

Featured Innovation: Part 3

The Providence Active Palliative Care Benefit:

An Interview with Karen Bell, RN, BSN, MBA and Rick Warren, APRN, BC

Providence Health System in Portland, Oregon is a founding member of the Supportive Care of the Dying Coalition and one of the three winners of the 2003 Circle of Life Award. This comprehensive health care system includes two tertiary care hospitals, one community hospital, hospice, palliative care services, ambulatory care services, an HMO, and a Program of All-inclusive Care of the Elderly (PACE) site. This health system was selected for excellence across all these settings, but in this issue of Innovations, we focus on their design and implementation of their effort to provide a more seamless continuum of care for patients approaching the end of life called 'Providence Pathways.' In this following interview conducted by Innovations Staff Editor Holly D. Sivec, Karen Bell, director of both the Providence Portland and the Providence St. Vincent hospice and palliative care programs, and Rick Warren, an advanced practice nurse describe the design and implementation of the Providence active palliative care (PAPC) benefit. This bridge program was created to meet the palliative care needs of a group of patients who did not fit neatly into current reimbursement schemes. Staff from Providence participated in the Institute for Healthcare Improvement (IHI) Breakthrough series on advanced congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD). The PAPC benefit reaffirms the need for bridge programs for people whose needs do not match current hospice and home care regulatory requirements, and offers evidence that comprehensive health systems can find ways to provide palliative care to a broad range of persons.

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Need for a Bridge Program

What sparked Providence Health System's interest in creating an active palliative care benefit to bridge home care and hospice services?

Karen Bell (KB): We felt that there was a significant patient population who might not want or be appropriate for hospice care or home health care. In 1995, we came to the realization that hospice wasn't meeting the needs of all the people that we had in our health system, and home health wasn't able to fill the gap created by hospice regulations. To be eligible for hospice care under the Medicare Hospice Benefit, patients must give up any active treatment and have a prognosis of six months or less to live. Thus, hospice personnel didn't have the ability to go in and provide comfort care to patients who were getting active treatment for a life-threatening illness. Similarly, home health services are also constrained in what they can provide by regulations, which state that the patient must need skilled care, such as nursing, physical therapy, or occupational therapy. As you know, the focus of home health is really on *rehabilitating*

patients to regain their previous level of functioning or to become stable at their current rate of functioning, for example, after a stroke or following some other serious illness. Home health regulations spring from a model that does not include dying, or the assumption that excellent care and a downward trajectory of decreased function can be compatible. So, we made the decision to look outside of hospice and home care to create a program that could address the needs of patients who are not getting better. These patients are not so close to dying as to be eligible for hospice, but need excellent pain and symptom management, attention to psychosocial and spiritual issues, and a comprehensive overall plan of care that acknowledges both their disease and the value of aiming for best quality of life.

In the early to mid-1990s, we began thinking more carefully about an active palliative care benefit, in part, because of our brief experience with a pediatric hospice benefit, "Bridges for Children," which led us to rethink the boundaries around adult palliative care. The pediatric program made clear the awful dilemmas families face if forced to choose between treatment and supportive care—they can't. We found that payers wanted to pay for hospice-like care for children by using home health benefits. These benefits were quite limiting for social work, and offered no coverage for some of the other needs these families had, such as for art therapy, or even nursing unless we could define the care as "skilled." This resistance among third party payers meant that it took time for the idea of a palliative care benefit to take hold.

Pilot Program with the IHI Collaborative

Rick Warren (RW): In February 1999, Providence sent two teams to participate in an Institute for Healthcare Improvement (IHI) Breakthrough series on advanced congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD). I was the lead on one of those teams. Our charge was to develop more comprehensive, more seamless ways to deliver care to patients with end-stage CHF and/or COPD.

By early March, we put together a small team, including a nurse practitioner, a social worker, and several supportive physicians. We developed a plan to case manage a small group of patients with advanced disease. To our surprise, we had no difficulty gaining physician buy-in nor in finding physicians who would agree to refer patients. We used Dr. Mimi Pattison's screening question (Would you be surprised if this patient died in the next year?) as a way to determine which patients might benefit from this kind of intervention. Those patients for whom the physician's response is "No, I would not be surprised" are deemed eligible for the bridge program. This question has proven an effective way to get physicians to identify patients who might benefit from such a bridge program,¹ and they quickly identified 51 patients.

Were the patients receptive to these extra services?

RW: Well yes and no. The physicians sent letters to these 51 patients letting them know I would be calling and offering additional services to them at no cost. The letter explained that the goal of these interventions was to help them avoid exacerbations (bad days), help us better understand their preferences (complete advance directives and Physician Orders for Life-Sustaining Treatment, a document referred to as the POLST),² and help them access community services. (The POLST form was developed in Oregon and is a physician order that records the patient's preferences about CPR, antibiotics, IV's, and tube feedings. It is signed by a physician or nurse practitioner and is honored by emergency response providers.)

Interestingly enough, almost exactly half of these patients said, "You know, I see a specialist, I'm happy with my primary physician, I really don't need any additional help. So, thank you, but no thank you." The other half were very grateful for the service. So, although we didn't think much about it at the time, we had a built in control group.

I made regular contact with the 24 patients who were enrolled in our pilot. I provided education (most often about medications, disease process, or symptom control), support, values clarification, advance care planning, and access to resources. If these patients expressed a need to talk to a chaplain or social worker, I helped them access these resources.

The last session of that IHI Collaborative was in September 1999 and we continued our interventions through November. After that time, we phased out the CHF/COPD program and rolled our learnings, and any of the patients who agreed, into our other programs. This allowed us to continue to provide service to these patients as we developed new programs and interventions.

As we concluded the CHF/COPD pilot, we assessed patient satisfaction and cost of care. We noted a significant increase in utilization of community resources and advance directives or POLST forms in the study group. In addition, patients in the intervention group were very satisfied with our care: 93% reported that they were "more satisfied" with their medical care after the intervention as opposed to prior to it, and felt that we had helped them avoid at least one acute admission. They reported that as a result of participating in the program they had a better understanding of their medications and were able to manage symptoms better than prior to the intervention. We also looked at costs of managing their CHF and or COPD. The average cost for acute care for the study group was \$1.86 per day, while average cost for the control group was \$14.70 per day. We analyzed these cost differences over the course of the IHI participation, or approximately six months, and included only those costs related to this primary diagnosis. Most of the difference came from the higher rate of hospitalization among the control group, and from what we observed as better and more effective use of medications by members of the intervention group. One illustrative example: One doctor of a control patient was stymied as to why that patient was not doing well. When I visited that patient I noted that he was squeezing his inhaler 18-20 inches away from his mouth, so not getting an effective dose. Start up costs for the program, including my salary were not included in these cost comparisons—these numbers just reflect patient health care costs. While there were many limitations to this study it helped us garner more supporters and fueled enthusiasm for more comprehensive, seamless, cost effective end-of-life care.

Providence Pathways: Organizational Structure to Mirror Continuum of Care

KB: From an organizational standpoint, we wanted to create a reporting structure that took what we know about end-of-life care seriously. Patients' needs don't fit into current reimbursement structures easily. We wanted the bridge program and other outpatient programs addressing the needs of seriously ill patients to be under my auspices, as head of a new organizational structure named "Hospice and Palliative Care." At the same time, we created a cost center for palliative care to keep the charges and costs associated with palliative care separate from hospice.

Creating a seamless continuum of care for patients approaching the end of life has long been our goal. We now speak of end-of-life care, which includes traditional hospice care, the active

palliative care benefit (our bridge program), the Community Cares Project (a partnership with local churches), *Connections* (a telephone monitoring program run by volunteers), and all the evaluations, consulting, and outreach work done by the nurse practitioners. We chose the name "Pathways" as an umbrella that encompasses all our services.

What we have been able to do is to identify patients who are approaching the end of life, earlier on. Once they are identified, we can provide information that enables patients to make more informed choices, address their concerns, access services, and the appropriate level of care. Most importantly, we hope to help them remain in charge of their medical care, and direct it to meet their own needs, incorporating the kinds of care and support that they require.

The Evolution of the Active Palliative Care Benefit

On average, how many patients are receiving this "bridge" care per year?

KB: This year (2003), we've had 155 patients in the palliative care program. That's probably about ten percent of the number of patients that hospice will serve; we anticipate that approximately 1,600 patients will enroll in hospice this year.

Financing: Choosing a Per Diem for the Palliative Care Benefit

KB: The palliative care benefit is a defined, reimbursable model of care for us and covers only direct care. It's paid on a per diem basis, and includes all the core services including nursing visits, pastoral care, social work, and home health aide visits. The per diem does not cover medications and medical equipment. We carved out all the treatment, dressings, medications, equipment, and supplies that the patient would be getting so as to make the per diem more affordable, and to allow for treatment to continue, even as we provide supportive care.

Although the per diem is much less than the hospice per diem, this seems to be a financially viable program because we are not at risk for absolutely everything. This system allows us to work with patients who may be getting very aggressive treatment and to help them transition to hospice, as they are ready. We can provide pain, symptom control, and all the necessary supportive care and information they need to make informed choices.

There was some interest in having the palliative care benefit be paid on a fee-for-service basis; similar to the model used for home health services. We chose to use a per diem because it allows us the flexibility to use the appropriate resources without having to consult the payer for authorization each time we made an additional visit or when an unexpected change in the care plan was required. We wanted the flexibility to be able to provide pastoral care and other services, which are traditionally not covered under fee-for-service model.

In 2000, we were finally able to sign a contract with the Providence HMO that would permit us to offer patients an active palliative care benefit for which we would then be reimbursed. We continue to talk to payers at every opportunity to ask for the chance to prove to them that palliative care can improve care, produce cost savings, and improve member and physician satisfaction.

RW: We try very hard not to use the active palliative care benefit in place of hospice. It is not as comprehensive and was not meant to be a hospice substitute. We try to be very clear about that

with patients and payers when we explain what the program offers. The idea is to serve as a bridge program and give these patients and families time to adapt and make choices that are in keeping with their values systems.

It seems to be a win-win situation. Physicians are grateful to be able to offer these additional supportive services to patients (with advanced illness) who would not yet qualify for hospice. Patients and families are appreciative of the additional information, support, and comfort care services. Payers find that this program is cost effective and that these patients often access hospice services earlier, and the reimbursement to our palliative care program seems to be fair and reasonable.

Patients and Families: Needs-Based Care

Can you give me an example of a patient the active palliative care benefit might serve?

RW: Just yesterday I received a call from a woman expressing concern about her elderly father. He was diagnosed with recurrent adenocarcinoma of the lung and was receiving a course of radiotherapy. Halfway through the course he was losing weight, eating less, was in pain, more short of breath, and being worked up for a possible pneumonia. Placed on a break from radiotherapy, the family was left to consider options for his care. Home health had been ordered and they were addressing the pain, nutrition, and shortness of breath. The home health nurse I spoke to felt her involvement in this case might be brief. She sensed that the family needed more, but realized that they were not yet ready for hospice care. The family member and the home health nurse expressed concern, confusion, and frustration. I receive multiple calls like this every week. The names, diagnoses, and stories change, but the calls are all about patients who aren't being optimally served by our current models of care. Without any kind of bridging program, this patient would likely slip through the cracks. They might get optimal medical care or optimal end-of-life care, but too often they don't receive both.

KB: The program we've created is aimed to meet this kind of patient's needs. He doesn't have to qualify for or choose hospice, and he doesn't have to be getting better. We can actually frame care based on patient needs here, rather than on regulatory definitions of who can and cannot be served. We do view the palliative care benefit as a bridge program because we see it as providing a transition to hospice care, even if some patients never do get to hospice. These patients and their loved ones are making difficult decisions as to whether or not they should continue treatment or perhaps try something new. For example, we've had patients in palliative care who were potential transplant candidates, and they were on palliative care while they were being evaluated for a transplant. Two of them actually were on lists for transplants, but neither one of them survived to the point of being able to be transplanted. We aim to help people make those difficult decisions and get appropriate treatment while doing so.

Some patients receiving palliative care may make the decision to stop treatment, or the treatment may not be available to them after they've concluded their current protocol. Those patients may then be eligible for hospice care.

RW: Initially, we thought there would be a few patients who might benefit from this service, in particular, younger patients who choose to continue with therapy. For example, a young mother with metastatic breast cancer and three young children might never get to the point that she

would say, "Fine, I've lived a good thirty-eight years, just keep me comfortable." Because she chooses to continue with therapy she may not qualify for hospice, and yet, she would clearly benefit from hospice-like services. Palliative care has enabled us to better serve this population. However, the palliative care benefit has also helped us reach a population that's much broader than I anticipated.

Currently, the patients receiving care under this benefit are elderly, of Medicare age. Almost without exception these patients have multiple medical problems, including a life-threatening diagnosis. Their quality of life may be declining and they understand that their prognosis is poor. Typically, they have been offered treatment and do not yet want to rule out this possibility. Palliative care allows us to provide comfort care and the information they need to make informed choices. It offers patients additional support as they make some very difficult transitions. It gives patients the opportunity to "try on" hospice-like care. About half the patients we see have malignant diagnoses; half do not. That proportion of chronic illness-malignant diagnoses is borne out in our hospice program, too.

Staffing

Do you use volunteers in the palliative care program?

KB: We don't provide volunteers to the palliative care patients, although we've talked about doing that. However, there are some barriers to doing that. We have a large hospice program and the volunteers are pretty well taken up by providing support to the hospice patients. So, we feel as though we would need to recruit volunteers specifically for palliative care because hospice volunteers know that they have a time-limited commitment to a patient, usually for less than six months. But with palliative care, the commitment could be longer, and in contrast to the commitment made by volunteers whom we recruit for *Connections* (the telephone monitoring effort), it would involve in-person patient contact. So, we would need to be clear with the volunteers that this could extend out over a period of time. But, other than volunteers, all the other services that you would expect to see in a hospice program are provided to the patients and families receiving palliative care. Families are given the same emotional support that we would give anyone else. For bereavement care, if the patient does die on the palliative care benefit, we do a one-time mailing to them and invite them to participate in a variety of grief support groups that we run. If the bereaved person is deemed to be at high-risk, we would have a social worker make contact with that person and assist him or her with getting ongoing counseling. So, the palliative care benefit mirrors the hospice benefit in many ways.

How did you educate physicians to get them on board with the palliative care benefit?

KB: Both Rick and I spent a lot of time in physicians' offices with every doctor we could get an appointment with, as well as with their staff. We also did grand rounds at all of the major hospitals in the area and spoke with the primary care physicians and the sub-specialists. We also spent a lot of time with the discharge planners in the hospital, because they are the key to identifying potential patients.

In addition, we worked with the home health staff because it was really important that they understand this program and why we were doing it. We wanted them to understand that we recognized that it was very difficult for them to provide this level of care within the framework

and constraints of the home health benefit. Now, it's not uncommon at all for them to come to us and say, "I have a patient who I think belongs in palliative care. Can we talk about him?"

So, early on we did a lot of explaining and teaching about what the program meant and we continue to do so. Now, physicians, case managers, social workers, and staff nurses at the hospital regularly call us to inquire about, or make a referral to, the palliative care program.

Assessing Patients' Needs for Palliative Care

RW: When I get a referral from a physician, nurse, social worker, or even a family member, the first thing I do is to ask them about their concerns. Why did you contact me about this patient? I can then contact the patient and family and engage them in some dialogue about how things are going. "Tell me a little bit about your illness. Tell me about what this has been like for you this past six months or a year." Physical assessment is also part of the picture, but taking the history provides about eighty to ninety percent of what I need to know. People are usually quite good about identifying their needs, concerns, and frustrations. From that initial conversation I can get a pretty good idea of what the next steps should be and together with the patient and family we can begin to plan a course of action. It is really quite remarkable to watch patients relax and voice their appreciation for knowing that they have a guide, a resource that can help them navigate the system. Even when I'm giving bad news, patients seem to be able to take this in stride when they know they won't have to deal with this alone.

KB: I believe that nurse practitioners are ideally suited for this role for several reasons. Overall, they seem to be able to bridge the gap between medicine and nursing and combine essential aspects of both disciplines. We have come to rely on their knowledge of the medical model, superior assessment skills, ability to work with physicians, and apply the nursing process. We can also envision nurse practitioners having expanded roles in providing end-of-life care, and hope to be positioned to respond quickly if these opportunities arise.

Are you the point person for this next contact that you have with the patient?

RW: I am. Physician referrals to hospice or palliative care can be made directly to these programs. Any other type of end-of-life referral is first evaluated by the nurse practitioner. Physicians tell me that this makes it easier for them to make referrals to our programs. They understand that we will evaluate the situation and help the patient access the appropriate level of care. I am in touch with the referring physician and make recommendations. It is extremely rare that we disagree about what the next steps should be.

How do patients leave the bridge program—are they discharged? Do they die?

RW: Both. Some palliative care patients transfer to hospice when their disease progresses. Perhaps the chemotherapy isn't doing what they had hoped, or the side effects are just too burdensome, and the patient makes the decision to stop aggressive therapy. Some patients are never able to make this transition and die while still on palliative care. Other patients actually stabilize or improve, and we all agree to sign them off for a time. When we do sign patients off the program, we make every attempt to help them access community services. We would also continue to follow these patients under our *Connections* program so that they don't get "lost."

Additional Programs

What kind of service does Connections provide?

RW: *Connections* is a telephone monitoring program, run by volunteers and open to any patient in our system who has been diagnosed with a life-threatening illness, but who is not so ill as to be enrolled in a palliative care program. This program allows us to stay connected with patients and help them access services in a timely manner. We bought this element of our system directly from the Franciscan Health System in Gig Harbor, Washington. It was part of the larger set of programs, Improving Care Through the End of Life, created by Mimi Pattison and Georganne Trandum and colleagues, for which that health system received the Circle of Life Award in 2000. We adapted their program a bit and now *Connections* is often the initial entry point into our services for the end-of-life continuum of care.

Once identified, these patients are evaluated by a nurse practitioner and offered *Connections* at no cost. If they agree, they are contacted monthly by a volunteer, and they can access the nurse practitioner if needed. They often have chronic illness, such as CHF or COPD. About half have a malignant diagnosis. Although they are often functioning fairly well, they do have a disease process that is likely to be life-limiting. We have a wonderful group of about a dozen volunteers who stay in touch with these patients on a regular basis by a monthly telephone call. Each volunteer calls more than one patient and each call usually lasts for about a half-hour. The volunteer then reports back periodically to the nurse practitioner. The nurse practitioner doesn't become the primary care provider and we don't interfere with these relationships. We provide additional resources and support that generally aren't available otherwise.

Over time, the patient and volunteer develop a relationship and the volunteers can be a wonderful resource. They can help identify problems, provide information and access to resources, or just provide a listening ear as patients try to sort out their feelings and options. The fact that it is volunteer-run certainly helps keep it cost effective—as does using existing resources. We're using community resources as well as some of our own Providence resources to pull this program together.

As you would expect, a certain percentage of these patients transition to hospice care. When they do, they're much more likely to get there in a timely manner, by which I mean they have longer lengths of stay. This seems to be the common thread in all of our end-of-life programs. They allow us to recognize and identify patients in need sooner than we had been doing, provide easier and more timely access to services, gain a better understanding of patients' wishes because we help them complete advance directives, and doctors complete POLST forms and make more timely referrals to hospice.

How Volunteers Help

KB: People often ask us, "Well, how does talking to a volunteer once a month help?" First, the volunteers are trained, and the calls are scripted to some extent through a series of questions that they are given to ask when they call. When the patient or the caregiver is talking to the volunteer, often they are more forthcoming than perhaps they would be if speaking with their doctor. They'll say, "George seems to be in more pain," or "It's harder for him to get around," or "He's sleeping more." The patient or caregiver doesn't necessarily see that as a change; they're just chatting to the volunteer. Or perhaps they'll say, "I used to be able to get out and go to the grocery store. Now I can't leave my husband alone anymore." Those are all triggers that the

volunteers are trained to listen for from month to month, and they will report these changes to the nurse practitioner. If a change seems to be drastic, the volunteer would immediately call the nurse practitioner, who would then contact the physician, encourage the patient to visit the doctor, or take whatever next step makes sense. While it may seem like a very small intervention, these volunteer phone calls have really worked quite well.

One of the things I think we've learned from *Connections* is that families may not recognize changes in their loved one, because they make accommodations for people as they're changing, without quite realizing it. For example, take a patient suffering from congestive heart failure—he or she might be gaining weight and is now more short of breath. She can not walk to her kitchen chair without having to stop two or three times, or she is using more pillows to raise herself up and make it easier to breathe. Families just incorporate these new observations into how they see the individual. Until that family caregiver has a conversation with the volunteer or some other trained outsider, the family member may not make the connection between this new information and the disease progression.

Measuring Outcomes

RW: We believe that measurement and the ability to replicate successes are important aspects of this work. As I mentioned earlier, we measured patient satisfaction and cost of acute care of our CHF/COPD pilot. Although the measurements weren't terribly sophisticated, they seemed to indicate that it was very plausible to deliver more comprehensive, cost effective end-of-life care.

The measurements we compiled for the CHF/COPD pilot were specific to that program. We also wanted to measure the impact of care given by the nurse practitioners who provide education, consultation, assessment, information, and referral. When we evaluated the patients who had been served by the nurse practitioners (in any capacity), we found that they had increased use of home care services, longer hospice length of stays, and on average, a reduction in health care costs.

We just received approval from the IRB (institutional review board) to further evaluate the outcomes of palliative care. This study will be more robust, and we hope to have it completed later this year. We anticipate publishing these results, which we have not done in the past.

It is important to gather this kind of data because we feel strongly that models need to be cost-effective, sustainable (without relying on continued grant support), and replicable in other settings.

"Dow Jones" Index Tool

How have you demonstrated the effects of your program to upper management in Providence Health System to garner their ongoing support?

KB: All too often hospice length of stay is the sole indicator of the effectiveness of a hospice program. Our administrators have been very supportive and interested in our successes, but needed the information presented in a very concise format. We adapted a tool³ from the business sector that uses a family of measures index to show gains and losses in a variety of dimensions. We developed a baseline that allows us to track our overall progress quarterly.⁴ It also provides more detail so that we can evaluate each indicator individually and make adjustments as needed.

It's one sheet of paper that has come to be referred to as the "Dow Jones" because it offers a comprehensive way of looking at changes in the number of patients, lengths of stay in palliative care, hospice, and our other end-of-life programs. For example, we look at the average number of hospice patients with a length of stay greater than seven days. We look at the average daily census. We're also looking at family satisfaction, physician satisfaction, adequacy of pain control, and other quality measures. You can immediately zero in on where you are and whether you've improved from the previous quarter, and whether you're holding your own. If you haven't improved and you're declining, then this measuring tool gives us an opportunity to go back and delve into an aspect of care more deeply to see what the issue is and where we are.

Is that something you developed at Providence or does this come from elsewhere?

KB: The concept comes from outside of health care. The tool that we're using was developed here at Providence. In fact the family of measures index seems to be gaining in popularity and is now being used in the acute care setting as well.

One Picture of Success: One Person Moves Across Programs

RW: The idea behind all this is that we identify patients who need supportive care earlier. One patient that comes to mind, in fact, just died last Friday. She was quite ill when I met her in the fall of 1999. She was a part of our Institute for Healthcare Improvement CHF/COPD pilot program. She had already had two different primary sites for cancer, congestive heart failure, and advanced COPD. Her husband had died several years prior, also of COPD. She was a determined woman, a feisty lady who lived alone and was about as big around as your little finger. She had some good friends and a good support system that looked after her. She had some difficulty communicating with her physicians and we helped with that. We also helped her access some community resources that made her life a little easier, and we completed a POLST. Part of the assistance she needed was financial, part was house cleaning, shopping, and those sorts of things. With this level of support, she remained stable for quite a long time. I would visit periodically and just check in on her. Until about six months ago, she continued to refuse any additional services. In February of this year, I had the sense that she was starting to fail a bit more rapidly. I had a conference with her physician and he agreed that it might be reasonable to put her on hospice. She was resistant to this idea initially, but she agreed to hospice care at home. Over time, and as the needs arose, she slowly accepted a little bit more help. We started with bathing, first only once a week and later increased to twice weekly. She allowed our chaplain to call, but wouldn't let her come to the house. She also kept the social worker at arm's length. Slowly, she let the social worker into her life. The nurse visited more regularly. She was just getting to the point where she wasn't able to manage alone. Her good friends saw that, as did I. Just last Monday, I asked her whether she would let me come out to see her. She said, "Oh no, today's not a good day." She had never refused my visits before. I think she knew I was coming to talk to her about possible placement. Her friend visited Friday morning and she was gone. She remained independent right down to her last breath. I think she really didn't want to leave her home and knew she was going to have to before long. Fortunately for her, she died before she needed to make that move. Even with everything she had to deal with, the two different cancers and two advanced chronic illnesses, she had the opportunity to do it her way. She stayed at home and only accepted the support that she wanted and when she wanted it. Under the circumstances, I don't know how one would improve on that.

She got everything she wanted and everything she needed. She was comfortable, she let the people in that she knew and loved, and she was able to stay at home. Without the levels of support we provided under the CHF/COPD pilot, *Connections*, and then hospice I can foresee things playing out much differently.

Lessons Learned

What have you learned over this process of creating a palliative care benefit?

- *Be open to new ideas*

KB: One of the things that I've learned is that you have to be open to new ideas and you have to be patient. You cannot be set in your ways. When opportunities arise you have to be prepared to jump in, and take a risk. During the years when we were developing palliative care and working on getting the benefit covered, it took time for payers to understand and appreciate the concept. Fortunately we had developed the model and were ready to "come on line" very quickly when payers started to voice acceptance of this concept.

- *Recognize the need to bring other people along*

KB: I learned that you need to bring other people along. We are all passionate about what we do and understand the value of end-of-life care. We believe that we make a significant difference and have a very positive impact on people. You can't expect that others will share your passion but you can help them understand your vision. This is especially apparent in a very large health care system like Providence. This is something you just can't keep to yourself. You need to bring senior leadership along, and demonstrate the value of what you are doing. What worked for us was to go slowly in implementing the benefit, and to work closely with the case managers, requesting prior approval for each new patient.

RW: I, too, learned this early on. You have to be prepared to share your successes and information about your programs with everyone who will listen. Over and over and over again. It is a little like water torture, except you smile a lot and take food with you.

- *Communicate and collaborate with staff in the acute care setting and in physicians' offices*

KB: It takes a lot of time and energy to do this, but the more people you talk to about the value of palliative care and hospice, the more you share information, the more successful you will eventually be.

- *Cultivate physician champions*

RW: I believe that it is critical to have physician champions. We have seen several worthy programs flounder because they didn't have physicians who were actively involved promoting their cause. I was actually surprised how easy it was to find physicians that were very supportive. We began sharing our vision of improving the quality of end-of-life care and quickly identified supportive physicians from the health plan, critical care, and family medicine. They, in turn, helped inform other physicians and senior leadership.

- *Meet people where they are*

KB: I think there is a very strong feeling that we can run into within the hospice care world, which is that hospice care itself should be sufficient. This came to our attention first in the mid-nineties when we were undertaking a pediatric hospice program (Bridges for Children). I had said that we would accept a child who had a prognosis of at least twelve months, not the usual six. The hospice people pushed back and said, "Well, the parents need to be able to accept the fact that the child is not going to live for twelve months or even six months." However, we also recognized that the parents had to have that level of comfort conferred by saying that my child might live for a year. I've never forgotten one child. The day we admitted this child to hospice, there was a fundraiser going on in the community to raise money for him to go to California for an experimental treatment. Yet, at the same time that was happening, with the parents' blessing, we were admitting this child into hospice. To me, this said: on the one hand, the parents believed that their child had a chance at living, but at the same time, they were being realistic enough to recognize that they needed the support of a children's hospice program. I think we've seen that with adults as well. We can't impose a level of care on them just because we think the patient belongs in hospice care. This is why palliative care is so valuable. We can help them make that transition, but we have to accept where they are.

- *Listen to patients and families and help them frame their options*

RW: It is important to meet people where they are, to hear their stories. You can listen to their hopes, concerns, and fears. You can help them understand that they have choices and empower them to discuss these topics with their physicians. You can help them frame their concerns, provide access to resources, and support them in making difficult decisions. I find that if I can just be quiet and listen, most patients will tell me what they need. Once I help them understand the options, most people make reasonable choices.

- *Be willing to share and to give up control over what the final program will look like*

KB: This kind of program is entirely doable, but you have to build a foundation for it. You can't just go in and say this is what we want to do. Again, you have to bring other people on board. And you have to be open to giving up some of the control over what it's going to look like. That was not always easy, as we both know; however, it really was important. We were willing to do that, to share this with other people and have other people's ideas, recognizing that we needed those people, even though they probably thought they didn't need us. But we needed their support.

- *From the outset, consider how you will sustain the program*

KB: You want to build a sustainable model that works in your system. I think so many times, people secure grants to create a program, but they're not building in how they plan to sustain their program once the grant ends. Although we certainly have used grants ourselves, it was always with the idea that we would be able to fund this in our maintenance budget within a reasonable period of time. If we didn't think we could do that, then we wouldn't start a program.

RW: One of the keys to our success in this area is that we started small. We used a rapid cycle improvement approach, which I learned about from the IHI collaborative. After envisioning a

change, we planned a small pilot, evaluated our success, and then expanded what seemed to be working. This way, we didn't get bogged down with months of planning and trying to figure out how to fund a much larger effort. Whenever possible, we used existing resources.

New Directions

KB: Because Medicare does not have a palliative care benefit, Rick and I are collaborating with our home health care agency to provide palliative care to patients with straight Medicare. We hope to learn from existing models, and others we discover. We know of two, one at the San Diego Hospice and one at the Hospice of Michigan. What we hope to do here is to select home care staff and train them to provide palliative care. We also want to see the palliative care benefit adopted by other third-party payers in the state. We ask these payers to cover palliative care services now on a case-by-case basis. But we're working with Blue Cross, for example, to see if they will include it in their benefit package so we wouldn't have to keep going back to them on a case-by-case basis. We also strongly support efforts to have patient evaluation visits by a physician or a nurse practitioner covered by third party payers.

Our long-range dream is to have an adult foster home for terminally ill patients. Foster homes are very big here in Oregon. I don't know if they are in other parts of the country. In Oregon, it is a huge part of health care, which developed in the mid-to late 1980s, in part to meet the needs of patients who require custodial care, but don't need to be in a nursing home. Up to five patients can be cared for in a private home. Our Medicaid system reimburses that care, which is much more personal and more cost-effective than nursing home care. It just doesn't have the institutional feel that even the best-run nursing home has. Families have found it to be satisfactory. We see a significant number of patients in foster care.

We envision that transitions at the end of life will eventually be seamless. We hope that patients will not be forced to choose between optimal medical care and optimal comfort care. Ideally, they will have easy access to information, resources, and support as their needs change. I think that as we continue to document outcomes we can demonstrate the effectiveness and cost-effectiveness of this approach, just as studies of hospice care have demonstrated increased satisfaction and cost savings. I fully expect that we will find that palliative care produces these same results.

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