

## On Third Base but not Home Yet

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Happiness is when what you think, what you say, and what you do are in harmony.

—Mahatma Gandhi

**I**N 28 YEARS of a busy and rewarding medical career I have had the opportunity to work in three different environments during three distinct stages of my career and life. As with many other young professionals I had some reasonable knowledge about how and when I would get to first base (medical degree and specialty). However, I was not able to predict when or where the next stage would take me. In most cases professional decisions are greatly influenced by personal circumstances and therefore one of the life long challenges is to continuously adapt professional and personal goals to a changing environment.

This paper summarizes the first three bases in my run for home and some things I have learned along the way.

### FIRST BASE: EARLY CAREER IN ARGENTINA

The early 1980s were an exciting time for medical oncology fellows. Our lives were full of chemother-

apy protocol acronyms and some of them finally appeared to be working out quite well. For example, the follow up data of patients treated with mustargen-oncovin-procarbazine-prednisone (MOPP)<sup>1</sup> and adriamycin-bleomycin-vinblastine-dacarbazine (ABVD)<sup>2</sup> confirmed that we were able to cure a large number of patients with Hodgkin's disease. Early follow-up data with bleomycin, vinblastin, cisplatin (BVP)<sup>3</sup> or vinblastine, actinomycin D, bleomycin, cisplatin (VAB-6)<sup>4</sup> showed that testicular cancer, a disease of young patients that only a few years before had been almost universally incurable was now on the verge of being cured in most cases. Adjuvant treatments given to patients with no clinical evidence of disease such as cyclophosphamide, methotrexate, and fluorouracil (CMF)<sup>5</sup> were capable of reducing the recurrence of breast cancer. This body of knowledge was rapidly becoming part of undergraduate and postgraduate medical education.

However, in the daily practice of medical oncology I saw that the vast majority of our patients had cancer

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that could not be cured by our treatments. Our chemotherapy regimens caused very severe toxicity and patients ultimately developed devastating physical and psychosocial symptoms. We received very minimal education both on how to assess and manage symptoms and on how to communicate with patients and their families. I was fortunate to train in a highly academic center, Sanatorio Guemes, Buenos Aires, and with the support of my department chair (Dr. Reinaldo Chacon) I was able to conduct some research studies on cachexia, on the use of corticosteroids for the relief of pain, fatigue and for the prevention of chemotherapy induced emesis (in the pre-setron era) in patients with advanced cancer. I presented my first paper at the American Society of Clinical Oncology meeting in 1982 in St. Louis, Missouri.<sup>6</sup> This trip allowed me to talk with many American colleagues and to visit some of the American cancer centers. I was enormously impressed by the level of sophistication of American oncology. However, I also found out that there was very limited interest in the management of problems such as pain, cachexia, dyspnea, psychosocial distress, and family support.

Back in Buenos Aires I came across an announcement of a lecture by Dr. Vittorio Ventafridda from the National Cancer Institute in Milan on a subject called "palliative care." I attended this morning lecture in a large and frozen auditorium in the medicine faculty club. Even though the total audience consisted of five of us, Dr. Ventafridda gave a wonderful lecture and I returned to my hospital convinced that I needed to learn more about this subject. I obtained (in the pre-Internet era) all the papers I could from Dr. Cicely Saunders and the initial pioneers of the British hospice movement and based on the conference and my readings I decided that I wanted to dedicate my professional career to palliative care. I sent letters and my *curriculum vitae* to a total of 52 different cancer organizations in North America and Europe. Most of them responded and some of them offered research fellowships but only the Cross Cancer Institute in Edmonton, Canada under the leadership of Dr. Neil McDonald was interested in palliative care.

## SECOND BASE: A PALLIATIVE CAREER IN CANADA

I arrived in Edmonton in July 1984 to start a 1-year research fellowship in symptom control in cancer. At that time there were no formal palliative care training fellowships or a palliative care subspecialty in Canada. However, Dr. McDonald firmly believed that pallia-

tive care could make a major contribution to the care of patients with advanced cancer and their families. He also felt that we had a wonderful opportunity to make a contribution to the very poor existing body of knowledge. Thus, he provided the mentorship and administrative support that allowed me to start my academic career. In 1988 I was able to run a small palliative care unit at the Edmonton General Hospital while also keeping my appointment at the Cross Cancer Institute. Funding for palliative care clinical programs was a major problem and funding for academic programs in palliative care was almost nonexistent. While we were able to slowly and painstakingly sustain and foster our palliative care unit and to make some contribution to the literature, our real opportunity came in 1993. Major financial difficulties in the province of Alberta (the single health care payer) forced the health care system to consider alternate ways of delivering care with a shifting emphasis on community-based care (as opposed to acute inpatient care). After almost 3 years of planning and negotiating with the provincial government, in 1995 we were able to establish the Edmonton Regional Palliative Care Program. This program consisted of three inpatient hospice units each with a 20-bed capacity, an inpatient palliative care unit, mobile palliative care consult teams in all acute hospitals, and a designated team of specialist physicians and nurses to provide palliative care in the community. The funding for this program allowed us to greatly expand our faculty, to firmly establish an independent academic structure within the Department of Oncology, and to provide access to palliative care to more than 80% of patients with cancer who died in the Edmonton region. This program is now led by Dr. Robin Fainsinger, my first fellow from whom I have continued to learn so much over the years. It still is one of the largest publicly funded palliative care programs in the world, known for promoting consistent access to palliative care for patients with advanced illnesses.

Financial difficulties that threatened the continuation of our existing palliative care programs also created a sense of instability among the administrative leadership and a willingness to try different models for health care delivery. We leveraged this to our advantage and we were able to majorly expand the scope of our clinical and academic programs. It is to be noted that the United States is in currently a health care crisis (in terms of both fiscal issues and healthcare access) that is much worse than the Canadian crisis described above. This therefore provides us with a similar opportunity for leveraging an integrated palliative care program development in this country.

### THIRD BASE: CREATING AN ACADEMIC PALLIATIVE CARE PROGRAM IN UNITED STATES

In July 1999 I arrived in Houston to establish a palliative care program at The University of Texas M. D. Anderson Cancer Center. It was wonderful opportunity to demonstrate the value of clinical and academic palliative care within one of the largest and most respected cancer centers in the world. However, it was also a complex and risky process. Our primary priority was to create a small team of physicians, nurses, and other disciplines to establish the clinical palliative care programs. We also developed a mission statement, a strategic plan, and then approached faculty and other staff within the institution who were sympathetic to palliative care. Though our team mainly emphasized clinical programmatic development, we strategically built both a research and an education component into our core program. The most difficult part of our development was the establishment of the inpatient palliative care unit. However, this was the most rewarding and ultimately the most effective way of delivering care and promoting academic activity at the M. D. Anderson Cancer Center. In addition, we also established two mobile teams for consultations on the inpatient floors, the emergency center, and intensive care units, and an outpatient center. In parallel with the clinical program development we created a 1-month rotation for all the medical oncology fellows and also established a Palliative Medicine Review Committee accredited fellowship program with five fellows per year. On the research front, we created a robust research program with National Institutes of Health funding and typically have approximately 22 active research protocols at any given time. Finally, we also have a clinical and educational community outreach program actively involving all the local hospices with scheduled activity including a monthly bus round program for continuing education.

As was the case with the previous two stages in my professional career, it became clear to me that both administrative leadership and mentorship are critical factors. I was very fortunate to develop our programs in Houston under the mentorship of the head of our Division of Cancer Medicine (Dr. Waun Ki Hong), and the president of M. D. Anderson Cancer Center (Dr. John Mendelsohn).

#### SOME THINGS I HAVE LEARNED

- Our body of knowledge is solid—Our clinical programs are very successful in reducing physical and psychosocial distress in patients and emotional distress in their families. These excellent clinical results are what ultimately convince our colleagues and administrators to support palliative care development.
- Administrative arrangements are important—Over the years I had heard Neil McDonald say this very frequently but I honestly had no idea of what this meant. Our team and many others have learned over the years that having the right administrative structure is probably the most important condition for successful and safe program development. There is a critical need for a division or department leader who understands the unique challenges faced by palliative care teams and strongly endorses the programmatic goals, develops fair benchmarks for clinical and academic productivity and is capable of providing the right environment for growth. Because of the interdisciplinary and complex nature of palliative care some sort of independent administrative structure needs to exist as a way to provide a safe home for physicians from different specialties as well as other scientists. If the administrative environment is not supportive it is important to rapidly connect with institutional leadership and request a change in the reporting structure. If that fails, it might be best to quickly change jobs.
- Create an inpatient palliative care unit—The acute palliative care unit provides a distinct environment where palliative medicine specialists and an interdisciplinary team are able to provide primary care to severely distressed patients and their families. This setting allows us to succeed in alleviating physical and psychosocial distress in a manner impossible to achieve in a regular hospital ward. Moreover, the dedicated palliative care unit allows us to demonstrate to colleagues, staff, and administration what palliative care can really achieve and it provides a unique setting for education and research. Both in Edmonton and Houston as well as at least a dozen major programs where I was able to be actively involved over the years, the establishment of the acute palliative care unit was the tipping point in the clinical and academic success of the programs.
- Research is mandatory for enduring success—Research is more essential in palliative and hospice care than in other areas of health care. Our discipline originated during the late 1960s and early 1970s in the United Kingdom in response to the unmet needs of dying patients and their families. The origins of our discipline are mostly community based and non-academic. As a consequence, there is limited evidence to support the large majority of our

interventions. As an increasing number of programs emerge in major hospitals and academic institutions there is an ethical obligation for us in those centers to conduct research to contribute to that body of knowledge. As hospices grow in census and become highly profitable it is also their ethical obligation to protect some of the time of their faculty and staff so they can make a contribution to our knowledge about how to help patients and families.

- Hire talented junior faculty and provide them with mentoring and support—Young faculty entering a career in palliative care face a much lower income, uncertain job stability, uncertain academic progress and paucity of funding as compared to almost all established specialties at the present time. These individuals need special support and participation in the collective governance of a palliative care program. Over the years I have learned that what does work is to hire the most talented people available and to provide them with an environment where they can actively participate in collective leadership. The more traditional CEO/department chair/general leadership style, in my experience, has resulted mostly in individuals with big names and name recognition but poor clinical and academic programs.
- In each new palliative care job it is necessary to understand the culture and to change it—Nations and ethnic/religious groups have cultural values, but so do also hospitals and medical schools. The development of a palliative care culture among colleagues was essential for my survival and that of my programs over the years. In my experience cultural evolution in individuals and groups goes through four distinct stages: denial, palliphobia, pallilalia, and finally palliative.<sup>7</sup>

### THE RUN FOR HOME

When I discovered palliative care in the 1980s I immediately became convinced that this clinical approach was just perfect for oncology and many other specialties dealing with incurable, progressive diseases. I knew it was going to be difficult to develop the clinical programs and to incorporate this body of knowledge into the curricula of medical schools, postgraduate medical education and major congresses. However, the spectacular clinical results obtained with patients and families and the great intellectual opportunities led me to believe that this would be a 5-year process.

Twenty-five years later the “p” word is still not a significant part of the congress of the American Society of

Clinical Oncology, palliative care units do not exist in the vast majority of cancer centers and acute care hospitals in the United States, and there are very few academic palliative care departments in hospitals and faculties of medicine. Hospices in a time of enormous clinical and financial growth have not made a commitment to create well-funded or academically oriented positions for palliative care physicians. After the first generation of highly charismatic leaders who set the framework for palliative care I belong to the second generation that was supposed to firmly establish palliative care as part of the body of knowledge. Our generation has largely failed at achieving these goals.

### *We did make progress*

We have reputable journals, professionals associations, congresses, and a subspecialty in most developed countries. However, compared to areas of knowledge that are considerably younger than ours such as emergency medicine or critical care medicine we have failed to insert our body of knowledge into undergraduate and graduate medical education and to establish the solid administrative and clinical structures in hospitals, cancer centers, and universities.

My hope for our field is clearly focused on the new generation of junior faculty and fellows. I am amazed at how much better prepared these young colleagues are to face these challenges than my generation was. I believe the main job left to my generation is to use all our energy and leverage it to create the full-time academic positions and to provide mentorship so the next generation in turn will forever change the way we learn and practice medicine. I believe that this is the best we can do for our future patients and families. I believe we should also act fast for very selfish reasons since my generation is rapidly approaching the age at which most of us will become the recipients of the quality of palliative care we were able to establish.

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