Honored Communications: The Emergence of Hidden Stories Toward the End of Life

SCOTT JANSSON, MA, MSW, LCSW

As a hospice social worker, one of the things about life review with terminally ill patients, which has always fascinated me, is what gets left out in the telling. Whenever Pete talked about his life, for example, the story screeched to a halt when he received his draft notice in 1968. You could have built a fire under him trying to pull out a memory of anything that happened in the year or so that followed—any memory—but it wouldn’t have worked. “I don’t talk about that,” was his stock answer and he meant it. It was as though a piece of narrative thread had been cut out and spliced with events a year later where the story resumed. Everything in between was gone.

Pete never said a word about what happened in Vietnam but he talked honestly about the drugs, broken relationships, and occasional jail time that followed in the war’s wake. These were the “years of darkness.” According to him it was his kids, Tina and Shawn, who helped him finally find his way. After his wife left, leaving the kids with him, he knew he had to get his life straight for their sake. Pete meant it literally when he said that they had “saved” him.

Unfortunately, the many years of hard living had taken a toll and later Pete developed cirrhosis. As the illness progressed his condition became terminal and he started receiving visits from the hospice team. On one of these visits we were sitting outside his apartment waiting for the kid’s school bus. He talked about the future. Despite the fact that he’d been told his prognosis was about three months, Pete was anticipating what a great day it would be in 5 years when he would see Shawn graduate from high school. By then Tina would have graduated as well and he could die in peace.

Another of the things that has always fascinated me about life review are those unexpected occasions when something that has been left out is suddenly revealed. As we talked that day, strangers drifted in and out of the parking lot at his apartment complex. Watching the comings and goings, Pete complained about the increasing gang violence, crime, and drug traffic in the neighborhood. He worried about what would happen to his children when he was gone. “Once I see them through high school they’ll have some choices, but for now they need my protection.”

“You really think you’ll live another five years, Pete?” I asked.

He looked up as if thinking. “My kids need me,” he finally said, “I’ve got to live.” Outside on the porch he started telling more stories about how they had saved his life and how he owed it to them to be there for them when they graduated. As we talked, an argument erupted on the second floor walkway of his apartment complex, breaking his train of thought. It was a loud, ugly argument between unseen but shouting opponents. Threats were made. It sounded like there was shoving. Other loud voices tried to goad two men into fighting. When it fizzled, Pete was lost in thought. He seemed to be somewhere far away. Suddenly he got an intense, almost enraged, expression on his face. He looked me in the eye and...
He'd been haunted by those eyes. "Every day I think about those eyes. Every time I do it feels like a K-Bar knife slicing into my guts." (K-Bar knives—also spelled KA-Bar—had 7-inch blades and were standard issue for Marines during the Vietnam War.) They could be lethal in combat but were more often used as utility knives.

He wanted to say more, go a little deeper, explore the meaning, but he remained quiet. We sat in silence for a long time, letting it all sink in. Mindful of the power of such memories to evoke intense, potentially distressing thoughts and emotions, I tried to get a gauge on where he was. His breathing was a little shallow, his hands fidgety. He didn't appear to be shutting down into dissociation or ratcheting up toward panic or rage. I reminded him that we were in a safe place and waited for his breathing to return to normal. I asked if it would be okay for me to ask a couple questions. He nodded.

"Do you remember the guy’s name?" I asked. "Ray."

"What's it like for you to talk about this?" He straightened his back, "If you mean do I feel better talking the answer is no."

"That's not what I mean, Pete. I mean what's going on here," I tapped my chest near my heart, "right now."

"Overwhelmed. Numb." He took a deep breath, "But less alone, I guess. ... It feels good to say Ray's name."

I asked Pete what the connection was between his kids and the battle that day. The question jarred him, not because it hit a nerve, but because it made no sense to him. I reminded him of the sequence of events: he’d been talking about his kids saving his life and how he needed to be there for them until they graduated; there’d been a heated argument on the floor above and..."
then he’d gone right to telling about the firefight on that horrible day. Kids, argument, Vietnam—what was the connection?

Suddenly the tears he’d been holding back began flowing. After the first wave rolled through he dried his eyes with his shirt’sleeve, lit another cigarette, and said, speaking of his children, Shawn and Tina, “I can’t leave them on the field of battle. I can’t leave them under fire. Those streets, they’re a battlefield. They’re just kids. They’re counting on me to help them just like my buddies were in Nam. I lost two friends that day. I won’t lose two children.” Concerns about his children’s safety, it seemed, had reached deep down and connected with memories and concerns about the safety of his platoon mates during the war, reeling those memories all the way up to the surface.

The two sets of experiences, though separated by time, were somehow blended into a single alloy. Themes, thoughts, and emotions from both overlapped to the point where the battlefields in Southeast Asia had in some way connected with those outside his doorstep here in the United States.

At times it seems to me that each person carries within himself or herself many permeable layers where stories, conscious and unconscious, are remembered and organized. Stories closer to the surface are told often (in one version or another) and those deeper down less so. It is on these deeper levels that we often guard stories that evoke fear or vulnerability or pain, or which are so personal or existentially important that we are careful about when and with whom we share them. Often traumatic experiences, such as the things that happen in combat, are stored in these deeper layers, emerging only when circumstances allow or a level of trust has been attained.

But just because the levels further below the surface hold stories less likely to be shared, it doesn’t mean that they are any less important—in fact, sometimes the opposite is true. Nor does it mean they are not constantly present in one form or another in the mind of the person who carries them. Pete’s story about Ray may have been hidden from others in these deeper strata but not from himself. Probably it was no accident that Pete spoke of his children as lifesavers, the same role he’d tried so courageously to fill while in Vietnam. His protectiveness for his men and his children, as well as hard lessons in his limitations in being able to keep them safe were themes common in both layers of story, as was the visceral way he seemed to feel the analogy of the battlefield with the “streets.”

Pete and I could have explored these and other shared themes that day—for example, the intense pressure he put on himself to do the impossible, the guilt, the imminent possibility of death, the list goes on—but Pete wasn’t interested in such processing. His concern was for his children and that’s where he wanted to focus. For him the future was a dangerous place in which one fear was primary: the fear that his death would be an injury from which Tina and Shawn would not recover, a fatal wound that would plunge them into states of depression or anxiety (perhaps like the one through which Pete himself had traveled during those “years of darkness”), making them susceptible to the allure of the streets or the predators who waited there.

Pete’s fear that his death would cause irreparable injury was understandable. He’d seen many life-threatening wounds before, both physical and psychological. He’d sustained them himself as evidenced by his struggles in the aftermath of Vietnam and the persistence of painful haunting memories. But he also had firsthand knowledge that most wounds, however traumatic, are not fatal. As he saw it, what separated the fatal from the nonfatal had to do with how catastrophic an injury was and the action that took place before and after it was inflicted.

We further explored the things that Pete could do and had already done to prepare Tina and Shawn for what was coming and provide for their safety after he was gone—for example, he’d already arranged for his brother to move in when Pete’s condition worsened and to be the children’s guardian. He’d assured they would receive a small income from his social security, kept teachers, family, friends, and people from the church in the loop and enlisted their promises to keep their eyes on the kids. We talked about simple but powerful ways to ease the wounds of death when it came by being honest with Tina and Shawn about what was happening, answering their questions, listening to their concerns, and letting them know they were in no way to blame for what was happening. We spoke about Pete simply doing the best he could in what time remained to express love, say what was in his heart, and allow himself and his kids to be imperfect and thoroughly, humanly-fallible.
There is often an element of mystery as to how different layers of memory and story will intertwine, allowing, at times, a person to see current challenges in new ways, or to see older ones with new perspective. During our conversation there was a subtle interplay between the images, experiences, and wounds of Vietnam on the one hand, and Pete’s focus 30-some years later on navigating the challenges that lay ahead for him and his kids as they dealt with his approaching death on the other hand. Who’s to say how much of our talk about letting his children know his death was not their fault was about them and how much was about Pete and Ray? Who can know how much of our reflection on human fallibility and imperfection was about Pete as a father with a terminal illness and how much was about Pete as a young medic shouldering the weight of trying to keep his buddies alive while under incredible duress? Although they may have been separated in time, in his heart, Vietnam and the challenges of terminal illness beat as a single rhythm.

Much has been written about the elements involved in helping patients uncover, share, and integrate memories and life experiences at the end of life. Unearthing hidden stories can bring possibilities for healing, but it can also churn up emotional and psychological pain or distress. Great sensitivity and care are necessary when they appear, as is letting the patient decide where he or she wants to go, how far, and the pace at which he or she will go there. Much of what has been written about such excavations focuses on the ways professionals can help establish a context of safety and trust. Some writers offer insights on how to attune with patients and assist them with timely, appropriate, and well-paced questions and observations.

This is all well and good, but in our attempts to codify a systematic approach to such things we may obscure the fact that there is always an inescapable element of mystery and improvisation. We can help set the context, but the patient makes the choices and does the work. It is often impossible to predict when and how these hidden memories will emerge. What brings something into consciousness? What gives one the confidence and motivation to share that which has been hidden?

Who knows why Pete chose that particular day to begin talking about Vietnam? Was it that the protectiveness and responsibility he felt for his kids mirrored what he’d felt for his men? Was it the common experience of facing an imminent threat in his apartment building? Was it the awareness of his mortality? Did terminal illness bring up intense emotions, which reminded him of those emotions he’d felt during the war, such as anger, fear, dread, guilt, and so on? Was it the work of previous visits in establishing trust and rapport? Was it the argument and the danger it implied? Was it a combination of these, or something else? Who knows? And therein lay the mystery.

Pete was tired. The kids would be home soon and I didn’t want to push my luck, but I couldn’t resist another question or two.

“Pete, what do you think Ray would want you to know if he could come back and sit with us for a little while?”

Pete got a far-away look in his eye. For a moment I thought it may have been a mistake to ask such a potentially emotionally-laden question as the visit was winding down. Then he smiled, “He’d tell me to let it go. I did my best.”

“And what would you want him to know?”

Pete cleared his throat and swallowed hard. “I guess I’d want him to know I never forgot him. That just because a story isn’t told ... doesn’t mean it’s not remembered.”

Scott Janssen, MA, MSW, LCSW, is a Clinical Social Worker at Duke Hospice in Hillsborough, North Carolina.

The author reports no conflicts of interest.
Address for correspondence: Scott Janssen, MA, MSW, LCSW, Duke Hospice, Ste. 101, 4321 Medical Park Dr., Durham, NC 27707 (john.jassern@duke.edu).

DOI:10.1097/NHH.0b013e3182705ca6