

Ethics Consult: To Tell or Not to Tell

By Ellen Kolton

What should we, as witnesses to a life about to end, tell the family about a beautiful 18-year-old girl who is dying? While her grieving parents, brother, cousin and boyfriend hovered beside the bedside monitors displaying this teenager's ebbing vital signs, a group of clinicians and staff members squeezed into a room around the corner to debate our ethical obligation to her family. Everyone involved held a fragment of her story, a piece of a tragedy that spelled only failure and sadness.

The request for an ethics consult came from a young physician who repeatedly apologized for urgently calling the meeting, conveying the agony she felt for withholding a vital piece of information about the patient from her family. The question at hand was protecting a patient's privacy versus disclosing the information her next-of-kin would need to make an informed decision to withdraw life support. The boundaries between professional and personal obligations blurred.

None of the people who crowded into the ethics consult to discuss this Vietnamese girl had ever met her. We knew only a few facts: One, she had a history of suicide attempts; two, her family, from whom she was reportedly estranged, was willing to withdraw life support; three, when she was brought in by an ambulance two days ago, after her boyfriend had found her unconscious, lying face down beside an empty bottle of Benadryl, the emergency room doctors discovered she was in her first trimester of pregnancy.

To make a substituted judgment—that is, to decide for someone who is not able to decide for herself—the surrogate decision-makers need the same set of facts as that person would have needed to make this decision. But there were other questions: Did this young woman, who was now intubated and unconscious, her body swollen from multisystem organ failure, IV fluids, and other medicines aimed at prolonging her life, know she was pregnant when she took the pills? And, more importantly, would she want that information shared with her family?

When her pregnancy was discovered as part of her initial Emergency Room workup, the fetus was viable. Over the next several days, several ultrasounds were performed, and during the last one, there was no fetal heartbeat. The fact that the fetus was no longer viable subtracted pregnancy from the decision equation. We were not ethically obligated to inform the family.

But the question of disclosure still plagued us. Did her family have a right to know? And was it up to us to tell them? The somber group became vocal: "I was in a family meeting with them yesterday and they were so pained. I don't think we should add to it. They are suffering enough," said a nurse case manager.

"Isn't that paternalistic?" an intern challenged.

“Is it comparable to telling a family that a dying patient has AIDS?” asked a medical student.

“No,” replied a resident: “the code of medical ethics would not support that.”

“Technically, the family does not need this information to make an informed decision,” said the attending physician.

I was torn, knowing he was right, but identifying with the girl’s mother. I imagined her imminent and life-long grief. Would learning about her daughter’s pregnancy help her understand why she wanted to die? I thought of my own daughter, just a little younger, feeling so anxious that she would rather kill herself than face me. I would have wanted her to confide in me. I would have wanted to know why she attempted suicide. Would I be better off knowing, or would it just add to the inevitable guilt that any parent confronts when their child commits suicide? There was not an easy answer.

We turned to the Vietnamese interpreter, who had met the family and had come to the Ethics Consult to provide a cultural perspective. We peppered him with questions: What are their beliefs and practices surrounding unmarried pregnancy? About illness? Death? Is the patient religious? Is her family? How can we best honor this family as we transition the patient from life to death?

He spoke haltingly. Interpreters rarely have the opportunity to speak their own words. We wanted to show kindness and compassion for her parents, who were facing the hardest decision of their lives. And to have to do this in a strange city, with strange people, in a language they didn’t understand, probably only made a bad situation even worse.

The interpreter said the family had described the young woman as very independent. After she left home, they hadn’t had much contact. “They are Buddhists, but they are not religious. They do not follow Buddhist practices. They want this to be over quickly,” he said. “They want to take her body home to Michigan, where they live.”

The patient’s nurse entered the room, frowning. She whispered in the attending physician’s ear, and then she left. “The patient’s father just arrived, and the family wants to get this over with,” he said quietly.

We knew that given the circumstances, the medical examiner would take her body to pinpoint the cause of death. If the family requested the autopsy report, they would learn about her pregnancy. They would receive a report in a few months, in a language they didn’t understand. It felt cruel to allow that to happen. Ultimately the group decided not to reveal that she had been pregnant. However, the attending physician would invite her parents to call him with any additional questions in the weeks or months to come. Meanwhile, we would offer to arrange to transport her body back to Michigan.

After the meeting, the interpreter approached me, pulling a small card covered in Vietnamese writing from his pocket. “I know they are not religious, but I thought I could read this prayer with them,” he said. He told me that when he went home from the hospital the night before, he had confided his sadness to his own father, who gave him the prayer. “I hope it will be OK.”

I walked slowly back to my office, feeling sad and helpless. Given her condition, we couldn’t save her. Given the privacy laws, we couldn’t help the family to cope. And given the cultural divide, we couldn’t offer solace to the grieving family. I was impressed with the interpreter’s willingness to step outside of his job’s boundaries to offer a humble prayer. With his bow-tie and freshly combed hair, he appeared earnest and diligent. I watched him walk down the hall, clasping the small prayer card in his hand, hoping the family would appreciate

his gesture of sympathy and that their response would encourage him to continue to go beyond interpreting the words people use— because often words alone aren't enough to convey what is behind them.

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