# Pioneers in Palliative Care

Feature Editor: Vyjeyanthi S. Periyakoil

# Learning from a Life in Medicine

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I realize now That what is good on this earth Does not happen As a matter of course, It has to be created, It has to be maintained, by the effort of love.

Rebecca West

I WENT INTO MEDICINE to do social change. My parents were both developmental psychologists at U.C. Berkeley, and I struggled with the conflicting pulls of academic life and changing the world in concrete and practical ways. As I was making career decisions in the turmoil of the late 1960s/early 1970s, I viewed medicine as a profession in which I could both explore ideas, and change the conditions of life for people who were struggling with the experience of illness. I was attracted to the idea of doctoring as service to the community, to the intimacy of the close relationships that form in medicine, and to the construct that health is a foundation for empowerment and growth. I still believe in those core values.

#### EARLY CAREER

After medical school, I began my housestaff training in internal medicine/primary care at the Beth Israel Hospital in Boston. I remember making wonderful connections with patients with serious illness, and being frustrated by the care of dying patients that I witnessed. I particularly remember an incident in which I felt so morally distressed about a patient in the intensive care unit that I withdrew from the case with much agonizing and after many failed efforts to convince my attending that further intensive support was inappropriate for a young man who had clearly had a major bleed into his head from his recurrent leu-

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kemia, and whose family no longer wanted life-prolonging measures. About half way through my residency, I realized that I was interested in learning more about the psychological issues my patients were experiencing as they dealt with illness, and about the impact of the physician-patient relationship on the delivery of care. I conducted my first study, which surveyed the 100 most liked and disliked patients (and their physicians) in the primary clinic to understand more about the dynamics of healthy and dysfunctional physician-patient relationships. I was able to negotiate with both the departments of medicine and psychiatry at Beth Israel Hospital to complete residencies in both fields. While the Department of Medicine was very supportive of this individualized program, I think the psychiatry department was more skeptical, perhaps not quite trusting that I was serious about becoming a psychiatrist. I created a psycho-oncology experience as part of my consultation-liaison psychiatry rotation, and found I really loved caring for patients with cancer facing end-of-life issues. I anticipated practicing at the interface between psychiatry and medicine, and also training internists to do a better job understanding and meeting the psychological needs of their patients.

Toward the end of my training, I met my husband, Andy Billings, an internist and hospice physician, and I lost my mother; both of these experiences, in different ways, connected me more deeply with the work I do today in palliative care. Sharing love and work with Andy has allowed us to have a rich and deeply intertwined life together; our two sons, Josh and Gabe, continue to bring us joy beyond words.

#### **EXPERIENCING HOSPICE**

In 1982, as part of my first job at The Cambridge Hospital, I had the opportunity to become a hospice medical director. I found that I loved hospice work the intimacy of seeing patients in their homes; the ability to make them feel better with simple medications, including many psychiatric drugs that were not commonly used in hospice; the gratitude, palpable relief, and security my presence in the home engendered; and the challenges of interdisciplinary teamwork. I appreciated the "countercultural" elements of hospice, even as I felt frustrated by a resistance to medical and psychiatric input among the nurses who had built the hospice. Over time, however, we built a good working culture. I developed resident rotations in hospice, and was delighted to see the enthusiasm of trainees for this kind of mentored experience. I began attending the Academy of Hospice Physicians, where friendships with Bal Mount and David Weissman (among others) inspired me and gave me hope that there was a place for academically oriented physicians in the field.

#### **BECOMING AN EDUCATOR**

Around the same time, I became involved at Harvard Medical School (HMS) in developing the New Pathway in General Medical Education, a radically changed curriculum for our medical students. In college and medical school, I had been involved in substantial educational reform projects, and I jumped at the opportunity to thoroughly redesign the HMS curriculum, integrating behavioral and social sciences, problem-based learning, and longitudinal preceptorships into the curriculum. In my role as the Assistant Director of the New Pathway, I worked with a visionary and generative mentor, Gordon Moore, a general internist who had been involved in a number of large-scale change efforts, and who inspired me and gave me confidence to think about "the ideal" rather than "the possible." This experience also exposed me to the expertise of medical educators and evaluators, and gave me new range of competencies in medical education upon which to build in the rest of my career. As part of our initiative, we designed and implemented a randomized controlled trial of the new curriculum, and I found great satisfaction in being able to rigorously evaluate the impact of our reforms. Studying educational outcomes has continued to be a theme in my career.

#### **TURNING POINT**

In the early 1990s, I was at a bit of a loss about next steps in my career. I worked on the design of a new psychiatric residency but found that I missed my connection with medicine. I was seeing occasional psychiatric consultations for local hospices, but did not find opportunities to grow in that area. I transitioned into doing educational outcomes research, evaluating the impact of large-scale national medical education reform programs. However, in 1993, somewhat serendipitously, I had the opportunity to begin working with what became the Open Society Institute's Project on Death in America (PDIA). As a member of the Advisory Board of PDIA, we surveyed the state of the field and had the heady opportunity to think about how to spend \$15 million dollars (and ultimately \$45 million) to improve the care of the dying. We recognized the need for a leadership program for academic physicians and nurses; with my wonderful colleagues on the Board of PDIA, I led the development of the PDIA Faculty Scholars Program. During this time, I was deeply grateful for the mentorship of Dr. Kathleen Foley, and for the friendship of Professor Robert Burt. Over the 10 years of the PDIA Faculty Scholars Program, we supported 87 Faculty Scholars, many of whom went on to become the leaders of the field of palliative medicine. These Scholars also became my professional community and, for the first time in my career, I felt I had found "my people." We collaborated on many deeply satisfying, fun, and meaningful projects, enjoyed wonderful meals and hikes, debated the issue of physicianassisted suicide, sang campfire songs, and shared personal and professional struggles. I felt-and continue to feel-incredibly enriched by these connections. It was a dream job to run the program, and I am grateful, especially to George Soros, whose vision created the conditions for this experience.

#### **CONSOLIDATION PHASE**

In 1998, I was feeling professionally pushed and pulled in too many different directions, and had the opportunity to consolidate my focus by moving to the Dana-Farber Cancer Institute and Brigham and Women's Hospital. Leadership there wanted a psychooncology program, and I convinced them that they also needed a palliative care program. Over the ensuing 9 years, I have worked with an amazing team to build these two clinical programs, develop an inpatient palliative care unit, put together outpatient services, acquire a hospice for our system, develop a research center, and train fellows. I am particularly proud of the wonderful collaboration and synergy our program has created between psychiatry and palliative care, of our outstanding fellowship training programs in palliative medicine (with Massachusetts General Hospital) and psycho-oncology, and of the spectacular research being led by Holly Prigerson in our Center for Psychooncology and Palliative Care Research.

### LIVING A LIFE AND GROWING A PROGRAM

All along, Andy Billings—in addition to his other roles—has been my best professional friend, advisor, and collaborator, so much so that it is sometimes hard to know where my ideas end and his begin. We have invested considerable energy, again with terrific colleagues, in local and national faculty development activities. In the HMS Program in Palliative Care Education and Practice, we have now trained about 500 U.S. and 120 German palliative care faculty. We have developed a range of medical student and resident educational offerings. As our clinical programs have become solidly institutionalized, we have begun to work more on system-wide efforts to improve palliative care across the Partners Health System. Transitioning into new leadership responsibilities, it has been a special joy to watch our junior faculty take on former roles as "front-line teachers" of palliative medicine, and to see them try out their own ideas and approaches. I confess I am sometimes a little wistful about my diminished teaching role, but also so proud of their expertise, dedication, and commitment. They are extraordinary exemplars of the best of our profession.

### LOOKING BACK AND LOOKING FORWARD

I have had a lucky life in medicine, with few regrets. At 56, I am thinking about what to do with the rest of my career and how to feel that I am continuing to grow and contribute. I do not have clear answers for that question. There are few other things I can imagine that would be as rewarding as the work I am doing now, and maybe that will be enough. But I wonder about career tracks for senior palliative care leaders.

In terms of wisdom, I return to the words of my mother, Jeanne Block, who told me to "do what you love and the rest will take care of itself." This has been good advice for me. Other lessons I've learned along the way are:

- Work on a happy family life—nothing is harder or more important.
- Cherish relationships with people who stretch you (thanks especially to Andy, Josh, and Gabe).
- Embrace the zigs and zags in your career—they are inevitable and provide spice and new perspectives.
- Look for things to do at the interface between fields—there are lots of opportunities to contribute, to build bridges, and to address unanswered questions.
- Invest in the next generation and help them achieve their potential.
- Look for (or create) a work environment where you care about and feel cared about by the people with whom you work.

#### LEARNING FROM A LIFE IN MEDICINE

- Study what you do to see if it works; it is the only way to build a field.
- When teaching, work on creating a safe space for learning and then trust your students to grow.
- Never worry alone.
- Follow affect. It leads directly to what is most important.
- Make some time for reflection.

#### **MY HOPES FOR OUR FIELD**

I hope that we can integrate the best of both hospice and academic medicine into a vibrant, humanistic, reflective, evidence-based field that reflects the ideals of the profession of medicine and embodies interdisciplinary collaboration. I hope that we can develop structures that entice, support, and sustain young people who will be the next generation of educators and researchers in the field, and that we can contribute to the development of models of whole-person care that can be disseminated to other parts of medicine. If we stay true to this vision, we will create a compelling model that contributes to the transformation of the care of the dying and those with chronic illness, and creates a professional home for clinicians who want to work in this beautiful, heartbreaking, demanding, and extraordinary field.

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1. Vyjeyanthi S. Periyakoil . 2008. On the Endangered Species List: Palliative Care Junior FacultyOn the Endangered Species List: Palliative Care Junior Faculty. *Journal of Palliative Medicine* 11:3, 431-433. [Citation] [PDF] [PDF Plus]