Palliative and Supportive Care

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Too much to do for death

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Essay/Personal Reflection

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I could hear her screaming even before I turned the corner toward her room.

I hurried down the hallway. The patient, Lu, was shouting in Chinese, a language I knew but that the nurse with her now, Deborah, did not. I stopped right outside the door as Lu unleashed a verbal assault on her, criticizing her for her apparent lack of ability in caring for a patient.

I waited until there was a break in the barrage then poked my head in. "Hello," I said before she could continue her tirade, addressing Lu in Chinese. I'd worked with Deborah before, and knew her to be a kind and skillful nurse, someone patients usually adored. I couldn't imagine what she could possibly have done or said to warrant such a lashing.

As the new medical student rotating on Lu's palliative care team, I had been eager to meet her and see how I might help. My supervising resident had gone over the basics, information I had gleaned from her records: she was 32 years old and had an aggressive brain tumor.

Lu responded to me in Chinese, eyes narrowing. "Who are you?"

"My name's Henry," I said. "I thought I'd come down and introduce myself, since we haven't met yet. I've just joined your care team."

A man who looked to be Lu's age sat in the chair next to her bed, an uncomfortable expression on his face. Before I could say anything else, Lu asked, "Are you more competent than this one here?" She tilted her head toward Deborah and switched into English as she glared at her. "Just go. I don't understand—how can anyone get *better* when they're surrounded by people who can't stop talking about death!?"

Deborah caught my eye and raised her eyebrows before she walked past, her mouth tight. I wasn't sure if it was in apology, sympathy, frustration, or some combination of all three.

"Now," Lu said, once Deborah had left the room. "You going to be like the rest of them? Start talking nonsense about how I'm going to die?"

I took a deep breath. No one had yet mentioned anything to me about Lu's particular state of mind. The man's eyes darted between us, then down to his lap. Lu sat cross-legged on her bed, a colorful silk wrap covering her bald head. She wore stylish clothing — no hospital gown — but it was clear how thin she was underneath the colorful fabric. Glossy magazines were spread in front of her.

"I'm gathering wedding ideas," she said in an abrupt tonal shift when she caught me looking. Gesturing to the man, she added, "This is my fiancé, Jiang."

"Nice to meet you," I said when he stood up.

"You haven't answered me," Lu pressed. "Got anything more to say about dying?"

"No. I was just stopping by to introduce myself and see if there was anything you needed."

She regarded me with skepticism, but when I didn't follow up, her brows un-furrowed and her expression relaxed. "Well," she said to Jiang, "they finally sent *someone* who has the right idea."

"Everyone here is just trying to help," Jiang replied, in what must've been an exchange they'd had countless times.

"Do you have any experience planning weddings, Henry?" Lu asked.

"Uh, no."

"Then I guess I won't need any help from you." She began to thumb through one of the magazines. "What about these shoes?" she asked her fiancé, holding one of the magazines up. He leaned in and studied the page.

Afterwards, Deborah met me in the resident workroom. "I guess no one told you," she said.

I shook my head.

"We've tried every approach. She just doesn't want to hear it. We're treating her symptoms for now, but without her participation, we can't proceed with further care, palliative or otherwise. Her family either can't convince her to listen or don't want to push too hard."

I'd encountered a few patients in palliative care who had initially been resistant, even hostile, to their dire prognoses. But each had eventually come to some sort of understanding, some acceptance of their condition. Today was the first time I'd met Lu, but already I had a gut feeling she would be the most challenging patient yet.

As I visited other patients that afternoon, Lu was never far from my mind. A more in-depth review of her chart revealed the many ways in which her care team had tried to get her to come to terms, but Lu would always cut the conversation short, insisting she was not going to die

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and that there was nothing more to discuss. There was no advance directive or power of attorney in place.

The next day, when I went back, Lu was alone, scrolling through something on her phone.

"Hello," I said. "How are you?"

"Annoyed. There's so much I need to *do* that's impossible to do from a hospital bed. How am I supposed to look at wedding venues? Try on a dress? Jiang is amazing, but he can't be expected to handle all of these details." She swiped at the screen.

"Do you mind if I sit?"

She nodded.

"So, you're eager to get out of here?"

"Of course I am," she replied, eyes still on her phone. "It'll happen the moment I feel better than I do now."

"Have you considered that perhaps—"

"*Don't.*" Her dark eyes were on me now. "Don't say it."

"What?"

"Something stupid like how I should consider hospice care."

"Well no, but—"

"But nothing. I'll be out soon enough; I've got too much to do. Not only is there a wedding, but there's also a honeymoon. There's so much to do. No one seems to understand that."

"I can't even begin to imagine how much work must go into planning a wedding. Or a honeymoon," I said. "But you seem like the sort of person who would be really good at making sure everything is taken care of."

A twinkle flickered across her face. It was brief, but there. "I'm glad you understand. This morning a doctor told me I feel tired and have this headache all the time because I'm sick. Pfft, it's because I've got all these things that I'm trying to plan from a damn hospital room."

"What sorts of things are you trying to plan?"

She very easily slipped into a conversation detailing what sounded to me like a dizzying and complex list of things to do in preparation for a wedding.

As I had completed my other patient duties for that day, I was able to stay with her for an hour. It was remarkable how describing her dreams made her all the more vibrant. Later, as I was leaving, Dr. Jacobs, one of the oncology attendings, stopped me in the hallway.

"I don't think any medical professional here has gone this long without getting yelled at by Lu. You were in there for quite a while, having quite the discussion." He peered at me over the top of his wire-rimmed glasses.

His tone was hard to read. Accusatory? Curious? A mix of the two? "She was telling me about her wedding. I just thought … it felt like the right thing to do, to let her talk about it. I know we're all trying to get her on board with hospice care, but I got a strong feeling that trying to talk to her about her health wouldn't go over well."

He exhaled. "I don't agree with it, but maybe it's for the best." He gave me a small smile and a quick nod before moving off, leaving me to wonder just what it was he didn't agree with.

Lu died a week later. I was off duty that day, but Deborah told me Lu hadn't been in any terrible, protracted pain — she had still been discussing wedding plans with her fiancé the night before, and then, the next morning, she was gone.

Though my interactions with Lu had been brief, my thoughts returned to her rather frequently. She never accepted her diagnosis, insisting on treating her hospital stay merely as a fleeting hindrance. Because of this, she was able to look forward to and plan her wedding right up until she died. Would it have been better if we had demanded she confront the reality of her terminal condition? I don't know how much it would have improved the outcome. Perhaps if Dr. Jacobs had been able to get through to her, she would have instead spent the last weeks of her life anxious or scared or in deep despair.

The more I pondered it, the more I realized I could not come up with a definitive answer. But what I did know was that the last days of Lu's life were spent focused on the things *she* wanted to be focused on, and she had carried that hope and anticipation with her through her final moments. And when I looked at it that way, it really wasn't such a bad way to go after all.

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