, *Second Opinion* distinctively seeks to address all three. The Park Ridge Center created this publication in the hope that it will help form one public out of a number of related constituencies. This public will not only wish to relate ethics and faith to health issues, but should also, through lively and enlightened interchange, be better equipped to do so.



SECOND OPINION

Volume 18, number 4* • April 1993

A publication of The Park Ridge Center for the Study of Health, Faith, and Ethics

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All inquiries, including editorial correspondence, research suggestions, manuscripts, subscription orders, and requests for information should be sent to the Park Ridge Center, 211 E. Ontario, Suite 800, Chicago, Illinois 60611.

* *The first 16 volumes consisted of one issue each and were published every four months beginning in March 1986.*

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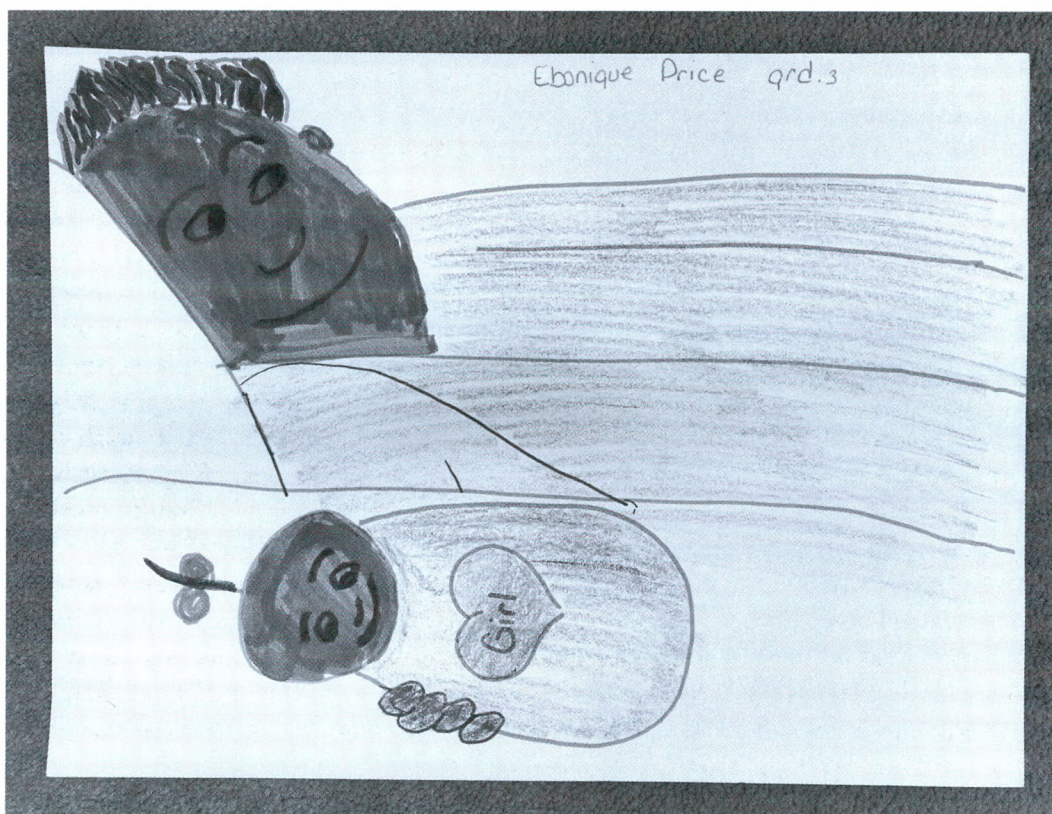
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Girl.

Drawing by Ebonique Price (third grade), Kilmer School, Trenton, New Jersey.

INITIAL COMMENT

On Their Own Terms

NO HINT OF CONDESCENSION TO CHILDHOOD and the world of children marks the writings in this, our "children's issue." All the authors show themselves to be curious about the young—and puzzled, bemused, and even awestruck by them as they cope with illness and suffering or gather resources to enjoy well-being. The children inspire a sense of wonder; they are anything but passive objects of scholarly expertise, technical mastery, adult pedantry.

Instead, the children are taken seriously on their own terms; therefore, they do some imparting. One of my teachers dedicated a book to his sons, attaching an epigraph by an author he did not identify but whose words I can easily call to memory. Of children: "Like Genius, simple; that is why they are the great teachers."

Having resolved to listen to children, we invited students at four elementary schools in the Trenton Public School System, Trenton, New Jersey, to contribute artwork to this issue. A number of their drawings enliven these pages, communicating directly something of the experience of health and illness from the children's point of view. (The *Second Opinion* staff would especially like to thank Carol Belt, art specialist for the Trenton Board of Education, and the art teachers at the four schools: Larry Brown, Kilmer School; Julia Kohut, Gregory School; Maryann Papero, Washington School; and Tracy Ross, Stokes School.) We also include pieces written by

two sisters, Rebecca and Colleen Heatherington, whose lives were changed when Rebecca was diagnosed with cancer.

Having resolved also to listen most attentively to those who give care to children, we took pains to approach a rather broadly defined set of professionals—almost all of whom push the boundaries of a particular discipline in order to hear and to reach children. Samples:

Fred Rogers, of television's "Mister Rogers' Neighborhood," has a rapport with children that many adults envy. Here Rogers draws on several encounters with sick children to remind us of the gift we give to children when we "can recall the full range of feelings" of our own childhood. Observing him observing a dying child who used silence in order to be in control of *something* helps us understand the qualities that have given Rogers the authority to speak about children's issues.

Chaplain Don Camp also gives care in the face of suffering and death and learns from a child who "knows how to maintain power in a world of chaos." Camp's account testifies strongly and eloquently to the power of imaginative play, while gently illustrating the virtues of listening with receptivity and simply "spending time with" a child.

Care for children requires sober attention to the traumas of suffering and the demands of ethics, which authors Loretta Kopelman and William Bartholome manifestly give. Philosopher

Kopelman draws our attention to the issue of neonatal suffering and looks at some under-explored consequences of the 1985 "Baby Doe" regulations. Her article provides welcome—and thought-provoking—clarification.

Pediatrician Bartholome spends more time than most of us could endure in the wards of dying children. Thus he speaks convincingly of the problems faced by these children's parents and caregivers and by the children themselves, and he recommends our faithful attention to the *children's* reality. Such attention, he believes, will equip us to treat dying children with the respect they deserve.

We could not envision a "children's issue" without consulting Robert Coles, the Harvard psychiatrist and teacher who has spent decades listening to children and interpreting their worlds. What is lacking in many interviews with Coles is an approach to the world he brings to his conversation and writing. We tried to see "where he comes from" before he goes to children with tape recorder and notebook in hand.

A sheltered and naive 18-year-old may be at the borderline between childhood and womanhood, but she qualifies for a place in this issue of *Second Opinion* because she is young, acted upon, controlled, and underestimated by adults. Religious, medical, and ethical issues get tangled in the case of an Israeli girl brought to the U.S. for the treatment of vaginal cancer that has

rendered her sterile. Pediatrician John Lantos describes the actual case; Rabbi Stacy Offner and religion scholar Tod Chambers look at religious and cultural resources that honor the emerging independence of an older teenager while acknowledging her continuing need for familial and social support.

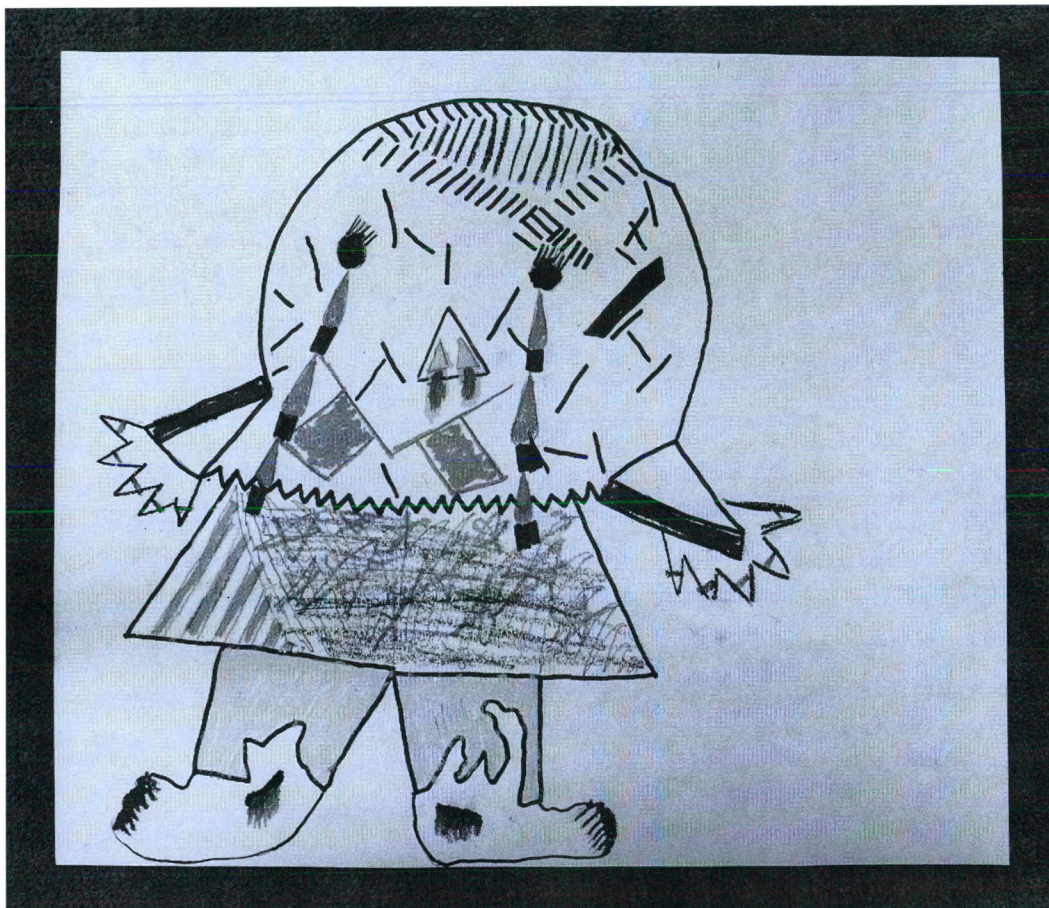
In this issue's "Reflection," another child on the verge of adulthood—a 17-year-old Vietnamese girl with a severely cleft lip—leads plastic surgeon Richard Matern to ponder where real value and real beauty lie. Impressed by her empathy for others' suffering, he concludes that "the real defect lies far less on another's face than within us."

A different kind of suffering and healing occupies Nancy Barcus, who teaches violin and writing in a public elementary school. Concerned about "urban and minority children with lost potential," she has undertaken to teach the fine arts to "those who, for many reasons, have not yet learned to dream."

The young people portrayed in these essays have found ways of embodying and expressing their issues compellingly. And now each parental and professional generation faces the task of responding.



Martin E. Marty



Drawing by Islah Din-Nurid (third grade), Gregory School, Trenton, New Jersey.



Be Strong in the Operation Room!

Drawing by Jenna Kettenburg (sixth grade), Kilmer School, Trenton, New Jersey.

Communicating with Children

One Neighbor's View

Fred M. Rogers

A FEW YEARS AGO I HAD THE GOOD FORTUNE to get to know Bob Sams, a teenager who had recently had his second liver transplant at Children's Hospital in Pittsburgh. I met Bob as we were interviewing patients in preparation for the annual hospital television fund drive, and we soon became friends. I also came to know his mother and father, his sisters and grandmother, and some of his school friends. In the months ahead, as I came to know Bob and the people who were close to him, I also learned more about myself and about some of the difficult challenges we face when we work with children who have terrifying health problems.

When Bob's second liver transplant failed, he (along with his doctors) chose to go through a third transplant; although that third new liver functioned very well, Bob's lungs and heart started to give him difficulty. Little by little, he was attached to more and more machines, via more and more tubes. Things he once could do were no longer possible for him.

Fred M. Rogers is the creator, writer, and host of the television program "Mister Rogers' Neighborhood."

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One day when I went to visit him, Bob didn't say a word. His mother told me that he had stopped talking to everybody. It was obvious that he understood everything we were saying, but he just wasn't answering. At first this was confusing for us, and then it started to make us feel bad. Here was somebody we once had had good, long talks with, and now he just wouldn't speak to us. I wondered if Bob was just shutting us out, "pushing away," getting ready to die. But somehow it didn't feel that way to me. Bob would actually smile as I talked to him. It seemed he was taking some kind of pleasure in not talking.

Finally, it dawned on me what must be happening. Right then, talking or not talking was about the only thing Bob could control. Everything else in his life was being controlled by doctors, nurses, and machines. It was a good feeling for him to be in control of something. Before he died, Bob did talk again. In fact, he looked at me, smiled, and said, "Hello, Mr. Rogers." I think he knew how much he had helped me grow through all of our visits. I certainly had told him so many times.

One day, not long after Bob had died, I was writing a new song for the television program, "Mister Rogers' Neighborhood," about the impor-

tance of finding something to do while we're waiting, and all of a sudden as I sat there at the piano, the tears started streaming down my face. I realized I was grieving the loss of Bob and all the other losses in my life which his death had evoked in me. That time reconfirmed how important our lives together had been.

The Roots of Our Wanting to Work with Children

WHY DO WE CHOOSE TO WORK WITH young people? What is it about us that allows us to make an investment of ourselves in children? I believe that adults' successful work with children is based on our having been children ourselves and having felt strongly enough about those early years that we came to believe that childhood was a time of real value. If we were loved and valued in our own childhood, we then have the opportunity to love and value the childhoods of others. Having identified with the adults who we sensed were the sources of our gratification, we choose professions that allow us now to be the adult in the adult-child mutuality.

Those of us who have chosen to work with children need children to confirm our identities. A teacher needs someone to teach in order to be a teacher. A nurse needs someone to nurse in order to be a real nurse. We who work for children need children in order for us to be who we are. Any threat to the lives of the children we work with is therefore a threat to our own identity—even the threat of children saying they're mad at us or that they never want to see us again! When children communicate to us that we're not the giving, gratifying one, it can hurt.

But why would children be uncooperative and noncommunicative? As with Bob, such behavior may be their only way of being in control of something. One thing is certain: there's a reason for every behavior.

I know of a six-year-old girl who was hospitalized for rheumatic fever. The medical team was very worried about her because she was so listless and wouldn't eat. She would simply lie in the crib and shift from one helpless position to another.

One day a family friend suggested that they make a nurse's outfit for little Janie to put on. *That* turned out to be one of the greatest helps of all. When Janie was given the nurse's outfit, she wore it every day, sitting upright in her bed. Somehow in that dress she didn't feel so helpless anymore. In fact, she became quite aggressive, giving orders to all who came near. To be sure, Janie was much more difficult to deal with in that nurse's uniform, but she had a much better chance of getting well. Somehow, playing the part of the authority allowed her to feel less the part of the victim.

The aggression of the sick child often has little chance for expression except within himself or herself. That "inside war," of course, is destructive to the child's bodily welfare, whereas, *in play*, it's usually acceptable to children and adults for aggression and anger to be expressed.

The Importance of Play

THROUGH PLAY, PEOPLE HAVE MANY WAYS TO communicate their angry feelings, and hospitalized children have many angry feelings that need to be expressed! Hospitalized children don't understand all the clinical procedures and why they have to go through so much pain and frustration. *They really don't*. Even though people tell them a hundred times that the hurtful treatments are going to help them get better, they're still angry about what's happening, and one of their desperate needs is to have a socially acceptable way of communicating and expressing their anger.

What's more, hospitalized children don't always understand why their parents have to leave them. Oh, they know somebody has to go to work and somebody has to take care of the other children at home, but why does it have to be their mom and

dad? And they don't understand why their hair has to fall out and why they can't be at home with their familiar, comfortable people and things. Being in the best hospital in the world is still second-best to being well.

Through play, children can use puppets or doll figures or art materials to express their feelings of anger and sadness at what hurts and who hurts; and they can do it without risking the loss of love, which just might be the result of screaming and kicking and tossing dinner trays on the floor or slapping nurses and technicians.

But for a child to be able to use imaginative play, he or she needs the encouragement and support of another person who accepts the play in a non-judgmental way, someone who helps the child generate enough energy to continue to play. The child needs an available person who knows how very important his or her play can be. The presence of this "available other" is even more important to sick children than it is to other children because so much that happens to the sick child—and particularly the hospitalized child—tends to foster regression. The child's play permits the expression of the regression, but the adult who is available to the child and in tune with him or her can help the child's regression or anger not go so far that it makes him or her feel completely helpless.

Some of the most important work we do for children through our television program is to deal with recognizing and expressing anger. The song "I'm Angry" says a lot in a few lines.

I'm Angry

I'm angry; I'm angry
And I can tell you why.
The reason I am angry
Is that somebody made me feel very small.
And all of a sudden I cried.
I almost lied and said I wasn't scared.
But I *was* scared
And now I'm angry.
I'm angry.

© Fred M. Rogers

There's another song I like to use about anger. In fact, the first words of this song are a question: "What do you do with the mad that you feel when you feel so mad you could bite?" And that question came directly from a child.

What Do You Do?

What do you do with the mad that you feel
When you feel so mad you could bite?
When the whole wide world seems oh, so wrong,
And nothing you do seems very right?
What do you do? Do you punch a bag?
Do you pound some clay or some dough?
Do you round up friends for a game of tag?
Or see how fast you go?

It's great to be able to stop
When you've planned a thing that's wrong.
And be able to do something else instead
And think this song:

I can stop when I want to.
Can stop when I wish.
Can stop, stop, stop anytime.
And what a good feeling to feel like this.
And know that the feeling is really mine.
Know that there's something deep inside
That helps us become what we can.
For a girl can be someday a woman
And a boy can be someday a man.

© Fred M. Rogers

One of the worst feelings is the feeling of being out of control, and one of the most helpful things we can do for children is to discover ways of encouraging them to find their own means of control.

I knew of a four-year-old boy who had a little record player in his hospital room. All day long he changed the records on that player: taking one off, putting another on, listening to it play, then taking the record off and putting another on. With his physical limitations, that was about all he could do. But he was in control of those records, and it was very important for those around him to encourage him to keep his active coping (his play energies) up as much as possible. When we look for it, we can usually find something a child can do to prove to the

world and self that he or she has some control and some way of expressing how he or she feels. We can't stress the fact enough: *Play is essential in helping children deal with their feelings of helplessness*. One thing caring adults in any profession can do is try to understand the *meaning* of children's play in order to respond in the most helpful ways.

Some Common Fantasies and Fears

WHAT MAKES A CHILD UNCOOPERATIVE, aggressive, unreasonable? I know of a little girl who doesn't want anyone to touch her and doesn't want to touch anybody herself. When people come near her, she flings her hands behind her back and refuses to "be in touch." Why? Well, from the time this child was an infant, she had had one series of tests after another: many frightening things, all of which had necessitated her hands being strapped down. Could that be one reason she doesn't want to let anybody touch her and doesn't want to touch anybody herself?

Another little girl I know of used to take the white caps from the colored marking pens and put them in her hair. She was insistent on doing this, even though her parents and nurses tried to save the markers from drying out. Finally, someone realized that this child, in her persistence, was trying to communicate something very important: She was very concerned about the electrodes used on her head in the EEG tests. The marker tops were the closest things to those electrodes that she could find to play with. Careful listening to her play revealed her fearfulness that every time the doctors gave her an EEG, either they were finding out what she was thinking, or they were going to electrocute her.

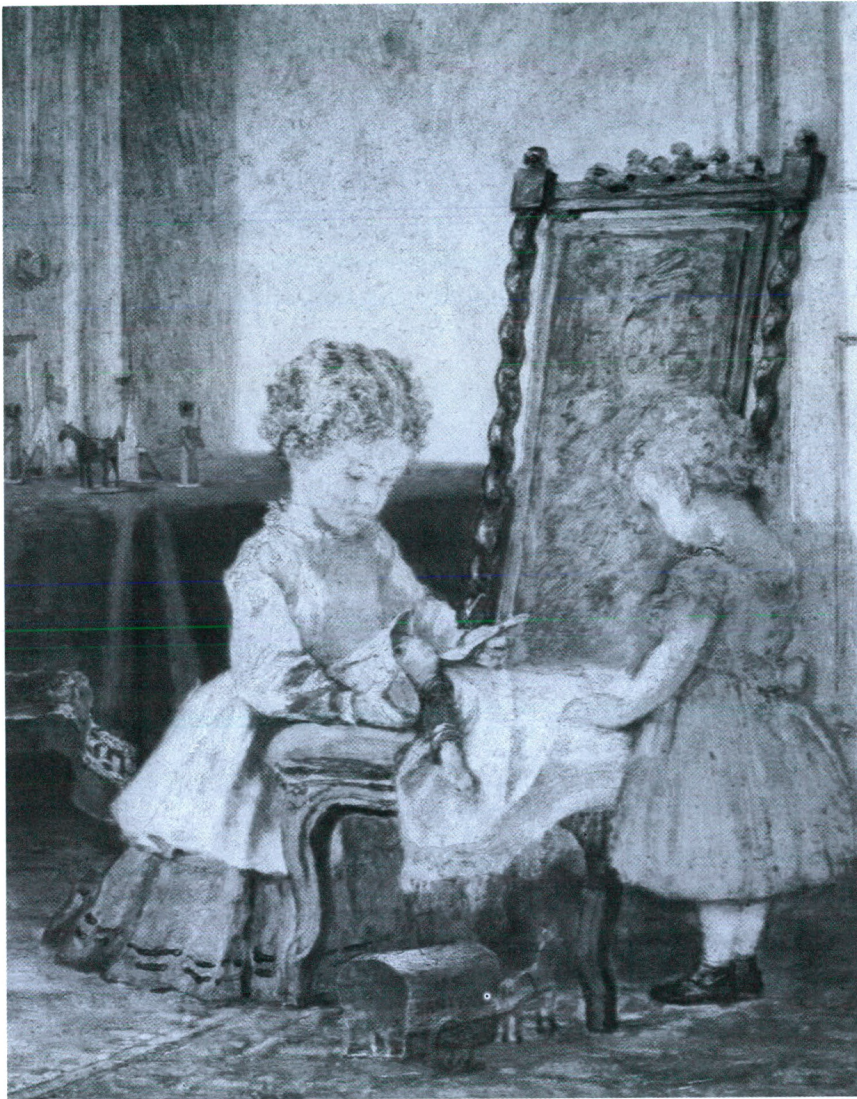
"Playing about" fears, concerns, problems, and even joys and sorrows is to a child very like an adult's "thinking through" a situation. Playing is a child's means of problem solving. But if a sensitive, caring person (an "available other") had not pursued that

little girl's behavior with the colored marker caps, she might have gone through the rest of her life believing (at some level) that machines *can* read people's minds and that when they determine that a person is bad enough, they annihilate them.

Children's fantasies about what might happen to them are often much more frightening than what the reality is. One day we were filming in the emergency department of a hospital. A five-year-old boy saw me and immediately told me that he was smart. (He was right: he was smart!) He told me that his friend was smart, too, but his friend had fallen down and cut his head, and nearly all his brains had come out. He said he wouldn't have been smart anymore if they had all come out. That's what a cut on the head can mean to a five-year-old.

It's natural, too, that children are going to project many of their feelings about their mothers and fathers onto hospital personnel. For instance, whenever doctors and nurses confer in a child's presence, the female professional is often perceived by the child as a mother (no matter what the woman's age is), and the male professional is perceived as a father. Some young, kindly male doctor may experience terribly unreasonable behavior from a four- or five-year-old boy who is fearful of his father and may be projecting his deepest fears onto that often unsuspecting doctor. That's one reason a child might be disruptive and uncooperative. He's afraid. And besides, he probably has a lot of angry wishes. Yet most children who are ill, as well as most of their parents, are *afraid* of their angry wishes. They're afraid that any anger in themselves and in any others around them might end up in death.

I've seen many children dramatize angry scenes with puppets and other miniature figures. One little girl made up a fantasy about wild animals in cages. She said no one could ever open the cages. "You just can't trust those wild animals with unlocked doors," she said. Little by little, as that child came to master her own angry wishes, she became more and more benevolent toward those play animals. One day she said, "I don't have to have the cages locked today because the animals aren't going to destroy people."



Playing Field Hospital. Oil on panel by William Morris Hunt, 1865.

She took some doll figures and put them up close to the animals with their open cages and said to the dolls, "You see, they didn't hurt you." What a wonderful thing it is to see children dealing with their inner struggles in their own creative ways!

I remember some impromptu puppet play that took place in California one day when we were filming in the home of an eight-year-old boy named Erik. Erik had cancer. He and his five-year-old brother, Brett, and two of their neighbors asked if they could play with the puppets that I use on television. I was glad I had them with me because those boys were able to act out some things that they were feeling. Here's what happened in that playtime:

Both Erik and Brett wanted to play with Daniel Tiger. Erik got him first. I asked "Daniel" how he was feeling. "Scared," Erik replied in Daniel's shy little voice.

"Can you tell me why you're scared?" I asked.

"I don't like all the noise," Daniel replied.

At this point Brett became determined to get the puppet Daniel to play with, and he asked me to take King Friday and command Erik, in King Friday's gruff voice, to give him Daniel. I suggested that he could make the king talk if he felt like it, and Brett did.

"Erik," said Brett as the king, "I want you to give me Daniel, okay?" But Erik still wouldn't yield, and Brett threw the king on the floor with a disgusted "Oh, rats!"

Putting the king on my hand, I said in a kingly voice, "Sometimes there are disappointments in my castle."

"And sometimes," said Brett, pointing to Daniel, who was still on Erik's hand, "I want *him*."

"Sometimes you want Daniel Tiger?" the king asked. "Can you tell me why?"

Quite agitated, Brett complained about Erik (his sick brother). "He gets control of every darned thing! Every darned time we play he gets it [meaning Daniel]! So I think it's fair for me to have it one time!"

"What shall we do about that, Erik?" asked the king.

"Well," Erik said after a pause, "I think it's really up to Daniel."

So the king turned to Daniel. "Daniel," he said, "Brett is anxious to have you with him for a moment. Do you think you could pass over to him?"

Erik, speaking in Daniel Tiger's little voice, said, "Yes, I think so."

"You think you could?"

"Yes."

"Do you think he'd take good care of you?"

"Yes, I think so."

"Do you think you could go back to Erik another time?"

"Yes."

"Well," said the king, "you do what you like."

So the puppet Daniel finally went to Brett for a time, and Brett took him behind a chair and talked to him about how hard it is when you're shy and you have to meet new people. Brett made Daniel firmly agree.

Meanwhile, Erik had become the king. He commanded Lady Elaine, another puppet who was on the hand of one of the friends, to appear before him. When she obediently did, he commanded her to stop doing magic with her magic boomerang.

"Why don't you like magic?" I asked the king (who was still on Erik's hand).

"She buckles up the whole place," the king (Erik) replied. "*I just want this to be an ordinary neighborhood!*"

I IMAGINE ERIK DID WANT TO LIVE in an ordinary neighborhood and live an ordinary life without periodic traumatic bouts with cancer. And his brother Brett had strong feelings, too, about himself and his sick brother and people who were intrusive in their world.

Those boys were telling us things through their play: how deep the feelings of loss are for people who have cancer, and how sad and angry brothers can get—even brothers who aren't ill. Grown-ups are often puzzled by children's play because we don't fully understand. But a child needs the freedom to play what we don't always understand and the support of caring adults who know that the play has great value for the child. In fact, the longer I live, the more I realize that one thing the whole world needs lots more of are adults who know how valuable childhood and children's play really are. The quality

of them form the foundation of all adult behavior.

I've always been interested to see how children use play materials that adults nearby feel comfortable with. That play would have been very different if I—or any other adult around—had communicated a disdain for boys using puppets. As it was, those boys were able to sense my interest—in fact, my great interest—in what they were sharing of themselves. And because it was the puppets who were talking, the children were allowed to express what they experienced and knew at both a verbal and preverbal level. It's most often easier for a puppet on your hand to say something, rather than your own mouth! Play allows us that safe distance, as we work on what's close to our hearts.

Whether we're children or adults, wherever those safe places are in our lives, they can also help fortify us when we need to talk openly and directly about deep (and often painful) feelings. We of Family Communications, Inc.—the nonprofit corporation that produces "Mister Rogers' Neighborhood"—taped a very poignant conversation with the Renlund family for our series of programs for families called "Old Friends . . . New Friends." The Renlunds told me I was welcome to offer our conversation to others. In fact, they said they hoped it would be helpful.

Fred Rogers: Would you boys tell me what you'd like to be when you're older?

Erik: Well, I may be three things. I don't know. One, an inventor; two, a paleontologist; and three, an archaeologist.

Fred Rogers: You'd like to do all those things?

Brett: Oh, and don't forget one more.

Fred Rogers: What?

Brett: Be a doctor.

Fred Rogers: You'd like to be a doctor. What would you do as a doctor?

Brett: I would fix people. That's what I would do. Why not? Give them shots.

Erik: For what diseases?

Brett: Leukemia, cancer, cancer of the bone.

Erik: That's all cancer, Brett. They all qualify as cancer.

Brett: Oh, then strokes, a whole bunch of things.

Fred Rogers: You'd like to help a whole lot of people, wouldn't you?

Brett: Uh-huh . . . I would help myself, even.

Fred Rogers: There must have been some times that were hard for you, Erik.

Erik: Uh-huh.

Fred Rogers: Did you have any trouble at school?

Erik: Yes. But I don't have it now.

Fred Rogers: What kinds of trouble?

Erik: Well, the kids would knock my hat off, or tease me. Maybe they're afraid they might catch what I've got so they really don't know how to react towards me.

Brett: That isn't true! Your thing isn't in contagious [*sic*]. Nobody could catch that!

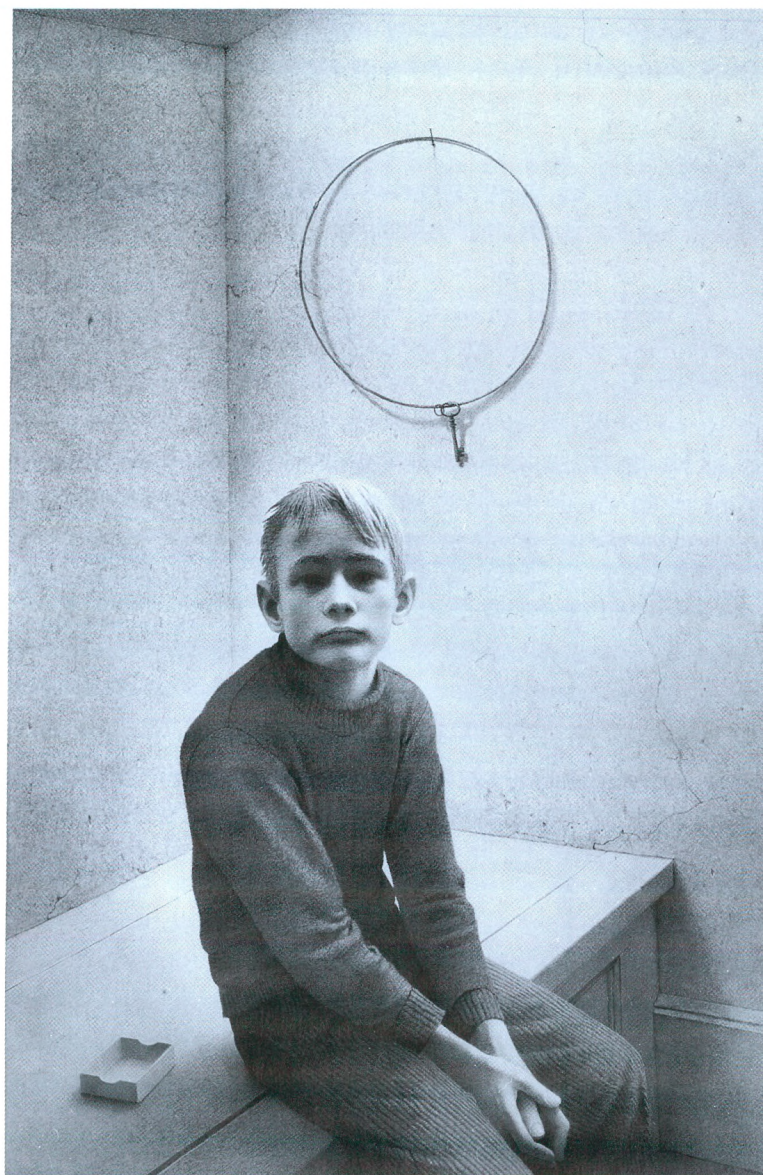
Mrs. Renlund: But you know that.

Brett: Yeah, I know.

Erik: And they don't.

Fred Rogers: Kay, what's been the most difficult for you as far as Erik's illness is concerned?

Mrs. Renlund: Well, I find it very difficult to accept. We've been at this for six-and-a-half years, and at first Erik told me he had a lot of anger. "Why me?" We talked a lot about that. I told him I felt the same way. There was an awful lot of anger on my part. "Why my child?" I don't know if you ever totally accept that. I think it certainly has made me think a lot about our values in life. We've really learned a lot about sharing love.



Corner Seat. Egg tempera on panel by Robert Vickrey, c. 1950.

Robert Vickrey/VAGA, New York 1993.

Erik: And I hope you keep sharing it.

Mrs. Renlund: I think it's also made me understand a lot more about people who have pain or sorrow or sadness. I have a real feeling for that now.

Mr. Renlund: That's exactly it. I remember the neighbors who left casseroles on our doorstep. You don't feel like cooking, you don't feel like cleaning house, you don't feel like doing anything . . .

Mrs. Renlund: So I think that kind of help is really important.

Mr. Renlund: It certainly helped. I had a relatively narrow emotional band to start with. It certainly stretched my band way from one side to the other, having to deal with a situation like this and to communicate. It is rewarding from that standpoint. I mean if there's a reward, there's reward in dealing with the situation and trying to cope.

Fred Rogers: What were some hard questions that Erik has asked you?

Mrs. Renlund: I think mainly about the possibility of dying.

Fred Rogers: When Erik talks with you about death, what do you say?

Mrs. Renlund: When he told me that he was afraid of it, I told him I was, too. But that we all are going to face it, that it's an experience for all of us, and that I don't think we'll ever be alone. Whether here or afterwards, I don't think we'll ever be alone.

Fred Rogers: We'll all have caring people with us, wherever we are. And I think that that must be the toughest thing . . . to think about not being together.

Our visit continued in a very special spirit, and after I left that day, the Renlunds and I kept in touch by letter and phone.

A few months after our visit, Erik died. I remember how sad people at our office were the day the parents called to tell us. We had formed bonds with that little boy and his family, and we had allowed them to change our lives.

I can well understand why some people would be afraid to allow themselves to become attached to a child who has a life-threatening illness. They might be afraid that their eventual loss would overwhelm them. Those are decisions that only we ourselves can make; and our honesty in dealing with such decisions can be a great help for those with whom we work and live. Although such grief at times can seem overwhelming and very scary, that grief need not destroy. In fact, working with children who have life-threatening illnesses can help us develop strengths we never knew we had. Personally, I'm a different man—a stronger man—for having known Bob Sams and Janie and Erik Renlund and all the other critically ill children who have welcomed me into their lives.

Erik's parents have founded a center for people who wish to talk with others about their children who are ill. That center is in memory of Erik and in honor of the difference his 10 years made in the lives of his family and friends. There are many different ways of expressing what's deepest within us, and this was Erik's parents' way.

Those of you who work with children have your own ways of expressing your care, but I hope you can trust all the many strengths you bring to children and their families. Perhaps the most important strength is that you were once a child who felt vulnerable and powerless, angry and afraid. That may seem obvious, but knowing that and remembering what it was like being a child can make a significant difference in the relationship between you and the children in your care. Some children are fortunate to be treated by adults who can recall the full range of feelings of their own childhood. Those are the people who are best able to engage the children they work with in a partnership for health which will serve them all their days. ☸

Many Losses



Our daughter, Rebecca Heatherington, was born on October 2, 1978. Her first battle with cancer (rhabdomyosarcoma) began in 1981 when she was 30 months old. After surgery, radiation, and two years of chemotherapy, we had just celebrated the “five-year disease-free mark” in 1986 when she was faced with her second diagnosis (osteosarcoma). This required the amputation of her right leg, hip, and half of her pelvis, as well as another arduous year of chemotherapy. She was not quite eight years old. Our family was in the middle of moving from New York to Chicago at that time, and Rebecca was very concerned about making new friends and adjusting to a new school just four weeks after her surgery, with only one leg and no hair (again). The paragraph included here is something she wrote in the spring of 1988, after a ski trip to Winter Park, Colorado. That trip was sponsored by a cancer support group called Special Friends, associated with Sunshine Kids.

Rebecca *did* make friends, and she learned to do almost everything. She swam, skied, rode a 10-speed, roller-skated with her prosthesis, took gymnastics lessons, played the violin, and had a lead in her sixth-grade play. She loved animals, parties, small children, junior high, and daiquiri ice from Baskin Robbins. But in the early spring of 1990, cancer returned a third time, and this time no treatment proved effective. She died at home on May 5, 1990, surrounded by her family and friends who loved her so much.

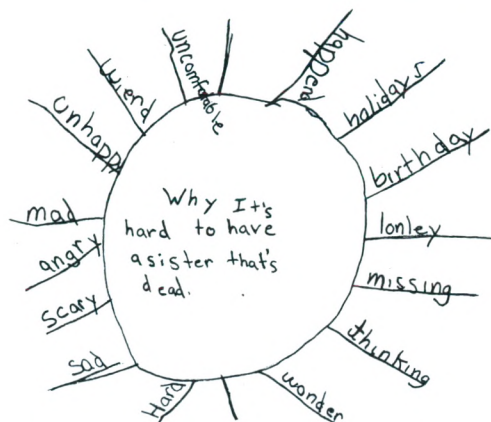
Our younger daughter, Colleen, was six years old and finishing first grade when Rebecca died. For over a year she was unable even to speak her sister's name. Then she became involved in Heartlight, a bereavement group for children who have lost siblings, and gradually she began to acknowledge her grief. In February 1992, 21 months after Rebecca died, Colleen wrote an essay for her third-grade teacher in which she expressed her feelings about how hard it is to live without her sister.

—Christine Heatherington

When I first found out I would have to have my leg taken off I thought that I would have no friends. I was moving to IL, and I thought people would think I was weird and hate me. My worst thought was that I wouldn't be able to do anything. Some examples are like riding, roller skating etc... When I got to the Special Friends I found out that tons of people would still be my friend. The best thing was that I found out how important friends were, just sitting around the fire and talking makes you feel so good. It made me feel ~~you didn't want~~ so special I can't explain it. I know other kids feel the same way. Special friends is very important to me.

Rebecca Heatherington

Colleen Heatherington



Why It's hard to have a sister that's dead

I think it's difficult cause I miss her alot. We would always play together. She would do things that I wanted, even when she didn't really want to. I will always remember when she bought me "yellow baby". I wish she was still alive.

.... Sometimes I wonder why it had to had to happen to me. Holidays are always hard. And I think that it always will be. But I'll always remember her smile. And how hard she fought for her life.

.... When I was younger she would never let me stay with her & her friends. But when I was 3 or 4, she would let me sleep in her room when I had a bad dream. I didn't think it was fair that she had a big room. I was always stuck in a Punie lion's cage. (There weren't any lions.) I miss her big smile. She was almost always happy. Even in chemotherapy.

.... She went to a group called Sunshine Kids. And the name was true. All the kids always had sunshine big smiles. Ear to ear. 😊 They went Skiing alot.

.... If she was alive I could play games & trade thigs with her. When she babysat me in a wheel-chair, I would stand on the arm and get ice cream for us. I had lots of fun with her. If I had my way, she'd still be alive.



Visit to the Children's Hospital. Lithograph by Käthe Kollwitz, 1926.

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Care of the Dying Child

The Demands of Ethics

William G. Bartholome

WE HAVE COME A LONG WAY SINCE THE pioneering work of historian Philippe Ariès (1974), anthropologist-philosopher Ernest Becker (1973), and physician Elisabeth Kübler-Ross (1969, 1983). Our deeply rooted “denial of death” has been breaking down for over two decades now. We have come to accept our responsibility to care for the dying in a manner that is respectful of their interests, rights, welfare, and dignity. In this country, the dramatic change in our attitudes and practices is most visible in the growth of the hospice movement. Yet almost since the beginning of what some have called the death-and-dying movement in this country, a storm of controversy has surrounded the question of how we are to discharge our responsibilities when the dying person is a child. I would share with you the experiences and thoughts of a father, a pediatrician, a “clinical ethicist.” I would also like to begin this essay by acknowledging my enormous debt to the scores of children and parents who allowed me to play the role of a hospice physician to them. By

caring enough about me to be my teachers, they provided me the opportunity to discover what it means to care for a dying child.

Provider Problems

MANY OF THE PROBLEMS INVOLVED in responding to the needs of dying children belong to the “big people” involved. Although we have come a long way in accepting the reality of death, most adults in our society still cannot accept the idea of children dying. Old people die. Adults with cancer, heart disease, and strokes die. But it’s not natural that children die. It’s not the way things are supposed to be. Although we may accept the fact that some infants die and that some children will die sudden, accidental deaths, children should *not* die of diseases. This idea is so unacceptable that many health care professionals in training rule out careers in pediatrics simply because they could not tolerate working with critically ill and dying children.

Parents and providers bring this attitude to their relationships with children, and they see death as the ultimate form of failure. The emotional burden of seeing oneself as having failed to protect an innocent

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child from this ultimate evil is enormous. Parents and providers expect that they can protect children from such evil or, at least, rescue children who become ill from this fate. When faced with a critically ill child who is not responding to their rescue efforts, they have a powerful need to deny the reality—to see the child as sick but never as terminally ill.

To this day, pediatric health care providers and parents strongly resist using the word *dying*. All too often, the result of this need to deny is that terminally ill children die, but they are rarely seen or treated by their caregivers as dying persons. In order to avoid painful feelings of frustration, impotence, and guilt, providers allow children to die only after they have done everything they could to reverse the course of illnesses. Children continue to die under the full-court press of every intervention known to modern medicine, in desperate attempts to save them. Providers withhold nothing that promises even the most remote hope of benefit. Moreover, most health care providers lack the training and skills needed to provide palliative care to their patients. In fact, few health care professionals receive formal training in the most basic aspects of hospice care.

Finding Terminally Ill Children

AS THEY MOUNT THESE ALL-OUT ATTEMPTS to rescue critically ill children, providers often overlook a crucial task, namely, identification of terminally ill children who are candidates for hospice care. Whose responsibility is it to “find” terminally ill children? I propose that the burden rests on health care professionals. They are the ones who should determine when a critically ill child has reached the point at which additional attempts to prolong life and prevent death are no longer appropriate. Although the child’s parents may recognize this point first, health care professionals are usually in a better position to make the determination.

This task, however, is not just *emotionally* challenging; it is also technically and clinically daunt-

ing. There are no widely accepted criteria for health care professionals to use in determining which critically ill patients are actually terminally ill. There are no examinations or blood tests or X rays with which a health care provider can determine that a child is terminally ill. Instead, health care professionals must continually evaluate the condition of the patient and the patient’s response to treatment. Although the nature and prognosis of the child’s disease may be such that death is a possible or even a probable outcome, the determination of an appropriate point for radically altering the goals of treatment from “curing” to “intensive caring” is both complex and demanding.

For me, the determination rests on four factors in addition to the nature of the child’s disease and the prognosis. The first—and least controversial—is the extent to which the treatments are having a measurable effect on the anticipated course of the disease. In terminally ill patients, treatments often are no longer producing any measurable effect. For example, the growth of a child’s tumor can no longer be stopped by anticancer drugs. The lungs of a child with cystic fibrosis are just as congested when he is taking antibiotics as when he is not.

The second factor might be called refractoriness, or resistance. Terminally ill patients seem to become progressively refractory to interventions: the dosage or number of drugs needed to achieve a desired effect increases progressively. Providers often have the sense that they are “climbing a mountain of gravel.” They are expending a great deal of time, energy, and resources, yet the patient seems only to become more and more dependent on drugs and technology without showing any evidence of improvement.

A third factor might be called the trajectory of the patient. By examining and plotting the child’s response to treatment over time, providers can often discern a pattern of the illness and its progressive failure to respond to interventions. The child with leukemia, for example, may have remained in relapse despite the use of three combinations of chemotherapy given over a three-month period. The weakness of the child with muscular dystrophy may

have become significantly worse over the course of the past year, during which she was hospitalized five times for treatment of pneumonia compared with twice in the year before.

The final—and most controversial—factor is the providers' own responses to the child and to the feelings they experience in their attempts to treat the child. Nursing staff often become aware of these responses first. For example, they may begin to feel that what they are doing and being asked to do *for* the child is more like something they are doing *to* the child; interventions start to feel more like “torturing” than “treating” the child. Or their willingness to perform painful procedures on their patients hinges on seeing improvement in the child's condition. If providers are willing to undertake this emotionally challenging task of discovering that they have terminally ill patients, they will be able to determine with a reasonable degree of certainty which critically ill patients are candidates for care as dying children.

Problem Identification

ONCE PROVIDERS HAVE DISCOVERED that they are caring for a terminally ill child, the next major obstacle is sorting out the tangle of “dying problems.” First, the encounter with a terminally ill child forces providers to encounter their own death and dying. To state the obvious, the idea of mortality, of one's personal death, is a big problem. Some have argued that it is the ultimate existential problem. Whether they want to see it or not, providers will face their own mortality in the face of the dying child. This is in *no* sense a problem to be solved. The ability to live with one's mortality is a largely impossible goal which must be pursued. To the extent that providers are able to acknowledge that this problem is present in their clinical encounters with dying children, to “own” it as their own problem, they can be more free to get on with the task of responding to the dying child. Second, coming face to face with a dying child triggers in providers—

most of whom are also parents—the fear of their own children dying. If they fail to acknowledge and own this problem, they often project it into their encounters with their child patients. The struggle to rescue the ill child becomes the desperate struggle to save their own children from this fate.

The combination of these two problems exacerbates the third problem (described above): the guilt and frustration that providers already feel over letting their child patients die. A fourth problem involves the dying child's parents. Facing the impending loss of a child, parents often turn to health care professionals for help, which places an additional burden on the care provider. Keeping these four problems separate and devising strategies for dealing with them allow both parents and providers to deal with the fifth set of problems: the problems children have with their own dying.

The Reality of the Child

THE MOST DAUNTING PROBLEM FACING PARENTS and providers who are caring for a terminally ill child is that the person they are caring for lives in a different reality. Today's parents and child health professionals owe an enormous debt to Jean Piaget and a generation of child psychologists who have carried on his work. Thanks to them we now know a good deal about the reality of children and how it differs from adult reality. This understanding forms a bridge between the adult world and the child's world and allows adults to understand children and their problems and needs in facing death.

Take the first word of this seemingly simple sentence: “I will die soon.” As adults, we have a fairly well developed sense of self, of what we mean when we use the word *I*. We tend to forget that we only gradually became aware of *self* and distinguished our self from other selves over a long period. As adults, you and I can make sense of the statements “I *have* a body” and “I *am* my body.” But the ability to reflect, to think about yourself, or—as my oldest daughter once put it—to “see” a picture of yourself inside your



I Don't Like It When They Give Needles in the Hospital.

Drawing by Radee Green (first grade), Stokes School, Trenton, New Jersey.

head, is something that rarely develops before the age of six or seven. But even after a child has developed a picture of herself in her head, the child's identity develops only very gradually and is rarely achieved or discovered before late adolescence.

The world of a child is also not neatly divided into animal, vegetable, and mineral. Animate and inanimate are rarely distinguished reliably before age ten. A child's whole world is alive and filled with consciousness. An unfamiliar object like a stethoscope is just as likely to bite as a dog or cat. Needles stick you and hurt you; if you move, they'll hurt you more. Adults also divide the world into fantasy and reality. We know the difference between thoughts and things, dream life and waking life. Not so for kids. The child who dreams of a monster under the bed wants Dad to check under there. If a child wishes Mom were dead—which means nothing more than that she would disappear for a while—and she gets sick, the child feels she probably caused the illness.

What about the second word in our simple statement: "I will die soon"? The concepts of chance and probability can be difficult enough for adults to grasp. But they are virtually absent from the world of a child. The idea of a chance occurrence is foreign to their world. Things don't just happen; everything has an immediate and proximate cause. For example, a sick child feels that somebody or something caused him to get leukemia; somebody must have been angry with him. Furthermore, the intravenous catheter for chemotherapy got infected because he didn't take care of it properly, and now his mother is taking him to the hospital to be admitted for punishment. Worse still, the child believes that it is because he messed up his last catheter that the

doctor is ordering (as punishment) an operation to get a new one.

A related problem is the egocentricity of children. When we say that an adult is egocentric, we hope to convey that he or she is inordinately concerned with self. But children have no choice in

this matter. They relate everything that happens around them to their own feelings, ideas, and actions. If a child sees his mother crying, he feels he must have done something to upset her. If the doctor who is trying to draw blood is sweating and swearing in frustration at not being able to find a vein, the child patient feels she must be doing something to make her veins hard to find. If the child's parents are crying about the result of his bone marrow test, he must try to cheer them up because

he was the one who "failed" this important test. If the doctor and nurse are talking in low voices in the hall outside his room, they must be talking about him.

In addition to this age-related sense of self, children have their own sense of time. What would the word *soon* mean to a dying child? Time for children is not a linear progression of hours, days, months, and years. A child of five or six cannot feel the difference between two weeks and two months. Both are merely a long time. Time is essentially collapsed into the present. If the child is told that her grandmother is coming to visit "soon," she may take that to mean that she should cancel her plan to go to the playroom so she can wait for her grandmother to come. In other words, the idea of having six months to live has no meaning for a child. Not only do young children have trouble with the idea of physical time, but until around age ten, they have no conception of personal time. They have no

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sense of a lifetime in which to plan and use their time.

Working within this distinctive world, children sort out their experiences in limited categories, using *concretistic* thinking. Having a tumor may mean something like having a big toe or having a baby in your stomach as mothers do or having a new dress. If the nurse says the shot is like a bee sting, the child might expect the nurse to pull a bee out of the drawer and sting him with it. If being dead is like being asleep, the child wants to keep the lights and the TV on in order to stay awake all night.

The Child's Conception of Death

ONE OF THE TRICKIEST WORDS FOR CHILDREN in the simple sentence "I will die soon" is obviously the word *die*. What in the world might that mean to a child of four or eight or twelve? Would it mean different things to children of different ages or different stages of development? This question has attracted the attention of scores of investigators. As a result, we now know a good deal about how the concept of death develops in children, particularly how this concept evolves in the thinking of healthy children.

In *The Dying Child* by William Easson (1970) and in several more recent works that review scores of studies (see Carey 1985; Spence and Brent 1984), investigators argue that a child's conception of death is linked to stages of cognitive development. For infants and toddlers, who have *sensorimotor intelligence*, death is simply separation. A child of this age would experience separation from a parent through divorce in the same way they would experience the death of the parent. Death means nothing more than "not present to me."

Preschool-aged children use what Piaget called *preoperational thought* and conceive of death as both separation and departure. To be dead is to be "living under unusual circumstances," like in a coffin that is nailed shut and buried in the ground. A child in this age range might well express concerns about

lighting arrangements inside the coffin or whether a favorite toy or pet might be allowed to accompany him. Furthermore, to preschool children, death is like sleep, and dead people can feel when individuals visit their graves. Some investigators have argued that children in this age range conceive of death as reversible at least in theory.

Children from the ages of six to ten use *concrete operational thought*. To them, death is real; it can happen to people, and it is irreversible. Some authors argue that children of this age tend to personify death and to think of it in terms of some outside agent.

After this age, and particularly with the development of *formal operational thought* in early adolescence, children conceive of death as involving irreversible decomposition of the body—as the "end of life." In late adolescence, with the development of a sense of self as radically separate and unique, death is also conceived of as the end of personal time, as a cruel personal blow, and as the loss of newly developed intimate relationships.

Although widely accepted, this analysis of the evolution of a child's conception of death has also been challenged on two fronts. One challenge comes from those who feel that the differences between children's conceptions of death and those of adults may have been exaggerated because of misinterpretation of the primary data (structured interviews of children and related instruments) or because of assumptions made about the so-called adult conception of death. One of the more interesting challenges to these stages (called here the standard developmental account) was offered by Gareth Matthews (1989:136), who points out that "the Standard Developmental Account seems to have as an implication that anyone, adult or child, who believes in the immortality of the soul, let alone the resurrection of the body, is cognitively retarded." Is the belief that personal continuity extends beyond death a child's or an adult's conception? How should one characterize the concept that the dead are living in a special place called heaven? These studies may well have been conducted with the assumption that

the most highly evolved conception of death is that it involves physical decompensation and personal annihilation.

The other challenge to this standard developmental account has come from work with populations of sick children. In the past, most studies of the child's developing conception of death were conducted in populations of healthy children. But beginning with the ground-breaking work of Myra Bluebond-Langner on children with leukemia (1978), investigators have discovered that the concept of death in many populations of critically ill children does not follow this standard account. Instead, in these populations the conception of death seems related to experience with illness and its treatment rather than to the child's chronological age or stage of cognitive development. These recent challenges should remind health care professionals to use information about the relationship between age and concept of death only as starting points in the dialogue with individual dying children.

Beyond "To Tell or Not to Tell"

BASED IN PART ON THE DIFFERENCES between the child's world and the adult's world and the early studies of children's conceptions of death, it was common practice during the 1950s and 1960s to shield children—particularly children younger than ten—from the realities of their illnesses. Some providers of care, however, objected to this "conspiracy of silence," asserting that parents would find it very difficult to maintain such an approach, and that children would sense the wall of silence and lose trust in their parents and health care providers. This led to a controversy that lasted almost a decade over whether to tell children the "truth" about their illnesses. Two widely read observational studies conducted in the mid-1960s with populations of children with leukemia challenged this protective approach (Solnit and Green 1963; Vernick and Karon 1965). It was not until the early 1970s, however, that formal studies of children with life-

threatening illness were undertaken.

One of the earliest, undertaken by Eugenia Waechter (1971), involved a population of children between the ages of six and ten with a variety of chronic diseases and a carefully matched control group of children with acute illnesses and children who were normal. The General Anxiety Scale for Children was administered to each child. Each child was also shown a set of pictures and asked to tell a story about the picture. The children's parents were also interviewed. Anxiety scores among children with fatal illnesses were twice as high as scores of other hospitalized children and three times as high as those of healthy children. Children with a poor prognosis related stories that indicated a preoccupation with death in spite of the fact that both parents and providers claimed that no information had been given to the child about the prognosis. And none of these children had directly told parents, providers, or the investigator herself about these feelings. Her study and others that followed confirmed the worst fears of those who had worried about the effects of silence on the child patients. On the other side of the wall of silence, children were struggling to deal with their anxieties, their fears, their preoccupation with mutilation, and above all, their loneliness and sense of isolation.

In the mid-1970s, John Spinetta and Lorrie Maloney (1975) published the results of their studies of children with leukemia. Their findings (confirmed by others) led pediatric health care providers and parents beyond the long-standing "to tell or not to tell" debate. Why? These studies documented that in spite of the best efforts to shield young children from the "truth" about their life-threatening illnesses, they managed to discover what was really going on. Even children as young as four years old were able to piece together information from the treatments they were undergoing, from their observations and conversations with other children, from overheard conversations between adults, and from their parents' nonverbal behavior. One of the more disturbing findings was that many school-aged children had actively participated in the



Pulse. Egg tempera on panel by Robert Vickrey, c. 1950.

Robert Vickrey/VAGA, New York 1993.

conspiracy because they didn't want to burden their distressed parents. Sick children were attempting to parent by protecting their parents.

Truthfulness with Children

PEDIATRIC HEALTH CARE PROVIDERS and parents have now taken the crucial first step toward truthfulness with child patients. They have accepted the flaws in the conventional approach of shielding or protecting children from the hard truths of their conditions. Children do not need to be shielded or protected from the truth. Furthermore, such efforts actually make things more difficult because they cut children off from the people who can help them understand and deal with what they are experiencing. Nondisclosure, deception, and the all-too-common practice of lying to children have been rejected. Realistically, this now widely accepted standard of openness with children may have resulted as much from the fact that conspiracies are impractical and create difficult and often noncompliant patients as from any ethical concern with the needs or rights of children to know the truth.

Truthfulness with a child involves a good deal more than the information-dispensing that health care professionals commonly engage in with their adult patients. For one thing, we still have the reality-gulf between the child's world and ours. Young children are likely to encounter significant problems in understanding the information they are provided. Giving them the "facts" or the "truth" about their condition is a dangerous and inadequate method of being truthful.

How, then, are parents and professionals to proceed? The first rule, and the most obvious, is to be aware of self. Communication with a child demands that we as adults become aware of what we are communicating to them before we even start trying! As Fred Rogers ("Mister Rogers") and a host of others have told us, children listen more to what grown-ups do than to what they say. Even small children are astute observers of adult nonverbal com-

munication. Because they have trouble interpreting adult language, they develop the skill of "reading" adult behavior. Not surprisingly, many children are better than adults at reading nonverbal behavior.

Second, we must be sure that we are really ready to be honest with them. Have we sorted through the list of dying problems described above? Are we ready to respond to the problems they have? Children have a built-in skepticism whenever adults approach them. They do not expect honesty. They do not expect adults to take them and their problems seriously.

Third, we must remind ourselves that communication with a child involves a willingness to avoid informing, explaining, and lecturing. Children expect adults to talk "at" them rather than "with" them. In fact, effective communication with them demands that we avoid talking as much as possible. It demands that we listen. It demands that we relinquish control and let them set the agenda for the conversation. Sounds simple. It's not. We are not used to letting children have control of anything, much less a conversation about dying and death.

Fourth, this process demands that we be willing to answer any and all questions the children might have. It means looking for clues to their desire to know and understand more. It means letting them set the pace. Truthfulness with children is a process, not an event. They will come to awareness in their own way and at their own pace. It requires something that few adults have much of—the ability to be patient with them.

And finally, it means seeing our task as *assisting* them in their efforts to come to awareness of their own illness-reality. It is their task. They want to do it, and we must believe that they can do it. Whether we want to or not, we cannot do this for them. John Spinetta and Patricia Deasy-Spinetta (1981) have described this process as helping children find ways of "fitting" the awareness of illness, even fatal illness, into their ongoing lives.

When we need to use language in this conversation, it helps to keep in mind the problems children

may have with adult language. Obviously, we should avoid references to time as much as possible. We should avoid references to things like chance and probability. We should use simple, concrete language and avoid analogies and similes. Because young children have limited capacity to deal in abstractions, we should avoid references to abstract philosophical, theological, and religious concepts unless we are certain of their "meaning" to the child. My favorite example is that of parents who become upset when conversations about going to heaven and being with Jesus are angrily rejected by children who would just as soon stay home. We also need to be prepared for anxieties, concerns, and fears that may appear irrational or even silly from our adult perspective. We "know," for example, that tumors are not conscious, that they don't decide to grow or to be resistant to chemotherapy. We know, too, that thoughts cannot cause physical changes to take place. We know there are no monsters or bogeymen. But our knowledge of the way the universe is put together is no help to children as they attempt to make sense of their condition.

Beyond Truthfulness: Children as Decision Makers

AS DEMANDING AND COMPLEX AS THESE TASKS may sound, they are just the beginning—a giant first step in the process of responding to the dying child. So far, I have described the process of responding to the informational needs of these children, of helping them develop an awareness of the reality of their illness. But respecting them means much more than being truthful. In the course of providing care to these patients, hundreds, if not thousands, of decisions must be made. Most of these decisions will involve interventions into their bodies, interventions intended to influence the course of their diseases, interventions that may profoundly affect their

lives. In the context of chronic and potentially terminal illness, these decisions often involve treatments that impose considerable burdens, significant pain and suffering, and disturbing side effects and risks. Moreover, in the context of terminal illness, these decisions often involve withholding or withdrawing treatments, even life-sustaining treatments. What role should the child patient play in making decisions about these interventions?

In the past, parents as guardians made all these decisions in concert with the child's health care providers. This was called *proxy consent*. However, as Langham (1979), Gaylin and Macklin (1982), and others have pointed out, many serious problems are associated with the idea that parents should make these choices (see also Fost 1986). I have argued against the concept of parental consent, particularly against a parent's right to refuse interventions of established benefit to children (Bartholome 1989). One of my major objections to the concept of parental consent in pediatric practice is that it rests on the mistaken idea that children lack the capacity to make decisions about their illnesses and their treatment. On the contrary, children have a right to be treated as developing persons, as persons with a developing capacity for rationality, autonomy, and participation in health-care decision making.

The foundation for this right to participate rests on the rapidly expanding literature in developmental psychology on the decisional capacities of children. During the past decade, investigators from a wide variety of disciplines have examined the ability of children to make choices in matters like participating in human-subjects research or receiving chemotherapy for treatment of their cancers, and in a wide variety of other situations (Melton, Koocher, and Saks 1983). The implications of these findings are profound. First, as philosopher Dan Brock points out (1988), these studies support the presumption of full decisional capacity for children over age fourteen. Second, these studies support the idea that children as young as age seven have developed many of the capacities needed to make

good decisions. This is not to say that children in the age range of seven to fourteen should be granted the right of independent consent granted to adolescents and adults. But it is to say that these children are fully capable of participating in the decision-making process.

What should their role be? What should parents and providers do to respect this evolving capacity? The concept that has evolved to describe this new role is called *child assent*. It was first formally incorporated into pediatric practice in federal regulations governing the participation of children in human-subjects research. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1977) recommended that federal regulations require investigators to obtain both the permission of parents to involve their children in research *and* the assent of the child subject. Many child health professionals, and I among them, feel strongly that child assent must become a standard part of pediatric practice in all decisions involving children from seven to fourteen.

Child Assent

THE CONCEPT OF CHILD ASSENT has four elements. The first (described above in the discussion of truthfulness) consists of assisting the child to develop a developmentally appropriate awareness of the nature of his or her illness. The second involves disclosing to the child the nature of the proposed intervention, whether a diagnostic test or a treatment procedure.

Even more important, it involves disclosing to the child what he or she is likely to experience in undergoing the intervention. The third element involves assessing the child's understanding of this information and the factors influencing the child's evaluation. And, finally, assent involves the obligation to solicit the child's expression of willingness to accept the proposed intervention.

An example of this process may be helpful. Mary, an eight-year-old undergoing treatment for leukemia, is coming to the clinic to have an examination, blood test, and a lumbar puncture ("spinal tap"). Her clinic nurse would reinforce the ongoing process of helping Mary to have a developmentally appropriate awareness of the nature of her illness. She might, for example, ask Mary once again to explain to her what was wrong with her or to clarify why Dad had brought her to the clinic that day. She would correct any misinformation, answer any new questions Mary might have, and provide education-

al materials. Obviously, this essential educational process is one that begins at the time of diagnosis and never ends. Second, both the laboratory technician and the physician would explain to Mary that she needed to have blood drawn and to undergo a spinal tap. They would make sure that Mary understood what she would experience in undergoing these procedures. The lab tech might remind Mary that having a blood test meant having a needle put in your arm for a minute to get some blood out. Third, they would assess the extent of Mary's understanding of the disclosed information and any factors that might be influencing her evaluation. They

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Worn Out. Oil on canvas by Thomas Faed, 1868.

London, *Forbes* magazine collection (FC 33371). Bridgeman / Art Resource, New York.

might, for example, ask Mary to describe what she understood was about to be done and to explain to them why these procedures were being done. And, finally, they would solicit Mary's expression of willingness to have her blood drawn and to undergo a spinal tap. The laboratory technician might ask Mary if she was ready to have her blood test. The physician might inform Mary that he was ready anytime she was ready to go ahead with the spinal tap.

One reason parents and providers resist the concept of child assent is that they fear, and don't know how to respond to, child *dissent*. Although I attempt to be sympathetic to this fear of having to deal with dissenting children, it is important to remember that children are very anxious to please adults and will do almost anything to earn and maintain the love and acceptance of parents and adult providers. I believe that children are extremely reluctant to dissent even when they should! Moreover, children often dissent only temporarily in an effort to gain some control over what is happening to them. Often they are attempting to understand, trying to deal with fear, or expecting something painful. The obligation to solicit assent forces providers and parents to hear and respond to these needs, even if an intervention is temporarily delayed. The obligation to solicit assent also forces providers to acknowledge that manipulation, coercion, and force are to be avoided as much as possible. Even when providers and parents agree that an intervention must be undertaken against the wishes of a child, assent requires that parents and providers explain the need for this procedure, acknowledge that the child is being forced to undergo the intervention against his or her expressed wishes, and apologize for the use of force. Finally, this obligation forces both providers and parents to acknowledge that their interests and needs may be very different from those of the children.

Parents of terminally ill children may be unwilling to let go. They may be willing to try anything to avoid losing their child. In contrast, the child who has been living the illness may be much less willing

to make a last desperate attempt. A model of decision making that allows the child patient to participate demands that mechanisms be created and made available to providers, parents, and child patients in such conflict situations. In most hospitals, such mechanisms do exist in case-management conferences, psychological and social service consultation and counseling, and ultimately, review by a hospital-based ethics committee.

The Child as Care Provider

HEALTH CARE PROVIDERS AND PARENTS, then, must respect the needs of the dying child for information and allow the child an active role in decision making. But the ultimate (and largely unmet) challenge in caring for dying children involves respecting children's developing capacity to care for themselves, to take control of their dying. Hospice workers have discovered that their patients cherish control as the most basic and important ethical value. Dying patients want the care offered and provided by their caregivers, but they want more than anything to be in control of their own dying process. Children use a wide variety of cognitive and behavioral strategies to reduce anxiety, to adapt to the demands of their illnesses and their treatment, and to achieve a sense of mastery and control over what is happening to them. To help them avoid feelings of helplessness and hopelessness, adult providers must find ways to support them in this important task. Allowing children maximum control over what is happening to them dramatically reduces the anxiety and stress of illness-associated pain and treatment procedures. The relief of suffering demands that all care support this sense of control and mastery.

If we wish to allow children to control their dying, we must face the almost universal preference of dying children to die at home. Dying children, just like dying adults, feel that at home they are likely to have more discretion in directing their dying process and in having their desires and needs

met. Children also need to be supported in doing the “grief work” of dying. They need to express their own sadness and sorrow at having to leave and to express their anger at having to die. Children also need to participate in planning funeral services and burial arrangements. All these measures help support the coping strategies of dying children and help them to have a sense of living to the end.

The Demands of Respect and Care for the Dying Child

RESPECT FOR DYING CHILDREN involves a series of challenges for their parents and health care providers. It means a willingness to acknowledge

our limited capacity to rescue them or to protect them from death. It demands that health care providers accept the responsibility for identifying terminally ill children. It means a willingness to respond to their experiences and to the problems they have with their own dying. It means being willing to be truthful and to assist them in developing their own understanding of the reality they face. It demands that we respect their developing capacity for autonomy by allowing them to participate actively in making decisions about appropriate care. And it means supporting them and their coping strategies as they attempt to maintain control over their lives to the end. It means, above all, a willingness and ability to trust that they can manage their own dying, at least as well as “big people.” ☸

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CAMDEN, he says, once had more industry per capita than any city in the world. "The record industry had its start here. Enrico Caruso first recorded here in Camden. Now we have to settle for scrap metal, sewage treatment and incinerators. When you're on your knees, you take whatever happens to come by. . . ."

Everyone who could leave, he says, has now departed. "What is left are all the ones with broken wings. I can't tell you what it does to children to grow up amid this filth and ugliness. The toxic dangers aren't the worst. It is the aesthetic consequences that may be most damaging in the long run. What is the message that it gives to children to grow up surrounded by trash burners, dumpsites and enormous prisons? Kids I know have told me they're ashamed to say they come from Camden.

"Still, there is this longing, this persistent hunger. People look for beauty even in the midst of ugliness. 'It rains on my city,' said an eight-year-old I know, 'but I see rainbows in the puddles.' It moved me very much to hear that from a child. But you have to ask yourself: How long will this child look for rainbows?"

—Jonathan Kozol, *Savage Inequalities*
New York: Crown, 1992, pp. 148–49



The Window. Lithograph by Marion Greenwood, 1950.

Collection of Madison Art Center, Madison, Wisconsin. Bequest of Rudolph and Louise Langer. 9 5/16" x 12 1/2"



Musical Trio. Oil on canvas by Marjorie Ryerson.

Photograph courtesy of Grand Central Art Galleries, Inc., New York.

A Gift So Free

The Healing Arts for Our Nation's Children

Nancy B. Barcus

EARLY IN THE MORNING ON ANY SCHOOL DAY they come—from all the streets surrounding their school, walking together in groups of two or three or climbing out of their family cars at the school doorway. They are carrying something in a long black case, and they carry it with great seriousness. Each of these children is part of the group of 125 students who proudly carry home a school violin once a week, play it for anyone at home who will listen, and carry it back the next morning to pass on to a different child. Faithfully they lay their violins on the steps of the school stage, asking when it will be their turn again. They know the answer: "Next week on your lesson day. We have 25 violins for 125 students!" But sometimes at the end of a day there are extra violins—the law of *five loaves and two fishes* at work—and a child gets an extra turn to take one home.

Home for these young violinists includes many settings, for each child has his or her own story, each a different reason for the intensity of enthusiasm.

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Among them is Raymond, who, with his younger brothers and sisters, lives nearby with his grandmother, because his family is separated and his father will not be returning for a long time. He shows an immediate aptitude for the violin and appears after school regularly, asking for another turn to borrow one.

There is Charla, who has lived in a series of houses with her mother—often with no heat, light, or running water—and sometimes practices her violin at a large vacant lot. There several adults sit on abandoned furniture, building a small bonfire to warm themselves, and remain together long hours into the night as the children roam and play around the edges of the lot. Charla's violin always comes safely back to school with her, and she hands it in with a smile.

There is Edward, from a large close-knit family who recently arrived from Mexico and lives with several other families in a big old house near downtown. At least a year behind in his schoolwork and slow in language development, Edward plays the violin by ear with a happy expression and good pitch. Often he needs to be prompted in the middle of a song, for he may forget the sound of the next line, but when he recalls it, he can play every note.

His older brother, now 16 and out late at night roaming the streets, showed the same love of violin when he was younger and mastered one song perfectly, always smiling as he played it. Now his younger sister is asking for lessons.

As I recall these and so many other students, I notice the zest with which children who have less than their share of this world's tangible benefits arrive at school each morning, once they have found something that *works* for them. I am struck by how much school seems to mean to them.

Watching them, I know again why I am drawn to teaching in my city's public school system, for I have come to believe that in the public schools good things may still happen for children in a world gone awry. It was this belief that drew me away at midlife from a career path as a college writing teacher and public relations specialist with a private violin studio on the side. I became instead a regular classroom teacher and then a special instructor in the fine arts, focusing on music and writing for young children. I wanted to do a simple thing—to offer to children what I knew of the fine arts and the creative experience.

I recalled teachers from my own childhood who had offered me hope, and I was determined to offer a similar hope to my own students. Through my love of creative writing and violin study, I had experienced the arts as a positive force in childhood. That experience became for me a tangible evidence that some things in life are beautiful and good and that anyone may possess that goodness in the inner life—no matter what is happening outwardly. I wanted to carry this experience from my own life to the children I now encounter, for I found that the arts could break through many kinds of personal despair and produce a degree of inner happiness. I believed that the arts could heal and sustain, for they had done so for me. I recalled my early experiences of the arts as personal building blocks, as whispers that life is about much more than can be seen, and I imagined that others too might find those beautiful and good things reflected in the arts to be symbolic of the finest attributes of God. I hoped that the arts

might somehow offer others a staying power, a promise of better things ahead. I recalled the power of music to promise what is yet unseen, sensed again the magnetism of color and texture in the visual arts as a hint of undiscovered beauty, felt the reassurance of a line of poetry rising to the top of my mind on unexpected occasions. I wanted to impart the staying power of these experiences to the children I knew.

Background

MY DESIRE TO TEACH IN THE PUBLIC SECTOR grew out of my association with Mount Zion, one of Waco's four black United Methodist churches, and with the children I met there. I began a pilot program in violin for the children of the church ages three through ten, using my experience in Suzuki violin instruction. I remember the first lesson of a boy barely three. I tucked the violin under his chin to show him how to hold it on his shoulder. Then I put the bow in his fingers, carefully. Usually I followed standard procedure and broke this difficult technique into several little steps, but I could see he just wanted to hold it and see how it felt, so I pushed the bow across the A-string, guiding his hand. His eyes widened; he looked up at his mother nearby and then down again, as I let go and he made his own sounds. For 10 minutes we watched his expression of fascination and surprise. I finally had to persuade him to let go.

The older children in the church responded similarly, and as they began to practice, they demonstrated what educators everywhere already know—that any child can learn anything if he or she really wants to. “What do you do about those children who can't learn the violin?” someone asked me. “We don't have any children like that at Mount Zion,” I responded. “Every child in that church can play the violin!” And during those years of the Mount Zion violin program, it was truly so.

The response of the children in the church program convinced me of the untapped potential in

many of our city's children and led me to explore a position in the Waco public schools. The career change came simply, when it finally came. In such simple ways, time ripens and the purposes we recognize as God's take shape without fanfare in our lives.

It was the fall of 1986. I had planned a friendly lunch with an official in the Waco school district. We had met at a volunteer recognition luncheon, and we had gotten together once or twice since to share our ideas about education, about children, about developing their potential. On that day, I told her of my decision to seek a teaching job—that it was time to act upon my emerging convictions. She listened with understanding and empathy. As we parted, she said, “I will call you.” When she called, she had three suggestions—all in the Waco Independent School District as an elementary teacher. I had no elementary certification, I reminded her. “There are ways to solve that,” she said. Suddenly the door was open. I could choose a school, apply for an emergency teaching certificate, and begin in January 1987. It was already November. I had six weeks to alter everything about my daytime life.

J. H. Hines Elementary School lay in East Waco, a predominantly black area. Its principal, a strong black educator, was—as it happened—already an acquaintance. She had called me a few months before to discuss my program with the children of Mount Zion and had even visited there one evening. When I visited her school in return, I had discovered she was someone whose educational goals and love for children coincided with mine. Now, six months later, she was looking for a first-grade teacher.

This was the school. These were the children. I would go to J. H. Hines.

The school is part of a typical urban school district in a midsize town—population 100,000,

not including the suburbs. The living here is not easy. Although the area does not have the magnitude of crime that larger metropolitan districts have, the children do not walk to school alone, and they talk about—and live with—the likelihood of household break-ins. Their family income qualifies more than 85 percent of them for free lunch and breakfast. Like most children everywhere, they come to school

dressed cleanly and neatly, sometimes with an extra quarter in their pockets—though its loss is an occasion for tearful outburst. Nearly all the children have someone at home who “wants them to make it,” though they may wish that the person were mother instead of grandmother, or mother and father instead of only one parent. Circumstances in their lives seem often beyond control, more so

than for many children their age. Money is short; light bills go unpaid; phones are suddenly taken out; addresses unexpectedly change; children are shifted from school to school as family luck rises and falls.

The children's scores on national and state standardized tests sometimes cluster at the lower end among schools in our city. In addition, the state of Texas has placed the school in a high-risk category along with other schools across the state that have a student population that averages around 80 percent economically disadvantaged, is more than 80 percent minority, and has a high school-to-school mobility rate.

The principal of our school welcomed me when I decided to cast my lot there, because she believed her children were capable of much more than they had displayed. She wanted very much to try some new approaches.

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Despair

I DO NOT LIKE TO RECALL MY FIRST SEMESTER of teaching. Never had I felt such hopelessness. The things I did not expect happened, and the things I most expected did not happen. All my previous experiences of success proved of no help. I was an immediate failure. The romance faded quickly. The children and I rapidly became real people, with all our imperfections surfacing from hour to hour. I needed more patience—with the children and with myself—than I had ever imagined. On the fourth day I called in sick. All day I thought hard about why I had wanted to do this difficult thing. I tried to remember and to hang on to my initial expectations, to understand anew why I had come. I saw that it was hard work I had taken on.

I was surprised how much I minded the confinement of the classroom. My other jobs had offered plenty of variety, and some had involved lots of coming and going—no hours-on-end within four walls, beneath fluorescent lights, and behind a closed door, without telephones; no friendly interruptions; only 20 minutes for lunch (not counting the 5 minutes to walk the children to the lunchroom and back again). There I was—a naive new teacher who wanted to help children—with the children themselves, who were more experienced at the game called “school” than I was.

I did not expect the noise problem—hallways that echoed—the need for precisely defined walking procedures. I knew nothing of the need to see that children picked up their feet instead of stomping them or making them click on the tile floors. Nor did I have an answer when the children tattled on each other, loudly, in front of other classrooms where they knew our noisy little group would be noticed. I did not know how to handle the constant bids for my attention in the classroom, the calling out of my name, the getting up and coming to my desk—one, then two, then half the class streaming toward my desk in a breakdown of order. Nor did I know the hazards of the pencil sharpener—the incessant grinding of the crank in the middle of a lesson and

the pencil leads deliberately broken to interrupt an assignment.

Hardest of all, too many children were incessantly active. Settle one, and another would pop up with an urgent request. And while I tended to it, still another outburst—Tony suddenly crying for his mother in Florida, Lettie taking off her shoes and kicking them where she could not reach them, Candy bursting into tears because she thought I did not like her, Tom kicking Susan to annoy her.

I tell the truth, because so many who are successful in this venture neglect to tell us about those first days. We watch them and seem to believe that some things are just easier for others, that we’re not one of the lucky ones. But for most of us, there is no shortcut. Those first days were the longest I had ever known. I had no idea that teachers’ days were filled with such things. I felt my mind jumping quickly to think what I must do, to anticipate the next crisis before it happened. My life became filled with strategies. I was exhausted every day. I wondered how the calmer and more seasoned teachers around me did it. And I began to watch them and to pray that I would soon understand something that now eluded me.

An Outsider’s Lesson: I and Thou

I BEGAN TO UNDERSTAND THAT ONE PROBLEM was my being an outsider to the children’s world—culturally, in my prior experiences, and physically, in my white Anglo-Saxon exterior. I looked and seemed like a stranger to them, and I had to bridge that gap, for them and for myself, before anything good could happen. I saw that any healing activity must be entered into with the same expression of spiritual redemption that I recalled in my reading of Martin Buber’s *I and Thou*.¹ I needed to see and encounter the children-as-myself and nonverbally communicate that level of care and acceptance. That attitude had to come first, before the gifts I offered



George Washington Jones. Charcoal and wash with Chinese white by Edward H. Potthast.

The Brooklyn Museum, 33.392, Peter F. Schofield Fund.

could be received. Whatever I hoped to impart was of no consequence without that message.

I discovered that to “receive another as myself” I had to put away any tendency to compare habits, life-styles, values, or anything else and seek only to understand the children in all the fullness of their personhood. Children, as cannily as adults—or more so—know when they are not received. My students tested my sincerity, as if to learn what I was “made of” and what I really thought of them. I found a need to hold steady and not to shrink mentally from their pressure, for that withdrawal would be the very signal they expected and were on the alert for. They did small but serious things to “assault my good intentions,” as if to say, “Will you also go away—and when?” I had come for good reason, and I reminded myself to hold out. If I had voiced what I was tempted to say in those hard-pressed moments, or believed what I was tempted to believe during those hard times, they would have been able to conclude, “Yes, it is as we thought. We have exposed your true feelings. We have detected what you think of us in just one slip of a phrase which seems like a pronouncement to us. We know more about you than you think.”

I saw how precisely the children could detect in my eyes any conviction that they were poorly regarded, how keen was their ability to pick up signals of despair or rejection. I learned, too, that children who act inappropriately—to test one’s reaction—really want to be well-regarded and ultimately to perform well. And I discovered, before it was too late, the kind of toughness required to stand before children and believe in their potential, even before they have given any evidence or encouragement to do so. I learned how to express my highest expectations more assertively, and still kindly, and

to insist that the children give me in turn what I came to expect from them.

I understood why many outsiders like myself, who come to places like this with the best of intentions, often leave. I have read the books by experts who have sojourned awhile and gone away to write their reports, narratives, chronicles, and statistical explanations, verifying and explaining the dire convictions they have come to experience through their own disappointing ventures. And I also understood the burden of history, that long legacy of racial mistrust that we still carry about with us and that the children have inherited without understanding what has gone before to separate us and confuse our coming together.

As I struggled to learn to be a teacher, I recalled the disbelief of co-workers and

friends when I had explained my decision to come to Hines. My listeners, even many who knew me well, had seemed afraid for me, had reminded me of my “many skills and accomplishments,” and had declared that I would be “lost” in such a setting. They had asked me why I couldn’t just live out my ideals in the setting I already had and offered a splendid list of reasons why my idea was ill-advised. Finally, they had said they were sorry—that I would be sorry too as time went on, and I would regret my decision. These thoughts assailed me many times. I remembered the admonition of Jesus that “No man, once putting his hand to the plough and looking back, is fit for the kingdom of heaven.” The words made me tremble. Disciples are not allowed to give up.

I went one evening to a concert of religious music, and I heard the glorious songs that once had inspired me and filled me with zeal. I listened and felt only anger. God did not seem to offer what those songs promised. I felt betrayed by such splendid

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feelings as these. And I felt flat and unable to respond to anything about the worshipful experience, as others around me sang and smiled and entered in. I felt only numbness. I've got to believe again, I thought, as I listened. I cannot continue to live this way. My thoughts flashed back to my schoolroom, where Tina said, "I can't do it," and Kenny broke all the new crayons I gave him, and Joseph stamped his new hard-soled boots in the hallway so they would echo clear to the cafeteria. As the singing continued, I prayed through my numbness that God would stand with me.

I want now to report life beyond these doubts and failures. Good things will happen if endurance is possible, and there are ways to wait out the storm and fashion a personal communication style that is effective amid numerous difficulties. I stayed long enough to discover these things. With a sometimes heavy heart, and a heavy reliance on the faith I had declared to lie at the root of my being, I simply turned stubborn and hung on.

Mixed Results

I REMINDED MYSELF, AS TIME WENT ALONG, to focus on the days when I had seen some good things happen—days that were, to be sure, mixed in their results, but with enough good to bring me back the following morning.

There was David, who liked to color instead of read and write—though he could do all things well. He drew pages of intricate swords, shields, saw-toothed implements, medieval weapons. He drew the human body with all its internal organs, copying freehand from the encyclopedia and labeling every part. He was a leading troublemaker—starting things, then getting out of the way while others took the blame, smiling mischievously as those less clever went to the "time-out chair" in the back of the room. There was Shayla, who could hardly read but began to write two-line stories with at least one unusual detail or image—a wrinkled dog, a lost piece of Church's fried chicken. And Corey, who began writ-

ing full-page stories about pet bears visiting him, while Susan, next to him, imagined pet cats, rabbits, and dogs coming to her birthday parties.

I noticed how many children responded to color and to the pictures in the stories we read. I brought my own box of crayons and a large easel pad, so I could turn all the restless eyes in my direction. I made the front of the room a "television screen," drawing pictures as I taught social studies, science, literature. The children asked for more pictures. I saw them begin to copy on their papers what I was drawing, asking me for directions so they could imitate. We put the mathematics problems on paper in picture form, with crayons or colored pencils—slowing down the math process enough for comprehension to dawn in children who found my lessons too rushed and too abstract. We became artists at work, from morning to afternoon.

I noticed that the children did not always respond to textbook lessons designed for "all children." I think too many "great" ideas are designed for children in ideal circumstances, devised by people who have not spent a long enough time where so many children in America really go to school. Daily, we must write our own textbooks—modifying, innovating, discarding. The students we most want to reach—those who seem intelligent to us in spite of their previous performance—need something else.

I recall a day in the classroom. Kevin is not listening. He is thinking about his pencil, which the girl next to him took and hid in her desk, because she said she needed one and he had five. His grandmother gave them to him, he said, and they are all he will get until next month. His mother has moved out of the house, and his grandmother is in charge of the seven children. It will not be his turn for pencils again for a while. He wants his pencil back and is not working—pouting, knowing the teacher will believe the little girl and not him, because things are usually his fault. He sits slumped over, works slowly, not saying why he is pouting, staring around him, picking at his paper with his fingernail, half-listening, waiting for me to notice.

I am trying to explain paragraphing. Sandra, a second-language student, is crying and not working because she doesn't know why everyone else thought the cat in the picture we are describing was a mother cat, when maybe it was the father; and why everyone else knew the cat was sitting on a bannister, when she didn't. (What is a bannister?) I take her aside for a lesson in personal worthiness. She is very intelligent.

The textbook assignments may ask children to write about building tree houses, or making scrapbooks, or taking trips to other cities—things beyond the experience of many families. Frustration and fears are easily triggered by unfamiliar requests. It takes flexibility, open-endedness, no preset demands, to teach. We must always be prepared to shift to another plan. The textbooks were not written for us. Every day we make up a new chapter!

Something was working. It made me certain that underneath the facade of commotion and distracting behavior was a wellspring of interest, ability, even talent, untapped because it was hard to get to it, the children as yet too unfocused for me to draw it out. I called upon this positive result every time I felt discouraged. I had seen some good things happen. There would be more.

The Resilience of Children

ANY READER OF ROBERT COLES'S MOVING narratives of conversations with children (1990) is struck by the children's resilience. While we shake our heads at "what children have to deal with" and at how much they hurt, we notice with amazement that they keep hanging on anyway, sometimes fashioning their own wisdom as they go along. Even

their eyes say they haven't given up yet. A brief season of kindness from someone, in words or in nonverbal gifts of hope, may keep them on the road just a little longer. In fact, they seem to wall themselves off from what is too painful in their lives, as if they know how much they can handle, and they

must temporarily set it aside so that they can live in the day at hand.

It is this resilience, this light of hope burning in each child, that became the foundation for what I hoped to accomplish. On that foundation I could begin to lay out the incremental steps that would lead to achievement—first steps toward writing fluency and first skills in violin performance.

And when achievement

slowly came—from one child and then another—I saw the importance of always delivering small incremental steps, in just the right size to be successfully received. Becoming more expert as a child-watcher, I began to discern what was happening as each child proceeded toward a degree of success in violin playing and in the development of verbal fluency. After a year, when I was reassigned as a roving creative writing teacher for the entire school with part of my schedule reserved for violin classes, I began to watch closely for every signal of success and to study what happened, as the children's interest in accomplishment began to quicken.

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A Change of Attitude

SUCCESS, THE FEELING THAT "I CAN DO something—something I really want to do," comes from participation in a very desirable activity. Once children have attained some skill in the arts, their feelings of accomplishment lead to success in other

areas of schoolwork. I watched some of the children and began to keep brief anecdotal records of the changes in their academic schoolwork and in their behavior. What happened justifies classifying the fine arts among the healing arts, for the children began to reflect a very different feeling about themselves, as if they knew who they were and no longer felt themselves drifting, angry, and unaccustomed to success.

Some students had seemed almost afraid to try. Demetrius erased line after line as he tried to draw a butterfly, because it did not “look right” to him. He seemed to want to erase it before anyone laughed at him or told him it was “not good enough.” Another child was reluctant to write more than a sentence and even more reluctant to show me what he had written, as if fearing I would point out a correction. “I know that’s not right,” he would say. “I was just in a hurry.” He did not want me to point out a single error. If anyone found a mistake, he would crumple up his paper and say, “I knew that wasn’t any good. I just wasn’t concentrating,” or he would make another excuse that meant “This isn’t really the kind of work I do. I really do everything perfectly. I just haven’t shown you yet.”

The reactions of these children make me wonder how many other children sit in our classrooms afraid of the verdicts that will be rendered against them. They have experienced enough of school to know the verdict is coming. Their only fear is *when*, and their only goal is to avoid any situation that will point out those shortcomings. Such children spend all their energy diverting the teacher and their classmates from the task of learning—by any means possible.

A chief element in all that happened was finding that respectful entry-approach to children, for its discovery led to their making “connections” with the arts, and to their inner selves. For some, the arts were a welcome alternative to athletics. Although athletics are well-accepted as a road to achievement—perhaps unrealistically—not all children feel successful in competitive situations. The arts can be noncompetitive—every story unique, every picture stamped with one’s personal style, every song played

recognizably and to one’s own satisfaction, sometimes even beautifully, and always enough to bring a smile. Best of all, the arts are inclusive. The talents needed for their achievement are inherent to some degree in each person. All who participate may achieve a tangible result—a poem, a story, a picture, a song sung or played.

The Arts as a Healing Activity

AN ARTISTIC ENDEAVOR AT ANY LEVEL can become a tangible expression of the Beautiful and the Good, and if one later moves toward a fullness of faith, one may discover that some of the essence of God has been reflected in prior artistic experiences. This sounds like a lot to ask of the arts on behalf of children, especially of children in pain. But in the day-to-day life of children, artistic experiences do have a soothing and a calming effect, once a climate can be sustained in which children will reach out to try them. As long as learning is presented incrementally, so that all results stand alone and are not compared with any other, each tangible result will be a cause for celebration. Maintaining a philosophy of inclusivism, however, is vital when we offer the fine arts as a *healing* art for children. This inclusivism is difficult for adults, and especially for teachers, because the more highly trained they are and the higher their own “personal standards” have been, the more demanding they feel they should be.

Yet we must look only at the journey of the individual child, doing nothing to hurt or hinder any who trusts us enough to learn from us and to put out tendrils of achievement. The temptation we hear in our heads is the voice of our own trainers who always “judged our results,” making us restless, dissatisfied, perhaps tempting us to disown the works of our hands. If we pass on this rejection from our own histories to the children whom we now teach, it will be felt by them without a word from us and may cancel all we have hoped to lead them toward, no matter how many the long hours of forward progress. Once these old censors are



Fish Ride. Egg tempera on panel by Robert Vickrey, 1972.

Robert Vickrey/VAGA, New York 1993.

removed, the encounter with the arts serves to free the human spirit as nothing else can do.

Many of the children I first worked with in our school had little experience in drawing or painting and felt insecure when I offered them the opportunity. “Show me how,” they would say, adding, “I can’t.” When we first began writing stories, they were quick to tell me they “didn’t know how” and had “nothing to write about.” When they asked their parents if they could learn to play the violin, a typical reaction to their question was “Why?”

But so much of that has changed now that it takes some remembering to call it back. Children are readily writing stories in numerous classrooms, in an approach to writing where expressing ideas is primary and correction for spelling and grammar comes later. A local art consultant has helped the children approach art easels for expressive painting with all the confidence in the world. And more than a hundred children happily carry one of the 25 school violins in and out of school once a week for home practice, returning them in good condition. Not many of them say any longer that they “can’t” or “don’t want to.” They have had a taste of what it is to accomplish something, and that makes them clamor for more. Sometimes they come knocking at the door after school to ask if “tomorrow is their day for violin.” They sometimes try to come through the doorway into class, even on days when it is “not their turn”—just in case it is *their day*, after all.

A few of the children who come to mind when I think of those who have made a *connection* with the violin are Tracy, Mary, Teddy, and David.

- Tracy, with the sweet smile and shining brown eyes, who wore slippers to school for several days while waiting for a pair of shoes; who still could not read or write coherently at the end of third grade—although a federally funded intervention program was gradually helping her; who adores her mother, a pretty lady who lived in a large house full of unrelated adults and often sat on the front porch with them all day long playing cards and entertaining the visitors who pulled up in their

cars. This child loved the violin and begged to take it home, although her mother sent word at first that she did not want the violin carried home—perhaps for security reasons—but later changed her mind. This is a child who faithfully practices and plays with perfect pitch but who needs the large posters with the color-coded notes on them, because she cannot remember the songs.

- Mary—whose awkward left-handed mastery of the violin took two years and who still looks uncomfortable when she plays; who keeps trying because she likes the satisfaction of producing a tune she likes; who often takes care of younger siblings at home when her single-parent mother is at work; whose sensitivity is also apparent when she writes stories with colorful and unusual images, the same aptitude we noted in her older siblings.
- Teddy—who needs a brief private lesson instead of a class lesson, because his frustration is easily triggered by competition from his classmates and his seething aggression consumes too much class time. By himself he is fully focused on the violin, playing tunes over and over with almost intuitive mastery. His mother has been remarried two or three times since Teddy began school and has never been to a recital.
- David—who does not play well because he is busy thinking and can hardly be jogged to attention for physical activity. He enjoys coming to class to read the books that are on the shelves for the children to read while awaiting their turn to play. He has perfect pitch, an intellectual understanding of how to play, and can learn a song in one session, though not with the physical skill necessary to become a seasoned player. I wonder if he thinks of his mother, who disappeared last year. He lives with his grandmother now.

Every time a child learned to play, I was amazed all over again. Those difficult and multiple coordination movements had finally resulted in a song.

I could hardly believe it, no matter how often it happened.

Before coming to J. H. Hines, I had taught children whose parents wanted them to learn. Now, the children coming to me had never considered playing the violin before, and their parents—when they went home to tell about it—were skeptical. I heard one mother say to her young son, “You?” and smile as if she doubted he could do it. But Kenneth had been begging me for a year to show him. Like so many other students at J. H. Hines, he did not believe in what he could do. When he first came to violin class with 20 other fourth-graders, he talked too much and often interrupted to get my attention during instruction. He was very impatient with himself and gave up easily on all his schoolwork; he displayed the same pattern in his approach to violin. But he loved the violin and seemed not to want to give up. His face would shine with a smile as he learned to set his fingers down on enough notes to play his first tune, “Twinkle, Twinkle, Little Star,” in four different rhythm patterns. His foot would tap slightly, and his body lean into the violin as he played the song.

When we began a new rhythm or a new tune in class, he would stop coming to class for a while, as if he could not succeed again and dared not fail. I stopped him after school one day and begged him not to be so hard on himself and made him promise to try again. He came back, interrupted the class to demand help, and nearly had to be sent out for causing a disturbance. But he cared so much about the violin that he somehow found the self-control to contain his emotions, and he learned the next song too. I watched him concentrate and learn it. He could do it. He was all right after all.

He played one of the few solos in the school concert that spring. Dressed in his Sunday clothes, the violin under his chin, he looked angelic, transported, as he played. The song was “Reach Out and Touch Somebody’s Hand . . . (make this world a better place—if you can).” That evening, he made the world a better place—because he could play. Tired as I was, day after day at violin time, I was

never too tired for this kind of miracle. Everything else must take a back seat. Transformation, new hope—that is the greatest miracle of all.

Practical Changes

BESIDES THE MIRACLE OF LEARNING to make music, other specific and practical changes took place among the children. Violin requires children to exercise the self-discipline necessary to master a complex skill. It requires differentiation of movement in the right and left hands and total bodily involvement. Before they can play, children must learn to screen out peripheral distractions and to concentrate on producing a song. By doing so, they have extended their concentration time. They have learned to correctly sequence many small steps. They have developed a sense of directionality involving right-left, up-down, back-front, and other paired distinctions. They are extending their ability to play by ear, to memorize, to refine eye-hand coordination, and to process a set of written symbols in the complex task of decoding written music.

In writing, they have extended their early fluency development into an extension of the imagination, finding other ways of thinking and feeling than the immediately obvious. Alongside such popular topics as Ninja Turtles, go-carts, mansions, and limousines, they incorporate in their writing the water lilies of Claude Monet or the sailboats of Vincent Van Gogh, for their writing is often based on visual art. They have learned to personalize famous paintings and to “step inside” a painting to create a story as if they were there. They have learned to mentally “live” in worlds beyond the one that presses most immediately upon them. They have “seen into” more worlds than their own, and more worlds than the ones in the popular media.



Drawing by Martisha McAllister (third grade), Stokes School, Trenton, New Jersey.

A Backward Look

NOT THAT EVERYTHING AT OUR SCHOOL is suddenly easy now, or that the days go perfectly. We live in the same world we began with. The difference is that we have cultivated many more expressive capabilities to occupy us from day to day and a

greater will to attempt new things. As a school we have taken up this vision a little more each year. In the five years since the changes began, we have also shifted to a Montessori educational philosophy that supports these same goals. My involvement, however, continues to be concerned with the impact of the fine arts on children. I simply arrived at this

school at the right time—at a time when the principal and the district were willing to undertake new things for children.

There may be no way that standardized tests can document the changes we believe to have occurred, but those of us who have worked with the children are certain that something significant has happened for them. We can only hope that they will be able to internalize enough of it to provide some staying power through the difficult years ahead. In the meantime, those who visit our school today say they can “feel” something different in the atmosphere and in the demeanor of the children.

I hasten to add that we are not producing prodigies or even future fine arts professionals at our school, though we may see a few before we are finished. There is not much financial support or transportation available for intensive, continuing private study. What we are seeing is an increasing number of children who have been exposed to the arts and have claimed them as their own, with the declaration that they “can do” them. We are seeing children who love and enjoy music, art, and words. We believe we are building a base for another generation of children who will gain parental support, as a result of the creative development which these children have enjoyed firsthand. And we know already that many of our children walk with a greater spring in their step on some days because of their accomplishments—achievements they now openly declare to others.

As for those first children—or even the ones still with us today—no one can say yet how much better they will fare in life as a result of these efforts. In many ways the children are as they were when we began. But in other ways, they are greatly changed. We know what we have seen. We know that they feel good now about some parts of their lives. We know that they enjoy sharing every small achievement. We have seen them smile. And we ourselves have felt the impact of those smiles, as we remember how it all began . . .

A Gift So Free

I REMEMBER THE DAY ALEX WROTE A POEM. He was a fifth-grade boy who was unpredictable, showing signs of something special in class but not always coming through with it. I had asked him to stay after school for a conference, and I sensed he was ready to show me something more. “Alex,” I said, “can you write a poem?” Suddenly he grabbed his pencil and began writing furiously, as if snatching the words out of the air. First he scribbled the title, “The Rose That Had No Stem.” Then his words followed like lightning. The rose had grown, his poem said, although it was separated from the stem. It grew, he said, because of the sun and somehow also because of some unspoken miracle. I looked at my bookshelf. There on top of it was a photograph of a rose growing so close to the ground that it appeared to have no stem. I had never viewed it that way before. The rose became an image of life and of all who labor, in spite of their difficulties, to become something special:

The Rose That Had No Stem

One bright sunny day I woke up to see
A bright red rose just below me.
But I noticed something that made me frown.
The rose had no stem to grow in the ground.
I said to myself, what a strange, strange sight.
How can a rose stand up, without a stem of might?
I said to myself again, I'll just sit and wait,
Till the sun comes out and makes it grow great.
Then the sun came around, a cloud of light,
And it shined on the rose, so clear, so bright.
There was a stem, so small and so thin.
My eyes got big—then a smile and a grin.
I'm so happy to see
The sun help me
And a rose grow a stem
As a gift so free.

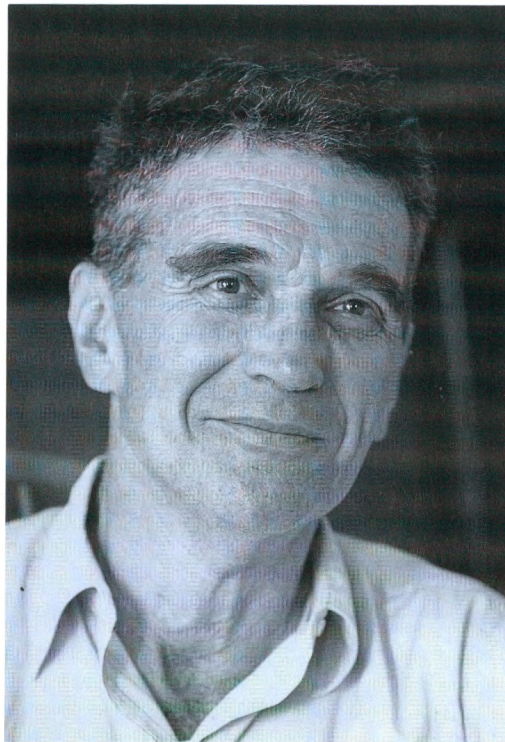
NOTE

1. Martin Buber, *I and Thou* (New York: Collier-Macmillan, 1987).

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“We are all children, and thank God we are. The problem is we don’t know it well enough. This is one of the things Jesus taught us—to struggle toward childhood and never forget it or outlive it. And to retain within ourselves whatever shred of innocence and trust and willingness to engage ourselves with the world in the yearning and unashamedly vulnerable way that children possess.”



Struggling toward Childhood

An Interview with Robert Coles

Robert Coles has distinguished himself as a physician, teacher, and writer who has made the world of children his specialty. Beyond the classrooms of the medical school and Harvard College, where he is an immensely popular teacher of undergraduates, one is likely to find the prize-winning author on the lecture platform or at the writing desk—or quietly reading authors on whom he has written at book length: Walker Percy, William Carlos Williams, Flannery O'Connor.

Other book titles, however, suggest his career-long interest in children: *The Spiritual Life of Children*, *The Moral Life of Children*, and *The Political Life of Children*, along with the earlier five-volume series *The Children of Crisis*. More than any other serious author, Dr. Coles has brought the needs of children to public attention. He has infused his questions with issues of spirituality and faith and has heard children speak out of their fears and hopes.

Editor Martin E. Marty recently spoke with Dr. Coles in an interview which set out to discern the world of this particular listener, to grasp the context out of which his concerns for children and for spirituality have grown.

Second Opinion: If you were asked to write a little book on a big subject, one that has a bearing on the meaning of life, religion, philosophy, theology, what would it be?

Coles: I'd have to choose *luck*, though social scientists are so bent on determinism that they don't usually allow for luck in their various methodological and theoretical explorations. Luck for me goes right back to my parents meeting each other at a dance in

Boston, where they both went to school—my mother was from Sioux City, Iowa, and my father from Yorkshire, England. Luck for me means having run into Perry Miller when I was an undergraduate; I not only took his course but stumbled into him in the library and had a conversation with him that eventually led to his being a tutor for me. Luck is his recommendation that I write my thesis on William Carlos Williams's long poem *Paterson* and my later getting to meet Wil-

liams. And luck is the result of being so taken with what he was trying to do that I myself became a physician—really in response to his life. Luck to me means my mother's long-standing interest in the Catholic Worker movement even though she was Episcopalian, and her telling me once when I was in the depths of despair in my second year of medical school, "Why don't you think of some other people besides yourself? Why don't you do something to be in touch with people who are

hurting?" So I sought out the Catholic Worker community on the Lower East Side and got to meet Dorothy Day. And finally, the most important luck was being stationed in the Air Force in Biloxi, Mississippi, in 1958 when the whole civil rights struggle was just beginning. I had fought like the devil not to get that assignment, but instead of going to London or Tokyo or San Francisco, I ended up in charge of the psychiatric unit of an Air Force hospital in Biloxi, Mississippi. Right before my eyes I saw some black people beaten up and arrested for trying to swim in the Gulf of Mexico. Then a year later I ran into Ruby Bridges. I was on my way to a meeting in New Orleans and asked a policeman why traffic was being diverted. I learned that the mobs were there because a black child was struggling to get into a desegregated school. She was the only child attending the school—the white boycott was total. I saw all this and then got so caught up with what I saw that my whole life changed. I stayed in the south, got involved with the civil rights movement, and spent years getting to know the black and white children who initiated desegregation. And one more example: when I was a resident in pediatrics at Children's Hospital in Boston, we happened to have a polio epidemic. Without that epidemic

I wouldn't have got involved with those kids, and I doubt that I would have developed my interest in stress and children.

So all life is luck. I'm just giving you one person's account, but isn't that the story for all of us? I think this is a big part of faith: we know in our heart of hearts that we're here by luck, we never know when we are going to leave, and we are at the mercy of fate and chance and circumstance. I think it is pride, if not hubris, for us to try to conquer our existential anxieties with formulations and constructs and theories and determinisms, to try to get control of what is ultimately uncontrollable.

Second Opinion: Theologian David Tracy says that we live our lives and do our thinking in the face of "finitude, contingency, and transience." You die. Things just happen. Everything passes. You chose the middle term: *contingency*. If things just happen and luck prevails, where do final meanings come in? Where does it make sense to talk about God?

Coles: God comes in for me because one tries to find some way of thinking about all this, morally, ethically, humanly. And God comes in for me because he was handed to me by my mother when I was growing up—in the form of the Hebrew prophetic tradition and the life of Jesus. I'm sure that people who grew up in other religious traditions find other ways to deal with "final mean-

ings," as you put it, but for me, going to church with my mother and listening to her talk were very important influences. I also got to listen to a continual dialectic between her and my father, an MIT scientist. He was half Jewish and half lapsed-Catholic, but he had no religious bearings. He was a very passionate positivist in the middle part of this century, a time when positivism reigned in the intellectual world. He was a scientist and a skeptic. And he and my mother carried on a 60-year conversation about these matters. My father was a Republican and had what I would call an enlightened conservatism. He worried about problems but was skeptical of human institutions, including political ones, and I have increasingly grown to respect that skepticism.

For me faith has been my mother's passionate interest in not so much the Christian church but the life of Jesus and the choices he made on earth—the people he kept company with, the people he was interested in, the people he wanted to heal. The fact that he came to us not as a college professor or a capitalist or a doctor or a lawyer, as she used to remind us, but as a carpenter who associated with poor and humble fishermen and peasants. My mother had a great deal of respect for the prophets—Jeremiah, Isaiah, Amos, Micah—and for the continuation of that tradition that she saw in Jesus. She reminded us all the time that Jesus lived among the poor and worried about the

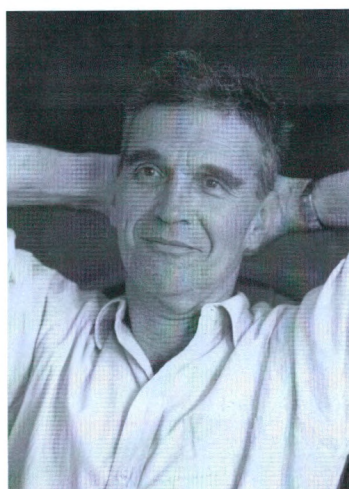
For citation: Coles, Robert. 1993. "Struggling toward Childhood: An Interview with Robert Coles." *Second Opinion* 18, no. 4 (April): 58–71.

poor, the hungry, the vulnerable, and also, she would always add, the outcasts, the rebuked, and the scorned, people who were not big shots, who didn't become professors at fancy universities or write books. That was the great moral lesson for her, which she tried to impart to us—though apparently with no great success in the sense that my brother and I are living the comfortable lives we have lived. But so did she, and she was aware of the contradictions that she lived out—preaching this to us, reading the *Catholic Worker*, but also living a very comfortable life herself.

Second Opinion: So we have your mother's world and your father's world. In American public life, people like you live mainly in the "father's world" of skepticism and science, where religion is criticized or regarded with suspicion. Where does "mother's world" come in? Do many of those around you fight off the world of faith, suppress the signals of religion, intentionally ignore theology or any talk about God? I find that in public settings like the academy there is ignorance of, or ignoring of, religion—but that behind the scenes many search for what religion has been directed toward. Do those who restrict themselves to the world of skeptical inquiry miss out on something?

Coles: I think there is a loss, and I think part of it is cultural and political. Our cultural world is

“I think this is a big
part of faith:
we know in our
heart of hearts that
we're here by luck,
we never know
when we are
going to leave,
and we are at the
mercy of fate
and chance
and circumstance.”

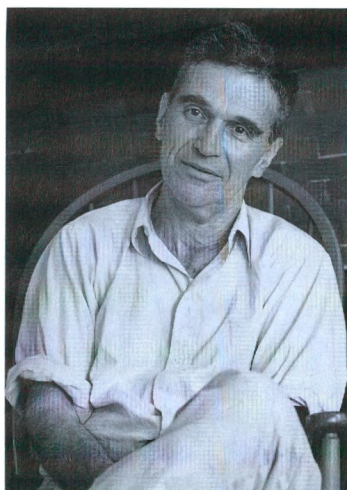


often embarrassed by moral and spiritual matters or is unable, or unwilling, to take them to heart, and the same goes for the political world. In the early 1950s I took Perry Miller's course called "The Classics of the Christian Tradition," and I remember Miller pointing out that this was almost the only course in the entire Harvard curriculum at that time in which these texts were taken seriously. He wasn't teaching them in order to be clever about them; he was teaching them for their moral and spiritual content. Then, a few years ago Bob Kiely, who is a professor of English here, and I gave a course in the core curriculum called "The Literature of Christian Reflection." And I felt that we were handing along a tradition to the students the way it had been handed to me, as at the end of Walker Percy's novel *The Moviegoer*. Many of the students were asking us the same questions you're asking: "Why do you teach this at Harvard? It just isn't done." Now, this college does have a spiritual tradition, and until around 1900 the college's mission was to instill character in the students. But that mission was lost in the early part of this century when science, social science, and the secular world took over in the name of "progress." And that's been happening ever since. Some individuals, of course, resist that and stand for other principles and values, but the general power of secular agnosticism is still very significant.

Second Opinion: You use the word *still*. The German theologian Gerhard Ebeling says that *still* signals a whole philosophy of history. It relates to something the way that cancer in the marrow or the worm in the apple does. Unwittingly, one is saying: "There will be less of it in the future." Is that the case with the reason, science, and progress that we associate with the older style of the eighteenth-century Enlightenment, which shaped our culture so decisively?

Coles: No, I think the Enlightenment will continue. I think there's a part of us that wants to know more. We have a God-given capacity to explore, to be curious and interested, to try to find out. And we also have a God-given capacity to invest that explorative capacity with our pride. So whether you call it narcissism (as the psychoanalysts like me call it) or the sin of pride (which is a better way of thinking about it because it's just part of who we are to take knowledge and connect it to our self-importance), we'll continue to believe in progress. But I do see some disenchantment. Who can look at this century and not take note of Goebbels, with his Ph.D. in comparative literature from the University of Heidelberg, and Heidegger with his distinctive philosophical achievements, both of them connected—one more virulently than the other—to the Nazis? Or Jung, with his great depth of knowledge about the human mind, who fell

"My mother reminded us all the time that Jesus lived among the poor and worried about the poor, the hungry, the vulnerable, and also, she would always add, the outcasts, the rebuked, and the scorned, people who were not big shots, who didn't become professors at fancy universities or write books."



prey to some of the crazier "science" of Nazism for a while? And others—in the clergy, in medicine, in law, in the intellectual world—have fallen into similar error. So this all comes back to what Ralph Waldo Emerson said over 150 years ago in his *American Scholar* address: that character and intellect are not necessarily the same. And once you have that awareness—that you can be very smart and evil, and not very smart and relatively good—you're on a different road. This century may have taught some of us that we no longer can connect the political rationality that's attached to Marxism, the exploration of the mind that's connected to Freud, or the social and economic reality of the progressive movement in this country to some notion that human beings are going to be fundamentally different. We may make some "progress," but the fundamental sinfulness, the fundamental humanity will still be there.

Second Opinion: Just as you used the word *still*, now you speak of *no longer*. We can "no longer" live with twistings of rationality as in Marx; but in our enlightened century serious people keep getting swept up into such twistings: we think of C. J. Jung, Martin Heidegger, Jean-Paul Sartre, and all the intellectuals who fell for fascism, Nazism, or communism. So what will replace critical faith or reason now: belief in one's tribe, one's race, one's nation?

Coles: Well, we've had plenty of racial and ethnic wars, and those continue. But I hope for a Christianity ever renewing itself for people like me, a Christianity that connects itself to what Jesus told us again and again in his pilgrimage. And a Christianity that I'd like to connect with certain writers—with Flannery O'Connor, with Walker Percy, with George Eliot (even though she might be a little embarrassed by it), certainly with Tolstoy and Dostoyevsky, with Dickens (who, in my opinion, is a deeply Christian writer—can anyone read *Little Dorrit* without thinking of Jesus?). These great novelists and great storytellers connect in my mind with Jesus, who himself was a storyteller. The parables are terribly important, and they connect, even for those writers who do not in any way regard themselves as Christian. Raymond Carver, for instance, is a wonderful American storyteller, and whether Carver said he was a Christian or not, his story “A Small Good Thing,” to my mind, is a message from a soul that can nourish us, just as, of course, Jesus can. “Bread and Wine” was written by Ignazio Silone, another lapsed Christian. But you cannot lapse in Christianity once you've written “Bread and Wine.”

Second Opinion: When these people draw on Christian themes, they are in the zone where one-third of the world's people live. But the other two-thirds do not live there, and Christians are not

going to convert everybody. Thomas Mann says that the world has, and will continue to have, “many centers.” There are worlds of Buddhism, Hinduism, Islam, and the like. How will these relate, be renewed, and change?

Coles: I hope that all these religious centers will be struggling in their own ways with their own idioms and traditions, away from the excesses of institutionalization and toward one another, toward our common humanity, our common vulnerability. As creatures of language and awareness, we have a common need to understand what this life means, to understand as best we can, in the existential sense, where we come from and what we are and where we are going. Not only in the biological or psychoanalytic sense of those questions, but in the human sense. Creatures of knowing and awareness want to understand the meaning of this brief experience called life as best we can, with the help of our Tolstoys, with the help of Jesus and the prophets who preceded him, and if I were in the Moslem or Hindu world, with whatever help they offer.

Second Opinion: In your book *The Spiritual Life of Children* we see that children do not have generic faith so much as a repertory of images relating to their family's specific faith tradition. Islamic children reflect their parents' world, and so on. What if that world is full of a religion engaged

less in healing than in killing—as are some of the extremisms, now code-named “fundamentalisms,” all over the globe? What is it about religion that leads people both to heal and to kill? Why do people of faith need to connect it to power, often murderous power?

Coles: Probably because we're so utterly, quintessentially human. Religion comes out of us human beings. It's a series of stories and fantasies—and I use the word *fantasies* in a nonpejorative sense—handed down over the generations by human beings from one to another as they struggle with some intensity and anguish to make sense of life. Even in children we see an intimacy between love and mean-spiritedness that is simply part of our human equipment. We don't need Freud to tell us this when he talks about Eros and Thanatos, or libidinal drives and aggression. We simply need to look in the mirror—each of us—to know that part of our equipment has to do with attachment and yearning and affection and goodness but that another part of us is our capacity for envy and competitiveness. A child in a family with another child feels moments of resentment, and these moments of resentment can be writ large and be part of the story of what hate is about. I was talking yesterday with a carpenter who was working on our house. He and his wife have a little boy, an 18-month-old, and they had just had another child. And this man said to me, out of his strug-

gles as a father, out of a perplexed innocence and also some anxiousness, "Why is it that my boy now is so moody and so testy and so difficult with this little baby and wants to be so mean toward his little brother?" I said to him, "Look, welcome to the human race. Here we are." This is our condition.

Second Opinion: At his stage it is primal, not yet related to formal symbols of religion. But at 18 he hears someone say, "Allah wants us to conquer that tribe, and so . . .

Coles: When he's 18 he'll come to Harvard College, and he'll find out how things can be sorted here, depending on which house students live in, or which club they belong to, or whether they are called jocks or nerds. But the animosities, the tensions, the distrusts, the skepticism—these are part of an ordinary community of privileged, enlightened 18-year-old college students in a strong country; they're not starving, not vulnerable as are many people in the Middle East, who often don't know where their next meal is coming from. And people wonder what's going on in Bosnia-Herzegovina.

Second Opinion: And Algeria . . .

Coles: Yes, Algeria. And then I listen to the way we talk about one another in our faculty meetings, or I hear people at the Boston Psychoanalytic Institute talking about a "rival institute." Here are

middle-aged people, all of whom have been analyzed and analyzed, and they're bad-mouthing a group of fellow human beings practicing the same profession. So war and hate are not only the property of religion; they are part of who we are. And these realities won't be altered by 35 years of psychoanalysis, by the best federal programs we can devise to rescue us from poverty and vulnerability, or even by democracy. They're part of our humanity.

Second Opinion: How, then, did Dorothy Day begin to begin to solve it? Why do some individuals, some groups, some communities that you met in Biloxi or wherever offer some exemplary alternatives?

Coles: Dorothy Day began to "solve" the question by just living with it, without proposing a clear and concrete solution. She didn't ever think this problem could be "solved," but she felt she could struggle with it herself and hope that by example others would struggle with it in such a way that they weren't hectoring and lecturing. Sometimes the impulse to teach and reform can be the basis for more, rather than less, trouble. Once we start taking upon ourselves the notion that *we* know something, that *we* should tell someone else how to behave, we're on a very treacherous path. I understand that we have to get on that path because I believe in teaching, in telling. But how you do it and with what sense of who

you are, whether with a sense of humor or with irony, whether you can laugh at yourself occasionally, whether there is a conversation you have with yourself, never mind with your students or those you want to change—this is all-important.

I lived one summer with the Catholic Workers. I remember Dorothy Day getting fed up and withdrawing. I remember her at times being tempted to argue and then apologizing. I remember her at other times becoming difficult and then a day or two later saying, "Well, look at the way I behaved. How sad for me. How sad for all of us." Well, that quality is rare. I don't think it's often encouraged in universities, in psychiatric and psychoanalytic training centers, or in churches either.

Second Opinion: You mention church and by implication the clergy profession. Let's look at what professionals have in common in medicine, law, and ministry. The professionals know something about the human stories you are describing. Do they know it as professionals? If not, what is it about their advanced professional schooling that causes them to have difficulty living off the stories? Can we break the bounds of a profession in order to stress the specific human dimension?

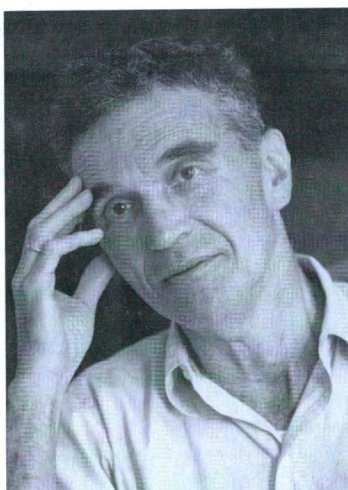
Coles: This is the tragedy: that medical schools don't regard discussing the issues we've just been discussing as their central mission. All too often in medical

training these issues are relegated to psychiatry. But psychiatry can be part of the problem; it isn't going to be the solution. Because once you relegate these problems to psychiatry, you're saying that they are an aspect of sickness, an aspect of psychopathology, which isn't true. These are human problems, and I'm waiting to find a medical school where the dean will talk to the faculty and the faculty will talk to the students in the confessional mode, the mode that Perry Miller used. *Augustinian self-scrutiny*: boy, do I know those three words. It's a kind of moral self-arraignment that shouldn't be confused with psychoanalysis. We desperately need that confessional mode. It pains me sometimes to go to Catholic churches and see those confessionals gone. My mother used to say the one thing that bothered her about Protestantism was the absence of the confessional tradition as it was institutionalized in the Catholic church. But then my father would say, "Look at the way they confess—in and out, in and out . . ."

Second Opinion: But they confessed.

Coles: They confessed. That's what my mother would say. I would love to see us in medicine share with our students our foibles, our mistakes, our blind spots as they inform our medical life. And the way to do this, I think, is through literature. William Carlos Williams does it. He

"We ought to come to our students not saying that we know something called 'the humanities' but that we are struggling toward the values the humanities offer, even as the writers whose work makes up the humanities also struggled toward those values."



does it in *The Doctor Stories*. He does it right in the middle of *Paterson*: he's writing beautiful poetry, and he stops and switches to prose. There's a confessional paragraph in which he describes a doctor who's standing in his office toying with a mayonnaise jar and thinking about his career as a writer. He's saying to the reader, "Hey, you, who are admiring me now as a writer whose poetry you've just bought, let me get you from the poetic to the prosaic, which means from the prophetic to the pastoral. Let me show you my humanity in another way."

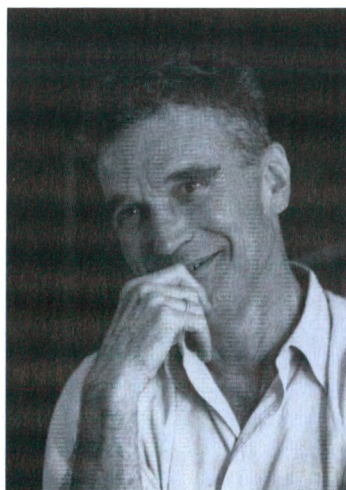
This is terribly important. I think we can ask students to read William Carlos Williams's *Doctor Stories* or Raymond Carver's fiction or Flannery O'Connor's short stories as they connect with medicine. We can ask them to read Chekhov's story, "Anyuta," which is the story he wrote when he was himself a medical student. It's a story about a student who is taking anatomy and learning about medicine but is a terrible, brutish person with his girlfriend. Every first-year medical student on the anatomy bench, before starting the dissection, ought to be assigned that Chekhov story. Then they would have this reminder: you will learn all the names of the bones and the muscles, you will learn a certain command over the body and over humanity, and yet look at your frailties and your vulnerabilities and, alas, the darker possibilities within you. Another of Chekhov's stories—"Two Tragedies"—is

the story of the cry of the doctor as hate and bitterness progressively destroy him. These stories—along with Chekhov's "Ward Six," a better-known story, or Tolstoy's "The Death of Ivan Ilyich" and "Master and Man"—are a reminder to us of what we in the medical profession need to think about even as we are learning the technology or the so-called information base of our profession. And this can be taught. The best way to teach it, I think, is for us teachers to teach it to ourselves first, and maybe, I repeat, to bring our students together—I say it only half in jest—for a general confession.

Second Opinion: I could name several people—you, John Stone, Kathryn Hunter, Leon Kass—who are working to help medical education bring back the humanistic dimension. Will this trend continue, or will being a "pre-med student" and then a "med student" and then a "medic" tend to rule it out most of the time?

Coles: It's a serious mistake for any of us who teach medicine to assume that we have this humanistic dimension. You never "have" it. You're struggling *toward* it all your life. This is a pilgrimage, a quest, and the people you mention are struggling with this too. And we are here to share that struggle with our students. We ought to come to them not saying that we know something called

"Many clergy members these days have an idolatrous respect for the social sciences and particularly for my profession. They don't want to be members of the clergy; they want to be therapists."



"the humanities" but that we are struggling toward the values the humanities offer, even as the writers whose work makes up the humanities *also* struggled toward those values. We are, thoroughly, strugglers and stragglers both. Raymond Carver wrote a wonderful poem just before he died called "What the Doctor Said," and in it he talks about what it means to go to the doctor and be told that you are going to die, and what intimacy exists between these two human beings. All of what's called "medical humanities" in a way is wrapped up in that poem or in Williams's stories, but the issue is not how it's "taught" but how we the teachers live with those stories and apply them to ourselves. If students get the message "Here's a story. Let's be *clever* about it. Let's *figure out* the message and then go on to the next one," the assignment ultimately becomes part of the problem—pedantic achievement rather than the heart and soul of the reader touched, informed.

Second Opinion: Next profession. In all of your writings I see that you know clergy well. You've marched with them, you've listened to them, you've been at the bedside with them, you've counseled them, you've been counseled by them. What, in your view, is a good clergyperson, and how did she or he get to be one in the world you're describing?

Coles: My definition could be applied as well to a physician or a

lawyer or for that matter to a carpenter or a cleaning person: it has to do with how we are with one another.

Second Opinion: Of all the pastors you've ever met, which one would you like to have had as your pastor?

Coles: Once I would have answered by naming Reinhold Niebuhr. I took his seminars when I was in medical school and loved the brilliance of his mind and his vast moral intelligence at work. But I think he taught me not to name him. Two others come to mind—Dorothy Day at her best (and of course none of us is always at our best, but I witnessed certain exemplary moments) and then a man that you knew, the brilliant young psychologically informed minister David Roberts. I got to know him when I was a medical student. He was a wonderful person—so sweet and kind and helpful to me at a time when I was floundering badly. Of course, whatever our strengths and whatever wonderful possibilities we have in our profession, we're always being tested in our personal lives and in our family life. I guess I can only hope that the people I mention—whether Dorothy Day or David Roberts or anyone I've met who has a very loving side—allow that side to inform their lives as much as possible.

Second Opinion: I gather that the pastor should be a leader on a

pilgrimage, someone who knows the story, someone who is loving. But I gather that such a leader should also help guide people in being able to scrutinize themselves and participate in confession. What about their actions? I am interested in seeing them as healers now, since all religions seem to have been born as healing movements.

Coles: I would hope that those people would not be idolatrous. Many clergy members these days have an idolatrous respect for the social sciences and particularly for my profession. They don't want to be members of the clergy; they want to be therapists. They are more interested in doing "pastoral counseling" than in being pastors. They are more interested in that posture of marching people through "stages" and "phases." They're too conscious of these psychological and, I might add, political formulations, to the detriment, I think, of what religious life is and ought to be about.

Second Opinion: We have a mandate from one of our founders to be experimental, innovative, and attentive—but not "nutty." Not long ago we published an article by Robert Fuller which shows how a century ago many experimental, innovative, and attentive people were nutty (and their movements remained that way). But the nutty impulse surrounds us. Should we avoid dealing with it?

Coles: It's hard to avoid the nutty stuff because the nutty stuff is in all of us, I regret to say. There's a hunger for answers at all cost, and a craziness that we all struggle with. But we all know, deep down, the crazy side of ourselves.

Second Opinion: How do you view the claims that praying a certain way, imaging one's disease, taking command of one's body has a measurable effect on the course of illness and healing in many cases? Is there empirical evidence on this?

Coles: Quite frankly, I think this is megalomania at work. I think this is an old, old effort on the part of the human mind to assert the authority and power of the mind. Whether you do it by constructing a theory through which you can encompass the whole world in your mental acts—by saying "Hey, my mind is so powerful and strong that it can understand and control any cancer or heart disease or illness that comes"—the answer is that we're all going to die. Is that because the mind has failed (and imaging could have corrected it)? Or is it because we're born, we live, and we die, and because there are genes in us that head us toward certain outcomes over which no mind has control? These people, with their theories about imaging and these other notions, are trying to say, "We can lick anything, even genes, even luck, even the final outcome that all of us are fated to." Baloney. But very instructive.

Second Opinion: The religious side of all this is now coded under the word *spirituality*. Thirty years ago the theologian Paul Tillich thought that the term had been so debased that it could never be recovered. Now it's a commodity, a best-selling item. How does spirituality fit into the healing search?

Coles: I think the fundamental spiritual search is always there, but it takes on many forms. One form is Marxism, another Freudianism. About 25 or 30 years ago many people who may now have different forms for this quest were searching for it through one analyst or therapist after another or through intense political involvement. Marxism as a religion was just beginning to die. Psychoanalysis was at its height but soon enough would yield. And if the search doesn't take those two forms, it will take other forms, like the New Age ones you just alluded to. But in one way or another we search for meaning. *We search for meaning.* Through politics, through self-understanding, through various kinds of religious experience. We may be upper-middle-class agnostics at heart and say that we're not interested in that kind of search; nevertheless, we will search.

Second Opinion: In a Center-sponsored forum on clergy ethics we heard from an Episcopal priest who is also a banker. She belonged to a kind of support group, and she deliberately wore her clerical

collar to their meetings in order to connect with the faith of the 80 percent of Americans who draw on biblical sources. The other 25 participants were "into" macrobiotics, Rolfing, Est, or Zen, or whatever. She wondered if she was the misfit. Why were her fellow members so engaged by everything but what they had been brought up on?

Coles: Because they're pagans, and this is an aspect of their pagan minds. They think they're so well educated and so well analyzed that they've gotten beyond religion, but then they do a complete circle and end up at a pre-Christian posture of gullibility, inanity, and weirdness that makes some of our fundamentalist brethren seem as if they're far advanced up the intellectual ladder. It's pitiable. Look at this support-group movement in America—here I'm sounding off my opinion—and look at Mr. Bradshaw, on public television no less. Look what this is about! Talk about narcissism! Talk about what George Eliot called "unreflecting egoism." Talk about the construction of a kind of incantatory, idiotic language, with these repetitive phrases like "I hear you" and "I understand where you're coming from," and these "stages" that they put one another through and this "inner child" that they're talking about. Talk about plain old silliness—there it is! As Adlai Stevenson said, calling on Lincoln, "You don't know whether to cry or to laugh."

Second Opinion: What about another intimate social form, the congregation? The "I'm so spiritual" sorts who place themselves above doctrine and ritual, religion and theology, certainly position themselves away from the institutional church. Thus they find themselves more free to be spiritual.

Coles: I'm afraid that sounds to me like some of the empty-headed egoism that's abroad in the land. Who can divorce himself or herself from institutional life in one form or another? We're all American citizens. We all live in a particular town or city or state. We send our children to schools to be educated (although some people even yank their children out of schools). We entrust an institution like the post office with our words, our passions as they are conveyed to others on paper. Institutional life is a very important part of us and ought to be. We are members of a *community*—even if that word has been turned into a banality—and it's a function of the sin of pride to think that we can separate ourselves from institutions. It sounds like hubris at work to say, "Hey, look! I am spiritual. I, the narcissist, don't need any institutional life, and here I am, having my conversations with God, or experiencing an 'oceanic feeling.'"

For me religion means coming to terms with the church in the neighborhood—going there and getting on my knees and praying even though I don't par-

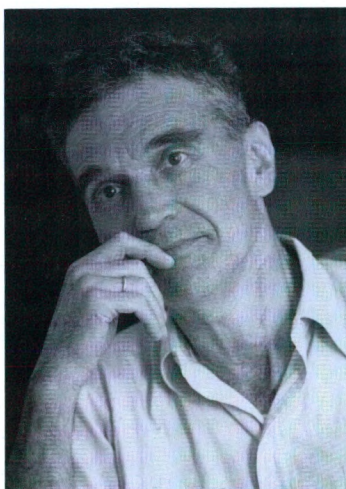
ticularly like something I've heard in the sermon and may not like a lot of the people around me in church any better than I like them in the post office or the local store or in their opinions as I know they've expressed them in the voting tabulations. But this church transcends all of us, and it's a church that, in my mind, is connected to the life of Jesus Christ and has been handed over to us. At our peril do we forsake that for private, culturally connected passions that get expressed by words like "my spirituality."

Second Opinion: Have you read Wendy Kaminer's *I'm Dysfunctional, You're Dysfunctional*?

Coles: It's a *wonderful* book! And particularly the ending, with that powerful moment from Kafka. The truth ought to cut through ice, and self-help is how we skate—all of us in these support groups and I'm afraid in a lot of other things called psychology and psychiatry. If the truth doesn't get deep within the heart and the soul, and if it doesn't somehow bring us to our knees (whether we are praying to God or not), then we're in trouble. That's a biblical book, and it took courage to write it.

Second Opinion: What about a parallel to the support group, the self-help pattern that we see in its most legitimate form in Alcoholics Anonymous?

"In one way or
another we search
for meaning.
Through politics,
through
self-understanding,
through various
kinds of religious
experience. We may
be upper-middle-
class agnostics at
heart and say that
we're not interested
in that kind of
search; nevertheless,
we will search."



Coles: Well, I'm afraid it has petered out into a lot of unfortunate banalities. Having just heard myself talk, though, I have to correct myself. Wonderful things can happen when people come into a room and share with one another and reach out to one another and hear one another. In no way do I want to be disdainful and condescending toward other vulnerable people. So I have to speak that caveat to myself.

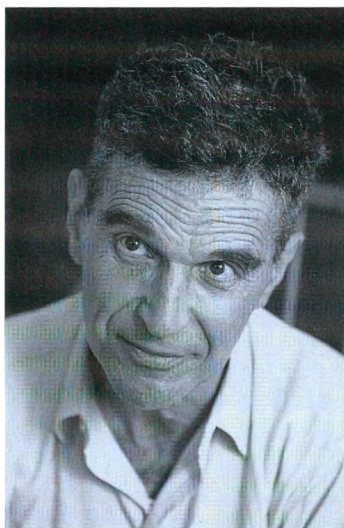
But what troubles me about all of these movements, whether it be my own profession of psychoanalysis and psychiatry or the AA movement, is that we get caught up with slogans and phrases and abstractions which then get wedded to a kind of tribalism. If you don't talk the way I'm talking, if you don't use words the way I'm using them, if you don't belong to this particular group, then you have *had* it. You are banished. And this is true of Christianity, too. And what happens then in the self-help group if you don't buy into that? We're going to say you're "hurting," or you seem to have your "problems"—and you can't fight that.

Second Opinion: We have talked about proper roles for professionals. What about the clergy, especially in times of crises, when they often feel irrelevant?

Coles: You know, when my mother was dying of cancer in Massachusetts General Hospital, she was in her eighties. She was

ready to die. She had a collection of Tolstoy's writings beside her—the short stories and *Anna Karenina*, which she had read about five times in the course of her life. Well, a minister came in, and he started on this psychological stuff. He asked her whether she felt angry because she was dying, whether she was hurting, whether she was feeling resentful, and she said, "Why, no!" He then started telling her that he could understand how she would say this, but did she want to talk to him some more about this? And he went on and on until she got so fed up with it that she exploded at him and said, "Why don't you read to me from the Bible instead of talking to me this way?" And instead of being courteous enough to respond to this Christian lady's request, he continued with his psychological questioning. When she called me up, she was livid. She said, "What has happened to the clergy?" I said, "They're brain-washed, lots of them, I fear. They've lost their faith, and they believe in this psychological clap-trap, and we have to pray for them." But she didn't feel like praying for them. She said, "I think they've gone to hell." That was about it! She had spotted that ideological bind, and she knew that the more she objected to this talk, the sicker they would say she was, because the objection becomes a basis for heightening the criticism on the part of the ideologue who will brook no criticism.

**"I'd almost like
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That's how
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Second Opinion: My colleague Don Browning, who wrote *The Moral Context of Pastoral Care*, reports that he sometimes speaks to chaplains who get burned out or worn down or dried up because they see people only in crisis, and never where they can build up a common story on which to draw. It takes some courage for him to make the case for a "moral context" among some specialists who never see people in groups and contexts at all, and make a virtue of the necessity of their way of life. Yet some other professions keep the context of family and community very much in mind. In fact, they find the human dimension to be one they can tap into and promote. I think of nursing . . .

Coles: Oh, boy, do I have feelings on this topic. I wish all of us doctors could learn to be nurses. I'd almost like to require medical students first to become nurses. That's how strongly I feel. Nurses have so much to offer us, and the way we treat them is scandalous. When I was an intern at Billings Hospital at the University of Chicago, the nurses were the guardians of my education: they were the ones who taught me so much about how to be a doctor and how to get on with patients. They were the ones who had not only a kindness and a thoughtfulness but a sense of confidence and dispatch about their work, some assurance about what they were to do. They melded knowledge with humanity almost effortlessly. I don't want to romanticize nurses.

I know that we're all human beings and that every nurse has failings, as do all human beings. But the nursing profession, at its best, possesses something that a lot of doctors really need and just don't get. In my mythical medical school we would admit people not on the basis of the premedical subjects they've taken—we wouldn't ask them to take those premedical courses or give them so much importance. We would instead ask people to work for a couple of years at community service, learn to be nurses, work at a soup kitchen or at a school. Then the letters of recommendation would not be from organic chemistry professors but from the people those would-be doctors had worked with, people who could say what kind of a human being this person was. Now, my colleagues might object, "But if people knew they had to do that to get into medical school, they'd just put in two years and do their best to earn some approval from the community or from the nursing supervisors." And I'd say to them, "If a person can do that kind of work for two years successfully, it might even become a habit." There is obviously something drastically wrong in the way many of us learn to be doctors without possessing whatever nurses learn in nursing school, without learning what nurses *are*. They have so much to teach us, just as ministers have so much to teach us, but they often don't know it, and they're

lorded over by these doctors just the way ministers are often lorded over by doctors, and particularly by shrinks.

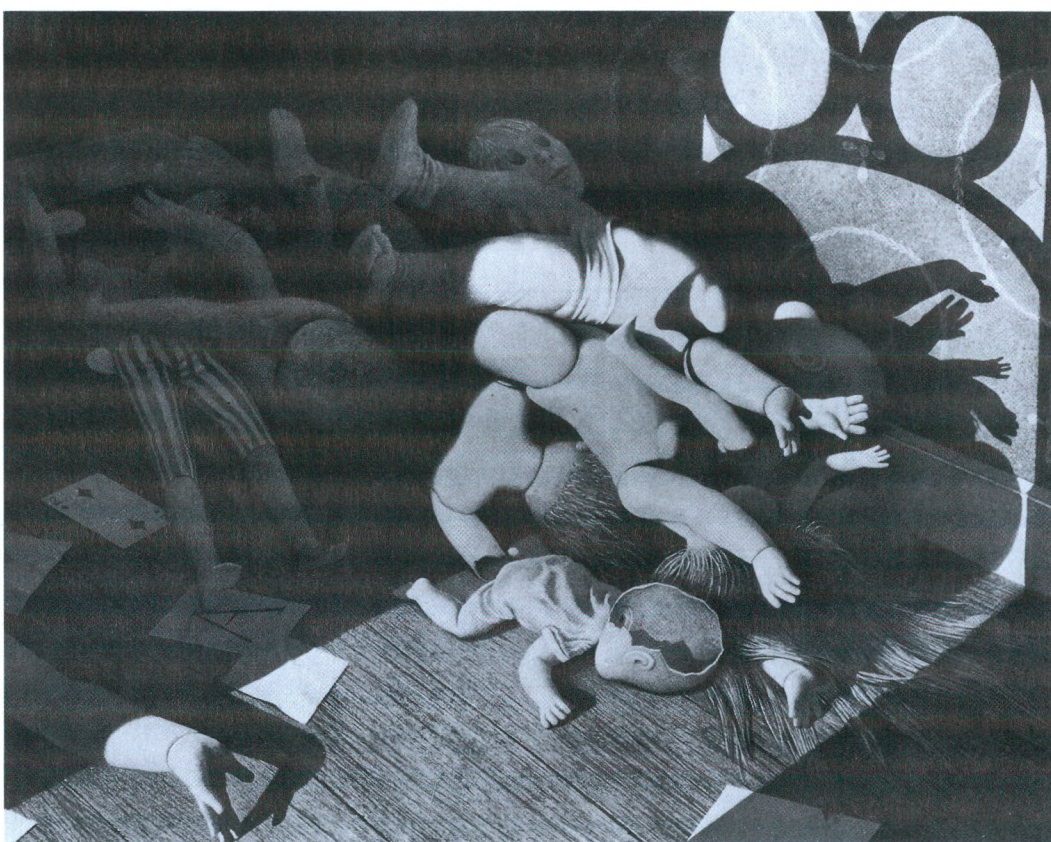
Second Opinion: I think we are facing new challenges these days when the "brain people" are making so many breakthroughs in studying the brain's chemistry. Some are reductionists who now say we are "nothing but" computers. Philosopher John Searle once said that in his lifetime he had already outlived eight final, all-purpose scientific explanations of what humans were "nothing but." In the face of these changes, what is ahead for psychiatry, psychoanalysis, psychology? Is the future strictly pharmaceutical and surgical?

Coles: Of course we'll make some strides. We'll learn from biochemists and neurophysiologists, as we keep learning in any aspect of medicine; but as long as there are human beings, we are going to need one another to talk to, to learn from. Psychoanalysis in that sense will never be outdated, insofar as it draws upon the tradition of "I-Thou," as Martin Buber put it. The fundamental person-to-person encounter will never be outdated. Insofar as psychiatry is part of the pastorate, it will live. Insofar as psychiatry stakes everything on its status in medicine, it is probably going to be in jeopardy, and what an irony. It has put all its marbles in this

medical corner, and it will end up being absorbed by medicine. Meanwhile we will find all these ways of learning from one another, and we will anoint certain people to teach us. And that's what psychiatry, without any embarrassment, ought to embrace. And that's what the medical profession ought to be *proud* to have psychiatry embrace.

Second Opinion: I had planned to ask more and have you talk more about children; but now let me ask, has most of what we have talked about today been about children best of all and most of all?

Coles: Yes, because we are all children, and thank God we are. The problem is we don't know it well enough. This is one of the things Jesus taught us—to struggle toward childhood and never forget it or outlive it. And to retain within ourselves whatever shred of innocence and trust and willingness to engage ourselves with the world in the yearning and unashamedly vulnerable way that children possess. This was one of his major lessons to us. And all this talk about being "mature" and growing up and progressing through stages and phases misses the point of how important it is to retain that *connection*—not to "the inner child" but to the sense of vulnerability and yearning that childhood is about. That's a big part of ourselves. Or it ought to be. ☉



Remnants. Egg tempera on panel by Robert Vickrey, c. 1950.

Robert Vickrey/VAGA, New York 1993.

Pastoral Care in Candyland

Maintaining Power and Life in a World of Illness

Donald J. Camp

AFTER MY FIRST MEETING WITH BRIAN in the pediatric intensive care unit, I leave feeling frustrated. He is on a ventilator and hence can only move his lips and occasionally whisper hoarsely; my attempts at lipreading fail. Physically weak, he cannot communicate through writing or drawing. During our first visit Brian introduces me to his black stuffed dog and tries to tell me his dog's name. I think the name is Max, but Brian shakes his head both "yes" and "no" when I ask him any questions.

Brian, a bright and perceptive six-year-old, is usually the only conscious child in the intensive care unit. He has spent six weeks at this hospital, following his transfer here after a four-week stay at another institution. Brian suffers from hemolytic uremic syndrome, a disease precipitated by an unknown viral or bacterial agent that sets off the body's blood-clotting mechanism. In Brian's case, this disease leads to kidney failure. In addition, the perforation of his bowel during the course of his illness has caused intestinal bacteria to spread throughout his

body—placing him in septic shock and bringing him close to death. Brian's condition remains critical from June, the time of my first visit, until the following autumn.

Medical staff members recognize that Brian's illness and long-term hospitalization isolate and frighten him. They ask me, a pediatric chaplain, to try to build a relationship with Brian; in this relationship I hope to offer empathy, reliable companionship, and opportunities for him to make sense and meaning, on his own terms, out of this chaotic and life-threatening situation. I quickly learn that Brian is quite resourceful in handling his situation. He fights his potentially isolating condition by smiling at everyone who walks by and engaging those who respond to his smile—as almost everyone does—in play activities. When I visit, Brian usually wants to play Candyland, and he always wants to win. If I do not lose naturally, Brian, without comment, takes extra turns or purposefully miscounts. He likes drama, and we both play with many exaggerated grunts and motions. "Brian, you won again, and I can never win," I say, banging the table; he laughs, points his finger at me, clicks, and motions for me to fall over. "Ahh! You got me again," and I fall onto the floor.

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Throughout the summer I play Candyland when Brian is able. Often he sleeps, and sometimes he becomes so ill that he must be sedated. Still, I try to visit him regularly and to develop a relationship that goes beyond the initial engagement of his charming smile. On a few occasions, I attempt to win at Candyland, but he never lets me—after all, in his situation winning at Candyland or any other game may be everything. In the world of Candyland he has power, control, and clear purpose, and he will not allow me to usurp his position.

In early autumn Brian's condition begins to improve. Though still in the intensive care unit, he is weaned from the ventilator; he starts talking, begins physical therapy, regains strength in his hands and arms, and relearns how to walk. When medical staff members notice a hearing loss, Brian receives hearing aids, which he wears with some prompting. A teacher tutors him regularly. In our times together Brian wants to play Candyland with less frequency, and when we do play, he sometimes lets me win. He regains some power and freedom in the real world, and he celebrates this with walks around the unit and visits to friends elsewhere in the hospital. Soon, as he feels better and grows more confident, he stops playing Candyland—at least with me.

In early October on one of my visits, Brian shows me a map he has drawn with a child-life therapist (a person who offers age-appropriate therapeutic activities to hospitalized children and counsel to families about children's development and self-understanding). On the map are his parents' home, a park, the hospital, and various other places. Brian proudly points out his new home at the hospital. We sit on the floor, explore the map, and drive cars on

its roads. Brian still delights in dramatic movements and noises—car wrecks, screeching sounds, exaggerated facial expressions, and frequent laughter. With his map of the real world, Brian explores his newfound power and confidence, and he exerts these with delight and playfulness.

The third time Brian shows me his map, I mention to Brian what I have heard from other staff

members—that a number of children from the intensive care unit have died in the last two weeks. I am concerned about his seeing the bodies or witnessing the procedures and rituals surrounding death. When I mention the deaths, Brian shakes his head yes but does not comment. When I say something about the importance of saying good-bye and crying when someone dies, Brian again shakes his head yes. I am uncertain whether he understands me, but when I ask, he indicates that he does. With his per-

mission, I add a cemetery to the map and draw a tombstone. By this time, Brian is giggling.

I can't tell whether this activity is important to Brian, for he doesn't want to draw or talk. I point to the cemetery and tombstone and remind him that this is where people go after they die; then I ask him if he knows anyone who has died. He laughs again and writes his name on the tombstone.

Brian's actions are puzzling. Does he understand this activity and all the deaths around him? Does he write his name on the tombstone to regain control of an interaction in which I have been too directed, or does this signify something else? I never overtly introduce this theme again, but Brian manages to struggle in a different way with the horror he has experienced and witnessed.

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As Halloween grows closer, Brian's map gets less attention, and he begins constructing his own house, his own world in the intensive care unit. The child-life therapist had introduced this activity, and it is clearly significant to him.

"Don, get some sheets," he says when I walk in to see him one day.

"Sheets, why?"

"To build."

I get sheets, and Brian starts setting up chairs. He shows me how to drape the sheets over the chairs to make a house.

"Here, this is mine—you want to come in?" asks Brian as he invites me yet again into his world.

"Sure!"

We sit on the floor under the sheets together.

"Get the ghost," Brian orders. He points to a ghost, made from sheets and hanging above his bed. I give him the ghost, and he starts wrestling with it—really wrestling! He hits it, rolls over it, and shakes it.

"I'm gonna get you."

"Go, Brian, go; fight the ghost. Do you need any help?"

"Get that knife over there."

I find a plastic knife and hand it to him. He starts stabbing the ghost and asks me to help. Together we hit and stab the ghost. Periodically, the ghost dies and comes back to life.

After Brian tires of ghost-fighting, I return the ghost to its place over Brian's bed. He leaves the house intact. I note that Brian has been more attentive and engaged during the house-building and ghost-fighting than during any other activity.

Soon after Halloween, Brian moves from the intensive care unit to a regular medical floor. On my first visit to his new room, he grabs my hand and leads me to the playroom.

"I wanna build a new home. You help me."

Brian and I move the toy stove and refrigerator around. We pretend that he is building a new house. Afterward, we sit and play a game, but a toy telephone keeps ringing, according to Brian.

I answer and say, "Brian, it's for you."

He grabs the phone, "Oh, no!"

"What happened?"

"Someone died. She died—oh, no," he exclaims and begins giggling.

"She died—why did she die?"

"I don't know."

"Brian, should we do anything?"

"No, they called the police."

"Did you know her?"

"No." And Brian sits back down and resumes playing the game at the table.

A similar exchange happens two more times. Once Brian pretends to cry, and I cry with him. At the end of our visit, I thank Brian for showing me his new house and ask if I can come to his house again; he invites me back.

It becomes increasingly difficult to see Brian, for he is busy preparing to be discharged. One day, though, I squeeze time into his schedule, and he takes me back to the playroom. He wants to build a house again, but this time with sheets. I find a stack of sheets, and we hang them to create a house.

I have extra sheets and ask, "Should I make a ghost?"

"Yes!"

I make the ghost and give it to Brian. He begins wrestling with it, as on the earlier occasion. I help him kill the ghost, and the ghost keeps returning to life. In the middle of this, another staff member comes to see Brian. He invites her into the house, and she also helps us with the ghost. After Brian sets the ghost aside, she and I try to start cleaning up. Brian refuses, for he is not finished. He wants us all to sleep. He experiments with different positions on the floor, while the therapist and I pretend to sleep in our chairs—an arrangement of which Brian approves. After 10 minutes of sleep, Brian leads us in taking down his house. With the sheets from the house, he sends the ghost to the laundry and banishes it from his presence, at least for now.

Brian returns home soon after this interaction, but his medical condition still requires extensive monitoring. A new phase of outpatient medical care begins with his discharge. Brian returns to the



I Went to Visit Someone in the Hospital.

Drawing by Lisa Blisz (third grade), Washington School, Trenton, New Jersey.

hospital three times weekly for dialysis, and he and his family begin waiting for the day when a kidney transplant from his mother will be possible. At present, his condition does not permit him to undergo the transplant surgery, and his mother is unable to donate her kidney because she is pregnant.

During the one and a half years that he waits for a kidney transplant, I see Brian infrequently. When I do, he remembers me and invites me, again, to play with him. On a few occasions we play Candyland. Other times we play cars. He never wants to fight ghosts again; the struggle and horror they represent Brian seems to transfer to car wrecks and the deaths that result from these incidents.

Finally, the time comes when Brian can no longer wait for his medical condition to improve.

His mother can now give her kidney, but physicians question whether Brian's body will be able to tolerate the surgery and then accept the kidney. Brian's parents and physicians decide to try the surgery, and the surgery itself goes exceptionally well. His medical condition, though, deteriorates seriously following the surgery. He has trouble breathing and spends his eighth birthday in a precarious medical state on a ventilator in the intensive care unit. Brian is scared. He knows the seriousness of his condition and responds with anger to anyone who comes near him.

Then, within a couple of days, Brian's condition improves markedly. He moves to a regular medical unit, and I visit him there.

"How are you, Brian?"

"O.K."

"Do you want me to stay now?"

"Yes . . . I'm having my birthday party tomorrow . . . are you coming?"

"Well, when is it?"

"Three in the afternoon."

I check my calendar and answer, "Sure, I can come."

"What are you going to bring—maybe something to drink? What kind of soda do you like?"

"Brian, I don't like soda."

Brian looks surprised and asks, "What do you drink, then?"

"Oh, water, fruit juice, coffee, stuff like that."

"Bring something you like—maybe that bottled water."

"O.K., I will. Now . . . what do you want to do now?"

"I don't know. I don't have nothing here."

"Nothing—at all?"

"No."

I see Matchbox cars and ask, "Are those your cars?"

"Yes, we can play with those."

Brian brings out his cars, and his hospital table becomes the scene of gore, death, car wrecks, and scenes of mourning.

"O.K., Don, now this car gets hit and my girlfriend has to go to the hospital . . . BANG! Now you have to call me and tell me."

I try calling, but Brian's phone line is always busy.

The play and violence escalate. For 30 minutes Brian narrates how his girlfriend, his brother, my brother, and a host of other characters are involved in serious car wrecks. An ambulance rushes them to the hospital, and many die.

"Try to call me and tell me she died," he says.

"O.K. Ring, ring."

Brian does not answer and then instructs, "No, Don, you have to come to my house and knock on the door."

"Knock, knock, knock. Brian, Brian, open up."

"I'm not going to open up. When bad things

happen sometimes the best thing to do is just sleep through them, so go away," Brian commands.

I leave his pretend house, and as the play continues, more characters die in car wrecks. Then Brian experiences a car wreck.

"I died," he says.

"You died," I reflect back to him.

Then Brian asks me, "How do you feel—are you crying?"

"I'm very sad," I say, as I begin to make crying noises.

"I'm dead," he repeats.

We sit somberly, and I cry some more. After a few moments, Brian's expression changes from somberness to happiness, and he looks at me with excitement: "Don, you know what—throw water on me—that'll make me alive!"

I cup my hands and dramatically act as if I am throwing water on Brian.

"I'm alive," Brian yells. "The water made me alive!"

With this, Brian stops the play and looks in my eyes: "Don, you're bringing water to my party tomorrow—right?"

"Right! I'm bringing water!"

The next day Brian's family and hospital friends gather for his birthday party. I bring bottled water, as Brian requested. We celebrate his birthday and also his new chance at living. Brian leaves the hospital not only with the knowledge that he has a new chance for life but also with the knowledge that he has the wherewithal to face illness and death and to get help in this process. That he could come through his hospitalization with such wherewithal intact is a significant accomplishment for him and for those he enlisted to help him. Brian can find others to fight ghosts with him and rescue him from death. He knows how to maintain power in a world of chaos, how to banish the ghosts that haunt him, and how to find water that brings life. Recognizing the fragility of life, Brian celebrates with those of us who have enhanced his life and who, undoubtedly, have allowed him to enhance our lives. ☺

WHO IS GOD? * WELL IT IS AN INVISIBLE
PERSON AND HE LIVES UP IN HEAVEN *
I GUESS UP IN OUTER SPACE * HE
MADE THE EARTH AND THE HEAVEN &
THE STARS AND THE SUN AND THE
PEOPLE * HE MADE LIGHT HE MADE DAY
HE MADE NIGHT * HE HAS SUCH POWER-
FUL EYES HE DOESN'T HAVE MILLIONS
AND THOUSANDS AND BILLIONS AND HE
CAN STILL SEE US WHEN WE'RE BAD *
HE STARTED ALL THE PLANTS GROWING * TO
ME I THINK OF HIM WHO MAKES FLOWERS
& GREEN GRASS & THE BLUE SKY &
THE YELLOW SUN * GOD IS EVERYWHERE
& I DON'T KNOW HOW HE COULD DO IT

Who Is God? Photo-offset by Ben Shahn, c. 1960.



Collection of the New Jersey State Museum. © Estate of Ben Shahn/VAGA, New York 1993.



Mina. Oil on canvas by Raphael Soyer, 1932.

The Metropolitan Museum of Art, New York. Bequest of Margaret S. Lewisohn, 1954. [54.143.6]
© Forum Gallery, New York.



*Ninth in a series edited by Steven H. Miles
and Kathryn Montgomery Hunter*

The Case

What Should Leah Be Told?

John D. Lantos

THE RADIATION ONCOLOGIST'S URGENT CALL to the clinical ethics consultation service at three o'clock on a Friday afternoon was my introduction to Leah's case.

"We have an 18-year-old Israeli girl with clear cell adenocarcinoma of the vagina. The family is ultra-orthodox. No DES exposure. Sent here from Jerusalem because we are experts on clear cell CA. The treatment, for her, would be a course of radiation therapy first, to shrink her tumor, and then a hysterectomy. Dad doesn't want us to tell her that she will be sterile. We don't feel comfortable operating without her informed consent, so we've got to tell her. What should we do?"

"What's her prognosis?"

"Well, it's complicated. If the tumor responds to radiation, then she can undergo surgery and probably has a . . . oh . . .

60–70 percent chance of two-year survival. If the radiation doesn't work, the surgery has to be much more extensive and probably wouldn't even be worth doing. Depends whether she has metastases. In that case, she probably has six months to live."

"Do you think the radiation will work?"

A pause. "Probably."

"Is there any way to modify the procedures to preserve fertility, even if it led to a worse prognosis for survival?"

"No way. With a tumor like this, she's probably infertile now. If not, the radiation will have to include her ovaries, and they'll be destroyed. Even if they aren't, if the radiation works, she needs a hysterectomy. No. No way. Look, it's pretty clear-cut. She'll die without therapy. With therapy she has a 60 percent chance of survival, but she'll definitely be infertile."

"OK. We'll come by and talk to her and her father, if that's all right with you."

"Great. Oh, and could you see them quickly? They say they have to be home before sundown for the Sabbath."

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A number of other people from our clinical ethics center were still in their offices. I gathered them up, and together we went down to the ward. We stood around in the hall outside Leah's room. She was lying in bed with her Walkman on. Dad spoke a little English. Leah didn't speak any. The oncology social worker had lived in Israel for a year and spoke a little Hebrew. Somebody had found a pathologist who could translate. Dad pleaded with us.

"Please don't tell her that she will be infertile. She was recently engaged. That's how all this started. When she went to talk to the rabbi's wife about . . . about . . . *niddah*, you know, the rules regarding marital relations, she told the rebbitzin that she was bleeding every two weeks. That led to the exam, just last week, and suddenly we're here.

"The wedding was to be next month. Now, it will be off, of course, but she doesn't know that yet."

"You mean he won't marry her now?"

"No. No. The law will not permit it. If a woman is known to be infertile, she is permitted to marry only an infertile man or a widower with children. It will break her heart. If she needs the treatment, give her the treatment. We will explain to her about the infertility later."

"We can't do that. She will need radiation therapy to her vagina, uterus, and ovaries and then will probably need a hysterectomy. We need her informed consent. We have to tell her that we're taking her uterus out."

"But she doesn't understand any of this. She cannot consent. Look, tell her you're taking her uterus out. Just don't explain what that means."

"Surely she'll know."

"She won't understand. She's very naive."

"I don't think we can do that. We have to be certain that she understands."

"How can she understand? I don't understand. . . . I need to talk to my wife about it. Can we wait until she gets here?"

"She should be treated as soon as possible."

"My wife is coming on Sunday."

"It's your decision."

"Can we go home for Shabbos?"

"Sure. We always start this treatment protocol on Sundays. Go home tonight and we'll schedule an admission for Sunday afternoon."

"Goodbye."

"Shalom."

"Shabbat Shalom."

LEAH DID NOT SHOW UP for her admission Sunday. On Tuesday, Dad called. He had gone to New York to speak to a famous rabbi. According to the rabbi, treatment was ethically obligatory. If life could be preserved, it must be. There was no choice to be made. Leah's mother and father agreed that she must be treated. They still requested that Leah not be told that she would be infertile but said they would abide by whatever the doctors wanted to do. "We are in your hands," Leah's father said.

The ethics case conference took place the next day. It was more crowded than usual. The ethicists were there, of course, and the gynecologists, the radiation oncologists, the oncology social worker, a couple of adolescent medicine doctors, the chaplains, and a rabbi. Obviously, the word about this case had gotten around quickly. The discussion that followed the case presentation was heated:

"She has to be told that she will be infertile. Her consent would not be informed consent without that information. You'd be sterilizing someone without their permission."

"Strictly speaking, we wouldn't be sterilizing her. She is sterile now. Her

tumor is so big that she couldn't possibly get pregnant. Without treatment, it will continue to grow, and she will be sterile and die. With treatment, she will be sterile and might live."

"Her life might not be worth living if she is sterile. That should be her decision to make. If she chooses to die rather than be infertile and live, her choice should be respected. But she can't make that choice unless she knows what we all now know. She must be told and must be allowed to decide."

"How can an 18-year-old make a decision like that?"

"According to the law, she can make it."

"According to your law. Not according to her law."

"What would happen if she were still in Israel?"

"She would not have to consent to treatment. Parental consent would be sufficient."

"What if she was 17 instead of 18, and was here?"

"Legally, her parents could decide."

"If it would be morally defensible to treat her without her informed consent in another country and morally defensible if she was just a few months younger, I'd say it would be morally defensible now. A few months or a few miles shouldn't change what is right or wrong."

"I don't think it would be right to treat a 17-year-old without consent if she can understand the treatment and the alternatives. It's wrong to sterilize anybody, no matter what age, without their consent."

"She is already sterile."

"Maybe."

"Definitely."

"It'll be more definite after a hysterectomy."

"I think we are only considering not

telling her because she is a girl. If we had a boy with a seminoma who required castration, you would certainly tell him the consequences. And you'd let him decide. We just think that a man without balls may not have a life worth living, but a girl without ovaries does."

"Is that discriminatory against women or men?"

"A boy could donate sperm before the operation, so he could still father his own children."

"Could she donate eggs?"

"She would have to be pretreated to stimulate follicle development. That would take time. The hormones might stimulate the growth of her tumor and make her prognosis with treatment worse."

"The problem is that her religion is a sexist, patriarchal religion. Infertility is abhorrent to her because a woman's life has meaning only if she has children."

"Infertility would be even worse for a Jewish man."

"It's more complicated for her. She was to have an arranged marriage. According to rabbinic law, if she is infertile she is no longer fit for marriage. The cultural influences are making the problem worse than it has to be."

"Aren't we all conditioned by our particular culture but allowed to make choices for ourselves anyway?"

"It sounds like we're culturally conditioned to think informed consent is a good thing, even though most people in the world do not."

"Don't you think infertility would be a problem for a marriage in any culture?"

"No. It's worse."

"In traditional Judaism, there is no role for patient autonomy. Lives don't belong to individuals. Life comes from Adonai. If treatment can preserve life, it is obligatory.

If it is obligatory, one cannot refuse. Consent and autonomy are alien concepts."

"But people can choose to believe in rabbinic Judaism or not believe in it. She could choose to reject her religion and exercise her autonomy."

"That would take unbelievable strength and courage. She's 18 years old, in a strange country, and facing a terminal illness. She needs all the spiritual and emotional support she can get."

"So the religious issue cuts both ways. If she really believes, she would have to consent, but the fact that she believes makes the consequences of consenting worse."

"It doesn't *make* them worse, it just formally recognizes that they *are* worse."

"It sounds like we're saying that, in order to refuse treatment, she would have to stop being a Jew. We're not interested in informed consent here; we're trying to convert her."

"Given the fact that she is already infertile, what difference does it make whether we tell her now or tell her after treatment is begun?"

"The difference is whether we respect her autonomy."

"But her culture doesn't believe in autonomy."

"Yeah, well, she's in America now."

"Great, informed consent as a form of philosophic fascism."

"It seems to me it would be acceptable to begin the treatment now without giving her information that will only make her depressed. Later, when she is recovering, she can be informed that one of the long-term consequences of her disease is infertility."

"After that, she'd never trust anything a doctor told her again."

"That's not true. People trusted doctors

long before doctors thought it important to tell people the truth. People want beneficence first. They'll forgive us a few half-truths if they were offered in good faith."

"But who should decide which truths are crucial and which aren't? The doctors?"

"Generally no, but occasionally yes. Maybe we've gone a little overboard with truth telling. We think it is the only ethical obligation. When informed consent was invented, there was always a sincere argument for therapeutic privilege. I think this is the rare case in which it would be appropriate to invoke the therapeutic privilege."

"What makes it appropriate in this case?"

"The patient is on the borderline of competence. The treatment is clearly in her best interest and is medically indicated. She comes from a loving family, and her parents have her interests in mind. Furthermore, she comes from a religious tradition in which treatment is obligatory. Finally, the information you want to give her is virtually irrelevant to the treatment decision. We are not making her infertile—she is infertile and has been so for a while now. What does it matter whether we tell her that now or a month from now?"

"It's the principle. She is not on the borderline of competence. She is clearly competent, as competent as we are. Furthermore, the treatment is not *clearly* in her best interest. You think it's in her best interest. She might think differently. The whole idea of informed consent is to allow patients to weigh the risks and benefits of treatment according to their own values. How do you know what she would think unless you ask her?" . . .

"Her rabbi has assured her that if God wants her to have children she will have

children."

"Well, I have nothing against a second opinion."

"What if you tell her, and she refuses the treatment?"

"We'd have to let her die."

"Would you feel good about that?"

"Of course not!"

"Would you feel you'd done the right thing?"

"Yes."

"In what sense?"

"I would feel that I had tried to give a patient all the information necessary for her to make an informed decision about her medical treatment and that I had respected her decision even if it differed from my own."

"So you think it is just as OK to refuse treatment as to accept it? You don't think treatment is morally preferable."

"You're not listening. I think treatment is morally preferable. I'm just not willing to impose my own views on another person."

"But you'd try to convince her?"

"Yes, but I'd give her the right to refuse."

"What if she was 17?"

"I don't know."

"Well, I think we have to tell her everything."

THE FAMILY CONFERENCE WAS THE NEXT DAY. Leah was there, with her Mom and Dad beside her. She looked a little scared but also intrigued to be the center of so much attention. About 10 doctors, two lawyers, a philosopher, and some medical students were present. It was like a presidential press conference. The gynecologist spoke slowly, pausing after every couple of sentences to let the pathologist translate.

"You have cancer of the vagina. It has

started to spread to your uterus. To treat it, we need to give you radiation therapy. If the radiation is effective, we will then do a hysterectomy. That means we have to take out your uterus."

"Isn't there any other treatment for this cancer?"

"No chemotherapy has been shown to have any effect on this type of cancer."

"Can I have the radiation without the surgery?"

"Radiation by itself doesn't work. Radiation just shrinks the tumor so that we can do the surgery."

"And if the radiation doesn't work?"

"We cannot do the surgery."

"And then?"

"Then survival is very unlikely."

Leah nodded.

"With treatment, you have a 60 percent chance of surviving for two years. Without it, the cancer will progress and you will die. After the treatment, you will be infertile. That means you will not be able to get pregnant or have children of your own."

"Isn't there always a chance that I can have children?"

"No. Not without a uterus."

"No chance?"

"None."

Leah and her mother spoke to each other quietly in Hebrew. Her mother asked, "Couldn't she have a uterus transplant?"

"Impossible."

"Could she have a child using a surrogate mother?"

"Her ovaries will not be able to make eggs. So we could not harvest the eggs for implantation."

Leah spoke. "The rabbi said I will still be able to have children."

"I disagree, but I respect your rabbi's opinion."

Slowly, silently, tears rolled down her

cheeks. She turned to her mother. Her father looked at the doctor with a baffled, uncomprehending look of pain. Her mother hugged her tight. The doctor massaged his forehead, his head bowed, elbows on his knees. Leah cleared her throat and looked up at the doctor.

"If I can't have children, I don't want the treatment."

The father sighed, shook his head slowly, and slumped in his chair.

"That is your choice to make. But we don't have to decide today. Go home and think about it. We always start the treatment protocol on Sunday. If you change your mind and decide to go ahead with treatment, call me. Do you have any other questions?" He looked at his watch.

"No. Thank you."

"Good-bye."

"Shalom."

TWO DAYS LATER, LEAH RETURNED to the hospital. She said she wanted treatment. She signed a detailed informed-consent form that was written in English but that the pathologist translated for her. She did not want to talk to the doctors about why she had changed her mind. She told the social worker that her rabbi in Israel had assured her that if God wanted her to have children, she would have children.

Leah came for treatment on Sunday. She responded well to radiation, underwent a hysterectomy, and returned to Israel after two months. Seven months later, she got married. Her fiancé, whom she had met only once, had recited the entire book of Psalms for her every day while she was gone. Told of her infertility, he insisted that the marriage go forward. Their rabbi did not object. The couple planned to adopt children. ☸

NOTE

This essay presents a reconstruction, rather than a transcription, of the conversations that took place regarding Leah's case.

Commentary

An Uninformed Choice

Stacy K. Offner

IT IS HORRIFYING TO THINK that all the doctors, ethicists, social workers, and chaplains gathered together to determine a medical course of action on behalf of an 18-year-old Israeli girl stricken with vaginal cancer could come so frighteningly close to allowing the cancer to survive rather than the human being. It is difficult to believe that a presumably intelligent and thoughtful group of professionals could allow their thinking to run so amok that they came so painfully close to the “logical” conclusion that an 18-year-old girl, whose life was in their hands, should die rather than receive treatment for her cancer.

There is modest comfort in the adage “all’s well that ends well,” for Leah ultimately chooses treatment and goes on to marry her fiancé. And yet it is hardly because of the wisdom emanating from the case conference. Though the conference could have focused on the degree to which treatment could prolong life weighed against the pain and indignities of the treatment itself, this is not the way the

discussion evolved. Where did the dialogue go wrong? Where did the discussion take its bizarre turn?

The first hint of wrongdoing in the presentation of the case is that throughout the manuscript dedicated to her situation, Leah is never referred to by her full name. Though this is surely a convention used to protect confidentiality, it is precisely in our conventions that some of our truest nature is revealed. I find myself wanting to address Leah by her full and proper name, to accord her the respect and affirmation that comes with the utterance of her complete name, to grant her complete personhood and fair representation. But I am at a loss. In the context of what I get to know about her, the woman whose life is in the balance does not have a full name. For the record, she is simply “Leah.”

What do we know about Leah that will help us make the right decision on her behalf? Not much. We know she is 18, she is engaged to be married, she lives in Israel, and she is a halakhic Jew (that is, she lives by Jewish law). We know that she speaks no English and that she has clear cell adenocarcinoma of the vagina.

Though they try to do the right thing, the group of medical, ethical, and mental health professionals

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end up by being disrespectful of two essential components of Leah's makeup: they are disrespectful of her womanhood, and they are disrespectful of her Judaism. Fortunately, the story has a happy ending: Leah accepts treatment and is able to proceed with her wedding. But the reason for the happy outcome is nowhere to be found in the discussion. The weaknesses inherent in the discussion must be addressed.

Permeating the discussion of Leah's case are some very significant issues of Jewish import. The conflict regarding proper treatment for Leah revolves around two presumptions regarding Jewish life and law. The first presumption is inarguable: human life is of the utmost importance. This presumption would lead to the definite conclusion that surgery is necessary, even though it would render Leah infertile. The second presumption rests on far shakier ground. The claim is made that once Leah is infertile, Jewish law will not permit her marriage to her fiancé. In the words of the case: "The law will not permit it. If a woman is known to be infertile, she is permitted to marry only an infertile man or a widower with children."

It is on the basis of this latter "law" that Leah's father implores the committee not to let Leah know the consequences of the surgery before it takes place. His fear is that, knowing that the marriage would be forbidden, Leah will opt not to have the surgery even at the risk of her own life.

My fear is that readers of this case can only arrive at some negative conclusions regarding Judaism itself: (1) "Isn't Judaism archaic to have such a horrid law?" and (2) "Obviously, the law doesn't really matter because the rabbi goes against his own law in the end, when he actually permits such a marriage to take place." Neither conclusion is fair or justified. Both conclusions are based on the assumption that we have been given the whole truth, but that is simply not the case.

Many Jewish legal codes indicate that infertile women may, indeed, marry fertile men. Judaism has always recognized that the primary goal of marriage is love and companionship. Procreation is of crucial but secondary importance. Specific reference to in-

fertile women marrying fertile men goes back to Talmudic times. A discussion arose concerning how long a woman had to wait after divorce before she could remarry (*Yevamot* 42b).¹ The rabbis determined that she would have to wait three months in order to assure clarity regarding the paternity of a child should she become pregnant. The discussion in the Talmud then turns to whether the woman would be required to wait even if she were barren. Clearly, the problem concerns only a waiting period, not the forbidding of the marriage itself! What emerges is a halakhic proof text for the permissibility of marriage between an infertile woman and a fertile man. Other cases as well point to the clear possibility of marriage for women who are infertile (*Even Ha-Ezer* 23:5; Isserles in *Even Ha-Ezer* 1:3).²

"The Case: What Should Leah Be Told?" exposes the fact that many people have a vastly oversimplified understanding of Jewish law which perpetuates some unwarranted myths about Judaism: that Judaism is a religion of law and not a religion of life, that Judaism is a religion of stern justice and not one of compassion, that Jewish law is rigid and unyielding rather than dynamic and evolving. As the Jewish scholar Hyam Marcoby (1991) has observed,

Halakhah is too often presented as a monolithic structure, in which all laws are of equal weight and all have similar Divine sanction. The reality is that the history of the halakhah is one of argument and differences of opinion, so that any decision, even when "fixed," is of a provisional kind, since it is the outcome of discussion and debate. Moreover, the provisional character of halakhah is itself sanctioned by Jewish tradition, which insists on preserving the dissident opinions as a basis for possible future contrary decisions.

None of the participants—not even Leah's father—seems aware of the sophistication of Jewish thought and practice. Might Leah's fiancé break the engagement upon learning that Leah was now infertile? Perhaps. But one hopes that he might react more

like the biblical Elkanah, who, upon learning of his wife Hannah's barrenness and of her distress, attempts rather to comfort her: "Hannah, why do you weep? Why don't you eat? Why are you so unhappy? Am I not dearer to you than ten sons?" (1 Samuel 1:8–9).

Fortunately, the famous rabbi with whom Leah's father consults is better versed in halakhah than Leah's father. The rabbi indicates that there is no choice to be made at all: treatment of the cancer is a necessity. Jewish law is overwhelmingly clear in this regard. Leah's case is not a complicated scenario that pits a choice between one human life and another. Nor is it even a case which pits human life against potential human life. The thrust of Judaism always renders human life as something most sacred—even when it is measured against potential human life. How much more so, then, in Leah's case, where human life is being weighed on the one hand only against the alternative of death. The choice put forth to the ethics committee in Leah's case is clearly the choice put forth in Deuteronomy 30:19: "I have set before you life and death, blessing and curse. Choose life, therefore, that you may live."

Leah's father believes that surgery is the right choice. He just doesn't trust that his daughter will agree. What should he do? He is now confronted with a choice rooted in his fear. If he tells his daughter the facts, she may very well choose to have treatment withheld. Given the father's beliefs, this is no mere medical option but a blasphemous choice of death itself. If he doesn't talk to his daughter, he may gain the outcome he seeks but at the price of an honest and trusting relationship with his daughter.

Sadly, no one seems to tend to the father's dilemma, and so he makes fear the victor when he implores the doctors not to seek informed consent.

Leah is also failed at this point—first by her father, who seeks to withhold information from her, and then by those among her doctors who choose to respect the father's wishes at the expense of the woman's rights. One wonders whether an 18-year-old son would be treated with the same disrespect.

When Leah is finally told of her predicament, the dialogue reflects a pitifully low level of true communication. In fact, the mood created is more like that of a press conference than of a conversation. The doctor's presentation is clipped and clinical. Leah's questions are answered directly, but the burden is on her to come up with the right questions. Gone is the free-flowing conversation that allowed participants in the case conference to grope, to probe, to consider their thoughts and beliefs and arrive at their conclusions.

Worse still: Leah ultimately arrives at a decision that is based on incomplete information! After hearing a brief presentation of some information, Leah decides: "If I can't have children, I don't want the treatment." But no one seems to have bothered to tell her that she would be infertile in any case! Leah's father, hearing her pronouncement, simply sighs and shakes his head. No communication, no further explanations, no effort to explain why another choice might be better.

What a shame. What could have been a demonstration of human beings struggling together to find the best response to life's circumstances is instead a tragic comedy of errors. In frustration over

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what might have been—what should have been—it is tempting to look for a lap in which to lay the blame. Judaism, as history exemplifies, becomes a convenient scapegoat: “The problem is that her religion is a sexist, patriarchal religion.” These words, which rise out of the heated debate regarding Leah’s life, have no identifiable source. Who spoke them? A doctor? A chaplain? A man? A woman? They are words that have been spoken by too many people, representing both genders and too many professions. These words also reflect a form of anti-Semitism, and though they do not arise from overt hostility, they are dangerous nonetheless because they arise out of ignorance.

The advent of case stories in the field of medical ethics has developed out of a realization that decision making is not particularly simple. Likewise, decision making involving Jewish law is not so simple, either. No real-life scenario is simply black and white. Nor would a real-life religion carve out a legal system that is strictly black and white. We are all tempted by the lure of the simple answer, but only a sophisticated approach to Judaism and a

sophisticated approach to Jewish women like Leah will bring us closer to the best in ourselves. Leah is but one woman living in the context of one religious system. Surely she serves as a reminder that all of our “second opinions” need to be sensitive to the depth of each person’s unique life circumstances.🌐

NOTES

1. *Yevamot* is the tractate of the Talmud that deals with marriage law.
2. *Even Ha-Ezer* is the section of the sixteenth-century legal code that deals with marriage and divorce. Isserles, a sixteenth-century rabbi, is considered one of the greatest halakhic authorities of all time.

REFERENCE

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Commentary

Caring for Leah

Tod S. Chambers

AFTER READING THIS CASE STORY, I wished somehow to see Leah from the perspective of her own community. It seemed that a group of Orthodox Jewish women could supply at least a hint of the tone and resonance of Leah's voice, which was absent from the medical team's discussion. I decided to present Leah's case to a group of American Orthodox women and listen to their response. I thought that these women—insiders to both Judaism and American culture—could provide insights into Leah's problem. The five women who participated in the discussion differed in ages, backgrounds, and life experiences. One was an artist, one worked part time in a day camp, and one was a social worker. The group included a young unmarried woman, a mother of teenagers, a grandmother, and a woman expecting her sixth child. One woman was a member of a Hasidic sect; another woman had not been raised in an Orthodox home.

Below are excerpts from a transcript of their conversation. I had given each of the women a copy

of Leah's case up to the point where the medical team decides to inform Leah of her condition. During their discussion the only information I added was that she had met her fiancé only once and that she could not use a surrogate mother. Otherwise I remained a silent observer. Although the women rarely addressed me directly, they were always aware of my presence as an outsider and included explanations when they thought it was necessary. Following these excerpts I add my own voice to the dialogue by comparing the two discussions of Leah's case.

The Discussion

"IT'S A VERY COMPLICATED CASE. How could it be that an 18-year-old girl who is about to get married doesn't know about sexuality, about uteruses and vaginas and things like that? Even in Me'ah She'arim [a right-wing Orthodox Jewish neighborhood of Jerusalem that is populated mainly by Jews from central and eastern Europe]? How could that be?"

"I think it's very common."

"Is it? Is it common that no one has

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spoken to you and it's just before you are getting married?"

"Do you personally know people who are that naive?"

"No."

"Does anyone here know anyone personally who is that naive? None of us can make a judgment because we don't know the people involved in the Me'ah She'arim community."

"In the Me'ah She'arim community are you allowed to listen to the radio?"

"Well, there are all kinds of people there. I know people who do."

"We don't know the level of religiosity of this girl. We don't know which cult, which background she is coming from."

"If there are people so sheltered, so naive when they are 18 that they don't know that if you take out your uterus you're sterile, I don't imagine . . ."

"It might be her parents' concept. It may not be her concept."

"It's strange that someone could be 18 and not have these basic facts."

"If none of us knows anyone like that, I don't think we can judge them."

"We shouldn't assume that she is from the Me'ah She'arim community. There is also Bene-Berak [an area east of Tel Aviv settled by Polish Orthodox Jews]. There are lots of communities. We shouldn't pigeonhole her into one community."

"The only thing that led me to believe that is that she had an arranged marriage. In a more modern Orthodox family it would be something of her choice."

.....

"Can I say my own personal response? If it were my own daughter, I definitely would have told her. I think that it would be criminal to do something to someone's body without telling them. According to halakhah, she would definitely have to

have the surgery. There is no question about that because it is saving her life. I am not really familiar with whether she can get married if she is sterile. I don't know a thing about that."

"I don't know that either, but I can tell you this: if it was me, not only would I want to know, I would definitely expect to know."

"I definitely feel that she should be told. There's a lot of emotional repercussions, and I think that's partly why the parents hesitated. This could create a tremendous depression in the girl. She's getting married very soon, and what will that do to her relationship? According to this it will be canceled. Again I don't know if that would be 100 percent sure."

"You know, if he loved her enough he would, he could, still marry her. I don't know the law."

"They could get married despite the law."

"I don't know."

"It might depend on her relationship . . . whether the people really know each other."

I broke into the conversation: "I can answer that. Leah and her fiancé have met only once."

"Only once?"

"We still can't conclude anything from that. We can't tell how deep their connection is. My grandmother met her fiancé only once. They took a walk around the block, and they decided to get married, and she was madly in love when she went to the wedding. So it can happen."

"But how does it affect her future? Will she be able to marry?"

"Yeah, I have a lot of very religious friends. I don't know how religious she is, but I can understand the way Leah's father is thinking because I know how my friends'

parents think. Once anything goes wrong, you're maimed and nobody is going to want you. It's a very different mind-set. Like there is something wrong with you."

"How would anyone know?"

"Word gets out. They'll ask your neighbors and your friends and your teachers and your father's best friend's brother. They know everything about you. I am assuming he is thinking that if anything is wrong with his daughter then for the rest of her life she's by herself."

"In a sense I don't think that we are talking about Israel versus America but one version of Orthodox Jewish law versus secular law. There is somebody who is not here tonight. When I called her, she said she was not very knowledgeable about Jewish law, but she thought she would have one thing to contribute and one thing only. I said, 'If you were to come and say that one thing, it would be so valuable,' and she said, 'Well, you can quote me.' [Laughter.] She said if you have a medical or ethical dilemma you go to your rebbe, you go to your special rabbi. She would rely on the judgment of the rabbi. Then she said, 'Probably that would be what most Orthodox people would do.'"

"That's what the father did."

"So the rabbi said that she definitely should have the surgery. There's the law that says to save a life is more important than anything else, even if you break Shabbat or whatever. But he didn't approach the rabbi about the consent part and whether he should tell his daughter—or at least we weren't made aware if he did. But that is certainly an issue that you can bring to the rabbi also. The rabbi's response, if it differs from the medical response, gives you something to discuss, but the rabbi might well agree with the medical opinion. And then you have your case solved." (Laughter.)

.....

"If she is already sterile, then the operation is not going to make a difference. The talk about what is going to be done because it's going to make her sterile is not really relevant. If she's already sterile, she's already sterile."

"It says that the tumor is so big that she cannot possibly get pregnant."

"It's an assumption. And something else that I question is the assumption that she cannot marry a fertile Jewish man. That's also assumed. I don't know, and I don't think anyone there knows. There are so many assumptions."

"I don't know."

"They are already engaged, so I would question it. I would also question her being so naive. They think they will remove her uterus without her realizing it. These are things I question. I think it is taken for granted here that according to secular American law she would have to give her consent, and according to Jewish law she would not have to give her consent. Another thing that is just assumed."

.....

"We don't know if these treatments will be effective at all. We don't know if halakhically this will affect who she could marry. Assuming she does want to marry the man she met and assuming he doesn't want to marry her—they are already engaged—we don't know if this means they would have to call off the wedding. We don't know what she is really thinking. Where does she fit in over here? We're talking about her, but we don't know what she thinks."

"Yes!"

"Yes!"

"I am wondering about the informed consent. The article is assuming it was necessary from a secular standpoint, not

from a Jewish standpoint. I wonder also if it was not just ethically proper that a father should tell his daughter about surgery and the repercussions of surgery but whether halakhically he must. This family is the type that would rely on the rabbi's judgment for such things. All these questions we are asking are questions that this rabbi should be asked."

"From my own experience, there is a tendency among people from Eastern Europe not to tell things to people—thinking that by not telling them they are protecting them. When my grandfather died, I was not told. What was the point? I was going to find out anyway."

"Yes, they are very respectful but secretive, not open. In my house everything gets said. There isn't anything that is held back, and I imagine in most homes it is very similar."

"I don't think that's a halakhic thing. It's just a coping mechanism. My mother lived in Russia during the forties, and her mother died, but her father did not tell her. His was not a halakhic decision."

.....
 "It seems cruel not to tell her, but in that culture they have a different standard."

"I had a cousin that came from that culture who had six children. After the sixth child was taken from her, they found something, I don't know what, and they did a hysterectomy at the time that they took the child. Even after six children she was devastated. Something we didn't discuss is that in that culture they have a lot of children. In the modern world you have two children. Four children is a lot."

"Based on what we know of the case, do you think that if this girl was told about her condition, she might opt for death rather than surgery?"

"I can't believe that she would choose to die because that goes against her whole religious philosophy. It goes against the rebbe's."

"She might opt to die because, for her, she has no reason to live. They don't go out and get jobs. Their whole life is their family."

"Some are teachers."

"Even if they are teachers, their whole mind-set is to have children and create a big family."

"In other words, she might be suicidal."

"She might be suicidal, and the father does not want to deal with the emotions presurgery—the depression, the anger, everything. He probably doesn't believe in psychologists or social workers. He could take her to the rebbe and have the rebbe speak to her. No parent wants to go through this. So this explains the choice from his viewpoint."

"And it is a male viewpoint."

"It's a patriarchal . . ."

"You have to understand the underlying reason. In Eastern Europe—well, we don't know if this family is from Eastern Europe."

"They could be Iranian!"

"Or Moroccan! We don't know."

"In the Sephardic community [Jews from the Mediterranean, the Middle East, and the Far East], the women are more subservient. Less so in the secular Sephardic community. It is much more a patriarchal social structure. The father is not questioned."

"He calls the shots."

"I would still want her informed. If she were in Israel, I would still want her informed. It's her body, her life."

.....
 "Suppose this was a Sephardic family from the most patriarchal of societies and

you were involved in this case as a physician or social worker. Would you say that in this patient's society the father calls all the shots, makes all the decisions, and therefore it is our duty to follow the father's wishes? Would you want simply to respect the culture? Or do we say that this woman needs to be told? Do you work on the father to get him to change his mind?"

"I would. The father and the mother."

"Yes, the father and the mother, both."

"If the father and the mother don't change their mind?"

"I think you should go back to the rebbe."

"If I could not get anywhere, I would try to get access to the rebbe. He has influence over that family. My experience of rabbis is that they give good answers that in the whole scheme of things make a lot of sense. I think it would be very respectful of their culture to try to work within their framework. If that still got me nowhere, I don't know what I would do."

"She wouldn't get her period. It wouldn't take her long to know . . ."

"I think we're all agreeing that it is to this young lady's benefit to be told."

"I mean physically she would know that there was a problem. She wouldn't get her period, and nobody would tell her. They're planning never to tell her."

"She's already in the hospital. She's already aware what's going on."

"Right."

"I think this young lady should be told, fully. And I think that most people—even the people in my own family who would not tell in this situation—they themselves would want to know and feel very angry if they were not told. So I think from what I am hearing we are all in agreement that this girl should be told. The question is, What if that clashes with the way that family works and their culture?"

"You don't want to destroy the relationship between the father and the daughter, and I am sure there are other children in the family. You don't want to destroy the father's role totally, and that has happened within that community. If a very Orthodox family immigrates to Israel, the father's role will totally change. The father will be depressed, sometimes suicidal. Males committing suicide—it's not publicized. You want to keep the family structure intact, yet you want to give the girl the right. It's a very fine line. I think the best way is to talk to the parents, talk to the rebbe, work within their system."

"I think we all agree about that. Does anyone have a suggestion about what to do if there is a deadlock? If you have worked through their system and the result hasn't changed, do you go with your belief that the family culture and beliefs should be respected? Or do you decide that she should be told, regardless?"

"To answer your question, I don't know."

After the women finished their discussion, I read the conclusion of the case. When I read how her fiancé recited the book of Psalms, a delighted sigh filled the room.

Commentary on the Commentary

JUXTAPOSING THE TWO DISCUSSIONS brings out telling differences. While the medical team conceives of the dilemma as a conflict between "our law" (secular) and "her law" (halakhic), the Orthodox Jewish women view it as a tragic situation that requires resolution within the Jewish community.¹ Where the physicians determine the boundaries of the conflict, these Jewish women strive to locate sites where the borders can be crossed.

The participants in the ethics case conference are primarily concerned with the abstract principles of autonomy, beneficence, and veracity. None of the participants demonstrates a specific relationship with Leah, nor do any of them express a desire to establish such a relationship prior to making arguments about her care. Further, their discussion lacks any concern for understanding Leah in terms of her community, her family, or—most important—her own story. Leah is defined simply as a “Jewish woman from Israel,” and the absence of her voice in the text (prior to the decision to inform her) vividly illustrates her lack of presence as a distinct individual in their considerations. Throughout their exchange, the medical team tends toward moral judgments based on abstract principles and detachment from the situation.

While these Orthodox Jewish women agree that it would be in Leah’s best interest to be informed, they focus their efforts on attempting to understand Leah’s place within a web of relationships in the Jewish community. From their viewpoint, *traditional Judaism* is not a stable, predetermined entity but a term covering a diverse group of communities bound by both ethnicity and religious orientation.

Leah’s case, however, provided only fragments and hints of her relationships. It was like a detective story with far too few clues. Leah’s arranged marriage suggested that she may have been from an “ultra-orthodox” faction. They hypothesized that she may have come from the Me’ah She’arim community or Bene-Berak. The father’s desire not to inform his daughter of her condition led the women to suggest that the family may have been of Eastern European descent. The women thought that if the family was Sephardic, this could explain the father’s apparent dominance in the family’s decision making.

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of the dilemma as a conflict
between “our law” (secular) and
“her law” (halakhic), the Orthodox
Jewish women view it as a tragic
situation that requires resolution
within the Jewish community.**

Throughout their attempts to restore Leah’s context, the women often engage in storytelling. Tales of Orthodox women in similar situations allow them to imagine the details of Leah’s story that the medical team’s discussion did not provide. They tell about a grandmother falling in love with her future

husband after knowing him only one day, about families asking rabbis for opinions on every action in their lives, about not being told of a relative’s death, about a mother of six who is devastated when she learns she can’t have any more children. Often in attempting to situate Leah, the women engage in their own stereotyp-

ing of various factions within the Orthodox community to confirm or subvert previous claims. In discussions of medical conditions, physicians often draw upon personal anecdotes to persuade other physicians of the validity of medical arguments (Hunter 1991:69–82), yet throughout this medical team’s ethics discussion, their arguments are based solely on principles and rights. The physicians do not have any stories of Leah or “someone like her” to draw upon. Without such stories, they remain outsiders to her community and to her worldview, and they must turn toward a review of ethical systems. But no matter how richly rendered, the women’s tales are unable to tell Leah’s story. As one woman proclaims, “We don’t know what she is really thinking. Where does she fit in over here? We’re talking about her, but we don’t know what she thinks.”

Gathering stories and knowing Leah within the web of her social relations are both preparatory stages to resolving this dilemma within her community. Communities have their own ways of resolving social conflicts, including bioethical ones. (As one woman observes in a comment not included above, “There are certain rabbis that specialize in

medical ethics. You would go to them.") The cultural anthropologist Victor Turner (1974) has argued that inevitably all societies experience periodic social dramas, and these dramas follow a universal structure. In response to the escalation of a crisis, Turner argues, societies move into a "redressive phase" in which formal mechanisms for reconciliation are brought forth. The ethics conference, which makes up the majority of Leah's story, is a rite of reconciliation often found in hospital settings. But Leah's case is actually two separate social dramas, Leah's and the physicians'. The women discuss ways of reconciling this drama within their community and subsequently refer to the mechanisms within the community. A comparison of the two groups' discussions of Jewish law exhibits telling differences. For the medical team, Jewish law is itself the reason for the conflict. But when the Orthodox women discuss halakhah, they view it not as an obstacle but as a way both to inform Leah and to preserve her connections within the community. Their questions reflect this orientation. Would a man necessarily be prohibited from marrying a sterile woman? Is the fiancé still obligated to marry Leah? Is the father obligated to tell Leah? Throughout their discussion they express the desire for a rabbi to be present. They know that the meaning of the law is not predetermined but bound to the interpretation of a *particular* rabbi. As one woman explained, "Different rabbis will do a lot of thinking and a lot of going back to sources and will sometimes come up with different answers." When I asked if you could "shop around" for a rabbi who would agree with your own interpretation, she responded that although you could not do this, you usually knew a rabbi's predilections for particular interpretations.² These women know well that a rabbi's role in a family's life extends beyond simply providing a reading of the law. The family rabbi also maintains social connections in Leah's life and permits resolution of the dilemma through the mechanisms of her own community. The women also demonstrate a willingness to bring other participants to the discussion about Leah's care and not

to be limited by the hospital staff. As one woman said, "I think the best way is to talk to the parents, talk to the rebbe. Go through the traditional links of communication. Use the system, work within their system." And another replied, "I think we all agree about that."

In the end the women do not determine a plan for resolution; they cannot. The case does not provide them with enough information. The most frequently uttered phrase in their discussion was "we don't know," and, ironically, neither did the medical team. Knowing Leah means knowing her story and her community's rituals of reconciliation. Through this concern with knowing Leah before making judgments for the course of her treatment, these women provide a radical critique of the orientation of the medical team's discussion that I did not expect. I had hoped that they, as Orthodox Jewish women, could provide Leah's voice. But they responded that no one could provide Leah's voice except Leah. ☸

NOTES

1. What makes any conclusions concerning the particular orientation of the medical team problematic is that a transcript of their conversation is not available, and the presentation of Leah's case may reflect the author's moral concerns as well as those of the medical team. The transcript given in this commentary was excerpted from a two-hour conversation among the five women present.
2. The rabbi consulted is the one whose judgment must subsequently be followed.

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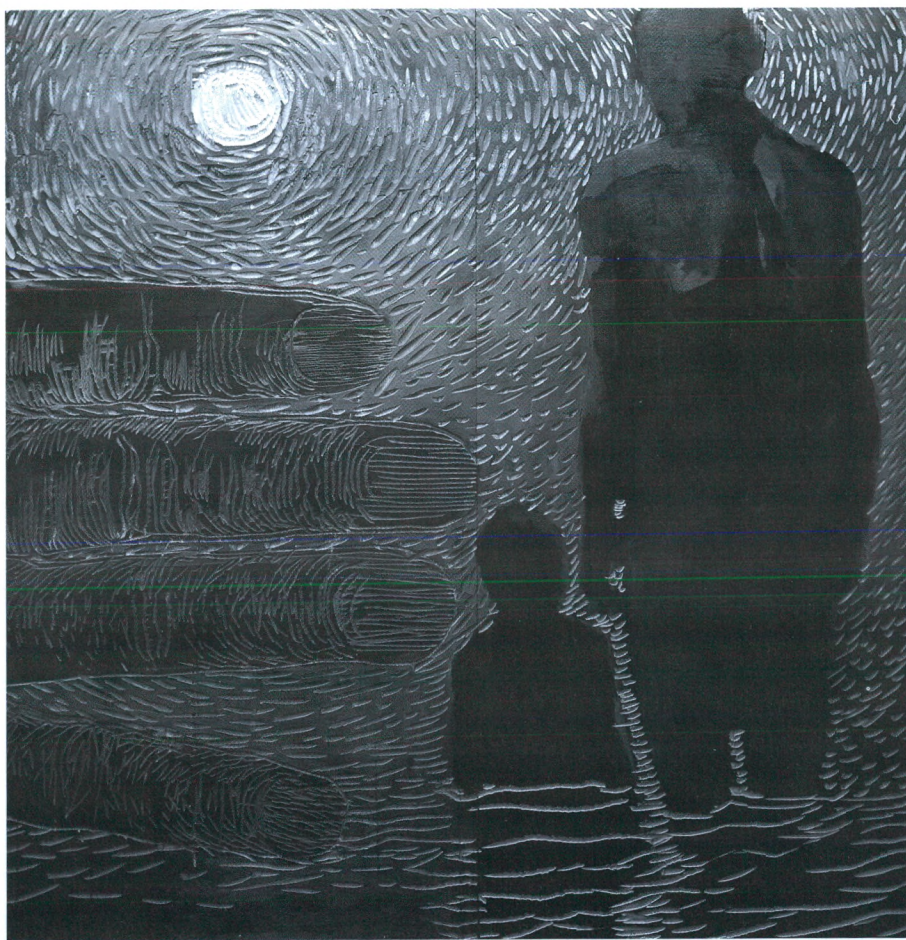
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In Peter DeVries's novel Blood of the Lamb, Don Wanderhope finds himself desperately praying for a remission of his 11-year-old daughter Carol's leukemia:

I do not ask that she be spared to me, but that her life be spared to her. Or give us a year. We will spend it as we have the last, missing nothing. We will mark the dance of every hour between the snowdrop and the snow: crocus to tulip to violet to iris to rose. We will note not only the azalea's crimson flowers but the red halo that encircles a while the azalea's root when her petals are shed, also the white halo that rings for a week the foot of the old catalpa tree. Later we will prize the chrysanthemums which last so long, almost as long as paper flowers, perhaps because they know in blooming not to bloom. We will seek out the leaves turning in the little-praised bushes and the unadvertised trees. Everyone loves the sweet, neat blossom of the hawthorn in spring, but who lingers over the olive drab of her leaf in autumn? We will. We will note the lost yellows in the tangles of that bush that spills over the Howards' stone wall, the meek hues among which it seems to hesitate before committing itself to red, and next year learn its name. We will seek out these modest subtleties so lost in the blare of oaks and maples, like flutes and woodwinds drowned in brasses and drums. When winter comes, we will let no snow fall ignored. We will again watch the first blizzard from her window like figures locked snug in a glass paperweight. "Pick one out and follow it to the ground!" she will say again. We will feed the plain birds that stay to cheer us through the winter, and when spring returns we shall be the first out, to catch the snowdrop's first white whisper in the wood. All this we ask, with the remission of our sins, in Christ's name. Amen.

(Carol dies a few days later.)

Boston: Little, Brown, 1961, pp. 228–29



The Promise. Oil on carved wood panel by Frank Hyder, 1987.

More Gallery, Philadelphia.



Drawing by Adam Kirby (third grade), Washington School, Trenton, New Jersey.

Do the “Baby Doe” Rules Ignore Suffering?

Loretta M. Kopelman

SHOULD PARENTS AND PHYSICIANS be permitted to consider the nature and quality of an infant's life when deciding whether to withdraw or withhold care from very sick infants? In particular, should they be allowed to take into account how painful the child's life is likely to be? Consider the following case:

Baby Girl W, born to a 16-year-old mother, weighed 740 grams (1 pound, 10 ounces) and had a gestational age of 26 weeks. The baby had an unusual appearance: a narrow face, down-sloped eyes, a lack of facial expression, and poor muscle tone. The infant immediately needed a ventilator for breathing, treatment for respiratory distress syndrome, and surgery for a life-threatening heart defect, a patent ductus. At six weeks old, she still lacks facial movements but now has rigid extremities as well. Studies of her brain show lesions that are either malformations or injuries. Baby W is unable to eat. She cannot swallow and frequently chokes, resulting in repeated pneumonia. Although conscious, she has severe

neuromuscular disease. Consultants predict that her inability to swallow will cause repeated aspirations of saliva and consequent pneumonia, and to prevent this they recommend that her larynx be sewed closed. If this is done to save her life, she will be unable to make any sounds. She will also then need a tracheotomy in order to breathe and a gastrostomy tube in order to be fed. Her inability to move or speak and the evidence of her brain malformation make it very unlikely that her mental development will be normal. Yet despite her severe handicaps, the life of this child can be prolonged indefinitely. On the other hand, she already suffers from being ventilator-dependent, and her suffering will continue or increase with the inevitable complications from the treatments needed to save her life, like the tracheotomy. She will have no discernible pleasures. The doctors have ruled out all other diseases that explain her symptoms. They have no hope for reversing her condition.

Baby W is one of a small group of children in neonatal intensive care nurseries whose lives will very likely involve intense and chronic pain with no prospects of improvement. Some children's health policies allow parents and doctors to weigh the quality of the child's life in making decisions about

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whether to continue or withhold life-support treatments. Parents and doctors using these policies can, for example, take into account that the child will live in chronic pain. Some recent policies, however, do not permit this balancing of the length and quality of a life.

Policies that do not permit quality-of-life judgments to play a role in decisions about whether to withhold or withdraw life-supporting treatments depart from a long-standing and well-accepted medical and legal policy known as the *best-interest standard*. The best-interest standard holds that when infants or other people cannot make choices for themselves, decision makers should select the action that is best for that individual. In concentrating upon what is best for the individual, decision makers try to identify the person's immediate and long-term interests and then determine whether the net benefits outweigh the net burdens. The best-interest standard permits complex judgments about what, on balance, is likely to be best for that individual (Buchanan and Brock 1989). For example, the benefit of obtaining a long and healthy life would outweigh the burden of enduring intense pain for a short time. The best-interest standard, however, might be used to justify withholding or withdrawing maximal life-support treatment from an infant whose life is filled with intense and chronic pain and who has neither prospects of improvement nor foreseeable pleasures, understanding, or capacities for interaction. Arguably Baby W would have such a life.

When we fail to acknowledge suffering as an important consideration in making treatment decisions, do we undercut the moral ideal that we should prevent unnecessary suffering or treat others in a way we would not want to be treated? The health policies that minimize the importance of suffering, I argue, are inferior to those that allow them, because they cause unnecessary suffering and do not give infants equal consideration and protection. If adults want their suffering to play a role in their own treatment decisions, then suffering also ought to play a role in decisions about infants.

The rules that have come to be called the "Baby Doe regulations" (U.S. Dept. of Health and Human Services 1985 [hereafter cited as U.S. DHHS 1985]) are one example of a policy that gives insufficient recognition to suffering. After discussing the inadequacy of the Baby Doe regulations in this respect, I want to answer some likely objections to considering pain and suffering as part of the evaluation of what is in the best interest of infants when decisions are made about whether to withdraw or withhold life-support care.

The Baby Doe Regulations

LET US BEGIN BY ASSESSING WHETHER the Baby Doe regulations would permit Baby W's parents and doctors to withhold life-supporting treatments. The rules state:

[The withholding of medically indicated treatment is] the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's (or physicians') reasonable medical judgment any of the following circumstances apply: (i) The infant is chronically and irreversibly comatose; (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. (U.S. DHHS 1985: 1340.15[b]2)

The Baby Doe rules prohibit withholding or withdrawing care from infants unless the child is dying or is in an irreversible coma. The child's suffering is considered relevant only when treatments would be *virtually futile in terms of survival*. If the child is not dying, suffering is not relevant to this decision. Baby W is not in danger of dying as long as she is provided with maximal care.

These Baby Doe regulations do not require maximal treatment to prolong the life of a child who is not dying, if the child is in an irreversible coma. Some dispute whether this is a realistic exception; they argue that this diagnosis cannot be made accurately in the newborn period (Coulter 1987). But in any case, because unconscious people presumably do not suffer, this exception is not relevant to our discussion.

Baby W is conscious and can survive, perhaps for many years, with maximal treatment. There is no provision in the Baby Doe rules to take into account Baby W's immobility or the suffering her condition and treatment will entail. The Baby Doe regulations therefore do not permit therapy to be withheld or withdrawn from Baby W.

The Baby Doe rules stress an important moral and medical ideal: when possible, one ought to preserve and prolong biological life. This ideal, however, is usually understood to mean that one ought to prevent unwanted or untimely death. Since Baby W's life is such a burden to her, some might question whether maximal treatment is in her interest or forestalls an unwanted or untimely death. Other moral and medical goals do acknowledge such concerns, for example, the dictum that we ought to relieve or prevent unnecessary suffering whenever possible. In the case of Baby W, the parents and doctors have to choose between preserving biological life (by means of a tracheotomy, a sutured-closed

larynx, a gastrostomy, and lifelong ventilator care) and providing comfort. If Baby W lives, she will be in considerable discomfort from the very technologies that keep her alive.

The Baby Doe rules do not acknowledge or justify preselecting biological survival as the only basis for deciding whether treatments can be withheld or withdrawn from an infant who is not in an

irreversible coma. In preselecting the goal of biological survival as the most important, the Baby Doe rules radically restrict standard medical practice. In a 1988 survey that my colleagues and I conducted, U.S. neonatologists indicated that the use of this policy for judging when to withdraw or withhold care results in overtreatment,

poor use of resources, and insufficient attention to suffering (Kopelman et al. 1988).¹

Some, however, criticized the results of our survey of neonatologists' views of the Baby Doe rules, arguing that neonatologists were inappropriately pessimistic about the prognosis of severely sick and handicapped infants and that they would be less so if they worked with older children. Furthermore, critics argued, the neonatologists did not understand these regulations, because the Baby Doe rules permit *any reasonable* medical judgment (Freeman 1988).

These criticisms are themselves problematic. First, it is unlikely that the neonatologists did not understand the regulations: the key portions appeared on the survey, and respondents could study the regulations as they responded. Second, the Baby Doe rules *do not* permit any reasonable medical judgment; they permit only a reasonable medical judgment that the conditions of the Baby Doe regulations have been fulfilled. Thus they alter standards of care if they restrict the range of reasonable medical decisions.

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In a series of case decisions, the courts concluded that the goal of an earlier and similar set of Baby Doe regulations (U.S. Dept. of Health and Human Services 1984 [hereafter cited as U.S. DHHS 1984]) was to alter standards of care for infants by restricting the range of choices that doctors could make. (To avoid confusion I will call the earlier set of Baby Doe regulations BDR-I and the later set BDR-II.) The Supreme Court (*Bowen v. American Hospital Association*, 1986) and the Second Court of Appeals of the Second Circuit (*United States v. University Hospital*, 1984) concluded that the earlier set of Baby Doe rules (BDR-I) sought, despite disclaimers, to alter standards of care. They were critical of such attempts. Judge Leonard D. Wexler wrote, "the government has taken an oversimplified view of medical decision-making" (*United States v. University Hospital*, 1984, 157). Judge Gerhard Gessel stated that the regulations were "arbitrary and capricious" and "intended . . . to change the course of medical decision-making" (*American Academy of Pediatrics v. Heckler*, 1983, 401, 404). He also said that they sought to require physicians to give maximal treatment for every nondying infant without considering parental views or the suffering it might cause.

The current Baby Doe rules (BDR-II) have not yet been tested in the courts, but they are also seen as seeking to alter standards of care. Defenders might argue that this is not true. They claim that physicians are required only to use reasonable medical judgments "that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved" (U.S. DHHS 1985: 1340.15[3]111). Furthermore, defenders point out

Certainty is an impractical and immoral standard to use because one can never be absolutely certain, short of death, that a patient will not improve; so this standard would never let us stop maximal therapy until the person died.

that in the Appendix the DHHS seeks to rebut charges that the BDR-II will cause overtreatment or overevaluation of infants on the grounds that it defers to reasonable medical judgment.

Once again, however, the defenders' reasoning seems suspect. The current Baby Doe regulations (BDR-II) only defer in the sense that physicians, ethics committees, or investigators are needed to make a reasonable medical judgment about whether the conditions of the regulations have been fulfilled. This is a necessary *technical* decision about whether the rules have been violated or not. In contrast, reasonable medical judgments are *traditionally* seen in broader terms that include *moral* as well as technical considerations about balancing what is harmful or beneficial to a patient as an individual and about taking care of some-

one in accordance with his or her best interest. The traditional view, unlike the Baby Doe rules, allows one to consider the quality of someone's life.

The survey shows, moreover, that less than one year after the current rules (BDR-II) became final, the regulations apparently have altered care practices. In responding to one case, a third of all pediatricians (32 percent of the neonatologists, and 36 percent of the others) said that they have changed how they practice medicine as a result of the BDR-II. In comparing responses to two items, we find that up to a third regard the BDR-II as requiring them to act in a way different from what they consider to be in the infant's best interest. Reasonable medical judgments are thus severely restricted by the Baby Doe regulations. Comfort care or triage is not permitted unless maximal treatment is not obligatory because the infant is dying or is in an irreversible coma.

Finally, the survey's critics were incorrect in

assuming that the harsh criticism of the Baby Doe regulations by the neonatologists was due to their inexperience with older children. Pediatricians are familiar with the outcomes for older children and so cannot be accused of being unrealistically pessimistic about their prognoses because of inexperience. Pediatricians who were not neonatologists responded in the same way that the neonatologists responded. Some additional data that my colleagues and I collected from pediatricians at the time of our original survey demonstrate the similarity of the pediatricians' and neonatologists' responses. The responses of the neonatologists are from 494 members (49 percent) Perinatal-Pediatric Section of the American Academy of Pediatrics. All members of

this section received a survey, and 49 percent responded. The responses of the pediatricians are from a randomly selected sampling of 3,000 non-neonatologist pediatricians supplied to us by the American Academy of Pediatrics; 730 (25 percent) responded (Kopelman et al. 1992). The information we collected shows that pediatricians are as critical of the Baby Doe regulations as are the neonatologists.

As Table 1 shows, the majority of neonatologists and pediatricians thought that the current Baby Doe rules (BDR-II) did not permit adequate consideration of an infant's suffering and resulted in overtreatment when the chances for survival were very poor. These rules, they held, affect parental rights to decide what

Table 1: Responses of Neonatologists and Other Pediatricians to General Statements about Current Federal "Baby Doe" Regulations (BDR-II)*

STATEMENT	% Agreeing	% Uncertain	% Disagreeing
1. <i>"The BDR-II allows adequate consideration of suffering."</i>			
Neonatologists	29	11	60
Other Pediatricians	30	14	56
2. <i>"Most critically ill infants are over-treated when the chances for their survival are very poor."</i>			
Neonatologists	56	13	31
Other Pediatricians	62	18	19
3. <i>"The BDR-II will not affect parental rights to consent for or refuse treatment based upon what is in the infant's best interest."</i>			
Neonatologists	19	15	66
Other Pediatricians	19	17	65
4. <i>"The BDR-II will result in improved care for all infants."</i>			
Neonatologists	5	14	81
Other Pediatricians	6	16	78
5. <i>"The BDR-II was needed to protect the rights of handicapped infants."</i>			
Neonatologists	14	10	76
Other Pediatricians	20	12	67

*Statements were ordered differently in the questionnaire. Because of rounding, some totals may not be 100%. ("BDR-II" refers to the current Baby Doe rules [U.S. DHHS 1985].)

is in their infant's best interest. They did not believe that these rules were needed to protect the rights of handicapped infants; nor did they believe that the Baby Doe regulations would improve care for handicapped infants.

The respondents also evaluated three cases concerning critically ill and profoundly cognitively impaired infants with a poor prognosis. The neonatologists overwhelmingly agreed (75–86 percent) that withholding aggressive life-support care was in each child's best interest. But in those same three cases up to a third perceived a direct conflict between their duty to act in the infant's best interest and the legal requirement to prolong life in accordance with the BDR-II. In each case, too, there was a significant difference ($p < .001$) in their responses to what was appropriate care for these infants and what the BDR-II required. The pediatricians' responses were similar for cases 1 and 2. (We believe that responses to the third case differed because in the third case the baby is described as "minimally responsive," a term meaning "comatose" to neonatologists. Upon reflection, we believe that "minimally responsive" does not have the same meaning for other pediatricians.) A greater number of pediatricians (62 percent) than neonatologists (56 percent) believed infants are overtreated in neonatal intensive care units.

Thus, according to both the neonatologists and the pediatricians who responded to our survey, the Baby Doe regulations radically restrict parental and medical discretion in trying to select the best treatment plans for very sick infants. These rules, they said, give insufficient attention to the infant's suffering. Those of us sympathetic to their views believe that this agreement grows from their expertise and commitment to the children's well-being.

Yet critics might respond that the fact that so many pediatricians and neonatologists agree that suffering is an important quality-of-life consideration in making decisions to withhold or withdraw care does not make it correct. It could, for example, reflect similar training or a resentment of outside interference. Critics may not even be convinced by

the fact that pediatricians and neonatologists in our survey offered reasons similar to those given by members of the U.S. Supreme Court in *Bowen* (1986) in rejecting an earlier set of Baby Doe regulations (BDR-I). These critics worry that quality-of-life decisions are easily abused and morally and medically problematic. I turn now to their concerns.

Criticisms

TO THE VIEW THAT PAIN AND SUFFERING should be considered in evaluating the best interest of infants when decisions are made to withdraw or withhold care, four important objections are offered: (1) the standard is not objective, (2) the standard may be abused, (3) the standard denies hope, and (4) the standard is opposed to the duty to respect the sanctity of life. I argue that none of these objections is persuasive.

1. *The standard is not objective.* Some object that an infant's suffering should not play a role in treatment decisions to withhold or withdraw care because pain is a subjective criterion and therefore liable to be misused. These critics worry that parents and doctors may misjudge the nature or length of the child's suffering because they are ignorant of or fearful about the child's condition. Moreover, decision makers, typically parents and doctors, may rationalize that they are considering the baby's suffering and best interest, when they are really worried about the emotional, social, or financial burden of taking care of the child. Such considerations may not even be conscious, but they are, critics hold, dangerous and misguided. In contrast, these critics maintain, considerations of whether the infant is dying or is in an irreversible coma as the criteria for withdrawing or withholding maximal treatment allow for an objective, factual decision based on probabilities concerning survival or physiological effects.

In meeting this objection, we first need to distinguish among several meanings of the words *sub-*

jective and *objective*. When *subjective* means having some relation to the experiences of subjects, then pain is subjective. But this does not make it either inappropriate or unreliable as a criterion. We try to reduce unnecessary suffering because we believe that people's suffering is important and should be part of our deliberations about what we ought to do. In addition, we would not want to rule out subjective considerations generally. Pleasure and happiness are also subjective in the sense of being experiences of subjects rather than properties of objects, yet we judge that treatments should be continued if the child might experience a life with pleasures or happiness.

Thus the subjectivity (in the sense of its being an experience of subjects) of the condition does not rule it out as an important factor in making treatment decisions for infants. Adults regard avoiding suffering as an appropriate component in making treatment decisions for themselves, and we deny children equal consideration and protection if it is not an appropriate consideration for them as well.

Moreover, if *objective* is understood differently, and taken to refer to what is intersubjectively confirmable, then some statements about pain are objective. If most of us agree that something is painful, we have an objective ground for claiming that something is painful. Most people who have been on a ventilator say that it is very unpleasant and that being unable to move or speak would be a further burden. The fact that most people would not want for themselves a life of chronic pain and immobility, with no hope of improvement, gives objective confirmation to a judgment that some experiences would be very painful.

Objective can also refer to something that is factual. Critics use this meaning of *objective* when arguing that the criterion of biological survival is more objective than the best-interest standard because it is a factual standard. These critics, however, are

mistaken about the kind of judgment that they make: they are not offering factual claims but moral judgments. They are advancing what they believe to be an *appropriate goal* one *ought* to use in making decisions about when to withhold or withdraw life-supporting treatments. This is a moral claim about how we ought to act, not a factual claim about the probability of survival or the physiological effects of procedures. Thus their claim is no more factual than other proposals we have considered.

**If Baby W lives, she will be
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2. *The standard may be abused.* Critics like former president Ronald Reagan (1986) and former surgeon general C. Everett Koop (1989) favored the Baby Doe legislation because they

believe that quality-of-life considerations are likely to be abused. But are these judgments more likely to be abused than other judgments of comparable complexity? Buchanan and Brock (1989) criticize the view that quality-of-life assessments will be routinely abused. They argue that the courts and others who reject quality-of-life judgments in making decisions for incompetent people have failed to note that there are two ways in which we can understand quality-of-life judgments. Quality-of-life judgments *based on considerations of social worth* try to decide the interests or value of a person's life in relation to the interests or value of other people's lives; they are *interpersonal*. In contrast, *noncomparative* quality-of-life judgments try to consider the value of the life to the person, comparing the value of living the individual's life to having no life at all; they are *intrapersonal*.

Let us consider the difference between these two senses of quality-of-life judgments with respect to the case of Baby W described above. A social-worth judgment would maintain that society can (or cannot) afford to take care of such a child, that the family has (or has not) the emotional and financial resources to take care of her. In contrast, the noncomparative

quality-of-life judgment would look at the value to the little girl herself of living a life like that of Baby W's; the judgment would be made without regard to her social utility however it might be calculated.

I agree with Buchanan and Brock that in using the best-interest standard to make a decision about what is best for the person, we should contemplate only the quality of the person's life *for that individual*. People's social value should not be a part of this assessment. These noncomparative or intrapersonal quality-of-life judgments should be very carefully circumscribed. We can estimate whether the life would be one of suffering, for example, and reflect upon whether most people would want to live such a life. Would most of us want to be conscious but unable to move, eat, speak, or understand, while suffering from ventilator dependency and repeated pneumonia? If we would not, then we should grant others equal consideration, agreeing that it might also be in their best interest not to forestall death in these circumstances. If people can make these decisions for themselves, doctors and parents should be able to regard them as relevant when they try to decide what is best for an infant like Baby W.

Unfortunately, some authors include both kinds of quality-of-life judgments when they discuss criteria for withholding or withdrawing care, without mentioning that they are radically different considerations. This conflation fuels critics' concerns that the best-interest standard is really a subterfuge for appraisals of the emotional, financial, or social interests of others and strengthens their conviction that quality-of-life considerations have no place in decisions to withhold or withdraw care from neonates. For example, one can find both the social-worth and the noncomparative senses of quality of life in a recent article by P. P. J. J. Sauer (1992). The

first two criteria he offers for assessing quality of life are primarily noncomparative, and quite appropriate for assessing the benefits or burdens of the infant's condition: the mental and physical burdens of the infant's life, and the infant's ability to interact with others and to express or have feelings about them. In contrast, Sauer's next two criteria entail social-worth or interpersonal quality-of-life assessments and are not appropriate for weighing the net benefits or burdens of the infant's condition *to the infant*: the extent to which the child will be a burden on caretakers, and whether the child will be dependent for most of his or her life on the health care system.

Using these criteria, which include burdens to people other than the infant, Sauer reaches the controversial conclusion that "neonates with severe spina bifida . . . should not undergo [corrective] surgery" (1992:730). This is controversial because children with severe spina bifida may have a life that they enjoy which is not filled with uninterrupted suffering or devoid of pleasures. Moreover, if people with severe spina bifida say that their lives are worth living, that conclusion should be definitive, using the intrapersonal or noncomparative sense of a quality-of-life judgment.

Critics, then, have some basis for concern about the possible abuse of quality-of-life considerations in the newborn period if people do not state clearly whose quality of life they have in mind in deciding whether they should withhold or withdraw treatments. The best-interest standard should use only the noncomparative or intrapersonal quality-of-life considerations. Critics are also correct that some people do not justify their claims that infants will really suffer chronic pain without compensatory benefits.

It would be a mistake, however, to conclude that intrapersonal or noncomparative quality-of-life

If a life is filled with pain and suffering, and the person can survive only with maximal treatment, is struggling to preserve that life fulfilling or thwarting a God-given duty?

judgments are especially open to abuse. Many other kinds of judgments are open to abuse if they are not justified. For example, one could make a mistake about the infant's prognosis based on faulty information or rationalizations. And critics have not shown that quality-of-life claims, such as those about suffering, are more likely to be abused than other claims. As we saw above, even claims about pain and suffering are in some sense intersubjectively confirmable or objective. In short, we have to keep the two kinds of quality-of-life judgments distinct; a good deal of abuse may come from failing to do this. For example, resource allocation issues are important, but they should not be folded into the best-interest standard.

3. *The standard denies hope.* Critics (see, for example, Reagan 1986) also object to using quality-of-life considerations to justify withholding or withdrawing treatment when there is a hope that the patient may recover, and unless one can be certain that a biological life cannot be prolonged, there is always a hope of recovery. Physicians have, of course, been mistaken in the past, and some charge that physicians tend to be too gloomy when making predictions about disabled infants. For example, we cannot be *certain* that Baby W will not improve or that some new treatments will not come along to regenerate her nerves and muscles.

Medicine deals with probabilities, not certainties, so it is true that one cannot be *certain* about any patient's prognosis. But certainty is an impractical and immoral standard to use. It is impractical because one can never be absolutely certain, short of death, that a patient will not improve; so this standard would never let us stop maximal therapy until the person died. Thousands of unconscious people would have to be supported, perhaps for many years, if we adopted this rule for making decisions. And it is an immoral standard because it would cause a great deal of unnecessary suffering. Suppose, for example, that only 1 percent of infants in some groups would live after spending 10 very painful months in the neonatal intensive care unit. Ninety-

nine percent of the infants in that group, then, would have to undergo painful intensive care for these months on the slim chance that they might be one of the 1 percent who would improve. Is it fair for the 99 to suffer for the sake of the one?

Adults would balk at a rule that they were required to suffer with maximal treatment for the sake of a small percentage who might survive or improve. Adults consider avoiding pain and suffering relevant to their decision when they have a very small chance for biological survival. Infants deserve equal protection from the kind of burdensome treatments that few adults would want. It does not seem fair to require parents and doctors to choose burdensome treatments for infants.

Even if critics say they do not mean that one must be *absolutely* certain before it is appropriate to make decisions to withhold or withdraw life-support treatments, they have the problem of deciding where to draw the line. Some may respond that there is a well-established, value-free, scientific cutoff point which physicians can use to decide: the 5-percent probability level. If the chances are better than 5 percent that the infant will survive or improve with treatment, then hope is reasonable and treatment should be continued.

But however useful the 5-percent standard may be for ending clinical research studies, it is not an objective standard. It is a moral judgment about how long it is appropriate to continue a controlled trial. If one continues a study too long, some subjects will receive what is increasingly known to be sub-optimal care. If one does not continue the study long enough to get reliable results, a wrong conclusion may be reached and either good therapies discarded or bad therapies adopted.

The 5-percent probability level is not an objective, scientific standard for assessing what hopes are reasonable, but a moral trade-off. Those who choose to adapt it to clinical medicine in deciding when to withhold treatments from very sick neonates, therefore, do not avoid moral judgments. In addition, for some, a smaller than 5-percent chance of recovery might be well worth taking (Kopelman et al. 1992).

How we assess hope thus depends upon our goals, upon what we hope for. Most adults hope to live, but they also hope to be free of pain. When these goals conflict, we sometimes prefer relieving suffering to lengthening our lives by aggressive medical treatments. We should give infants equal protection and consideration in making choices for them.

4. *The standard is opposed to the duty to respect the sanctity of life.* Some critics (see, for example, Koop 1989) object that respect for the sanctity of life demands that all severely handicapped infants must be fully supported unless they are dying. They believe that the problem of pain and suffering should be addressed, but not by means of withholding or withdrawing life-support treatments. Some defend this view on religious grounds, arguing that we have a God-given duty to preserve all life when we can do so, or that God judges us by how we treat the most helpless people under our care (see Doerflinger 1989). The sanctity-of-life argument is not always grounded in views about God's will or intentions, however. Some defend it on moral grounds alone, arguing that as a community we need to preserve all human life whenever possible in order to teach and show respect for each human life (Koop 1989; Reagan 1986; Bopp 1990).

Sanctity of life is a complex concept whose meaning and use are difficult to clarify (Clouser 1973). Despite this, we can indicate some difficulties with appeals to the sanctity of life to show that all severely sick infants must be fully supported unless they are dying.

Some use the sanctity-of-life argument in appealing to a God-given duty to preserve human life when we can do so. But appealing to such a duty does not tell us how to fulfill that duty. If a life is filled with pain and suffering, and the person can

survive only with maximal treatment, is struggling to preserve that life fulfilling or thwarting a God-given duty? Appeals to God-given duties have been used in arguments for and against wars, abortion, euthanasia, and most other controversial stands. If such appeals do not give the reasons that the duties should be fulfilled in a certain way, they do not help us settle our disagreements about what we ought to do. Such appeals may only harden in people's hearts the belief that they are correct, while failing to give and defend reasons for their correctness.

Second, some assume that we have a duty to save every life we can out of respect for the sanctity of life (Bopp 1990; Doerflinger 1989). Yet defenders of the sanctity-of-life position have to give and defend their reasons for believing that maximal care is always the appropriate care for

those we are charged to help. Some sincerely believe that a merciful God would not want an infant to endure a life of suffering; or they do not view death as an evil always to be opposed (May 1983). Defenders of the sanctity-of-life view thus cannot assume that the appeal to sanctity of life will result in a conclusion supporting their intuitions.

Third, even if we grant that it is of great importance to us as a community to acknowledge the duty to preserve and protect human life from unnecessary death, defenders of the sanctity of life need to give and defend their reasons for believing that keeping a child like Baby W alive is preserving and protecting a human life from an unnecessary or untimely death. Many would argue that preserving such a life is inappropriate (see, for example, May 1983). Moreover, a moral community has important responsibilities in addition to mutually prolonging each other's biological life. Other important moral goals include preventing unnecessary suffering, promoting empathy, and doing to others what we

**Officialdom devises ways to
ignore the suffering of others,
because once suffering
is acknowledged,
doing nothing becomes
too uncomfortable.**



Doubtful Hope. Oil on canvas by Frank Holl, 1875.

New York, *Forbes* magazine collection (FC 15312). Bridgeman/Art Resource, New York.

would have done to us. If we do not acknowledge the suffering that others have to endure, we may lessen our empathy for others and our need to respond to their suffering.

Conclusions and Qualifications

IN CONCLUSION, HEALTH CARE POLICIES that do not permit quality-of-life judgments in deciding whether to withhold or withdraw care from very sick infants are inferior to those that do. Furthermore, policies like the Baby Doe regulations that prohibit such judgments are not more objective, more factual, or less likely to be abused. In disallowing considerations of pain and suffering, such policies breach two well-established moral ideals. The first is that we ought to avoid or relieve unnecessary

suffering. This goal is so important that a part of the justification of all moral judgments is an assessment of whether the proposed action would inflict unnecessary pain and suffering on others. When a life has no other prospects but severe and chronic pain, and we must fight to prolong it by extraordinary means, then we ought to consider whether such actions may inflict unnecessary suffering.

The second moral ideal that I have stressed is that we should treat others as we would wish to be treated. In this regard infants merit equality of consideration. When adults are faced with a choice between prolonging life and preventing suffering for themselves, they sometimes believe that there are worse things than dying. If this seems a reasonable choice for adults, infants deserve equal consideration and protection from the kind of suffering that adults would not wish to bear. That is, if we agree that it

is wrong to do to others what we would not want for ourselves and that we would not want a policy that ignores suffering for ourselves, then we should not adopt such a policy for infants. Because infants cannot make decisions for themselves, it is up to adults to determine what is best for them, and we should not have a policy for them more burdensome than we would want for ourselves.

Several qualifications shape my defense of the best-interest standard. First, the quality-of-life considerations that should be used for deciding the infant's best interest should be noncomparative or intrapersonal. They should not be interpersonal or social-worth calculations. Judgments about resource allocation, for example, should be made independently of the best-interest standard. Second, suffering, while important, is neither a necessary nor a sufficient condition for making these judgments. It is not necessary because it might be inappropriate to continue life support for an irreversibly comatose person who does not suffer. It is not sufficient because we would not withhold care when the suffering is reversible or there is hope of improvement. Third, institutional safeguards should be in place to determine such important considerations as whether all the reasonable and available options have been considered; whether the decisions are accurate and defensible; and whether the primary decision makers are competent, informed, and able to choose freely.

A final qualification is the acknowledgment that reasonable and informed people of goodwill may disagree about how to apply the best-interest standard. Not all loving and informed parents acting on the advice of doctors will make the same decisions. Moreover, what one person considers futile, another may find useful. If the best-interest standard is somewhat objective and impartial, however, this should not happen very often. Indeed, our survey confirmed a remarkable agreement among neonatologists and other pediatricians about when discontinuing life-support treatments would be in an infant's best interest. In every neonatal intensive care unit, however, certain cases will elicit sustained

disagreement. These situations stand out in our minds clearly because they are so disturbing. The disagreement may be based upon misunderstandings, insufficient data, different understandings of one's duties, or value conflicts. If disagreements were the rule rather than the exception, it would be hard to justify the best-interest standard or use quality-of-life assessments. But we should not be surprised that disputes occasionally arise; similar disagreements arise concerning how to apply standards or principles in difficult cases in all fields.

In his novella "Ward Six," Anton Chekhov shows that insulating ourselves from the reality of suffering has dangers for the individual who minimizes others' suffering and for the society that promotes this in its policies. The story is about a hospital in a remote town in Russia at the end of the nineteenth century. The central character is the ineffective and weak-willed director of the hospital, Dr. Andrei Ragin, who eventually becomes a victim of the very system that he has helped sustain. When he arrives, he finds that the inmates not only suffer from illnesses and misdiagnoses but lack food, clothing, and even basic cleanliness. The attendants are brutal; they openly beat and steal from the inmates. Ragin resolves initially to improve the hospital's wretched conditions, but eventually he decides that the inmates' suffering is not real, and over time he even stops seeing it. He recognizes that this view is evil only when he is committed against his will to Ward Six, the psychiatric section of the hospital.

Chekhov's story bears on this discussion of the Baby Doe regulations because he displays the impossibility of minimizing the reality and power of suffering when it is personal. If we want to foster an empathetic community, we must admit that unnecessary suffering is wrong and treat others as we wish to be treated when we suffer. Officialdom devises ways to ignore the suffering of others, because once suffering is acknowledged, doing nothing becomes too uncomfortable. Chekhov writes, "People such as judges, policemen, and doctors, whose attitude to human suffering is strictly official and professional, become so callous in the course of

time and from force of habit that they cannot treat their clients in any but a formal way even if they want to; in this respect, they are not at all different from the peasant who slaughters sheep and calves in his back yard and does not give a thought to the blood" ([1892] 1964:137).

The best-interest standard is preferable to health care policies like the Baby Doe regulations because

it permits a complex determination of the net benefits and burdens that most of us would want to make for ourselves. We must make it possible for health care workers to respond to suffering so that they do not become callous. We want policies that acknowledge we should treat infants as we would want to be treated and that recognize the power of disease and the reality of suffering and death. ☹

NOTE

1. We published the neonatologists' responses in Kopelman et al. 1988 and then published the rest of our data in Kopelman et al. 1992.

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My Mom Died.

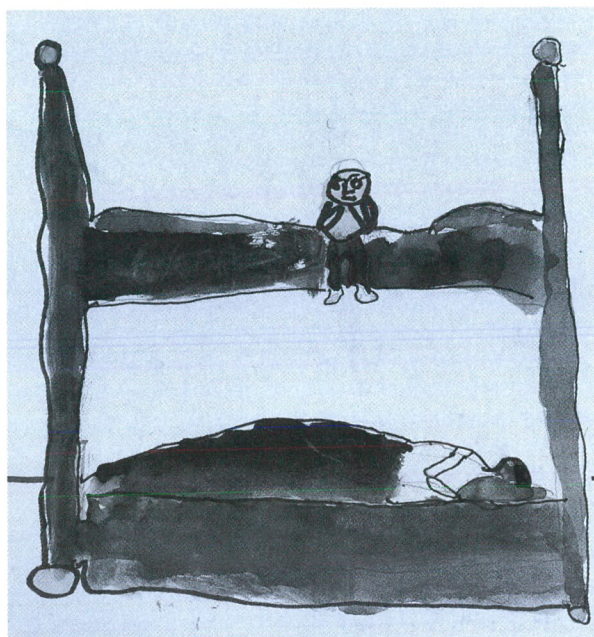
Drawing by Chimere Johnson (second grade),
Gregory School, Trenton, New Jersey.



Drawing by Azriel Alston (fifth grade),
Stokes School, Trenton, New Jersey.

Drawing by Donald Hamer (third grade),
Washington School, Trenton, New Jersey.

*"I'm sitting with my mom. She has pneumonia
and might have to go to the hospital."*



Drawing by Kimberly Delgado
(third grade), Washington School,
Trenton, New Jersey.

*"This is a picture of myself after my leg surgery.
It was very painful."*

REFLECTION

Looking on the Heart

Richard Matern

"For the Lord does not see as mortals see;
they look on the outward appearance, but
the Lord looks on the heart."

—1 Samuel 16:17

YEARS AGO I HAD THE RARE PRIVILEGE of being asked to help a 17-year-old girl with a severely cleft lip. This was in Vietnam, and she was, though thoroughly imbued with the finest traditions of Asian politeness, a very avid missionary for the Marxist cause. Of course she intrigued me; she could spell out the grave injustices of society, and especially American society, with a forthrightness and clarity that amazed me.

In those days (1967) I was not altogether sure she was always telling the truth, but from what I could remember to check subsequently, she never told me anything untrue. That is, if we can ever count simply one side of any story as being, nevertheless, truth. The American unemployment rates, our levels of poverty, the inequities in our medical care, the oppression of African Americans, these and more were issues she had to raise for me. During the war, I served as a volunteer in a civilian physician capacity, and these domestic problems had assumed a secondary importance in my own mind because of my single-minded devotion to the sick. But what she said had the ring of truth, and with it she would and could wound me.

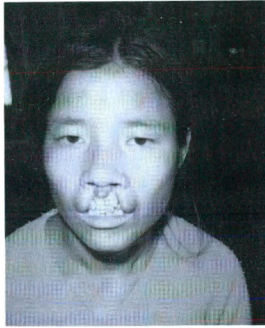
Richard Matern is a surgeon at the Chinle Comprehensive Health Care Facility, Chinle, Arizona.

On one occasion she must really have reached me, unprepared as I was for hearing from a 17-year-old expressions of so much purpose in life and so much concern for the victims of the wrongs of this world. This was especially the case because her words gainsaid much of my optimism about the future and the brightness of the long experiment we call America and home. She—who had certainly suffered much injustice with her own affliction—was such a quiet decent soul, anything but the hate-spewing, angry revolutionary that the term *Marxist* might conjure up.

It was her self-control that got the better of me that day. Being totally unprepared to meet her on common ground, I reacted, a bit tongue in cheek, trying to justify our ways to her. I answered her comment about the world's inequities regarding health care: "Co, if you know so much of all this, why did you not know until now that your face could be fixed through surgery?"

She shot back without hesitation: "Only five days ago a friend told me about you, so I came to see you about it. No one in our village had ever heard before that work like this could be done, and there was certainly never anyone there who could do it." Immediately a little spirit arose within me, wanting to declare to her that she should understand that there is another side to her picture of America. But I held back, for in the next instant I felt covered with a sense of my own shame.

Of course, it is fun to create—I've been so controlled by that feeling—and especially fun to shape an ugly face into a beautiful one, one that to me really expressed the soul of this girl. (I have always thought that that is probably why God made the heavens and



Sanu Maya



4 days after surgery



6 months after surgery

the earth—for the fun and beauty of it all.) This surgery would change this girl's life. She would be able to look forward to the joy of having a husband and family, would "fit in," and would lose the stigma that produced low self-esteem. But it occurred to me that this defect on her face and the uncharitableness its appearance had occasioned in others were precisely what had given her the ability to reflect deeply on the unhappy estate of humans, with a maturity far beyond that of most 17-year-olds.

Had I not already discovered a beauty in her soul long before that which she had later in her face? Where was the deficit? In her lip and nose, or in the hearts of all of us, as lost children of God? Why must it be that *her* face change? It seemed suddenly to flood me with light; the deficit is inside *us*, that we simply do not accept, we do not appreciate, the true beauty of one another, the true value of one another as God gave it to us. It was God who called forth all the real ugliness within us to view in contrast to the grandeur of soul openly portrayed for all in the life and death of Jesus.

To this day when I pray for the success of a cleft lip repair with one of my patients, I can never forget my 17-year-old Viet Cong friend and the lesson she taught me—that the real defect lies far less on another's face than within us, in our hearts and in the prejudice with which we perceive what we look at or

don't wish to look at. At that instant long ago, I felt my own ugliness, and the ugliness of all of us within, far more than the ugliness of her face.

I wish I had taken and kept a picture of this young friend, but from my medical encounters elsewhere I have kept many. Let me pass on to you one of Sanu Maya, a Nepali whose name means "Little Love." I've always thought that in such sequences of pictures we first see a naked feeling of what I call "it-ness." Then comes, "I guess this is better, but I've completely lost myself, who I am." Finally comes the confident charmer that Sanu had always been but could never appear to be before the surgery. I like to think that photographs like these are analogues for the change that comes in the eye or in the soul when we have learned where to locate the real value of persons.

ON THE BIOETHICS FRONT

In the midst of attending to patients' experiences, rights, perspectives, and duties, we all too easily overlook the concerns of their caregivers. It is the liberating era of the U.S. Patient Self-Determination Act—a time when family members and health professionals are more readily associated with the oppressors than with the oppressed. Dena Davis and David Fletcher, however, remind us that more lives than one are deeply affected by each patient's illness. They take us through the literature of ethics and gerontology, through the lore of fiction and the analysis of medicine, to sensitize us afresh to how different the same event can appear through different eyes. In these reflections we meet a woman who cannot accept her husband's death while his transplanted heart beats on in the body of another. We meet a man who wonders why he shouldn't have the same say in the treatment of a close family member that he has always had in other events of her life. Those of us who expect sometime to witness the serious illness of someone we care about may even see ourselves.

— John F. Kilner

Heartbreak and Heart's Ease: Thinking about Organ Donation

Dena S. Davis

Richard Selzer. 1990. "Whither Thou Goest." In *Imagine a Woman*. New York: Random House.

Stuart J. Youngner et al. 1985. "Psychosocial and Ethical Implications of Organ Retrieval." *New England Journal of Medicine* 313, no. 5 (1 August): 321–23.

THE TWO WORKS UNDER DISCUSSION are very different: one a short story in a romantic mood, the other a scientific article appearing in a medical journal. Both pieces address an important bioethical issue: the donation of cadaver organs. Despite the passage of the Uniform Anatomical Gift Act and the legal recogni-

tion of brain death, only about 10 percent of potential donors actually give their organs, leaving a significant shortfall (Youngner, p. 321). This organ "gap" has engendered many strategies for increasing the willingness of Americans to donate, everything from bumper stickers ("Don't Take Your Organs to Heaven—Heaven Knows We Need Them Here!") to required-request laws that obligate health care personnel to raise the subject with families of suitable donors. Most states now make it extremely easy to signify one's consent, for example, by checking a box on one's driver's license. But these strategies have not proven successful, and in their different ways Youngner and Selzer suggest one reason: the legal and medical logic that grounds such tidy categories as "brain-dead" founders on our human experience, and on our very language.

Youngner focuses on the "disturbing effects" of the organ retrieval process on the health professionals involved. It appears that even intensive-care-unit per-

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sonnel and operating room nurses, those high-tech professionals to whom we owe our very capability to transplant organs, are confused and disturbed by the dissonance between their experience and their intellectual understanding. Intellectually, they know that the patient is dead, but their immediate experience contradicts that understanding in a number of important ways. First, they "may find it difficult to ignore the signs of life that constantly bombard their senses as they provide brain-dead organ donors with intensive and intimate medical care" (p. 321). Cadaver donors, although legally dead, appear very much alive; thanks to support systems, their skin is warm, their color is good, and they continue to digest and eliminate.

Second, many of the medical processes that maintain these cadavers are the same as those used for live patients who are critically ill. "Monitoring and intervention continue at maximal levels in order to protect and preserve organs," and cadavers who undergo cardiac arrest will be resuscitated (p. 321). Like a live patient with a hope for recovery, the cadaver "patient" is taken to surgery, but in the latter case, the rituals of surgery are played out in reverse. Organs are not repaired but removed, the patient does not awaken at the end, and the final destination is not the recovery room but the morgue. The goal of surgery on live patients is the patient's well-being, but in the case of cadaver donors, the "patient" is a means to some other end. This removal of the "patient" from moral center stage presents a number of ethical problems for the medical participants. Retrieval seems to violate the obligation to treat human beings as ends in themselves. Further, the removal of organs and "the mutilating nature of some procedures" (p. 322) appear to violate our cultural and moral traditions that require respect for the dead.

Although Youngner does not specifically mention this, the confusion and dissonance health care professionals feel is often reflected in an awkward and oxymoronic use of language. "Brain-dead" bodies are kept on "life-support" systems. It is common to hear even nurses and doctors speak of brain-dead patients "dying" or "really dying" when the ventilator is disconnected. If medical personnel are this conflicted, how can families be expected to understand that their living, breathing loved one is actually a corpse?

One way to get at some of these issues, especially in the classroom context, is by reading and discussing a fictional account that animates Youngner's arguments. Fiction has an indispensable role to play in thinking and teaching about bioethics. Fiction is particularly helpful in exploding the dry, logical categories that "ought" to govern our thinking. Through fiction, we can transcend limits of gender, age, and experience to achieve new levels of empathy and understanding.

One of the most powerful writers of medically oriented fiction is Richard Selzer, retired surgeon, essayist, and creator of wonderfully imaginative short stories, of which the latest collection is *Imagine a Woman*. The story "Whither Thou Goest" helps us to understand why logical and scientific thinking can fail us when it does not make room for emotion, experience, and culture.

Hannah and Sam, a married couple in their thirties, are on their way home from a weekend at the beach when Sam is shot in a roadside mugging. Sam is declared brain-dead, and Hannah allows the hospital to "harvest" his organs. A week after the funeral, she receives a letter from the hospital thanking her for her generosity and telling her that, thanks to "the miracle of modern science," seven people have benefited from Sam's organs, including the heart recipient, "a man just your husband's age in a little town near Arkansas" (p. 4).

Three years later, Hannah finds that she cannot get on with her life: "At least if your husband were all dead you could one day get over it . . . But this! This state of bafflement. Maybe, she thought, maybe it was a matter of percentage—if more than 50 percent of your husband was dead, you were a widow. Whom could she ask?" (p. 7). Worse yet, Hannah is beginning to resent Sam. "Here she was, living in this sort of limbo, while he . . . was participating in not one but seven lives, none of which had anything to do with her" (p. 7).

Eventually, Hannah decides that the only way she can resolve her doubts and go on with her life is to find the man who is carrying Sam's heart and listen one last time to that dear familiar rhythm. Likening herself to a woman whose husband had been declared missing in action in a war, she sets out on her quest. With only a small amount of effort and deception, she finds the name and address of the recipient and carefully writes

a letter introducing herself and inquiring after his health. "Dear Mr. Pope," she wrote, and then set down the pen. There was something absurd about that *Mr.*, considering that she had been married for seven years to a significant part of the man. But she would let it stand" (p. 16).

After a great deal of resistance from the recipient and his wife, Hannah finally is allowed to visit their home and listen, for one precious hour, to the object of her quest:

Oh, it was Samuel's heart, all right. She knew the minute she heard it. She could have picked it out of a thousand. It wasn't true that you couldn't tell one heart from another by the sound of it. This one was Sam's. Hadn't she listened to it just this way often enough? When they were lying in bed? Hadn't she listened with her head on his chest, just this way, and heard it slow down after they had made love? It was like a little secret that she knew about his body and it had always made her smile to think of the effect she had on him. (p. 27)

At the end of that hour of concentrated listening, Hannah is ready to go home and take up her life. "Never, never had she felt such a sense of consolation and happiness" (p. 28).

Selzer's artistry highlights some of the cognitive dissonance that Youngner documents. The doctor tells Hannah that Sam is "brain-dead" and then adds, "The only thing keeping him alive is the respirator" (p. 3). The confusion Youngner points to is sharpened in the fictional story, as Hannah reacts to the doctor's deliberately ambiguous language. The doctor ex-

plains, "That way your husband will live on. He will not really have died. . ." (p. 4). No wonder Hannah cannot visit Sam's grave:

It wasn't Sam in that cemetery, not by a long shot. It was only parts of Sam, the parts that nobody needed. The rest of him was scattered all over Texas. And, unless she had been misinformed, very much alive. (p. 7)

In the end, Hannah is glad for the gift she made of Sam's body parts. The term *harvest*, which she had rejected when the doctor first used it (the "real names of their deeds [were] dismemberment, evisceration" [p. 7]), now seems appropriate, as she describes Henry Pope's chest as "a field of golden wheat in which, for this time, it had been given to her to go glean" (p. 28). (Interestingly, Youngner views the term in a negative light, "because of the unpleasant associations it conjures up for many health professionals" [p. 323].)

Neither Youngner nor Selzer is opposed to the removal of organs from cadavers, but each is asking for a more sensitive approach to families and others involved in this difficult process. Youngner talks of new rituals and practices that would acknowledge the emotional significance of the moment when a brain-dead body is withdrawn from life support. He suggests that family members be invited to see their loved one at the end of the process, when organs have been taken, tubes removed, the body "cleaned and covered," and the deceased person is "at peace" (p. 323). Selzer's story tells us why this sensitivity is so important and vividly captures the puzzle and paradox that are never very far off when we retrieve living organs from dead bodies.

The Difference That Family Makes

David B. Fletcher

Marshall B. Kapp. 1991. "Health Care Decision Making by the Elderly: I Get By with a Little Help from My Family." *Gerontologist* 11, no. 5 (October): 619-22.

James Lindemann Nelson. 1992. "Taking Families Seriously." *Hastings Center Report* 22, no. 4 (July-August): 6-12.

FOR THOSE OF US WHOSE THINKING about bioethics was shaped during the 1970s and 1980s, nothing could be more natural than to frame and discuss its issues using the principles of autonomy, beneficence/nonmaleficence, and justice. This period witnessed a great bioethics explosion, a flourishing of interest, activity, conferences, publications, associations, and institutions to address bioethical issues. The discussions proceeded from the fairly narrow perspective supplied by philosophy, which emerged as dominant among the several disciplines that brought their resources to bioethics, and were relatively uninformed by faith traditions, particular ethnic, regional, or political loyalties, or other sources of values.

In virtually all textbooks in bioethics from this period we are instructed to view bioethics as the resolution of hard cases using only these principles, particularly individual autonomy. Autonomy, according to Beauchamp and Childress's influential and representative *Principles of Biomedical Ethics*, is a principle that insists that "autonomous actions and choices should not be constrained by others" and that "asserts a right of noninterference and correlatively an obligation not to constrain autonomous actions" (Beauchamp and Childress 1983:62). These authors derive the principle exclusively from secular philosophical sources: from Kant's respect for persons and Mill's position on individual liberty. For

Beauchamp and Childress and for many others, autonomy admittedly could be overridden by other competing principles in particular cases, especially when the patient's competence was in question or her welfare unreasonably jeopardized by her unwise exercise of autonomy. Yet autonomy, understood as individualistic decision making free from interference, still occupied pride of place among the various possible considerations that could be drawn from philosophical, religious, or other sources.

The emphasis on autonomy may have been narrow and one-sided, but it was not entirely inappropriate. Autonomy provides a particularly effective way of resolving situations in which the individual's wishes and interests are to be weighed against the overreaching demands of others, particularly of paternalistic health care professionals and powerful governments and institutions. It enshrines our deep conviction that individuals are of immense value, a value that cannot lightly be traded for other considerations. Yet by its emphasis on the isolated person, autonomy can falsify and distort our understanding of bioethical issues, causing us to fail to recognize some of the most pervasive situations that arise in biomedical ethics. For example, although autonomy seems particularly useful in determining our answers to questions about the decision making of competent adults in acute-care situations, it is particularly unsuitable for deciding the treatment of less competent adults, those in chronic care, or children. Even the extension of the notion of autonomy in such domains as proxy consent and substituted judgment emphasizes our individuality rather than our connectedness.

The significance of the fact that virtually everyone belongs to a family is surprisingly masked from the bioethicist who holds too exclusively to the autonomy model. So great has been the hold of the philosophical principles mentioned above that we simply have not given significant weight to the family as a decision maker, nor have we paid adequate attention to the fact that families can be profoundly affected by medical decisions regarding one of their members. Two recent articles have emphasized the importance of family in bioethics, not only as a locus of decision making but

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even as the end to be served by the decisions: Marshall B. Kapp's "Health Care Decision Making by the Elderly" and James Lindemann Nelson's "Taking Families Seriously."

Three questions suggest themselves as we begin to examine the relevance of family for bioethics. (1) What is so special about families that they ought to receive greater attention in bioethics? (2) If family is so important, how do we account for the fact that we have failed adequately to recognize this? (3) In what ways will attention to the family alter our customary ways of thinking about bioethics?

1. Families are important for a number of reasons. As public health specialist Marshall B. Kapp notes, the family, a basic social unit, is the individual's school of values; we learn and hone our ethics and values in families (p. 620). Family decision making may enhance a member's power to make decisions, as Kapp finds in his study of elderly patients and their families. He believes that mentally capable elderly persons typically desire and can benefit from family assistance in making decisions. He cites studies to show that such patients in fact "do not behave as lone, isolated, atomistic agents . . . , but rather rely heavily on family members . . . for assistance in medical decision making" (p. 619). "Older individuals are not islands when it comes to making health care decisions. The majority of older persons get by in this context not solely by themselves, but with a little help from their families" (p. 622).

Family members have important interests in whether a member undergoes treatment, as both articles recognize. Further, although their place has not been fully acknowledged, family interests already figure in a great many bioethical decisions that arise in such areas as long-term care, intensive care, and the treatment of imperiled neonates.

2. Several factors help to explain why the role of family has not been adequately acknowledged or explored in bioethics. First, the dominance of the principles-oriented approach seems to slight family perspectives. More fundamentally, according to ethicist James Lindemann Nelson, standard theories of moral philosophy are "inherently suspicious of the notion that something as particular and contingent as intimate relationships could really be of any deep moral importance in themselves"; within these theories such relationships are seen as threats to proper

ethical impartiality (p. 7). In addition, medical practice has pursued "the interests of the individual patient, in splendid isolation from her social context," and has seen family relationships as solely of instrumental value, as sources of information about patients' desires and as "reservoirs of emotional support" (p. 7). On the legal side, Kapp reminds us that although the law recognizes individual autonomy, it has yet to find a place for family decisions.

3. How does family decision making work, and how does it relate to autonomy? The two authors seem to envision a family conference for "frank and concrete discussions between the . . . patient and family," in Kapp's words (p. 620). Kapp believes that family should serve to enhance the autonomy of patients, in particular the elderly, by sharing the burden of decision making. Family becomes the basis of "assisted or shared consent" when the patient does not desire the entire burden of information and control or when her capacity diminishes to something *between* full autonomy and incompetency. Kapp argues for a "rebuttable presumption in favor of families supporting rather than overpowering a capable patient's decision making," rather than "presumed distrust of families and routine outside intervention" (p. 621). In order to facilitate familial decision making and to deal with the inevitable conflicts that will arise, Kapp calls for changes in the law by "developing for medical decision making purposes some workable analogue to joint banking accounts, joint tenancy, tenancy in common, and other legal devices" with a long history in property law. He advocates a "joint medical consent account" established between patient, designated family member, and health care provider, agreeing to joint consent of the patient and family member while the patient is competent, and consent by the family member after competency is lost (p. 622).

Nelson believes that family conferences will reflect and express "familial character"—the particular patterns of choosing projects and setting goals, expending energies and resources, and assigning burdens that constitute a family and its sense of itself—and that this character will importantly shape their familial decisions.

Though these two authors would agree that our present individualistic medical ethic is deficient, they disagree about the way family considerations ought to affect the process and content of decision making.

Nelson makes much of a point that Kapp also acknowledges, that there may be disagreements between non-patient family members and between family and the patient. How are we to proceed when there is a disagreement between the patient and her family about her treatment? This potential for conflict is particularly troublesome because both authors eschew "the claim that one kind of family is morally canonical" (Nelson, p. 6) and insist that "family" may include lovers and others who are not related and may exclude individuals who are related but not judged to be "close."

The answer to the question of conflict will look different if we consider the *patient's* welfare as preeminent, so that the disagreement is about how best to advance this welfare, or if we consider that the welfare of other *family members* must also be considered. The possibility presents itself of family members' attempting to assert their wishes over those of the patient to benefit not the patient but themselves, a situation clearly anathema to traditional autonomy theorists. Philosopher John Hardwig (1990) has argued that we must give weight to the medical and nonmedical interests of *both* patient and family and that sometimes the patient's interest should be sacrificed to those of the family. As he says, "I am a husband, a father, and still a son, and no one would argue that I should or even responsibly could decide to take a sabbatical, another job, or even a weekend trip, solely on the basis of what I want for myself. Why should decisions about my medical treatment be different?" (Hardwig 1990:6).

Kapp finds this approach unacceptable; he believes that the vulnerability of patients, particularly elderly patients, requires that they be protected from familial coercion intended for the benefit of either the patient or the family. In conflict situations, Kapp supports the patient's wishes over those of the family and calls on physicians in some circumstances to "intervene to protect the patient from the family" (p. 621). Nelson steers a middle course between Kapp and Hardwig. He believes that family wishes and interests should be factors in the family conference, but he explicitly stops short of requiring family consent to a procedure the patient might desire. He believes that the special vulnerability of patients should make us cautious about bypassing patient consent (or lack of consent) in favor of family interests. While stopping

short of requiring the patient to get family consent before undergoing a treatment, Nelson wishes to expand the decision-making role of the family conference and to admit the relevance of the treatment's effects on the family as a whole. For Nelson, a patient's treatment decisions should be treated as "rebuttable presumptions in her favor," but the family should have the option of challenging patient consent through institutional mechanisms not unlike present-day ethics committees (p. 11).

What is the religious believer's response to this trend? Is the recovery of the role of the family in bioethics something to be celebrated or to be feared? The discussions offered by these authors suggest that both responses are reasonable. Our embeddedness in family is an important resource that can enrich our approach to ethical decisions. It is in family that we develop our religious convictions, our sense of what is important in life, and our sense of responsibility. Along with the newly recovered virtue and narrative approaches to ethics, which insist that our ethical concepts are rooted in communities and their stories, attention to family can help us break out of the overly restricted and secular language offered us by recent philosophers. Unlike the major philosophical traditions, religious traditions generally conceive of individuals as members of families that play crucial roles in treatment and patient-care decisions. And religious bioethicists have never been as neglectful of the importance of family as have some others.

Nearly every faith tradition would also be concerned with the definition of *family* that seems to be operative in these articles. Faith traditions typically preserve some sort of "canonical" concept of the family such as our authors reject on grounds alien to religious concerns. Although religious believers may well recognize the changing complexion of the American family, they still generally argue that one's spouse, to whom one is bound in covenantal faithfulness, occupies a place that a less committed lover cannot, and that one is bound covenantally to children and parents with indissoluble bonds that are stronger and of more significance than feelings of "closeness" in one's present friendships and relationships. Although it is indeed appropriate to find a role for lovers and friends, for the religious believer the line between families bound in covenant and other people has a special spiritual significance.

The blurring of the line between family and non-family in these two articles exacerbates the problem of deciding what is to be done when a disagreement arises between patient and family and between family members themselves, disagreements all too common in real life. If family decisions and patients' decisions are to be given similar weight, such disagreements will pose serious problems of adjudication. And as we find ourselves taking account of the nonmedical burdens of treatment on family members, there is strong reason

to believe that the welfare of vulnerable patients will be compromised. Serious problems will arise when we subordinate the interests of the patient to those of true family members, let alone to those of people judged "close" to him. The bioethics community and the broader society will need to engage in serious, committed discussion of these conflicts between individual and family and to search for decision-making procedures that adequately recognize the claims of both.

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NOTEBOOK

Amid great controversy, preventive-health clinics opened at three high schools in Denver four years ago. Today, surveys show 95 percent of students and parents like the concept.

"These programs are very threatening to all kinds of people," acknowledges Dave Kaplan, M.D., chief of adolescent medicine at Children's Hospital in Denver. For the first few months of their existence, the clinics made the front page of the local newspaper almost once a week. At least one religious leader fanned fears that the clinics would provide abortions. "Disrupting institutions to this extent, I knew we were making real changes," Dr. Kaplan said.

Staffed by registered nurses, nurse practitioners, and clinical social workers, the three school-based clinics together now log more than 1,000 visits a month. At a yearly cost of \$150 per student, they offer sports and job physicals; immunizations; psychological counseling; and treatment for acne, respiratory infections, strains and sprains, and sexually transmitted diseases. Support groups serve gay teens, teens grieving the death of a parent, suicidal teens, and those who have been kicked out of their homes. Some students use the mental health services up to 100 times in a school year.

"Now, when you see a depressed kid who's been kicked out of his house, instead of referring him to a nurse, who refers him to the community, where there are no services, that student is taken care of," Dr. Kaplan says.

"This is a new frontier, a redefinition of school health," adds Kaplan. "If you really want to reach kids, you go to where kids are."

(*American Medical News*, 21 December 1992)

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The diagnosis of developmental problems in a child can throw a family into crisis. When a child is diagnosed with a genetic or chromosomal problem that will cause developmental delay, the physician's job is only beginning. A study in the October 1992 *Journal of Pediatrics* looks at how parents were informed of their child's diagnosis and how they would like to have been told.

Investigators surveyed 189 parents. At least half the parents gave physicians high marks for being caring and for allowing them to talk. Nevertheless, 95 percent would have preferred more opportunity to talk, 94 percent wanted a chance to show their feelings, 97 percent wanted physicians to show more caring, and 93 percent wanted doctors to express their own feelings. Forty-two percent felt they did not receive adequate information at the time of diagnosis. Although 87 percent of parents strongly desired contact with a family in similar circumstances, only 19 percent were referred, including only 8 percent of parents learning of the diagnosis at birth.

(*Journal Watch*, 1 December 1992)

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Africa has the highest child mortality rate in the world: 10 times the rate in the industrialized world. Twelve percent of the world's children under five are in Africa, but 33 percent of the 40,000 children in that age group who die each year are in Africa.

([UNICEF's] *First Call for Children*, October–December 1992)

Children's self-esteem is affected by memories of their successes and failures and by the way adults important in their lives responded to both. But "the single most critical factor in self-esteem is physical appearance," said Dr. Susan Harter, a professor of psychology at the University of Denver who studies low self-esteem in children. "Children who feel they're not good-looking tend to have low self-esteem," Dr. Harter continued, adding that this is a particular problem for girls.

Children's feelings about themselves color how they interpret the world. Those with high self-esteem are likely to attribute their success to skill and effort, while those with low self-esteem often attribute success to luck. They distrust their own accomplishments and anticipate failure.

"Low self-esteem becomes more entrenched and resistant to change as children reach adolescence," said Dr. Martin Ford, a developmental psychologist and associate dean of the school of education at Stanford University in Palo Alto, California. "Younger children



usually don't interpret each bad thing that happens as a confirmation that there's something wrong with them."

One problem for parents and teachers is telling the difference between poor self-esteem, which can often be helped quickly and strikingly, and depression, which is more dangerous because of its association with drug and alcohol abuse and suicide. One important measure is whether the children are still actively involved in their social, family, and academic lives.

(*New York Times*, 21 January 1993)

Paternity leave is offered by 31 percent of the nation's largest 1,000 companies, but only slightly more than 1 percent of eligible employees take advantage of the option. *Reason:* Many men refuse to take paternity



leave because they fear losing their job . . . getting passed over for advancement . . . being considered a "wimp" by their fellow workers.

(*Bottom Line*, 15 January 1993)

Several years ago therapists debated whether children could be depressed at all; now the diagnosis is sometimes made as early as the age of 2. The main reason for the debate is that depression in children can look very different from the way it looks in adults. Sadness is frequently not the most prominent symptom, especially in children under the age of 8. Instead, the depression can show up as anger, belligerence, irritability, trouble concentrating in school, or vague physical complaints.

A child can display some of the signs of depression for several weeks without there being any lasting problem. This is especially true when the symptoms seem to be a reaction to a specific stress or trauma, such as a death in the family or a move to a new town. Symptoms that persist for more than a month and markedly change a child's personality and ability to participate in daily life may be an indication of depression.

(*New York Times Magazine*, 2 October 1992)

Prevention is the goal of the new guidelines for adolescent health developed by the American Medical Association and the Centers for Disease Control. The Guidelines for Adolescent Preventive Services take a comprehensive approach to combating the health threats to young people. The product of two years of research and consultation with medical specialty societies and other experts, the guidelines make 24 recommendations in these key areas:

(1) delivery of health services, calling for annual checkups for all people 11 to 21 years old;

(2) health guidance, urging doctors to provide information and advice to adolescents and parents on how to cope with the physical and emotional changes of adolescence;

(3) screening for health problems most likely to affect adolescents, including eating disorders, smoking, depression, and sexual behavior that could result in unintended pregnancy or sexually transmitted diseases;

(4) immunizations, including hepatitis B vaccination for adolescents who engage in high-risk behaviors.

The ambitious goals of the recommendations can be realized in large part during normal visits by adolescents to their doctors.

(American Medical News, 18 January 1993)



Millions of U.S. children are not receiving a healthy start because of a lack of health insurance and access to doctors, hospitals, or health clinics, stated the Children's Defense Fund (CDF) in a recent report calling for major changes in the nation's health care system. The CDF cited the nation's "scandalous" immunization rates—fewer than 60 percent of 2-year-olds are fully immunized in most states—and the re-emergence of preventable diseases as major reasons for taking action.

First lady Hillary Clinton serves on the children's advocacy group's board of directors. In the report, the CDF urges the Clinton administration to take prompt executive action to consolidate vaccine purchases and distribution for all children in federally funded health programs, improve Medicaid coverage of immunizations, and require that all federal employee health benefit plans cover the full cost of childhood vaccines.

The group reports that every dollar spent on immunizations would save at least \$10 in later treatment costs and that a new universal childhood immunization plan would save billions of dollars in future costs.

The CDF stated that Medicaid, although it assists many indigent Americans, needs expanded governmental support because it does not reach the



near-poor and middle-income families who lack employer-based insurance. On the state health front, the report looks favorably at recent initiatives in Minnesota and Hawaii to expand health insurance coverage. But it cautions that "particularly dangerous for children are plans that seek to control costs in Medicaid and other low-income health programs without applying cost containment measures."

(AHA News, 25 January 1993)



The main section of the old Ashton hospital complex in Ashton, Idaho, is now a nursing home, and the surgical wing has been converted into a day care center. The young and the old get together for a weekly skit or activity, and some residents are visited by the toddlers during the week. Nursing home resident Lillian Miller says, "Everybody loves the little ones. It helps keep the older ones younger because our hearts are young."

(American Medical News, 14 December 1992)

BOOKS

Varieties of Postmodern Pain: Recent Narratives of Witness and Response

Arthur W. Frank

David Bearison. *"They Never Want to Tell You": Children Talk about Cancer*. Cambridge, Mass.: Harvard University Press, 1991.

Kathy Charmaz. *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, N.J.: Rutgers University Press, 1991.

Arthur J. Greil. *Not Yet Pregnant: Infertile Couples in Contemporary America*. New Brunswick, N.J.: Rutgers University Press, 1991.

David B. Morris. *The Culture of Pain*. Berkeley and Los Angeles: University of California Press, 1991.

Jenefer Shute. *Life-Size*. Boston: Houghton Mifflin, 1992.

NO MATTER WHAT MY INTELLECTUAL or professional reasons for reading books on pain, those are not the real reasons. What truly motivates my reading is the sense that pain circumscribes my life; I begin and end in pain. Between beginning and ending I search for

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responses to pain, both my own and others'. Responding to pain is not easy, because pain is both here and there; both where it hurts and in the mind that signals hurt; both in my body and in its environment. Pain is the most concrete of sensations and the most mobile of phenomena.

Although pain is a constant in human existence, it is an elusive constant. Pain's elusiveness appears to be increasing, and that increase leads me to adopt David Morris's trendy term *postmodern* for the title of this review essay. Recent books about pain convince me that we have crossed some threshold, here as elsewhere. Pain does not just remain the same; what counts as pain changes, as do the remedies for this pain. Even pain is not what it used to be.¹

Good books on pain are hard to find. David Bakan's *Disease, Pain, and Sacrifice: Toward a Psychology of Suffering* (1968) is a classic, and important recent works include Arthur Kleinman's exploration of lives lived with chronic pain in *The Illness Narratives: Suffering, Healing, and the Human Condition* (1987) and Eric Cassell's study *The Nature of Suffering and the Goals of Medicine* (1991). William F. May places pain at the center of medical ethics in *The Patient's Ordeal* (1991). The latter three books are purposively and justifiably illness-centered, but we cannot understand the pain of illness by considering illness alone. The contribution of David Morris's *Culture of Pain* is to show how pain permeates culture and how culture determines the experience of pain.²

Tragedy, Boxing, and Medicine

MORRIS OFFERS SOME REAL HELP responding to pain, but what he offers did not become apparent to me until rather late in his book. From the start I admired the breadth of his scholarship: *The Culture of Pain* is a valuable archive of quotations and anecdotes, of art works, and of medical research restated in lay terms. I appreciated what Morris had put together, but too much material was being passed through too quickly; I had to be patient with his haste.

Morris's thesis is clear: "pain is not just blindly felt or unreflectively endured as a series of biochemical impulses. It changes with its place in human history" (p. 45). This thesis is more controversial than we may first realize; it is certainly recent. Morris presents an illustration from Descartes's *De l'homme* (1664), showing how nerve responses travel from the peripheral site of pain to the brain. What is most interesting about the figure in the illustration is that it is ageless, sexless, and without race. "Its blankness probably reflects a desire to situate scientific truth in an abstract or universal realm," Morris writes; "Descartes, in this early version of the organic model, gives us what amounts to a picture of pain in a vacuum" (p. 271).

Medicine still considers pain to lie within a Cartesian "vacuum." But pain for Morris exists only in a context, and to prove this point he shifts from one context of pain to another. Morris speaks alternatively as field researcher in a pain clinic, as art and literary critic, as epidemiologist, as medical historian, and as lay expositor of science. He is more comfortable in some of these voices than in others, but all are done well. The glimpses of pain in each context are provocative, but Morris stops short of analysis. I was engaged, but my deeper needs for reading were unmet.

Morris's chapter "Tragic Pain," however, moved me from merely respecting the book to valuing it. Morris begins with an invocation of pain in *Oedipus Tyrannus* and in *King Lear*. The culminating moments of both plays involve not speech but a cry: Oedipus's "single, repeated cry of agony: speech rolled back into mere sound and torment," and Lear's words that "are not so much words as sounds, less spoken than bel-lowed like an animal cry" (p. 248). The chapter then proceeds to contrast Sophocles' little-known tragedy *Philoctetes* with Joyce Carol Oates's recent nonfiction

book *On Boxing*. In this contrast of tragedy and boxing, Morris critiques the medical view that dominates our contemporary thinking about pain.

"The sternest wisdom of Greek tragedy may be that suffering cannot be shared: only witnessed," Morris writes (p. 253). Oates attends boxing matches as a witness to the tragedy of the body. She describes this tragedy: "The defeat of one man is the triumph of the other: but we are apt to read this 'triumph' as merely temporary and provisional. Only the defeat is permanent" (quoted in Morris 1991:261). Morris turns these insights back onto medicine: "Only in pain . . . does the boxer, like the tragic hero, truly live. This is the thought that medicine finds so intolerable, why it must resist the tragic at all costs" (p. 262).

Morris's argument for this statement rests on asking a question that at first appears trivial but becomes one of those details that solve great puzzles. Why, among all the unhealthy activities that organized medicine might criticize, do medical associations have the easiest time passing resolutions to ban boxing? "Why single out boxing?" Morris asks (p. 262).

Oates has pinpointed the reason: boxing presents a tragic image of the irremediable pain of the body. "Medicine simply cannot carry out its work gripped by a vision of permanent defeat," Morris concludes:

Tragedy, like a dark alter ego, strips away the illusion that living well or eating well offers any protection against the destructive forces within ourselves and within our world that we cannot control or defeat but only endure, until endurance itself becomes too terrible to bear. (p. 265)

Reading this, I gained a new perspective on issues like why medical associations oppose physician-assisted suicide for terminal patients in extreme suffering. I also became better able to question my own resistances to images of destruction and defeat.

Morris concludes with the useful notion of *postmodern pain* (p. 280). Not only does this term reinforce his argument that pain never remains the same, it also suggests why his book must shift, even jump, from one context of pain to another. Those rapid shifts are precisely the postmodernity of pain. Morris finds the most salient of the postmodern characteristics of pain in philosopher Jean-François Lyotard,

who "defines postmodernism as the condition in which vast, overarching, general systems of explanation (he calls them 'metanarratives') lose their power" (p. 282). Christianity, Marxism, and medicine are all metanarratives, and Morris's point is that within postmodern culture, none of these, *by itself*, can provide an adequate response to pain.

Postmodernism is controversial because many of those at the height of their professional powers have built their careers by advancing explanations and interventions based on one metanarrative. The fundamental postmodernist claim that no narrative is "meta" to others is no easy pill to swallow. But when we have traveled with Morris through all the variations of pain and comedy, tragedy, hysteria, sex, pleasure, and politics, we realize there is no one privileged narrative but rather a labyrinth of connections and reciprocal effects. The postmodernist case for the demise of any metanarrative becomes compelling.

But one narrative does still dominate our sense of pain, and Morris's central concern is with medicine. He manages to be neither a skeptic nor an apologist: he recognizes medicine's achievements as well as its limits and gives both their due. But his point is that medicine alone cannot address postmodern pain.

By the end of my reading, my only contention with Morris concerned his title. We have, on his account, not so much "*the* culture of pain" as "cultures of pains." Medical "pain control" is inadequate unless the patient's suffering is also responded to. We continue to need medicine, but its narrative hegemony has broken down. To respond to a proliferation of pains we need a proliferation of narratives. In several recent books we find both this proliferation of experiences that count as "pain" and a parallel expansion of narrative forms witnessing that pain. In these narratives pain is no longer just spoken *of*; its telling is not reserved to experts. Now pain speaks, told by those who live it.

The Pain of Disappearance

JOSIE, THE ANOREXIC PROTAGONIST of Jenefer Shute's novel *Life-Size*, might appreciate the discussion above on boxing. The boxer prepares his body to a point of perfection, the better to have it battered. The anorexic perfects her body to the point of its own

battered disappearance. I wonder if Josie would see the boxer disappearing into the blows of his opponent, blows he wills without wanting.

Anorexia nervosa is a postmodern disease not because of its apparently recent prevalence but because its pain confuses us: it looks self-inflicted. A nurse placing Josie on the ultimate medical regimen before tube feeding tells her, "It's up to you," and so it can appear to be. Josie responds, "When has it ever been up to me?" (p. 73). The achievement of Shute's novel is to bring us to believe that little has ever been up to Josie, but perhaps, with luck, her future can be her own.

Life-Size is a sustained first-person monologue, and only this form could wind us so deeply into Josie's pain. Shute relieves the tension of this monologue by flashbacks and some dialogue, and an intermittent "Diagnostic Profile" form, to which Josie supplies answers that would be funny: "*Have you ever ceased menstruating for more than two months? Whenever possible*" (p. 141). The final question: "*Did any particular events in your life trigger this behavior? List as many as applicable:*" (p. 176). The colon is left open because the whole book, Josie's whole life, is the only answer.

Clinicians could single out a childhood incident of sexual abuse, or later sexual encounters that are voluntary but dissociated, or disgust with her mother's self-indulgence as being "causes" of Josie's disease; but why not call it the vacuousness of her postmodern world? Josie sees nothing but pretense around her. Sex is only slightly more ridiculous than eating; in both people gorge themselves without pleasure. At a distance we could say the anorexic's disease makes her see people acting this way, but Shute's art allows us to share Josie's vision. Josie's vulnerability is her half-clever ability to see through the hypocrisy but not beyond it. Thus she chooses to reduce herself to pure will, the only thing left that can be pure.

When Josie's parents surprise her with a visit, she describes her response: "I remained unmoved by the door . . . feeling something in me begin its familiar decampment to a cool, untouchable place just under the sternum" (p. 73). Everything in her life has led toward that cool, untouchable place into which her body is enfolding, disappearing. Anorexia is a final bid for control: "I don't want any involuntary responses; soon, in this body, everything will be willed" (p. 5).

Josie reduces herself to pure will, sealed on itself, keeping others out. When we see Josie's life as she does, we as readers encounter little we would want to let in. Anorexia as a choice is given coherence, and my realization that I shared the coherence of that choice was deeply disturbing.

Josie's pain is the acceptable by-product of exercising her will: "My skin is red and scaly from scrubbing (since I've been eating so much, I never feel clean), my arms covered with bruises and pin-pricks [hospital inflicted], my legs like twigs in hospital-issue scuffs" (p. 98). The greater pain is isolation. At one of her turning points, she begins to make human contact (again, or for the first time?) and asks a nurse to feed her (p. 79). Hearing this request, we realize others have only fed on her. She needs nurturing but also limit: if another feeds her, the other will know when to stop, and this is what Josie has never learned. "That's how we first know the world," she writes, "through the ecstatic workings of lips and tongue, but now some current has reversed in me, and I negotiate the world by keeping it out. Because if you begin taking things in, how will you know when to stop?" (p. 169).

The terror of this absence of limits is the postmodernity of Josie's pain. "Some current has reversed," and in a world of surfeit, lack must be self-imposed. Anorexia is a disease of reversals, paradoxes, and contradictions; life follows the negative narrative of exclusion, shutdown, refusal. The only will is negation, which presents the paradox of writing anorexia, not writing about it, but writing from within it. A book, with its promise of fullness, is the last thing an anorexic could produce. Shute's achievement is to retain anorexic emptiness within authorial production. Josie's emptiness remains bearable to read because Shute continues to feed us words.

What I value most in *Life-Size* is that author and editor did not compromise the ending; there is no heroic cure or salvific caregiver. Josie does develop a relationship with a nurse, but between them understanding remains tentative. The psychoanalyst Donald W. Winnicott described the best mothering as "good enough." Josie's nurse is "good enough," and for just that reason she is able to help. We never find out whether she feeds Josie physically or not, but in her presence Josie starts to eat.

At the end they discuss Josie's two choices: to live or to die. The reader certainly hopes she will live, but it's not certain. Josie will return to the same life, full of the same people who still want to feed on her. Her survival depends on whether she has changed enough to encounter that life differently. Maybe—the book is too honest to assure us—she now has a choice that her younger self never had.

But if having choices can lessen some pains, choice can also be a source of pain, as the situation of the infertile demonstrates.

Medicalized Pain and Failed Theodicy

"YOU CAN'T GET RID OF THE PAIN," an infertile woman tells Arthur Greil (p. 81). In some specific treatments the pain is physical, but the deeper pain of infertility is the sense of personal failure, the loss of identity, and the loneliness. Infertility is private enough that few share it, but also public enough to render the infertile constantly vulnerable to the insensitivity of others, the "Why haven't you had kids?" questions. Because others often assume their infertility is voluntary childlessness, the infertile feel stigmatized. It says volumes about infertility that few are able to reframe their lives to make voluntary childlessness an acceptable option. Greil found that *no* couple in his sample (admittedly a biased one) "reconciled themselves to childfree living" (p. 98).

Men and women describe infertility as "engulfing." They speak not only of the condition but of its promised cure. "As with chronic illness," Greil writes, "the infertility treatment regimen can easily overshadow other aspects of patients' lives" (p. 97). This same engulfing inseparability of the pain originating in the body and the pain of treatment reappears below, in the discussions of the chronically ill and of children with cancer. Medicine can relieve some pains, but it also causes others.

Greil writes as a sociologist who has been where his research subjects are. The back cover of *Not Yet Pregnant* tells us that he and his wife "discovered their infertility in 1981." Arrested by this phrase, my mind flashed a revision of Genesis 16:1—"Now Sarai and Abram discovered their infertility and entered into a

surrogacy contract with Hagar." The same bodily conditions still cause us pain, but is that pain the same when new institutional arrangements have given it new names?

Greil probably saw irony in the book jacket's description of him, because his topic is "the social construction of infertility," and the phrase "discovered their infertility" exemplifies how society constructs. Nor is my biblical free-association misplaced: society constructs the pain of infertility through religious institutions and meanings. Meaning is the third aspect of infertility that Greil focuses on. The other two topics are how infertility both reflects and affects contemporary marriage, and how infertility is defined by medicine. Because of space limitations I will skip marriage and discuss medicine and meaning.

Childlessness has recently become a medical condition: *infertility*. All those in Greil's interview sample were, at least for a while, committed to medical diagnosis, treatment, and the promise of cure. This medicalization of the infertile has a good deal to do with the professional organization of gynecology, and Greil has some provocative statistics on how infertility treatment has resolved a supply/demand imbalance for physicians practicing in that area (p. 45). More relevant to this review is how medicine affects pain.

The picture of doctor-patient relationships reported in *Not Yet Pregnant* is not comforting. Tales of medical insensitivity are chilling. Physicians who have no special expertise in fertility issues prescribe treatments they understand less well than their patients do. Patients fabricate the stories they know physicians wait to hear before some treatment is initiated. Some physicians, and more nurses, get praise; these are not the best technicians but the ones who will "cry with" their patients. The response to others is summed up by one respondent: "I have much less faith in [physicians]. I realize how many mistakes they make. Before I used to think they were quite perfect. I don't have the feeling they really care" (p. 87).

Whether the medicalization of infertility constitutes a social problem depends on several issues, including the often questioned safety of drugs currently prescribed. Greil apparently considers this issue outside his purview; that none of his interviewees raises it suggests again that they are a biased sample. But Greil does tell us about another central question

of medicalization—how much pressure physicians exert on patients to seek and continue treatment.

Greil reports that initially most patients, who are wives almost exclusively, had to "coax their *physicians* into a more active stance" in starting infertility testing and treatment. Once treatment was initiated, however, respondents reported being pressured to continue (pp. 88, 102). This medical coercion is summarized by a sign hanging in a clinic where in vitro fertilization (IVF) is practiced. It reminds patients: "You never fail until you stop trying" (p. 102).

The biggest problem of medicalization may be that the treatment emphasis excludes consideration of other options like adoption. Medical treatment availability thus increases "normative pressure" on women to remedy childlessness by continuing to try to have their own (and their husband's) biological children (p. 184). This pressure is certainly greater on women than on men. Greil concludes, "The escalating medicalization of reproduction during the course of the twentieth century has meant that women are increasingly living lives punctuated by medical intervention in ways that men's lives are not" (p. 184). Regardless of which spouse has the physiological problem, wives think of themselves as infertile, and medical intervention is disproportionately directed at women's bodies, with side effects including medically caused infertility, as in the DES failure.

If those in medicine find that Greil's research raises hard questions, clergy will be no less challenged. Speaking about church, one respondent says, "God, that is the worst place to go if you're infertile" (p. 59). The reason is the constant definition of families as including children. One of the most moving anecdotes told of a Mother's Day service when the minister "asked all the children to go around and hug all the women that didn't have children in church" (p. 62). However well-intentioned that gesture, the couple found it the most painful reminder of their infertility and "refused to go" to subsequent services.

Religion dominates the search of many infertile couples to find some meaning in their experience—a meaning that medicine simply refuses to address. Infertility, like any form of suffering, requires some justification or theodicy. Greil defines a theodicy as containing two parts, "an interpretation of personal suffering and a mechanism of social control. . . .

Theodicies simultaneously explain suffering and warn people away from culturally proscribed behavior" (p. 155). Because of their social control component, theodicies tend to fail as compassionate responses to suffering; they fail by blaming the victim.

Available theodicies leave the infertile questioning God. A Catholic woman says, "There's nobody I can really be bitter at other than God. It's terrible to say, but I've quit going to Mass because [voice faltering] I feel that God's let me down, that He's punishing me, and I've never done anything to deserve it" (p. 161). That an intelligent woman who has led a religious life could hold such beliefs should be disturbing, and her comment was not isolated. Most respondents felt that "there must be a reason" (p. 164), and alienation from God seems to have been frequent. Those who have what Greil identifies as the strongest religious background feel the strongest alienation (p. 167). As sad as this loss of faith is, I was more unnerved that respondents whose infertility problems ended happily reported an increase in faith. Is faith measured by payoff? For many people, apparently yes.

"To accept the kinds of answers traditional theodicies give implies a spirit of resignation," Greil concludes (p. 173). Such traditional, blaming theodicies are what his respondents find in church. That report is the frightening, challenging finding of Greil's research.

Not Yet Pregnant is the best entree I have found into the lives of those undergoing infertility treatment. Greil's policy conclusions, however, gloss some troubling issues. He writes that "most IVF clinics implant all fertilized eggs in the uterus to avoid criticism from Catholics and others who feel that allowing a fertilized egg to die is tantamount to abortion" (p. 183). He does not point out that if all these implanted eggs "take," there then must be a "selective reduction" to a number that the womb can sustain. But in my experience women are not always told about selective reduction as part of informed consent for treatment.

Greil is equally uncritical of medicine's inevitable arbitration of family values when it treats infertility. He seems to applaud clinics that limit their clients to married couples (p. 183). People disagree on how parental marriage agreements and sexual orientations affect children; unlike Greil, I'm pleased that my university's hospital no longer restricts their services

to married couples. But our respective preferences are not the point. Whatever values one holds, do we want medicine—and not just physicians but medical bureaucrats from politicians to insurers—deciding the issue? Medicine cannot enter the fertility business without becoming an arbiter of values—a role for which practitioners have no special expertise or mandate.

But these issues are tangential to the book's central contribution. The pain of infertility may be best described when Greil writes that those in treatment can neither escape their infertility nor accept it as inescapable (p. 177). Quitting becomes failing, and no couple reports reconciliation to childlessness. Those of us outside this pain can easily say "just let go of it"; as the nurse says to the anorexic Josie, "It's up to you." But I imagine many of Greil's respondents would answer as Josie does, "When has it ever been up to me?"

"Undramatic" Pain

THE SECTION HEADING IS FROM DAVID MORRIS, who also calls chronic pain the "defining illness" of our era. But despite the number of those who suffer,³ chronic illness is comparatively invisible. Morris writes that chronic pain "keeps its low profile by doggedly failing to convey the macabre glamour of deformity, contagion, and imminent death" that attracts attention to diseases like AIDS (p. 66). Although Morris's research included fieldwork among the chronically ill, he tells us little about how pain constructs their daily lives. We thus turn to Kathy Charmaz, a sociologist whose *Good Days, Bad Days* is the result of a decade of intensive interviews with the chronically ill.

The term *chronic illness* becomes increasingly vague as medical technology renders previously acute conditions long-term. Charmaz includes persons with forms of cancer and heart conditions among the chronically ill. The distinction between diagnosed and undiagnosed chronic pain is passed by equally quickly, though Charmaz coins the useful phrase "diagnostic relief" to express the importance ill persons place on having a legitimating "disease" label (p. 24).

Charmaz's real interest and what distinguishes chronic illness for her is time. Illness is chronic when it forces the person to revise his or her sense of the

temporal continuity of life. Temporal continuity, or its lack, is in turn the basis of the self. The physical pains of chronic illness ultimately become losses of the self, losses experienced as disruptions of the self's continuity through time.

The physical pains of chronic illness take us back to the screams of Oedipus and Lear:

A young woman with severe dermatitis and colitis said: "At that moment when you're alone in your room, the itching is so bad you want to claw your skin off or the pain is so bad . . . with colitis, [I'm] crying, sitting on a toilet or just curling up in a ball in bed and covering up my head and crying, crying. There was nothing I could do. I just had great pain. I was out of control. My body was taken over at that point." (pp. 86-87)

Chronic illness begins with the body being "taken over" by pain. Soon this bodily pain is compounded by social pains. Another woman describes how she is treated in a medical clinic: "You are raked across the coals and torn apart bit by bit until you are no longer the person you thought you were . . . they are clawing you apart" (p. 102).

This treatment pain is having identity stripped away and replaced with medicine's version of self; a patient says: "If your previous definition, or basis, or whatever, has been knocked all to smithereens, you are left with their definition—it's all you have" (p. 103). Charmaz summarizes the destructive power of medical staff to define the selves of their patients: "Implicit or explicit feeling directives from powerful others provide frameworks for 'understanding' and experiencing self and situation, even when these frameworks demean or devalue oneself" (p. 222).

The particular medical treatments the chronically ill receive reflect their economic circumstances, and the combination of impaired ability to work and high medical costs over long periods of time means that most of Charmaz's interviewees are living in reduced if not impoverished circumstances. One man's income forces him to choose between food and medication; he cuts the medication. A neuropsychiatrist doing research, not treatment, assessed his drop in IQ from 140 to 85. He stutters, suffers headaches and dizziness. "It's really sad to see a man with such brilliance and creativity slip into a state over which he has no con-

trol," the psychiatrist concluded, with an irony that does not seem intended (p. 187).

The other side of poverty is the amount of time and energy the chronically ill must devote to maintaining what "benefits" they do receive. Paperwork and other bureaucratic demands compound physical symptoms. We hear of "fighting for my Social Security," straightening out what computers have "messed up," "bargaining to cover expenses," "getting information about getting help," traveling to workshops that teach how to apply for benefits. One person describes her constant struggles:

Chaotic. Things are too chaotic now. . . . Foodstamps said they overpaid me; now I have to pay them back. General Assistance asked what kind of help I'm getting by having my mom here and cut me off. Welfare isn't even interested in you if you don't have a child at home. (p. 188)

What the United States has, Charmaz concludes, "is an illness care system founded on profits. What chronically ill people need is a *health* care system based upon *services*" (p. 263).

The effect of this illness-for-profit system on physical pain is direct. Programs and policies "limit access and medical intervention until the chronically ill person's health has deteriorated into a crisis," thus mocking the idea of preventive medicine (p. 263). On a day-to-day basis, stress-related disease conditions are exacerbated by the volume of paperwork required by treatment and its payments (pp. 77-78).

Other sources of pain include betrayal by friends and lovers who exploit the illness condition (p. 217), sheer boredom (p. 243), and finally meaninglessness. An elderly man tells Charmaz that the only significant times in his life are her visits and those of a volunteer. "All the rest means nothing. *Nothing*." (p. 244). In that emphatic, existential "nothing" pain and suffering each pervade the other. Charmaz looks at this pain squarely, without softening its destructive force; like the other books discussed here, hers does not compromise.

She is not so specific as Greil about the question of theodicy: what meanings do the chronically ill find in their suffering, and how do they explain it? One of my slight frustrations with *Good Days, Bad Days* was that when the respondents seem on the verge of talk-

ing about their spiritual insights, Charmaz cuts to another topic. There is one lovely moment when an elderly woman says,

Here I sit all crumpled in this chair not being able to do anything for myself and still there's a purpose for me to be here. [Laughs] I wonder what it could be?

What does He want me to do? (p. 256)

We get intimations of such thinking among others but little more, even when spiritual pursuits seem important parts of their lives.

What Charmaz does make explicit is the power of stories in the lives of the ill. Near the start of the book she quotes a woman who refused radiation treatment for Hodgkin's lymphoma until she met another patient whose story inspired her to persevere (p. 11). As fundamental as the needs for help, housing, and health care are (p. 189), the ill also need stories. By telling, reliving, and retelling what has happened to them, the ill gain new perspectives, discover positive significance in events, and eventually gain closure on painful events (pp. 211, 219). "Retelling," Charmaz writes, "leads to deciding on a view of reality; it shapes actions and emotions" (p. 219).

Changes in stories are essential to the creation of new selves better able to survive the illness (p. 260), but here also pain enters in. Family traditions can silence stories: "Christine Danforth's father had died a painful death from cancer, but no one in the family ever discussed his pain and suffering. Similar patterns repeat themselves" (p. 115). Christine finds it difficult to talk about her lupus; the help others find in forming new stories is closed to her. Other stories are shut off in other ways. One patient refuses to talk to a woman he meets in a clinic because he sees her as a "negative role model." "I don't want to listen to that," he says, "I don't want to be like that" (p. 177). His judgment may have been sound for his needs, but we can only hope that the woman finds someone else who will listen, painful as her story is.

In one of her wisest conclusions Charmaz tells us, "Many ill people do not know what to feel. . . . Ill people *experiment* with both their feelings and actions. And, their feelings are often mixed" (p. 222). The contingencies of family situations, physical ups and downs, and treatment by the welfare-medical bureaucracy constantly change this mix of feelings.

The unpredictability of these changes leaves people even less sure what to feel. And becoming attached to feelings is dangerous for the chronically ill: something else happens, and that feeling no longer fits. But many still manage to sustain a coherent sense of self and even to enhance that self.

Charmaz's realism about the brutality of society's response to the chronically ill underscores the power of individuals who do achieve a sense of meaning and value. One woman says of her illness, "I wouldn't trade that time for anything. Dealing with it made me the person I am today" (p. 201). "Dealing with it" is the human condition. Forcing people to deal with it in the conditions described in *Good Days, Bad Days* is society's shame.

Innocence and Insight

IF ALL THESE BOOKS ARE "MUST" READING, David Bearison's recordings of children with cancer may be, as one of the children might say, the most must. Bearison is a New York psychologist who conducted intensive interviews with more than 75 children in several pediatric oncology centers. The simplicity of his thesis reminded me of the original intent of Elisabeth Kübler-Ross, to listen to the ill rather than treat them as objects of intervention. "Children need to be able to talk about their cancer experiences," Bearison writes, "as a way of helping them adjust to the continuing struggles and uncertainties of having cancer" (p. 171). But unlike Kübler-Ross, Bearison does not construct a theory from what he hears. Instead he lets the children tell it, and he simply edits what he has been told. The directness of their voices is the power of *"They Never Want to Tell You."*

The book has two parts. The first presents eight exemplary narratives in which a child tells his or her experience. "Child" is a bit wrong: ages are not given, but most of the interviewees seem to be teenagers; one girl talks about her boyfriend's reaction, and a young man claims the one advantage of chemotherapy is that it lessens his chances of getting one of his girlfriends pregnant. We are clearly on the outer edge of childhood. But these are children. Their fundamental innocence is not just their initial ignorance about cancer (which quickly turns to being highly, if eclectically, informed, mostly by other children), nor is it

their parents' role in shaping their responses, though this is considerable. Innocence has more to do with not approaching cancer from a position already fixed in a world they have already made up their minds about. The children have an openness to all the possibilities of illness. Cancer is their initiation into a world they have hardly begun to experience.

The second part of the book collects short interview fragments—from a couple of sentences up to several pages—on eight themes that Bearison found in all the interviews: the “Why me?” question; reliance on God and prayer; fears created by cancer; hair loss; advice for others with cancer; cancer's effect on friendships and family; how they have changed through cancer; and the need to talk about cancer. Bearison's introductory comments to each section are useful but tactfully brief. In an afterword he discusses the problems of professionals working with children who have cancer, and their need for talk of their own. The book is short, elegant, and in the most serious sense, respectful.

The children do not say much about their pain, but here is one passage that reminds us of the reality underpinning their lives:

It's like those days are so hard to remember because most of it, I was in tears and crying with the pain. My mother would bring me soup and food, and I couldn't eat none of it, and I was losing a lot of weight, and it was just like you would say set there to die because I wasn't eating much, it was hard to eat, every time you sit up it's pain, every time you lay down it's pain, and with the bed moving up and down every time it hits a position it's more pain, less pain, you can't get in the right position. All you could see from my face is shedding a lot of tears, a lot of tears. (p. 59)

This pain is what gives the rest of the children's words their weight as moral testimony, as in the following:

It made me a person, you know, made me the kind of person that was able to realize their feelings. Some people can go on, you know, years and years in their lives and not know how they feel or how to express their feelings. And I'm able to do that now. (p. 168)

When this testimony turns to God, innocence is at its most compelling:

But my biggest advice is to learn to think about God. . . . It also gives you that peace. . . . A lot of people don't think about Him until something happens to them, that's when you know Him, and that's not bad, but then I would say learn how to pray because people can't always be there for you. (p. 152)

Here we have the purest theodicy of pain: “that's when you know Him, and that's not bad.”

Other theodicies include justifications (“it'll make me a stronger person” [p. 92]) and process (“I'm not sure what I believe in right now, and . . . I hope it will help me figure out what I do believe” [p. 131]). These searches for meaning point to what was, for me, the book's profound insight. One child says, “Why me? I kept asking the doctors that. They gave me bullshit, telling me that people get a tumor, it just happens” (p. 128).

What is the “bullshit” the child objects to? Tumors do just happen; most of the children come to accept the randomness of disease, though some persist in self-blaming. But this child is asking about something else. The question sounds medical, but the child's concern is existential. His or her doctors fail to hear that existential overtone. The doctors' explanation may be right, but to ask someone to live through the pain of cancer without a sense of purpose is, in the directness of that child's language, the saddest sort of bullshit. The child's insight is to know there has to be more.

As Bearison presents them, these children are more able than many adults at sorting out the medical randomness of cancer from the spiritual purpose, and keeping each in its proper sphere. They leave what is medical to their doctors, whom they usually respect but feel little closeness to, and they pursue what is spiritual by themselves.

When we first encounter these children's pain, it's almost unavoidable—but not very useful—to be overwhelmed by pity. Bearison leaves us certain they would not want that. When he promised prospective interviewees strict anonymity in any published reports, many were disappointed. They wanted to be known, as widely as possible. What we can do for them is know them. As one child says of a friend: “I know

him real good and now he knows me real good. And he knows what I'm going through, and I know what he's going through" (p. 179). Perhaps that is how the child who spoke of prayer felt about God.

Postmodern Pain

MORRIS LISTS SEVERAL QUALITIES of postmodern pain; these can summarize and conclude this exploration.

First, Morris forecasts that soon we will "no longer think of rigidly separate categories called physical pain and mental pain" (p. 277). In specifying the different pains described in each of these books, the distinction between the mental and the physical falls apart. Josie's anorexic pain perhaps entwines these two dimensions most closely; we simply cannot tell where the physical stops and the mental begins. The physical/mental distinction makes no greater sense for the infertile, the chronically ill, or children dying of cancer. Physical pain becomes mental suffering, which then acts on the body and makes it more vulnerable.

Second, Morris reports that there is and will continue to be "new research and new rules in the arena of medical treatment" (p. 280). All those whose stories are told in these books benefit from new medical techniques, but their experiences disincline me from being too optimistic about "advances." Reports of pain experienced by the chronically ill and by children with cancer show how far medical pain control still has to go. The distinctive postmodern change is the inextricability of disease pain from treatment pain; medicine's collusion in pain, as much as its remediation of pain, is the postmodern feature.

Bearison's research points to the paradox of iatrogenic pain: most of the children's pain is from their medical treatments, and treatment advances often mean more pain, at least immediately. The infertile also suffer increased pain from treatment innovations, because each new technique perpetuates their stay in treatment and makes it more difficult for them to resolve their infertility by other choices. Certainly medical advances are real in their benefits, but we should hardly think medicine will soon reduce the total quantity of pain being experienced.

Third, Morris presents a variety of texts, from Nietzsche to Norman Cousins, on the new capacity of

the sufferer to "take charge" of pain. Nietzsche decides to deal with his pain by calling it "dog," and thus makes himself its master (p. 284). Cousins says we should "defy rather than deny" pain (p. 285). "Taking charge" does not mean forgoing medical treatment, nor does it mean accepting personal responsibility for having caused one's own pain. People want all that medicine can offer, and they are becoming aware of the danger of victim blaming. Morris understands taking charge as becoming aware of "our power to create and to reshape" the meanings of pain. In the reports from those in pain, do we see this power emerging?

Any "yes" must be highly qualified. Josie may have crossed some threshold of empowerment, she *may* be able to choose to live or die, but she is hardly creating and reshaping her pain, at least not yet.⁴ The infertile and the chronically ill seem even less able to reshape their pain. The infertile are swept along by expectations of medical intervention; they are *being* shaped in their attitudes, hormones, and soon even in their chromosomes. The chronically ill are too overwhelmed by the multiple oppressions of their bodies, family responsibilities, paperwork and medical bills, and demands of everyday survival—eating. A person in pain requires some release time in order to create and reshape. When the pain and its attendant demands are simply unrelenting, the ill have no reflective space where they can stop, think, possibly pray, and then refashion meaning.

Finally, we return to the most salient characteristic of postmodern pain, that it

cannot be enfolded within a single overarching metanarrative or system of explanation. . . . Instead, postmodern pain calls into being multiple systems or subsystems or explanations, each with its own distinctive language or discourse, none of which holds absolute priority. (Morris 1991:283)

The breakdown of single explanatory narratives seems true, but with a complex twist: none of the explanations people are left with is new in itself. Only the juxtapositions and combinations of these explanations are new.

The medical metanarrative has lost its totalizing power, even as medicine becomes more extensively involved in people's lives. In *all* the books we learn of

patients playing their doctors, strategically controlling the information they give them, predicting in advance what answer to a physician's question will elicit what medical response. People truly *use* medicine, for better or worse, making up their own stories from fragments of the medical narrative. The postmodern patient talks *about* medicine, rather than being a passive character in a story told by physicians. But if medicine is only part of the explanatory narrative of pain, what are the other parts? Explanations based on religious beliefs figure significantly.

The religious narrative is no more free of paradox than the medical one. Why are the infertile generally alienated by their theodicies, while the children with cancer find support? Here the postmodern turn may be a *return*. The infertile are reacting against what happens in church. The children are left alone, very alone, to find a direct relation to God as a way through their pain. The children don't think up God for themselves: "I was mostly glad . . . that I knew God before this thing happened to me," one child says (p. 152). But the God they come to know is known through pain and solitude: "I would say learn how to pray because people can't always be there for you" (p. 152).

The children are simultaneously more dependent on medicine than the infertile are—their own lives depend on their doctors—and they have a greater distance from medicine. None of the infertile mediates medicine through God, as one child does: "God's gonna cure you, second come the doctors they cure you with the medicine, first God and with the doctors' help and with God's faith you're gonna beat it" (p. 130).

I should not overgeneralize the children's faith. Another child says,

I'm Catholic and I totally just don't want anything to do with the religion or God or anything, because . . . I couldn't believe there could be a God if there were so many young kids that couldn't have done anything, infants, that are so sick. (p. 96)

This child speaks from an adult theodicy; he or she theorizes, trying to rationalize an explanation, and that does *not* work. This failure of rationalized theories is the point of the postmodern breakdown of metanarratives: old *systems* are what no longer hold. Those who find comfort in God simply relate to him, very simply.

What may be most postmodern about Josie's pain or the pain of the children with cancer is that they, unlike many of the infertile, have given up trying to solve the mystery of what is happening to them.⁵ "Mysteries," Morris writes, "in resisting closure and in retaining an essential openness, refuse to yield up every quantum of their darkness to research or to bright ideas." The true mystery, "cannot be known *apart from* the veil that separates us from a full understanding" (p. 24).

What have postmodern times done for those in pain? Little positive change can be reported in how society treats the ill, and medicine's ability to ameliorate pain has been limited and often offset by iatrogenic increases in pain. The postmodern breakthrough—if there is one—may be openness to mystery.

NOTES

1. The weak claim is that what society defines as pain has changed, and thus people interpret their pains differently. The strong claim is that the body's physiology of pain changes. The books under review do not authorize this strong claim, but it is advanced by Caroline Bynum when she writes that her studies of medieval asceticism have led her to consider that "the body itself may actually have a history" and be capable at certain times of new forms of behavior (1991:195).
2. The most ambitious claims for pain as the origin point of culture are made by Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (1985). Morris makes effective use of Scarry's ideas. For his full review of her work, see Morris 1987. In brief, "Scarry views pain as the unseen basis for every act of cultural creation, from a wool overcoat to Keats's 'Ode to Autumn'" (Morris 1991:6). In contrast to Scarry, Morris considers medicine as a kind of cultural metronome for responses to pain. Thus Morris's work stands between the focus of Cassell and Kleinman on a medical approach to pain, and the nonmedical interests of Scarry.
3. See Morris 1991:19 for statistics on types of chronic pain.

4. If we read *Life-Size* as autobiographical—and it is so compelling that I could not do otherwise—then Shute is reshaping her pain as she creates her text. But it would be a lack of tact to overidentify Josie as the younger Shute. As the novel leaves Josie, reshaping remains in question.
5. Morris's emphasis on pain as mystery can be usefully compared to William F. May's (1991) parallel emphasis on suffering as mystery, not puzzle.

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LITERATURE DIGEST

Children and violence

Betsy McAllister Groves, Barry Zuckerman, Steven Marans, and Donald J. Cohen, "Silent Victims: Children Who Witness Violence," *Journal of the American Medical Association* 269, no. 2 (13 January 1993): 262–64.

THE AUTHORS, TWO SOCIAL WORKERS and two physicians, call our attention to an unnoticed group of victims in the public health epidemic of violence—the children who witness violence. Pediatricians in urban practices have young patients who report hearing gunshots outside their homes, seeing shootings on the playground, or having a family member involved in violence. In addition, some 3.3 million children are at risk for witnessing domestic violence. What impact does the witnessing of violence have on these children, their development, their outlook on the world, their relationships?

Children's development, emotional stability, ability to function in school, and attitude toward the future are adversely affected by exposure to violence. The child's closeness to the violence, the child's relationship to the victim, the presence of a parent or caretaker who could buffer the intensity of the event—all these factors determine the severity of the child's response to the violence. The authors' clinical experience suggests that witnessing domestic violence may have consequences more severe than those of witnessing community violence. Studies show that children who witness domestic violence identify, along gender lines, with their parents' relationship: "boys become more abusive as adults; girls become

victims." The children may view violence as appropriate within a close relationship and as a proper way to resolve disputes.

New studies of preschool children suggest that they, and not only adolescents or children in elementary school, may be particularly vulnerable to the effects of exposure to violence. Because these younger children are not yet able to convey their fears through words, adults may tend to deny the serious effect of violence, sometimes assuming or wishing that young children "will not understand and will forget what they have seen." But the play and drawings of children exposed to violence demonstrate its profound effect on their perceptions of the world.

Parents living in high-risk neighborhoods are concerned about their children and radically alter their child-rearing to adapt to the dangerous environment. Practices like keeping children inside much of the day and teaching them what to do if they hear gunshots are at odds with children's normal developmental needs. They convey the idea that the world is a dangerous place at a time when the child's developmental task is to explore the world and move toward independence.

These conclusions, the authors say, indicate certain responsibilities of physicians and health care professionals both with individual patients and on the social-policy level:

1. While taking a routine patient history, physicians should ask about violent events in the child's life. If the answer is affirmative, further questions should clarify the child's worries and thoughts about the event and establish whether the child has anyone to talk to. It can be therapeutic simply for a child to speak about a frightening experience.

2. If the child is preschool age, the physician can ask the parents or caregivers about the child's exposure to violence. Thus the parents learn that the physician is concerned about violence and its effect on children and that it is an appropriate topic in an office or clinic visit. If the parent reports concerns about the child's witnessing of violence, the physician should recognize the child's fear and tell the child that the parent will try to keep the child safe. This, the authors say, "mobilizes the most important resource the child needs in responding to overwhelming events: the parents."

3. Children who have seen violence or who show severe reactions to instances of violence should be referred to psychotherapists and mental health services specializing in treatment of traumatized children and children with posttraumatic stress disorder.

4. If mental health services are not an option, the physician can talk to the parents about the symptoms children show when they have been exposed to violence and the ways parents can reassure the child. Written material can also provide the child and parents with helpful information.

5. Finally, the authors challenge us to meet our societal obligation to provide children with a safe environment. We have not secured tougher gun-control laws; nor have we fully comprehended the cost of raising a generation of children "who must, out of necessity, become numb to the violence around them." These children may not take care of themselves, believing that their lives are too insubstantial to warrant care. Some may try to escape their fears through drug abuse, or they may inflict violence on others.

"Children who witness violence," the authors conclude, "must be added to the clinical and policy discussions regarding the consequences of violence. They are victims and need treatment."

—Agnes Coveney
Research Assistant

AIDS, women, and children

Gena Corea, *The Invisible Epidemic: The Story of Women and AIDS* (New York: HarperCollins, 1992).

Global AIDS Policy Coalition, *AIDS in the World 1992* (Cambridge, Mass.: Harvard University Press, 1992).

Marsha F. Goldsmith, "'Critical Moment' at Hand in HIV/AIDS Pandemic, New Global Strategy to Arrest Its Spread Proposed," *Journal of the American Medical Association* 268, no. 4 (22 and 29 July 1992): 445–46.

Mary Guinan, "HIV, Heterosexual Transmission, and Women," *Journal of the American Medical Association* 268, no. 4 (22 and 29 July 1992): 520–21.

Marta Gwinn et al., "Prevalence of HIV Infection in Childbearing Women in the United States," *Journal of the American Medical Association* 265, no. 13 (3 April 1991): 1704–8.

Marian Sandmaier, "Vessels of Infection," review of *The Invisible Epidemic: The Story of Women and AIDS*, by Gena Corea, *New York Times Book Review*, 15 November 1992, p. 26.

Suzanne Smeltzer, "Women and AIDS: Sociopolitical Issues," *Nursing Outlook*, 40, no. 4 (July–August 1992): 152.

THESE RECENT PUBLICATIONS DOCUMENT the statistics on the increasing AIDS epidemic in women and children. In varying degrees, their authors address the underlying causes of the alarming spread. Some are concerned explicitly with the fundamental societal attitudes that they believe have contributed to much of the spread of the epidemic among women, and thus to a large degree among children.

The statistics themselves are startling. According to the study *AIDS in the World 1992* (released in late 1992 by the Harvard-based Global AIDS Policy Coalition and summarized in Marsha Goldsmith's article in the *Journal of the American Medical Association*), more than 2.5 million people worldwide currently have AIDS. Perhaps as many as 13 million are HIV-infected, up from 100,000 in 1981. Of these, 7.1 million are men, 4.7 million women, and 1.1 million children. To

date, nearly 2.5 million people worldwide have died of AIDS. By 2000, the study estimates, as many as 120 million people will likely be HIV-infected, and at least 24 million adults and several million children will suffer from AIDS. Approximately 42 percent of these infections will occur in Asia (the current estimate is only 6 percent), and 31 percent of them will occur in sub-Saharan Africa (the current estimate is that 66 percent of all HIV infections occur there).

Consider also the following statistics: in the next three years, 5.7 million adults and 1.2 million children will become HIV-infected, and nearly 3.8 million people will develop AIDS. This number represents almost double the number of people who have developed the disease up to now. According to the Global AIDS Policy Coalition's study, by 1995, the number of children contracting HIV infections will double, the number contracting AIDS will nearly triple, and the number orphaned by AIDS will more than double.

In her article in *Nursing Outlook*, Suzanne Smeltzer notes that, in the United States, the profile of the epidemic seems to be changing from a disease affecting primarily gay men to one that now threatens women and children in unprecedented numbers. Women now represent more than 40 percent of the population of HIV-infected adults, up from 25 percent in 1990. AIDS is now the leading cause of death for women between the ages of 20 and 40 living in major U.S. urban centers. These statistics bear a critical relationship to the epidemic in children. As the study by Gwinn et al. points out, more than 75 percent of women diagnosed with AIDS are of childbearing age. Perinatal transmission of HIV, from mother to infant, accounts for over 80 percent of pediatric AIDS cases. This study concludes that in this country alone, 80,000 women of reproductive age may be HIV-infected. It estimates that in 1989, 1 in every 2,200 infants born in the U.S. was infected with HIV due to perinatal transmission.

However, as Corea, Sandmaier, and Smeltzer argue, these statistics, unless viewed in the proper context, obscure aspects of the causes of the epidemic in women and are open to potentially dangerous misinterpretations. They point out that the epidemic in women has long been ignored in this country by the medical and governmental research establishment. In her recent book, *The Invisible Epidemic: The Story of Women and AIDS*, Corea argues that the medical estab-

lishment has vastly underreported cases of AIDS in women, and by refusing to recognize certain symptoms of AIDS that occur only in women, has misdiagnosed cases. These errors have effectively shortened the lives of some women (by disqualifying them from treatments that might otherwise have been available), and falsely reassured other, predominantly middle-class women that their chance of contracting HIV infection is misleadingly small. The American medical establishment, she charges, has persistently refused to recognize that AIDS in women does not always present the same symptoms that it presents in men. She cites evidence that, perhaps because of pervasive gender bias, authorities refused to fund studies early on in the epidemic that would have explored links between certain gynecological abnormalities and HIV infection. This lack of research in turn has contributed to the Centers for Disease Control's restrictive definition of AIDS. (As of January 1, 1993, the CDC, partly in response to the urging of various women's coalitions, has revised its definition of AIDS to include two illnesses that, many believe, will capture a large number of new cases of AIDS in women that would not have been reported under the old definition.)

Moreover, as reviewer Marian Sandmaier notes, Corea rightly argues that the emphasis society may place on the results of studies that link AIDS in women of reproductive age to perinatal transmission of HIV and to AIDS in infants may foster the view that women should be seen primarily as "vectors of perinatal transmission" of the disease, not as sufferers in their own right. Smeltzer also urges this point. This concern becomes increasingly critical as state legislatures begin to consider laws requiring HIV testing in pregnant women. In light of the fact that a disproportionate number of HIV-positive women are disadvantaged minorities (Gwinn's study reports that HIV seroprevalence is consistently higher in black women, a pattern that resembles that observed among women and children with AIDS), the dangers of racism and coercion resulting from testing and counseling are real.

In response to many of these concerns, Smeltzer calls attention to the need to develop appropriate conditions for HIV testing for pregnant women that minimize or avoid coercion and racism, and simultaneously encourage women to be tested so that they

can be given the most advanced treatments. Echoing these concerns, Mary Guinan advocates the need for a comprehensive national program to prevent HIV infection in women, which would emphasize the safety of celibacy and having one lifetime sexual partner but would not neglect the needs of uninfected women who have infected or high-risk partners. Moreover, she calls for speedy development of an effective method of HIV protection whose use women can control—one that does not depend on the cooperation of their male partners (as heterosexual contact has become the leading cause of HIV infection in women).

However, as Sandmaier warns us, Corea regards government-sanctioned AIDS prevention efforts as having been “ludicrously naive about the actual relationships between men and women.” More fundamentally, Sandmaier argues, in light of the frightening numbers of expected HIV-infected people and AIDS cases in this country, particularly in women and children, our government and our society must at last openly confront the true relationship between the sexes in this country. For example, the much-publicized advice that women interview their male sexual partners about their sexual history ignores the reality that many men lie to have sex. The government, Sandmaier and Corea argue, “won’t touch these subjects . . . because to do so would be to speak the unspeakable truth about the imbalance of power between the sexes in our culture.”

These pieces remind us that the alarming rates of HIV transmission and AIDS in women—and thus in children—bear an inherent and currently unfortunate relationship to our attitudes as a society toward women generally. As these voices urge us, only by confronting the latter, underlying condition can we hope to treat meaningfully one of its most overt and horrifying manifestations—the HIV and AIDS epidemic in women and children.

—Steven I. Berlin
Research Assistant

When a baby dies

Jane Marie Lamb, “Parents’ Needs and Rights When a Baby Dies,” *Health Progress* 73, no. 10 (December 1992): 52–57.

WHEN PARENTS EXPERIENCE THE DEATH of a child in miscarriage, ectopic pregnancy, stillbirth, or newborn death, both the grieving parents and the hospital staff may not know how to begin to address the loss. Lamb, a sister of Saint Francis and the founder of SHARE, a support center for bereaved parents and caregivers, offers some sample rights for these parents and for the baby. (SHARE is based at St. Joseph Health Center in St. Charles, Missouri, and has over 200 chapters.) Not absolute mandates but rather guidelines for staff and for parents, the rights outline what can be done to make this period of crisis and grieving more manageable for the parents. The rights, first developed by the Perinatal Bereavement Team at Women’s College in Toronto, have been revised and expanded by SHARE in consultation with its hospital ethics committee. Hospital staff, in turn, may use the rights to develop and modify institutional policies on perinatal death.

Most parents do not know of their needs and choices at this tragic and confusing time. The list of rights gives them options that are within the boundaries of state, local, and institutional policies. The rights entail responsibilities for hospitals and caregivers who must apprise parents of their options and provide them with time and support for decision making. It is crucial, notes Lamb, that grieving parents be treated with sensitivity and respect and that staff honor parents’ reasonable requests. Within these guidelines, parents have the following rights:

1. *To see, hold, and touch their baby.* Hospital staff should prepare parents for what they will see and give them time to consider their decision. Individual differences in grieving should be taken into account, and staff should avoid “protectionism.”
2. *To have photographs of their baby taken.* If possible, family members should be included in the picture, and parents should be allowed the option of not viewing the pictures right away.
3. *To be given as many mementos as possible.* Note families’ requests and be creative in offering mementos.

tos. If no birth certificate is issued, a certificate of recognition of life may be given.

4. *To name their child.* Offer suggestions when requested. If the sex of the baby is not known, encourage parents to use a name suitable for either gender or to follow their intuition. Hold a service of naming.

5. *To observe cultural and religious practices.* Ask parents about their customs and what is important to them. If specific requests cannot be granted, discuss acceptable alternatives.

6. *To be cared for by an empathetic staff.* Really listen when parents express their feelings. Encourage continual education of staff in perinatal loss. Though parents' wishes may not be understandable to you, respect them. Give parents time to consider their options.

7. *To be with each other.* When possible, give the father overnight accommodations in the same room with the mother. Review and revise hospital policies that might unnecessarily exclude the father (for example, during ultrasound to confirm the death of a baby).

8. *To be given time alone with their baby.* Ask the parents how much time they need, and negotiate if your expectations differ. Allow the parents privacy and their personal expressions of grief. Let the parents know you are available.

9. *To be informed of the grieving process.* Give simple, informative printed material on common grief experiences. Make the environment a place where open expressions of grieving are accepted. Do not impose expectations on the parents who do not express grief. Encourage the couple to talk to each other and address them as a couple.

10. *To request an autopsy and to choose whether to have a pathology examination.* Provide information and clarify the extent of the procedures so that informed consent is possible. Tell the parents that autopsy information may help in a subsequent pregnancy.

11. *To have information presented in understandable terminology.* Avoid medical jargon, repeat information, and ask for questions. Remember that parents have difficulty understanding in a crisis.

12. *To plan a farewell ritual, burial, or cremation.* Be aware that the farewell ritual may be the only time for the parents to replace the child's "lifetime of rituals." Consult with people familiar with the family's cultural

group. Give parents written information on local regulations.

13. *To receive information on support resources.* Research support sources in the area, including grief counselors who work with grieving parents. Consider addressing unmet needs. Call the parents at set intervals and at anniversary times.

The baby has certain rights as well:

1. *To be recognized and named.* Avoid clinical terms such as "fetal tissue" and "products of conception." Mark the baby's life and death by giving a written document. Call the baby by name.

2. *To be seen, touched, and held.* Tell parents that others have found comfort in seeing, touching, or holding their baby. Let parents decline this option. Use a real baby blanket when presenting the baby to the parents.

3. *To have life ending acknowledged.* Help the parents prepare a farewell ritual if they wish. Inform parents of ways to announce and acknowledge their baby's birth and death.

4. *To be put to rest with dignity.* Know hospital policies and offer the parents choices. Study institutional practices and, if possible, include more sensitive options.

Lamb's article challenges hospitals to reconsider their conventional practices and policies in light of the current understanding of perinatal loss. The hospital that responds to the loss and allows grief shows care for the parents at a time when their spiritual and emotional well-being is at risk.

—A.C.

Physician-assisted suicide

Timothy E. Quill, Christine K. Cassel, and Diane E. Meier, "Care of the Hopelessly Ill: Proposed Clinical Criteria for Physician-Assisted Suicide," *New England Journal of Medicine* 32, no. 19 (5 November 1992): 1380-83.

A SHIFT IS OCCURRING IN SOCIETAL ATTITUDES toward assisted suicide and active euthanasia. Over the past few years, a number of events have signaled this change—among them, referenda in two states, articles

in medical journals, the popularity of Derek Humphry's *Final Exit*, and Jack Kevorkian's 12 assisted suicides. This article by Quill, Cassel, and Meier is the first published proposal by American physicians of criteria for implementing the practice of assisted suicide.

The purpose of the article is to call for the legalization of assisted suicide and to "propose criteria that would allow physicians to respond to requests for assisted suicide from their competent, incurably ill patients" (p. 1380). The authors have in mind those patients for whom comprehensive efforts to provide comfort have been tried, but who continue to experience intolerable suffering. Assisted suicide, they believe, should never be regarded as a substitute for considering, and preferably trying, every means available to address the physical, psychological, and social needs of a dying patient. Rather, it should be regarded as the last on a continuum of options for providing comfort care.

The authors exclude active euthanasia from this continuum. Because the physician not only provides the means in active voluntary euthanasia but also carries out the act, his or her power over the patient is significantly increased. This in turn increases the risk of error, coercion, or abuse. Furthermore, access to medical care is currently too inequitable in the United States, and many doctor-patient relationships are too impersonal. The authors recognize that this exclusion will deny a hastened death to some competent, incurably ill patients (for example, those who are unable to swallow or move). For such patients they propose instead, with some regret, to offer to forgo life-sustaining measures, to provide aggressive comfort measures, and to search for creative alternatives.

What then are the conditions that must be satisfied before implementing physician-assisted suicide? First, the patient's condition must be incurable (though not necessarily imminently terminal) and be associated with severe and unrelenting suffering. Doubts about the patient's diagnosis or prognosis must be resolved, and the patient must understand both and be apprised of the available means of comfort care.

Second, it is incumbent upon the physician to insure that the patient's request is not a result of inadequate comfort care. Never should physician-assisted suicide be an excuse for not doing everything reasonable to provide comfort care.

Third, the patient's request to die must be clear, convincing, and repeated and must result from the patient's own initiative and free choice. Furthermore, the physician should thoroughly understand what continued life would mean to the patient and why death seems preferable. This is a critical step in evaluating the patient's rationality.

Fourth, the physician must be confident that the patient's judgment is not being distorted or impaired by some psychological or mental condition which, if reversed, would likely alter the patient's perception and decision. The patient must be able to understand the import of a request for assisted suicide and the consequences of that action.

Fifth, physician-assisted suicide should be carried out only in the context of a meaningful doctor-patient relationship. This does not necessarily mean a preexisting relationship, though that would be ideal. It does at least mean, however, that the physician must get to know the patient well enough so that he or she can understand why the patient considers death to be the preferable option. The authors believe that the same physician who has tried to provide comfort care to the patient should be the one to provide the patient with assistance in suicide. The patient should feel confident that the physician will stand by and provide whatever care is needed until the time of death.

Sixth, consultation with another experienced physician is required to insure that the patient's request is voluntary and rational, that the diagnosis and prognosis are correct, and that measures to provide comfort care have been adequately explored. For the consultant, this would include examining the patient and relevant documentation.

Seventh, there must be clear documentation to support each of the criteria, and the patient, primary physician, and consultant must each sign a consent form. Whom to inform about the decision for assisted suicide should be left to the discretion of the patient, though informing the family and even involving them in the decision-making process is strongly encouraged. Their wishes, however, should never override the decision of a competent patient.

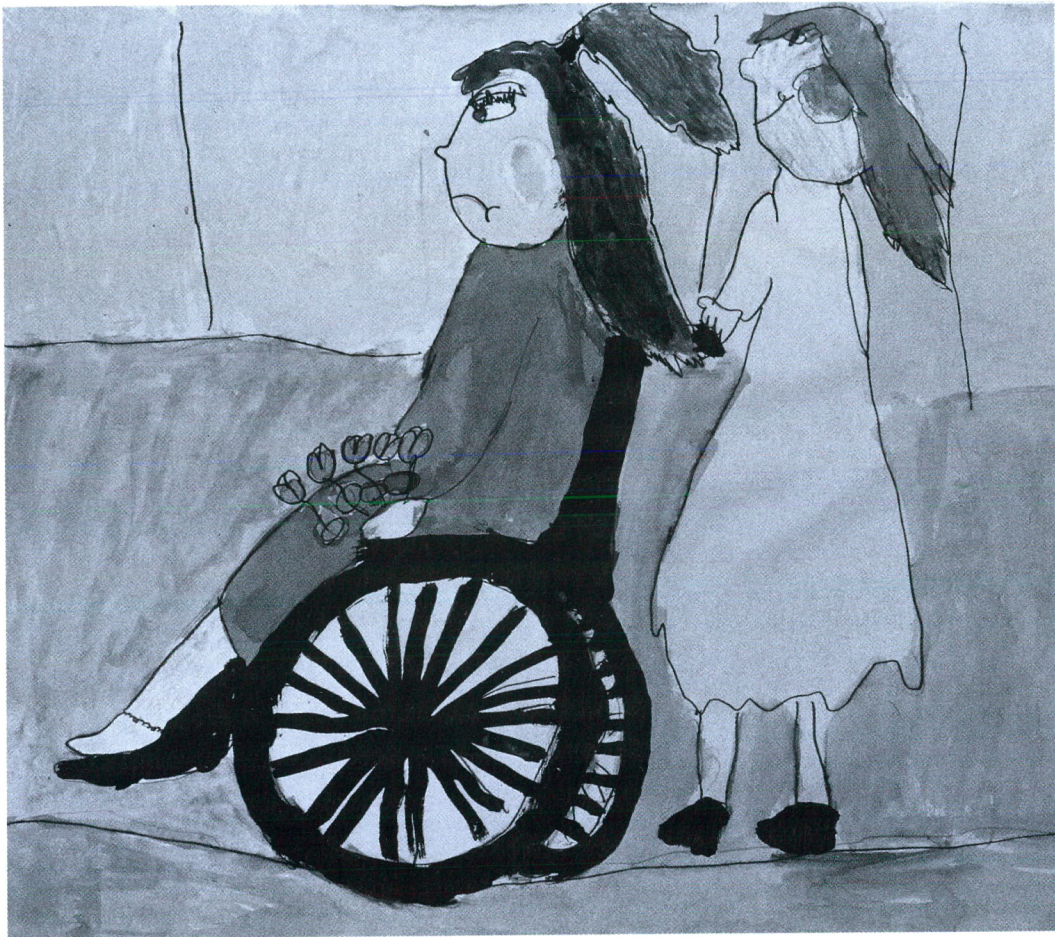
If the patient and physician agree that there are no acceptable alternatives and that all these conditions are met, they can, in the judgment of the authors, proceed with the assisted suicide. The method selected should be reliable, should not add to the patient's

suffering, and, ideally, should be carried out in the physician's presence. It is of the utmost importance that the patient not be left alone at the time of death, unless he or she specifically requests it. Other health care professionals and the patient's family should be encouraged to be present if the patient is agreeable. "The time before a controlled death can provide an opportunity for a rich and meaningful goodbye between family members, health care providers, and the patient" (p. 1383).

In conclusion, the authors believe that an open practice of assisted suicide, restricted to competent patients who meet carefully defined criteria, is preferable to a covert practice because it better protects vulnerable patients and the integrity of the profession. It remains for policymakers, other physicians, and voters to decide whether this is in fact the case and whether the proposed criteria are a sufficient bulwark against the feared abuses cited in slippery-slope arguments.

—Ron Hamel





Drawing by Krista Hummel (third grade), Washington School, Trenton, New Jersey.

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Examples

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