

On Finding a Balance

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THIS PAPER WILL BE PUBLISHED within months of my thirtieth anniversary of becoming a nurse, which occurred in May 1977. That event also coincides with my thirtieth wedding anniversary. I begin with this observation to say that pioneering or enduring a professional commitment to palliative care for me has only been possible because I have been committed to a balanced personal life that soothes, comforts, and nourishes my daily being.

My career began as a nurse on an oncology unit in Oklahoma. After 3 years in that setting I moved into home care and hospice. During my years in the inpatient setting I was drawn to the care of patients in pain and to dying patients. At the same time I left the hospital setting, I also returned to school for a master's degree to become a clinical nurse specialist so that I could impact the care I increasingly saw as inadequate to meet the needs of dying patients and those in pain. In the process of pursuing this clinical goal I was forced to take a research course. My research paper lead me to work alongside many hospice pioneers who were using compounded medications like Brompton's solution and also introducing opioids like oral morphine to alleviate the suffering of patients dying at home. What I discovered as I learned basic research skills was that contrary to commonly held beliefs, research was

not the irrelevant, purely academic, sterile pursuit of data. Rather, research could change practice, and most importantly, it could improve care of patients.

I continued working in hospice and began doctoral studies, commuting 180 miles each way from my home in Oklahoma to what was at the time one of only 24 doctorate programs in nursing in the United States. Our daughter was a preschooler during these years and she grew up believing that all mothers left the state once per week.! Of course, I waited until I graduated to explain to her that was not quite true.

After completing my doctorate in 1984, I pursued the "usual" course and ventured into academia as a nursing faculty member, but soon realized that my primary love was research. Having relocated to California (kicking and screaming) so that my husband could pursue a geriatric medicine fellowship, I found a rare opportunity for a full-time research position at the City of Hope National Medical Center.

I have been at City of Hope as a Research Scientist for 18 years. Being a researcher in a clinical setting has been an experience rich in opportunities for collaboration. It is also challenging to pursue the work of palliative care in a very intense setting whose mission promotes cure and survival often over comfort and quality of life. I

have seen progress and believe we are miles closer to systems of care that embrace palliative care as an essential aspect of quality care and I feel very fortunate to have witnessed this transition.

THE CALL

I do believe that my entry into this field has been a "calling" and that the work we do is sacred. My "epiphany" literally occurred in a closet in Oklahoma. In 1978, 1 year into my nursing career, I went to the local American Cancer Society office looking for patient materials on mucositis. The secretary led me into an entire closet filled with cancer brochures. As I browsed the sea of materials on cancer and treatments, I finally came upon a booklet on hospice written by Jeanne Quint Benoliel, a nurse scholar.

I began reading the booklet and was so taken by the words describing the philosophy of care that valued pain relief, family centered care, bereavement support and interdisciplinary collaboration that I stood in the closet transfixed until I had read every page. In my heart, I knew instantly that this was the work I wanted to do.

SO WHAT?

My work as a researcher has been constantly informed by clinical interactions with patients and families. As a researcher, I have tried to stay closely connected to the clinical world and to continually challenge myself with the "so what" principle I learned in my first research course. "So what" will you learn by doing this study? If this study you are proposing were to be successfully completed, "so what" would you know? "So what" would it mean for patients care? We all need to stay focused on the mission of transforming health care systems, education, and research such that the care of people is improved.

"STUDY US"

Some years ago I received a telephone call from an angry woman with ovarian cancer who was angry to see all the attention on breast cancer. She called me, as a one of the guilty researchers, and when I asked her what she wanted me to do she

said, "Study us." I began a collaborative effort with her (Cindy Melancon) that included reading more than 21,000 letters written by women with ovarian cancer in order to speak for these women and their families through research focused on their needs. Cindy Melancon died days after we published that work and presented it at a major oncology meeting.

I have kept this lesson close to my heart. It is a good thing when we can be guided in our research by the people whose care depends on it.

COMPETING DEMANDS

I have been fortunate that my career has spanned the time from when people could not even pronounce the word hospice ("Hos-pice? What is that? Where is it?") to now when palliative care is being slowly integrated into every aspect of health care. Thus, there is never enough time to do all the work that needs to be done. What I have learned is that juggling the endless demands of a growing field requires personal retreat and self-reflection. Hence, over the past several years, I retreat twice yearly and spend time in silence in a Benedictine Monastery in Santa Barbara. Through escape and silence, I find that can I hear clearly the internal voice that offers constant hope of renewal and focus. In addition, I also returned to school and will complete a master's degree in Theology, Ethics, and Culture in May 2007. I have learned much by reaching out to other disciplines to guide what I believe about our own.

STAYING THE COURSE

I have stayed the course of 30 years in the field for one reason. I have been supported by my family and my colleagues. My husband, Bruce, and daughter, Annie, have offered unconditional support that has allowed me to be often consumed by my work. Even when I am present, I am often "absent." I have also been supported throughout my career by a very large family of professional colleagues who I consider my greatest strength and support. My colleagues in Nursing Research at the City of Hope are a daily foundation of supporters equally committed to our work. We work hard and we laugh a lot. My larger national network of colleagues offers mentorship and support I could

never have imagined. In 2000, we launched the End-of-Life Nursing Education Consortium (ELNEC), a national educational effort. The support and commitment of my ELNEC colleagues has surpassed what any person could hope for.

HINDSIGHT

I have few regrets about the professional choices I have made. Working in palliative care is much harder than I ever imagined. The obstacles to transforming a culture of care, seeking financial support to sustain research and educational programs and maneuvering the political obstacles is draining. The rewards of seeing barriers broken down, participating in an emerging field, and truly feeling connected to a national cadre of colleagues who are deeply committed to this work is also much deeper than I could have imagined.

My one overall reflection is that I believe we in the field have been too passive in our efforts. The characteristics of silent presence, peaceful approach and timid voices that may serve us well at the bedside have hurt us in the broader realm of health care policy. We have not been militant enough. We believed for too long that governments, organizations, and institutions would embrace palliative care because it is right. We have discovered that the cultural avoidance of death and the ever increasing fight for limited resources requires that we speak up loudly and clearly for what we believe if we are to improve the care of those who are seriously ill and dying.

So now, I will tell you what I really think. I think that the care for the seriously ill and dying in this rich nation is pathetic. It is a moral outrage that people in the year 2007 live and die in pain. It is inconceivable that the federal research budget devotes less than 1% to any topic related to our field. Care for the poor and other vulnerable groups in our health care system in general, and in palliative care specifically, is shameful. A Medicare hospice benefit that denies care to those receiving disease focused care concurrently is insane. We are forced to have "bake sales" to support palliative care efforts that should be basic elements of care respecting human dignity. Families should not go broke caring for a dying loved one. Major organizations and institutions that have ignored, diminished and denied the imperative of palliative care should be publicly shamed.

I hope that in the decades ahead, my voice and the voice of the field will be one of both compassion and outrage. Our patients deserve better.

HOPES AND DREAMS

My greatest hope is that the field of palliative care can be strengthened individually and collectively. Each profession including medicine, nursing, social work, chaplaincy, psychology, and others have critical needs to strengthen their own disciplines. We have also made great strides in advancing interdisciplinary care. Palliative care is still an endangered species. We will only survive and advance the field if we speak in a collective voice as united disciplines. We must abandon any tension between hospice versus palliative care and between disciplines. As with many other social change movements, the greatest enemy in our field is us. We must find the way to work together.

WISDOM

Because my primary professional role has been as a researcher, I will end this paper with words of wisdom about palliative care research. I am encouraged and believe strongly in the current movement toward evidence-based practice. Our discipline needs an evidence base and our patients deserve clinical care grounded in tested approaches and best practices.

But our science is a caring, deeply human science and our research discipline should reflect the profound meaning of caring for people who are dying and the existential dimensions of this phenomenon we have labeled palliative care. We need some randomized clinical trials but we also need qualitative science that can express the aspects of care that are unquantifiable.

Let me end with an observation. Today, in many hospitals in America a child will die in an intensive care unit with young parents at the bedside. They will witness their child die in pain and there will be no chaplain present. Well-intended compassionate professionals will try hard but largely will be overwhelmed by the circumstances. In less than an hour after a child dies, these young parents will leave the hospital with no plan for follow up or support. There are over 4000 other deaths that will occur today and we

could change the place, disease, or age but the message would be the same.

I hope that research will answer some of the questions but I also hope that our field is as much about social change, revolt and conscientious objection to immoral care as it is about an evidence base. We should do many things in our field as decent humans. I know we can.

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