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Baylor hospital team helps families forge their own path at life's end

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Fourth of five parts

Doctor by doctor, patient by patient, attitudes were shifting upstairs, Dr. Robert Fine told a dozen palliative team members that sunny Thursday morning in a basement meeting room at Baylor University Medical Center.

The palliative team leader recapped his share of their current cases: A liver doctor called for help, but had done good end-of-life work. Two years ago, that doctor wouldn't have recognized a family's distress, much less known how to help them. On the other hand, the relatives of a man on his 49th admission shushed any mention that he was dying. "A conspiracy of silence," Dr. Fine said, shaking his head.

Palliative care nurse Min Patel rattled off her cases: People struggling. Relatives venting. A family gathering to say goodbye. Their patriarch, Charlie Ribron, went 15 minutes without oxygen before paramedics revived him.

Ms. Patel said she was about to see Bobby Jackson, an unemployed roofer in hepatitis B-induced liver failure. He was on a ventilator in intensive care, and there was a family member fighting a do-not-resuscitate order. "The wife was really mad because the doctor said, 'I'm going to make him a DNR, whether you like it or not,' and just left," Ms. Patel said.

Drive-by medicine was not what the palliative team did. Exploring choices instead of dictating them took hours and days of emotional visits. Yet encouraging patients and families to share in the decisions helped them gain a sense of control over their medical care and, ultimately, their lives.

The palliative team's Thursday meetings had a similar consensus-driven intensity. Team members bore witness to one another's stories of living and dying, and of relationships with patients and families that, though brief, stayed with them. They laughed and sometimes cried, and hoped that what they did took root and spread across the medical center.

On this Thursday, Dr. Fine opened a printout comparing the number of days patients in hospitals around the country spent in intensive care in the last six months of their lives. Baylor ranked in the middle of the pack, according to the data he read from Dartmouth Medical School's Medicare database.

A continuing challenge, Dr. Fine said, was getting staff to consider whether patients were in their last six months and whether ICU care was appropriate. Quality of life was the issue, not cost – though a recent Baylor study indicated that its palliative patients averaged \$3,178 less in hospital costs than other patients

with similar diagnoses who didn't get palliative care. That savings to patients, their families, their insurers and the hospital mirrored findings from several recent national research studies.

For the past decade, studies have shown that expensive, agonizing dying was the end result of throwing high-tech gadgetry, chemotherapies, invasive procedures and other aggressive treatments at a condition until a patient died. One recent study showed that the comfort care offered in hospice actually helped people live longer – and better.

Baylor ranked far ahead of the pack in hospice referrals. Dartmouth's Medicare database showed that nearly half of Baylor patients were on hospice in their last six months. That was better than most hospitals in *U.S. News & World Report's* health care rankings.

"We're in the top two or three in the top 100 hospitals because of the culture we've built," Dr. Fine said.

"I want to encourage us to increase those numbers, because that's really what's best for our patients," he said. "Getting the patient and the family the right treatment at the right time and in the right place."

What were they prolonging in Room 406 of the ICU that Thursday morning?

Life or death?

On one side was Judy Jackson and desperation. On the other were physicians and facts. In the middle was Bobby Jackson, 54, a semiconscious man on machines. He had a bad liver and kidneys. Exploratory surgery found septicemia with no clear cause. Infection flooded his gut, drowning organs one by one.

Mrs. Jackson, 58, wanted everything done for her husband of 10 years. It didn't matter that he told her he didn't want to linger.

Too bad, she'd say to anyone who asked. He had never written down his wishes, and she was the one awake – not him. She'd already had three husbands die on her, and she had watched doctors unplug one from a ventilator. Loss weighed heavy on her sunken shoulders. She just couldn't bear more.

The out-of-work waitress had only her Bobby's swollen hand, squeezing hers. No car, no insurance – not even a home, if his brothers threw her out of the ragged house they shared in Pleasant Grove.

So the gray, waxen man lay in a web of tubes and restraints, ringed by IV pumps and a ventilator. Mustard-yellow liquid nutrition dripped through a tube in his nose, and greenish bile and tea-colored urine collected in bags at the foot of his bed.

All Mrs. Jackson saw was her Bobby, the wonderful man she'd known since childhood, who tended his flowers and cooked for her every day.

Doctors and nurses saw what was coming. It showed in their grim chart notes and careful tone with Mrs. Jackson, a woman with steel-gray hair who, as the surgeon in charge wrote, "implanted herself" by the bed.

Mrs. Jackson was furious when one specialist said her husband was dying and wanted to write a DNR order.

Death was un-American, that exasperated doctor said of such cases. It was so hidden in hospitals that

people forgot that death was a natural part of life. The hardest thing for physicians to do was nothing, even when they knew procedures and tests and therapies wouldn't help. But they weren't in the business of killing hope.

So Mrs. Jackson lived at Baylor, napping in a waiting-room chair. Dozens like her staked out corners and chairs in Baylor's fourth-floor ICU waiting room, islands of hope bounded by Wal-Mart bags, handmade posters and get-well cards. They shared stories and prayers and takeout, a community of strangers floating in ICU limbo.

On that Thursday, the 19th day of Mrs. Jackson's wait, Ms. Patel ushered her to a quiet family conference room where they could talk.



SONYA HEBERT/DMN

Chaplain Alfonso Serna, left, prays with Judy Jackson, her dying husband Bobby and other family members hours before he passed away.

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Mrs. Jackson explained they had no insurance, so they'd spent a year in and out of other hospitals, unable to get a diagnosis for his stomach pain. It felt like a gift to clutch her husband's rough hand and say she loved him. At the sound of her voice, Mr. Jackson blinked and cried and squeezed her hand.

"You know," Ms. Patel said, "his body's tired."

Mrs. Jackson rocked herself on a loveseat. "I can deal with natural," she said. "I just can't do unplugging."

If only, she kept saying, he got one more chance to breathe on his own, without machines.

"We're going to give it to him," Ms. Patel said. "We always have hope and faith."

Hope was a balancing act. Ms. Patel and her teammates tried to steer families to different kinds of hope. For good memories. For meaningful moments. For a passage to death without suffering.

People like Mrs. Jackson needed their beliefs honored. Science and religion were different worlds, both valid, Dr. Fine often said. "Validate their faith and explain medical reality."

Ms. Patel's cellphone rang. One floor down, in another ICU, a family wanted to let go.

We gather at the edge of life, said the pastor at the bedside in 3 North ICU.

Ms. Patel held Lola Ribron's hand. Her father, Charlie Ribron, was a gnome in a green hospital gown, his head tilted right and his mouth frozen in a wide O around a ventilator tube.

Machines popped and whirred, breathing for him and pumping drugs. Overhead monitors hummed and beeped and pinged. Electronics in an ICU sounded oddly like slot machines, the din of a gamble for more time. Everyone in Room 312 wanted those machines gone.

Ms. Patel was their guide. Some weeks, her team was asked to help take eight or nine dying patients off ventilators.

"We have a lot of medicines. We have one hell of a lot of machines. And we try really hard, but we fail," she told families. "We have choices. And they are really difficult."

"God will take over," she'd say. "It's not up to us."

At Ms. Patel's suggestion, the daughter had invited her one-time Methodist pastor, the Rev. William Jennings Bryan III. Ms. Patel nodded and he began, his warm baritone soothing like a blanket in the stark white room and softening the clinical chill. He'd pray, he said, and then lead them in the Lord's Prayer. "We'll add 'forever and ever' at the end," the pastor told them. "How about that. 'Forever and ever' – what that means for right now."

They gazed at Mr. Ribron. The 76-year-old patriarch had gone in and out of the Dallas VA Medical Center with heart and lung failure – his running tab from Vietnam, 22 years in Army fatigues, and a smokes-and-beer existence.

He was the sergeant who got recruits through gas-mask training, their pride and breakfast intact. He was the clown who'd swig and spit Agent Orange at new jungle boots.

He'd worn one uniform after another – city of Dallas, 7-Eleven, and Bert's Concessions at the State Fair of Texas. "Riunite on ice! So nice!" he'd call from a stand by the log ride. "Made by a little ol' wino! Me!"

We gather as family, the pastor had prayed. We gather as a ZIP code. We gather as State Fair folks. We gather as those who enjoyed Charlie's hospitality. We know the love of this circle and His love beyond.

Oldest son Chuckie Ribron smoothed his father's white hair. Second son Henry stood with a friend and cousins beneath the muted TV set on the A&E cable channel. Ms. Patel kept an eye on Mr. Ribron's younger brother Franklin, flown in from Georgia. The old man sat blinking in a corner, clutching his brother's white-pine cane.

We spend so much time living in the middle of life, the pastor had prayed, give us grace and courage and comfort and wisdom at this moment, at the edge of life.

Together, they had the strength to let go, knowing it was what Mr. Ribron wanted. He'd had his doctors at the Dallas VA hospital write a DNR order during his last hospital stay. He went home to East Dallas for two good days, saying he loved everyone. Then he sat in his recliner and stopped breathing. His daughter called 911 in a panic, and the paramedics revived him.

Her family had never heard of an out-of-hospital DNR. People needed to know, the daughter said, that doctors had to sign special DNR forms and send them home with patients.

"I know my husband died at home," Hazel Ribron said. "I feel like he's not there."

Ms. Patel had explained to them Baylor's protocol for withdrawing machines when someone couldn't survive without them and wouldn't wake up. The hospital had one of the country's first step-by-step monitoring and medication guides to ensure that those patients didn't suffer.

Dr. Fine led its development in 2001 after several emotional ethics cases, one involving a lawyer stranded on a ventilator.

The lawyer had a living will saying no to life-sustaining machines. His doctor began taking him off the ventilator but didn't use enough comfort medication, and the patient was soon in agony. His anguished wife demanded that he be reconnected. Furious, the patient mouthed pleas to be let go.

Ms. Patel, then an ICU nurse, called Baylor's ethics committee. Dr. Fine, head of the committee, spent days restoring the patient's trust in his wife and doctors and promised to let him go peacefully, when he was ready. National experts consider Baylor's resulting protocol a model.

Each withdrawal was unique. One family had draped their mother in a Virgin of Guadalupe blanket and crucifixes. Ms. Patel encouraged kids to come and say goodbye, making sure they felt safe. With her help, one 8-year-old boy crawled onto an ICU bed and read 20 birthday cards to his dying dad.

She conspired to sneak dogs into ICU rooms and helped spouses hold dying husbands and wives. In the alien environment of intensive care, people hesitated to even touch their loved ones. She gave them permission to hug each other, to grieve together, to be families again.

Mr. Ribron's family laughed and cried and told his stories. They showed a photo of him grinning. He had ice-blue eyes, a leprechaun's beard and a Bert's Concessions hat covered in State Fair pins. They'd bury him with that hat.

We know that life, death and resurrection are in your hands, and we are led along that path by Jesus Christ, the pastor had prayed. We ask your blessing for Charlie. Receive him. Comfort him. Let him know he is loved and missed and remembered, and that his story lives in all of us.

"We'll remember the good times," someone said as they filed out. The oldest son went last. "I love you, Papa," he kept saying, stroking his father's hair.

Ms. Patel and an ICU nurse shut the door and untethered Mr. Ribron from the ventilator. His chest barely rose and fell as the ICU nurse pushed out the machine, a squat, tan console the size of a file cabinet.



SONYA HEBERT/DMN

Surrounded by son Chuckie and wife Hazel, Charlie Ribron takes his last breaths after the ventilator is turned off and withdrawn.

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They changed Mr. Ribron into a blue hospital gown because they thought it looked nicer. They propped up his head with pillows and lay his arms atop a neatly squared blue blanket. A warming light replaced the harsh fluorescent, giving the bed a golden glow.

Mr. Ribron's sons resumed their places around their father. He looked peaceful, they said – like himself again.

Ms. Patel went to the waiting room where their mother was holding vigil, unable to bear seeing her husband of 44 years that way. "He's really comfortable," Ms. Patel reassured her.

Our greatest thanks are for your son Jesus Christ, the pastor had prayed, who holds him and encircles him even as we do, now at this edge of life.

Numbers bounced down on a hall monitor tracking Mr. Ribron's vital signs. His chest was still. He gasped once. "It's OK," the oldest son said. "We're all here, Papa."

The red pulse line on the hall monitor went flat.

"I can't find anything," the oldest son said. "And he's getting cold."

The ICU nurse was already headed to another room. "I'm sorry. I have to take care of the living," she said. "I have to keep moving on."

The oldest son continued talking to no one in particular. His father had hurt for a long time – arthritis, other injuries and effects of Agent Orange. He'd said he might not make it much longer.

"I've been working on making myself ready," the son said, "but all that goes out the window."

In the waiting room, the family hugged Ms. Patel.

"There's some paperwork," the daughter said. "Then we need to go home and start calling people."

A chaplain brought a yellow form with the time of death: 2:24 p.m. The ICU nurse gave a final report to another medical official over the telephone: Three-pack-a-day smoker, congestive heart failure, cardiopulmonary disease, probable infection.

"We have to do what we can," the ICU nurse said, as she hung up the phone. "It's a dance."

We remember the prayer, the pastor had prayed, about the kingdom that lasts forever.