

written extensively about a related aspect of health care which he terms the problem of "acknowledging, disclosing and coping with uncertainty." [See especially his book *The Silent World of Doctor and Patient*.] The problem is so basic that it is difficult to discuss without sounding simplistic. I will offer a number of formulations.

Health care professionals are unwilling (unable?) to admit that patients (and family members) possess knowledge relevant to decision making. They do not see themselves as needing to know much of anything about a particular patient in order to know which treatment is appropriate or "right" for that patient. When they encounter patients in clinical situations, they regard themselves as not only knowledgeable, but also as capable of knowing which particular intervention is "indicated" in the treatment of each patient. The bioethics movement has influenced physicians' practice to the extent that they see themselves as obligated to procure the patient's "informed consent" and to respect the patient's rights, especially the right of self-determination. However, these obligations are viewed as imposed on them from the outside. They are often regarded as "necessary evils." They are not seen as intrinsic to the practice of medicine or nursing. Many doctors see the emergence of clinical ethics as little more than an impediment to practice that resulted from the civil rights movement or the consumer movement or the influence of the legal profession. They regard this evolution as a sign that patients no longer trust them. Unfortunately, these attitudes leave the underlying parentalism of health care professionals largely intact. Professionals continue to see themselves as "knowing best." They continue to use the language of "compliance" in describing the patient's role in health care.

What is clearly missing is an acknowledgement by providers that extensive education and training do *not* prepare them to know all that they need to know to determine the "right" treatment for a particular patient; that medical or nursing or social work expertise does *not* include "ethical expertise"; that *no* health care intervention is ever "indicated" in the sense that objective scientific knowledge can be applied straightforwardly to an individual case. Encouraging highly educated and skilled professionals to see and acknowledge these limitations on their ability to know is the greatest challenge facing those of us who do ethics in a clinical setting. Patients and families bring knowledge that is both unavailable to providers and essential to good decision making. This knowledge is the highly personal insight one acquires by living with a disease, being the "subject" of an illness. It is also the knowledge of oneself as a person: one's history, social relations, work, values, goals, fears, hopes, dreams, plans and the like. For a health care intervention to be "right" it must fit into the lived life of a particular patient and be seen as "right" from that patient's perspective. The right treatment for an individual patient must always be a "discovery," the outcome of sustained dialogue between caregiver and patient. How are we to get providers to stop lamenting the alleged loss of patient trust in them long enough to see that the real problem is persuading them to trust their patients? How can we enable health care professionals to acknowledge this crucial limitation on their ability to know, to see themselves as depending on knowledge that only patients can bring to the decision making process? How can we support providers to see, acknowledge and cope with the extent of this necessary ignorance?

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## Imprisoned

by William G. Bartholome

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"He looks pale. Doesn't he look pale to you?" she asked.

"Would you stop with this pale-business! You've said David looked pale at least twice a week for the last month! If you think he's pale take him to the damn doctor, but I've had it with you and your constant fretting about that boy," he snarled back.

"That boy just happens to be the only thing in my life I give a damn about. And I *am* taking him to the damn doctor," she snapped.

It seemed like David was the only thing that either of them gave a damn about. It had been that way for as long as she could remember. He constantly accused her of "fretting" or "doting" or "spoiling." She constantly accused him of ignoring their son or picking on him. If they weren't arguing about David—his hair, his clothes, his room, his toys, his school work—they didn't have much of anything to say to each other. David was out of the house on his way to school as soon as he could get dressed in the morning and didn't come back until his mother had called for him to come home for

dinner at least three times. After inhaling his dinner he immediately went to his room pleading "home-work" to enjoy the company of his tapes, television and the phone. He was very hard to find on weekends after chores on Saturday morning.

That Saturday, however, she took him to see "Doctor Joan" promising not only "no chores" but also two movies for the recently acquired VCR. She watched as David sat passively while the pediatrician performed the examination. She silently reported to herself: "He does look pale. Bet he needs more iron. Damn junk food. Can't blame myself, no mother can get a nine-year-old boy to eat right." She noticed that the doctor seemed to be taking much longer than usual to examine David.

When she finished the examination, she came over and sat down across the desk: "I think I'm going to need to run some tests on David. I agree with you that he looks a little pale. Let's, let's . . . a . . . let's get a . . . let me see. Let's get some blood tests. You know, blood counts and stuff. O.K.?"

As they sat waiting for the test results which Doctor Fitzgerald had asked for "right away," David's mother could feel herself growing more and more frightened. She thought: "Oh God, what if it is something! What would I do? Oh God, if anything. . . . Oh, David." She reached out and took his hand. She was surprised when he let her have it and moved closer to her. She scolded herself: "Oh God, I've got him scared now."

David wasn't O.K. In fact, they went directly to the hospital. He was more than a little pale. The tests revealed that he had a *very* low blood count. Doctor Fitzgerald said that David would need more tests: "I can't tell you what's wrong. But I can tell you there is something very wrong . . . with his blood, I mean. I . . . I don't mean to frighten you. I'm sorry. . . . Oh, I don't know what to say. I'll call them . . . up at the hospital, I mean. They'll be waiting for you." She had never seen Doctor Fitzgerald so flustered and upset. She didn't speak. She accepted the papers from the receptionist. She ignored David's questions: "Mom . . . hey mom, what's wrong? Mom, what does Doctor Joan want us to go to the hospital for? Mom?"

As she drove to the hospital she heard her husband's voice: "If you think he's pale, take him to the damn doctor." She clenched her teeth: "Damn bastard!" "What mom? What did you say?" David asked as he leaned toward the dashboard to look at her face: "Mom . . . why are we going to the hospital?"

By early afternoon they had been to "admitting" and gone to the Children's Unit; had more blood

drawn—"seven tubes," David proudly announced to his father; and were now sitting in the conference room waiting to see "the specialist."

"I'm sorry, honey, I don't remember what kind of doctor she said he was. Some kind of blood specialist. . . . I don't know. Why don't you go call her if you want to know now? Jesus, I've been at this since 8:30 this morning. I'm going crazy over here and you're on my back for not remembering some medical gobbledegook! Jesus."

The specialist was a pediatric oncologist. "I work with children who have diseases of the blood and tumors," he explained. When she heard the word "tumor" it all fell into place and she knew. She knew why her son was so pale, why Doctor Fitzgerald was so frightened, why she had rushed them over to the hospital, why the oncologist was there. The words were out of her mouth before she realized that David was not just exploring the soda machine but was listening carefully to what they were saying. "He's got leukemia! Oh God, he's got leukemia! That's it, isn't it? Oh God!"

The oncologist turned slowly and reached for her arm. She pushed it away and buried her face in her hands and sobbed. He put his hand softly on her back and turned to David's father. "We won't know exactly what kind of problem David has with his blood until we can do a special test. It's called a

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bone marrow test. I will be doing the test myself as soon as the people from the lab call and say they are ready. It's a simple test, nothing to worry about. I'll explain it all to you both in a few minutes."

David's father sat frozen in his chair staring at the wall. His face was empty. David walked over, sat down in the chair next to the doctor and looked up at him. "David, why don't you come with me for a few minutes," he suggested. "Let your mom and dad have some time to talk. I'll show you around." David accepted his hand as they left the conference room.

The bone marrow was "positive." David did have leukemia: "acute myelocytic leukemia" the oncologist reported after the two of them had tried to eat some supper in the hospital cafeteria. They took the booklet he gave them, told David to call home before he fell asleep and left.

Back home, as darkness settled into the room, they sat across from each other at the breakfast table. An awful silence filled the house. "He's all we've got, you know," she said. "Yes. Yes, I know. And I'm gonna make sure he doesn't get away," he responded. And then he continued talking into the darkness of the room: "He's my boy. By damn, I'll make sure he beats this thing."

Over the next few weeks David learned what it all meant. He learned all about bone marrows, IV's, shots, bone scans and spinal taps; he also learned about chemotherapy and platelet counts, about side effects and hair loss, about remissions and relapses. He learned his lessons well. "An excellent little patient," the oncologist reported proudly, "he's been no trouble at all." Not only did he learn well, but his parents were told he had done "extremely well." The oncologist continued: "We're very pleased with the way David has responded. He's a real trooper, you know. For a while there I didn't think he would ever stop vomiting, poor kid. I realize he's lost a lot of weight, but he'll put on those pounds real soon. And, the hair grows back . . . remember?" Her son looked like pictures she had seen of the people they found in the camps in Germany at the end of the war.

He was home for three months except for one short stay in the hospital for a high fever and antibiotics. The possible "life-threatening infection" turned out to be "just a virus." "It's soooo good to have you here with us," his mother told him, "this place was empty without you."

With a lot of coaxing, David started back to school. He seemed to like going. He seemed to be feeling O.K. He did gain a little weight. But it never seemed like he got all better. He was so serious. "Too serious for a nine-year-old boy," she told his father. "What do you expect?" he responded.

David started complaining about bad headaches. "They're not like regular headaches," his mother explained when she took him to the clinic, "it's like they never go away. He cried most of the day yesterday and didn't eat a thing." The spinal tap revealed that the leukemia had relapsed in the spinal fluid. "The central nervous system is the most common site for a relapse," the oncologist reminded them. "It will be necessary for us to restart induction therapy right away. We'll need to use a combination of some of the same drugs we used initially and several new ones."

After ten days of his new "chemo" David looked so awful his mother had to force herself to look at him. He lost six more pounds. She had to leave the room while his nurse gave him his sponge bath. When she left that day she looked back into his

room. She could see him through the bars of his bed lying motionless with the emesis basin wedged against the side of his face, eyes staring out at nothing.

The oncologist told her that he had asked for David to be seen by the psychologist who worked with oncology patients. "It's fairly common for them to get depressed, you know. But with David it's different. He's really withdrawn. The nurses have to fight to get him to leave his room. I worry about him."

The hoped for remission didn't come. David had been in the hospital for almost five weeks. The psychologist requested a "case conference." The oncologist presented information about new developments in bone marrow transplantation for children with leukemia, but reminded them that David was not a candidate for this procedure. David's "care plan" was to provide all the support and comfort and company they could. His primary care nurse, Julie, reported that she was now able to get him to take "little walks" every day. "We had our first 'real talk' Tuesday," she reported. They all knew what she meant by "real."

At an appointment following the case conference, David's doctor told his parents that he was still in relapse. "As we discussed earlier, aside from the bone marrow transplant—and David's not a candidate—there is really very little we can offer you at this point. I mean, there are other drugs—experimental drugs—but there are no established treatments for you to consider. As you know we all

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*After ten days of "chemo" David looked so awful his mother had to force herself to look at him.*

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met for a case conference Thursday. We talked about a program for him, a plan for what to do now. He'll need a lot of support, you know. He's been through a lot."

She was surprised, at first, when he spoke, but listened attentively as her husband leaned toward the physician and stated calmly: "Doctor, you give him any medicine you've got. We want you to do everything. Give him all the experiments it takes. The wife and I decided when this thing first happened that we were never gonna give up on this. We're not gonna let him get away. He's all we've got, you know. He's it."

When the oncologist arrived on the unit the next morning with the signed consent forms and began explaining the new protocol to David's nurse, she

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*"Doctor, give him all the experiments it takes. We're not gonna let him get away."*

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was shocked. Sensing her disbelief, he explained: "Julie, I know how you feel about this. I know what he's been through. I don't like this any better than you do. I mean . . . what the hell am I supposed to do? He's all they've got, you know?"

Julie was rocking back and forth on her heels. She began swinging her arms. She looked at him: "You can't. Oh God, not David. Another Phase II protocol? Do you *have* to?" She was crying now: "Oh Jesus. They don't even know what's going on. Don't they know how he feels? What he's been going through? Did they even talk to him about it? He's all they've got! I'm so sick of hearing that!"

As he turned to continue writing in the chart, she grabbed his arm: "We can't. I mean, it's wrong. You can't. I mean, you're David's doctor. There's got to be something you can do. I mean . . . I mean, I'm not going to give him any more experimental poison. I'm not going to put him through any more. What about the case conference? You agreed to the new care plan, remember?" She stopped crying: "I'm not going to let this happen. He's my patient too, you know. I have the feeling *I'm* all he's got."

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## Sheila and Nick and the World

by Julie Heide

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Is this where I'm s'posed to be at? Is this the place? You all are nurses? This guy says you wanna know how to relate to your patients better. He said he'd pay me if I came here and talked. Is that right? What do you want me to say? You know, this mighta been a mistake. I'm jus' not sure where to start.

*Tell them about your experience with the Veteran's Administration. Your boyfriend Nick has been a patient at the VA. Tell us about Nick.*

Okay. Nick is a United States Army veteran. He was in Viet Nam. He went over in 1966, when he was 17. He was an army paratrooper. He jumped outta helicopters into the jungle, and went on search an' destroy missions. Most of the time, Nick he wore the radio. See, that shit's heavy. They usually give it to a big man, like Nick. Course when you're carrying that shit on your back it makes you a good target. Charlie liked to knock out the radio, see—so the unit'd be cut off. They taught him to kill people—he was good at it. He knows somethin' 'bout survival. 'Lotta his buddies died. He caught a little shrapnel, nothin' too serious. Mosta his wounds is invisible.

I met Nick in 1988 when he was doing time at Lansing. This girl I was living with, her ol' man was in the pen and he asked her to get somebody to write to Nick and come out for visits. So I started writing and visiting, and 'bout a year later they let him out on parole. We been together ever since.

Nick had gone to barber school in the penitentiary. Thought he could get a license to be a barber. I told him from the beginning, I didn't think so. He's too big and he's got too many tattoos. He's a good lookin' man, but he's not exactly somebody a stranger would want cuttin' on him. You wanta see a picture? That's from back in '88. They took that picture at the prison on Mother's Day. I don't know if you can recognize Nick from this picture, he's gotten pretty skinny since he's been sick.

When Nick got out he tried to get that barber's license and then he gave up an' got him a part-time job loading boxes and running a forklift. It was a good job. We started out livin' in this one apartment. It was real nice. We had sixteen ashtrays. Had about four in every room. We had pictures on the walls. A picture of George Washington, and this one of a cocker spaniel dog standing on a red carpet. Then we had a couple a pictures of birds. I'm a nature freak. So's Nick. We're both nature freaks. We like animals, and the open sky.

It was real hard on Nick to be locked up. He don't like it when he's confined. When he had his surgery and he couldn't go outside—when you people wouldn't let him go out—that's when things was really rough. When they take yer kidney out,

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