Reforming the Care System to Support Those Coming to the End of Life

Joanne Lynn, MD, MA, MS

Energetic national collaboration in quality improvement is teaching new insights into how to improve care at the end of life.

Background: Health care has shifted its focus regarding dying patients toward improving care rather than striving for cure.

Methods: The Center to Improve Care of the Dying and the Institute for Healthcare Improvement sponsored a quality improvement collaborative from July 1997 through July 1998 to learn how to accomplish this.

Results: (1) Classifying persons as "dying" or "not dying" does not help to ensure quality care at the end of life. The impossibility of predicting time of death in many illnesses demands not only a shift to asking whether a patient is sick enough to die of the current illness, but also targeting special services to those patients. (2) Quality improvement strategies in this arena regularly yield important gains in such fields as pain control, bereavement support, and advance planning. (3) Serious reform probably must originate in system design and routine practice rather than in exhortations to customize decision making. The Study to Understand Prognoses and Preferences in Outcomes and Risks of Treatment (SUPPORT) found that 80% of the substantial variation in the rate of death at home correlated with hospital bed supply.

Conclusions: Based on the inadequacy of the current classification system and on the unpredictability of the timing of death, a conceptual model is proposed for many patients that mixes conventional "aggressive" care with palliative care and is triggered by illness severity rather than by prognosis. High leverage reform in end-of-life care is available now through quality improvement strategies.

Introduction

All of us will die, and most will die slowly in old age. This is a hard truth for many people; we live mostly as if death were somehow beyond the horizon. Our stock in trade in health care has been to give hope for a cure — a goal that is often beyond reach. At the same time, we have mostly spurned hope for living well despite bad disease and for an emotionally satisfying period of time while dying, even though these often can be obtained. Recent years have seen a major revision in this approach. Research, professional education, and practice are converging to engender substantial innovation and improvement in care for people with serious chronic disease. Only recently have we had textbooks for palliative care, multiple journals, and myriad research projects. In the past 20 years, hospice programs have been established in many countries, often showing that good care for the end of life is within reach for a wide array of patients and cultures. The Project on Death in America has supported 50 academician-leaders who are transforming medical education.

Reforms are sorely needed. In our Study to Understand Prognoses and Preferences in Outcomes and Risks of Treatment (SUPPORT), family members reported moderate or severe pain most of the time in half of those who were conscious near the end of life. Only one third of patients or families remembered having anyone discuss resuscitation, and most patients died with multiple medical interventions — and in the hospital.

One need not go to the professional literature, however, to know that citizens do not ordinarily have good experiences with health care for someone who is near death. Virtually everyone has a story — or stories — of outrage and calamity. Many report pain that dragged on and on, or physicians who were never quite honest, or family disarray and dissension. Even people who have a rewarding, comforting story to tell often start in a most curious way. They start their tale with the invocation that their loved one or the family "was lucky," and they say that nothing that they could have done would have ensured that things worked out so well. That is quite an indictment of the care system. People who have good experiences feel obliged to excuse themselves as being the recipients of undeserved good fortune!

From July 1997 through July 1998, the Center to Improve Care of the Dying and the Institute for Healthcare Improvement sponsored a collaborative quality improvement endeavor for 48 teams from as many health care programs. All aimed to improve care for persons facing the end of life. They formed goals, devised measurements, and tried innovations. Together, participants in the Breakthrough Collaborative in Improving End-of-Life Care learned a great deal about dying and about what the care system can do to improve the time spent with a serious and eventually fatal disease.

Who is Dying?

First, we learned that the population that needs special care is not limited to the population that is usually labeled as "dying." When Kübler-Ross started interviewing patients about dying, she could get no referrals in a large hospital; she was told that no one was "dying.5 While we learned in the 1970s to allow that label to be applied to some patients, we have used the term as a sharp category: "dying" or "not dying." This fits with what has been called a "transitional" model. A patient who has been among the "not dying" (yet) gets sicker and is clearly losing ground. Only then does the patient have a relatively brief period of being recognized as "dying," whereupon the care pattern is said to "shift from cure to care."

This stark redirection of goals fits only a few patients well. Most patients want palliation of symptoms ALL of the time; and most are well served by some preparations for dying, even while there is substantial hope for a long reprieve with "aggressive" treatment. In fact, most patients are probably best served with a model that mixes treatments to correct physiology (or to extend life) with treatments aimed at symptom control and alleviation of disability.6

The unpredictability of the timing of death helps to underscore the importance of mixing conventional medical treatment and palliative care. Even in lung cancer, which is among the most predictable of the common causes of death, the median patient still has approximately a 50-50 chance of living two months on the day that actually turns out to be seven days ahead of death. Fortunately, some evidence now intimates that patients do not have to be accurate about the risks of death to make thoughtful decisions — they just need to acknowledge that they are anything less than 90% likely to live for six months.
The unpredictability of the timing of death is most striking in diseases such as chronic congestive heart failure, stroke, and dementia, which together probably account for nearly half of all dying. In these diseases, patients gradually become quite disabled (in terms of exercise capacity or self-care), but they live within their constraints. Then some complication arises, such as a hip fracture, a heart attack, or an infection. With that new stress, the person is suddenly quite ill. Usually, the patient will be “rescued” a few times. After a few such rescues, all concerned feel that these periodic exacerbations and complications are almost routine and that the patient’s life is not threatened — they are waiting for something really serious. The fact that the illness is already serious and will almost certainly cause eventual death is simply not part of their awareness.

In light of this, our Collaborative partners learned to ask, “Is this patient sick enough to die?” rather than “Is this patient dying?” Another phrasing might be, “Is this patient sick enough that you would not be surprised to find that he or she had died six months (or a year) from now?” It turns out that the question of whether a patient “is dying” is answered in the affirmative only when a cancer patient is losing weight and bedridden or when a patient in the Intensive Care Unit is losing blood pressure — only when the death is virtually certain within a short time. However, the question of whether it would be “surprising” to find that the person had died included many other diagnoses and occurred much earlier in the course of care. It also turns out that people who are “sick enough to die” are usually appropriate targets for care that recognizes the eventuality of dying, even if any particular patient may live for many months.

How to Make Changes?

For two decades, Americans have tried to improve end-of-life care through improved decision making. We have tried granting patients the “right to refuse treatment,” have insisted on informed consent, have pushed advance directives, and sometimes have supported physicians’ claims that a treatment would be futile. New options have arisen that include not only mainstream medical treatments, but also alternative medicine, hospice, and physician-assisted suicide. Reformers have largely assumed that if one made these services available and worked to assure good decision making, informed choices would be enough to let the right program grow.

We now have some intriguing evidence to show that this emphasis on decision making may well be misplaced. In SUPPORT, the hospital with the highest rate of inpatient death was compared to the hospital with quite low rates of hospitalization at the time of death.1 There was a seven-fold difference in the odds of a person dying in the hospital at the first and last hospitals. This is quite a variation, especially since we adjusted for prognosis, comorbidity, family support, wealth, and dozens of other factors. The same sort of variation was evident in the patterns of location of death in Medicare data. Patient and physician characteristics such as preferences for aggressive treatment, comfort, and availability of family to provide care at home are significant but quite modest predictors that, taken together, explain less than 10% of the variance. However, one factor accounts for 80% of the variance — hospital bed supply, which is probably a marker for a whole set of arrangements that support certain patterns of utilization. The SUPPORT hospital that sent most patients home had doctors who followed patients after they left the hospital, had on-site and well-integrated hospice programs, and were located in communities where providers expected family caregivers to take time off from work. Most likely, if one region added more hospital beds, that region inadvertently learned to implement more marginal hospital-based treatments. Probably that region also did not learn to make the adjustments necessary in order to care for very sick people at home or in nursing homes.

Perhaps the time has come to force changes in the supply of services and in practice routines rather than spending most of our reform efforts to persuade patients to take on customizing the care system. More generally, perhaps the way to ensure that good care becomes routine is to focus on routines — providing excellent and reliable care for the person who does not speak up or advocate for himself or herself. People can still customize the care when it makes a difference to them, but we should start with a care system that is already good, even before the customization.

What Could Care Programs Improve?

Early in the project, we realized that the potential targets for improvement were grouped around four issues for which most care systems could be held responsible: (1) pain and symptom relief, (2) advance care planning, (3) support of family and meaningful relationships, and (4) continuity across programs, sites, and time.

Severe pain would seem to be a good first target, since many experts contend that almost all patients can be physically comfortable throughout the course of advanced chronic illness with presently available methods.10 The deficits here are often merely those of inattention, inappropriate prescribing, and inadequate follow-up. Teams that tackled pain nearly always realized substantial gains. One hospital team was stunned to find that a patient in pain ordinarily waited three hours before steps were taken to relieve it. By tackling all the sources of delay, they gradually whittled the waiting time down to under one hour — still too long but much preferred. Many teams realized substantial gains by making visible pain, ie, charting it each time the vital signs were charted. This approach was instituted in the entire Department of Veterans Affairs hospital system. Oncologists, it would seem, are obliged to be experts at pain and symptom management, but that expertise has been lacking in surveys of oncologists.11 Education alone is probably insufficient because the principles are so readily available if practitioners were eager to learn. More likely, programs aimed at improving professional expertise will have to study how to motivate their practitioners so that symptom management is a high priority.

Quality improvement teams had more uneven success in tackling other symptoms. One hospice team virtually eradicated troublesome dyspnea by using a protocol and frequent assessment. Hospital teams that tackled dyspnea were hampered by a widespread reluctance to risk any attenuation of the drive to breathe and thus could not implement strong protocols. A few teams tackled anxiety or depression, and they made modest but meaningful change.

The drive for reform through standard living will forms has largely given way to an interest in more detailed and customized advance care planning.12 Our quality improvement teams and others are beginning to report substantial success with this approach. In La Crosse, Wis, 85% of the entire population has written advance care plans at the time of death, and the median time for having an advance care plan recorded is a year ahead of death.13 One of the Department of Veterans Affairs hospitals in our quality improvement Collaborative instituted advance planning reminders in the electronic chart, feedback to teams on performance, and an advance care planning clinic. As a result, the proportion of its end-of-life patients who had a written plan increased from one-eighth to seven-eighths. Many teams found it important to implement concrete arrangements (eg, providing kits at home with medications or rehearsing how to call the care team instead of the emergency medical system) to handle what otherwise would be emergencies.

Virtually all of our teams that tried to improve family support and enhance spiritual meaningfulness had success.14 This must reflect the paucity of attention to such issues in most of health care. A few teams implemented specific arrangements to facilitate family caregiving — beepers to allow temporary absences or a room to shower and rest in the hospital. Many teams developed ways to inquire about spiritual concerns and then provided appropriate support. One team made this inquiry part of their intake questions. Many teams also developed techniques to support or monitor bereavement. Some sent cards or made a follow-up telephone call, and some provided nurses with a “kit” of prayers, poems, and advice. A few teams found that their programs sent the last bill to the now-deceased patient, and if the program did not note his or her death, and that was changed.

The most difficult of our original four targets was the aim to reduce and ease transitions across programs and to ensure continuity over time. There is no locus of accountability for these patients’ experiences over time. Each program feels overwhelmed with dealing with quality within its own services, and few even get any feedback on how patients and families experience transfers and disruptions in relationships with caregivers. The Program of All-Inclusive Care for the Elderly (PACE) and hospice programs incur a serious discontinuity at entry, but thereafter they are solidly allied with the patient and family. Other “systems” shuttle patients from one to another with no ability to make promises that endure over time and often even very little understanding of the quality of care at the next location. This seems to be a promising area for serious reform.

Some reforms depend on longer-term investments in change. Physician and nurse education is obviously deficient and will take many years to change. The research base for symptoms, function, and emotional experiences is quite thin, as is the health services research about how to make improvements happen.

Most Americans now die within the US Medicare payment system, yet with the exception of the hospice program, it has no focus or funding that supports good care at the end of life. Fee-for-service care has little incentive to ensure continuity, to accept responsibility for patients’ experiences across multiple programs, or to assure prevention of exacerbations. Without these, quality is always deficient. Capped care systems have the flexibility to customize care and the reason to assure continuity and prevention, but they are paid the same to take care of sick patients as to take care of healthy ones. Thus, they do not want to enroll or retain sick patients, and they certainly do not want a community reputation for doing a good job in this area. Interestingly, this has left the Department of Veterans Affairs as a dominant innovator, since they have disproportionately sick patients, flexibility in spending, long-term obligations to the patient, and a fixed budget.
It seems that some "rapid-cycle quality improvement" is needed in our financing structures. Perhaps populations with established serious illness could be matched with a special service array that emphasizes symptom control, family support, function, reasonable planning for death, and continuity. Such a service array could be priced at a rate that would make it possible to compete on quality. The reforms that might thereby be engendered could greatly change the experience of dying for Medicare patients. In short, our society is at the threshold of major reform. The numbers of people who are growing old together in the "baby boom" threaten to overwhelm our frail and already inadequate care system for the end of life. We need a period of energetic innovation and evaluation. We need to build on successful programs such as hospice and PACE, and we need to enhance the services of long-term care facilities and home care. Also, we need to develop ways to ensure reliability and comfort. This is exciting work, and it is cause for optimism that more researchers, educators, and policymakers are seeing it as an important focus.

References

11. From the George Washington University Medical Center, Washington, DC.

Address reprint requests to Joanne Lynn, MD, MA, MS, at the Center to Improve Care of the Dying, George Washington University Medical Center, 2175 K Street NW, Ste 820, Washington, DC 20037-1803.

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