

Reforming Care for Persons Near the End of Life: The Promise of Quality Improvement

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Most people in developed countries will live with a serious, eventually fatal, chronic condition for months or years before dying; yet, the delivery of health care services has only just recently begun adapting to this reality. Quality improvement methods have been effective in helping clinical services to make substantial changes quickly.

Quality improvement requires stating an aim, measuring success, and testing possible improvements. The testing of changes requires a clinical team to Plan, Do, Study, and Act on new insights (the "PDSA cycle"). Repeated PDSA cycles generate deep

understanding of complex systems and make sustainable improvements rapidly.

This paper discusses a composite case study in a nursing home setting, which builds on experience with multisite collaborative efforts and introduces quality improvement methods in the context of end-of-life care.

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Dr. Evan Thomas, a hospitalist, was called to the emergency department to admit an 84-year-old woman from a nearby nursing facility for hospitalization. He started to perform a routine work-up for fever and administered intravenous antibiotics. The patient had no family, and her court-appointed guardian was unavailable. After experiencing many complications, the patient developed decubiti from fighting restraints and was "barely hanging on." Dr. Thomas called the patient's nursing home facility to find a nurse who knew her, but none was available. The patient had a feeding tube and a resuscitation attempt before she died.

Thereafter, Dr. Thomas was increasingly troubled by his patients from nursing home facilities. Few of these patients had any living family, and almost none had plans about issues like resuscitation. These patients comprised one third of Dr. Thomas's caseload, but he was not sure that the care he provided served their interests.

RECOGNIZING A PROBLEM

Dr. Thomas has taken the first two crucial steps toward improvement. First, he is developing the will to make changes because he sees that his care falls short, at least in managing symptoms and planning for advance care. Second, he recognizes that this care pattern affects many patients. Accepting the status quo is what blocks most opportunities for improvement, and ferreting out a particular person responsible for one error rarely yields important improvements. Substantial gains result from correcting a behavior pattern that affects dozens of patients.

STARTING A PROCESS

Dr. Thomas sought better options in professional literature and in programs to serve severely demented adults. He talked with the directors of nursing and social workers at two good local nursing home facilities as well as experienced geriatricians. He listed possible improvements, most of which required agreement about practices and plans among the nursing

home facilities, the emergency medical system, and the hospital. He decided to bring together a dozen concerned persons to see what might be done.

Dr. Thomas has learned much about the problem, has assembled a team that cares about it, and has developed a list of changes to attempt. This process could lead to responsible and effective implementation of changes. To facilitate improvement, someone has to identify shortcomings in how care is delivered, examine the impact of those shortcomings, consider alternatives, and initiate action. Generating quality clinical environments depends on recognition by his hospital's chief executive officer and by his other colleagues that improvement is important and deserves their support, despite the disruption this may cause.

GETTING STARTED

Dr. Thomas's group gathered. They told stories of shared patients and commented on what worked well. They also discussed frustrations and identified gaps in continuity and services. They settled on two immediate actions: 1) to get all health professionals in the area to agree on one way to communicate patients' decisions to forgo resuscitation and 2) to make plans about advance care planning at each quarterly review at one nursing home. Although they hoped eventually to involve a wide array of physicians and organizations, the group started small, working with those who were easily persuaded to make improvements.

The director of nursing at a nursing home facility offered to arrange meetings of the group and keep everyone informed by e-mail. Three people agreed to find or develop a form for communicating decisions about cardiopulmonary resuscitation, and the entire group agreed to meet again in a month.

This story is a composite drawn from broad experiences, but most stories of success start this way, with the "frontline" providers committing to real change. This group has bypassed the common diversions of spending too much time gathering information and making plans or

putting all their efforts into standard continuing education projects. Instead, they are trying two changes on a small scale. They will have evidence of how those attempts are working in a month, at which time they can make adjustments, can continue that work, and start new projects. They will use the *PDSA cycle*, a routine of Planning a change, Doing it, Studying its effects, and Acting on the insights gained. On the basis of what they learn, the group will spread the useful changes more widely throughout their institutions.

MAKING CHANGE HAPPEN

While seeking a common tool for communicating resuscitation decisions, the team encountered Oregon's Physician Orders for Life-Sustaining Treatment (POLST) (1). They adapted the POLST, including negotiating agreements from legal authorities, community leaders, and health care organizations. That work got a boost when the local newspaper published a series of articles on end-of-life care that highlighted this project. However, a local religious leader wrote a strongly worded letter to the editor, cautioning that the poor could be pressured to forgo treatment just to save money. After several conversations, the letter writer agreed to join the group to watch over the process.

The coalition realized early on that it would need to measure results. The rate of documented do-not-resuscitate orders in the minimum data set (standard data collection for nursing facilities) in five local nursing facilities that adopted the POLST went from 28% to 52% over 6 months, and the rate of transfer of do-not-resuscitate orders to the hospital went from 2 in 12 during the 3 months before the project to 6 in 8 during a 3-month period that started 6 months later.

The team at the nursing home that was attempting to institute routine consideration of advance care planning had its problems, too. First, they found that many patients had pre-existing written advance directives that were not included in the facility's records. Second, clinicians did not routinely ask patients or their families to make decisions in advance, in part because they were uncomfortable having these discussions. A chaplain at a nearby hospital was asked to provide training for the entire interdisciplinary team of nursing facility representatives. Although an audit of medical records initiated by the project found only 12% of the patients having advance care plans documented, a repeat audit 1 year later found 34%.

The pace of change varies: Some issues move along quickly, while others require struggle. The challenges that arise can be instructive. For example, the hostile letter to the editor of the newspaper gave voice to a realistic concern, and including that perspective in the work was valuable. Likewise, the chaplain's training of the staff was more effective because it arose from the experience of thwarted improvement attempts. Success requires a rapid and visible pace of change, along with leadership support. Most teams can sustain a few simultaneous improvement activities, and the most effective teams become infectious, passing along

their enthusiasm and the essentials of their approach. However, although the quality improvement method structures the work and improves the likelihood that reforms can be implemented and sustained, this work is still very difficult, and even the most successful quality improvement projects will encounter barriers and difficulties.

THE TRACK RECORD OF REFORM IN END-OF-LIFE CARE

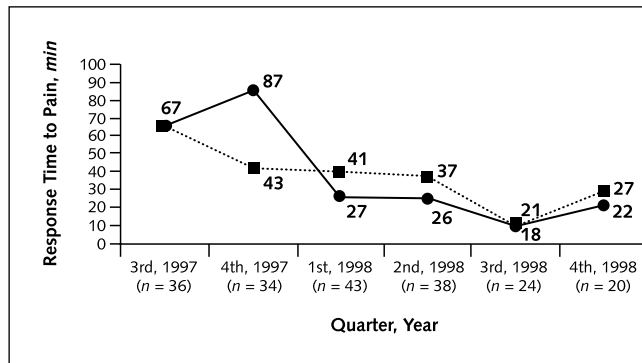
Over the past 30 years, end-of-life care has gradually improved, at least by some measures. The rate of per-capita opioid use has increased by more than 10-fold (2). In years past, physicians often did not tell patients of a diagnosis of cancer, nor did they provide patients with effective pain relief. Now, however, virtually all such patients receive at least a diagnosis and basic pain treatment. Hospice has shown that better care is possible in targeted, dedicated, and comprehensive care systems (3).

Nevertheless, most efforts to improve care delivery have been less clearly effective. The Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatments (SUPPORT) (4) tried to enable thousands of very sick patients to shape decision making but failed to change behaviors or outcomes. Research has not found improvements in patient care on the basis of standard advance directives (5, 6); however, a recent report (7) found that the level of anxiety among family members was reduced by planning for complications and death. The strongest determinant of locus of care at the time of death across regions is the availability and use of hospital beds (8), not the patient characteristics that ethical standards advocate.

Researchers and political leaders offer basic research as a method of reform, and improved therapeutic options have contributed substantially to improved care. Still, the care system routinely fails to use proven methods. Most people who have serious pain do not need advanced methods; they just need the morphine and counseling that have been available for centuries. Most patients with congestive heart failure do not receive the best drugs, and most do not know how to manage their illness (9). Most patients with asthma do not even know how to use their inhalers (10, 11). Research has created opportunities that cannot be fully implemented without a focused system to deliver better care. That gap is what makes it important to improve care through practical, common-sense efforts to improve care, like those of Dr. Thomas.

In July 1997, the Institute for Healthcare Improvement and the Center to Improve Care of the Dying launched a yearlong collaboration among teams from four dozen provider organizations across the United States and Canada (12). With the guidance of experts and sound methods for improvement, most made substantial improvements for their patients. One hospital-based team found, much to their chagrin, that the average patient with cancer waited 3 hours for pain medication. Within just a

Figure 1. Response time to pain by quarter-years and split by time from assessment to orders and time from orders to administration.



Shown are the average time elapsed from assessment to orders (*solid line, circles*) and the average time elapsed from orders to treatment (*dotted line, squares*). Used with permission from Jean Brontoli, St. Mary's Health Center, St. Louis, Missouri.

few months, the team was able to decrease the average response time to less than 1 hour by working to improve and standardize assessment and treatment (Figure 1). Another team found that patients received medications more quickly when an on-the-scene nurse was authorized to adjust dosages within an agreed-upon range. Many found that pain was simply being ignored, and they required measuring pain as “the fifth vital sign.” One team virtually abolished severe and persistent dyspnea in patients receiving hospice care by prioritizing responses, having a physician-endorsed treatment protocol, having a back-up physician if the attending physician did not respond or the problem persisted, and having appropriate drugs already present where the patient lived (ready to administer with a telephone call) (Figure 2).

Virtually every team that worked on family support made improvements that mattered. Some initiated bereavement support. Some tackled fixing issues that made families angry. For example, many hospitals were sending the bill for the final hospital stay to the deceased patient, and families viewed this as evidence that no one cared. However, by changing the computer address to “The estate of [the deceased patient],” the problem was fixed. Other teams ensured follow-up with family after a death, and two teams provided beepers to family caregivers so that they could be absent from the patient (for example, to take a nap or run errands). Another team provided a place to shower and nap while a loved one was in the hospital.

These teams not only improved their programs but also learned several generalizable insights. For example, teams learned to identify patients to target for special services by using the question: “Which patients are sick enough that it would not be surprising if they died in the next 6 months?” It does not matter whether one asks about a few months or a year—either way, the question encourages physicians to recognize that the patient is very sick,

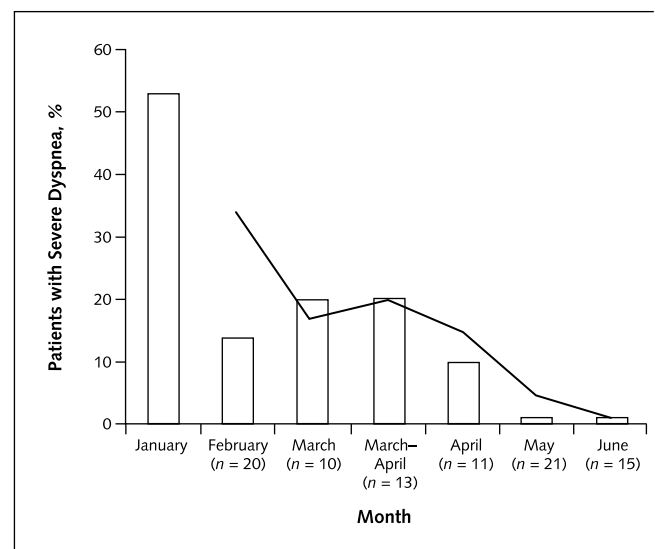
although some who are “sick enough to die” will actually live a long time. By using this approach, many more patients were identified far enough ahead of death for hospice and other end-of-life services to make a difference in their lives.

A few years ago, health care providers in La Crosse, Wisconsin, started a community-wide effort to improve advance care planning (13). They instructed elderly persons in senior centers, patients coming to office visits, and ordinary citizens through a mass media campaign. As a result, 85% of more than 500 decedents in La Crosse had an advance directive at the time of their death, and the directive had been written, on average, more than a year before the patient died. Ninety-eight percent of dying people had deliberately forgone some treatment, and virtually all of the advance directives were followed. How did the health care providers accomplish this? They supported shared goals through an array of trials of interventions, assessments, and broader dissemination and implementation of successful efforts.

RAPID-CYCLE QUALITY IMPROVEMENT

Associates in Process Improvement and others have designed an effective and useful method of rapidly initiating changes (14, 15). The PDSA model for improvement starts with teams asking themselves three fundamental questions: 1) What are we trying to accomplish? (aim); 2) How will we know whether a change is an improvement? (measure); and 3) What changes can we make? (changes).

Figure 2. Rate of dyspnea that persisted for more than one hospice care shift.



Shown are the quarter-year rates (*bars*) and 2-month moving average (*solid line*) of severe dyspnea not relieved by end of shift. Used with permission from Joan Teno, MD, Brown University, Providence, Rhode Island.

What Are We Trying To Accomplish?

The answer to this question is the foundation for the team's goal. Compelling aims are usually brief, measurable, and important to patients and families. The aim should be documented and circulated for comment to those with a stake in the outcome of the project.

How Will We Know Whether a Change Is an Improvement?

Measurement is an important part of the improvement process; it allows teams to quantify the impact of changes and determine whether they work. Measurement should answer specific questions—for example, “Did the rate of pain decrease after instituting a protocol?” “Did written information, reminders, and the tools to manage exacerbations at home lead to lower rates of visits to the emergency department?”

What Changes Can We Make?

Patients, families, providers, and managers all have ideas about “what would work better.” A review of the literature and of the experiences of others often finds changes that are well tested but not extensively used in clinical practice. With complementary answers to these three questions, teams can then test the most appealing changes by using the PDSA cycle.

THE PLAN–DO–STUDY–ACT CYCLE

The model for improvement is based on a trial-and-learning approach. The PDSA cycle provides the framework for effecting change by planning the change, trying it, observing the consequences, and acting on what is learned from those consequences. All four steps are important. All too often, a change is tried but not evaluated, and nothing useful is learned.

Even an ambitious and innovative change can be tested first on a small scale—for example, with one or two physicians, with the next five patients, over the next 3 days, or one component at a time. The change that is eventually implemented could be a substantial departure from current practice; however, implementing small increments repeatedly can overcome some of the reasons for inactivity, such as fear of risks, lack of resources, and a lack of confidence that the change will work.

Measurement of effect is critical to learning from tests. The most convincing measures are documented in a time series—for example, percentage of clinic patients *per month* who have had an advanced care planning discussion or the average response time for pain relief on the oncology unit *each week*. The temporal relationship between changes made and the results builds evidence that the changes led to improvement. Sometimes measuring before and after or intervention and control is sufficient. If such a measurement strategy is used, additional qualitative assessments of the effects of the changes help innovators to learn from each cycle and to refine the changes. The team should aim

to have just enough evidence to confidently assess whether changes resulted in improvements or problems.

Testing multiple changes among dozens of teams during collaborative quality improvement provides an opportunity to quickly learn complex system behaviors. Those insights can provide leverage to other organizations interested in improving care (16).

QUALITY IMPROVEMENT IN RELATION TO CONVENTIONAL RESEARCH

In science today, carefully designed randomized experiments and tests of hypotheses are often the only trusted avenues to gaining knowledge. Other formal research methods, such as case-control or cohort studies, are also trusted to provide insights. However, the art of medical care involves a continuing, individualized search in which the physician tries to match incomplete scientific knowledge of disease and treatment with incomplete knowledge about particular patients and local care systems. Physicians do not often know the way but find it step by step, inductively learning from experience caring for real patients. Often, in discerning how to care for a specific patient population, steady investigation with small-scale tests of change is more useful than are randomized, controlled trials. The alternative to using a sequence of PDSA cycles and data plotted over time is not usually a randomized trial followed by widespread implementation; instead, it is usually continuing present practices or making changes without evidence or evaluation.

When linked to important aims and thoughtful reflection, PDSA cycles are powerful tools for learning in complex, improvement-oriented systems. Practice patterns vary widely in every medical discipline across the United States (17). For example, U.S. rates of breast-conserving surgery for breast cancer vary more than 30-fold (18). Similarly, most elderly persons with a myocardial infarction do not receive β -blocker therapy after the acute management stage of care (19). Rates of cesarean section range from 8% to more than 40% among hospital service areas (20). Practice patterns vary so widely that not all practitioners can be right.

When the relative benefit of a particular drug or operation is uncertain, a randomized, controlled trial is the study design that regularly yields a confident comparison. However, clinical trials will not help to develop an improved patient flow or to adapt a specific treatment or flowchart for use in a local setting. Indeed, most learning and improvement in real-world settings come neither from erratic trial and error nor from randomized experiments but from “PDSA” science (14).

In the late 1980s and early 1990s, the Northern New England Cardiovascular Disease Study Group (21) assessed variations in outcomes and processes of care among participating heart surgery centers. Round-robin visiting among surgical teams and analyses from a voluntary database on

surgical outcomes and complications allowed clinical groups to identify promising changes in numerous components of cardiovascular surgery, including patient selection, preoperative preparation, bypass pump management, hemostasis, and anesthesia. These observations led to numerous local PDSA cycles, the results of which were reported back to the group. The overall result was a 24% reduction in the number of deaths from coronary artery bypass graft surgery throughout the region. It is hard to imagine how formal, large-scale, randomized trials could have been implemented and achieved this dramatic change.

Of course, it might well be appropriate to test a drug or device in a randomized, controlled trial in the same patients with whom teams are working to find ways to diminish waiting times or to smooth transitions from hospital to home. In short, the method that is implemented needs to be appropriate to the issue being addressed.

LESSONS TO LEARN

Dr. Thomas and the group did many things that other innovators could take to heart. For example, Dr. Thomas took responsibility and got things started, and he got the right people involved, including senior leaders. The group took on problems that affected patients and for which they were responsible. They also used existing knowledge as the basis for their changes, adapted existing tools and skills from other areas to their own needs, measured results over time, and started small (with just one nursing facility) for the tougher problems and built knowledge about the changes sequentially. Finally, their successes catalyzed larger changes and an attitude of welcoming innovation and improvement.

CONCLUSION

The time is right for innovation and change in end-of-life care, guided by measurement and catalyzed by effective networking among innovators. Rapid-cycle quality improvement creates momentum for change that reformers can respect and use and has been widely effective in improving the care of seriously ill patients (12, 16). The health care system needs multifaceted change that aims for consistent, high-value, high-quality care at the end of life. Each of us must ask what shortcomings in end-of-life care affect the places where we practice, how they can be addressed, and how improvements can be accomplished. To prepare to meet the needs of our aging population, we must harness our resources and commit to these efforts now.

APPENDIX: MEMBERS OF THE ACP-ASIM END-OF-LIFE CARE CONSENSUS PANEL

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Kettering Cancer Center (New York, NY); Ira Byock, MD, Palliative Care Services (Missoula, MT); Kathy Faber-Langendoen, MD, State University of New York Health Science Center (Syracuse, NY); Lloyd W. Kitchens Jr., MD, Texas Oncology (Dallas, TX); Paul Lanken, MD, University of Pennsylvania (Philadelphia, PA); Joanne Lynn, MD, RAND Center to Improve Care of the Dying (Arlington, VA); Diane Meier, MD, Mt. Sinai School of Medicine (New York, NY); Timothy E. Quill, MD, The Genesee Hospital (Rochester, NY); George Thibault, MD, Partners Healthcare System (Boston, MA); James Tulskey, MD, Veterans Affairs Medical Center (Durham, NC). Primary Staff to the Panel: Lois Snyder, JD (*Project Director*), ACP-ASIM (Philadelphia, PA), and Jason Karlawish, MD (*Clinical Staff*), University of Pennsylvania (Philadelphia, PA).

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