“Not a Colon Cancer Patient but a person”

Tess Cersonsky, Teaching Assistant

American Studies UN3930.6: Life at the End of Life, Palliative Medicine and Service

Final Reflective Paper

“Sometimes you have to accept that you’re a colon cancer patient. Don’t sugar coat a diagnosis, don’t sugar coat death.”

These are words, paraphrased, that I heard in one of the sessions of American Studies (AMST) UN3930.6: Life at the End of Life. This class is unlike any I have ever sat in; I don’t often cry in class unless I’m overwhelmed by the amount of orgo work I have to do, or if I haven’t slept enough and it’s cold outside and I end up crying anyway. I am not volunteering, and therefore I cannot imagine the emotional experiences of others in the class. I can’t know what it feels like to sit with residents at TCC for four hours per week, if it is overwhelming or fun or upsetting. I do know what I experience in class; I sometimes find myself in intense conversations but more likely think so much about whether or not everyone is engaged in the conversation. There are times that certain lines stick out to me, though. And the line above, does so incredibly.

Our minds have a tendency to gravitate towards what we know. I am a musician, so when someone starts discussing musical theatre I listen more. Our brains are sensitive to those things we already know, making neural connections between what we know and what we are learning. Spontaneous release of neurotransmitters from presynaptic neurons strengthens neural connections to increase neural plasticity.¹ So it is inevitable that, when a speaker in our class

¹ http://news.mit.edu/2015/brain-strengthen-connections-between-neurons-1118
brings up “religion” or “chronic disease” or “colon cancer” or any other variety of topics with which I have experience, I follow these words and phrases closely.

This leads me back to the original quote. When I was 11 years old, my father was diagnosed with colon cancer. He died when I was 14, and those neural connections linking topics such as colon cancer, death, family, etc. are still strong even 8 years later. So, I perked up and took note of a mention of this specific term. Since I don’t have TCC residents with whom I can empathize, I turn instead to a patient I knew: my father. In this paper I will attempt to uncover the connections between my understanding of my father’s illness with the person he was, as, contrary to the quote above, he was defined by both his diagnosis and his personhood, but neither descriptor fit him alone. Through an analysis of both my experiences in class and some papers of my dad’s from 1968, I will attempt to understand the individuality of this person I knew so closely in order to bring that awareness and empathy to those for whom I will provide emotional and medical care as a future doctor.

Part I: What I learned from my dad’s essays

My cousin sent me a folder of papers from my grandparent’s storage bins, full of report cards and kid’s art and tons and tons of homework assignments. Most of these point to a smart but mildly disorganized 15-year old young man in senior year of high school (he skipped two grades). I found something that spoke to me more than anything else - 12 pages of reflective essays written in 1968 “In Partial Fulfillment of the Requirements in English 4X.” I did not anticipate what would come next:

One of my main concerns is the prospect of death. Pain is not my worry. My concern is where my brain stops what will there be. I cannot see that nothing follows. This prospect, although possible, is not anything to look forward to, and I do not consider myself a fatalist. So I much imagine an afterworld. But what kind of afterworld?
I couldn’t believe it; my father, at 15, talking about death candidly and openly, with such reflection that I hadn’t even gotten close to until I was almost 21. No one talks about how scary death is, and yet, here it was, the words of my dead father talking about death. My dad was diagnosed with Crohn’s disease (a disease I now also share with him) when he was much younger than this, and he had already had a surgery to ameliorate the symptoms. So here I attempt to understand: what would it have felt like to be 15 and young for your grade and always sick, always dealing with some disease you can’t understand because even now, 48 years later, we barely understand it. I know how frustrating it is for me, but how frustrating could that have been to be so young and so sick? It is inevitable that one fears death when faced with serious illness at such an early age. But I couldn’t imagine facing that fear so openly at 15, just about the same age I was when my dad died. Talking about death, about that taboo, was scarier than death itself.

I would have thought that writing about this would have also scared me beyond what I could imagine. However, my time at TCC made that less difficult. At TCC, you can’t avoid chronic illness. I tried to avoid it because I found it hard to face, and that made me even more anxious. When I finally faced it and allowed it to let me face my own mortality and life, it allowed me to be happier. It’s easy for me to say that I avoided chronic illness because I wasn’t the one experiencing it. But when we think about those experiencing it, we have to realize that they can’t ever avoid it. My dad seemed to sum that up quite well:

My concern of death is not only for myself. I worry for others. I have never lost a close relative, but I worry where they will go when they die? Will life exist for them, or will it be like that second of anesthesia during my operation - only not for a second but for a much longer time - indefinitely. I am thoroughly concerned about death, but I will live my life to the fullest and let it come when it may.
We can’t know what death is like, just like I can’t imagine what anyone reading this is thinking while they read. But my main concern here is that my dad did not define himself by the notion that he may die someday. Like me, he probably feared that it would come sooner rather than later because of our chronic illnesses (he died at 58). But he said “let it come when it may” and continued to live. When he had cancer, he did not let that define himself either. He grew a beard and having cancer was another part of his identity, but not his entire identity.

He wrote about many other things, from love to prayer to God to capital punishment to happiness. Death and illness were only a portion of my dad’s journal. He spoke mostly of finding happiness amidst all of those things:

I must here state my purpose of life. Before, I have said that I will live it to the fullest. But this vague statement does not express my complete emotions. I strive for what the Peanuts characters are always exhibiting - happiness. How to achieve happiness is another point entirely, though.

We search for achieving happiness because illness does not define everything. That is incredibly easy for me to say, though, because, even though my own illness runs much of my life, I do not live in a place where I am sick and have few other choices. This is, from what I understand, what it is like at TCC most of the time. I haven’t been there in quite a while, but, like a hospital, the medical feeling permeates. So it must be difficult to separate one’s life from their illness if they are constantly faced with a medical environment.

I’m getting off track. What am I learning from these essays? This feels like I am reading a deep historical memoir, but for the first time ever, it no longer feels cold and old. It feels intimate and meaningful. I see myself in this, and it feels like I’m talking to a friend. One of the hardest things is that it only makes me want to get to know him more. I think we would have been able to talk about mortality and life on a level that is not often achieved by others.
I feel like I’m reading the diary of Anne Frank because it is written so well, and so meaningfully. But unlike Anne Frank, I knew this person, but I didn’t really know him. Reading these essays makes me realize how little I knew of the person I called Dad, and how much I now want to know. I can’t regret not knowing more because, after all, what emotional intelligence or maturity can one expect from a 14-year old? There is no regret, only sadness that I can’t be friends with this person whom I am just discovering is more than a collection of stories or half-formed young memories.

I am amazed at how much of his thoughts are so close to my own. I know I am genetically half-my Dad, but this feels like I am connected by more than genetics. I am brought closer to him through a shared consciousness, a shared being, a sense of people who are close but individual and influencing one another regardless of current plane of existence.

Part II: What I experienced myself when my dad was sick

I have to reconnect the world from 15-year old Jeff Cersonsky to 14-year old Tess Cersonsky. I have never before critically reflected on what it was like to take care of my father in the last days of his life, but I think that this helps make the connection between the personhood that still existed and defined him in conjunction with his illness.

When I was about 13, I started taking care of my dad. I stayed home from school one day because he had a pinched nerve. It felt oddly protective. I had never seen him so vulnerable, and I can’t think about what that must have felt like for him. He was a 58-year old pediatrician under the care of a 13-year old middle school student. I had no clue what I was doing, but it seemed to be pretty okay. It felt like I was helping him in whatever small way I could, which not only provided me with the confidence that I could indeed help people and do something good in this world, but also helped me connect with my dad on more of a peer level. Sure, I couldn’t possibly
say I was as medically astute as him (I’m still not as medically astute as he ever was; a lack of medical school training tends to do that) but he treated me like a peer because maybe that’s the only way that he could reconcile his youngest daughter treating him.

Is that why we make connections between ourselves and residents? If they share their lives and we share ours, then we can be more like peers. That seems absurd; how could I be a peer of a 90-year old? Or a 50-year old patient with diabetes? Is it appropriate to see oneself in that way?

Maybe the answer lies in what we learned about as “emotional intelligence.” Emotional intelligence is a broadly defined term, but one of the most concise definitions given is “a set of abilities (verbal and non-verbal) that enable a person to generate, recognize, express, understand, and evaluate their own and others’ emotions in order to guide thinking and action and successfully cope with environmental demands and pressures.” The idea is not necessarily that I am a peer of a 90-year old akin to my status as peer to my classmates of the same age or generation or grade level, but I am a peer of emotions. My emotional or psychological state matches with another at a given time and place, providing a link through which we can establish a shared empathetic consciousness. With that empathetic consciousness comes a sense of understanding that makes it easier to bear someone taking care of you. I can think about how, although my doctor has much more training and knowledge than I do, if he relates to me on the level at which I am, as a college student with a chronic illness, then I feel more at ease with his advice and treatment.

My dad went through a lot of treatment between 2005 and 2009, much of which I did not know all that much about. I knew he had a portion of his colon removed and had an ileostomy

---

bag; I knew he had chemo and radiation and many other things. Maybe it is a testament to my age and lack of understanding and maybe it points to his persistence in all things that defined him besides his cancer (being a doctor, parent, friend) but he did not seem to me to only be a colon cancer patient. I saw mostly everything but. It is probably the blindness of youth that led me to that, but nonetheless it defies the notion that in order to accept one’s diagnosis, you must see yourself defined by it.

In late February 2009, my dad came home on Hospice care. I had never heard of this before and yet it was now in my study where the piano once was. I remember lots of family around, the principal of my middle school coming to my door (that’s a fun story), and lots of pizza. I also remember wanting to help, but my uncle’s wife stepped in because she was actually an MD. I didn’t really know what was going on, and I still don’t. But I think some of the confusion of this time was important. If I was 14 and completely comprehended the situation, it would have overwhelmed me beyond anything else. I was no longer in a state where I could operate as a peer or have any empathy. My dad was comatose by now, and the shift turned to me from caregiver to one who needs care. I stepped into the role of someone who needed to be treated, which I can only understand now, even though those who were around me could tell right at the moment.

Part III: What I learned from the class about it all

As I’ve said, I’m not volunteering, so I can’t imagine what it is like to be in the minds of anyone volunteering. Regardless of whether or not I’m volunteering I can’t even do that anyway, because I can’t be in the mind of anyone else. I can, however, try to empathize. If this class has taught me anything, it is the importance of empathy.
Empathy is what my family and friends tried to bring to me in 2009, but I’m not sure if I had empathy on my mind when I was taking care of my dad when he was sick. Maybe it was there, but I couldn’t quite realize it. I cared about helping him feel better not because I had some paternalistic view of the situation by which I needed to be a savior, but because someone I cared about was in pain and I could feel that pain too.

Do we need to be aware of being empathetic in order to do so? I think about being 13 or so - how could I have possibly understood my empathetic role in the relationship at the time? I argue that, no, we do not need to be aware of empathy in order to be empathetic. But then do we reap further benefits and “increase” our empathetic abilities if we are indeed aware of it? I honestly do not know, and I do not know if I could ever find out. I could maybe measure how emotionally fulfilling a situation is when I am aware of empathy, but how could I do so in a situation in which I am not aware of my empathetic nature? It is not a scientific study that one can perform, although one rarely performs scientific studies on themselves (or at least I do not in the sense of identifying and studying an independent variable). Nor is it a scientific study that one could perform on another, because how indeed would we be able to measure the empathetic nature of another person without being in their mind or revealing to them that they are being empathetic? It is a paradox, but we must question whether or not we need to attempt to solve it. What benefit would come from understanding empathy in such a way, other than to provide evidence whereby more people can be convinced of the importance of empathy in any interaction, whether medical or not.