

## Risks and Rewards

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Take time to deliberate; but when the time for action arrives, stop thinking and go in.

Napoleon Bonaparte

I AM HONORED to be the inaugural contributor to the *Journal of Palliative Medicine* series on palliative care pioneers. I look back at the path that I and many of my peers like Andy Billings, Jim Hallenbeck, Robert Arnold, Charles von Gunten, and other leaders have traveled, and I am both awed and humbled by how far we have come in such a short period of time.

I was a rather typical, academically naïve, junior faculty member when I started my career at the Medical College of Wisconsin (MCW) in 1986, directly from my fellowship in medical oncology. My area of interest was neuro-oncology, I was doing basic research on peritumoral brain edema with the goal of establishing a research and clinical care program in neuro-oncology.

My journey toward palliative care started 2 months after I came to MCW, when I saw a flyer tacked to the bulletin board outside my research laboratory. An innocuous notice, tucked beside more insistent notices about research RFAs and apartments for rent. The flyer announced an upcoming organizational meeting for the Wisconsin Cancer Pain Initiative (WCPI). I read the notice and immediately thought back to my fellowship

mentor who demonstrated that residents and oncology fellows, myself included, could not do even the most simple equianalgesic calculations using commonly available clinical resources. Reflecting on his leadership in cancer pain, I thought to myself, "I should probably see what this is all about, maybe I can be of some help to their efforts." Two weeks later I went to Madison and listened to Dr. Jan Sternsward, head of the World Health Organization's Cancer Control program, graphically describe the international problem of poorly treated pain, and the opportunity we had in Wisconsin to make a significant difference, not only for Wisconsin residents, but throughout the world. That single speech changed my career, as I realized that the need to improve pain management, a basic human need with implications for everyone, resonated more closely with my interests in patient care, than my more narrow focus of neuro-oncology. Furthermore, I was impressed by the commitment of the health professionals, patient advocates, and health policy experts who all shared a common vision and goal. Over the next 10 years I served as WCPI Director of Physician Education, developing regional

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and national pain education programs and started a cancer pain clinical care program at MCW, all of which formed the foundation for my subsequent clinical and educational work in palliative care. It was this work that sparked a heretofore unknown passion for both community outreach and medical education, and also taught me that education alone is not sufficient to overcome the entrenched attitudes so commonly found in pain and palliative care.

### TIPPING POINT #1

My work in cancer pain was rapidly drawing me into the larger world of hospice medicine, as it did so many of my peers, Mike Levy, Russ Portenoy, Ann Berger, Neil Ellison, Betty Ferrell, to name a few. Although the Medicare Hospice Benefit had been introduced in the early 1980s, the hospice movement had, with a few notable exceptions, failed to penetrate acute care hospitals and academic medical centers.

In 1989 I attended the annual meeting of the American Academy of Hospice Physicians (AHP: the forerunner of the Academy of Hospice and Palliative Medicine) seeking to learn how I could interface hospice philosophy with the academic environment. It was at that meeting in Estes Park, Colorado, that I finally found my tribe and my true academic home. Suddenly I was not just an outlier oncologist unduly fixated on pain and symptom management. There were other community-based and academic oncologists who talked about patient care with a passion and intensity that was concordant with my feelings. To find support and synergy within my own professional colleagues was exhilarating and empowering; to paraphrase Susan Block, this was my transformative experience. I knew instantly that this was what I had been missing at MCW. When I heard Derek Doyle speak about the interface of physician practice and palliative care, I got my first taste of the practice and promise the palliative care movement. I left the AHP meeting charged with new energy. On my return flight to MCW, I drafted my first proposal to start an academic palliative care program.

I wanted to start a consultation service but I needed an advance practice nurse to help me. While I had philosophical support from my division director and selected faculty, I could not obtain the financial support from the hospital lead-

ership. So for the next 3 years I wrote and rewrote innumerable proposals (does this sound familiar to anyone?) to start a clinical consultation service, while gathering clinical data documenting problems in care. Despite an obvious prevalence of poorly treated symptoms and terrible coordination of care, I was frustrated by the lack of management buy-in. In fact the hospital vice president for clinical affairs openly challenged me, stating somewhat condescendingly "Dr. Weissman, this is an acute care, surgically oriented hospital. Our patients do not die!"

### TIPPING POINT #2

In 1991, in recognition of my interest and growing expertise in cancer pain and medical education, the Dean for Student Affairs asked me to become course director for MCW's required second-year class, *Death and Dying*, which had previously focused on death and bereavement psychological theory. Poor student feedback had doomed the prior course director. Being the educational pragmatist, I thought that students might respond better to practical information about caring for seriously ill and dying patients. Starting with a blank slate, I designed a 6-week course focused around clinical care issues rather than theory; the course was a hit with students and eventually was merged with the bioethics course into a required 10-week course which continues to this day, *Medical Ethics and Palliative Medicine*. When second-year students from the course began asking me about clinical opportunities in palliative care during their third and fourth years, I knew that the consult service had to be implemented as the educational platform for clinical palliative care education.

While pursuing the goal of starting a palliative care program in the early 1990s, I was also busy developing a national cancer pain education program designed around an interdisciplinary care model. In 1993 the National Cancer Institute approved my grant application for the Cancer Pain Role Model Program, which including a full-time nursing position to work on the grant with me. I quickly placed an advertisement in the local media for an advance practice nurse and received only one application. Julie Griffie, an experienced oncology nurse with recent work in nursing education and long-term care, but no experience in academic medicine, came to my office for the in-

terview. I explained what I hoped to accomplish and fortunately she accepted the position. Five days after Julie was hired we started the palliative care clinical consultation service, with no marketing or business plan, or for that matter, no real idea what we were getting into.

Julie and I saw every patient together, in our spare time, me between my oncology and educational activities, and Julie, between her work on the grant and building the core infrastructure of our clinical service. Those first months were a steep learning curve for both of us as we had to learn to work together, doing clinical work for which neither of us was trained, while walking through the land mines of a consultation service that was totally foreign to our very traditional academic medical environment. Our nonclinical efforts focused on marketing, developing educational outreach relationships with hospices and long-term care facilities, and mending the wounded egos of referring physicians, discharge planners, nurses, and social workers, who all questioned our role in patient care. To say we were naïve would be a gross understatement (as the saying goes “ignorance is bliss”). Yet, we both new from the start that this was the work we had been “called” to do, it just felt like the right time and right place to be doing this extraordinary work. In 1997 Sandra Muchka joined us as a second palliative care nurse and together these two wonderful nurses worked tirelessly to help the program sink deep institutional roots through their commitment to excellent patient care and leadership as health educators and community advocates.

### CONSOLIDATION PHASE

A number of events took place to help solidify the MCW palliative care clinical and educational programs. First was my decision to give up my general oncology and brain tumor clinical practice, and embark on a full-time career in palliative medicine. By 1996 I was seriously burned out after 10 years as the sole oncologist in a primary brain tumor clinic. I knew in my heart that making the move away from oncology practice was the right thing to do, although I could not deny a faint disquiet at the thought of turning my back on traditional oncology. I was fortunate to have a supportive division director and to obtain Project on Death in America (PDIA) grant funding for

career development. Second, I was given the opportunity to serve as a community hospice medical director, and as a palliative care consultant for a long-term care facility. Not only did these two positions help fund a portion of my salary during some rather lean years, but they gave me invaluable insights into realms of clinical practice of which I had little experience.

By 1998 I still could not get the medical center to commit funds to support the two full-time nursing positions, nor commit to hiring an additional physician to help me. Feeling angry and rather disenchanted with the whole process, I issued an ultimatum to upper management—if they could not fund my staff, I would leave. Fortunately, in 1998 there was a turnover in hospital administration to a more palliative care—friendly chief medical and nursing officer, who rapidly caved after my threat and agreed to fund one nursing position. Since then, the hospital has annually increased support for the clinical program including palliative care nurse and physician positions, a designated inpatient unit, hospital-wide nurse education programs, a bereavement coordinator, and institution of a palliative care committee, reportable to the medical staff, to coordinate hospital-wide quality and educational activities.

There have been four constants in the MCW program that are responsible for our continued growth and sustainability.

1. **Ability to identify specific program goals:** Starting with my return from Colorado in 1989, I had one clear academic goal, namely, to bring the principles and practice of hospice medicine into the academic environment to improve clinical care and educational programming. This single goal was the touchstone for all subsequent personal career and program decisions.
2. **Ability to build and sustain a respected clinical service:** Without a well-respected clinical service we would never have been able to move from a great idea to sustainability. The clinical service is the “face” of palliative care for the hospital staff and our many local and visiting trainees; it is where theory and book knowledge are translated into excellent patient care, and more recently, the recognition of substantial hospital cost-savings.
3. **Ability to adapt and evolve:** A willingness to try new ideas, and learn from those that fail, has been a constant of my work. Despite the

outward success of our program, we have stumbled and bumbled many mistakes along the way. The ability to seek out opportunities, to take risks, and to evolve to changing situations, is critical for both new and established programs.

4. **Ability to build and sustain a team:** Having the right people to work with is critical. Without the support of my dedicated team of clinicians and administrative staff, who know how to provide outstanding care and simultaneously maintain a sense of humor about their work, I would have quit medicine years ago and focused on my other passion, flying.

Looking back, what could I have done differently? I probably should have threatened to leave several years before I actually did as a means of securing more institutional support. We often tend to underestimate our worth and value to the health care system. Strategic noncooperation can sometimes help us overcome seemingly insurmountable barriers. Finally, I would have been better prepared for the leadership and management roles of my job if I had recognized the need to seek special training for these skills earlier in my career.

#### MY HOPES FOR OUR FIELD

Our field has embarked on an exciting new trajectory with subspecialty designation. My hope is that we do not get complacent. The excitement I see in new programs comes from the energy to meet very real problems in patient care. However, starting a consultation or inpatient unit, im-

proving hospice access, or starting new educational programs, will not by themselves solve all the health professional and health care system barriers to the kind of care we know is possible. Be innovative, try new ideas, reinvent yourself from time to time, learn from your mistakes, seek out respected mentors, and keep trying. This is what I am still doing.

#### ACKNOWLEDGMENTS

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