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WHAT YOUR PATIENT IS THINKING

Why is dying not seen as a diagnosis?

Audrey Chia explains why seeing dying as a diagnosis is important for patients at the end of life.

Audrey Chia

My mother developed rheumatoid arthritis in her twenties and had joint replacements for knees and elbows. After a series of infections at the age of 70, her prostheses were all progressively removed to save her life, and she could no longer walk or feed herself. She asked to be cared for at a nursing home. Although she later had cancer and a minor stroke, she was generally in good spirits.

One Sunday, my mother refused her favourite spicy noodles. She commented that everything tasted worse than before. The following week, she refused another favourite, braised pork with vegetables. My mother had not been eating much. She could not swallow. She felt nausea, as if something were pressing against her throat. She calmly told me she was going to die soon.

Tests and investigations

I took my mother to see a health professional she knew well and trusted. My mother's eyes no longer sparkled. She looked tired, thin, and fragile. The doctors were deeply concerned and admitted her for observation. We discussed the possible causes and the battery of tests began. The medical team diligently went about their investigations but it troubled me that there seemed to be little thought or questioning about whether the tests were reasonable with her condition.

The tests and treatments all caused her pain. My mother was so thin that every attempt to draw blood or to insert a drip caused even more pain. The process of giving the tests seemed automatic. There seemed to be little consideration of alternative means of obtaining the information needed. I kept wondering, could there have been less invasive or painful ways to help my mother?

Time to go home

After two months there was still no diagnosis and my mother's condition had not improved, even after multiple efforts by the medical team. With my sister and a close friend, I made the decision to cease my mother's treatment. My mother had entrusted me to make her decisions for her, partly because she did not speak much English, and also because she felt I was better able to make these decisions. This is common in Singapore, where I live.

The drips, blood tests, scans, and attempts at 'scopes were stopped and it was time to go home. Her medical team found this decision hard to accept. They pressed me to persuade her to allow just one more test. I told them my mother had suffered enough and needed to

rest. She received palliative care and died peacefully a week later.

Accepting death

During my mother's care I had a good rapport with her doctors. They kept me informed through everything. But the only times we had discussed death and dying were before her surgeries. Perhaps, in our minds, dying was something that would occur quite suddenly during an intervention. We had not imagined it could instead happen gradually, over several months. Why did we not see that my mother was right? Her symptoms were consistent with the signs of dying. Perhaps we were unwilling to accept death because there was no diagnosis. As we had to learn, "dying" is a diagnosis, too.

What you need to know

- Recognising when a patient is dying and having open conversations will help patients and their families better prepare and feel involved
- Understanding a patient's values, goals, and preferences will help ensure that care is appropriate and in line with their wishes
- Ensure patients and their families are involved in decision making around what tests should be conducted

Education in practice

- Think of a patient in your care who is approaching the end of life. How might you better understand their needs and preferences about their care?
- How would you approach a conversation about death and dying with a patient and their family?
- How can you ensure that patients and their families are involved in the decision making around investigations and that their input is considered?

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