

## Both

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The gasps were audible behind me, I didn't need to turn around to know the expressions on the faces of my housestaff. My index finger dragged along the scroll wheel of the computer's mouse, unveiling the mass-like consolidations that overwhelmed the pulmonary parenchyma of this young mother of four. Her lung cancer was widely metastatic. Despite aggressive therapy for the past 2 years, she suffered repeated episodes of respiratory failure with post-obstructive pneumonias and malignant effusions, ultimately requiring a tracheostomy. It was my fourth block in the medical intensive care unit (ICU) as a first-year pulmonary and critical care fellow. I systematically scanned the scan for some new information to reveal itself as the cause for her respiratory failure and I grew ambivalent. We treated her pneumonia. We drained her effusions. Her cancer progressed. Her critical illness was incurable. Every time she left the ICU, a mucus plug threatened her discharge and her life, bringing her back to the ICU. Here we were, having "the talk" again.

She knew the potential paths forward. (1) Charge onwards with another round of chemotherapy (fifth line), and see how much time that could afford her, with sights on her son's graduation in a few months. (2) Re-treat for infection and give it some time. (3) Transition to comfort measures and go home with hospice. The sign-out was: "she can't decide." I could see the worry and frustration on the faces of the residents who cared for her. We outlined options, explaining the risks and benefits thoroughly and put the ball in her court—a decision to be made with autonomy given how clear her mentation was. I could not suppress the intensivist-pessimist burrowing inside me, scoffing and thinking "chemotherapy feels crazy." I was unable to disconnect my own judgment of her situation from our daily conversations.

"Good morning!" I said brightly. Her hollowed temples filled with creases from her eyes as she smiled wide and put a finger to her

tracheostomy stoma. "Doctor Deepa... it is so... good... to see you... this morning!" She spoke in short bursts of expired air as her warm spirit permeated the sterile ICU room. Two of her children were with her today, I greeted them both and turned back to her. "How are you feeling today?" I asked. Her expression suddenly shifted as fear overcame her eyes. "I am afraid. I can't decide today. I just want to see how things go each day." I responded without blinking. "Of course! There is no rush to make a decision. We're here for you, let me know how I can help provide more information. We'll keep working on daily progress in the meantime!" My feeble attempts at exuding patience and support were drowning underneath my concern that a delayed decision would only leave space for another complication, another setback, and a decision left to her distressed family.

As I look back on our interactions, I am troubled by two things. First, she knew we were waiting for a decision—she responded to an unsaid question and felt pressure to find a response from the minute I walked into the room. Second, through fear, she said "I" can't decide today. She assumed she was making this decision on her own.

We are lucky to have moments with our patients to understand who they are, what their narrative is, and how they envision living with their ailments. We frame preference-sensitive decision-making as putting the patient in control, respecting autonomy, and empowering them to make the decision most aligned with their values. But what if what they desire is both longevity and comfort? Autonomy means that everyone has the ability and opportunity to exercise self-determination—to exert control over their life with their decisions. Yet autonomy does not mean that an individual exerts this power independently, without the support of loved ones, confidantes, and advisors, which may include clinicians on the medical team. When we present patients with a decision, do we actually abandon them to

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make a choice on their own? We aim to arm patients with knowledge and statistics, but inevitably, the options are heavily framed. When we say “and,” do we actually mean it?

Confronted with rare diseases, unique patient circumstances, and the burgeoning public availability of medical information, we are expected to provide answers to questions. *Why did this happen? Why me? What are the next steps? What is the prognosis?* Patients confide in us, explaining the intimate details of their lives so we can assess their story, use our expertise to connect it to the pathophysiology of their condition, and treat them. We deliver the answers we learned through our training, clinical experience, discussion with colleagues, and review of medical literature. However, in telling us their narrative, patients become part of *our* stories. We create an illness script built from the phrases, exam findings, lab results, and outcomes with pieces built from every patient we have seen. Our communication about a condition evolves with each patient we treat. We practice and we refine. Yet answers may remain elusive.

When patients ask for a recommendation, seeking longevity, we answer with options for life-sustaining treatments. However, when life-sustaining treatment conflicts with another patient-oriented goal, such as limiting pain and suffering or allowing for that time to be at home or with loved ones, shared decision-making may be employed to reconcile the difference. In shared decision-making conversations, we unintentionally but undeniably develop our own opinions about our patients' priorities. It is human nature to do this. While it is important to retain one's opinions as a clinician, we must also recognize how our opinions manifest in our daily interactions with patients and their loved ones. Voicing concerns aloud about our own doubt or internal conflict may be one of the most powerful things we can do, not only to engage patients in a discussion about their autonomy and their choices, but to be explicit about the existence of unanswerable questions. These unanswerable questions can be framed as opportunities, which may give reason for pause, but not reason to lose hope.

One way I inserted my own bias was by hedging. We hope for the best, [and plan for the worst. We aim to be realistic about the likely outcomes [and hope for a miracle. I was expressing that we should try for both, but I didn't believe it. This lack of belief weighed on me as weariness and skepticism. Not being honest with myself nor the patient of my concerns and my bias came to feel like an inappropriate valuation of my priorities, and not the patient's.

Another way in which I consider my bias in answering the question “what would you do if you were in my position?” In truth, this question has no answer, as each person's unique scenario is

impossible to recreate. Do I word recommendations differently because I have made assumptions about this young woman, surrounded by her family members, radiating positivity? How would I have discussed the options differently for a patient who was withdrawn and isolated? Do I communicate my concerns about my own bias to patients?

My patient ultimately made the decision to receive additional chemotherapy, and she lived months. I smiled as I looked through her chart after she had passed away, watching the rest of her story unfold as I clicked through each encounter. This outcome, to me, was astonishing. Despite knowing the incredibly variable prognostic capacity of ICU clinicians, I still had strong, overtly skeptical feelings about aggressive care. The thrill of feeling humbled by her narrative swatted aside my ambivalence. I hoped my pessimism had never once impaired her autonomy, and now I had another narrative to add to my arsenal of reasons to keep any future pessimism in check.

I consider every day how discussing unanswerable questions with patients and their loved ones can give patients the confidence and strength to proceed knowing we are attempting to achieve ALL of their goals. I am reminded there is much hope to be had and room to be surprised. We cannot eliminate our bias completely, and we shouldn't, as it shapes our view of the world and unique interpretation of narratives. However, we can be honest and forthcoming about the bias we bring to these conversations. It is normal to want both and ultimately, it is not about the decision made. The reward is the journey and exploration of oneself—as a physician experiencing and accumulating these narratives—that leaves a legacy in our memories for the next patient.

#### CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest.

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