

The New York Times

August 16, 2005

In the Hospital, a Degrading Shift From Person to Patient

By BENEDICT CAREY

Mary Duffy was lying in bed half-asleep on the morning after her breast cancer surgery in February when a group of white-coated strangers filed into her hospital room.

Without a word, one of them - a man - leaned over Ms. Duffy, pulled back her blanket, and stripped her nightgown from her shoulders.

Weak from the surgery, Ms. Duffy, 55, still managed to exclaim, "Well, good morning," a quiver of sarcasm in her voice.

But the doctor ignored her. He talked about carcinomas and circled her bed like a presenter at a lawnmower trade show, while his audience, a half-dozen medical students in their 20's, stared at Ms. Duffy's naked body with detached curiosity, she said.

After what seemed an eternity, the doctor abruptly turned to face her.

"Have you passed gas yet?" he asked.

"Those are his first words to me, in front of everyone," said Ms. Duffy, who runs a food service business near San Jose, Calif.

"I tell him, 'No, I don't do that until the third date,' " she said.

"And he looks at me like he's offended, like I'm not holding up my end of the bargain."

Entering the medical system, whether a hospital, a nursing home or a clinic, is often degrading. At the hospital where Ms. Duffy was a patient and at many others the small courtesies that help lubricate and dignify civil society are neglected precisely when they are needed most, when people are feeling acutely cut off from others and betrayed by their own bodies.

Larger trends in medicine have made it increasingly difficult to deliver such social niceties, experts say. Many hospital budgets are tight, and nurses are spread thin: shortages are running at 15 percent to 20 percent in some areas of the country. Average hospital stays have also shortened in recent years, making it harder for patients to build any rapport with staff, or vice versa.

Some hospitals have worked to address patients' most serious grievances. But in interviews and surveys, people who have recently received medical care say that even when they benefit from the expertise of first-rate doctors, they often feel resentful, helpless and dehumanized in the process.

In a nationwide survey of more than 2,000 adults published last fall, 55 percent of those surveyed said they were dissatisfied with the quality of health care, up from 44 percent in 2000; and 40 percent said the quality of care had gotten worse in the last five years. The survey was conducted by Harvard University, the federal Agency for Healthcare Research and Quality and the Kaiser Family Foundation, an independent nonprofit health care research group.

"The point is that when they talk about quality of health care, patients mean something entirely different than experts do," said Dr. Drew Altman, president of the Kaiser Foundation. "They're not talking about numbers or outcomes but about their own human experience, which is a combination of cost, paperwork and what I'll call the hassle factor, the impersonal nature of the care."

### Loss of Identity

It is practically a patient's birthright to complain about arrogant doctors, foul hospital food and the sadistic night nurse. These are real problems at some places, and since at least the early 1980's, medical schools and hospitals have worked to solve them, giving doctors classes in bedside manner and including patient representatives on staff, among other things.

Yet the deeper psychological transformation from citizen to patient that occurs in almost any medical setting can be more jarring, and anthropologists say it begins immediately at admission.

A clerk, often distracted, often sitting behind glass, hands out confusing forms that demand detailed personal information. The newly designated "patient" then strips to underwear and puts on a flimsy hospital gown, open at the back, a humiliating uniform that often bears the name of the institution.

The psychological dynamics of this identity change have evolved little since the 1950's, when the sociologist Erving Goffman detailed the deprivations of life inside a mental institution in his classic book, "Asylums."

After a patient's admission, Dr. Goffman observed, a kind of psychological contamination occurs. In normal life, people can keep intimate things like ailments, thoughts and their bodies to themselves. In an institution like a hospital, "these territories of the self are violated," he wrote. "The boundary that the individual places between his being and the environment is invaded and the embodiments of the self profaned."

Sandra Ramundt, 52, felt this so deeply that she decided to break out of the hospital while recovering from brain surgery last year.

Ms. Ramundt's room was private - she paid extra for that, she said - but despite her expectations, staff members came and went without knocking and rarely closed the door, and the hallway noise was relentless.

Despite repeated requests, no one cleared away the scattering of French fries left by the previous occupant, she said, and sometimes, unwitting attendants would leave her bedside phone just out of reach.

On the night after surgery to remove a tumor, Ms. Ramundt said she lay in mute agony. The emergency call-button was attached to a retractable railing on her bed, which was in the down position, also out of reach. She fell to the floor reaching for the button and lay there for a long time, she said; a friend found her and helped her back into bed.

When, weeks later, Ms. Ramundt had the strength to move, she disconnected her I.V., dressed, stole off the hospital premises and bought herself lunch. She ate it at a neighboring park, before returning to the hospital.

The outside lunches became a routine.

"I did it because I could, and because, to be honest, I was concerned about losing my mind," said Ms. Ramundt, who lives in Los Angeles and is a nurse. "There's this overwhelming sense being a patient of having no boundaries, no privacy, no control over anything, and you feel so awful you can't do anything about it."

At least Ms. Ramundt had some idea how hospitals work, and she could eventually advocate for herself without feeling that she was being unreasonable. Others have found that even minimal objections win them a reputation for being difficult.

Michael Sieverts, a cooking instructor in Santa Monica, Calif., who had brain surgery in 2001, said that one of the most awkward moments during his care was when a nurse tried to insert an intravenous line in preparation for radiation treatment.

At the time, Mr. Sieverts had not yet decided he wanted radiation, he said, and he needed time to research the treatment. Yet in refusing to allow the insertion of the intravenous line, "it was clear that I was putting the nurse into a terrible predicament," he said in an e-mail message.

"She had been sent in to do a job, and she was going to come out of the room having failed," he added. "At that moment, I became a 'bad patient.' "

### The Psychology of Illness

Even when doctors, nurses and nurses' aides take care to treat people more graciously, as they often do, the patient may have a vastly different perception of the service.

In the winter of 1998, Jeanne Kennedy, then the chief patient representative at the Stanford Hospital and Clinics, in Palo Alto, Calif., broke her knee cap rushing to a meeting. A member of her staff wheeled her to the employee health department, where a nurse practitioner she had worked with for years began arranging for her care. But the nurse spoke to the woman pushing the wheelchair and ignored Ms. Kennedy.

"It was crazy," she said. "Here I was in my own hospital, hurt but perfectly capable, and she's being very professional but she's talking over my head as if I were a child. And we worked together. She knew me!"

Ms. Kennedy, who retired from Stanford University hospitals in December after more than 25 years and now speaks to health care groups, said injury and illness make people more likely to perceive slights than when they are healthy. "Even if the nurse says, 'Sure, I'll go get that,' and does so promptly, it can sound rude to the patient in this vulnerable condition," she said.

This vulnerability, many patients say, makes noises seem louder, time seem to slow down and anything that is less than indulgent compassion feel like coldness.

People who have had chronic pain know this dynamic intimately. For a

nurse responding to a request for pain medication, appearing five minutes later may seem a prompt response. For the patient, the same minutes may seem a purgatory, or even a kind of punishment, into which a desperate mind can project its worst fears.

"When you are in rip-roaring pain," Ms. Duffy said, "you're asking for drugs all the time, and you're thinking: O.K., am I an addict? Am I asking too much? Am I offending the nurses? Are they taking so long on purpose to get back at me?"

So it is that hostility grows between conscientious, reasonable nurses or doctors and conscientious, reasonable patients. And once the feeling is there, some patients begin to fear the very people who are caring for them, they say, and are very reluctant to call a patient representative or file a formal complaint.

### The Importance of Names

After spending almost a year in an oncology ward being treated for leukemia, where she said she was spoiled by the nurses, Shawna Needham, 31, of Thomasville, N.C., had what she called a nightmare experience in a rehab unit.

"The nursing staff was inconsiderate and lazy; it would take them 15 to 30 minutes to answer, just to get help going to the bathroom," Ms. Needham said in an interview.

But she was afraid to complain to the hospital. "If I did that, that's the big time," she said, "and if they got into trouble and found out I complained, well, I didn't want anyone coming at night to slit my throat, put it that way."

Besides, she said, "I really had no idea who my nurses were; I knew none of their names."

Names matter enormously, patients say.

In Dr. Goffman's account of life in a mental institution in the 1950's, he describes the admission process as a stripping away of possessions, "perhaps the most significant of which is not physical at all, one's full name."

In modern medicine, patients more commonly become exasperated because they do not know the names of the doctors or other medical staff. At

many clinics and hospitals, staff members come and go without introductions, patients say. Name tags are in lettering too small to read easily; the names embroidered in script on doctors' coats can get lost in folds.

In hundreds of focus groups conducted by Planetree, a nonprofit group based in Connecticut that helps hospitals become more responsive to patients needs, one of the most common complaints that patients had was that they could not tell who was on the care team or who was doing what, said Susan Frampton, president of Planetree.

"What we encourage hospital staff to do is introduce themselves, always, and patients should demand it," Dr. Frampton said.

James Edwards of Kinston, N.C., devised an especially effective technique. After being blinded and suffering severe injuries in a chemical plant explosion, Mr. Edwards spent about six months in a burn unit, where he got to know the medical staff by the sound of their voices.

Mr. Edwards was pleased with his care over all, but he became upset when hospital staff members entered his room without speaking to him.

After one doctor slipped into the room unannounced and tried to give him an injection, Mr. Edwards decided that he had had enough, said his father, James (Red) Edwards Sr., in an interview. His son posted a sign on the outside of his door. It read:

"ATTENTION:

1) Please announce yourself when you come into my room (let me know your name and why you are here).

2) Please let me know what you're going to do and how it will feel before you touch me for any reason.

Thanks - Jim and Red"

The hospital where he was treated, at the University of North Carolina in Chapel Hill, has included Mr. Edwards's sign in a training video for its staff.

Grim, drab, soulless, disorienting - these are the kinds of words patients often use to describe medical buildings, and the words evoke both the buildings' designs and their effect on guests, experts say.

Even the humble doctor's office, if laden with medical tomes and framed medical degrees, can make a patient feel like an intruder in an exclusive space; unwelcome or even unworthy, say environmental psychologists.

Larger facilities can pose more practical, mundane complications: many people have trouble navigating the parking garage, much less finding the front door or the admissions office. And once patients check in, they may get nothing more than a wave of a hand pointing them to an assigned room.

"And then off you go, into this dreary, unattractive maze" that is often entirely cut off from the natural comforts of the outside world, said Dr. Roger Ulrich, director of the Center for Health Systems and Design at Texas A&M University.

### The Discomfort of Noise

Noise levels may be more integral to effective care than hospitals realize. Television sets blare, moans issue from the room next door, nurses gossip in the corridor.

In a recent study, Dr. Ulrich and researchers at the Karolinska Institute in Sweden monitored the health of 94 heart disease patients. About a third of the patients received care in a unit with commonly used plaster ceiling tiles, which bounced sound waves back into the room. The other two-thirds were treated in rooms with sound-absorbing ceiling tiles, which muted echoes and reduced overall noise noticeably.

After three months, the study found, the patients in the quieter rooms were less likely to be readmitted for further health problems than the others, and on questionnaires they rated the staff higher. They also had significantly lower pulse amplitude at night, a marker of better circulatory health.

"Not to mention that when it's quieter, you can actually hear and understand what staff members are saying to you," Dr. Ulrich said. "These are the kinds of environmental factors that do not show up in a hospital's brochure but we're finding are very important not only to outcomes - how fast people get better - but to their overall experience as patients."

Experts say that many hospitals have already incorporated design

improvements, including clearer hallway signs, courtyards, fountains, even flat-screen television sets in some rooms. In May, Dr. Ulrich was in England to advise the government on patient-friendly design for some \$40 billion in new hospital projects, he said.

But if the social and psychological culture of patient care is to improve, experts say, it is likely to depend on patients and families knowing their rights and acting on them.

Ms. Duffy now works as a hospital volunteer, giving other breast cancer patients advice on how to avoid situations like her post-operative humiliation: Stop being a good girl, she says; you've got a mouth; you should use it. Have someone with you at all meetings with doctors, if possible. And take notes.

"Otherwise," she said, "you cease being a person and become 'the carcinoma in Room B-2,' like I was."

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