

Improving Care Through the End of Life: Launching a Primary Care Clinic-Based Program

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INTRODUCTION

IN MAY 2000, Franciscan Health System West's Improving Care through the End of Life received the American Hospital Association's Circle of Life Award for innovative practice in end-of-life care. Improving Care is a primary care clinic-based program in Tacoma, Washington, in which primary care physicians identify patients with serious and progressive illnesses, talk to them about expectations for the future, and then link them to a nurse care coordinator. The nurse care coordinator works with these patients and their families to help them access community services, as well as aiming to ensure continuity of care by trouble-shooting various obstacles the patients and families may experience. In the following interview, with Innovations Associate Editor, Anna L. Romer, Dr. Pattison, medical director for Palliative Care Services and Improving Care Through the End of Life for Franciscan Health System West describes the key concepts underlying the program; the processes of identifying, contacting, and referring patients to it; and factors that impede or facilitate acceptance of this kind of "bridge" to supportive services for people with grave prognoses who are not yet eligible for hospice care. This interview is excerpted from a thematic issue, "Building Bridges for Better Continuity of Care," Vol. 2, No. 5, 2000 of the online journal Innovations in End-of-Life Care at <http://www.edc.org/lastacts/>. For further details about the genesis and implementation of the program as well as tools related to replicating such an effort, see the interview with Georganne Trandum, R.N., O.C.N., director of Improving Care through the End of Life, in the same online issue.

What are the key concepts that underlie the Improving Care through the End of Life program?

The first key concept is that one must have a true understanding of the dying process today. Dying is different from what it used to be. Today few people die suddenly; rather, the majority of people die slowly, with multiple chronic illnesses. I'm speaking from a physician's point-of-view. We get so focused on the individual condition or symptom that is causing the patient problems

that we forget to look at the whole picture. During the process of developing the program, Improving Care Through the End of Life, and in our work with the Center to Improve Care of the Dying, not only did we learn a rapid quality improvement process, but also we gained a much better understanding of what living near the end of life involves today.^a

The second important concept is a willingness to talk about death and the process of dying. Once we understand the process of dying, it is then easier to identify those patients who are likely to die

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^aCenter to Improve Care of the Dying (CICD) (www.gwu.edu/cicd/) is an interdisciplinary team of committed individuals engaged in research, public advocacy, and education activities to improve the care of the dying and their families. Joanne Lynn, MD, director of CICD, and other CICD staff, provided leadership and served as core faculty for the Institute for Healthcare Improvement's collaborative, Improving Care at the End of Life, which convened in 1998. Franciscan Health System West was a member of this collaborative.

and then we must be able to have the difficult conversations with these patients and families. It is only then that we can refer patients to supportive services and begin to improve care.

In our program, Improving Care through the End of Life, I think the biggest challenge was to identify those patients who are entering that dying phase. When I say “dying phase,” I don’t mean active dying or being within hours or days of death. I am talking about weeks or months. The program, then, is about changing the experience of this last phase of life for seriously ill patients and their families. That begins with conversation and planning with the patient, family, and physician. A key aspect of that conversation is what the physician expects will happen with the patient during the next weeks to months. Our goal is to find out what is important to each patient and family, to understand what their values are and to look at spiritual issues. We want to look more closely at symptom management and the ongoing monitoring of symptoms, and to assure continuity of care. Continuity—the follow-up and ability to resolve problems once they have been identified—is central to the program. The nurse care coordinator is the keystone of the program; she has direct access to the primary care doctor and is right in the same clinic.

Can you walk us through the process of contacting and referring patients to the program? How does the primary physician become involved in this process?

The first problem was how to get physicians to identify patients who were dying, not tomorrow, but those who were gravely ill and could benefit from supportive services, now. We tried a number of different interventions that did not work. Then, we came up with a screening question that has made all the difference. Initially, we were looking at just certain diagnoses—heart disease, Alzheimer’s disease, cancer, and advanced lung disease. So, we distributed lists of patient names to individual physicians, patients that they have seen over the last month or two, with these certain diagnoses. At the top of the list, we asked the question, “Would you be surprised if any of these patients died in the next 12 months?” If the answer to that question is, “No, I would not be surprised,” then we encourage the physician to refer the patient to our program.

What proportion of patients for whom the answer is, “No, I wouldn’t be surprised if this patient died in the next year,” does the physician actually refer to the program? Is it every single person for whom the answer is “No”? Or are there other factors that the physician is considering before referring patients to the program?

That is a key question. Other criteria, for example, the hospice criteria for pulmonary disease, often are really difficult to meet or even to remember. So, I think the question really taps into physicians’ clinical sense of what is happening for that patient. The only other factors a physician might consider would be family caregiving factors; for example, if the primary caregiver’s health also has taken a downward turn, or if he or she has been diagnosed with something new, or is failing. Otherwise, it is a one-question referral process.

Now, occasionally, some patients will enter the program in crisis, or at the time of diagnosis of a serious or terminal illness. But the majority of our patients are coming to the program through the physicians asking themselves, or being asked, “Would you be surprised if this patient dies in the next 12 months?” This question seems to allow physicians to think in a new way about their patients and those patients’ needs. It is as if a switch has been flipped. We’ve worked with our physicians so that now they will say to the gravely ill patients whom they have identified, something like: “My expectation is that this condition is going to continue to worsen over the next few weeks to months, and we need to plan for that. I have a program that I’d like to refer you to, or, I have special support in our clinic that I’d like to refer you to.” With that, the program is introduced, and the nurse comes in, takes over right there, and then talks to the patient and family. After that initial meeting, which we try very hard to have occur in the clinic, the nurse does a formal interview and evaluation process over the phone. It probably takes about an hour.

Who is at the meeting that occurs in the clinic?

When the patient comes in for a routine visit, or problems are identified, or the decision is made to refer, the nurse care coordinator often will come and meet the patient and family that day.

It may be a brief meeting, depending on time schedules. It may last 15 or 30 minutes or so. It's variable. This meeting either occurs with the physician, or just after the physician has seen the patient.

How is this meeting framed for the patient?

We tell the patient that this is about identifying his or her needs, and offering the support that he or she needs. The nurse's goal in this initial face-to-face meeting is just to provide a name, title, and phone number, with the implication that one can gain immediate access to her. In addition, she wants to communicate that she will be calling the patient, or the family member who is going to be the spokesperson, to ask for more information.

How have families been reacting to that initial opening—"We've targeted you for special services"?

In general, extremely well. Initially, however, we had some physicians in the program who were really reluctant to begin to have that "bad news" talk, and asked us to just go ahead and call the patients. We didn't call and say, "We're from Improving Care through the End of Life," but referred to the program as "Improving Care" or a "Special program in your clinic. Your doctor has asked me to call you." We took that approach only a couple of times because it was such a disaster. The patients and families want to hear bad news from the physician. They don't want to hear it from anybody else.

So you've learned that you have to have the physician in person, speaking directly to their patients about the prognosis and need for supportive services.

Absolutely! Physicians *have* to be involved, *have* to give that information, bad news, if you will, and then refer the patient. It's nice to have that referral the very same day, or very soon. That works the best. We've taught them some language skills. We use the word "expectations." We don't say, "This is what's going to happen. You're likely to die in 3 months." Rather something like, "Based on what has happened to your condition over the last few weeks or months, this is what I see. These are my expectations of what may happen in the future." If the physician wants to define that future, that's fine.

You mentioned that you started out with target diseases in generating that list of patients to inquire about with the doctor. Do you include diseases for which the prognosis is really more clear, such as pancreatic cancer, or some forms of lung cancer?

We do. In general, those patients are referred very quickly on to hospice. We do include those patients for whom the trajectory is much clearer, so as to capture them all in our clinic. We start them in the Improving Care program because we can provide something right away. For example, if the patient comes in with abdominal pain and is found to have a mass that looks very suspicious, during that work-up period, the patient will be offered some support from the program. In fact, I have a patient like this right now, who for the last 2 weeks has been going through diagnostic testing, and some cells have been shown to be cancer. Obviously, a very small tumor has been hard to find on computed axial tomography scans or magnetic resonance images. So I enrolled that patient in the program a couple of weeks ago. In the next week or 10 days, the situation will be clarified as to exactly what's going to happen, how quickly things are going to go. But I didn't feel comfortable referring to hospice yet. Fortunately, I have this other program for awhile. So this patient likely won't be in our program long, but will move on to hospice. With this particular patient the cells were from the bile duct so this tumor is very hard to resect surgically, does not respond to chemotherapy, and is in an anatomical place where it does not have to be very large to do a lot of damage.

So, you do not frame this program as purely a confirmation of a downward trajectory?

No. In fact, with pancreatic cancer, it's pretty clear cut. We're very honest. But it's less clear with someone who comes in, for example, with worsening heart failure, or worsening lung disease and maybe has been in the hospital two or three times. What's really very interesting is that once support is offered and things are improved at home, often patients' conditions stabilize, and they get better for awhile. That has not been an uncommon experience in the program.

Do those patients whose conditions improve leave the program?

We never really discharge anybody from the program. We may put them on inactive status, where they're only checked on every three months.

What work did you do with physicians to get them to the point of referring these patients?

I think the important thing is that we started our program in a clinic where I actively practice. It's a matter of being there, being present, "talking the talk" at every opportunity, whether it is just a brief visit in the hall, a formal presentation, or an item on regular meeting agendas. We call it "being in their face all the time." They can't forget about us. We set up our office, initially, where we could find space in the clinic, which happened to be with the obstetrics/gynecology nurse practitioner, but the office was on the way to the lunch room, where there was a lot of traffic. As physicians walked by, they would often run in to Georganne Trandum, R.N., O.C.N., the program director. That physical presence in the clinic is very important.

It sounds as though you do a lot of informal networking.

Probably more informal than formal. We found that formal training is less effective. However, we also conducted targeted continuing medical education (CME) offerings for the primary care doctors who were going to refer patients to the program. We required these doctors to have a minimum of 5 to 6 hours of CME credits. Basically, we offered an overview of dying in America today, including some statistics that stick in people's minds, and highlighted the differences between dying today and in earlier eras. Then, we explained the process of the program. We did sessions on pain management, symptom management when patients are actively dying, giving bad news, and advance care planning. We modeled the process of breaking bad news and doing advance care planning for them.

What kinds of changes had to occur in the primary care clinic for this program to take hold? In particular, as you think about how physicians and nurses work together, were there any issues you had to address?

I go back to helping physicians identify appropriate patients, and then encouraging the doc-

tor to take a broader look at the patient and family, and how they are doing. Changing how physicians think about these patients allows them to consider whether these patients would benefit from greater support. We aren't asking the physicians themselves to offer greater support, just to think about the patients in a slightly new way, and speak to them about their prognoses. Then we can link these patients with existing community services as well as the nurse care coordinator as a personal contact for support.

Implementing this change requires working with the physicians and their nurses, informally, in addition to identifying the appropriate patients. We've worked with the physicians' own nurses because they are the ones getting the calls, and are often triaging the problems that patients are encountering. We encourage the nurses for those patients to ask the physicians they are working with whether this patient would be appropriate for the Improving Care through the End of Life program.

Did you do anything to enhance the relationship between the nurses who are coordinating the supportive care and the physicians?

No. I think the personality of the nurse care coordinator is really critical. It has to be somebody who is passionate, experienced, and whom the physician can immediately recognize as a resource. For example, Georganne Trandum, the program director, is well skilled in pain management, and brought substantial oncology and bone marrow transplant experience to this role. She was able to offer them help right away, which made her credible.

Were there structural changes in the clinic, i.e., new meetings, or other events that had to occur to implement this program?

Not really. We made end of life an agenda item on our regularly scheduled meetings and made it a part of existing routines. You can not go in and set up new meetings or new requirements for attendance if you want the program to succeed. In our experience, that won't work.

Have you tried to track the impact of the program on physicians?

We've tried to assess physician satisfaction. When I hear some of the stories that our physi-

cians have been willing either to write or tell about the program, there's no question but that they feel supported, as well as being able to offer greater support to their patient. The program allows them to give a different level of care, and individual physician job satisfaction and sense of comfort has improved remarkably.

Do you have any ideas about what allows physicians to make this shift that you have clearly made?

I think physicians need to feel a comfort level, which comes from having positive experiences with patients near the end of life. When a physician has one positive outcome, he or she begins to get some feedback, and then begins to have some understanding about how much patients and families appreciate being asked these questions. A couple of times we've had rather dramatic responses from families, once we've called them and they have really begun to understand what the program offers. For example, patients have said things like, "You're calling me from Dr. Smith's office? I can't believe he cares about me that much to have referred me to this special program. That is wonderful!" And we make it very clear when we call that we are calling from the physician's office. We're not calling from a program that's separate, but on behalf of the patient's physician. That link is key.

Are there incentives or disincentives for physicians to be involved in this program?

If anything, there may be a disincentive because of the extra time that is involved, particularly in the advance care planning sessions. Dealing with this extra time issue is another key challenge. There is still not good reimbursement for the physicians for that type of counseling activity. There also may be a disincentive to participation in terms of time spent and income lost because the participating physician does more care coordination, which, today, has no reimbursement unless the patient is in home health or hospice. Many of these patients are not being served by either of those programs.

Does the physician end up doing more coordinating for patients even though a nurse care coordinator is involved?

For patients enrolled in the Improving Care program, more care coordination is being done,

and the physician has oversight of that activity. In the end, this coordination makes care easier. But the physician doesn't get reimbursed for that time.

Right now this program is costing our clinic money. Once the program is totally funded by the clinic, at certain times *less* money will be coming to physicians because that money will have to pay for program staff salaries, including the nurse care coordinator. However, the reality is if we keep patients out of the emergency room and keep them out of the hospital, where they *don't* want to be, then there's going to be more money left in the pot, if you will. So during this time of transition and in a mixed payer system, it is hard to really sort the financial piece out. Lack of appropriate reimbursement is a barrier.

Is there any kind of financial relationship between patient enrollment in the program and what the physician earns?

I would say, probably not. Right now we have a mix of capitated care and fee-for-service. We don't separate those patients in any way.

As medical director of the program, what have you learned from this experience?

My greatest learning has been that the physicians are often the biggest barrier to good end-of-life care. I say that in front of groups of physicians, or in front of anyone. They *are*. There is no question about it. I do not say that in a critical fashion but in a practical sense with the way modern medicine has evolved. The reluctance to begin to have that difficult conversation is a key barrier to good care. I think that is true the majority of the time. There are exceptions—physicians who are more skilled and so perhaps able to be more sensitive. But in my experience in implementing this program over the last three years, working with a variety of physicians in different settings in the hospital and the clinics, I have found that the physician often is the biggest barrier. Physicians frequently want to hold out more hope, and to look at more medical treatment interventions, as opposed to being able to ask the patient the questions such as, "What is it that you want at this point? What's the most important thing to you?"

What are you still curious about as you continue to do this work?

I think there are cultural barriers among patients and families that are the same as the ones

the physicians are encountering, such as fear of death, lack of understanding about death, lack of familiarity with death, with the exception of a lot of high-tech death. Most people today in this country have not experienced a loved one dying at home. So, I'm curious about the best ways to overcome these barriers, and to get the culture, if you will, or the community more willing to talk about death and dying. I think the Bill Moyers series that aired in September 2000 created a tremendous opportunity.^b At Franciscan Health System West, we convened community members in public forums for open dialogue about these issues, offering an opportunity to speak about dying in America.

I think we need to work with the community and our health care systems need to reach out in ways we have not done before. People today are fascinated by technology in medicine, by new technical innovations. And yet, people are desperate for a sense of compassion and caring. The challenge is how to integrate that compassion into our care. How do we overcome the intrigue and allure of technological fixes?

Do you think the allure of technology is related to financing issues?

Absolutely! Technical procedures are reimbursed. The second greatest barrier to our program is reimbursement. There is no good reimbursement for advance care planning or other conversations about treatment goals with patients. A few months ago, I led a session for staff in cardiac services in our system. We invited all of the cardiologists, the cardiovascular surgeons, the nurses, all of the people associated with their programs.

Attendance by cardiologists was disappointingly poor. Our program has the strong support of one cardiovascular surgeon who commented that it was a lot more attractive to be in the cath

lab that morning than here talking about caring for the dying. It is important to remember in this context the number one cause of death in America—cardiovascular disease. I have learned this from colleagues in other parts of the country who are promoting change in end-of-life care. This experience is not unique to our particular medical community.

If other physicians are interested in replicating your efforts, what do they need to consider?

I still see that the biggest issues are getting comfortable with having "that conversation," and learning how to conduct that conversation. A related issue is for clinicians to be willing to admit what they don't know, i.e., that they have gaps in their knowledge in this domain. There are tremendous resources available to physicians today—hospice educational efforts and the Education for Physicians in End-of-Life Care (EPEC) program,^c the End-of-Life Physician Education Resource Center (EPEC).^d We can all upgrade our skills to improve our every day practice of medicine.

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^b"On Our Own Terms—Moyers on Dying" www.pbs.org/wnet/onourown/terms/. This four-part PBS series led by Bill Moyers and Judith Davidson Moyers reported on the end-of-life issues facing Americans and was first aired on September 10–13, 2000.

^cSee Education for Physicians in End-of-Life Care at www.epec.net for more information about this training effort.

^dSee End-of-Life Physician Education Resource Center (EPEC) at www.eperc.mcw.edu/

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