
Hospice vignettes

Care and hope for the dying

Victoria Y. M. Fan

“The ultimate lesson all of us have to learn is unconditional love, which includes not only others but ourselves as well.”

—Elisabeth Kübler-Ross

It's 10:23 PM, and I am massaging 40-year-old “Uncle Johnny” (in Taiwan, it is a social custom to address those older than you as “uncle” or “aunt,” “grandpa,” or “grandma”) who has terminal brain cancer. The right side of his brain has undergone surgery a few times. What is presumably the tumor protrudes from his head and has the circumference of a half dollar. Because of the tumor, he is always freezing cold. Twenty-four hours a day, the light heater is on to warm his body. Even a slightly cool touch of the hand is too much for him to bear. Because of the tumor, Uncle Johnny's left side has languished terribly, and he has lost complete control of his left arm. His slow, deliberate movements remind me of an old elephant, or maybe an 80-year-old grandfather.

Victoria Y. M. Fan, Massachusetts Institute of Technology, Department of Anthropology and Mechanical Engineering Undergraduate Program, Cambridge, Massachusetts.

It is my second night shift as a volunteer in the Heart Lotus Palliative Care Unit, a hospice in the Buddhist Tzu Chi General Hospital. I have delayed starting college to volunteer in eastern rural Taiwan for a year. Since I was 16, I have wanted to be a full-time volunteer for at least a year before I go to school.

I check to see that the blankets cover Uncle Johnny's body while quietly humming a lullaby. My hands softly press and push his neck and shoulders, where he says it aches. Approaching the bareness of his neck, I smell a familiar odor—musty and stale. I smelled it once before, among the patients in an AIDS community in Thailand. Perhaps it is the smell of the dying. In Thailand, the smell was much stronger.

Was it really a few months ago that I had visited Lopburi, that part-hospice, part-community for about 500 social outcasts with HIV/AIDS, that place where no one is wanted? Kate, a friend and fellow volunteer, and I traveled from Bangkok to Lopburi for a few hours, bumping along down dirt roads, seeing sparse huts and plentiful grass fields enveloping the community. Could the location be any more remote and isolated, I wondered?

In the morning, Kate showed me around the community. “Every day, at least three people die here. Sometimes, you have as many as six or seven,” she informed me. “Then the coffins stack up high in the wards.”

We saw bony, naked corpses left out as an exhibition to show just how many people were abandoned and unclaimed. We saw endless piles of unwanted ashes of unwanted people. In the wards, we saw scores of bed-ridden patients with faces twisted in pain and suffering. As they stared blankly at the ceiling, I sensed a silent desperation, as if death could not come soon enough. Most patients had probably been rejected both by their families and society at large. Of the hundreds of people living in Lopburi, nearly all had no family by their side.

Although there were so many patients, there were only a handful of caretakers. In total, there were probably 10 volunteers from places like Holland, Japan, and America. “Pain relief” in the hospice, Kate told me, consisted of Ben-Gay ointment, as there was not enough money for medication. At least there was a place for these people, I consoled myself. It was better than the polluted streets of Bangkok.

In the afternoon, Kate and I ventured again into the wards to massage patients. Kate asked me if I was ready to begin. I confidently replied that I was. The weird thing was, I rationally knew that approaching the patients was not a problem. I had learned about the ways one could contract AIDS, and massage was not one of them. But somehow, seeing what seemed to be a sea of patients, bed after bed, I noticed how my hands—and my heart—hesitated. I suddenly felt afraid of this terrible disease. I took a deep breath and forced myself to begin.

As I massaged my first patient, a nearby sound of gasping caught my attention. I glanced over to the neighboring bed. Wearing only a shirt and a diaper was a stick-thin woman in her 30s. I still hear the sound of her breathing—the sound of gasping for air, the struggle to breathe in and out. I wanted to stop massaging my patient and attend to the auntie, but I told myself to finish the job well first. Kate went over, gently touched the auntie's shoulder, and bent over to hear her. She murmured that she was in great pain. Kate spoke a few words in Thai and quickly notified the caretaker at her desk. Kate told me that there was nothing we could do, so we went back to massaging our original patients.

Not long after, the sound stopped. The breathing stopped. It just stopped.

The Buddha once said, "Life lies in the space of a breath." How could I have known that she would leave so suddenly, that life held so much impermanence? As Kate went to tell the caretaker, I looked around frantically, wondering what to do.

A few minutes later, a caretaker came with another AIDS patient, together carrying a large wooden coffin into the ward.

"There are not enough people to care for the patients, so other patients must help," Kate answered my silent question.

They placed the wooden coffin down in the ward. Here is a coffin sitting in the middle of this ward where all the patients can see, I repeated to myself, as if to make it sink in. I don't think the patients even noticed the coffins. They just kept staring blankly at the ceiling, motionless. It was probably just another day in Lopburi, except that it was not their turn to go.

The two workers stripped the patient's clothes off quickly. The caretaker held a horrifically large pair of metal tongs and began using them to stuff cotton up the woman's orifices. "It's to prevent further contagion," Kate explained. I flinched as I saw the motion of the stuffing and momentarily forgot to breathe. I stared at the young caretaker's hands as she did the stuffing, swiftly and deeply. It was like stuffing an animal. She had done this many times before. Shouldn't we take a moment to pray for her? I thought, steadying my breath as the caretakers moved so nonchalantly.

"Do you want to try it?" Kate asked me, referring to the stuffing. I lifted my eyebrows and my eyes widened instinctively. I took a deep breath and automatically lifted my hands as if pushing away. "Maybe next time," I said.

She gave me a warm and understanding smile. It all seemed too inhumane, too horribly routine.

After the stuffing was finished, they proceeded to put a clean set of clothes on the woman. The assisting patient lifted one leg, put on a sleeve, and dropped the leg. Bang! The patient's heel hit the bed. Bang! Her other heel hit the bed after the assistant dropped it. Even though I knew the auntie was dead and could no longer feel pain, still I froze again, seeing the assistant treat a dead body as if it were nothing, as if it had not so recently held a life.

I wouldn't even treat someone alive like that, I thought to myself. What is wrong with this picture? I could not

stop my racing mind. She was just alive, I thought to myself. She just said that she was in pain. She was alive, moments ago, but now she is dead. What can I do? What must we do? What hope can they have, this ward of fifty patients, just lying here and waiting to die? I felt I had nothing to offer them. It seemed that the trip was so hopeless, so pointless. My attempt at "caring" seemed entirely artificial; all I did that day was walk around, smile, give a few massages, and soon I would go, leaving behind nothing.

All at once my racing thoughts stopped. In that mental space, a gentle voice inside my head slowly emerged. To others, this dead woman was nothing: her life was devoid of value. To others, she wasn't even a person. She not only died in great pain but also was left alone without a soul by her side and without the thought that someone cared. She was probably unwanted by anyone, considered the garbage of society and discarded from the world she once knew. After she died, she was also treated with little respect. She passed away just as she had lived, barely human.

Finally, I mourned silently for her. Because of my own neglect, I missed the chance to simply hold her hand, to console her fears. I had been too late. I could only give a silent prayer that she was in a better place.

I suddenly refocus my attention to Uncle Johnny. "Is this okay?" I softly say, referring to my massaging. He nods and uses his right hand to express "thank you" in Chinese sign language. He smiles, "Stop if you get tired."

In only a few minutes' time, I traveled to two totally different worlds. I look around this ward: blankets, a light heater, curtains, an electric bed, a call button for the immediate attention of a nurse, a doctor on-call. Every day, the attending physician checks on Uncle Johnny, nurses attend him in regular shifts, nurse assistants help to

clean him. There is also a special bath and shower facility for bed-ridden patients and a massage room for family members. There is a kitchen, a living room, and an entertainment room, just like in one's own home.

Then I check the visitor's bed next to him. Yes, his affable gray-haired mother sleeps next to him, like she does every day. His adorable eight-year-old son, other relatives, and friends visit regularly, too. And several volunteers like myself work in the 18-person hospice every day. The sound of laughter is common, and there is a palpable joy on everyone's face every day, even those who are dying. This, I say to myself, this is the peace that I hope everyone, myself included, can leave this world with.

Uncle Johnny and that nameless auntie had much in common, though they come from different parts of the world. They were both relatively young when diagnosed with incurable and painful diseases. They both had ordinary lives and regular families before they got sick. And they were just people who, like me and everyone else, hope for the care and love of others.

Yet, I can't help make the comparison. After I glanced into the fearful, pleading eyes of that auntie in Thailand, I can never forget her empty sadness. Like the 3 million other people with AIDS who die every year around the world,¹ the auntie was a victim not just of a horrible disease but of a deprived socioeconomic world. Perhaps she was sold into prostitution or forced to stay in the business just to survive each day. Perhaps she was pressured into drugs. Perhaps she was born with HIV or infected by her husband. Rejected by her family, society, and even welfare agencies, all she had was that secluded place, Lopburi, and nothing else.

But in the bright, wide eyes of Uncle Johnny, there is hope. When he dies, he will know that the people around him love and respect him. He will leave this world affirmed as a human being—intrinsically worthy of love and respect.

If not Ben-Gay or even analgesics can remove the pain of dying, how can one leave this world in peace and joy? We cannot predict when we will die; we only know that we will. So all we can do in the meantime is to do our

best to make sure that everyone around us feels our care and knows that it has no conditions, no demands, and no expectations for return.

I will not let that pressing question, "What can I do?" bring me to despair, too. This world full of endless suffering, will not daunt me. It is the question that calls me to action and awakens me from a paralysis of fear and doubt. I am a witness. I'm a pair of gentle hands, a smile, a kind word, a loving embrace. Even though I may feel powerless and useless, even though the problem is larger than mere individuals, and even though I am just one person, just an 18-year-old high school graduate, I must believe that I can offer my fleeting life to others, those who suffer and those who are dying. This is my sincere prayer.

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