REFLECTION

Dad's Last Week

Jennifer E. DeVoe, MD, DPhil

Oregon Health & Science University,
Portland, Oregon

ABSTRACT

I had intended to spend our spring break week in Montana with my kids and my dad, going to parks and museums together. Instead, I spent the week in the hospital, helping my dad make end-of-life choices and learning more about the importance of communication in health care settings and the preciousness of close relationships in life. I am a better person and a better physician because my dad trusted me to be there while he was dying. During his last week, I was grateful to have spent years studying medicine and years getting to know my dad. This combination of professional and personal knowledge enabled me to help him choose his own end-of-life path. As someone who does not like hospitals, I have always wondered why I became a doctor; now I know.

Ann Fam Med 2016;14:273-276. doi: 10.1370/afm.1908.

There are no physicians in my family. When asked years ago why I went to medical school, I remember telling people that having a doctor in the family would help us navigate the complicated health care system. At the time, I did not fully comprehend what that statement meant. After spending my dad's last week with him, I now understand. The week began Monday when we arrived in Montana to visit Dad for spring break. My kids were eager to see their Bumpa, and I planned to take him to meet them at the park that afternoon. As the only child of an aging father, I wanted a few hours of uninterrupted time with him first.

As I drove to Dad's trailer, I rehearsed my speech expressing concerns about him at home alone with emphysema, urging him to reconsider assisted living. Dad was not at the door with his usual big bear hug; I felt a pang of fear and hurriedly went inside. There was Dad, slumped in his chair, struggling to breath. We didn't know it yet, but it was Dad's last week.

"Dad, are you okay?"

"Took 30 minutes to walk 20 feet…(deep breaths)…my oxygen levels won't go above 80%."

I glanced at his oxygen condenser—10 liters, maxed out. Whoa, I thought, he was only on 4 liters last month. "Dad, I'm taking you to the hospital."

"Not sure what they can do for me at this point, Jenny."

"But, Dad, you can't stay here."

"I know. I'm scared to be here alone." Gasping for air between words, he described shivering all night, afraid to walk to the thermostat for fear of passing out. We embraced, realizing his health was worse than either of us had been willing to admit—until that moment. Finally, he said, "I'll go."

"Great, Dad, I'll drive you."

"You'll have to call 911 because I can't walk." He was right, he did not walk again.

Conflicts of interest: author reports none.

CORRESPONDING AUTHOR

Jennifer E. DeVoe, MD, DPhil
Department of Family Medicine
Oregon Health & Science University
3181 Sam Jackson Park Road, FM
Portland, OR 97239
devoej@ohsu.edu

ADMISSION TO THE ICU

By Monday afternoon, Dad was in the intensive care unit (ICU). Despite 15 liters of nasal cannula oxygen, his levels hovered in the 80s. Dad fixated on this low number. Each time the alarm beeped, he asked, "What's my 'number,' Jenny?"

"It's 87, Dad."

"Oh, I wish it was 90."

"You look better, more comfortable. That's most important."

"I guess so."

The ICU nurse announced, "Your Dad's ABG (arterial blood gas) looks bad, he needs bi-pap (bi-level positive airway pressure)." Dad was happy that his number stayed above 90 on bi-pap; however, he hated that the bi-pap mask covered his nose and mouth leaving him unable to talk, and he winced in pain with every ABG.

The hospitalist physician stopped by: "Good news, no lung clot, might be pneumonia or emphysema exacerbation. You'll stay overnight in the ICU. Intravenous (IV) antibiotics and steroids might help." A stay in the ICU was bad news to me: I had promised my kids an afternoon with Bumpa, and kids were not allowed in the ICU. It was not until later that I realized this rule might have prohibited his grandchildren from saying goodbye. On some level, his care team (including me) acknowledged the fragility of his life. However, we had not yet accepted that he was dying.

Tuesday morning, his pulmonologist announced, "We need to do another 'bronch' (bronchoscopy)!" I learned they had tried a bronch last week but aborted the procedure. "This time, we'll go to the operating room where we can use a breathing tube." Dad was on bi-pap and could only nod. Was this informed consent?

Later, Dad was stable enough to remove the bi-pap mask and say, "Jenny, I know I could die in the procedure tomorrow, and that is okay with me." I held his hand, held back tears, and nodded. I wanted him to know it was okay with me, too.

Wednesday, my phone rang before dawn. "Jenny, I'm the on-call anesthesiologist. I'm concerned that you don't have your Dad's living will notarized. We're going to intubate him for the bronch, and I don't think we'll be able to get the tube out … ever."

"He might spend the rest of his life on a ventilator?"

"Yes."

Realizing that Dad had accepted he might die during the procedure but was likely not okay with this outcome, I said, "Do not do the procedure, I will be right there!"

When I arrived, the pulmonologist was wheeling him into the operating room. He said, "Don't worry, it will be just like the last bronch." "What?" I thought, "How could this bronch be just like the one in the outpatient setting? Would Dad be driving home tonight after this one?" The pulmonologist interrupted my thoughts, "We need to find out what is wrong."

We already knew much of what was wrong, I thought. Dad had survived 3 heart attacks and colon cancer, smoked cigarettes for nearly 60 years; he had end-stage emphysema, lung scarring from a blood clot, and congestive heart failure. My mind was working overtime to block from consciousness the truth about his prognosis. Finally, I stammered, "What are the chances you'll find something treatable?"

"We don't really know. We might find something reversible, maybe a fungal infection," said the pulmonologist.

I knew from Dad's medication bottles he had just taken several pills to combat potential infection. One antifungal had cost over half his monthly income and made him too nauseated to eat. I spent a few more moments lost in thought: Did Dad want to turn back the clock to repeat the past month on increasing amounts of oxygen, barely able to breathe? Did he want to undergo a procedure if the most likely outcome would be long-term intubation, not able to breathe on his own again, barely able to speak? I sensed that my silence was unsettling to those in the room, waiting for me to agree with the doctor's plan. So, I blurted out: "We understand he has little chance of a successful extubation. This means he will spend the rest of his life on a ventilator."

"That is a risk, but he will be comfortable with sedation."

"Dad will hate being intubated and not able to say goodbye."

"The sedation can be turned down; he can use sign language and write in a notebook to communicate."

I looked out the window, imagining Dad writing his last wishes and goodbyes in a notebook. I said 3 words to myself over and over, "please, don't cry." Impatient with my silence, the pulmonologist interrupted, "Ms. DeVoe, the procedure is scheduled for this morning. You need to hurry up with your decision. There's a short window of time… before it'll be too late…"

Holding back tears of anger and sadness, and trying to appear courageous despite being terrified, I replied, "We don't want this procedure."

Stripping off Dad's bi-pap mask, the pulmonologist said sternly, "You are putting words in his mouth. I want to hear him say he would rather die than have this procedure."

With all the energy he could muster, Dad said, "You're going to kill me, then bring me back to life on a ventilator…(deep breaths)…I don't want this procedure. I want hospice."

"I have to respect your wishes," the pulmonologist said as he left the room. We never saw the pulmonologist again. The room fell silent. I longed for someone who could confirm we had made the right choice: our family physician. Where was our trusted friend who had cared for Dad during numerous past hospitalizations? The hospital in my hometown had recently transitioned to a hospitalist model of care, and our family physician had moved to another town. If our family doctor had been there, I think he would have reminded us of Dad's own words every time we tried to convince him to quit smoking: "I'd rather have quality of life than quantity of life, doc!"

LEAVING THE ICU

We discussed taking him home. His hospitalist warned he might not survive the trip, and Dad was scared to go home. She offered a transfer to the medical floor with inpatient hospice. Dad was elated when we wheeled his bed out of the ICU. No more bi-pap, ABGs, or beeping alarms. Comfort care. When his nurse rolled in the pulse oximeter, Dad expressed concern that his number was 85 on 15 liters by nasal cannula. "So," she said, "why not add another 15 liters by re-breather mask?" A few minutes later, he was much happier with 92 and happy that he was still awake and able to talk on his own!

All of a sudden, the realization hit me: my Dad was dying. Within a few short days, I had transitioned from being a mother bringing her children to visit Bumpa for spring break to a family physician by the bedside of a dying patient I had known for 42 years. I was also a helpless, scared daughter whose dad was rapidly slipping away. To avoid being paralyzed by fear and doubt, I kept busy thinking of ways to make him more comfortable. "Shall I remove your IV, Dad?"

"Well, I need to breathe. I want to talk…(deep breaths)…if I keep IV fluids, I won't have to eat much."

Thank goodness for this small medical intervention, I thought, since each bite required dozens of recovery breaths. "Okay, great plan, Dad. We'll keep the fluids running. And a few more days of IV steroids for extra energy."

"That sounds perfect, Jenny."

It was great to see Dad stop worrying about low oxygen alarm beeps and start complaining that the hospital TV was too small for him to watch March Madness games. We rigged up his laptop to live-stream the games from his bedside tray table. He was thrilled.

His hospitalist arrived with the hospice team (luckily between games!). I suspected she would encourage us to remove his IV, so I asked, "Can we keep his IV fluids and steroids going for a little longer?"

She replied, "We consider that aggressive therapy that will prolong his life unnecessarily. It is usually not part of the comfort care plan." Recognizing the tears in my eyes, she added, "…but, I think we can make an exception." Thankfully, I knew to ask.

Later that night his friend commented, "You are getting better, they moved you out of the ICU."

Dad replied, "No, but this was the best of my 3 choices. They told me if I had the procedure I could die in the operating room, spend the rest of my life on a ventilator…(deep breaths)…or my third choice: no procedure." Then, he turned to me, "I didn't know I could make this choice. I'm so glad I did."

"Me too, Dad."

SAYING GOODBYE

On Thursday and Friday, we called dozens of folks to tell them Dad was dying. How does one do that?

"Hello. This is Jenny. I'm calling you from Dad's hospital room to tell you he has lived his 9 lives, and he's not going to make it to 10…"

(Long pause.) "Can I talk to him?"

I held my phone up to Dad's ear and heard his buddy shout, "I love you, Merle! We've squeezed 9 lives into 1. Go up to heaven and get the fishing gear ready for us!"

A tear welled up in Dad's eye and trickled down his cheek, "I love you, too, pal!"

Another friend rushed to the hospital as soon as he got my message. He asked me to step out in the hall so he could ask me the question that was on everyone's mind, "Jenny, how much time does he have left?"

"Days," I replied, and then I held him as he sobbed. In this moment, I was reminded of my dual roles as a daughter and as a trusted family physician by the bedside of a dying patient, helping to navigate conversations with hospital staff, family, and friends. This role is one many family physicians have experienced.[1]

By Saturday, visitors were pouring into his room. A friend asked Dad if he felt ready to die. He replied, "I think I'm ready to go but not until the visitors stop coming to see me…" When folks asked if he was comfortable, he always replied, "I couldn't be more comfortable. I have no pain…(deep breaths)…and I'm right where I want to be." He loved being able to have unlimited visitors any time of day, including children!

My kids were so excited to see their Bumpa. My 7-year-old daughter washed his hair using a warm shampoo-infused shower cap. She gave him a foot massage and said, "Mom, he desperately needs a pedicure." I wish I had gone to get some nail polish that day.

My son bounced into Dad's room, hopped onto the bed, and said, "Bumpa, I saw kangaroos in Yellowstone Park!"

Dad hugged him tightly and said with a big grin on his face, "Wow, tell Bumpa about the kangaroos!" Dad was excited to learn something new in his last days—from a distance, running elk look (to a 2-year-old) just like kangaroos.

By Sunday, Dad could barely push his call button. He called for help onto the commode. As his oxygen levels dipped into the 50s, he warned his nurse he might pass out. She said, "Don't worry, Merle, we are just about done here." He smiled and replied, "You bet I'm just about done. I'm going to 'kick the bucket' right here on the pot!" Even in his last hours, he charmed us with great sense of humor.

Monday morning, I sat quietly holding his hand. He opened his eyes, squeezed my hand, and said, "Now, everything is perfect!" He spent his last day with friends and family, sharing memories, and reminding us how much he enjoyed his life.

By Monday night, he was gone. As I sat in his silent room holding his hand for the last time, I replayed the week in my mind. Was there anything I could have done differently? Did I prolong his agony? Did I hasten his death? Luckily, I kept remembering Dad's words: "This was the best of my 3 choices…I couldn't be more comfortable…Now, everything is perfect!"

In revisiting the important conversations and decisions of that week, I am grateful to the anesthesiologist who helped me consciously acknowledge that Dad was dying and advocate for a treatment path that enabled him to say goodbye with dignity. I am grateful for the hospitalist, nurses, and hospice team for their willingness to be flexible and give Dad some control over the pace of his death. I am grateful for friends and family members who bravely kept visiting—bringing stories, pictures, hugs, conversation, and snacks. The outpouring of love and support in my dad's last week gave us strength to face death with humor, grace, and peace. It also reminded me about the importance of friends, touch, and conversation throughout life, especially at the end.

It was such a privilege to spend the last week of Dad's life by his side. He wanted control over as many end-of-life decisions as possible. I was grateful to have spent years studying medicine and years getting to know Dad, which enabled me to help facilitate choices for him. Most patients do not have a daughter who is a medical professional to help them navigate the complicated health care system; however, this special combination of professional and personal knowledge does not have to be embodied in 1 person. A team of friends, family, and health care professionals can serve as navigators and advocates. And, all patients should have the opportunity to build a trusting relationship with a primary care clinician who knows them well, knows their family, can help prepare them for complex health care decisions, can talk with them over time about options and personal choices before a crisis.[2] Everyone should have a primary care clinician on his or her team from birth to death, in the hospital and out of the hospital, in sickness and in health.[3-7] As daughters, sons, and medical professionals, we should expect should expect nothing less from our health care systems.

To read or post commentaries in response to this article, see it online at http://www.annfammed.org/content/14/3/273.

Submitted June 3, 2015; submitted, revised, November 6, 2015; accepted November 30, 2015.

Key words: health care communication; family medicine; primary care; patient-physician communication; patient engagement; end-of-life

Acknowledgements: I wish to acknowledge LeNeva Spires and Sonja Likumahuwa-Ackman for inspiration and assistance. And, thank you to the health care teams, neighbors, family, and friends who cared for my dad throughout his life.

References

1. Chen FM, Rhodes LA, Green LA. Family physicians' personal experiences of their fathers' health care. *J Fam Pract.* 2001;50(9):762-766.
2. DeVoe JE, Nordin T, Kelly K, et al. Having and being a personal physician: vision of the Pisacano scholars. *J Am Board Fam Med.* 2011;24:463-468.
3. Doohan NC, Duane M, Harrison B, Lesko S, DeVoe JE. The future of family medicine version 2.0: reflections from Pisacano scholars. *J Am Board Fam Med.* 2014;27(1):142-150.
4. Goroll AH, Hunt DP. Bridging the hospitalist-primary care divide through collaborative care. *N Engl J Med.* 2015;372(4):308-309.
5. DeVoe, J. When knowing more about a patient enables us to do less. *JAMA-Internal Med.* published online Aug 17, 2015.
6. Stadler DS, Zyzanski SJ, Stange KC, Langa DM. Family physicians and current inpatient practice. *J Am Board Fam Pract.* 1997;10:357-362.
7. McConaghy JR. The emerging role of hospitalists-will family physicians continue to practice hospital medicine? *J Am Board Fam Med.* 1998;11(4):324-326.