Baylor palliative care nurse driven by personal end-of-life struggle

06:22 PM CST on Sunday, December 14, 2008

By LEE HANCOCK / The Dallas Morning News
lhancock@dallasnews.com

Second of five parts

Hardly a day passed that Min Patel didn't relive her choice that morning nine years ago: Have her brother resuscitated if his heart stopped? Or let him slip away, accepting that medical heroics couldn't save him?

SONYA HEBERT/DMN
Nurse Min Patel, center, comforts Odell Stephens after her sister, Catherine King, died following the withdrawal of life support.
View larger More photos Photo store

Her journey from England to Texas, from the high-wire act of ICU nursing to that helpless moment by her brother's hospital bed, could've filled several lifetimes. It was all prologue for the role her favorite chaplain called "the angel of death," at Baylor University Medical Center at Dallas.

Desire for a better way drew her and everyone on Baylor's palliative care team to challenge what they termed "the medical-industrial complex," an intervention-driven system whose default responses could dehumanize patients and prolong suffering and dying.

Ms. Patel and her teammates believed that helping the sickest of patients and their families approach the edge of life in comfort and peace was a healing vocation as important as any.

Breaking barriers was a birthright for Ms. Patel. When she was 6, her Indian parents brought their six children to England with little but hope for a better life. As a nursing student in London, she tried to get into an intensive care unit, only to encounter locked doors and be told she couldn't set foot inside. Yet within a year, she became an intensive-care nurse and ran a transplant ICU.

She reveled in that adrenaline-stoked world and loved helping the sickest patients, but she wearied of stodgy bureaucratic resistance to anything new. After a maddening workday and a chance encounter with recruiters, she applied on a lark to work at Baylor – a hospital she'd never heard of in a foreign city she'd seen only on TV.

A year after arriving at Baylor in 1990, Ms. Patel became a supervisor in its new liver-transplant ICU and then its manager.

In 1999, a phone call from her older brother Arvind changed everything. He was 40, a successful accountant in Oregon with a wife and two young kids. He told her he had leukemia and needed a bone-marrow transplant.

Ms. Patel cried, combed the Internet and corralled experts. She battled her brother's insurance company to have the procedure done in the best West Coast hospital. She prodded doctors who didn't take time to explain things to her frightened brother. And she discovered that she was the only sibling whose bone marrow matched her brother's.

She'd never been a hospital patient and was terrified of needles, so her favorite transplant surgeon armed her with a stuffed koala from Baylor's gift shop. She awoke after her bone-marrow operation shivering and aching, clutching her little bear and asking for her brother.

He initially recovered well enough to go home, but his body began rejecting the transplant. Ms. Patel talked daily to his treatment team, her fear rising as falling lab numbers and vital signs indicated that her brother's body was crashing. She later said she had known the worst when a doctor told her to come as quickly as she could and she found her brother in an ICU, ringed by pumps and machines.

She would never forget the feeling of claustrophobia as a nurse pulled her away from a clutch of worried relatives in a hospital waiting room at 2 a.m. and asked about doing cardiopulmonary resuscitation (CPR). Somehow, Ms. Patel found the strength to say no and let her beloved brother go.

She returned to Dallas devastated. She hid in her Baylor office, unable to look at any of the 50 staffers she supervised. She had to turn and flee the first time she ventured into an ICU pod, overwhelmed by the sights, smells and sounds so reminiscent of her brother's dying moments. She took the dozens of sympathy cards she got and stuffed them into a shoebox, unopened.

From that raw grief emerged a deep resolve.

A nurse focused on medical heroics transformed into a fierce advocate for patients and families. She put her arms around people because words weren't enough. Fear that her brother's memory would fade prompted her to help patients and families preserve their memories. She guided them in writing journals and making memory boxes, and she and other nurses started making plaster casts of patients' hands, so their kids and grandkids could always hold them.

Understanding families' desperation for information, she called more family meetings and pushed doctors to be clearer and more realistic. She didn't hesitate to butt heads. Her way of demanding, "What

are you thinking?" even with senior physicians stunned other nurses.

A wounded healer, the 46-year-old nurse approached every Baylor room as if her brother were in the bed.

If it took pounding it out of a Baylor telephone, number by number, Ms. Patel would get good news for Jack Garrett that Monday morning. He was overdue.

Her liver- and kidney-failure patient had argued again with his wife, Debbie, demanding to leave Baylor. He hated waiting for insurance to OK drug coverage so he could go home to DeSoto. He felt trapped in a body that kept falling apart. His life had collapsed into one symptom after another and endless waiting, flat on his back in a cold room with nothing he liked on TV.

Ten floors down, Ms. Patel worked a hall phone. "Hey, I was wondering about Mr. Garrett ...Oh, you don't," the palliative nurse said. "Can I talk to a social worker?"

On hold, she grimaced. Taking on health-care bureaucracy felt like slamming into concrete walls.

She liked hitting walls.

She was an instructor at Wujido Martial Arts in Garland, adept at taking down men twice her size. The style of kung fu she studied hinged not on force but on focus, intention and energy – controlling yours to anticipate and redirect another's. More than an outlet or avocation, she said, it shaped everything she did – including phone combat with a bureaucrat.

She didn't attack bureaucrats; she enlisted them. She never took "no" for an answer and called back as many times as it took.

Knowing how stories of hope and suffering moved people to action, she'd tell them about her patients. She'd offer her cellphone number, a rarity in a world where private phone numbers of doctors and nurses are closely guarded secrets.

She'd always call back to offer thanks and report happy endings. It was all about building relationships and trust.

"Thank you, honey," she said into the phone. "How are you? How was your weekend? Went quick, didn't it? Hey, have we made any headway on his antibiotic coverage?"

She dialed again.

"Hey, this is Min with palliative care. I want to know some information about Mr. Garrett," she said. "Yeah. I know he wants to go home. I wanted to be sure we're on top of it."

She holstered the phone. She shouldered her black Liz Claiborne tote. She smiled.

Jack Garrett would be home tomorrow.

A half-dozen patients later, Ms. Patel sat at her desk in a converted eighth-floor ICU pod. Pepto-Bismol pink, the office overlooked the guts of the sprawling medical center, ductwork, Dumpsters and driveways. Personal touches came from patients – a photo of two little girls she'd played with to prepare

them to see their dying mom, cards from grateful families, a plaque that read: "Life is short – Eat dessert first."

Dr. Robert Fine was on his way to discuss new cases. He and the team's five other doctors worked a week at a time on call, adding palliative patients to their busy practices. Ms. Patel roamed full time for palliative care.

After years of working together, she and Dr. Fine thought and even walked alike, at a clip that left colleagues trailing. He liked to say she was his right and left hands, and he worried that she needed to slow down.

He was her mentor, and the reason she stayed at Baylor. "We can't part from one another, me and Dr. Fine," she'd say.

She soaked in the quiet until he loped in and plopped at a conference table, a takeout box in one hand and his BlackBerry in the other. Lunch at doctor speed involved eating, talking, fielding two pager calls and a phone call, all in 15 minutes flat.

Even that much face time was a luxury. With the frenetic pace of hospital work, communication usually came in scrawled notes in patients' charts, terse calls and e-mails, and random hallway encounters.

The palliative team gathered every Thursday in a cramped basement conference room to troubleshoot and talk for an hour about the 12 to 18 patients they saw weekly. Dr. Fine occasionally walked teammates a block down Gaston Avenue to a dive bar called the Elbow Room for beer and sympathy. But most interactions happened on the run.

Ms. Patel shuffled a stack of pink and blue patient information cards as Dr. Fine polished off an Asian chicken wrap.

"Mindarella doesn't have time for lunch," she said.

"Can you see one?" he asked. "Breast cancer?"

"Right up my alley," she said, wiping up a dab of his peanut sauce from her table.

He'd take the heart patient, Darlene Logan, he said.

"I'm just trying to catch up," Ms. Patel said.

"I can do the other patient, too," he offered.

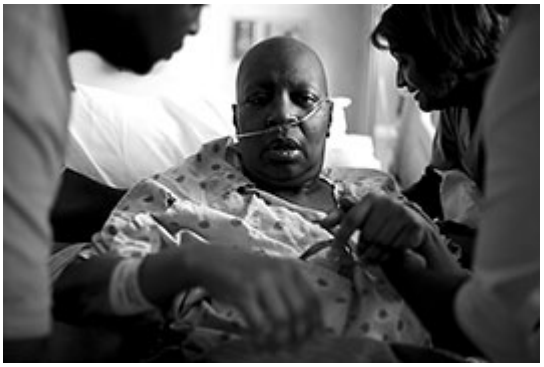
"No," she said, jotting "Beverly Freeman" and "Room 405" on a pink card.

No one was driving the bus in Room 405. That much was clear an hour later as Ms. Patel read Beverly Freeman's medical chart.

Mrs. Freeman's breast cancer had spread to her brain and liver. The 55-year-old U.S. Postal Service secretary had gotten most of her treatment at a suburban hospital. After coming to Baylor for a second opinion, she showed up in the emergency room with excruciating leg pain. She'd been in the hospital for six days.

Her Baylor chart had entries about discussing hospice but no action. A pulmonologist wrote that he'd tried to find the cause of her breathing problems and detected what looked like a lung mass, but had to stop his procedure when Ms. Freeman nearly went into cardiac arrest. It didn't help that the Baylor oncologist who'd seen her was on vacation.

"Just a lot of confusion," Ms. Patel muttered, racking Mrs. Freeman's chart in the hectic nurses' station as she headed to the patient's room.



SONYA HEBERT/DMN
Kelly Fuller, left, and palliative care nurse Min Patel help patient Beverly Freeman sit up in her hospital bed.
View larger More photos Photo store

As the nurse walked in, Mrs. Freeman was wide-eyed, gasping into a breathing mask. Her son, Kelly Fuller, stared from a corner. Her best friend, Gladys Lowery, sat by the bed.

Ms. Patel explained that she wanted to help sort things out. Her team treated pain, too, and could help discuss their future.

Mrs. Freeman tried to speak and slumped over, wheezing: "Help me, Jesus!"

Her son and friend jumped up and helped the nurse prop her up.

"Why don't you just take it easy," Ms. Patel said to Mrs. Freeman, "and let me talk to Gladys and your son?"

Mrs. Freeman and her husband Charles lived in Duncanville and had four grown children. He was an electrician. She doted on friends and family, with greeting cards for every occasion. "She's like Houdini with a card," her son told Ms. Patel.

Since 2005, Ms. Freeman had had a mastectomy, chemotherapy, and rounds of radiation, the last in February. Her breathing problems had begun a few weeks back, followed by leg pain. Before that, she'd been active, driving, shopping, cleaning house.

Ms. Lowery, a registered nurse, worried that her friend wasn't sleeping enough, with so many visitors.

"Well, I'm going to let you rest," Ms. Patel said, patting Mrs. Freeman.

Outside the room, Ms. Patel asked Ms. Lowery what she knew about her friend's prognosis.

"I'm just not there," Ms. Lowery said. "When it comes down to that, the medical side of me can't help."

"I've been there, too," Ms. Patel said.

Ms. Lowery was unnerved that her sick friend wanted to speak alone after a serious visit with the pulmonologist who brought in Ms. Patel. "You know, the talk," she said, "the 'what do you want us to do in case of – .' "

"And that talk has to happen," Ms. Patel said. "We need to have that conversation as a family. I'm already worried because of her shortness of breath and the way she looks. I'd hate to put her on machines."

Ms. Patel asked if Ms. Lowery knew that the pulmonologist had found a lung mass.

"If it's a tumor obstructing," Ms. Lowery said, trembling, "then what are we doing here?"

"That's why I'm here," Ms. Patel said.

"We really need to know what are we working with," Ms. Lowery said.

"Absolutely," Ms. Patel said. "That's what I'm going to explore with you. I still have a lot of questions myself."

Asking permission to sit, Dr. Fine introduced himself to Darlene Logan that same afternoon.

"We see patients like you who have bad heart disease – not that there's any good heart disease," Dr. Fine said, his voice slower and softer than usual. "We help explore, 'How can I live as well as I can with this disease, even though the doctors can't cure it?'"

He pulled a chair to the bed and leaned in. He liked to say that every gesture had a message: He was her adviser. She was in charge. They were on equal footing. He had time to listen.

"To be able to help you," he said, "I need to know about you."

Cocooned in layers of blankets, the 51-year-old woman pulled from an oxygen tube in shallow gasps. A teddy bear lay beside her, from a relative who felt that she needed something to hug. It made her look like a wizened child.

She'd been in Baylor nine days, after coming to the emergency room frantic for breath. Five days ago in the ICU, her blood pressure was nearly undetectable.

Her cardiologist talked to her about CPRand then wrote in her chart that she only wanted CPR "for a little while" if it came to that again.

In February, she'd had CPR for more than 20 minutes. She still had nightmares – the weird darkness, the feeling of chaos, the sound of people rushing and yelling. She hit the nurse call button in a panic sometimes, to chase those dreams away.

A cardiologist had told her she might live a year. After that doctor went on vacation, a partner called Dr. Fine, worried she didn't have that long.

SONYA HEBERT/DMN
Darlene Logan lies in a hospital bed at Baylor University Medical Center, suffering from congestive heart failure.
View larger More photos Photo store

Ms. Logan told Dr. Fine that she hurt just lying there. Getting out of bed wore her out. A West Texas native**,** she did computer work until she got sick 14 years ago. She lost her husband to alcohol.

She lived alone in a Garland apartment and had three sons: one in prison, a second who painted parking lots, and a third who was a mechanic. And no, she said, she hadn't told them much.

"Do you think they need to know?" Dr. Fine asked.

"Of course they do," Mrs. Logan whispered.

"How is your spirit holding up?" Dr. Fine asked.

"Whenever I have my problems," she said, "I take mine to the Lord in prayer."

What did she pray for?

Mrs. Logan closed her eyes and sucked in air.

"Just praying for breath."

Had her doctors helped her plan for when God called her home?

She shook her head no.

"I know this is bad," he asked, "but when you cross over the river Jordan, what's it going to look like?"

"I've already planned my funeral," she whispered. "Five years ago."

Hospice had special care for heart patients, and often they lived longer than with more aggressive treatment. He told her they'd work on that, and medicines for her pain and shortness of breath. He'd talk to her family and contact the prison about visiting her son.

He took her hand. "I'm not going to cure you. I'm not trying to bring any falsehoods in here."

"No, I understand."

"That's part of God's plan for all of us, and you're not going to be blessed to be old," he said. "That's not going to happen."

"But when I go," she smiled, eyes closing, "I'll be in such peace."

"Yes."

"And I know," she said, "that's exactly what I want."

Dr. Fine was troubled. Mrs. Logan's doctor had told her she might live a year. After she had CPR in February, the palliative team wasn't called to see her, though its members tried to convince doctors that such patients would benefit from getting palliative care.

Mrs. Logan's heart could stop again at any time, and she was so weak that at best, another round of CPR would probably give her a lingering death in an ICU.

"I wonder if her primary cardiologist knows," he said later, writing in her chart, "that she already had planned her own funeral."

Mrs. Freeman needed to talk. Returning to Room 405 about 5 p.m., Ms. Patel found her with her friend Ms. Lowery.

She gasped like a drowning woman. Forming words exhausted her. Yet she seemed driven to speak.

The best friends were discussing the worst: What about CPR?

Mrs. Freeman said she needed to talk to family.

Ms. Patel whipped out her cellphone. She'd get an oncologist in tomorrow to see how bad things were.

Ms. Lowery feared they were near the edge, and she didn't want her friend enduring a "code blue," a resuscitation that couldn't save her and would only prolong her suffering. She'd seen and done too many resuscitations as a cardiac nurse.

The medical data was sobering: Less than one in seven CPR recipients lived to leave a hospital. CPR was mandatory unless a doctor wrote an order saying do not resuscitate (DNR) or allow natural death (AND). Yet the emergency intervention was developed for unexpected cardiac arrest – not for trying to rescue the terminally or chronically ill.

Studies showed that few cancer patients or older patients lived to leave a hospital after CPR. Nurses told horror stories about older patients' ribs cracking with the first chest compression. One palliative team doctor recalled paramedics telling him in medical school that you weren't doing it right if you didn't break ribs. A recent palliative team meeting fell silent when someone described how a resident begged an old lady to give her dying husband a DNR order, so his last moments wouldn't be torture.

Veteran physicians didn't always recognize the limits of CPR, an intervention that, as one Baylor doctor put it, made them feel like gods when it was introduced in 1960. In April, the palliative team began distributing cards to medical staff with national and Baylor CPR outcomes. An amazed surgeon told Dr.

Fine that he hadn't known survival numbers were so low.

Mrs. Freeman, crying, told Ms. Patel she didn't know what to do. One of her doctors had scolded her for calling him about her terrifying breathing problems. She came to Baylor, not knowing where else to turn. She told Ms. Patel she felt abandoned.

Ms. Patel was stunned. She felt all health care had failed Mrs. Freeman. She'd have to work fast to help her.

"Time to rest, isn't it?" Ms. Patel told her. "I'll be here tomorrow. I'm going to take good care of you. Will you close your eyes for me?"

"It would bring me so much joy," Mrs. Freeman gasped, her eyes suddenly brightening. "Oldest brother. To see him. My oldest brother passed away."

"We'll talk tomorrow," Ms. Patel said, her voice thick.

"I'm going to take care of you. I'm going to take care of your family. I'll always be here. I'll never abandon you."