

Why Palliative Care Shouldn't Exist

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I had finished my "presentation" of my patient, in which we had discussed Tyler's plan for the day. Tyler was particularly medically complex, and it had taken over 30 minutes to review his treatment as a team. The most important changes to his plan that day included the following: (1) continuing to attempt intravenous placement with needle pokes in his arms and legs after multiple failed attempts; (2) initiating treatment with extremely strong antibiotics for a possible but unlikely infection, which would require frequent laboratory draws to make sure his kidneys were not damaged by this medicine; (3) sending him to the radiology suite for a special dye study to make sure that his feeding tube was working properly; and (4) checking his blood work 3 times during the day to make sure that his body's salts and sugars stayed in balance. As I presented, my fellow physicians reviewed their individual computer screens once more to ensure all of their orders had been entered correctly, clicking through the typical alerts as they popped up.

Tyler's father had been caring for him for his entire life, splitting time at home with his wife to provide around-the-clock care for the past 7 years. Tyler had never spoken a word, had never been able to walk, took all of his food through a tube in his stomach, and wore a mask to help him breathe at all times. As we went over all of the lines, tubes, and invasive tests needed to "optimize" his medical management, his father only wanted to know how to make him comfortable and continue to support him.

After morning rounds, I came back to talk to his father. Instead of reviewing each of Tyler's medical problems, we focused on what an incredible job his parents had been doing to make sure that he is comfortable, well cared for, and extremely loved. We talked about what it would mean for Tyler to get "better." The plan we had outlined that morning would fix the salts in his blood, treat any possible infection, find out if his feeding tube was working, and give us a way to give him medications to revive him temporarily should his breathing continue to worsen and his heart stop. When I asked what "better" meant to his father, he answered more quickly than many parents are able to, having had years to reflect upon this. "His mother and I want him to be at home with his family. We know that he is not going to live long, so we just want him to spend what time he has left peacefully." Tyler, after all, had been seeing the palliative care team for many years, with routine discussions on how to best honor his comfort and quality of life. When in the hospital, his father was used to an increase in intensive interventions with minimal improvement in his overall health. But when at home, he relied on regular phone calls to the palliative care team, with physicians, nurses, and social workers who discussed the cost versus benefit of each intervention, reflecting carefully on Tyler as a whole person. So, we started from scratch, looking at each "to do" for the day with a fresh set of eyes. Some tasks remained on the agenda and others were deferred because they might hurt Tyler and provide little improvement to his overall well-being.

During my residency, palliative care providers (true healers and expert physicians) have inspired my practice. There are few teams I respect, admire, and model my patient care after more than the palliative care team. In addition to

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important end of life conversations, palliative care doctors are called in to discuss complex medical issues, management of symptoms, and chronic pain control.¹ They center care on the patient and bring the focus back to the individual with a holistic approach to treatment that is tailored to a patient's hopes and dreams. Although some patients and families establish rewarding long-term relationships with palliative care teams, many see them, and have these issues addressed thoroughly for the first time, only at the very end of life.² However, as I have progressed in my training, I have become increasingly uncomfortable with the concept of palliative care as a consultant service. It seems hard to justify relegating tasks like difficult conversations about a patient's goals for medical treatment and how to manage complex and chronic symptoms to a consulting team instead of the patient's primary doctors.

In fact, modern, empathy-driven curricula in medical schools promote just this type of humanistic, individualized model of patient care.³ As students, physicians-in-training cannot wait for the opportunity to sit face-to-face with a patient and compassionately create a tailor-made plan of care to fit that patient's needs. So why, then, do we physicians find ourselves in a situation in which we delegate this essential doctoring task to a group of subspecialty physicians? I would argue that the primary reasons are time constraints in the setting of a dysfunctional health care system paired with a flawed understanding of the definition of palliative medicine.

As we all know, the past decades have seen a boom in the use of electronic medical records (EMR), a double-edged sword that provides equal parts increase and decrease in medical efficiency.^{4,5} As a resident, I can personally attest to days on the wards when I had to spend so much time at my computer that I was unable to carve out time for in-person discussions with my patients. Residents and attending physicians

alike are consistently frustrated with burdensome documentation, and it is clear that the majority of EMR use does not optimize patient care when the majority of a doctor's day is spent facing the screen and not the patient. The issue of maintaining the advances of EMR use while striving to eliminate its large function as a barrier between patient and doctor is a complex one, but one that deserves our full attention. We must understand that devoting our energy to reengineering this technology for improved physician use and efficiency is in fact a clinical endeavor, and one that it is essential to our daily work as doctors.⁶

But another issue, perhaps even more important than time constraints, involves a failure of the medical profession as a whole to truly grasp the meaning of palliative care. Many non-palliative-trained physicians still view palliative care as synonymous with end-of-life care or hospice. What is not understood is that palliative medicine simply refers to the art of tailoring a patient's care to best enhance quality of life as personally defined by that patient. In a world in which "goals of care" has become synonymous with do not resuscitate or do not intubate status, it is clear that we have yet to truly embrace individualized medicine. Although creating standard of care practices and algorithmic guidelines has had a tremendous impact on patient safety and represents incredible scientific advancement, it also has the potential to do harm when taken literally. Each patient is a unique human and may not fit exactly into the model of treatment proposed by a randomized controlled trial. And more importantly, the outcomes listed in a seminal paper may not be the outcomes desired by the patient. If we do not resist the temptation to follow evidence-based guidelines to the letter of the law, we run the equally dangerous risk of losing the art of medicine and forgetting our calling as healers as well as scientists.

This balance between science and healing, between art and medicine, is what palliative

care physicians understand and incorporate daily into their practices. Most patients and families understand what is important to them, but they do not have the years of medical training and knowledge to know how to translate values into medicine. That is the job of the physician, to incorporate years of medical education and scientific research into a personalized plan of care for every individual. In short, palliative care specialists do the work that all physicians should be doing, work that with proper system-based and medical training reform we are all capable of doing and that we are morally obligated to do. When my health is seriously compromised, I hope that there will be no need to consult palliative care on my behalf. Instead, I look forward to working with my palliative-trained primary team to discuss my individual goals and create a tailor-made plan of care.

REFERENCES

1. Center to Advance Palliative Care. About palliative care. Available at: <https://www.capc.org/about/palliative-care/>. Accessed February 8, 2018
2. Rodríguez KL, Barnato AE, Arnold RM. Perceptions and utilization of palliative care services in acute care hospitals. *J Palliat Med*. 2007;10(1):99–110
3. Gonzalez SC. Adding empathy to the medical school curriculum. 2015. Available at: www.tmc.edu/news/2015/09/adding-empathy-medical-school-curriculum/. Accessed February 8, 2018
4. Young K. Half of physician time spent on EHRs and paperwork. 2016. Available at: www.jwatch.org/fw111995/2016/09/06/half-physician-time-spent-ehrs-and-paperwork. Accessed February 8, 2018
5. McRae S, Hamilton R. The burden of paperwork. *Can Fam Physician*. 2006; 52(5):586–588
6. Verghese A, Shah NH, Harrington RA. What this computer needs is a physician: humanism and artificial intelligence. *JAMA*. 2018;319(1):19–20

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