The Last Line of the Story:

Reshaping the Conversation Around Palliative Care

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Class of 2023
Medicine is about healing. It’s about treatment, cures, and fixing what is broken. It’s about pushing the limits of biology, and promoting health and survival. So, what if I told you that one of the most endearing parts of medicine, for me, are the patients that we can’t fix? Would you think it was strange to be drawn to medicine, not only for the ability to help those who are sick, but to accept that fate can’t always be controlled by machines, technology, and medicine? Sometimes, our role as physicians doesn’t lie in another treatment regimen or blood test, but it lies in prioritizing the experience of aging and dying for what it is - an inevitable, meaningful end to a story. If we are lucky enough to find ourselves interspersed in the stories of our patients, it is our duty to redefine the conversation, and recognize that sometimes our job is much larger than we imagined it to be. Sometimes we must have the courage to face what is right in front of us, to understand that our purpose is not to bury ourselves in our own fears of what might make us failures in a modern medical culture. We have to recognize that our fears and our hopes are not what matters most. Sometimes we need to drown out the noise of institutions, clinical trials, risky treatments, and intensive care units, and we need to look at and truly understand the person who is in front of us. Because they are counting on us to shape the end of their story, and to do anything but allow them to remain the main writers of that story, would be an incredible disservice.

Palliative care isn’t something that is talked about a lot when you think of going to medical school. Isn’t exactly the easiest thing to explain to your family and friends that you want to become a doctor so that you can help people die. But something that has always been clear to me is that death is not really about dying; it’s about living. Palliation is not about making sure the patient has a “good death”, but it is about ensuring they live a good life, up until the very end. Of course, as doctors, we will be making it our lives work to help our patients grapple with illness, and what medicine can do for them. But we must also be courageous enough to help them deal with what medicine cannot do for them. We must be able to put our own hope, our own fear, on the backburner, and ask our patients: what are your hopes? What are your fears? We have to sacrifice our comfort as healers, as scientists, to make room for the discomfort in recognizing both realities in medicine. We are in a position of great privilege, and we must not abuse this position by refusing to sit with the uneasiness of decline and death. A dying patient should not be seen as a failure; in fact, the cruelest of failures would be a lack of courage to recognize the priorities of the patient as they extend beyond the hospital bed. We must not be reluctant to peel back the curtains and not only focus on the health and survival of the patient, but on maintaining the integrity of their life, their character, their desires, and ensuring they stay connected to what makes them who they are. Everybody has their own definition of what makes life truly significant, and who are we to take that away from them?

The discussion around palliative care is fairly novel in medicine, and my hope is that I will get to witness the shift in perspective that comes with the new generation of physicians as we are being trained to view patients, not as a function of their illness, but as whole, unique, complex human beings trying to maintain a sense of self during the scariest moments of their lives. I believe that medicine should be about communication, honesty, and how the illness impacts the person, not how the person fits into our ideas of illness. I am not saying we should convince patients to terminate treatment or die prematurely. What I am saying is that we need to widen the lens with which we look at the experience of illness, and find out what gives meaning to the lives of our patients and how we can use that to help them create their own path, un-obscured by deception or forced agendas. We need to listen to our patients, hear them, understand them, trust them, believe in them. To put it in the simplest of terms, patients are people. And sometimes people need a pillar of strength, a shoulder to lean on, a hand to hold. And if that is all we can do for our patients while we help them navigate their illness on their own terms, then I think that’s pretty special.
Something that I have really only thought about recently is that palliation has a place in all aspects of medicine. It doesn't always mean patients with incurable cancer or elderly nursing home residents. Palliative care, to me, doesn't even need to involve death or end-of-life care. Palliative care is about optimizing quality of life, and mitigating suffering in people who have complicated and serious illnesses. I think there is a large gap in understanding when it comes to this, because most doctors don't consider themselves to be palliative care doctors. But if palliative care is about the improving the quality of life for our patients, shouldn't we all strive to integrate palliative care into our work?

Palliation is really centered around culture. We must not neglect the fact that practicing medicine in a diverse society demands that we understand and take cultural context into account when we are trying to understand our patients experience. In particular, when we are dealing with vulnerable and traditionally under-served populations, we are often practicing palliation, and we must put cultural considerations at the fore-front. Patients who present with complex physical and mental health problems, are on income support, are low income earners, patients who are struggling with addictions, are victims of abuse or trauma, or are living on the streets. These are a population of patients who may come to us from a completely alternate reality and culture from what most of us are used to, and we must not put up even more barriers than these individuals already have to face. We must continue to truly acknowledge the right of the patient to define the end of their life experience from their own perspective. We must not shake our heads when homeless patients refuse to use in-hospital services. We must not get angry when a patient struggling with addiction misses their specialist appointment. We must understand that things like compliance and medication use become complicated when you have a homeless patient, or a patient who is struggling with addiction and substance abuse. Most importantly we must treat each patient as a unique case and understand that the complexity of their problems is much larger than us, and all we can do is be there for them. Many people say that you can judge a society based on how the most vulnerable individuals are being treated, and I believe that as physicians, we have a responsibility when it comes to ensuring that our most vulnerable patients are given the same chance to experience illness and the end of their lives with dignity.

I have learned a lot so far in medical school, like how to analyze a chest xray, how to listen to a patient's lungs, and how to do a differential diagnosis. But I truly believe that the most valuable experiences I have had so far stem from communication with patients. We are in a position of great privilege, to have so many people touch our lives throughout our careers. To me, that's what medicine is about, and that's what motivated me to get here. It's hard not to get lost in the world of exams, memorizing anatomy and learning how to perfect your percussion skills. But at the end of the day, medicine is about people and it is about connection. It is about checking your ego at the door, and recognizing that we have a role in somebody else's story, and we must take every measure that we can to honor that, without judgement. In 10 years' time, I am more likely to remember the first time that a patient felt truly heard by me, or the first time I am able to make a patient feel a little less afraid in a whirlwind of fear, than I am to remember the first time I put sutures in a patient. And maybe that is an obtuse way to look at medical training; maybe I am the exception and not the norm when it comes to what has driven me in medicine thus far. Maybe it is even a little strange. But, I know that I will spend my career feeling immensely grateful to have met so many people, to be lucky enough to know what makes them who they are, to have played a fleeting part in their story, but most importantly, to have allowed them to write the final line. And if that is strange - I am okay with that.