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Spirituality in hospice and palliative care

Steven J. Baumrucker, MD, FAAFP, FAAHPM, Associate Editor-in-Chief

In this issue, Hart et al. present a survey on physician-initiated spiritual discussion in 16 terminally ill patients.¹ Although the study size was small, the results confirm what we have feared for years: many patients want to discuss spiritual matters with their doctors, but few are offered the opportunity. In their survey, 73 percent of patients favored physician inquiry about their spiritual beliefs, but only 13 percent reported having such a discussion.

How can providers know which patients want to discuss matters of the spirit? Simple open-ended questions like “do you consider yourself religious” or “do you want to discuss spiritual matters with me” should be part of the routine whole-person assessment. Certainly, if a patient brings up the subject, it should be pursued. As one of the patients in the Hart study said:

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“[If] the patient comments on [a painting in the doctor’s office] and says ‘you know I really like that painting,’ that should trigger something...in the doctor’s mind...the patient is telling you something.”

Although the story I am about to tell has been told previously in the pages of this journal,² it is probably appropriate to retell it here, as the teller has acquired a little wisdom in the years intervening between the events and the present. In any event, the story illustrates the need to discuss spiritual issues with our patients and how failing to do so can result in needless suffering.

In 1987, I was a second-year resident in Family Practice and, at the time of this story, was the sole resident on call for the in-patient service. I was called to the emergency department to see an elderly patient who needed admission. At the time, my attending physician was otherwise occupied, and I had no interns or medical students working with me. The unfortunate patient in the emergency room would have to contend with me as his sole provider.

On arriving at the bedside, I found

a patient near death. He was 60 (but appeared 80) and was tachypneic, febrile, and hypotensive. I reviewed his record and discovered that “Mr. G” had metastatic carcinoma of the liver and was considered terminal. He had refused in-patient care on multiple occasions and presented to the Emergency Department on a regular basis complaining of a “demon” in his abdomen. Generally, he was given an injection of Thorazine and discharged with a diagnosis of hepatic encephalopathy, paranoid delusion, or other psychiatric disorders.

Everything in Mr. G’s current workup indicated sepsis; it was obvious he was critically ill, and his chances for survival were minimal. I came to his bedside to discuss my findings, and eventually the discussion came to “code status.”

“Do you want me to put a tube down your throat to breathe for you if you stop breathing?” I asked.

“Yes, yes, do everything you can to keep me alive,” he replied.

“Do you want me to shock your heart if it stops beating?” I asked.

"Yes, yes, do everything you can to keep me alive," he replied.

I must admit this bothered me, as I believed he would die no matter what we did, but that his end would be messy and undignified if we complied with his wishes. In addition, while I was writing his admission orders, Mr. G began yelling "Lord, don't send me into that lake of fire!" at the top of his lungs and began singing southern-style hymns as loudly as he could. This began a pattern that was consistent throughout his brief admission, pleading with God and then loudly singing hymns of praise. Initially, it seemed that he was disoriented and this was a form of confabulation; I considered administering Thorazine, as it had apparently been used previously with good results. Although I had enough dumb luck to hold the antipsychotic medication, the true depth of my ignorance was not apparent until it was almost too late to redeem myself (and save my patient from an ignominious end).

Since complying with his wish to "do everything" included vasoactive support with dopamine, we rode the elevator to the ICU together. The singing hymns and pleading for his life continued while we were hooking up the monitors, catheters, and other technological wonders that we'd use to keep our patient alive. The ICU staff gently berated me for bringing them a terminal patient who would not benefit from their ministrations, but I explained that complying with his wishes demanded nothing less than intensive care. As soon as he was fully admitted, however, Mr. G became unresponsive.

At that moment, I did what I consider to be the most morally and ethically reprehensible move of my career, for as soon as my patient could no longer express his wishes, I searched around trying to find someone to make him a "no code." I felt I

knew better than the patient did what he needed, and what he needed couldn't be given in the ICU.

Fortunately, the woman who brought him in to the ER refused to take responsibility for end-of-life decisions, as she was simply a concerned neighbor. She did give me the telephone number of Mr. G's brother, who lived approximately 10 hours away by automobile and was his power-of-attorney. The brother was home and, when I explained the situation and attempted to get a "no code" phone order, stated "don't do anything new until I get there." He was on his way. Until he arrived, we'd continue to comply with the wishes of our patient to "do everything."

For the next 24 hours, Mr. G intermittently awoke, yelling "Lord, don't send me into that lake of fire!" and singing hymns incredibly loudly for someone in his state of health. The antibiotics and dopamine improved his fever and blood pressure, but he was obviously failing. The time would soon come when we would either have to perform a "code blue" or allow him to die naturally.

Mr. G's brother arrived on the afternoon of the second day. I briefly explained his condition and then led the way into the ICU room. Mr. G was indeed awake and recognized his brother, who began to ask questions.

He asked, "Brother, do you want to live?"

"Yes, yes," Mr. G replied.

I couldn't resist butting in, asking "Do you want to live *like this*?"

"No, no, I don't want to live like this," he replied.

I was still confused, but salvation, in the form of a brother's love and wisdom, was near. I took Mr. G's

brother to the meditation room, and we began to discuss his case.

"You know what the problem is?" he asked me.

"If you know, I really wish you'd tell me," I replied.

"He's never been saved."

I said, "Believe me, anyone who talks to God and sings that many hymns, he's been saved."

"No, no, you don't understand. I mean he's never been baptized."

He went on to explain that his brother felt that if he died unbaptized he'd be condemned to the fires of hell. In addition, he explained that Mr. G called the pain in his liver "the demon" because he believed it symbolized talons that were embedded in his abdomen, ready to drag him into the netherworld the moment he died.

At that moment I experienced an "eureka" moment, an epiphany. What we were dealing with was not psychosis, but merely dysfunctional problem solving. Mr. G's internal algorithm went something like this:

- I've never been baptized.
- If I die unbaptized, I'll go to hell.
- Therefore, *I must never die.*

I thought a more appropriate algorithm that might result in a more attainable goal might be:

- I've never been baptized.
- If I die unbaptized, I'll go to hell.
- Therefore, *I must get baptized.*

I also realized that the doctors who had treated him previously had

essentially prescribed Thorazine for his spiritual beliefs. His complaints about "the demon" made perfect sense once I understood the framework from which he was operating.

I asked the brother if he thought Mr. G would respond to being baptized in the ICU, and, like me, he thought it was at least "worth a try." At that point in my career, I knew how to insert a central line, perform a lumbar puncture, and diagnose a variety of rare diseases. I had no idea, however, how to arrange a baptism in the ICU. A quick call to the operator resulted in the beeper number of the chaplain on call.

"Can you perform a baptism in the ICU?" I asked.

"I can perform a baptism *anywhere*," he replied.

"Well, I have a stat consult for you, then."

The chaplain arrived and, after a brief consultation with us, entered the ICU room and closed the sliding door. There were a few snickers from cynical staff as the volume in the room began to increase, but Mr. G's brother

and I sat outside the room in rapt attention. We could hear the chaplain's voice, but nearly drowning him out was the voice of Mr. G singing hymns and cursing the demon in his abdomen. This cacophony persisted for a few minutes, and then the room fell strangely silent.

The chaplain opened the door, waved at everyone, said, "I'm done, thanks," and left, our own version of the Lone Ranger who saved the day at the last minute but never asked for anything in return. For when we entered the room, we encountered a very different patient than the one who had been there only minutes before.

Mr. G appeared to have died at first glance, but on closer inspection he was simply breathing normally, with no signs of discomfort. The room was quieter than it had ever been, even when he had been comatose. As his brother approached the bed, Mr. G opened his eyes.

"How you doing, brother?" his brother asked.

"I want to go home," Mr. G replied.

I consulted hospice immediately

(yes, it was a very late referral), and Mr. G returned home to the care of his brother and neighbor. He was on a minimal morphine drip, and pain was never again an issue. After his death three days later, his brother told me he'd never seen Mr. G a happier man.

This case affected me profoundly and was instrumental in igniting my interest in hospice and palliative care. More universally, it illustrates the need to talk to our patients about spiritual matters. If any of us in the medical field had taken the time to talk with this patient about his beliefs, perhaps he could have been treated with water, instead of Thorazine, sooner and had a longer period of contentment in his last days. As the patient in the Hart survey so correctly stated: ". . . the patient is telling you something." In truth, once we broach the subject, we merely have to listen.

References

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