

Featured Innovation Part II

Raising the Standard of Care for Imminently Dying Patients Using Quality Improvement: An Interview with Marilyn Bookbinder, PhD, RN

The Department of Pain Medicine and Palliative Care (DPMPC) at the Beth Israel Medical Center developed the Palliative Care for Advanced Disease (PCAD) pathway to guide the interdisciplinary management of imminently dying patients in that hospital setting. Marilyn Bookbinder, PhD, an expert in quality improvement and evidence-based practice, had previously designed similar pathways to improve pain management and to improve the screening for fatigue assessment when she joined this project.^{1,2} In this interview conducted by Anna L. Romer, EdD, Dr. Bookbinder identifies the PCAD as a way to raise the standard of care for these patients using quality improvement (QI). The actual pathway is available on the department's website along with instructions for its use and ancillary tools. [See the Resources and Tools page of this issue for links to specific pages and tools.]

*Dr. Bookbinder describes PCAD, its design and evolution, as well as the initial results from the pilot implementation of the pathway in two treatment and three control units.³ PCAD is the first such effort of its kind in the United States. The DPMPC is one of three winners of the American Hospital Association's 2001 Circle of Life Award. [Citation: Bookbinder M, Romer AL. Raising the standard of care for imminently dying patients using quality improvement: An interview with Marilyn Bookbinder. *Innovations in End-of-Life Care*. 2001;3(4), www.edc.org/lastacts]*

The Palliative Care for Advanced Disease (PCAD) pathway

Can you describe PCAD?

When you pull all the pieces together, PCAD is both a process and set of tools to raise the standard of care for patients who are likely to die during the current admission to the hospital. Our goal in the hospital is to cure people and send them home. But as we know, people do die in hospitals. Once clinicians, patients and families agree that a patient is likely to die, the care should be primarily directed toward comfort and support. We must meet the patient's needs by adjusting the goals of care, optimizing palliative care, and avoiding unnecessary treatments.

PCAD has been one aspect of my broader role in the department. Among other things, I run our QI initiative. Most hospitals have a systematic quality improvement process in place and in this case, we have mobilized it on behalf of the needs of dying patients. My role is to bring in research methods when I can: better tools, better outcomes assessment, a better approach using theories about the implementation and change process. In this instance, we developed the tools, the pathway and the education, and can now track process and outcome data related to end-of-life care in a hospital setting. To raise the standard of care, it is important to establish a clear benchmark of excellence and then measure behavior against that standard in order to know what level of care we are offering. At that point, clinicians can work to improve care.

This effort is part of the larger effort described by Dr. Portenoy to establish a premier department

of pain medicine and palliative care. [See [Featured Innovation: Part 1.](#)] I joined Dr Portenoy a few months after the DPMPC began. One of our goals from the beginning was to bring the continuous quality improvement (CQI) process to this task of establishing and implementing guidelines for care of patients who are dying. First, you decide on a process that needs improvement, then you organize a team that knows that process well, work with the team to clarify current knowledge and understanding of that process, and then in our case, create new guidelines or a pathway that establishes a standard of care. CQI involves a circular process of planning, data gathering, checking results, and acting on the results. It is iterative and one can start at any point. The key is to keep feeding information back, reassessing and adapting behavior based on the information you collect. It is crucial to link this process to a clear standard of care, so that you are, in fact, changing something that is worth changing, in the direction of excellence.

PCAD consists of three components (all available in PDF format on our website).⁴ First, the actual PCAD Care Path is a two-page set of guidelines in the form of a chart that lists suggested treatments, consults, and actions to create an interdisciplinary plan of care for imminently dying patients. It also tracks pre-admission criteria and discharge outcomes. Second, the MD Order Sheet is a documentation tool used to activate the care path as well as to suggest symptom control approaches. The reverse side of this form includes medications for consideration in treating pain and 13 other frequently experienced symptoms of patients who are dying. Third, the Daily Patient Care Flow Sheet is a tool that nurses use to document daily assessments and interventions. For example, there are places on the form to note the presence of advance directives, results of a comfort assessment, vital signs as specifically ordered, and results of pain assessment, as well as a space to document any patient/ family education.

In addition to these tools, which are essential to the implementation of the PCAD pathway, we also designed several tools to evaluate its use. Specifically, we have a chart audit tool (an outcome measure), a process audit (a process measure), and a palliative care survey or quiz (knowledge measure). We also used focus groups, feedback from the QI team, and qualitative comments of the study team mentoring the clinicians who were implementing the pathway.

Implementation Process

To set the PCAD into motion, we created a flowchart with five steps:

1. Patient identification. Our referral question is based on Dr. Mimi Pattison's work⁵ that has been well publicized by Joanne Lynn, MD. We modified Dr. Patisson's referral question: "Would you be surprised if any of these patients died in the next twelve months?" for our purposes. Any staff member (e.g., nurses, house staff physicians and assistants, social work, chaplain) may suggest candidates for PCAD, based on an affirmative answer to the question: "Is this a patient who could die during this admission?" The goal here is to identify the imminently dying, a challenge that physicians have not been all that successful at, according to research on prognostication of death.⁶ Yet, in our setting this question seems to do a pretty good job at identifying an appropriate pool of patients whose goals of care need clarification and would possibly benefit from PCAD. Parenthetically, I should say that our experience in this initial pilot of the PCAD suggests that it may be worthwhile to supplement the referral question we used with another: "Is this patient a candidate for comfort care?"

2. Interdisciplinary Assessment. An interdisciplinary team consisting of a nurse, social worker, chaplain, and physician house staff discusses the patient as a candidate with the attending physician. Once there is agreement, an order for PCAD is pending by the attending physician or house staff officer.

3. Provider Clarification: Family Meeting. The attending physician (and usually a social worker or nurse) have a "family meeting" to clarify the goals of care with the patient and family as a first step. The attending physician orders PCAD if end-of-life supportive care is the primary goal of care.

4. Implementation. The house staff physician or nurse practitioner, in the case of the Geriatrics unit, initiates the pathway using the MD order sheet, rewriting orders for the patients. Nurses complete the demographic information on the PCAD pathway and initiate the tracking of patient symptoms and care with the PCAD Daily Patient Care Flowsheet.

5. Discharge. The patient may be discharged, usually to hospice or to an alternative care setting, but sometimes to home. Some patients die on the unit, and after the patient's death, bereavement activities are initiated, and staff members conduct a debriefing session.

What are the goals of this pathway?

The goals of PCAD were to shape the responses of staff to ensure patient comfort by minimizing symptom distress and unnecessary interventions, reinforce respect for values and decisions, optimize the use of consultants and resources that are appropriate for the goals of care, and provide support for the family.

Designing the Pathway Using Quality Improvement (QI) Methods

Could you take a step back to discuss how you and your team constructed the pathway and the quality improvement process you are using?

Prior to implementing the actual pathway and documenting practice in the pilot and control units, we developed a 22-member QI team. As I mentioned, the first step in starting a QI project is to identify the process or the standard you are trying to improve and then recruit the people most closely involved in that care to be part of the change process.

We included all the disciplines that are involved in end-of-life care (chaplains, social work, nurses, physicians, pharmacy, ethics) and key people from the two pilot units. I refer to these key people as the champions, those who are going to lead the effort at the unit level. On the oncology unit, the champions were the clinical nurse specialist, nurse manager, and case manager. On the geriatrics unit we targeted the nurse practitioners, nurse managers, and the case manager.

Then we set out to educate the CQI team. The team met monthly over the year. We broke up into four working groups that met weekly for about four months to develop the evidence-based care path, flowsheet and order sheet. A second work group developed implementation strategies and a timeline. Brainstorming, another QI technique, was done with unit staff and the QI team to uncover the barriers that we might face. For example, finding extra time for meetings was difficult. We learned that 7:30 a.m. on Wednesdays was the best time for our work groups to meet. The QI team pilot units saw Dr. Portenoy as providing expertise and leadership throughout the project, as evidenced by the good attendance at our meetings. They appreciated his willingness to hear the "nitty gritty" process of getting PCAD going on their units. A third work group developed educational strategies for nurses, assistants, and house staff; and the last group, composed primarily of our study team, developed the evaluation methods.

The timeline shows you the phases of implementation: planning, introduction, roll-out, evaluation, and reporting. Phase Zero is called planning. We received approvals from 1) the Institutional Review Board to conduct the study, 2) the medical records committee because PCAD involved using new

forms for documentation, and 3) the hospital's patient care committee because positive results of the pilot to improve end-of-life care would potentially mean bringing PCAD to other units at our hospital and our two other sites.

The next phase "Introduction" begins the work of "getting buy in" from clinicians and colleagues in the pilot units. Dr. Portenoy was asked to present at physicians' medical grand rounds about end-of-life care and the pilot study. Dr. Portenoy and I were invited by QI leaders in the oncology and geriatrics units to present the concept of the pathway. We told them we had the approval of the IRB and described our hopes and expectations for the pilot implementation, including their involvement. They agreed that they wanted to be a part of this effort.

The implementation phase is the "rollout" of PCAD and the evaluation measures. We conducted in-services for all staff on the use of PCAD and determined a weekly schedule on each pilot unit for the study team to meet with leaders and review patients: both those who might be candidates for PCAD and those who died. It took us one month on each unit to assess the nurses' knowledge, to conduct the in-service about how to use the tools and implement the pathway.

What kinds of baseline assessment measures did you make on the pilot and control units before you started training and implementation?

Another QI principle relates to the need for "continual learning" in organizations. In order to measure changes in practice there needs to be an assessment of baseline competency. We used a simple knowledge quiz.⁷ It has 20 items, is validated, reliable, and is a great tool. We gave the palliative care quiz to staff on the experimental units. We used it with house staff and nurses, but I only reported data on the nurses.

We used the palliative care quiz as a teaching tool as well. For example, we often gave it to house staff and fellows before a case study was presented by one of our staff physicians. In that case, we used it as a way to begin dialogue with them about important issues at end-of-life, such as futility, the DNR discussion, and hydration at end-of-life. The physician leading the case study discussion would then use their responses to the quiz as a starting point to grapple with these thorny issues.

We also used a chart audit tool to look at deaths in all of the units—the control (including hospice) and the experimental units—one year prior to implementing the pathway, and again after implementing the pathway. We documented length of stay, diagnoses, and patient demographics, such as age, gender, and ethnicity, admission/referral data; end-of-life decision-making; symptom assessment/management; death and utilization data. The tool tracks more than 100 items.

The Pilot Study

Which units did you choose to pilot the PCAD and why?

We had two experimental units—oncology and geriatrics. Using QI principles to help direct us, we picked units to improve the standard of care in which end-of-life care was the most problem-prone, high-risk, or had the most deaths.⁸ The units that had the most frequent deaths were geriatrics and oncology. We also had two control units, which were medical units (not surgical units) that had chronic illness and were similar in terms of acuity of care to the pilot units. The inpatient unit of the Department of Pain Medicine and Palliative Care (which includes hospice, non-hospice palliative care, and pain patients) served as a third control.

How does the palliative care/hospice inpatient unit figure into this?

We consider our inpatient unit to be the "gold standard" unit. [See *Featured Innovation: Part I for description of its evolution from a strict hospice inpatient unit.*] For purposes of the pilot study, we only targeted the hospice patients for the pathway. We included our inpatient unit along with the two pilot units (geriatrics and oncology) because they requested it, and because we thought that comparison with a unit that was farther along would yield important comparative data. The culture and practice of palliative care was already firmly established on this unit, whereas on the oncology and geriatric units, we assumed that introducing these guidelines for supportive care would be a change in practice.

The hospice staff used PCAD as a standard of care and as a tool to help them document their practice. As the nurses and doctors told us, "It helps the team get on the same page," so to speak. About one-third of the hospice unit patients were dying, and we targeted these patients for the pathway.

Staff Education

What kinds of in-services did you conduct?

The diffusion literature tells us that to successfully implement new ideas or innovative practices, we need to have champions to role model the new standard, educators to reach as many people as possible in a target audience with a relevant, practical message, and multiple media strategies for communicating and increasing dialogue. To educate every staff member, we scheduled two sessions for each shift: days, evenings and during the night as well. Our first barrier was the difficulty in getting staff off the unit—together—for more than 20 minutes. In the first session, we provided food and simply introduced ourselves and the study. In the second session, all staff members, chaplains and nursing assistants included, took a pre-test questionnaire, were educated about the principles of good end-of-life care, and how the pathway would be used. We encouraged the nurses to evaluate their case load on a daily basis and ask the question, "Is this someone who could die during this admission?" If a patient was identified as such, then the nurse reported to the clinical specialist, or nurse or case manager, who would then be the liaison with the attending physician to consider the patient for PCAD.

It took us about one month to work out a routine schedule of when and how we would identify candidates for PCAD and for staff to process the principles of implementing the pathway. All house staff (including physician assistants) nutritionists, dieticians, even the nursing assistants were educated about the pathway and its goals.

During the in-service, staff members actually took a tool and demonstrated how to put a patient on PCAD, how to document their actions and observations. Every nurse was able to practice going through the steps. These activities were part of the one-month process of assessing skills and introducing the guidelines to staff on the unit. It took that long to reach all of the day, evening, and night staff. We first did this on the oncology unit, then went through the same process on the geriatrics unit, and then followed one month later with the hospice unit. We gave specific in-services as per staff request, such as the "physiology of dying." We tried to meet educational needs weekly as they arose.

We also educated the large QI Team by showing scenarios from the EPEC Series.² Drs. Portenoy and Wollner, both faculty for the national program, led the sessions and discussion groups.

Implementation of the Pathway

How did you implement the pathway with real patients on the unit?

Following this intensive month of in-services to introduce the PCAD, we began implementation on each pilot unit. Someone from our study team was present frequently, sometimes every day and at least once a week. We worked with the staff, primarily nurses, as they reviewed patients for PCAD. We asked the following kinds of questions: "Are you asking the referral question?" "What difficulties are you having?" "What is happening with this?" "Is this a patient for PCAD?"

The study nurse and I mentored the two pilot units as the staff began to implement the pathway. Each pilot unit had 32 beds, but only one or two patients on each unit were actively dying at any one time. We decided with each leadership team how we were going to evaluate patients for PCAD. We began discussing this on a daily basis and moved to a weekly schedule. We were invited to join the weekly discharge planning rounds on the geriatrics floor. During the early stages of implementation we found that the term "palliative care" needed clarification by the clinical nurse specialist and staff.

Another QI principle is to "bootleg" the new practice, or add onto existing routine practices. Because nurses report on patients every morning, they chose to review patients for PCAD at this time. As they take or give report, they now ask, "Is this a patient for PCAD?" or "Is this a patient for comfort care? Let's consider PCAD."

Evaluating Efforts to Implement the PCAD

Can you describe the process audit?

The [process audit tool](#) is a variance tracking tool of sorts, similar to those used by case managers monitoring pathways. Remember, the pathway is a set of guidelines, but since we are treating individual patients, we anticipate variation and wouldn't want people to implement the guidelines blindly. The concept of a pathway brings up questions of practice and variations in practice: "Did we do x? Did we do y?" This process audit tool helps evaluate whether the guidelines are being followed or not and if not, they provide an opportunity to learn why not. The study nurse who is monitoring the implementation of PCAD asked the nurses on the unit questions such as, "When you spoke with the physician about putting the patient on PCAD, what was his or her response?" I would inquire with nurses about what they were doing: "I see you didn't chart x. Can you explain? I'm trying to make sure that the tool is really capturing what we want." It is best to learn what works and what does not from the nurse recording the practice rather than trying to infer it from the chart itself. So, the process audit tool helps you to see whether or not the pathway is meeting the need of the patient, and meeting the need of the discipline to actually document care. This tool allows us to learn if the implementation is going as we planned and provides us with data about what needs to be fixed. It reveals some of the barriers to implementing the pathway.

Barriers to Implementation

Added Paperwork. We identified one important barrier with the implementation of the MD order sheet. It is one of the three components of the pathway, which requires not only a physician's order, but it required them to rewrite all the orders. This adds a layer of paperwork that is a real barrier to implementation. This is another thing we hope to change in the future, with physician input. I would go back to the physicians, which we're going to do, and ask them to help us redesign the intervention. "How can we make this easier for you, and at the same time make sure that all of these areas are addressed?" The reason we asked physicians to rewrite the orders is because we are asking

them to reassess the goals of care at the point the patient enters the pathway. We want the clinical caregivers to think about what it makes sense to do or stop doing in terms of treatment. Patients who are dying may find it burdensome to be woken up to have a daily weight taken or have their vital signs checked, for example.

On the back of this new medical order sheet we posted guidelines of how to treat the 14 most prevalent symptoms experienced by people near the end of life. The physician house staff appreciated the guidelines and used them to write orders on non-PCAD patients as well.

What other kinds of problems and issues did you see?

Initially, the 22-member team identified the areas that they suspected might present the biggest obstacles, and in fact, the areas they identified were the most difficult. The team predicted that we would encounter discomfort and a lack of readiness on the part of all disciplines to identify patients as imminently dying and then change their treatment plan to fit that trajectory. Readiness on the part of clinicians was less of a problem than for families. Clinicians and patients and families had to acknowledge that the patient was imminently dying in order to begin the pathway, so the physician had to have a conversation with the patient and family as part of the process. Readiness—on the part of patient and family—was an issue.

We found that the biggest barrier was this readiness of patients and families: most wanted "everything" done, not wanting to give up hope and chance for recovery to go home one more time. While we may agree that having conversations at this late stage (two days before death) may be too late, this scenario is still the reality and we need to figure out how to make this better.

Did you have to do special training with the physicians to teach them how to open up that conversation with families?

Our project did not directly address this issue. However, the hospital's Ethics Committee has an ongoing educational program to help house staff (who rotate each month) become more comfortable with discussing end-of-life issues with patients and families. The clinical nurse specialists and the nurse practitioners—the champions on the units—educated physicians about PCAD by having discussions about patients whom they thought were candidates. Within one year, all full-time physicians on the study units had placed at least one patient on PCAD. So I cannot say that they are totally resistant to this. We think that they choose patients sparingly—choosing only those patients who were clearly dying and whose families shared that view. Nine of 31 patients who died on oncology and geriatrics during the six-month study period were placed on PCAD. Most patients were identified, but some died before we could get the process going, others wanted everything done, some we missed over a weekend or holiday, and some improved making them ineligible.

Who has the discussion with the patient and/or family?

The attending physician or the house staff is responsible for the discussion in concert with the nurse who's taking care of the patient and sometimes the social worker would be involved. It was usually interdisciplinary, meaning at least two of them were present. This is a conversation that goes on all the time. Did we educate them to do it better? I don't think we assumed they needed help doing it.

So you didn't see that as a barrier?

We didn't see it as a barrier to PCAD implementation, but that is not to say that we don't see communication as an issue. We did not target this area specifically, but I think we now know that

communicating bad news is a skill most clinicians can improve.

Findings from Pilot Study of Implementation of PCAD

We showed several positive outcomes within this short pilot period. Symptom assessment improved on all the units involved in the study, namely, the experimental (including the inpatient unit of our department) and control units. In particular, assessment of pain, cognitive impairment, and breathlessness improved.

Practice moved in the direction we wanted it to. The control units improved, but not as much as the experimental units, and the experimental units i.e., geriatrics and oncology, moved closer to the level we documented on the hospice and palliative care unit, in other words, the gold standard.

Given these results, i.e., improved symptom assessment on all units, how can you make claims about the specific utility of PCAD?

It is true that the control units also improved and the differences between the study units and the control units were modest. Remember, however, that simultaneous with this QI effort, our new department was offering pain and palliative care consults throughout the hospital. We think that the combination of the department's broader efforts, and diffusion from the study units, combined to produce "contamination" of our efforts to measure the impact of the pilot implementation of the PCAD. Nonetheless, the finding of some differences between study units and control units at a time when this contamination was happening, and in only a period of a few months, makes us think that PCAD does indeed have real value as a means to produce change in the standard of care.

We believe we initiated a cultural change in how people think about the care of imminently dying inpatients. This is a much broader mandate than showing statistically significant differences in symptom assessment. We walked onto the study units and tiptoed about until we could figure out where the openings were to begin to shape practice and educate staff. Our team didn't directly conduct in-services with physicians, but clearly a great deal of education occurred informally.

Engendering Cultural Change

Can you say a bit more about what you mean by cultural change and how you documented this phenomenon?

First of all, the unit language related to end-of-life care has changed. Clinicians now talk about goals of care—nurses, physicians. Focus groups with staff indicate that they are less afraid to use the "d" word, i.e., death, and are more confident asking, "What are the goals of care for this patient?"

The study team collected informal information every week about what changes were happening on that unit. We perceived that there was a social process going on. Data about behaviors need to be collected when you do this kind of research. Some of this information can never be obtained in the chart audit tool, or the process audit tool.

How were you documenting what you saw as cultural changes?

We both observed and asked questions of the nurses on a weekly basis, when we did the review of all the patients and discussed who would be eligible for PCAD. We noted a change in the discussions about care. These began to include the comment, "Refer to PCAD." We asked, "How have you seen change in behavior here?" Nurses told us, "We feel that there are more referrals to hospice. We are at least thinking more about patients who are eligible for hospice."

Did you then actually document increased referrals to hospice? Was that a goal of the implementation of the PCAD?

We did see an increase in referrals. But you have to understand some of the nuances here. If the staff is doing a great job on the oncology unit, maybe patients don't need to be admitted to hospice right at the end of life. So, just seeing improvement in referrals is only one measure of success, and perhaps not the most important one.

Nurses told us that they feel they assess patients sooner for hospice. But our numbers may not reflect the increase because a) the patient may not have been eligible for hospice, or b) the family chose to keep their loved one on the unit where he or she was receiving excellent care. Our sense was that there's more discussion about whether a particular patient is eligible for hospice or might be a candidate.

Distinguishing between Unit-Level and Patient-Level Outcomes

The chart audit tool is used to assess how well we implemented the pathway, for instance did staff members assess a greater range of symptoms with greater frequency? It does not tell us if someone had a good death, or had a peaceful death. The process assessment is really about implementing the PCAD and not about patient outcomes.

Our analyses thus far have been on the entire unit, not the patient. We did go into charts, but we aggregated the data rather than looking at individuals. We did not compare pain scores of individual patients over time. We did not look at Mrs. Smith's last three days of life based on her chart, how the medications changed, how many she was on, what was withdrawn, what wasn't withdrawn, or if there was an interview with the family. We did not look at that kind of micro-level detail.

Instead, we sought to understand whether we could implement PCAD on a unit. Could we teach clinicians to treat patients using a new standard of care and access specific services that would be of benefit to dying patients? So, our data collection and analysis were conducted to assess how well we were implementing this pathway. One immediate goal was to begin to change the culture of a unit. Initiating use of this standard of care is a step along the path to improving patients' outcomes and quality of care.

To get patient-level outcome data, you would have to do a concurrent QI study where you examine the death, as close to the event as possible. Understanding individual patient outcomes is the next step. I think this needs to be done at the time it's happening. This is what I want to do next. You would look at the death of say, Mrs. Smith, and obtain data about the experience, perhaps from an after-death interview with the family, or perhaps from assessment of outcomes directly from the patient immediately before death. Then, the nurse looks at how well pain was assessed. The physician looks at the drugs that they used. Someone else looks at respiratory distress. Did we follow our guideline? Do we need a protocol? The chaplain determines if the patient had spiritual distress and whether a chaplain was involved, or whether there was any indication that one was needed. Looking more closely at the individual deaths on a unit with an interested team—at what they did and didn't do—using some guidelines of what is the ideal would be one approach to improve overall practice on a unit in terms of patient-level outcomes.

Other Evidence of Impact

We saw more consultations to the pain and palliative care team, because the unit staff and physicians realized how much we could offer families, especially once patients went home. They began to request continuity by the team for family support, symptom management, and titration of multiple drugs.

We learned early on in the project that our hospital needed to improve bereavement services. The hospice has excellent bereavement services, but then bereavement has always been integral to hospice. That is not the case for most hospital care of dying patients.

How did you identify this deficit?

We conducted a debriefing session when a patient on PCAD died. The first part of our process was to debrief with nurses and the nursing assistants—about the patient's death. The debriefing was part of the PCAD educational process. Staff members loved it! The units have continued this practice on their own when they feel the need. The oncology unit, of its own initiative, is now doing a memorial service every six months for patients who died for the benefit of the staff.

For families, we have created a condolence card from Beth Israel, which will be sent by the unit Manager. The card is sent with an educational booklet, "Going Through Bereavement When a Loved One Dies." And on the back we list "Bereavement Resources" available in the community an 800-number (Hospice Link 1-800-331-1620) for local bereavement groups sponsored by the Hospice Education Institute.

Limitations

What do you think the limitations of PCAD are?

Regarding implementation, I think the added paperwork of the MD order sheet, which required that they rewrite all orders, was a barrier and is probably also a limitation. From a research perspective, the influence of the Consultation Service in the Department of Pain Medicine and Palliative Care could be seen as a limitation. Their presence and education of staff on all units (experimental and control) may have contributed to the increase in the standard of care (i.e., improved symptom assessment and treatment) on control units as well as the experimental units. The influence could be viewed as contamination, or diffusion of an innovation. Another limitation to generalizability to others is that we just tested this intervention in one hospital. PCAD is not a "magic bullet" to assure best practice in end-of-life care. It does, however, serve as an education and documentation tool, an interdisciplinary standard of care, and a catalyst to begin dialogue about the kind of care we all—clinicians, patients, and families—should expect when someone is imminently dying.

Advice

My suggestions for others, especially those working in a community hospital, wishing to implement the pathway with little or no additional funding:

1. Start small. Delineate the scope of your project: unit, service, and hospital.
2. Work both "top down" and "bottom up." What I mean by that is gaining the buy-in and support from administration, unit physicians, and leaders who will pilot the intervention. The "bottom up" approach means getting the buy-in from staff who will be implementing the tool. The staff at the grass roots level, gives you feedback, and are crucial for working with you to make the intervention practical and relevant.

3. Apply and adapt the PCAD tools to make them fit your own setting and disciplines. For example, the MD order sheet—If doctors don't want to use it, come up with your own solution to getting goals of care addressed and treatments to reflect that patients are dying.
4. Collect data to measure your current practice and to move the standard forward. Go to the literature—find the best practice—seek to meet the benchmark. Keep yourself inspired by joining listservs or participating in Internet discussions, such as the one associated with this journal, or reading other QI success stories.¹⁰
5. Be patient, and recognize that unit culture, like any change, takes time.
6. Find and cultivate champions on the units targeted for change. Champions are essential to this process. These are the people who find opportunities, strategies to increase dialogue and educate staff members and who keep the momentum going and role model the innovation. Leaders need to continue to mentor champions because it is easy for enthusiasm to wane after the initial trial period.

Next Steps

I would like to develop a focused QI study with oncology and geriatrics unit teams (nurse, doctor, social work, and chaplain, dietician, ethics) to examine individual patient deaths, by asking the question, "Was this a peaceful death, or a good death?" In addition to learning about professionals' knowledge and attitudes about end-of-life care, I believe we would then learn a great deal about current practice, the systems impeding care, and areas deserving accolades or needing improvement.

I think we could develop a brief set of indicators to evaluate the salient factors such teams believe characterize a good death. What are the criteria? Is the staff satisfied with how they cared for the patient and family? Is the family satisfied? Were symptoms well managed? Did we know what the patient's wishes were and did we meet them? Once the team can define what a good death would be on their unit, we can build the tool to help them measure themselves against that benchmark, and the quest to reach a new standard begins. So, that's what I will do next on these three units.

We are still seeking funding to test PCAD at a larger level. Until then I'll start small, and follow the steps I just laid out for others without funding! Get a team, get the dialogue going, develop a tool to track changes, give feedback, and be available with resources and ideas and support to make changes and raise the standard one more time.

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3. The department received one year's funding from a New York State Department of Health Quality Measurement Grant to develop and pilot test PCAD.

4. www.stoppain.org See [Resources and Tools](#) page for annotated notes on what is available here and links.

5. See "Building Bridges for Better Continuity of Care" Featured Innovation "[Improving Care Through the End of Life: An Interview with Mimi Pattison, MD.](#)" *Innovations in End-of-Life Care*. 2000;2(5), for more on the development of this referral question.

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9. EPEC: Education for Physicians on End-of-Life Care is a curriculum and training project. For more information visit www.epec.net

10. See for example: Lynn J, Lynch Schuster J, Kabcenell A. *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*. New York: Oxford University Press, 2000. and Solomon MZ, Romer AL, Heller KS, Weissman DE. *Innovations in End-of-Life Care: Practical Strategies & International Perspectives, Volume 2*. Larchmont, NY: Mary Ann Liebert, Inc., 2001.