

Long Hours, Luck, and a Cast of Thousands

Joan Teno, M.D., M.S.

We never lost sight of the values that were so important to David: commitment to openness, openness to challenge, and the absolute priority of patients' own views on what they need.

—Dame Cicely Saunders



ON THE THIRD DAY OF THE VIGIL for my Mom, I walked in to see my 19-year-old niece sleeping in a chair next to her grandmother with my black lab, Moki, sleeping under the bed (Fig. 1). Moki, an enthusiastic 7-month-old puppy, regularly visited my Mom, usually bounding into her room and licking my Mom's hand. For four days, he slept under my mother's bed. This scene of my niece and my dog sleeping at the bedside of my dying mother was the gift of hospice. With assiduous use of medications, my Mom was no longer seizing, her breathing was comfortable, and she appeared peaceful. This gift allowed us as a family to be at her bedside and focus on saying good-bye as opposed to the terror of watching her in pain or with another distressing symptom.

Four days after my Mom's funeral, I took (and passed) the ABIM Hospice and Palliative Medicine Certification. Growing up in rural Pennsylvania, I would have never imagined that one of my proudest statements that I make on a daily basis is: I am a physician who is privileged to work for

hospice. The majority of teachers and family would have never predicted my success, let alone that part of my job would be based on my ability to write. My brain is definitely not wired right. For many years, I signed every note to my now 20-year-old niece, "Love, Anut Joan." I probably wrote that a thousand times not picking up on the obvious misspelling until my older sister told me, "You are a NUT, but I want you to be an aunt to my child." We are all given our own crosses to bear. Through perseverance, long hours, lots of luck, and a cast of thousands, I have been fortunate to make a small contribution to the emerging field of palliative medicine. Here are a few lessons that I have learned along the way:

1. Listen to your gut.
2. Find a good mentor.
3. Have a plan B.
4. Building bricks and mortar.
5. Persevere.



FIG. 1. Moki and my niece, Joan Hanna, at the bedside of my dying mother.

Lesson 1: Listen to Your Gut

Early on in your career, you are told time and time again that your ideas are not good enough, your writing is not strong enough, or that you are too inexperienced to be able to make significant contributions. With enough publications and gray hair, all of sudden you are labeled "brilliant." Neither is true. A key survival skill that I tell residents, fellows, and junior faculty is to listen to your gut. Develop your own barometer of your strengths, weakness, and successes.

Lesson 2: Find a Good Mentor

One key to a successful academic career in research or otherwise is to find a good mentor. If I had to choose one person to label as the mentor most responsible for my success, it would be Vincent Mor, Ph.D. Vince is passionate about research informing public policy and improving patient care. I have tried to model my own career after this passion as well. There is nothing more important during the early years than finding a good mentor—a person who defines his/her own success based on your success; someone who can also pick you back up after the many failures along the road; and someone who can be a sounding board during the good times and bad.

Lesson 3: Have a Plan B

I returned to Brown University in 1997 to work at the Center for Gerontology and Health Care Research and Home and Hospice Care of Rhode Island (HHCRI). HHCRI was integrating into Lifespan with the hope of developing a true continuum of care. I would love to tell you that it all went as planned but it did not. Unfortunately, the HHCRI-Lifespan integration failed thereby dashing my hopes for my plan A. Taking stock of changing demography of site of death in Rhode Island, I was able to work with HHCRI on the development of a long term care hospice team and a nurse-practitioner-based palliative care consult service focused on the neglected needs of nursing home residents. I have been blessed to work with Terry Rochon and Bonnie Evans, who truly made this program a success.

I still remember the first consult that I did with Terry. We were asked to see an elderly woman who was despised by the nursing home staff because she repeatedly hit her aide during morning care. The patient was aphasic and paralyzed on her left side, but she still had a good right hook. As we reviewed her chart, I was shocked to see multiple Minimum Data Set assessments that said that she had "excruciating" pain at its worst and that she was in pain all the time. With the use of opiates, she went from the nursing home resident that everyone hated to the resident they began to love. I later wrote a paper that reported how often a nursing home resident had this level of pain.¹ Sad to say, it was simply too frequent an event and too many patients stayed in this level of pain. Later, Terry and I partnered with Quality Partners of Rhode Island to create a rapid cycle quality improvement intervention that resulted in 41% reduction in severe pain.² Our initial study of a handful of nursing homes was replicated in 149 nursing homes across the country with similar reduction in pain among over 10,000 nursing home residents. One patient's story of excruciating pain led to this journey. One of the most

valuable things that you can do as physician scientists is to rely on your own clinical experience to provide you with key questions that matter.

Lesson 4: It is not Just the Paper in *JAMA* but Building Bricks and Mortar

In 1990, I was given the extraordinary opportunity to work on the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). This study was a once-in-a-lifetime opportunity and one of the best on-the-job training that a junior faculty intent on a research career could receive. The negative findings of the SUPPORT study were disappointing and it was easy to ask how \$28 million dollars could yield such results. Much to the credit of The Robert Wood Johnson Foundation and our project officer, Rosemary Gibson, there is a lasting legacy from this negative study that helped provide funding for some of the infrastructure for the emerging field of palliative medicine. The brilliance of Rosemary Gibson, Victoria Weisfeld, and the staff of The Robert Wood Johnson Foundation was to focus on building the bricks and mortar through funding of several national projects that would help to create the infrastructure to improve the quality of care at the close of life.

Lesson 5: Persevere

So what do you do after spending the first 5 years of your academic career on a failed randomized control trial? Working at the Center to Improve Care of the Dying at the George Washington University, Joanne Lynn, Barb Kreling, and I identified that among the fundamental barriers to improving the quality of care at the close of life was lack of actionable measurement tools. Inherent in the development of these tools was defining "high quality of care." Through a series of conferences that brought together multiple stakeholders,³ we created a survey that measured bereaved family member perceptions of the quality of care. The tool has been validated and a nationwide study was published in *JAMA* in 2004.⁴ While the *JAMA* article was an important accomplishment, the most important work that we did was the partnership with the National Hospice and Palliative Care Organization to adapt this tool for use by hospices across the country⁵ and now in many foreign nations. We created a data repository that not only provides benchmark data but now provides hospices with research that will help to improve the quality of hospice care. This would not be possible without the hard work of Stephen Connor, Carol Spence, and the leadership of NHPCO President, Don Schumacher. It is important to dream big and seize the opportunity to build brick and mortar. This effort is equally, if not more important than the article in *JAMA*.

While I was very fortunate to get an R01 early in my research career, that success came only after I was rejected for virtually every faculty development grant for which I applied. Rejection and deferred gratification is part of the bargain for the joy of working as a physician-scientist. The creativity, ability to solve problems, and the chance to make a small contribution is worth all those rejection letters. It is a struggle, but persevere. I cannot think of any other job that I would want to do.

Conclusion

So why do I spend part of my week working for hospice? The picture of my now 20-year-old niece, my black lab puppy, and my mom dying in October 2008 is my answer. The staff at Home and Hospice Care of Rhode Island expertly managed medications, provided emotional and spiritual support, and volunteers who sat vigil with my Mom. As a physician-scientist focusing on defining and measuring the quality of end of life care, I have listened to countless number of interviews of bereaved families relaying the horror of watching their love one being in severe pain or struggling to breathe while dying. Even when the interview occurred two years later after the death, families vividly recall the horror of seeing their loved one in distress while dying. There are all degrees of how intolerable the dying process can be. Through the lack of appropriate medical care—families' memories of dying become marred for the rest of their lives. Things can go so wrong. This is the reason that I work for hospice.

Similar to Bob Arnold,⁶ I am going to state the obvious life lessons that I learned from being a hospice physician. Live your life with passion, work hard, but remember what is so important—family. Each week, block out on your calendar the time that you are going to spend with your family and the time that you are going to spend on yourself. Both Bob Arnold and Lachlan Forrow were coresidents at Rhode Island Hospital (to be historically accurate, I was Bob's senior resident for a week or two). They got me involved in teaching ethics while I was struggling with what I would do with my life.⁷ Their collegiality and enthusiasm was contagious. Indeed, this is my hope for this emerging field. Debate is important and competition for funding is the norm, but ultimately we need to treat each other with respect and kindness. Our job in the coming century is to create health care systems that are patient and family centered. The task is daunting and so important. I cannot think of anything else that I would want to do with my life.

Acknowledgments

Early in my career, I was very fortunate to work with and learn from Marilyn Bergner (now deceased), Frank Harrell, and Joanne Lynn. After moving to Brown University, I have been very fortunate to work with colleagues at the Center for Gerontology and Health Care Research at Brown University (Pedro Gozalo, Vince Mor, Fox Wetle, David Dosa, Ramona Rhodes, Sylvia Kuo, and Susan Miller) and wonderful collaborators from the University of Pennsylvania (Dr. David

Casarett), Harvard University (Dr. Susan Mitchell), and National Hospice and Palliative Care Organization (Drs. Stephen Connor and Carol Spence). They are just some of cast of thousands. I thank those that I have mentioned and the many more I did not for their collaborative advice, assistance with projects. Most of all though, I thank them for their friendship. Each week, I work with several interdisciplinary teams at Home and Hospice Care of Rhode Island. They always seem to make the impossible possible. They are the true heroes. Last but not least: Carol, Jack, Joan, and Fran, you are the best.

References

1. Teno JM, Kabumoto G, Wetle T, Roy J, Mor V: Daily pain that was excruciating at some time in the previous week: Prevalence, characteristics, and outcomes in nursing home residents. *J Am Geriatr Soc* 2004;52:762–767.
2. Baier RR, Gifford DR, Patry G, Banks SM, Rochon T, DeSilva D, Teno JM: Ameliorating pain in nursing homes: A collaborative quality-improvement project. *J Am Geriatr Soc* 2004;52:1988–1995.
3. Teno JM, Byock I, Field MJ: Research agenda for developing measures to examine quality of care and quality of life of patients diagnosed with life-limiting illness. *J Pain Symptom Manage* 1999;17:75–82.
4. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88–93.
5. Connor SR, Teno J, Spence C, Smith N: Family evaluation of hospice care: Results from voluntary submission of data via website. *J Pain Symptom Manage* 2005;30:9–17.
6. Arnold RM: Live lessons in palliative care. *J Palliat Med* 2007;10:1050–1053.
7. Arnold RM, Forrow L, Wartman SA, Teno J: Teaching clinical medical ethics: A model programme for primary care residency. *J Med Ethics* 1988;14:91–96.

Address correspondence to:
Joan Teno, M.D., M.S.
Warren Alpert School of Medicine at Brown University
Community Health and Medicine
121 South Main Street, Room 612
Providence, RI 02912

E-mail: joan_teno@brown.edu

