

The Medical Commencement Archive

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Who Is Your Doctor?

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Thank you so much for giving me the honor of speaking to you today. It is a real privilege and pleasure. One of my mentors, Bob Klein, would always ask patients on rounds “who is your doctor”? The patient would often laugh and say they saw a lot of “white coats” on rounds but they were unsure if any of them was their actual “doctor”. He was lamenting the fact, now 35 years ago, that there was a lot of treating of disease in our health care system, but relatively few long-term committed relationships. When really hard decisions had to be made, the doctor – patient – family rarely knew one another well enough to allow the doctor to base recommendations on deep personal knowledge of the patient, nor was there enough trust to guide really tough medical decisions. There are still some doctors who step up in the modern environment to serve this role, and today I am going to strongly encourage you to eventually become one of those doctors.



Having trained in Rochester with its famous biopsychosocial model, you have many of the building blocks to becoming an outstanding physician. Technical competence is an absolute must. Although it is impossible to carry all of the ever-changing medical facts in your brain, you have also learned how to access the latest literature and apply them to your patients. Having trained in Rochester, you have also learned how to get to know your patient as a person, in context of family and broader life values. This creates a foundation for combining disease based decisions with person-centered medicine. This is particularly relevant as people get sicker and the treatments that are available have difficult burdens and smaller benefits. In such circumstances, patients and families need interpretation and real person-centered guidance as to tradeoffs between quantity and quality of life, and ongoing support no matter what course they choose. There are doctors within each field that you have been exposed to who have this important combination of skills. These are the doctors you would want to care for you or someone from your family if you get sick. Our fervent hope is that you will become one of these doctors over the next phase of your training.

How does palliative care, my main field, fit into this mix? Because the term is not well recognized by the general public, I will start for the benefit of your parents and family defining what it is. It is the biological, psychological, social, and spiritual care of patients with serious illness. Notice that the definition says nothing about end of life care or hospice, but rather it is a comprehensive approach to treatment directed to all patients with serious illness. Intensive pain and symptom management are cornerstones – people with effective management of their symptoms feel better, spend less time in the hospital, and are able to accept more aggressive treatments of their disease. But palliative care is provided alongside all potentially effective medical treatments. It also provides assistance with difficult medical decision-making. We talk with patients and their families truthfully about the tradeoffs of different treatments and the real odds of success, and try to help them make the best possible medical decisions in difficult medical cir-

cumstances. Some of our patients are getting the most aggressive treatments available such as transplantation or aggressive chemotherapy. Other times it involves a transition to hospice care when aggressive medical treatment no longer are effective or no longer meet a patient's goals. Most often it is given along side any and all effective medical and surgical treatments.

Recent studies with stage III lung cancer showed that palliative care delivered from the time of diagnosis alongside standard cancer treatment resulted in better pain management, less time in the hospital, and less futile aggressive care at the end of life - all of which were expected. But the surprising finding was that patients who got palliative care from the outset lived almost 3 months

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longer than those who received standard cancer treatment alone. That extension of life is the equivalent of a blockbuster new drug! It is not entirely clear why this happened. It may be that better symptom management allowed for more cancer treatment or, perhaps more likely, it may be that near futile aggressive cancer treatment near the end of life may shorten life more than it lengthens it. Numerous studies show that palliative care improves patients' quality of life and also saves money by helping patients and families make more informed decisions, and spend

less time in the hospital. Many of the most sophisticated health systems in the United States, including Partners in Boston, Kaiser, and the University of Rochester Medical Center, are investing heavily in palliative care as a way to improve quality and save money.

This raises the question: should you all become palliative care physicians? (Here most of the parents are saying “please no!” – that is not why we sent you to medical school!) But the answer to this question is yes and no. Very few of you will actually become palliative care consultants like me. Those who do will help manage the toughest of the cases - relieving hard to treat pain and symptoms, providing added support to patients and families in real medical crisis, and helping them make more informed medical decisions. It is very meaningful work, and the satisfactions are great, but being a palliative care consultant is definitely not for everyone. In fact, most of this work should be done by the main treating physicians

regardless of specialty. There is much too much need for such support to have a palliative care specialist involved in every case, and it would not be desirable even if we had sufficient specialists (which, in fact, we don't.)

Yet almost all of you will take care of very ill patients. The current medical model at its most extreme has a specialist tending to every organ system of a seriously ill patient, but too often there is no one looking at the big picture and talking to the patient and family about what is really going on. As you look to the role models who really stand out in your training, you will remember clinicians in every domain (whether it be primary care or each of the subspecialties) who were identified as the "main treating physician" – the one who engaged with patients and their families and helped guide them. This means not just providing patients and families with medical options, but making clear recommendations among those options based on their medical knowledge and their knowledge of the patient as a person. What would you recommend under these circumstances if this were your family member, your mother, or father, or child. That kind of guidance and engagement, which is both medically competent but also very personal, is what will make you a really exemplary doctor. It might be a primary care provider or it may be a specialist, but it is a clinician who engages with the patient and family and assists them in decision-making as decisions get tougher. The floor goes back to that basic biomedical competence, without which your recommendations, no matter how personal, will not be meaningful. But then engaging and guiding the patient and family in medical decision-making using both your knowledge of medicine, as well as what you have learned about the patient as a person is the best practice. You will be both a guide and a partner to the patient, getting help from other specialists when needed, but not shying away from this central role.

So when someone asks a patient or family member "Who is your doctor?", among residents and fellows, there are those who begin to progressively take charge, coordinating care, making key recommendations, guiding patients and families—caring that their patients make the best possible decisions, which make the most of the medical treatment possibilities in the context of the reality of their disease and their own personal values. I am urging you to become one of those residents, and eventually become one of those doctors who you would want to care for your family members or yourself if you got seriously ill.

How might this work in the complex world of biomedicine today? I am going to focus on two elderly patients with congestive heart failure who were being considered for a treatment that is one of the real technical successes of modern medicine – a ventricular assist device (VAD), which is a form of an artificial mechanical heart. On balance, VADs both improve quality of life and extend life, albeit at high expense, both economically and sometimes personally.

The first patient who I will call Mr. A was an 84-year-old man with very advanced congestive heart failure. He was very short of breath, and had been repeatedly in and out of the hospital for the last several months despite maximal evidence-based treatment of his heart failure short of a VAD. He was the main caregiver for his wife who had dementia. His medical choices basically were hospice versus trying a ventricular assist device. We were asked to do a palliative care consult to help manage his shortness of breath as a symptom and help with decision making. The heart failure doctor had been his main doctor for the past 5 years, and helped him work through this decision getting input from the cardiac surgeons and palliative care team. This was a high risk decision given his age, but he was a strong-willed person, otherwise generally healthy, and without his staying alive his wife would have to be admitted to a nursing home. He was willing to roll the dice and get the VAD.

He had a rocky initial post-operative course, but eventually recovered and regained his independence. During his surgery, his primary treating heart failure doctor and his palliative care doctor remained involved, though the bulk of the treatment was temporarily guided by the VAD surgical team. He was able to live independently for another 6 years. He kept his wife at home for 4 of those years before she died of dementia at age 90. He also had a range of very complex medical problems over that period including infections of his artificial heart, kidney problems and lastly urinary bladder cancer, which eventually was his demise. The heart failure team and the palliative care team worked together to help him live as well as he could for as long as he could. Toward the very end of his life, his heart failure doctor with the assistance of his palliative care doctor, both of whom knew him and his family very well, eventually helped them make the transition toward a purely comfort-oriented approach. At the very end, he was able to die very peacefully in the presence of family and the medical team who cared deeply about him.

Mr. B was another 80-year-old man faced with the same decision point based on his severe end stage congestive heart failure. His prior admissions were to an outlying hospital, and he too was receiving state of the science medical treatment for his heart failure delivered by his primary care physician. He was referred to our hospital to see if he had any other options. After being evaluated, he was also faced with the same decision about hospice or trying a ventricular assist device. Mr. B's social context was different from Mr. A's in that his wife had died and he had lived alone for the past 5 years. He had made a decision that he definitely did not want to undergo major surgery, but his children and the consulting cardiac team felt he was a good candidate for a VAD, and were surprised by his refusal. They tried (unsuccessfully) to convince him that it was a good idea. Palliative care was also asked to help him with the decision. We met with Mr. B, his family, and called his primary care doctor who confirmed that his saying "no" to the VAD was very consistent with this patient's past values and priorities. He was a very religious man who was prepared for the end of his life if it was his time. In this context, we supported his decision to not have a VAD, and referred him back to his primary care doctor and to hospice care in his own community. He continued his heart failure medicine, and had opioids available for shortness of breath, and returned to live with his children in his home town. He lived for another 4 months on hospice, and had an outstanding quality of life for that time until he died peacefully in his children's home.

Both of these cases had the marks of very successful medical care, and illustrate how personalized care and palliative care work together to help patients sort through their medical options. They also illustrate how having a doctor who knows the patient well guiding the process can make the care so much better. In the first case, the main treating heart failure doctor remained centrally involved at all stages. He started with state of the science management of his heart failure, helped him make the decision to have a VAD, helped manage his con-

dition after the surgery, and finally helped him through the final transition toward end of life care 8 years later. The palliative care clinician was also involved throughout the course of his surgery, recovery, treatment of complications, and eventual cessation of treatment. Other clinicians with special skill and expertise were called on along the way, but the patient and family could count on the presence of his main doctors at each phase. In the second case, the main treating physician was the local primary care doctor who sent the patient to the academic medical center to ensure that all options were being explored, and then received him back to oversee his hospice

care for the last months of his life. His doctor encouraged him to look at the possibility of very aggressive medical intervention toward the end of life, but also supported his decision to forgo that treatment and was then ready to care for him at home for his hospice care at the end of his life.

So after all this, what are my final works of wisdom to you, the Class of 2014: become one of those doctors who is not only technically very competent, but also very willing to engage with patients and families in difficult decision-making. Don't be afraid to guide patients and families, and tell them what you really think is the best course for them given your

medical knowledge and your knowledge of their values even in the face of considerable medical uncertainty. Patients and families are yearning for such help and guidance. In short, learn to provide the kind of care and advice you would like if someone you love and care about was your patient. You have seen many of your finest mentors do this, and it is your job to follow in their footsteps.

In closing, I want thank you for the honor of being one of your speakers. I hope that you enjoy the ride on which you are embarking, and implore you to take good care of yourselves in your next phase of training while you take good care of your patients!

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