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England's Approach to Improving End-of-Life Care: A Strategy for Honoring Patients' Choices

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ABSTRACT: In the U.S. health care system, and in those of many other countries, the care of dying patients is generally not performed well, with pain and other distress frequently undertreated and patients' preferences not respected. England's evidence-based End of Life Care Strategy could prove instructive. This issue brief discusses the origins, content, and implementation of the Strategy, as well as its potential impact. Both England and the United States struggle with similar challenges, including looking beyond the province of hospice and palliative-care specialists and initiating palliative services before the patient's final days. Aspects of the English approach that may be useful in the United States include strategies to help physicians recognize when patients are entering a trajectory that may end in death, the use of "death at home" as a metric for measuring progress, improving the skills of clinical and caregiving personnel through Web-based training, and developing a national improvement pathway.

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OVERVIEW

Ideally, the care of patients at the end of life would be humane, respectful of their dignity and wishes, and helpful in coping with the accompanying physical and psychological insults. But the reality is too often quite different. What happens to us at the end of life depends very much on the health care system of a country. And in the American system,¹ and those of many other nations, the care of dying patients is generally not performed well.

In the only available international comparison of care at the end of life, the *Economist* magazine's Economist Intelligence Unit (EIU) developed and applied a "quality of death" index made up of some 24 indicators pertaining to the basic end-of-life care environment as well as to the availability, cost, and quality of end-of-life care. In the 2010 report, *The Quality of Death: Ranking End-of-Life Care Across the World*, the EIU made comparisons among 40 countries. The United Kingdom and

Australia were ranked as having the best quality of death. The United States tied with Canada for 9th place.²

This does not necessarily mean that end-of-life care in any country approaches the ideal. In fact, the United States is ahead of the U.K. in some respects—for example, a higher percentage of patients receive hospice and palliative care in the U.S. at the end of life. An important difference between the two countries, however, is that the U.K. made a governmental decision in 2008 to adopt a systematic strategy to improve end-of-life care.

This issue brief addresses England's End of Life Care Strategy—a 10-year plan that was adopted in 2008 by the country's Department of Health and National Health Service.^{3,4} England's adoption of the Strategy provides an opportunity to see how improvements in end-of-life care are being pursued in a health system that was already, in international terms, doing relatively well. The author discusses why the strategy came about, what it consists of, how it is being implemented, and what is known about its impact.⁵ This account is based both on published sources and on some 15 interviews in London in early 2010 with individuals who have been deeply involved either with the Strategy and its implementation or with end-of-life and palliative care.⁶

A CHALLENGE FOR THE UNITED STATES

Though most Americans (71 percent in a recent survey⁷) say that their home is their preferred place of death, only 25 percent of U.S. deaths occur at home.⁸ Most of the 2.5 million deaths each year in the United States occur in institutional settings (45 percent in hospitals and 22 percent in nursing homes)⁹ and over 25 percent of Medicare expenditures go to beneficiaries' final year of life.¹⁰

Moreover, researchers have found that the pain and other kinds of distress that commonly occur among dying patients are frequently undertreated in the U.S.¹¹ Medicare's hospice benefit, though intended to facilitate palliative care (relief or prevention of pain and suffering) at the end of life, is limited to patients who forgo other treatment for their terminal illness; the benefit is used by fewer than 40 percent of dying patients, often only in the last few days of life.¹² (The median length of stay in a hospice is about 20 days, and about one-third of patients

live less than a week after admission.) In general, communication about end-of-life care between patients (or their families) and the patient-care team is inadequate, sometimes resulting in unwanted interventions that only prolong the dying process.¹³ Clearly there are discrepancies between the care that people envision for themselves and the care they typically receive.

The challenge of improving end-of-life care in the United States was tackled in 1997 in the Institute of Medicine report *Approaching Death*.¹⁴ Although its authors recognized positive developments in hospice care, palliative care, and patient autonomy, they found major problems in the quality of end-of-life care and recommended many ways to make improvements. However, none of these recommendations was directed at any specific entities—governmental or nongovernmental—that could be held accountable for implementing them.

How might the challenge be handled in a different health care system?

WHY AN END-OF-LIFE CARE STRATEGY IN THE U.K.?

As defined by British policymakers, “end-of-life care” should help people with advanced, progressive, and incurable illnesses to live as well as possible until they die.¹⁵ But there was considerable evidence in the mid-2000s that end-of-life care was inadequate in England, despite the excellent models that existed there—particularly in the hospices that had been introduced as charitable organizations several decades earlier. The majority of deaths in England occurred in hospitals, even though surveys indicated that few people stated a preference for hospitals as the places where they would wish to die (50%–70% said they would prefer to die at home).¹⁶ About half of the 16,000 complaints within the National Health Service (NHS) from July 2004 to July 2006 pertained to care given in acute hospitals, and within that fraction 54 percent related to end-of-life care.¹⁷ The primary criticisms involved communication problems, lack of basic comfort, inadequate symptom control, unmet psychological needs, and late referral to specialist palliative care. Care within hospitals thus came to be flagged by the NHS as a critical problem.

About the NHS

Health care in England, including hospital and physician services and prescription drugs, is provided to all residents through the National Health Service (NHS). The NHS is financed primarily through general taxation and requires very little patient cost-sharing (mainly for outpatient prescription drugs, dental care, and optometry care). About one of 10 residents has supplementary private insurance that covers the individual's choice of specialist and faster access to elective surgery.

Eighty percent of the NHS budget is controlled by 152 primary care trusts (PCTs), which contract with physicians and hospitals to provide care to a geographically defined population. Hospitals are organized as trusts (responsible to England's secretary of state for health), with varying degrees of autonomy. Specialists are mainly salaried hospital employees, although many supplement their income treating private patients.

Since 2003, the NHS has purchased a small but increasing share of routine elective surgery and diagnostics from private providers. Primary care providers are mainly private, operate under an annual national contract, and are paid directly by PCTs through a combination of salary, capitation, and fee for service. The 2004 general-practitioner contract introduced a comprehensive pay-for-performance initiative that provides substantial financial incentives tied to achievement of clinical and other performance targets. Since 2003, a new payment framework has been gradually introduced, basing contracts with acute, mental health, ambulance, and community service providers on activity. Since 2009, a proportion of these providers' incomes are conditional on quality and innovation.

Demographic trends lent urgency to the need for improvement. The number of deaths, particularly among the very old, was certain to increase substantially over the next decade. This added an important, if implicit, economic dimension to the issue. Although the Strategy was not proposed as a way to save money, there was hope that such care could be improved without adding to the overall cost of health care. This objective seemed feasible, given that a review of the evidence by the U.K. National Audit Office suggested that many hospital admissions for patients at the end of life were avoidable, resulting from problems such as lack of access to timely advice and medications for people living at home and in nursing homes, as well as coordination problems among the different organizations that provided care near the end of life (e.g., ambulance services and out-of-hours general practitioners being unaware of patients' "do not resuscitate" orders).¹⁸

Professor Sir Mike Richards, the London oncologist and palliative-care specialist who led both in the development and implementation of the Strategy, identified two additional matters that it needed to address.¹⁹ First, a general societal reluctance to talk openly about death and dying meant that few people were discussing

their care preferences with relatives or friends and that professionals were reluctant to initiate conversations with patients about these matters. Second, end-of-life care had a low profile within the National Health Service and social-service organizations. Having not been identified as a priority, the quality of end-of-life care was variable and often low.

Shortcomings in end-of-life care in Britain may seem surprising because it was the place of origin for the modern hospice concept—to provide a more humane alternative to the ways in which people near the end of life were treated in hospitals. Beginning with Dame Cicely Saunders' St. Christopher's Hospice in 1967, hospices became widespread in Britain, and the idea of palliative care that was associated with hospices gained widespread acceptance in many countries. However, this does not mean that the hospice itself was integrated into the health care system. In Britain, hospices developed as charitable organizations that were external to the National Health Service and its hospitals and health professionals, though today some 40 hospices and a growing number of palliative-care consultant physicians are part of the NHS.

The success of hospices had a paradoxical effect. They came to be seen as providing Britain's standard of excellence for care of the dying, but this led to feelings of inadequacy in the hospital settings where most patients die. As Professor John Ellershaw, director of the Marie Curie Palliative Care Institute in Liverpool, has put it, the "hospice model of excellence can lead to the generalist feeling that the only place patients can die well is in a hospice, resulting in de-skilling and a sense of failure within the health care staff who are not based within the hospice sector."²⁰

In the mid-2000s only 16 percent of cancer deaths and only about 5 percent of all deaths occurred in hospices.²¹ (Hospices were also involved in the care related to another 5 percent of deaths that occurred elsewhere.) If dying patients were to benefit from the end-of-life care expertise associated with hospices, such care needed to be transferred beyond these facilities themselves. That was the idea behind the development of the approaches on which the end-of-life care strategy built.

THE END OF LIFE CARE STRATEGY

The End of Life Care Strategy laid out 10 objectives, including the need to enhance public awareness, improve end-of-life care, and increase relevant knowledge and skills among health professionals (Exhibit 1).

Several aspects of the Strategy are particularly notable. First, it emphasized the need for understanding and respecting the wishes of patients in how they are cared for at the end of life, as well as for offering people more choice about the care they receive, particularly with regard to location of care (e.g., home or hospital). Professor Richards emphasized that the Strategy's approach existed within the "current legal framework" and thus did not involve euthanasia or assisted dying.

Second, the Strategy enunciated a vision of quality of care based on what is involved in a "good death" for patients, including being treated as an individual and with dignity and respect, being without pain and other symptoms, and being in familiar surroundings in the company of close family or friends. There was an explicit recognition that there is no single end-of-life trajectory and that the process by which patients approach death is in part a function of the disease involved. Because the downward courses are typically quite different for cancer, organ-system failure, and frailty/dementia, for example, these variations need to be recognized in providing end-of-life care.²²

Third, the Strategy was evidence-based in several respects. Research had documented the shortcomings in existing end-of-life care that the Strategy sought to address. Also, as is discussed later in this brief, the

Exhibit 1. Objectives of England's *End of Life Care Strategy*

- Increasing public awareness of death and dying to facilitate people's discussion of their own preferences and help drive improvements in service quality.
- Ensuring that people are treated with dignity and respect at the end of their lives.
- Ensuring that pain and suffering are kept to an absolute minimum by providing access to skillful symptom management.
- Ensuring access to physical, psychological, social, and spiritual care.
- Ensuring that people's individual needs, priorities, and preferences for end of life care are identified, documented, reviewed, respected, and acted upon.
- Ensuring coordination of services so that patients receive seamless care.
- Ensuring that high-quality care is provided in the last days of life and after death in all care settings.
- Ensuring that caregivers are appropriately supported.
- Ensuring that health and social care professionals receive the education and training necessary for providing high-quality care.
- Ensuring that services provide good value for the money to the taxpayer.

Source: Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (London: Department of Health, 2008).

Strategy's ideas for improving end-of-life care came from pertinent models and research already in existence. And it was recommended that a strong research component be built into implementation, both for monitoring progress and assessing outcomes.

Fourth, a recurrent theme in the Strategy involved crossing boundaries that had previously limited the application of the best ideas and service models for end-of-life care. The Strategy was explicit about going beyond cancer care to meet the needs of all patients with advanced, progressive, and incurable illnesses. The Strategy recognized that good end-of-life care should be the province not only of hospices and palliative-care specialists and should not be limited to certain settings, whether hospice or hospital. (A complication for end-of-life care in Britain is that the general practitioners with whom patients have ongoing relationships provide care exclusively outside of the hospital, as do the providers of social care, while disease-specific specialists are usually hospital employees.) The fact that some necessary services are provided in the voluntary and private sectors as well as in the National Health Service provides additional boundary-crossing challenges, and so does the fact that the care homes where many frail elderly reside lie outside the NHS and beyond its care and quality-control capacities. An additional boundary involved timing. Under the Strategy, services oriented toward the end of life could begin a year or more before the patient's final days.

These and other central ideas for improving patient care were built into a "care pathway" that would be followed by professional and organizational providers of care and supported by the NHS's processes of planning, budgeting, and contracting for services. The steps of the care pathway were:

- The physician identifies patients who are within a year or two of the end of life and initiates discussions of their care preferences.
- Care plans are developed for patients based on their needs and wishes, and these plans are regularly reviewed and modified as needed.
- A doctor or nurse coordinates a patient's care among the multiple organizations with which the patient

might deal—hospitals (and their specialists), primary care doctors (GPs), care (i.e., nursing) homes, out-of-hours medical services,²³ district nurses who provide home care, social care providers, ambulance services, and hospices and specialist palliative care services.

- These and other pertinent organizations deliver high-quality services.
- Care—particularly "comfort care"—is provided to the patient in his or her last days of life.
- Care is provided after death (for the patient's body) and for the needs of families and caregivers.

Notable among these steps were the focus on early identification of patients who are approaching the end of life, the emphasis on coordination, and the recognition that death does not end the need for services related to end of life. And crosscutting the six steps in the pathway were strands reflecting the need to provide spiritual care, to support families and caregivers, and to supply high-quality information.

The elements of the Strategy's care pathway were based on existing models and tools that had been developed in hospices and by the NHS but that were still only in limited use. The Strategy sought to transform end-of-life care by promoting the wider use of these models—namely, the Preferred Priorities for Care, Gold Standards Framework, Delivering Choice Programme, and Liverpool Care Pathway for the Dying Patient—each of which had emerged in an ad hoc way in a particular location or sector of the health care system in response to the needs of patients at the end of life. Although they have separate origins and different emphases, they have much in common. Each of these models merits brief description (Exhibit 2).

Preferred priorities for care.²⁴ Not an actual model of care, preferred priorities for care (PPC) is similar to the "advance directive" family of documents in the United States in that it can be put in place well before the need for end-of-life decision-making.²⁵ The PPC consists of a form on which people answer three open-ended questions about 1) what has been happening to them

Exhibit 2. Models and Programs Used in Developing the End of Life Care Strategy

Model/Program	Implemented by	Focus	Aim
Preferred Priorities for Care	Patients	Document patient preferences for end-of-life care	Facilitate care that meets patient's preferences
Gold Standards Framework	Primary care teams	Guide care in patients' last year of life	Enable patients to receive high-quality end-of-life care as much as possible at home
Delivering Choice Programme	Discharge and home care nurses	Facilitate end-of-life care at home for hospitalized patients	Enable patients near end of life to be cared for at home if they wish
Liverpool Care Pathway for the Dying Patient	Multiprofessional teams in hospitals	Meet psychological, spiritual, and physical needs of patients in their last days and hours of life	Provide dying patients with comfort, pain management, and relief from distressing symptoms

Source: Adapted by author from materials at the following sources: <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare/>; <http://www.goldstandardsframework.nhs.uk/>; <http://www.mariecurie.org.uk/en-gb/healthcare-professionals/innovation/Delivering-Choice-Programme/>; <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>.

regarding their health, 2) their “preferences and priorities” for future care, and 3) where they would like to be cared for in the future. There is also space for recording any changes in preferences and priorities as well as for contact information on people involved in the patient’s care. The document containing this information is to be taken by the patient to the various places in which he or she may receive care; in that way, medical staff can follow the patient’s wishes should his or her capacity be lost toward the end of life.

The Gold Standards Framework. The Gold Standards Framework (GSF), developed as a grassroots initiative by Yorkshire general practitioner Dr. Keri Thomas, is designed to assist primary care teams in providing the best possible care for people nearing the end of their lives. The Framework’s goals are to provide high-quality care that is consistent with patients’ preferences, anticipates and plans for their needs, and is more home-based than hospital-based.²⁶

Application of the GSF begins with identifying people who may be in their last year or so of life, as opposed to hospitalized patients who are already close to death. Identification may begin with the so-called surprise question that doctors could ask themselves, “Would it surprise you if this patient died in the next

year?”²⁷ The Royal College of General Practitioners has developed a set of clinical indicators to help clinicians recognize differences in the trajectory of dying with different conditions (e.g., cancer, heart failure, HIV/AIDS, or dementia).²⁸ The second step is to assess the patient’s current and future clinical and personal needs, taking into account his or her preferences and those of the family. The third step is to develop and carry out a plan to meet those needs and preferences. This involves the “7 Cs”: communication, coordination, control of symptoms, continuity of care, continued learning, caregiver support, and care of the dying.

Originally developed for cancer patients, the GSF can now be used in a variety of settings for any patient with a life-limiting condition. The National Gold Standards Framework Center has prepared guidance for physicians and nurses in primary care, care (nursing) homes, and hospitals in carrying out the GSF.²⁹ At the time the End of Life Care Strategy was prepared, estimates were that about 50 percent of the GP practices in England reported using the GSF, though not all of them were fully implementing it, and there was great regional variation.³⁰

The Delivering Choice Programme. The Delivering Choice Programme was begun in 2004 by Marie Curie

Cancer Care, one of Britain's largest health charitable organizations, which operates nine hospices and provides free nursing care to terminally ill people who wish to be cared for and to die at home, supported by their families. The program, aimed at overcoming locally identified barriers to the effective provision of end-of-life care, has several key elements. They include "discharge community link nurses" who facilitate discharge from hospitals by coordinating home care services, the provision of information and advice to patients, the conveyance of patients' needs to home health care teams, and "rapid response teams" that make emergency as well as planned visits to patients in their homes during off hours.

An evaluation of the Delivering Choice Programme in Lincolnshire by the Kings Fund in 2007 found a substantial increase (from 19% to 42%) in deaths at home among patients who had used the program's services and no change among patients who had not.³¹ No differences were found in hospital usage or in costs over the last eight weeks of life. A separate evaluation in Lincolnshire, based on assessments of patients and their families, found that rapid response teams (RRTs) were effective in providing care and support, particularly for cancer patients in crisis at night.³² The Programme enabled some families to keep patients at home until they died, and the availability of services by phone provided reassurance that help could be summoned when needed. One-third of the cancer patients who died in the two locales studied had used the service, and 73 percent of cancer patients who died at home had received RRT support.

The Liverpool Care Pathway for the Dying Patient.

The Liverpool Care Pathway for the Dying Patient (LCP), which was developed in the 1990s by the Royal Liverpool University Hospital and the Marie Curie Hospice Liverpool,³³ focuses primarily on the last days and hours of life of hospitalized patients. It provides caregivers with guidance on meeting the physical, psychological, and spiritual needs of dying patients, including comfort measures, anticipatory symptom control, and the discontinuance of interventions that are not conferring benefit. The LCP is brought into use for particular

patients when a trained multiprofessional team agrees that the patient is dying and that all possible ways to reverse the current situation have been considered and found to be either ineffective or infeasible.³⁴ The patient's need for comfort, pain management, and relief of distressing symptoms are to be addressed and reassessed at least every four hours. Rescue treatment can be resumed if changes in the patient's condition warrant it.

The LCP lays out detailed steps regarding what information should be obtained and documented about the patient's wishes. The pathway also contains guidance about informing the patient and relatives when the focus of care has changed and about communicating after death with the patient's family and general practitioner. At the time the End of Life Care Strategy was published in 2008, the LCP had been implemented in at least three hospital wards in more than 80 percent of hospital trusts, but it had been introduced to all appropriate wards by only 17 percent of trusts.³⁵ The Strategy sought to increase the use of the LCP.

IMPLEMENTATION OF THE END-OF-LIFE CARE STRATEGY

The Strategy laid out actions to make change happen.³⁶ One set of actions was focused on increasing public awareness that patient care at the end of life could be guided in ways that responded to patients' preferences. A second set was aimed at improving the capacity of purchaser organizations within the National Health Service (primary care trusts at that time) to carry out the responsibilities implied by the end-of-life pathway. A third set of actions involved providing guidance to, and creating expectations and responsibilities for, the organizations and professionals that provide care to patients at the end of life. And a fourth was the development of a set of measures by which progress could be assessed.

Publishing a strategy is one matter; changing the services provided by the NHS and its 1.3 million employees to England's 50 million people (of whom about half a million die in a given year) is quite another. The number of people responsible for implementing the Strategy was remarkably small—fewer than half a dozen people each in the Department of Health and the NHS.

The End of Life Care Strategy was incorporated into the operating framework of the NHS, and it was made a priority in the overall quality-improvement effort known as the Next Stage Review. This effort worked through the structure of the 10 regional strategic health authorities, which oversee the 152 primary care trusts in England that purchase the services of general practitioners, hospitals, and other providers within the NHS. (In the wake of the elections of 2010, the regional authorities and primary care trusts are to be phased out in 2013 and replaced by physician-based purchasing arrangements.³⁷)

Specific implementation activities, often in the form of pilot projects, have varied across these entities, and lessons are being shared. For example, guidance (including information about “good practices”) was published so as to assist in the purchasing of end-of-life services and in providing such care. Implementation made use of incentives as well, and also it included the collection of data indicative of progress. The Department of Health also had some new money (£286 million [US\$460 million] over the first two years) with which to encourage implementation of the Strategy’s directives. Some of this funding was used for workforce development, but most of it went to the primary care trusts for their use in purchasing services.

One of the most direct implementation tools, initiated before the Strategy was published (though while it was in development), involved the Quality and Outcomes Framework (QOF) that was part of the NHS’s standard contract with general practitioners. Provisions related to palliative care were included among the QOF measures on which GPs received incentive payments for their performance.³⁸ To encourage providers to pay attention to the needs of patients who might be entering an end-of-life situation, the NHS gave GPs three QOF points for creating a list of their patients thought to need palliative care or to be in their last year or so of life; and the NHS awarded three additional points for reviewing those patients at multidisciplinary team meetings. Data reported for the one-year period ending March 2010 showed that 94 percent of the 8,305 practices reporting met the former target and 84 percent the latter.³⁹ Though these physician actions did not themselves change patient

care, they were essential steps in applying the Gold Standards Framework.

Markers of progress. The implementation of the Strategy, like its development, emphasized the importance of evidence. Soon after the Strategy’s publication in 2008 the Department of Health drafted a set of “quality markers” for end-of-life care and then invited comment; in 2009 the agency published a revised set of quality markers based on the resulting feedback.⁴⁰ These markers were structure and process measures, as well as measures of compliance for use in audits and evaluations. There were separate measures for commissioners (purchasers) and for the various kinds of providers—e.g., primary care providers, hospitals, hospices, and ambulance services. For commissioners, there were markers for activities in increasing public awareness, strategic planning, oversight of providers’ activities and service capacities, coordination across organizational boundaries, workforce planning, and monitoring. For providers, quality markers focused heavily on capacity, with appropriate variations for the type of provider. (See Exhibit 3 for the top 10 quality markers for providers.)

Progress reports. The Department of Health issued progress reports one year and two years after publication of the Strategy. Progress was reported largely in terms of steps taken by strategic health authorities (SHAs) and primary care trusts (PCTs). Progress reporting was rather cumbersome, because both types of entities were given much autonomy in adopting the End of Life Care Strategy. For example, improving end-of-life care was one of 50 priorities from which PCTs had to choose eight, and SHAs could develop their own emphases—one might focus on changing public attitudes, another on the use of electronic health records to coordinate care, and another on implementing the Delivering Choice Programme (to help develop local services that enable palliative care patients to be cared for in the place of their choice). The hope was that the SHAs would learn from each other’s experiences with different components of the overall Strategy.

Exhibit 3. Top 10 Quality Markers for Providers

1. Have an action plan for delivery of high-quality end-of-life care that encompasses all patients' diagnoses and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of caregivers are appropriately assessed and recorded.
6. Have mechanisms in place to ensure that care for individuals is coordinated across organizational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end-of-life training opportunities and enable workers to access appropriate programs relevant to their needs.
9. Adopt a standardized approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and results of end-of-life care and submit relevant information for local and national audits.

Source: Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (London: Department of Health, 2008).

In the first year, some 69 PCTs (close to half) designated improving end-of-life care as one of their eight priorities. The tools they possessed for achieving this goal were some funding for enhancing the training of health care providers, a reporting system for the percentage of deaths that occur at home, and the offering of incentives to general practitioners to recognize and pay attention to their patients who are nearing the end of life (the first step in the care pathway). The only outcome measure in this set was percentage of all deaths that occur at home. In recognition that additional outcome measures are needed, pilot testing has been taking place for a national survey (entitled VOICES) that solicits the views of bereaved relatives about the end-of-life care of their loved one.⁴¹

The second annual report attested to continued progress on several fronts.⁴² One was the launching in early 2010 of an Internet-based education program for health and social care professionals regarding end-of-life care. Another was the availability of capital funding for several new hospice facilities. Pilots were initiated both for the local registries of people facing end of life as well as for the VOICES survey of the bereaved. Two widely recognized experts in end-of-life care—Dr. Teresa Tate,

the medical advisor for Marie Curie Cancer Care, and Professor John Ellershaw, who had led development of the Liverpool Care Pathway—were appointed deputy national clinical directors for end-of-life care. The report, and the implementation effort itself, continued to focus on identifying and publicizing examples of good practices, with the aim of encouraging their wider adoption.

There were also some early lessons. One was that the Vital Sign measure for end-of-life care—the number of people dying at home—was flawed; for many people, a nursing or care home had become their residence and was therefore an appropriate place for death for people not wanting to die in a hospital. The report thus stressed the need to recognize care homes in implementing the strategy.

Two other related problems were recognized as well. First, primary care trusts had been very uneven in their efforts to implement the strategy, leading to the concern that a post code (zip code in American terms) lottery would determine what care people received at the end of life. Second, the funds that had been allocated to PCTs for end-of-life care had not been “ring-fenced,” and a third of them were unable to report on what they had done with that money. (The PCTs that had made best

use of the funding were the same ones that had historically done well at end-of-life care.) But these problems resulted from limitations in the administrative structure for implementing a national strategy, not from the Strategy itself.

STRENGTHS OF THE STRATEGY

Although the NHS is still early in the 10-year horizon envisioned for implementing the End of Life Care Strategy, there is reason for optimism. This brief has already identified a number of strengths in the English approach to improving end-of-life care, including comprehensiveness; heightened public awareness; successful models of care to build on; enhanced training of health professionals; an emphasis on evidence; and the use of incentives, education, and oversight as levers of implementation.

A striking characteristic of the Strategy itself is its level of acceptance by the leadership of the relevant medical societies (British Medical Association, Royal College of Nursing, Royal College of Physicians, and Royal College of General Practitioners) and caregiving organizations (Macmillan Cancer Support and Marie Curie Cancer Care). Reasons for this acceptance may include the following: the participatory process by which the Strategy was developed, involving work over two years by a distinguished advisory board and six working groups plus consultations with 300 stakeholders, was widely admired; the clinical directors of all of the strategic health authorities were involved in the process; the development and implementation of the Strategy was led by an eminent palliative-medicine specialist, Sir Mike Richards, national clinical director for end-of-life care; the Strategy was built upon, and harmonious with, previous policy initiatives; and it fit into a much broader effort, undertaken in the 2000s, to improve care in the National Health Service—for example, a policy thread that the Strategy shared with several components of this overall effort was to expand patient choice.

CHALLENGES FACING THE STRATEGY

Several end-of-life challenges remain. First, successful implementation ultimately depends on the willingness of individual physicians to build the relationships and undertake the conversations that reveal patients' wishes—and to respond accordingly. Effecting behavioral change among physicians is always difficult, and the literature on the problem of diffusion of innovation in health care organizations is huge.⁴³

A second challenge arises from the fact that the triggering act for initiating end-of-life care—recognizing when particular patients are entering the end-of-life situation—can be difficult to do and is potentially controversial.⁴⁴ The Gold Standards Framework is envisioned for implementation a year or more in advance of patients' deaths. Regarding patients who die in hospitals, many do so unexpectedly and thus might not be subject to the Liverpool Care Pathway. On the other hand, the possibility that hospitalized patients could be incorrectly identified as dying raises the danger of misapplying the Pathway. A controversy developed in fall 2009 when six experts wrote a letter to the *Daily Telegraph* claiming that some patients were incorrectly being put on the Pathway. The problem, it appears, was less in the Pathway and its elements than in the need for better training of clinical personnel in making the difficult judgment that a patient is actually in the process of dying.

A third challenge, which can arise in any policy implemented by government, is the possibility that the party that champions it may be voted out of office. This in fact happened in England in 2010 with the replacement of the Labor government. In several interviews that the author conducted shortly before that election, no one believed the Strategy was vulnerable to a change in government because the need for improving end-of-life care was widely recognized and the Strategy had generated almost no organized opposition. Also, because the Strategy was clinically led and “owned,” it was more about professional standards than political ones. But only a few months after the election the coalition government proposed to eliminate one mechanism by which the Strategy was being implemented—the strategic health authorities—and to replace the primary care trusts with

a purchasing mechanism controlled by general practitioners. More reassuring has been the public statement by Paul Burstow, the current Minister of State, that the Strategy is to be taken further and faster.⁴⁵ End-of-life care is also addressed in several documents of the new government, including the Coalition Agreement (relating to a per-patient funding system for palliative care). A review of how this system might be implemented is under way.

A final challenge pertains to marking progress. Mechanisms are in place to measure various structural and procedural aspects of the quality of end-of-life care, but measuring the outcomes of the Strategy itself is more difficult. The only available outcome measure is the percentage of deaths that occur at home or in the care homes that are the final residences of many people. The planned VOICES surveys to collect information on the experiences of bereaved relatives should provide additional useful markers of progress, as may the ongoing analyses of complaints within the NHS.

COMPARISON WITH THE UNITED STATES

End-of-life care in the United States has already been hugely influenced by ideas associated with hospice and palliative care in the U.K. Thus, for example, the patient-choice issues that animate the English End of Life Care Strategy, including legal developments pertaining to patients' advance directives regarding end-of-life treatment, are now familiar to U.S. stakeholders. Americans, however, often go their own way, as with their organized payment system for hospice care, which is more advanced than its English counterpart; such services are built into the Medicare program rather than largely supported by charity, as in the U.K. And the share of deaths occurring in hospitals is smaller in the United States than in England—45 percent (37 percent if only inpatient deaths are counted) compared with 58 percent in England.⁴⁶

Despite such differences, it is striking, when comparing end-of-life care in the two countries—which have such different health care systems—that the challenges in end-of-life care are so similar. There is a general reluctance in both countries to discuss preferences for end-of-life care, and there are shortages of professionals

with the requisite training. Both countries struggle with what we described earlier as “boundary” challenges: going beyond cancer care to meet the needs of all patients with advanced, progressive, and incurable illnesses; extending end-of-life care beyond the province of hospice and palliative-care specialists; initiating services oriented toward the end of life but before the patient's final days; and gaining acceptance of the idea that palliative-care services can be appropriate no matter the stage of a patient's disease.⁴⁷

Meanwhile, important elements of the British approach that do not depend on the existence of a National Health Service may be applicable to the United States. The Gold Standards Framework and the Liverpool Care Pathway both provide guidance that could be useful for American physicians and other health professionals, and research on the Delivering Choice Programme shows that the introduction of services such as discharge community link services and rapid response teams can markedly enhance the feasibility of caring for U.S. patients at home during their final days, if that is their preference. The idea of using survey research (e.g., the VOICES project) to obtain survivors' assessments of the quality of end-of-life care of their loved one is another idea worth emulating, as was suggested in the Institute of Medicine report *Describing Death in America*.⁴⁸ The last federally funded mortality follow-back survey in the United States was done in 1993.

Other aspects of the English approach that may be useful in improving end-of-life care in the United States include: the strategies for encouraging and helping physicians to recognize when patients are entering one of the trajectories that may end in death and to implement approaches to care that are based on that recognition; the use of “death at home” as a metric for measuring progress; the focus on improving the skills of clinical and caregiving personnel through the use of Web-based training; and the development of a national improvement pathway such as the Gold Standards Framework. However, the English approach that the government should try to increase awareness of the need for end-of-life care planning contrasts strongly with the situation in the United States, where the idea of compensating physicians for

having end-of-life care conversations with their patients prompted fears, however unfounded, of the creation of “death panels” that would determine who deserved to live.

When asked about important lessons for the United States, most of our English interviewees cited the End of Life Care Strategy itself—the fact that a set of ideas about patient choice and palliative care could be built into the very structure of the health care system. My own choice for the most important lesson pertains to the value of approaching end-of-life services as a quality-of-care issue for which measures are needed. Work on the development of such measures is taking place in both countries.⁴⁹

NOTES

- ¹ Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academies Press, 1997).
- ² Economist Intelligence Unit, *The Quality of Death: Ranking End-of-Life Care Across the World* (London: EIU, 2010).
- ³ Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (London: Department of Health, 2008).
- ⁴ Different versions of the strategy were implemented in England, Northern Ireland, Scotland, and Wales. For simplicity, we focus here on England.
- ⁵ We follow two conventions in citing the strategy. First, the word is capitalized only when referring to the document itself. Second, the term “end-of-life care” includes hyphens except in reference to the document itself, which did not use hyphens.
- ⁶ Interviews were done in person or by phone in April 2010 with Rachel Addicott, senior research fellow, Kings Fund; Maureen Baker, honorary secretary of council, Royal College of General Practice; Martin Bardsley, Nuffield Trust; Amy Bowen, assistant director of research and innovation, Marie Curie Cancer Care; Tony Calland, chair, British Medical Association Ethics Committee; Lara Carmona, head of policy development, Marie Curie Cancer Care; Jayne Chidgey-Clark, director of end-of-life care, Guys and St. Thomas’s Hospital Trust; Jonathan Ellis, director of public policy and parliamentary affairs, Help the Hospices; Baroness Ilora Finlay, independent crossbench member of the House of Lords, past president of the Royal Society of Medicine, and professor of palliative medicine at Cardiff University School of Medicine; Irene Higginson, professor of palliative care, policy and rehabilitation at King’s College London and scientific director of Cicely Saunders International; Tessa Ing, head of end-of-life care, Department of Health; Tim Jackson, Guy’s Hospital nurse director, South East London Cancer Network; Professor Sir Mike Richards, national cancer director and national clinical director for end-of-life care, Department of Health; John Saunders, chairman, Royal College of Physicians Committee on Ethical Issues in Medicine; and Teresa Tate, deputy national clinical director for end-of-life care at the Department of Health and medical advisor to the Marie Curie Cancer Care, and consultant in palliative medicine to the London NHS Trust.
- ⁷ Harvard School of Public Health/Robert Wood Johnson Foundation poll, April 22–May 15, 1999.
- ⁸ IOM, *Approaching Death*, 1997, 2.
- ⁹ National Center for Health Statistics, *Deaths from 39 Selected Causes by Place of Death, Status of Decedent When Death Occurred in Hospital or Medical Center, and Age: United States, 1999–2005* (Hyattsville, Md.: NCHS, 2009), tabulated from the National Vital Statistics System, Mortality. Available at <http://www.cdc.gov/nchs/nvss/mortality/gmwk307.htm>, accessed June 21, 2011; and D. C. Angus, A. E. Barnato, W. T. Linde-Zwirble et al., “Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study,” *Critical Care Medicine*, March 2004 32(3):638–43.
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- ¹³ J. C. Hofmann, N. S. Wenger, R. B. Davis et al., "Patient Preferences for Communication with Physicians About End-of-Life Decisions," *Annals of Internal Medicine*, July 1997 127(1):1–12.
- ¹⁴ IOM, *Approaching Death*, 1997.
- ¹⁵ This definition comes from Britain's National Council for Palliative Care.
- ¹⁶ M. Richards, "The End of Life Care Strategy: 16 Months On," in R. Addicott and R. Ashton (eds.), *Delivering Better Care at the End of Life: The Next Steps* (London: The Kings Fund, 2010).
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- ¹⁸ National Audit Office, *End of Life Care* (London: National Audit Office, 2008).
- ¹⁹ Interview in London, April 13, 2010.
- ²⁰ J. Ellershaw, "Care of the Dying: What a Difference an LCP Makes!" *Palliative Medicine*, July 2007 21(5):365–68.
- ²¹ Office for National Statistics, *Mortality Statistics, Series DH1, no. 37* (London: Office for National Statistics, 2004).
- ²² J. Lynn, *Sick to Death and Not Going to Take It Anymore: Reforming Health Care for the Last Years of Life* (Berkeley: University of California Press, 2004).
- ²³ The out-of-hours system makes care available to patients outside the time that doctors' offices are open. That is, the system operates both at night and on weekends.
- ²⁴ <http://www.endoflifecareforadults.nhs.uk/assets/downloads/ppc.pdf>, accessed June 21, 2011.
- ²⁵ C. P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," *Milbank Quarterly*, June 2010 88(2):211–39.
- ²⁶ Extensive information about the Gold Standards Framework and its application is available at <http://www.goldstandardsframework.nhs.uk>, accessed June 21, 2011.
- ²⁷ Although this question sounds subjective, there is evidence that it has predictive value. See, for example, A. H. Moss, J. Ganjoo, S. Sharma et al., "Utility of the 'Surprise' Question to Identify Dialysis Patients with High Mortality," *Clinical Journal of the American Society of Nephrology* Sept. 2008 3(5):1379–84; and Lynn, *Sick to Death*, 2004.
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- ³⁵ Department of Health, *End of Life Care Strategy*, 2008, 83.
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- ³⁹ NHS Information Centre for Health and Social Care, *Palliative Care: Quality and Outcomes Framework (QOF) for April 2009–March 2010, England*.
- ⁴⁰ *End of Life Care Strategy: Quality Markers Consultation* (London: Department of Health, Nov. 2008); *End of Life Care Strategy: Quality Markers and Measures for End of Life Care* (London: Department of Health, June 2009).
- ⁴¹ This approach is based on the research of Professor Julia Addington-Hall of Southampton University.
- ⁴² *End of Life Care Strategy: Second Annual Report* (London: Department of Health, Aug. 2010).
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- ⁴⁴ See Lynn, *Sick to Death*, 2004.
- ⁴⁵ Personal communication with Tessa Ing, Department of Health, July 19, 2010.
- ⁴⁶ National Center for Health Statistics, *Deaths from 39 Selected Causes*, 2009.
- ⁴⁷ Meier, Isaacs, and Hughes, *Palliative Care*, 2010. See also A. S. Kelley and D. Meier, “Palliative Care—A Shifting Paradigm,” *New England Journal of Medicine*, Aug. 19, 2010 363(8):781–82. The Medicare requirement limiting hospice services to patients judged to be in the last six months of life is seen as a barrier in this regard.
- ⁴⁸ J. R. Lunney, K. M. Foley, T. J. Smith et al. (eds.), *Describing Death in America: What We Need to Know* (Washington D.C.: National Academies Press, 2003).
- ⁴⁹ I refer in the United States to work now being done under the auspices of the National Quality Forum.

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