



Where We Die

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Until well into the 20th century in the United States, the appropriate place to die was a foregone conclusion: by expectation and practice, it was at home, surrounded by family and friends (Fig. 1).

A case in point was death from consumption (tuberculosis) in pre-Civil War New England. In tightly knit, homogeneous communities, a network of friends, neighbors, relatives, and clergymen comfort-

ed the dying, expecting, as Sheila Rothman has written, to walk with them “down to the borders of the River of death.”¹ Physicians, once they had ascertained that the disease was in its last stages, were peripheral to the process.

There were, of course, exceptions. Since consumption, it was believed, might be curable in warm climates, men and occasionally women traveled southward to Georgia, Cuba, or Bermuda. Although some survived the round-trip voyage, others died far from home, much to their families’ anguish. It was unbearable, as one brother wrote to another, “that your eyes would be finally closed by foreign hands in a foreign country.”¹

The most serious challenge to these shared expectations, however, was the Civil War (Fig. 2). Soldiers who were wounded on the battlefield represented, as Drew Faust puts it, “an exemplary text on how not to die.”²



Figure 1. Dying at Home.
Sarah Dillwyn's Deathbed, by Charles Robert Leslie.

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Figure 2. Dying on the Battlefield.

“Petersburg, Va., April 1865; Dead South Carolina soldier in trenches,” by Thomas C. Roche.

Fellow soldiers and nurses made great efforts to serve as surrogate families, which provided some consolation to parents. In one popular Civil War song, a dying soldier asks his nurse to “be my mother till I die.” Even more troubling was that both Union and Confederate units left many dead soldiers unburied or interred in unnamed blocks. After the hostilities ended, families undertook the grim task of traveling to the battlefields to try to locate their kin and arrange proper burials.²

The norm of dying at home persisted even through the extensive societal transformations brought about by immigration and urbanization. Ethnic origins and social class increasingly divided communities, but each group typically took care of its

own. Again there were exceptions. Indigent people lacking families or friends, for instance, had no choice but to face death in public hospitals that were indistinguishable from almshouses. More portentously, in the era after Robert Koch discovered *Mycobacterium tuberculosis*, patients with tuberculosis were frequently confined (often against their will) to sanatoriums as part of a campaign to cure their disease and prevent contagion. The staffs of these institutions made only limited efforts to discharge patients before they died, and when they did so, their aim was as much to reduce institutional mortality as to allow patients to return to a comforting environment for their final days.

The phenomenon that transformed both public expectations

and experience was the emergence of the hospital as the locus for scientific medicine. In the early 20th century, hospitals began to deliver curative care, and patients began to willingly occupy their beds. Inevitably, in the course of treatment, some of them died there.

The shift to a hospital death, however, was not immediate: into the 1940s, most people still died at home. In 1949, only 40% of Americans older than 65 years of age died in the hospital. But over the next several decades, as the hospital increasingly monopolized acute care delivery and its reputation for cure soared, the trend toward hospital deaths accelerated (Fig. 3). In the late 1970s and early 1980s, more than half of U.S. deaths occurred in hospitals, while the proportion occurring at home dropped to 15%. Even in 1989, which was 6 years after the implementation of the prospective payment system (whose predetermined and fixed reimbursements might have encouraged hospital discharges) and the introduction of Medicare reimbursement for hospice care, 49% of deaths still occurred in hospitals and only 15% occurred at home.³

In fact, within the hospital, death and dying were increasingly segregated from routine inpatient care through the introduction of intensive care units (ICUs) equipped with novel medical technologies and staffed with new types of specialists. The iron lung of the 1950s gave way to the respirators of the 1960s, along with innovative imaging and monitoring devices. The early ICUs served not only to render care more efficient and effective but also to isolate the sickest pa-



Figure 3. Dying in the Hospital.

A patient with end-stage pancreatic cancer and her husband and physician, Lebanon, NH, June 4, 2011.

 An audio interview with Dr. Rothman is available at NEJM.org

tients. The units, sealed off by heavy double doors, seemed mysterious and frightening. Visiting hours were either nonexistent or very brief, and even when a patient was dying, family access was limited. Thus, the process of death and dying was twice removed and rendered invisible, once through hospitalization and then through ICUs.

It was probably inevitable that reaction would set in. Beginning in the 1980s, a movement to desegregate death and dying from hospitals and other health care services took hold in the United States, and its impact has mounted steadily. The benchmarks are well known: Dame Cicely Saunders pioneered the hospice movement in Britain and helped bring it to the United States. Elisabeth Kübler-Ross (author of *On Death and Dying*) renewed the case for dying at home. The Medicare hospice-benefit program expanded, and palliative care became a recognized and widely practiced

specialty. Foundation programs, including the Project on Death in America (the Open Society Foundations) and Last Acts (the Robert Wood Johnson Foundation), helped to fund relevant physician training and promote public responsiveness.

The data on where we now die testify to the scope of the changes that have followed, even as they provide food for thought and render the article by Cook and Rocker about dying with dignity in the ICU (pages 2506–2514) all

1989 and 2007, the proportion of deaths that occurred at home increased from 15 to 24%. Teno et al. calculate growth from 30.7% in 2000 to 33.5% in 2009. And the percentage of people dying in hospitals is shrinking — according to CDC data, from 49 to 35%, and according to Teno et al., from 32.6 to 26.9%. Clearly, the dominance of hospital deaths is fading.⁴

Yet simultaneously, the likelihood of an ICU stay is growing. Dartmouth Atlas data indicate that the proportion of patients with an ICU stay lasting 7 days or more during the last 6 months of life rose from 15.2% in 2007 to 16.7% in 2010. Teno et al. also found that “the rate of ICU use in the last month of life has increased,” from 24.3% in 2000 to 29.2% in 2009.

What are we to make of these seemingly contradictory trends — more deaths at home and fewer in hospitals, but greater ICU use? First, a cultural shift back to dying at home has occurred, not only in terms of preferences expressed in polls but also in actual decision making. Second, by common agreement, hospitals are no longer the best place to die. But third, however strongly patients prefer

In the mid-20th century, the process of death and dying was twice removed and rendered invisible, once through hospitalization and then through ICUs.

the more salient. Although samples and methods vary, by all accounts the percentage of Americans older than 65 who die at home has increased. The Centers for Disease Control and Prevention (CDC) reckons that between

to return home, they are often reluctant to do so until the most advanced medical technologies have been tried. The result is that a substantial number of patients die in ICUs in the midst of extraordinary interventions to save them.

Under these circumstances, and however anomalous it may seem, the idea of bringing death with dignity to the ICU is highly germane. I believe that not only should the barriers between family and patient in the unit be minimized (and indeed many ICUs have now implemented such policies), but the process of decision making should also more fully reflect the principles of palliative care. Such an ICU culture would not only promote aggres-

sive treatment but also help patients and their families make wise decisions about managing the end of life. This approach, as Cook and Rocker observe, may seem paradoxical, but it is nevertheless altogether essential.

Disclosure forms provided by the author are available with the full text of this article at [NEJM.org](http://www.nejm.org).

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Drug Safety in the Digital Age

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The Internet is increasingly redefining the ways in which people interact with information related to their health. The Pew Internet Project estimates that more than half of all Americans sought health information online in 2013, mostly through search engines such as Google and websites such as Wikipedia and WebMD.

In this digital age, engaging with new media offers an unparalleled opportunity for medical and public health professionals to find information they need and to interactively reach out to patients and their support networks. One domain where these capabilities may have far-reaching effects that are currently undefined is drug safety. As the volume of health-related information on the Internet has grown, important questions have emerged. How are messages from regulators — for example, warnings against using a drug in a specific patient population — diffused digitally? And are the messages still accurate when they reach the general population?

To explore these questions, we selected new drug-safety communications related to prescription medicines that were issued by the U.S. Food and Drug Administration (FDA) over a 2-year period between January 1, 2011, and December 31, 2012 (see Table S1 in the Supplementary Appendix, available with the full text of this article at [NEJM.org](http://www.nejm.org)). Despite debates over its credibility, Wikipedia is reportedly the most frequently consulted online health care resource globally¹: Wikipedia pages typically appear among the top few Google search results and are among the references most likely to be checked by Internet users.² We therefore evaluated Google searches and Wikipedia page views for each drug in our sample. We also examined the content of Wikipedia pages, looking specifically for references to safety warnings. To control for secular trends, we examined results from a 120-day window around the date of the announcement (from 60 days before the announcement to 60 days after it) and constructed a base-

line period for comparison that ran from 60 days to 10 days before the period of interest began.³

We identified safety warnings for 22 prescription drugs that are indicated for a range of clinical conditions, including primary hypertension, chronic myelogenous leukemia, and hepatitis C. Collectively, these drugs triggered 13 million searches on Google and 5 million Wikipedia page views annually during the study period. FDA safety warnings were associated with an 82% increase, on average, in Google searches for the drugs during the week after the announcement and a 175% increase in views of Wikipedia pages for the drugs on the day of the announcement, as compared with baseline trends (see line graph and Fig. S1 in the Supplementary Appendix).

Did users find accurate information on the drugs' safety? We found that 41% of Wikipedia pages pertaining to the drugs with new safety warnings were updated within 2 weeks after the warning was issued with information provided in the FDA an-