Case report

"Morphing Around the Universe": Reflections on Caring About a Dying Person

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ABSTRACT

Guiding a Family Medicine resident through a series of difficult encounters with a seriously ill patient can be a challenging academic experience. While this first year resident is the primary care physician, he realizes very quickly that his skills and abilities understandably fall far short of the multiple demands and asks for help and guidance. His patient is not going home from the hospital, and decisions (both medical and psycho-social) have to be made with the patient.

This case study follows the resident and the Behavioral Sciences Educator with a patient named Joe. The changes in their relationship are demonstrated while Joe reviews and then modifies his will, follows through on a family meeting, and completes his journey through life and passes away in hospice. The Educator long remembers the depth and quality of their relationship.

MeSH Headings/Keywords: teaching residents, techniques to reduce "night visitors" of loneliness, isolation, fear, facing death, and hospice

Case Study

I first met Joe when I was consulting at a hospital. The Family Medicine resident asked me to see Joe with him because the options for care were becoming less and less, and he felt unskilled as a new physician in training with this very uncomfortable and anxiety provoking experience. I was introduced to Joe as the Behavioral Sciences Educator and Joe said he didn't need a shrink, but he needed a way out of this cancer. He said that his cancer was "impossible to control" and he was expected to make some difficult decisions about his future: nursing home, hospice but returning home was probably not possible. There wasn’t much more the hospital could provide. Joe and the doctor had a few days to think this through, but since the resident was uncomfortable doing this alone, he asked me to be part of the conversations. Little did I suspect how much of Joe's life I would be part of and share, and for how long I would think about him.

We met the three of us, for some grueling and tough talks. We also asked the hospice nurse to join us for a session, and Joe's questions became more and more intense as she explained about the concept of hospice and she said the word death. I remember even now, how the word filled the room with an eerie intensity that brought tears to the doctor's eyes and Joe was speechless as the word sunk in. I heard him almost whisper, "I am going to go to hospice to die. What do you think, Professor?"

I waited a moment and then said that how he felt was really going home from the hospital, and decisions (both medical and psycho-social) have to be made with the patient. Joe just took to all this. He said it was like learning a new language to help him deal with his life, and now his death.

Finally, he spoke. “I am glad you told me. It must have been hard to do.” It was.

Energy between us picked up after that. We began discussing deep breathing, imagery training, and basic meditation. I related that mindfulness techniques were frequently helpful for me, and for many I had worked with, and I knew it would be helpful for him. Joe just took to all this. He said it was like learning a new language to help him deal with his life, and now his death.

I met his family: two sons and their wives and four grandchildren. They talked with the oncologist and hospice nurse and it was difficult for them all. I found myself wishing I could make all this go away, and Joe could return to his home and live many fruitful years.

One day Joe was transferred to hospice.

Joe called and asked me to visit him. There was much he was now ready to talk about. And so, we made a plan. I would stop at Joe's every Friday on my way to the hospital and we would talk: no therapy, no patient and therapist, just two men on their own journey through life, meeting and sharing, with an occasional Jungian concept thrown in so I wouldn't get too rusty.

I suggested a family meeting when Joe talked about his will and plans for his estate. He wanted his grandchildren to get a good chunk of it and his children to get the rest. I asked him to think about the following questions and respond to them before he decided on all this.
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I brought up God and religion and even the concept of heaven. Joe looked at me and I will never forget what he said: 
"Alan, you are an educated and very smart man. Why would you bring up such stuff? And don't say it is a requirement of your job." My response was that I would certainly want him to speak to some chaplain if he had questions or concerns that were out of my league.

Joe completed the questions and we spent an hour on the phone one night going through them. I won't share his answers, but he changed parts of his will. When I asked what he planned, he said he had his lawyer keep the grandchildren where they were, but that he wanted an endowment at a small community college for student grants in his name and his wife's, who had passed many years ago, for the rest of his estate.

"I really do want a legacy that will live through my grandchildren from their inheritance, and the students who will use my endowment for college."

I asked Joe if he would like to talk about religion, spirituality, and purpose. He said yes.

"I feel that I am a survivor. I feel that I have avoided many personal tragedies. I am still here. And I want to be here."

"I have tried to be a good father and grandfather and have tried to do it in a loving way."

Joe began to feel time running out on him and was on increasing doses of medication to bring relief from the pain. We reinforced the early meditation and imagery training with hospice staff, who all took to him so easily. I was pleased they were so kind to him. One Friday, he told me that the "visitors" had left, as they had for me. No announcements, no playing of bugles, and no warning. For both of us, they left and never came back. He was proud of this and said it was a real accomplishment for a guy who was dying not to be so afraid.

The following day I went back because I had a feeling there was something else going on. Joe was in what first sounded like a shouting match with the ChaplainRabbi. Joe blurted out that the Rabbi said it didn't matter if he ever went to synagogue or even believed in God, but it was important that he believed in a "something" for himself after he died. Joe began to weep and said that he wanted desperately to believe that he and his wife would "morph through the universe, forever," a term he would later employ, numerous times. The Rabbi held Joe and asked me to join in. As the Rabbi left, however, Joe told him not to expect any contribution from him. The Rabbi, unshaken and as warm as he'd been upon his entry, turned and blessed Joe. This, Joe seemed willing to accept.

Since Joe had opened an emotional place we were now in, I suggested a family meeting. I wondered if it would be their last, but one in which I would ask to be there and facilitate the meeting. Joe must choose the people he wanted to be there and what he wanted to say and what he hoped to hear. I then suggested the additional areas below to include with his thoughts to complete the circle of Joe's life. This was challenging for us both, for Joe was going to spell out his requests for a funeral and no family gathering after only a tombstone, he wanted, and clarity about how it would be paid for. He wanted to be buried next to his wife, Hildy. Then he winked at me and said it would be easier for him to find Hildy's soul if he was next to her so they could begin "their morphing around the universe."

Below are 6 messages Joe composed for his family:

1. Forgive me for my mistakes and mindless ideas and comments.
2. I forgive all of you for your mistakes.
3. I have tried to be a good father and grandfather and forgive me when I have failed.
4. I love you all and am sorry I did not tell you or show you enough of my love.
5. I am sorry I have to leave you.

As I look back, I remember the room Joe was in, with all his family around him. He decided to ask the grandchildren to attend with the idea they could skip out to the hall if they needed or wanted to. They all stayed, and as the sunset began to show through the windows, Joe said all he wanted to say and then more. He talked about his great excitement at seeing his family thrive after a rough time he and Hildy had in Europe before immigrating to the United States. He was pleased with them all and was sad to have to leave. Each adult child had something to say to Joe, as did their partners and the kids also.

As they all piled out of the room, Joe asked me to stay. He told me that he and I shared the same religion but that he respected whatever my personal views on that were. He also instructed me not to go to his funeral or the shiva (eight religiously prescribed days of family mourning) his family insisted on having, saying only, "Our relationship is ours." Joe also told me no rushing to the hospice if they called me that he was passing. He grabbed my arm and said that some part of my spirit was within him and made him feel sort of okay, and that he would return it after he passed, since he would not need it any longer. Even I had nothing to say at that point. I hugged him and left.

Joe passed away the next morning. Like the “night visitors.” No bugles, no announcement, no fanfare.

As I reflect back on this meeting, there was something very emotional, very spiritual about it. There was an intensity, energy and warmth that is not there in any other kind of family meeting. I have spoken with other therapists, ministers, nurses, and volunteers who conduct and guide such meetings, and they all seem to agree that this phenomena occurs, but some had been reluctant to talk about or share it with others. How strange that we do not easily share such an acute sort of blessing.

While not alluding to this in the story of Joe, it is paramount that anyone of us who was with him in most any circumstance had to be fully "in the moment" with him. In other words, we must have the insight, skills, and desire to be completely in
that moment with him; physically, emotionally, and spiritually. Sometimes, we can fool people about how smart we are or how much we know, but never about whether we are fully in the moment with them. We cannot fake being present when we are, in fact, preoccupied with what we have not accomplished in life, or overly anxious about what we will do later. We are simply to be here and now for them. This is the only bridge to real compassion and deep empathy with someone who is struggling with life and death.

Finally, for those who have traveled this journey as I did with Joe, there is a calmness that pervades us, a settling in of our most intense feelings, and a sense of gratitude for the experience. It has been said that for many elders, life is a series of losses. What makes it easier to cope with this reality, is the ability to say goodbye to those we love the most. Joe was indeed lucky to be able to do so. Maybe this made his passing easier for him and for those left to mourn him. I know it did for me.

May Joe's spirit have found that of his wife’s. May it be that they have begun their “morphing around the universe”.

ADDRESS FOR CORRESPONDENCE

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