

Featured Innovation

Developing an Integrated Department of Pain Medicine and Palliative Care:

An Interview with [Russell K. Portenoy, MD](#)

In 1996, the United Hospital Fund awarded planning grants to 12 hospitals to analyze their needs, resources, capacities and program development strategies. Beth Israel Medical Center in New York City was one of five programs to receive a further implementation grant from UHF in 1998 to continue their efforts.¹

The Department of Pain Medicine and Palliative Care (DPMPC) was established in 1997-1998 under the leadership of Dr. Russell K. Portenoy, MD, a neurologist with special expertise in pain management and palliative care. By drawing together the specialized care and resources involved in pain medicine, inpatient and outpatient palliative care, and hospice care, this department is the first of its kind to exist as an integrated department within a hospital system. As such, it serves to provide one of the most comprehensive and integrated models for palliative medicine found in the United States. With its focus on multidisciplinary teamwork, symptom management and pain control, and the integration of hospice into the practice of palliative medicine, Beth Israel Medical Center's DPMPC brings together the benefits of expert medical practice and psychosocial care to patients and families in one comprehensive center.

*The Department of Pain Medicine and Palliative Care has been awarded the American Hospital Association's 2001 Circle of Life Award. In the following interview with Karen S. Heller, PhD, Dr. Portenoy speaks about the unique opportunity he has had to create such an integrated department within the hospital institution. He discusses the strengths and successes of such a comprehensive and coordinated program, as well as the limitations and challenges that still lie ahead in the field of palliative care. [Citation: Portenoy RK, Heller KS. Developing an integrated Department of Pain and Palliative Medicine: An interview with Russell K. Portenoy, MD. *Innovations in End-of-Life Care*. 2001;3(4),www.edc.org/lastacts]*

History of the Pain Medicine and Palliative Care Department at Beth Israel Medical Center

When did you first start thinking about developing a pain and palliative care program and how did it happen?

The senior leadership at Beth Israel had a very long history of interest in humanistic care and end-of-life care that dated back many years. In 1997, the administration responded to an RFA (Request for Applications) from the United Hospital Fund (UHF) that was focused on plans to build palliative care infrastructure at various hospitals around New York City. The Beth Israel Medical Center (BIMC) grant was originally designed to provide some education in palliative care to housestaff.

I was contacted by the administration after they received the award and asked if I would consult for the educational program. I went down to BIMC for a preliminary meeting about the program, and began to talk a little bit about what palliative care is, and where palliative care was going in the

United States. The senior medical staff to whom I was speaking literally pushed the grant application aside and said, "What would you want to create here if you could create a model program?" I began to speak to them about things that I had been considering for more than five years in what was then my current position as Co-Chief of the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center. We had begun to work at Sloan-Kettering to try to bring a more comprehensive palliative care approach to what had been a pain program.

I described a program with inpatient and home care elements, which would be focused on quality-of-life-oriented care throughout the course of an illness, as well as excellence in end-of-life care. They were immediately interested and asked me to put my ideas down in writing, which I did over the next day. Four days later, I received a call saying that the administration had decided to go for the package, that they wanted to recruit me and essentially give me whatever I wanted in order to try to build this palliative care program.

The recruitment was an incredible adventure for me. It included a personal visit from the chairman of the board of trustees to my office at Sloan-Kettering, during which he told me that they were totally committed to this area, they really wanted this activity, that it was entirely in line with the mission and vision of their institution, and they would support it in any way I wanted.

Well, for an academic physician to be told that there's a true blank check — I was astonished, incredulous ... my heart stopped for about an hour! Then I collected myself and began a series of very serious negotiations with the administration, speaking with both the medical side and the business side of the administration. Early in those discussions, as I learned more about the facilities and resources that Beth Israel Medical Center had, I realized that their pain program was very limited. I had been doing pain management — nonmalignant disorders like low back pain and headache — for many years, and I brought up the possibility of perhaps linking a multidisciplinary state-of-the-art pain management program to the development of this new model of palliative care that we had been discussing. The BIMC administration said, essentially, "Go for it. Show us what you would need in terms of facilities and personnel, and we'll see if we can accommodate it."

Planning a Conjoined Pain and Palliative Care Program

Over a period of months, I negotiated with the institution to establish the essential organizational structure and the requirements for this very large program, which would include a multidisciplinary pain management program as it has been traditionally configured for twenty years in the United States, and also a model of palliative care that would not be limited to end-of-life care, but would cover a full range of services for inpatients and outpatients.

During those negotiations, the institution pointed out to me that they were already supporting a hospital-based hospice program, one of only two in New York City — the Jacob Perlow Hospice Program. They suggested that the hospice program be administratively moved and linked to the model that I was talking about. I had already planned to use the hospice program as a resource for end-of-life care within a broader model of palliative care, but the opportunity to administratively join the hospice program with this new program I was developing was a tremendous advantage to the model itself. It provided a way of creating policies and procedures and budgetary devices that allowed real linkages to form.

After the required personnel and other infrastructural issues were agreed to, I was left with the reality that I was being offered an opportunity to build something that included many people in multiple disciplines, an inpatient unit, and space for ambulatory practice in both pain and palliative care, as well as this relationship with the hospice organization. I began to talk with the hospital's

senior leadership about what this entity could possibly be within the bureaucracy of the institution. At one point, I said to them, "Something this substantial, if it weren't in this area of medicine, would probably be called a department," and they said, "Well, we have no problem with that, let's call it a department."

There was this long silence while I was trying to restart my heart again, and I said, "Well, you understand that there are no other departments devoted to either pain medicine or palliative care anywhere in the United States. To create one would represent a very significant statement about the status of these fields in the institutional hierarchy, and it would also carry with it a number of very significant obligations over time."

I got a call from the president and CEO of the institution about a day later and he said, "I just want to clarify for you that we have absolutely no concerns about naming this a department. In fact, in my view I would guess that in about five years there will be departments all over the country." With this decision, I was clearly being offered an unprecedented opportunity. I was being provided with personnel, space, and resources to build both a state-of-the-art pain program and a new model of palliative care, which would integrate a well-established and highly respected hospice program. And it included an opportunity to house the entire thing within a departmental structure, which would essentially have me on equal footing with medicine, surgery, pediatrics, obstetrics/gynecology, and every other department in an academic medical center.

What, if anything, predisposed this institution to be so welcoming to a department of pain and palliative care?

While I was being recruited, I really tried to find out the answer to that question because it was difficult to believe. I came to understand that there was a very long tradition at Beth Israel of humanistic health care, and a very strong commitment on the part of a senior leadership that had all worked together for many years.

Beth Israel began as an infirmary on the lower East Side set up to care for first-generation Jewish immigrants, who were not allowed to enter any of the uptown hospitals. There has been a very long tradition of care for the poor and populations that are underserved or excluded. It was the first hospital to do away with isolation approaches for patients suffering from AIDS and one of the few to establish a hospice program. In the early 1990s, a few years before I was recruited, the hospital allowed a reporter for *The New York Times* to review the charts of more than ten patients who had died in the hospital, interview the family members, and discuss in-hospital deaths in New York City. This ended up being a front-page series, and it occurred at a time when the whole concept of discussing end-of-life care in the media was not happening as it is today. It took tremendous courage for the hospital to be so open about this subject. The concept that people don't go to hospitals to die, but rather to get fixed, was so embedded in the American conscience that it was a really courageous act to actually admit that people die in our institutions, and that care of the dying is part of what we do. Parenthetically, I remember reading that series in the *Times*, turning to my wife and saying, "Boy, this is so unusual for an institution... I wonder if they're interested in palliative care, and would want to hire me to do it?"

The Changing Financial Environment of Health Care Institutions

In discussing the genesis of my program, I think it's very important to note that the difference between 1997 and 2001 in terms of the financial viability of institutions in New York City is like night and day. In 1997, Beth Israel was coming off of a very long period of surpluses in the operations budget. It had an annual investment budget that was between 50 and 60 million dollars

for capital improvements and program development. It was pursuing the concept of centers of excellence in a variety of different areas — complementary medicine, cardiac disease, cancer — and the new focus on pain medicine and palliative care was consistent with the vision of growth and investment.

Between 1998 or 1999 and the present, there has been an incredible financial turnaround in the hospitals in New York City. All of the major hospitals are losing money on their operations now. The hospitals are refinancing debt, and investment income is way down. I have no question at all that the hospital couldn't even consider starting a program like mine now, and, in fact, it's to their great credit that they're so totally committed to sustaining my program at a time of so many financial challenges. But, unfortunately, the idea that this could happen now on the scale that was originally offered to me seems unrealistic given the current financial environment. Rather, institutions like mine will be seeking ways to start smaller, phasing in programs as interest grows and the financial implications become clear. If there is commitment, I am sure that this can still happen. The extraordinary "right place, right time, right people" opportunity that I had might be harder to come by, but things can happen if there is willingness to explore the concept of a specialized palliative care model, to think through the financial stakes, and to work together on a viable business model.

Financing a complex, comprehensive program of care

How is your program financed overall?

Because of very complex accounting methodology, the lack of cost accounting, the fact that revenue streams originate in so many different places, and the fact that personnel can be placed on many different cost centers that are themselves sustained by different revenue streams, it is incredibly difficult to answer that simply. Speaking in general, all programs are essentially funded through some combination of clinical revenue, philanthropy, and grants, and clinical revenues are generated only by certain personnel within a department — physicians, nurse practitioners, and psychologists. My department has eight physicians, two psychologists, and several nurse practitioners who have limited practices. Staff that do not generate revenue include a social worker, many nurses, a chaplain, and support personnel. I would guess that the clinical revenue from the collections generated by those individuals who can bill for services support only a very small piece of what we provide in terms of services. Other revenue to the institution generated by these clinicians — by admission to the hospital, facility fees for procedures, new patient referrals, and the like — cover some of our work as well.

Some of the staff are being supported by hospital revenues generated directly through our inpatient unit. We have a 14-bed closed inpatient unit that we try to keep occupied with patients who need our services. The patients in that unit are either hospice patients or non-hospice palliative care patients, or patients with pain who are being admitted for some appropriate reason, for example, the trial of intraspinal therapy or treatment of a pain crisis. The hospice patients are paid by the hospital per diem rate, and the others are paid under the DRG (Diagnosis-Related Group) rule. The hospital realizes income from those admissions and that money is used to support the staff of the inpatient unit.

We also have a large amount of philanthropy that we generate from industry, from corporate America, and from foundations. Much of the philanthropy goes to support educational programs, such as a program to create a clinical guideline for the care of the imminently dying inpatient, a caregiver program, a program on cancer-related fatigue, and a program on Internet educational activities. We have a very large website² that has generated millions of dollars in philanthropic revenue in the last few years. It does this because there is a very profound need out there, both

among the corporations that sell medications that may be used for symptom control, and also among philanthropies, to use the Internet in a positive way.

Finally, we also try to obtain government and corporate grants to support our work. The clinical guideline for the care of the imminently dying, which we call the Palliative Care for Advanced Disease (PCAD) pathway, actually began as a grant from New York State. We also do many clinical trials, most of which are industry-sponsored.

All our grants, in addition to providing direct revenue to support personnel in my department, provide an indirect payment to the institution. When the institution is making a decision about whether or not to continue the salary of our social worker, our nurses, our support staff, our administrators, they also look at these contributions to the general operating fund provided through indirect payments from grants and philanthropic contributions. So, our fundraising success has had both direct and indirect benefits for our program.

One last statistic gives a sense of the complexity of funding for the department. About 20 people in the department, those in our Institute for Education and Research in Pain and Palliative Care, are entirely supported by soft money—grants and philanthropy. About 60 or 70 people are entirely supported by our hospice budget, which will only provide support for those who are actually working for hospice patients. The staff of our inpatient unit is partially supported by hospice dollars and partially by hospital operations. And the rest of the department, some clinical people and some support staff, are funded almost half through operations, almost half through grants and philanthropy, and the rest through the hospice budget. The doctors are all full-time and, in one way or another, are ultimately expected to support themselves. As I said though, the clinical income that we generate still is insufficient to support the clinical work we do, and it's completely irrelevant to all of the programmatic work we do. We are dependent on grants and philanthropy to support a lot of people.

Patient Referrals and Integration with Other Hospital Departments

How do you get your referrals?

Our ability to interact with the various departments in the hospital is very much service-dependent. So, for example, we have a very strong reciprocal interaction with oncology. This includes not only a large number of inpatient consultations, but also two sessions per week for ambulatory patients that are devoted to pain and palliative care and occur right in the cancer center. Each week, the director of cancer supportive services attends the interdisciplinary meeting of our departmental Palliative Care Division. So, we have a very strong interaction with oncology. We also have a strong relationship with the AIDS program, and we have set up a weekly ambulatory session right in the AIDS center, which is manned by a physician, who is a palliative medicine specialist, and a fellow. In addition, we have a strong program in sickle cell disease, which includes a specialized monthly treatment session that involves both music therapy and pharmacotherapy for pain, as well as other palliative care interventions needed by that population.

Beyond that, our specific relationships with other departments are very much *ad hoc*, really based more on whether or not an individual attending physician thinks his or her patient may be appropriate for our service. We have very little integration with the ICUs at Beth Israel, in part because the ICU attending staff has a very strong interest in end-of-life care and actually is widely regarded as having a high level of expertise in that area, which predated my coming here. End-of-life planning, the withdrawal and withholding of life support, the ethical basis for intensive care medicine — all of that's happening on our ICUs at a very high level. In fact, the person who runs

the program has contributed a chapter to a new and highly regarded book on end-of-life care in ICUs.³ BIMC does have an ethics department, which is separate from ours, and ethics consults are sometimes requested in the ICU.

We are involved with the Emergency Department in terms of pain, but not palliative care. We're not too involved with geriatrics, a historical situation that we've been working to change. We've incorporated our PCAD project into the geriatrics unit as an outreach effort, and have begun to train geriatrics fellows.

Is this one of the challenges facing you—do you feel the need to generate more referrals, to expand into these areas?

I think that as a general rule, health care providers and administrative staff in institutions don't understand what palliative care is. There is still a tendency — which in some places is strong and in some places is very subtle — to link palliative care simply with end-of-life care. As those in hospice organizations have learned, if you link programs specifically to the imminence of death, you have a problem. Because we're not good at predicting when death is going to occur, and because all of the psychological, social, and medical reasons that focus on providing aggressive life-sustaining therapies in institutions, this simple linkage tends to work against trying to provide concurrent, comprehensive, coordinated palliative care.

So I think that we're constantly in a situation of trying to educate about who we are, what we offer, and how we are going to integrate ourselves with the primary team. We do not try to take over the care of every patient, but rather, want to work with the primary team to assist or to comprehensively manage the quality-of-life-oriented care. We're available to provide a comprehensive team approach to patients who have very far advanced disease, whether or not they decide to opt into hospice. It's a constant, ongoing effort to educate every new generation of house staff, and to educate physicians who are disinclined to believe in this new field. The process of education and integration is one that has to be addressed at multiple levels.

Lessons Learned: Outreach

What are some of the lessons you have learned that you perhaps did not anticipate?

The first lesson was *outreach*. One of the things that I really strongly believe in now is the necessity of outreach. I didn't believe in this so much, or didn't understand how important it was when I first started at Beth Israel. By outreach, I mean setting up programs in the cancer center, setting up programs in the AIDS center, setting up programs in long-term care facilities, setting up programs in geriatric units, setting up PCAD-type programs to actually provide unit-based tools for end-of-life care. The goals are to create models within our model, so that palliative care can be "owned" by the clinic, the service, or the unit. Neither the understanding of what we do, nor the referral of patients as a consequence of this understanding is going to happen automatically. With growing concern about the economics of health care, the tendency to be "territorial" about patients may be increasing and this works against the kind of easy sharing of patients between services. There has to be a more compelling reason to make the referral. Having specialists with a high level of expertise at the sites where potential referrals originate facilitates referrals and education. That's very much what we're trying to do now.

Lessons Learned: System Change through Quality Improvement Mechanisms

The second lesson is *the power and the necessity of system change through quality improvement mechanisms*. As a

physician, I wasn't really imbued with quality improvement (QI), except insofar as I understood that everybody had to collaborate with those people doing those QI projects.

One of the first things that I did when I got to Beth Israel was to hire Marilyn Bookbinder, PhD, RN, who is an honest-to-goodness, bona fide quality improvement expert. [\[See Featured Innovation: Part II.\]](#) I began to participate in quality improvement activities both in our own department, and also through an outreach mechanism in other departments. Through this involvement, I began to feel at a very personal level what the literature shows, which is, basically, you don't ever create practice change just by telling people things. Lectures don't work, and reading materials don't work. What works is creating changes in a system such that people's behavior is shaped in a way that leads to a higher standard of care. It's raising a standard of care by creating system change. The best way of doing that is by providing people with the tools to take ownership over the change mechanisms that allow them to achieve a higher standard of practice.

This was really a profound lesson for me. I'll give you two examples. When I came to Beth Israel, the Jacob Perlow Hospice program maintained an 8-bed hospice unit that had been in existence for about eight or nine years. Only patients who were hospice patients, and only patients who had signed DNR documents, were allowed to be admitted there. The standard of care on that unit was very much devoted to providing a dignified and comfortable death. The staff used basic symptom control techniques and provided wonderful psychological support for the patients who were gravely ill, and also for families. That was the goal of the unit, and that was how it operated.

When I came in, the institution renovated and converted the unit into a 14-bed unit for the department, which would care for hospice patients, non-hospice palliative care patients, and pain patients. On this one unit, we could have a 30-year-old man with low back pain, who is entirely healthy except for chronic pain being treated with a neuraxial therapy, and a person dying of some serious medical illness, who may or may not be a hospice patient.

Challenge of Converting from a Hospice to a Palliative Care Unit

The challenge in converting this unit was enormous. We had significant staff turnover despite repeated in-service training and meetings. We needed to get a new nurse manager. Slowly, however, using QI as the foundation, we made this transition to a wonderful and unique unit. It would have never happened without the emphasis on creating policies and procedures in collaboration with the nurses, so that there was a sense of collegiality, support, and ownership over change. For some people it was too much, and they left. Others have really bought into our model, and they're going to be with us for the duration. That was the first dramatic example of how system change is the stuff by which one raises the standard of care.

Creating a Clinical Pathway for Palliative Care

The second example is PCAD. We had begun to do something like this clinical pathway at Sloan-Kettering. Marilyn Bookbinder and I recognized that there was a need to improve end-of-life care in the institution, and that the best mechanism for doing this was one that encouraged system change through quality improvement. We created this clinical guideline, implemented this quality improvement model, and we now have data that really shows that after just nine months of piloting we have had significant improvement in a whole variety of outcomes related to end-of-life care. [\[See Featured Innovation: Part II for interview with Marilyn Bookbinder.\]](#)

It's very dramatic, and also very profound to think of how little is accomplished with all the lecturing and all the writing, unless it is linked to system change. All of the didactics are needed and may have

subtle, culture-changing impact. But if you want to go into a place where people are sick, and get them better care, you have to create systemic change.

Does the same staff care for the patients who will go home and those who won't? If so, how stressful is that for them?

Yes, it's exactly the same staff, and I think that there are no easy answers to that question because the stresses involved in caring for the imminently dying can be very significant. There is clearly a great deal of stress in caring for sick people who are highly symptomatic. I think there's less job stress if the patients one is dealing with are not so symptomatic. If a patient has pain, depression, and family disruption, there's going to be stress associated with interacting with that patient, whether or not the context is serious medical illness. If there's serious medical illness and death is imminent, sometimes the stress is more difficult, but sometimes there's an acceptance, a sense of support from the family that makes those experiences less stressful for a staff. In our environment of both pain and palliative care, the sources of staff stress can be very complex.

In all honesty, when I started at this institution, I did not really understand the complexity of creating a unit environment that could support the state-of-the-art management of such diverse patients, all of whom have high level of symptoms, distress, and sickness of one type or another. I was naïve in my understanding about how to really approach the creation of a support system for staff. I think what I learned is that, for any program that establishes an inpatient unit as part of that program, attention must be paid. There has to be time, expertise, and reassessment of the status of that unit to make sure that the standard of care continues to be at a high level, and that the staff members are supported, because it's a very tough place to work.

Hospice as a Resource in the Integrated Model of Care

What is the relationship between your program and Jacob Perlow Hospice? What distinguishes the care provided by the hospice, as opposed to the care provided by the palliative care division of non-hospice patients that nevertheless might receive hospice-like care?

With my arrival at BIMC, the Jacob Perlow Hospice (JPH) was administratively placed into the Palliative Care Division of my department. Initially, that didn't mean too much. The hospice has its own executive director, Paul Brenner, MDiv, a very well known figure nationally in hospice. JPH had its own policies and procedures, and its own tradition of providing care for both outpatients and inpatients. There was limited physician involvement.

The process of creating an integrated model, in which hospice is considered to be a resource for end-of-life care within a broader model of palliative care, is still ongoing. It has been quite challenging given the regulatory and procedural realities of the hospice, and given that hospice is mostly home care, which means that most of the practitioners have very little interaction with the rest of the palliative care team. But this process has actually begun to create some very interesting outcomes that I do think make it a model worth continuing. When we started, we hoped that the integration would result in both an increase in hospice census and an increase in length of stay. We have succeeded in increasing the census, which averaged about 80 when I arrived at BIMC and is now about 105. Our length of stay bumped for a while, but then settled back where it had been.

One of the most important points was for everybody to get on the same page about what our vision was in terms of this integration. In a variety of settings, the leadership of the hospice and others from the department used both clinical team meetings and administrative meetings to discuss the

critical issues, such as continuity of care, involvement of departmental physicians, and staff training. This has continued to take place at our weekly interdisciplinary team meeting, at which hospice and nonhospice professionals sit together to discuss cases. This meeting facilitates referrals into hospice and has worked well.

The first thing that we needed to do to make that happen was to look at the resources provided by the hospice program and the rest of the program in the Palliative Care Division, and ask the question, "Is it possible to create uniform services, which, to the extent possible, are provided by the same professionals?" The inherent challenge is that the hospice budget must fund individuals who are doing hospice work, and this necessitates complex accounting mechanisms if we want the same persons to provide both hospice and non-hospice palliative care. Most of the home-care nurses, social workers, and so forth, are spending their entire day in the field, and we could not have these people also perform hospital-based work. The logistics, along with the funding mechanisms, are very complicated. Ultimately, we decided that the hospice nurses and social workers would continue to care solely for hospice patients.

When we looked at the non-hospice palliative care part of our work, we realized that we were in need of a chaplain and volunteer services. We convinced one of our hospice chaplains to accept half his salary from the non-hospice budget. The same chaplain is now actively involved in the care of non-hospice palliative care patients and the hospice patients. This provides a beautiful mechanism for continuity of spiritual care.

We also tried to create a joint method for providing volunteers to patients. The Jacob Perlow Hospice program has more than 165 volunteers and a very good volunteer support program. In the hope of providing similar services in the home-care environment, we funded, through philanthropy, a half-time volunteer coordinator to try to bring volunteer services to non-hospice palliative care patients. That is something that actually has *not* worked out as we had expected and we ultimately eliminated this position. For a variety of reasons, the number of nonhospice palliative care patients who could be hooked up with a volunteer in the outpatient setting was small and did not appear to be growing as we became busier. In the end, it was more efficient for us to focus outpatient volunteer services on the hospice population and to continue to work on integration of volunteer services for inpatients.

In contrast to our failure to get a vibrant outpatient volunteer program going for the nonhospice patients, we have been successful in using volunteers on the inpatient unit. The volunteers on the unit do a whole range of activities, such as feed patients, provide support, read to patients, that sort of thing. They now work routinely with both hospice and nonhospice patients.

We not only asked how the palliative care program could become more "hospice-like." We also asked, "What are the things that need to be improved in the hospice?" There were two general areas. The first was the care in the inpatient unit, which needed to be broadened to include the intensive medical piece, particularly for patients who weren't imminently dying. The second was that the home-care nurses needed to have access to physicians with palliative care expertise. Like most hospices in the country, the medical piece for the Jacob Perlow Hospice was very limited before my arrival and did not include access to a medical director who was a palliative medicine specialist.

We have been able to offer to our hospice home care patients access to a palliative care physician through telephone contacts with physicians in the department and through a small program that we call "The Drop In Program." Any hospice patient who is visited by a home-care nurse and is perceived to have a need for medical evaluation can be brought to our unit by ambulance, and be evaluated by a palliative medicine specialist. This includes patients whose care has been transferred

to the hospice medical director and those whose care continues to be managed by an outside physician. As long as the primary attending agrees to the consultation, that patient can have at least some access to a specialist in palliative care.

There are other things that we must do. We have plans to begin piloting a physician home visit program for the first time this year. I have no idea yet whether or not it will be successful or sustainable, but it makes sense conceptually. Hospice programs in various parts of the country have found that physician home visits can be a very powerful way to provide physician input within the interdisciplinary team approach. Palliative-hospice care linkages can be further engendered and improved by having physician home visits that can go either to palliative care patients or to hospice patients, without regard to how the bills are being paid.

Insights to Guide Others Embarking on Similar Efforts

What, for you, have been the most difficult and challenging aspects of this whole process, that would give some insight to someone else who's embarking on this road?

Create a strategic business plan. The first insight is that individuals who want to do program development in this area have to learn to speak with the business people at the hospital. As a physician, I was never taught to do that, and at Sloan-Kettering, I was generally protected from it. I never had to learn how to create a business plan, elaborate a needs assessment in a way that made sense to the business people, or do a resource assessment, so that one could determine whether or not there were existing resources that could be linked to new resources for program development.

Administrators in hospitals think in these terms. As the climate in the health care gets more fiscally tight and as money for program development gets harder to come by, people who want to do program development in palliative care must learn how to speak the language of those who are running the institutions. They have to learn how to be fiscally responsible, to monitor profit and loss in a way that helps demonstrate sustainability of a program. They have to learn some basic tenets of business, or they have to know how to ask for help from appropriate people and bring them into the team.

I've made a very strong effort in my role as department chairman to talk to the administration in the language of the business plan and the strategic plan. I try to communicate in a way that doesn't appear to have me asking for more and more and more, but rather places me in partnership with the institution, aware of my fiscal obligations. The goal lies in trying to create good business opportunities, while providing things that are good for our patients.

I also ask a lot of questions of others who know more about this than I do. I have an administrator who is much more savvy about some of the inside business aspects of the institution. For others who are building programs, it is good advice to strive for both a detailed understanding of the business side and access to those who inevitably have more knowledge and skills in this area.

Try to mainstream palliative care. Palliative care and hospice are not yet mainstream. In the process of creating palliative care programs, particularly those that link in a meaningful way to hospice, we must work to mainstream what we do. What this means is constantly reaching out to other departments, services, units, and individual health care providers. We need to teach them about what we do, and to change the systems within which they work, so that they can begin to participate in expert palliative care and know when to make a referral to a specialized service. I think that the process of mainstreaming is going to take at least another decade, but will probably be the difference between sustainable programs and the whole movement being just a flash in the pan.

Define palliative care as a specialist service. The third thing I've learned is that we who are doing program development have to continue to portray ourselves as offering specialist-level care. We have to work to define what that means in a very clear way, and understand that the most likely way that we will be integrated into mainstream medical care is as a specialty service comparable to any other specialty service in medicine, such as cardiology, gastroenterology, or neurology.

What that realization means, in part, is that those of us who are doing program development are obliged not just to develop our own programs, but also to try to do things that raise the overall level of care for those patients who are not being referred for specialist-level care. This obligation will work to our advantage because a higher standard of generalist level care will facilitate appropriate referrals and create better ways of integrating with primary teams. We have an obligation to reach out to those teams and encourage them to realize that they actually provide services that fall under the umbrella of palliative care every day. They need to value the quality-of-life interventions that they offer, and recognize when specialist-level care is needed to provide help at any point through the course of the disease. As specialist-level teams, we are particularly well suited to offer help at the end of life, because that's when most of the help seems to be needed.

What would you like to improve in your own program? What do you feel you do best and what would you like to do better?

There are several things that we really have to do. The first is to reach out to the long-term care community. We have a grant written, which has not yet been funded, to establish our model in one nursing home in the New York area. We have contracts to provide hospice services in some nursing homes, but have not yet created a broader model of palliative care in any facility. Our hope is to use access to hospice as a first wedge to open the door to program development based on a link between palliative care and hospice. The need for this type of palliative care in long-term care is staggering.

The second thing we must improve is the system for continuity of care for patients who are consulted on in the hospital and then go home. Too many of these patients could benefit from our case management approach to palliative care in the home environment, but are lost to follow up until the next time they are admitted into the hospital.

What are some of the barriers to further improvement in this continuity of care?

There are many reasons for problems with continuity of care, some of which we cannot solve. The barriers include primary teams that do not encourage the patient to follow up with us and our program, and patients who are already so burdened in getting medical care from multiple different venues that the idea of seeing one more service makes it very difficult for them. Other barriers are financial and systemic. Many of our patients at Beth Israel are indigent; they may lack insurance or have chemical dependency problems. Continuity in general is problematic in these cases. Some patients have insurance, but the coverage makes it difficult for the patient to follow up with us. They may not have money for transportation, or, they may have a deductible on their insurance company that they haven't met yet, so they can't pay for extra services.

We have enormous system problems to address. As an example, the doctors in my department variably participate in something like 23 separate managed care programs, as well as Medicare and Medicaid. The programs have different formularies, different in-network and out-of-network stipulations for what care can be offered, different pre-authorization requirements. Every one is different. So, when you think about taking a patient who's already seeing a radiation oncologist and a medical oncologist, and then providing access to a palliative care medicine specialist, a nurse, a social

worker and a chaplain, all the while ensuring the ability to obtain drugs for symptom control, and maybe equipment—you can imagine the complexities of dealing with multiple reimbursement systems to make this happen routinely.

To sum up, with all of these efforts that are underway, what do you feel your program does best?

I think we have the unique capability of providing both an interdisciplinary model of palliative care to patients who are not hospice candidates and a system for transitioning patients from non-hospice palliative care to hospice care at a specialist level. When this works well, this type of model has the capability to provide people with serious illness a very sophisticated level of care for months or years. This is what we mean when we talk about providing patients with comprehensive quality-of-life-oriented care, including intensive palliative care at end of life. When we're able to do it well, when the stars align so that we have the support of the primary team, and a patient and family in our system with adequate resources, we are able to offer a level of integrated care that provides continuity across venues of care, across reimbursement systems, and across disease trajectory from early to late. That is really state-of-the-art, in my opinion, and that's what we do the best when it works.

References:

1. For the full UHF Report, see: Hopper SS. *Building Hospital Palliative Care Programs: Lessons from the Field*. New York, NY: United Hospital Fund of New York, 2001.
2. <http://www.stoppain.org> is the website. See the [Resources and Tools](#) page for description and links to specific tools.
3. Curtiss JR, Rubenfeld GD, (eds.). *Managing Death in the ICU: The Transition from Cure to Comfort*. New York: Oxford University Press, 2001.