

What My Dying Father Taught Me

By Colleen Corcoran

That which chokes one person can save another. And that which saves one person can choke another. That same sip of water that eases one person's suffering—that soothes, lubricates and demonstrates care for the most basic of needs—can stifle and end another individual. They choke. They are suffocated. They are not heard in our well-intentioned efforts of kindness. What can be vital to another to sustain life, can drown another. These definitions, these experiences are in constant flux, as are our perspectives in them. Sometimes it takes a pandemic and all that is uncovered with it to make us truly question everything, including how we define even our most basic of terms.

I lost my father on March 29, 2020. He died alone, very early in the morning hours. I like to think he passed as the first pale orange streaks of sunrise stained the sky. He died in the dementia wing of a nursing home where he had only recently been placed with advanced Parkinson's disease. For me personally, this was the worst-case outcome. I became a healthcare provider with one mission: to stop people dying alone, and to reform how we die in this country. I have a more elaborate personal mission statement than that, but it all really boils down to helping people die better. The one person I was not able to do that for was the one that mattered most to me, my own father.

My declarative statement on this experience is built on the presumption that I know better, that I know better how he should have died, and that I as a clinician know the best outcome. But this man was not my patient, this man was my father. And my presumption that I know better as his daughter also doesn't ring true in this case. The hard truth of the matter is I didn't and don't know better than he did for himself in either role. What would have been the greater suffering? For him to die alone as COVID-19 restrictions fell hard and heavy, severely limiting any human interaction with the outside world, or for him to go on and on in it, miserable and as he was at the time, constantly plotting escape and speaking to how much he hated his life. What is the successful outcome in such a case, if it even exists?

He had been telling us and showing us for a long time he was ready to die. We just weren't listening. We are a large family, and as is so common in such cases, everyone has an opinion and not everything is as everyone would wish it. Slow death and ambiguous loss like that which is seen in cases of Parkinson's disease or Alzheimer's, is very difficult for everyone involved to navigate and endure. For my father, at the time of his death, his daily life was a fresh pain and the constant and continual loss of no one coming to see him. With this total loss of interaction came a diminishment of any tangible strings still tying him to his life and who he was, he became very quickly lost physically and in time. Any sparks of his life that he could verbally and viscerally trace back were now veiled in a quarantine he also couldn't recall, and his spirits waned in kinship with his physical being. His life had become untraceable to any outsiders, and he was the only insider.

My father's last words were "I have a plan," spoken to my mother on the phone in a rare conversation at the time. And he did indeed have a plan. He died a few hours later after a restless night and some peaks of lucidity he hadn't seen in many, many months. This was his successful outcome, though not by any of his medical providers' definition, and not by my own, neither as a daughter or a medical provider. His death didn't seem like a real ending. No ceremony or demarcation of his life was possible due to pandemic restrictions and my family being dispersed all over the country. I returned to working with patients, so many of whom brought to me their own stories of loss and death and endurance in the ongoing pandemic. In all these intakes set amongst the backdrop of a call to social justice long overdue, and growing public health awareness, the way a "successful outcome" is defined has continued to gnaw at me.

The present times challenge us all not just to redefine our terms, but to also at times not define them at all, instead letting the person most affected, the person living it, define their own terms. They are, like my father, the insider of their own health narrative. The human story has the power to empower, and the power to transform both its teller and listener in the best of circumstances. In the case of clinical practice, this opportunity comes in the intake. If I think I know what the terms mean already, if I come in already knowing what a successful outcome means for this patient, I could be wrong. One of the gifts of working in Integrative Medicine is I have the gift and luxury of a bit more time with my patients. But if I fill that time with proverbially offering water because I "know" the human in front of me must be thirsty, I miss the mark. I miss the mark diagnostically, and I miss the opportunity to learn who this person is and what their definitions of health and life are, in their own terms. What is their own successful outcome, and do they even need or want a drink?

In Traditional Chinese Medicine, we utilize observation keenly in our patient intake, to listen, inquire, smell, palpate, and observe with openness is key to how we hear the language of the whole body in both the words spoken out-loud, and all the non-verbal cues expressed in softer tones. But none of this training matters if I turn a deaf ear or enter a closed-door definition onto my time with my patients. It would be easy to think working on the fringes of standard care practice at a hospital system in Integrative Medicine, it is easier to hold an open-ended question with patients. But I am human, and find myself presuming I know what the best outcome is and what my patient means when they try to tell me what their terms are for them without always taking the time to really find out. I presume the answer when I ask the question at times, and the world we are living in now is begging me, all of us, to stop doing that. Instead of already knowing the best outcome, or how a patient is experiencing a process or pathology, let them tell us. Let the patient tell us their version of a successful outcome. And hear it.

For my father, his best successful outcome was death. His body and his words had been speaking this truth for a very long time. We just couldn't hear the sound through the noise, not his care providers, and not his family. He had, for a very long time, been trying to tell us that the very water we were offering him to save his life, was in fact choking him, and his words. The best thing I can do to move forward, to honor his living and his death, is the work of listening, the work of dropping the presumption in all ways that I already know. If there was ever a time to better learn and apply this skill, to be open, it is now. Because none of us want to be the well-intentioned provider, offering life-saving water to an already choking patient, now drowning in our efforts of "knowing what's best."

Colleen Corcoran practices in the field of Traditional East Asian Medicine at the University of Kentucky Integrative Medicine & Health. Prior to being in medicine, she had been in the arts with a BA in English Literature. “My heart is in combining it all to honor the human spirit and the story the body tells,” says Corcoran. Her Field Notes essay “What My Dying Father Taught Me” appears in the Fall 2020 *Intima*.

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