Pioneers in Palliative Care

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Life Lessons in Palliative Care

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Be kind, everyone you meet is fighting a hard battle.

-John Watson

To practice medicine with a good spirit does not mean to be in a place where there is no noise, trouble or hard work. It means to bring your calm and loving heart into the midst of it.

-Rachel Naomi Remen

WRITING THIS PAPER feels a bit like the first time you are asked to write your own letter of recommendation. The first time I was nominated for an award, one of my bosses said that I should write the first draft because, "I knew more about what I did than he did." While that was true, I have never recovered from the uncomfortable feeling of writing a self-congratulatory letter.

I also feel guilty because there are numerous people who have done as much as I have to promote palliative care—who are much more deserving of the title "pioneer." In particular, I want to recognize the founding members of the American Academy of Hospice and Palliative Medicine who have toiled long and hard in the vineyards when the soil was really inhospitable: they are the true pioneers of palliative care. The ground that I toil in is a lot more fertile because of their work. Moreover, I have always felt that the real medical heroes are the thousands of full-time hospice and palliative care clinicians who provide superior care for patients week in and week out. What I do may be more public; it is clearly NOT more important.

Still, being asked to write this paper is an honor. I am also opinionated enough to want to share the lessons I have learned along the way. The lessons are simple:

- 1. It takes a village.
- 2. Set yourself up to succeed.
- 3. Be intentional.

First, a short biography is needed to provide some context for the lessons. My journey to palliative care while seemingly predetermined—has been circuitous. I decided to be a doctor after my older brother died of leukemia when I was four years old. As an undergraduate at the University of Missouri-Kansas City's 6-year MD/BA program, I fell in love with philosophy and decided I wanted to have an academic career in medical ethics and internal medicine. As a primary care resident

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at Rhode Island Hospital, I was exposed to what is now the American Academy of Communication in Health Care and found an incredible group of educators who taught me how to operationalize ethical theory into clinical medicine via communication skills. It was then that I decided to focus my career at the intersection of medicine, communication and ethics. During my RWJ Clinical Scholars Fellowship, I took a job at the University of Pittsburgh and I have been here ever since. Moving from ethics and communication (and HIV care) to palliative care seemed like a logical step.

Second, two caveats. As a male Caucasian, I realize that I have had many societal advantages not available to other physicians. I have not experienced some of the obstacles that others have and I am sure my list of lessons is incomplete. Third, I am an academic palliative care physician. While I believe these lessons are applicable to other settings, my recommendations should be taken as tentative suggestions as I am not so presumptuous to know the best way to develop other careers.

IT TAKES A VILLAGE

I have been lucky enough to have wonderful mentors throughout my career. Having good mentors in one's developmental years is critical to success. What is underestimated, however, is the need for a network of mentors and colleagues who can provide help and support in different ways. One needs senior mentors to teach content, to give career advice and to help make professional connections. Colleagues are critical for brainstorming, generating new ideas, and working on projects. Finally, as one gets older, fellows and junior faculty teach you new content and keep you on your toes. Every junior faculty needs two to four senior, and three to five peer mentors and colleagues who will serve as the village that helps them succeed.

While having great mentors is critical to one's success, it is not sufficient. My success has, to a large degree, been dependent on building a network of extraordinary colleagues. When I started to develop my interest in doctor-patient communication and palliative care there was no one at my university with similar interests. I decided I needed to identify colleagues who had similar interests and began to read abstracts from general medicine, oncology, and geriatric meetings. In my search, I read an abstract from a RWJ Clinical Scholar at USCF who was studying how residents talk with patients about code status. I called him and asked if we could work together. I have worked with James Tulsky for over ten years on the most important projects in my career. I would never have become a palliative care doctor if not for James Tulsky's urging that I apply for the Project on Death in America Faculty Scholarship and his wise advice on how to structure my application. This relationship taught me the importance of building a community and working with others wherever I find them.

My experience is that the leaders in palliative care are extraordinarily generous and, given the internet and multiple methods of communication, your colleagues can be anywhere. For example, seven years ago, I became interested in doctors' emotional reactions to patients' deaths and emailed Susan Block in Boston. She was willing to talk to me about the subject, recommend things for me to read and then, as we talked more, to work with me to publish a series of articles looking at how medical students and doctors react to emotional strains in professional practice. My advice is to actively look for the people who are interested in topics that excite you, and build your village. If you are working in a hospice, find the leaders you want to emulate; contact them and ask if you can connect and get advice from them once a month. My guess is that many will be willing to help.

It is not just professional colleagues who support you. My patients and my family have been crucial. I started my career in primary care and quickly gravitated to caring for HIV positive patients. I was an human immunodeficiency virus (HIV) doctor pre-highly active antiretroviral therapy (HAART), when all we could offer was palliative care. From my patients I learned the importance of presence and language. I will never forget the angry patient who told me that, "I did not fail my &*^%%\$! medicine, the medicine failed me." My patients, more than any lecture, taught me that when I ask, they will tell me what they need. They taught me that while I could not make everything okay, my being there was important.

About family and their importance to my professional life, words fail me. For better or worse, those closest to you are your best supports and your most honest critics. My children, for example, have taught me that the words I say do not matter as much as the spirit with which I say them. My wife has taught me what unconditional support really is. The best-laid plans will not work if those closest and most important to you do not value and respect what you value.

SET YOURSELF UP TO SUCCEED

It would be great if the world was a meritocracy. It is not. While hard work and being smart and productive is important, it may not be enough. I learned that you need to negotiate a work environment that improves the likelihood of success.

First, make yourself indispensable by focusing your interests on topics that are important to your institution. Figure out what your boss needs and how you can help make his/her job easier. If they do not need someone to teach medical students palliative care, teach in the internal medicine clerkship (and then integrate palliative care into the clerkship). Find the intersection between your own goals and your boss's goals and work there. Once you show your boss that you can succeed and have made yourself indispensable, you will have more leverage to negotiate for time and resources. For example, I was hired at the University of Pittsburgh because the Center for Bioethics and Health Law had received a grant to develop clinical training programs on ethics for third and fourth year medical students. While my boss and I thought it was an important topic, it was not a priority at either the medical center or within the Division of General Internal Medicine. I needed to find a way to do what I loved and make my supervisors happy. I therefore began to focus on areas that the Division did value such as primary care. This allowed me to teach my areas of primary interest-ethics and communication. When the ethics grant ended, I became program director for the Primary Care residency program, which made me more indispensable to the Division and allowed me to build new palliative care educational programs.

Second, negotiate by focusing on what your bosses want. Shortly after being funded as a Project on Death in America Faculty Scholar, I decided that we needed to build a clinical palliative care consultative service at the University of Pittsburgh. In talking with my colleagues around the country, it was clear that a primary barrier was getting financial support for clinicians' salaries. We spent almost 2 years developing a business plan and negotiating with our hospital for support. While our administrators care deeply about quality care, the primary selling points for them had to do with length of stay and decreasing costs. While I believe palliative care is much more than this (and our administrators have come to appreciate this), I learned to negotiate using the metrics that our administrators cared about most. This point was driven home when we developed a relationship with our heart failure program. In the first five years of our service, we rarely saw patients who had chronic congestive heart failure despite our administrators reminding us that this was the most common diagnosis, the most common reason for readmission, and an extraordinarily important cost center for them. We, therefore, began having bi-monthly meetings with the leaders of the heart failure program to try to understand what they wanted from palliative care and how we could be responsive to their needs. We learned that what they wanted was help dealing with pain, depression, anxiety, and disposition. They feared we would talk too quickly about end-of-life topics. By focusing on their needs, we won their trust. We now get more consults from the heart failure and heart transplant programs than any other service at our institution.

BE INTENTIONAL

Unless you have unlimited time, you have to choose what counts in your life. My style is to say yes to everything. This may be a good start-up strategy when you have to scrounge for resources; however, it is not what a mature program needs. A mature program needs to have a strategic plan so that resources can be distributed in a strategic manner. A mature program needs processes, policies, and a structure that faculty and staff can depend on. When I am constantly overcommitted and living at the edge, I do not have time to reflect on what the program really needs. This is why, despite my natural inclination, I have tried to be more intentional about program development.

We currently have two meetings per month where all discussion is focused on our programmatic goals and how to achieve them. We talk about what people want to attain in their personal and professional lives and how we can structure the program to help them meet these goals. While the process is difficult, I believe it works.

This advice also works in your private life when trying to decide how to balance work and home. Time is limited. As someone who is not very good at setting limits, I often missed dinner, much to the dismay of my wife. It seemed like there was always an emergency meeting with patients' families that caused me to be late. While my reasons for missing dinner were valid, the result was that I was not present enough with *my* family. It took sitting down and thinking about what was important to come up with a creative workable decision. (I go home at 6 PM regardless. If I need to back, I go after dinner.)

CONCLUSION

The last ten years of my career have been a joy. I often feel blessed to be paid to do work the that I love

and care about so deeply. I hope the three lessons discussed above will help the next generation find their way, much as I found mine.

My final wish would be that people continue to treat each other as kindly and compassionately as they treat their patients. Much of what has been a joy about doing palliative care is the sense of collegiality and friendship I have found among my colleagues. I hope, as the field matures, that we keep that sense of joy and compassion. Address reprint requests to: Robert M. Arnold, M.D. UPMC-Montefiore Hospital University of Pittsburgh 200 Lothrop Street Suite 933 West Pittsburgh, PA 15213

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