Compassion: A Two-Way Street?

Category: Stories
written by Carey Candrian | March 16, 2018

Carey Candrian ~

I am an assistant professor of health communication. Since 2008, as a volunteer, educator and researcher, I have been active in hospice care. As many people know, hospice teams (nurses, social workers, doctors, chaplains, volunteers) help dying patients and their families live as fully as possible during their remaining days together.

In November 2016, right before the presidential election, I started a project aimed at identifying the best practices in communicating about hospice to prospective hospice patients. The intent was to help them make an informed choice about whether or not to enroll.

For six months, I observed hospice nurses, patients and caregivers during prehospice consultations, and interviewed most of them.

I saw a wide array of patients—families, single, divorced, undocumented, gays, straights, African-Americans, Native-Americans, homeless, ex-prisoners—and in many settings, from homes to nursing facilities and hospitals.

Starting out, I knew already that compassion is intrinsic to hospice care. No patient is turned away because of race, sex, age, gender or ability to pay.

But after the election, I became keenly aware of just how many patients, caregivers and nurses harbor social and political values that differ starkly from my own. This raised a series of internal dilemmas that I'd never imagined possible.

To illustrate, here is one of my initial visits.

November 10, 2016: I read my first email of the day.

Hi Carey, we have a hospice visit this afternoon with Becky (RN). Let me know if you want to shadow. Notes about the patient are below.

I scroll down.

Mr. Banks is 75 years old with prostate cancer and no longer seeking treatment. Wife would like to talk about hospice.

"Sounds great," I type. "I'll see Becky at 4."

3:30 pm: "Take a right on Bolton Road and proceed for one-point-five miles," my GPS says. By the roadside, I see one Trump sign, then another. "In a half mile, take a right on Lilac Lane; your destination will be on the left." As I pull up, two more signs pop into view.

Becky is in her car, reviewing the patient’s chart. She waves me over.

“He went to the doctor last week and was told that the cancer has spread,” she says. “They’re worried he doesn’t have much time left. His wife and dog are inside, and he’s a veteran.” We head for the house.

“I’ve been waiting for you!” Mrs. Banks says, opening the door. An excited Labradoodle leaps up on us.

“Down, Ruby, down!” Mrs. Banks says. “Take the stairs, turn right, and then you’ll see Johnny.”

His room is filled with displays of war medals, American flags, family photos and a gigantic TV screen. Mr. Banks lies on a hospital bed in the corner.

“Sit down,” Mrs. Banks says.

“My man, my man!” Mr. Banks says as Trump flashes across the screen.

For ninety minutes, Becky talks with Johnny and his wife about where they are in the illness journey, what they want, what they need and how hospice might help.

Becky listens to their stories (“We’ve been married for fifty-three years…We go to Hawaii every summer; this year we’re bringing our grandkids”) and never rushes. She hears their fears (“I was exposed to Agent Orange in the military, and I’m a decorated vet, but this illness scares me more than anything”) and never judges. She understands their goals and wishes (“I don’t want to be in pain…I want to die at home, with my wife and kids”) and offers solutions.

After discussing everything with Becky, Johnny and his wife decide to start hospice care.

The word “hospice” comes from the Latin *hospes*, meaning “guest or stranger.” In short, hospice takes care of strangers, no matter who they are, where they are or what their illness.

Paradoxically, *hospes* also means “host.” I’ve realized that my fellow hospice workers and I haven’t talked much about how we “hosts” fit into the equation—and how, exactly, the guests and strangers may view *us*.

I’ve gone into houses that feature Confederate flags and Trump signs. I’ve felt less safe there than in some homes racked with squalor and inhabited by ex-prisoners.

Why is that?

Because I’m a woman. Because I’m gay. Because I’m married to a woman who speaks English as her second language.

Walking into a house and knowing that its residents have voted for someone whose stated beliefs deny my basic humanity and worth as a person, I feel it in every cell of my body.

Do I ever choose not to enter one of these houses? No. Because I know that, even in these places, a transformation can take place.

As soon as I enter a patient’s space, I look into his or her eyes. Not a fleeting glance, but a long, steady gaze, as if I can see into the person’s mind, and vice-versa.

In this moment of deep connection, nothing else matters—and something palpable happens. Something shifts, and something softens.

Meeting a stranger made vulnerable by illness, I see something so real: the deeply wrinkled skin, the faded brown freckles, the oxygen tank and foggy eyeglass lenses. I see the arthritic hands, the bony chest expanding and contracting, the eyes slowly opening and closing as the head twists towards whoever is speaking.

I start to hear things differently, too.

“We’ll be married sixty years in April.”

“The pain is so bad, I pray I don’t wake up in the morning.”

“Losing my mom will be tough, but not as tough as burying my own two kids in the Eighties.”

“I’ll lose my job if I miss another day being here with my dad.”

“The hospital says they can’t do anything more for me.”

When we talk about something as fragile and meaningful as the end of life, it’s as if that simple act has the power to tame hate, to tame judgment, and all the noise that goes with them.

I don’t fully understand this mysterious power, but I know that it’s real—at least, for me.

I felt the softening happen as I listened to Johnny and his wife talk with Becky, and as their eyes met mine. The stereotypes I’d slapped on them slowly unraveled. They, in turn, responded with gratitude and appreciation to us for being there, for listening and for helping them get the care and support they needed.

Feeling their humanity so profoundly, all the while knowing that they might not accept mine, creates an enormous tension within me. And it raises many questions.

Must we talk about something as momentous as life and death for our differences to melt away?

When I give patients like Johnny my compassion, can I hope that it will be reciprocated?

What happens if, when we look into each others' eyes, my anger and resentment turns to empathy, but his doesn't?

And when I give compassion freely, knowing (or fearing) that it won't be reciprocated, what does that do to me?

For caregivers facing this situation, *is* compassion, in fact, the best practice?

What can we ask ourselves to give? And what can we expect in return?

About the author:

Carey Candrian is an assistant professor in the division of general internal medicine at the University of Colorado School of Medicine, in Aurora. Her book *Communicating Care at the End of Life* was published in 2014, and her works have appeared in newspapers and medical and social-science journals. "During my training as an ethnographer (one who studies people and cultures), I was taught to write about everything: what I was hearing, seeing, feeling—even what I was smelling. I also learned to write about what *wasn't* being said, felt, seen, heard or understood. My writing tries to give voice to these silences as a way of rethinking how we care for one another, and vice-versa. I felt compelled to share this story to illuminate the challenges of responding to differences with empathy—and the need to do so, now more than ever. On a personal note, I love being with my family; I also love yellow Labs, the Mediterranean Sea, tall mountains and *paella*."

Story editor:

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