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HUMANITIES

FALL 2013

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Oklahoma HUMANITIES

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OHC is an independent, nonprofit organization whose mission is to provide meaningful public engagement with the humanities—disciplines such as history, literature, film studies, ethics, and philosophy. The humanities offer a deeper understanding of ourselves and others by confronting us with the questions, values, and meanings of the human experience. As the state partner for the National Endowment for the Humanities, OHC brings people together to explore these ideas through programming and community grants that support book groups, exhibits, film festivals, teacher institutes, and more. OHC engages people in their own communities, providing forums for education, critical thinking, and productive civil discourse.

The opinions expressed in *Oklahoma* HUMANITIES are those of the authors. Any views, findings, conclusions, or recommendations expressed in the magazine do not necessarily represent those of the National Endowment for the Humanities, the Oklahoma Humanities Council, its Board of Trustees, staff, or donors.

Reader letters are welcome and may be directed to the editor at: carla@okhumanities.org or by mailing to the above address. Letters are published subject to editorial discretion and may be edited for clarity or space.

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ON THE COVER

Skeleton Dream, Corazon Watkins. This is our second cover from internationally-exhibited artist Corazon Watkins. Thanks to her thought-provoking work, our Fall 2012 “Ethics” cover took first place in the annual SPJ awards [turn to page 5 for details]. Corazon is a multi-media artist, whose work explores political, spiritual, and personal themes. She holds an MFA in Fine Arts from the University of Oklahoma. www.corazon7.moonfruit.com





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THE FIELD OF MEDICINE conjures images of test tubes and prescription bottles, doctors and nurses, hospitals and emergency rooms. We know that health care workers are well-educated in anatomy, chemistry, and other sciences. But when challenged by major illness or a terminal diagnosis, what we hope for (beyond the best science has to offer) is compassion and *care*. Medical schools are recognizing that the humanities can bring insight and perspective, that teaching med students to probe for the “story” in each patient results in better outcomes for everyone. Instilling empathy is not only essential to “good doctoring,” it can be a natural byproduct of engagement with history, literature, and philosophy. The humanities reveal who we are—and offer clues to why we may or may not respond to treatment. In this issue, we’re prescribing a healthy dose of humanities perspective.

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From the Executive Director
ANN THOMPSON

We've often had discussion in this magazine regarding the benefits of a life that is engaged with the humanities disciplines. This is a large part of what we do here at the Council: explaining what the humanities are; why they are essential to our democracy; how they change people's lives; and why they should be funded. A recent report by the American Academy of Arts and Sciences (AAAS), called "The Heart of the Matter," attempts this on a large scale. The need for this study is clear: Americans today are sorely lacking in the basic skills and understanding needed to be fully engaged citizens. What is even more clear is the need to act upon this report.

Commissioned by Congress, the distinguished Commission on the Humanities and Social Sciences assembled by the AAAS focused on three goals: to educate Americans in the knowledge, skills, and understanding they will need to thrive in a twenty-first-century democracy; to foster a society that is innovative, competitive, and strong; and to equip the nation for leadership in an interconnected world. The humanities disciplines are, simply put, the means to those ends.

What the humanities have to offer us are critical thinking skills, analytical abilities, background knowledge, historical perspective, written and oral communication abilities, and the connection to thoughts and ideas that make us part of the human experience. We need not face off with proponents of STEM (Science, Technology, Engineering, and Math) initiatives. A well-balanced education, a well-balanced individual, will have both.

As the report shows, three out of four employers want schools to place more emphasis on these skills that the humanities and social sciences teach, yet federal funding for such education and training continues to be cut. It is in the national interest to support humanities education and programming that is critical to a democratic society.

To view the full report or to view a seven-minute video on the importance of the humanities, go to:
<http://www.humanitiescommission.org>.

Letters

WORLD CLASS

As a laborer in the field of the humanities in Oklahoma, I have read *Oklahoma HUMANITIES* magazine for the past several years; and though it has always carried items of interest, it has in recent years taken a giant leap in quality and relevancy. To my mind, it is now a "world class" publication. I read a large array of periodicals and, because my time is limited, my usual method is to peruse the



table of contents and select only the ones that interest me to read. Each time I open an issue of *Oklahoma HUMANITIES*, however, my method fails because each and every article is of interest.

In the latest issue (Summer 2013) I find "Beyond Partisanship" by Mickey Edwards (one of my professors in law school almost 40 years ago), a thoughtful statement from one of the foremost political thinkers in our country today. And there is Michael Sandel's treatise on the pervasiveness of marketplace mentality in our society, a not uncontroversial subject, by another of the world's great thinkers and philosophers. And, of course, the wonderful exposition by Nathan Brown, Oklahoma's current State Poet Laureate (and to my way of thinking, the best poet laureate ever!) extolling the "common good" of poetry.

I am especially impressed and pleased with the way the magazine's coverage does not shy away from subjects that readers may disagree on, and that it is always presented in an intelligent and courageous manner. Congratulations on the exemplary work of the editor and staff, as well as to the board and executive director who have the wisdom to give this editor her head! Great work is being done by the Oklahoma Humanities Council. I am proud of you.

—Dorothy Alexander, Cheyenne

ABOVE AND BEYOND

Oklahoma HUMANITIES magazine never fails to offer outstanding, stimulating articles; however, "The Common Good" issue [Summer 2013] rose above and beyond. After more than eighty years, most of which was spent in Oklahoma, I am so proud (yes, and relieved) that such an outstanding, thoughtful and enlightening publication still originates here. As a lover of history and as a poet and writer, this issue was a feast for all my hungry mental cells. Thank you for your offerings.

—Joh Gainey, Sulphur

Send your comments, questions, and suggestions to Editor Carla Walker at: carla@okhumanities.org or mail correspondence to *Oklahoma HUMANITIES*, Attn.: Editor, 428 W. California Ave., Ste. 270, Oklahoma City, OK 73102.

SMALL TOWN OPPORTUNITIES

I would like to express my sincere gratitude and appreciation to each of you for making the Oklahoma Humanities Council such a wonderful organization. The program and grant opportunities offered through OHC are really amazing and you offer, especially for us smaller libraries, the opportunity to provide truly enriching events for our communities that we wouldn't be able to do without your help.

Here in Guthrie, we have enjoyed much success with our *Let's Talk About It, Oklahoma!* programs; our customers enthusiastically read the books and delight at the opportunity to attend the discussions and soak up the insights of our generous and delightful scholars. Your commitment to facilitating meaningful and quality educational experiences for the people of Oklahoma enhances our collective awareness and appreciation of the arts and humanities. Thank you so much.

—Cynthia Selinger, Guthrie Public Library

CALLED TO SAY

Via voice mail: I'm calling to compliment you on the Summer 2013 issue of *Oklahoma HUMANITIES* magazine. It's really outstanding. I appreciated the profiles on the writers. The graphics layout is exciting and your content is superb.

—J. Don Cook, Oklahoma City



From the OHC Board of Trustees
DR. WILLIAM BRYANS, CHAIR

I recently celebrated my sixtieth birthday. Not since turning eighteen has a birthday given me pause. At eighteen, my future seemed boundless; at sixty, I fully realize it is more limited. Frankly, this stage of life does not overly concern me. The wisdom that comes with age tells me that the quality of life is as important as its length. With some effort on my part, my senior years should be as rich and rewarding as any.

Experts tell me that, going forward, health issues and medical professionals will increasingly be a part of my everyday existence. Except for waiting rooms and those awful hospital gowns, I also find that acceptable. I have the utmost respect for medical professionals. I especially admire that they must remain detached and rational in dealing with patients suffering minor and major health issues. The best, of course, also combine the rationality required to practice medicine with a sense of compassion.

A program offered by the Oklahoma Humanities Council encourages an understanding of the humanistic dimensions of medicine. Oklahoma actually is one of many states offering *Literature and Medicine* to health professionals working in hospitals [see page 7 for details]. In it, scholars lead discussions using poetry, fiction, non-fiction, and plays to provide perspectives on various medical issues from both the patient's and practitioner's perspective. Participants where the program has been presented report that it fosters greater empathy for patients and colleagues, improves communication, and generates greater job satisfaction—attributes I most certainly welcome among those caring for me.

Literature and Medicine is just one illustration of the relationship between medicine and the humanities. This issue of *Oklahoma HUMANITIES* explores others. As you read it, keep in mind the many ways the Oklahoma Humanities Council enables the humanities to enrich all our lives. And please consider supporting its efforts.

A yellow rectangular graphic with black and blue text. At the top left is the SPJ logo (a black circle with 'SPJ' in white). To its right is the word 'oklahoma' in a large, lowercase, sans-serif font. Below 'oklahoma' is the text 'SOCIETY OF PROFESSIONAL JOURNALISTS' in a smaller, uppercase font. Underneath that is 'PRO CHAPTER' in a large, spaced-out, uppercase font. The main headline is 'We Did It Again!' in a large, bold, blue font. Below the headline is a paragraph of text: 'Oklahoma HUMANITIES magazine continues its award-winning streak. Many thanks to the authors, artists, archives, and donors who make this publication possible.' At the bottom, there are three award announcements in bold black text: '2013 SPJ Awards', '1st Place, General Writing: "Lottery Night" by Kim Stafford', '1st Place, Best PR Publication Cover: Fall 2012 "Ethics" Issue', and '2nd Place, Best PR Publication: Summer 2012 "Reconciliation" Issue'.

World Literature Today invites you to attend

The 2013 Neustadt Festival

of International Literature & Culture

October 29 to November 1, 2013

on the University of Oklahoma Norman campus



Featuring
NSK Neustadt
Children's Prize winner
Naomi Shihab Nye

Festival Highlights

Tuesday, October 29 @6:30pm

A celebration of poetry featuring a Poetry Out Loud competition and readings by Neustadt jurors

Wednesday, October 30 @3pm

Readings, reception, and a book signing featuring members of the Neustadt jury

Friday, November 1 @10am

The 2013 NSK keynote by Naomi Shihab Nye, with music and a discussion of Palestinian culture

For more information, call *WLT* at (405) 325-4531 or visit

neustadtprize.org

Celebrate Arts and Humanities Month! October 2013 Hear | Read | See | Experience

OHC supports a plethora of free cultural programs—and Arts and Humanities Month is the perfect nudge to find an event near you. Visit our website calendar for dates and locations. Here's just a sample of what's happening in Oklahoma. okhumanities.org/calendar

New Harmonies:

Celebrating American Roots Music
Through September 21 | Frederick
September 28 – November 9 | El Reno
November 16 – January 4, 2014 | Alva
Exhibit explores the heart of American music.

New Harmonies: Celebrating American Roots Music is part of Museum on Main Street, a collaboration between the Smithsonian Institution and the Oklahoma Humanities Council. Support provided by the U.S. Congress. Oklahoma programming supported by BancFirst; Bank of Commerce; Beaver Express Service; The Boeing Company; Choctaw Nation of Oklahoma; E. P. & Roberta L. Kirschner Foundation; University of Oklahoma Press; Weyerhaeuser Giving Fund; and the National Endowment for the Humanities.



Allan Houser and His Students
Through May 11, 2014 | Oklahoma City
National Cowboy & Western Heritage Museum
Exhibit honors Allan Houser's 100th birthday with a look at the artist as teacher and mentor.



Reading and Discussion Programs

American Icons | Hooker | Tulsa
Making Sense of the Civil War | OKC | Woodward
Much Depends On Dinner | Duncan | Waurika
Oklahoma Private Investigations | McAlester | Perkins
The Way We Were | Tishomingo
Writing Worlds | Guthrie
The Worst Hard Time Revisited | Alva



Smoke Signal, Allan Houser, 1993, (bronze 57 x 23 x 31 in.). Courtesy National Cowboy & Western Heritage Museum.

Public Program Grants

Does your cultural project need a financial boost? Twice each year, OHC awards grants to encourage public humanities programming at the local level. Earlier this year, OHC grant awards and offers to ten organizations totaled more than \$66,000. Funded projects include exhibits, discussions, and other cultural events. Fast-tracked Opportunity Grants are awarded year round. Applications and detailed guidelines are available at our website: okhumanities.org/grants

Deadlines

Major and Challenge Grants

For projects beginning after July 1, 2014
Mandatory drafts are due March 1, 2014
Final applications are due April 1, 2014

Research Grants*

For projects before Oct. 31, 2014
Applications are due Dec. 15, 2013

***New Research Grant Guidelines:** A specific plan for public dissemination of work is now a required and emphasized part of the application. Review the new guidelines at: okhumanities.org/grants



The Gulf Coast Cardinals celebrate victory, 2009. *Hometown Glory*, Brenda Read Photography.

2015 Museum on Main Street Tour *Apply Now for Hometown Teams*

Looking for a way to increase the visibility and patronage of your small town museum? Apply now for the next Smithsonian Institution traveling exhibit, *Hometown Teams*. The deadline for host site applications is Oct. 1, 2013. *Hometown Teams* examines how our beloved sports have shaped America's national character. The project is designed to benefit rural communities with less than 20,000 residents, and is

made possible through Museum on Main Street (MoMS), a partnership of the Smithsonian Institution and the Oklahoma Humanities Council. Benefits include higher visibility, increased attendance, professional museum training, and capacity-building improvements. Interested communities may download the application from our website: okhumanities.org

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Film Festival
Poetry Siam University
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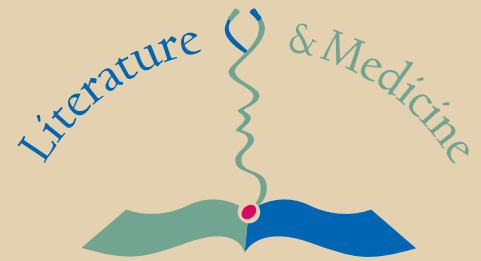
OUR AUDIENCE – YOUR MARKET

Be a part of our award-winning team.
Advertising is limited—so your ad stands out!

Oklahoma HUMANITIES magazine has a print circulation of 10,000 and full issues are posted on our website.

Rates and guidelines:
okhumanities.org/publications

Contact Traci Jinkens:
traci@okhumanities.org or 405/235-0280



humanities at the heart of health care

A New Program for Health Care Communities

The Oklahoma Humanities Council (OHC) is accepting applications from health care facilities across the state for its program *Literature & Medicine: Humanities at the Heart of Health Care®*. This innovative program, created by the Maine Humanities Council in 1997, invites health care professionals to discuss literature and explore ideas. Participants report that the process leads to overwhelmingly positive outcomes: deeper empathy for patients, better communication with colleagues, and greater job satisfaction.

Literature & Medicine participants (small groups of 10-25 people) meet for six sessions to share a meal and discuss key themes within fiction, nonfiction, and poetry. Diversity in participants is highly encouraged, as varied perspectives enhance discussion. A humanities scholar will select the readings based on the concerns and needs of the applying hospital. Topics can cover themes such as death and dying, the patient's perspective, religious and cultural barriers that may impede care, and using a patient's "story" to assist diagnosis.

OHC will oversee the program, find a qualified humanities scholar, and pay the scholar honorarium. The hospital is responsible for meeting logistics, publicity, meals, and the purchase and distribution of texts.

The deadline for applications is September 30th for programs taking place between January 1 and June 30, 2014. Information and guidelines for the online application are available at: okhumanities.org/literature-medicine.

To learn more, contact program officer Kelly Elsey at (405) 235-0280 or kelly@okhumanities.org.

History of Medicine vs. Organic Chemistry

Lessons beyond the Lab

By Sarah W. Tracy

Medicine's history of missteps and advances offers essential perspective.



Can a course in the history of medicine prove as valuable in the long term as, say, a course in organic chemistry? This is a question I often ask my aspiring pre-med students at the University of Oklahoma Honors College, where I've taught since 1999. I'm an historian of medicine, so admittedly there is a certain bias that frames my question. I also direct the OU Medical Humanities Program—make that bias².

Before arguing the merits of history and chemistry, however, we should begin with a definition: the *medical humanities* (including the "history of medicine") encompass the study of health, disease, and the healing professions from the perspectives of literature, history, philosophy, ethics, anthropology, sociology, and religion. A close examination of the political, spiritual, ethical, cultural, and historical dimensions of health and the management of disease offers vital insight into the nature of medicine. Why? Because medicine is a social enterprise, one in which scientific practices are informed by cultural values and moral principles. A disease is shaped not only by its underlying pathology but also by the demographics of its sufferers and its perceived cause and prognosis. Ultimately, deepening our understanding of health, disease, and medicine through the interpretive lenses of the humanities has a practical payoff: more effective health care and (I hope) better health.

Back to my Honors students and that all-important question. How do they respond? Well, they're bright and frequently pragmatic; they know that the *conventional* answer is "no." Organic chemistry is, after all, a course required for admission to most U.S. medical schools. Earning an "A" in organic chemistry impresses a lot of people (mostly fellow pre-med students and physicians who sit on medical college admissions boards). Whether or not practicing physicians regularly refer to organic chemistry is another question. Still, the responses of students in my "Historical and Ethical Issues in American Medicine" courses are divided.

Many reply that if your immediate goal is to get into medical school, doing well in organic chemistry is unquestionably helpful. They're right. A sizeable percentage of students, however, realize that I'm being deliberately provocative, and they enjoy pushing themselves to think in new ways. "Sure," they say, often pointing to the value of biography in the history of medicine. Studying the lives of doctors such as William Osler (the Johns Hopkins physician known for his consummate diagnostic powers and insight into the human organism) and Elizabeth Blackwell (the first woman in America to receive a medical degree) provides inspiration to future physicians, for these historical figures offer superb examples of professionalism, tenacity, and dedication to the betterment of humankind. Studying these physician exemplars



Washington, D.C., Aug. 23, 1937. The new trailer-laboratory for the U.S. Public Health Service arrived in the Capital today. Dr. L.E. Burney and Nurse Fran Miller will travel with the trailer built for a syphilis project in Georgia, equipped with an operating table and other equipment to [treat] sufferers of the dread disease.

Photos courtesy Library of Congress

reminds students of the core values of medicine, reveals the true nature of medical practice—both science and art—and cultivates a sense of shared history in a hallowed profession.

Other students, echoing the famous words of George Santayana, note that those who are ignorant of the problems of medicine's past may be condemned to repeat them. One such disturbing episode is the infamous Tuskegee Syphilis Experiment (TSE), conducted by the U.S. Public Health Service (USPHS) between 1932 and 1972—research that was published in major medical journals during that time. In the experiment, USPHS doctors tracked 600 African American men in Alabama (399 with a syphilis diagnosis and 201 who served as controls), from the moment they entered the study until their death and autopsy. USPHS officials withheld treatment for the disease (even after penicillin was available) and misled participants to believe they were being treated for “bad blood,” which they were not. The study's real goal was to see if syphilis progressed differently in blacks versus whites.

The rationales for withholding treatment were shaped by racial biases of the early twentieth century. Some investigators believed that the men would not have the discipline or interest to comply with the long-term follow-up required for the arsenic treatments of the 1930s and 1940s. Others considered black men inherently hypersexual and promiscuous—two then-prevalent stereotypes—and likely to be serially re-infected, rendering treatment ineffective. Still others thought the men would never receive appropriate treatment because they were poor and living in the rural, segregated South, with little access to medical care. These researchers were content to capitalize on the men's misfortune “for science.”

The TSE left a complicated legacy. Two of the most important outcomes were that: (1) many African Americans came to distrust the medical profession, in general, and medical researchers in particular; and (2) in 1974, following revelations about Tuskegee, Congress passed the National Research Act, mandating that universities and research institutions establish review boards to monitor biomedical and social science research involving human subjects, and to require researchers to obtain *informed consent* from participants. Tuskegee reminds us that medicine's first priority is the patient, and that researchers must ensure that their subjects' rights are respected in the acquisition of “useful scientific data.” Indeed, the TSE highlights how the definition of “useful

data”—including how it is acquired and how it is applied—can be affected by social assumptions, including stereotypes about human differences.

But is this sort of knowledge—studying the missteps of clinicians and researchers, as well as the successes of the past—useful to physicians, medical students, and patients? Might it lead to better health care? I believe the answer is “yes.” Knowledge of the Tuskegee case, for example, can help clinician-researchers better understand why they may have trouble enrolling African Americans in their clinical trials. Physicians who are unable to get full cooperation from middle-aged or older African American patients may come to appreciate the real and historical reasons these patients may be reluctant to comply with their advice. Doctors in such situations may need to go the proverbial extra mile to secure patients' trust.

Though we have come a long way from Tuskegee, it is clear that history can help us understand some of the structural impediments to accessing health care and achieving good health. For example, the large disparity between white and black median household incomes (\$32,229 for blacks; \$55,412 for whites in 2011, according to U.S. Census Bureau information) is due, at least in part, to the legacy of slavery and post-Reconstruction Jim Crow laws. Health care disparities accompany economic inequality—not just for African Americans, but for *all* demographics. The relationships among geography, poverty, and health status were mapped as early as 1830 in the neighborhoods of Paris by French physician and public hygienist Louis-René Villermé as part of a larger effort in nineteenth-century France to analyze disease inside and outside the hospital.

Physicians, already overwhelmed with steady streams of sick patients, may fail to recognize how their patients' most basic needs affect the success or failure of treatment. For instance, it takes more money to eat a healthy diet. Adherence to special dietary recommendations can be difficult if one lives in a “food desert,” an urban or rural area far from grocery stores stocked with fresh produce and meats. Compound this with inadequate public transportation and “compliance” can be a challenge.

Studying the history of medicine demands that we explore the systems of healing practices as interwoven with the social, political, and economic fabric of a particular age. It requires and develops critical thinking. Today's physicians may not have the time to serve as social workers or urban geographers, but if they

think systemically and draw connections among social institutions and medical practice, they should be able to deliver more effective health care. The University of Oklahoma School of Community Medicine was recently established to train physicians to think as Villerme did: to treat the environments, communities, and poverty that contribute to disease, as well as to apply clinical skills to cure individual patients.

The history of medicine can also offer healthy doses of skepticism and humility. Take another historical example: the case of lobotomy, the surgical severing of the frontal lobes from other parts of the brain as a treatment for severe mental illness, a practice that took place in the 1940s and 1950s. Today we regard this psychosurgical technique, a procedure that sometimes killed and frequently altered the personalities of those on whom it was performed, as barbaric. And yet its originator, Portuguese neurologist Antonio Egas Moniz, received the Nobel Prize in Medicine in 1949 for introducing this type of surgery to Western medicine. Lobotomy was adopted and adapted widely in the U.S., where an estimated 40,000 surgeries were performed on psychiatric patients.

Understanding the popularity of lobotomy requires us to appreciate the horrendous circumstances in mental hospitals across the United States in the 1930s through the 1950s. They were overcrowded dustbins of humanity. Patients checked in, but they didn't check out. Rarely was one's mental status improved by a visit to a mid-twentieth-century state hospital. Within this context, lobotomy was a therapy of last resort, offering people with severe mental illness the opportunity to leave the "asylum" and live at home. In fact, lobotomy was just one of several heroic organic therapies that offered psychiatrists and their patients hope of resolving mental illness in a manageable, if not wholly satisfactory, way. Electroconvulsive shock therapy (still used today as a therapy of last resort), malarial therapy, and insulin-shock therapy were others in the years before anti-psychotic medications came on the scene and facilitated the de-institutionalization of mental patients across the country.

The case of lobotomy reminds us not only of the progress psychiatry has made over the past sixty years but also that specific historical circumstances may make some therapies, particularly risky ones, appear reasonable. Because I have faith in medicine and medical research, I can envision a day when people look back on chemotherapy and radiation treatments in much the same way we view lobotomy today. Students of the future may ask incredulously: "You mean doctors willingly *poisoned* their patients

with derivatives of mustard gas, and purposefully exposed patients to high doses of radiation to heal them? And cancer patients were willing to risk radiation burns, 'chemo brain,' depressed immune systems, infertility, painful neurological symptoms, and secondary tumors to be cured of the disease?"

Desperate times require desperate measures.

The history of medicine encourages us to regard our own practices as our forebears regarded theirs: The best that we have available—no better, no worse. As I remind my students, there is no "stupid period" of history. We save life, something as close to perfection as we may ever know, through imperfect means. This is an important, sobering message about the nature of medicine—and one that is easy to forget when golden-hued ads for drugs that will restore our health, youth, and sex lives are peddled like automobiles on the evening news, and cancer centers promise cures through the glowing testimonials of vigorous-looking

survivors climbing Mount Rainier or paddling in the Florida Everglades.

One of my history of medicine colleagues at Princeton University observes that, from the Earth, the Moon looks like a perfect sphere. When we get closer to the Moon, however, we see that it is anything but smooth and perfectly shaped. He views history as one way of taking a similar "up-close" look at medicine, of getting to know it better. Only by seeing the varied terrain of the moon can we begin to understand it as a celestial body. Only by taking a closely calibrated view of medicine—by seeing it as it is, rather than how we imagine it to be—can we engage the healing professions most effectively.

History offers one means of understanding medicine. By examining the trajectory that medicine has taken over the centuries, by appreciating the contingency of that path—dependent upon

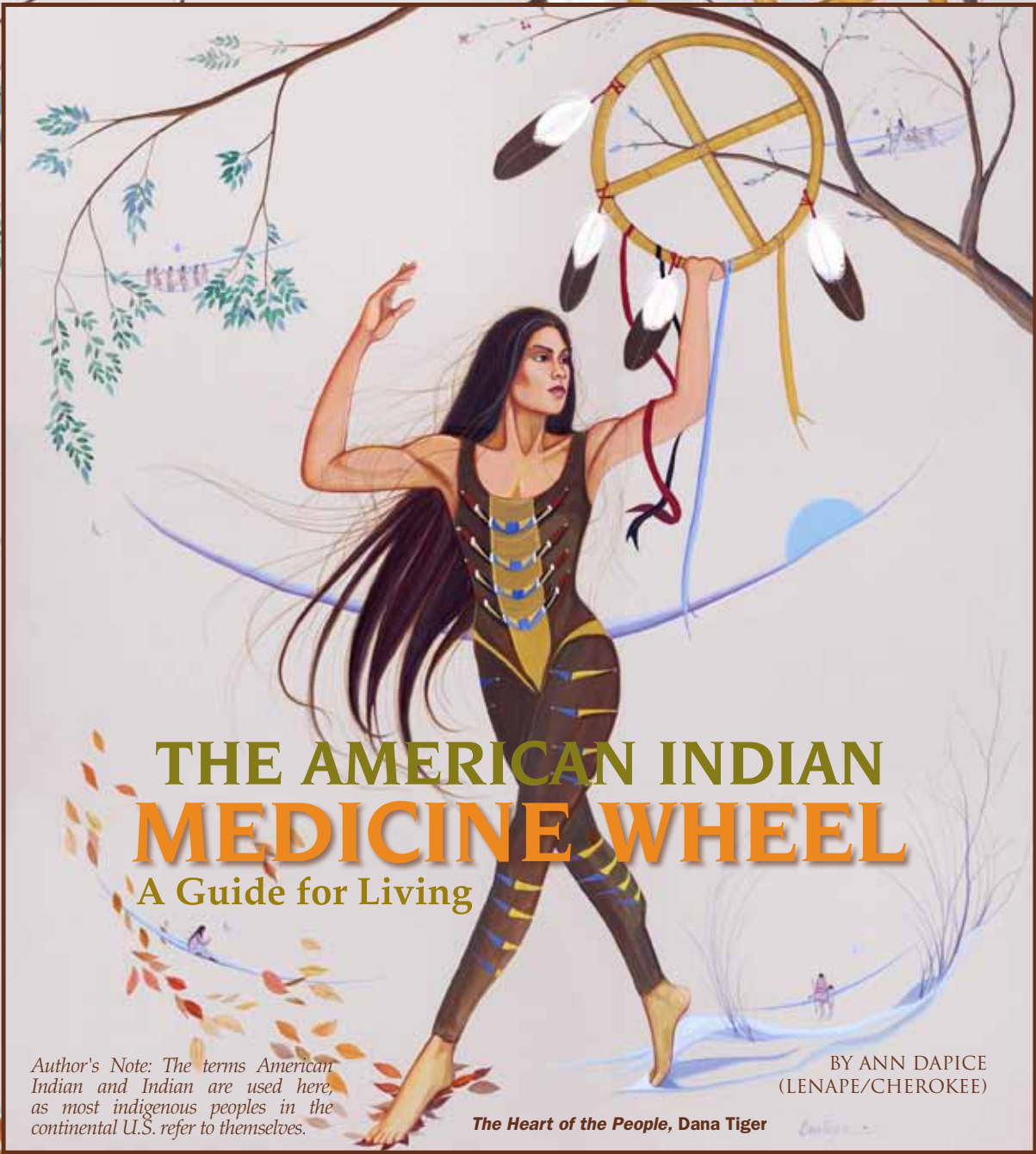
generations of well-intentioned, if imperfect, humans—we may come to know and appreciate medicine as it was, is, and may be in the future.

That knowledge is every bit as important as organic chemistry.

SARAH W. TRACY is Associate Professor of the History of Medicine at the McClendon Honors College of the University of Oklahoma. Tracy directs the Medical Humanities Program at OU. Her books include *Alcoholism in America from Reconstruction to Prohibition* (Johns Hopkins University Press, 2005) and with Caroline Jean Acker, *Altering American Consciousness: The History of Alcohol and Drug Use in the United States, 1800-2000* (University of Massachusetts Press, 2004). She is currently completing a biography of American biomedical scientist, champion of the Mediterranean diet, and bestselling cookbook author Ansel Keys (1904-2004).

EXTRA: Link to discussion questions, readings, and information on the history of medicine, food deserts, and the medical humanities at: okhumanities.org/extra





THE AMERICAN INDIAN MEDICINE WHEEL

A Guide for Living

Author's Note: The terms American Indian and Indian are used here, as most indigenous peoples in the continental U.S. refer to themselves.

BY ANN DAPICE
(LENAPE/CHEROKEE)

The Heart of the People, Dana Tiger

Humans are mind, heart, body, and spirit encased in what we know as brain and body. This marvelously functioning organism is affected by inspiration, perspiration, inculcation, and legislation in ways, large and small, that impact our health. While holistic medicine gains recognition and respect, traditional medicine still divides us into parts treated by specialists with small, focused areas of expertise. The American Indian Medicine Wheel, a belief used by Native healers for centuries, helps us put the parts back together in an understanding of how the mental, emotional, physical, and spiritual aspects of health are all related. Science increasingly validates this conceptualization.

The human body has been honed over millennia. Though once adaptive, with rapid external changes, our bodies no longer serve us well. Skeletal remains of California American Indians living more than 10,000 years ago show that those humans were healthier than we are today. The reasons are easily explained. Exercise was an essential part of life—whether through the labor of subsistence or rituals of drumming and dancing. Feasting was not a daily event. Early hunter-gatherer societies ate healthy proteins, fats, and carbohydrates with no separation between food and “medicine.” They gathered meals from plants they knew well, substances that were important for survival and health.

Though once limited by the environment, our modern-day

“success” leads to “excess” and global disease. It is said that our brains have no brakes in times of plenty. Great *access* leads to great *excess*. The result is that we are left with related diseases of obesity, type 2 diabetes, heart disease, hypertension, cancer, Alzheimer’s disease, and a host of mental health problems. It is time to revisit the past for lessons we can apply to our present and future.

HISTORIC SYMBOL

To American Indians, the medicine wheel is a universal symbol of wholeness. The wheel includes four directions, each with its own aspect—mental, emotional, physical, and spiritual. No one aspect is complete; all are considered sacred and equal. This is expressed in the philosophy of Mitakouye Oyasín, a phrase from a Lakota prayer which, translated, means “all my relations” or “we are all related.” Indian traditions express this philosophy with a focus on community, including all of Creation in the medicine wheel: people, animals, plants, seasons.

There are a variety of medicine wheels used by different tribes, who assign different characteristics to each of the four directions. For this discussion, we will examine a generalized example. The wheel begins in the east (with the sun, as does the day) and continues clockwise to the south in the heat of the day. From there we approach the darkness of night in the west (as the sun sets, a time of rest), then on to the north, symbolized by snow and a new sense of wholeness and purity. The animals and plants associated with the wheel are representative of those found in the four directions. The colors represent the four human races. Thus we have:

- East (the *mental* direction): yellow, eagle, tobacco
- South (the *emotional* direction): red, red-tail hawk, cedar
- West (the *physical* direction): black, bear, sage
- North (the *spiritual* dir.): white, white buffalo, sweet grass

The figure of “medicine man” or “medicine woman” and the “shaman” are the myth of popular culture. Indian traditions are about community, not the individual; keeping the community whole in all activities is the work of everyone. Prayers for healing, preferably in one’s tribal language, can be done alone or in groups. These prayers are generally focused on gratitude and the good of all—not supplication for personal wants and needs. People who are expert in plant medicines use this knowledge to benefit themselves and others. There are also limited, service-oriented roles for people who lead sweat lodges or build fires for the lodges, and for pipe carriers who perform certain seasonal traditional ceremonies.

The medicine wheel combines differing views of Eastern and Western philosophies. Western philosophy assumes linear cause and effect and tends to be interventionist. Eastern philosophies tend to be cyclical with the understanding that “what has been will be”; change is not possible, so intervention is not necessary. In recent years, some have confused Eastern philosophies with those of American Indians, ignoring an important difference. The medicine wheel includes cycles, seasons, and passages, but also assumes that change and growth *can* and *will* occur each time we continue through the life of the wheel.

Today, humans (or “two-leggeds”) all too often ignore the rest of the universe, without which we cannot exist. In doing so we are out of balance and we cause imbalance in all that is around us. In truth, we are active players in the universe who affect and are affected by all that exists. Thus, the medicine wheel is not just a symbol of healing for the individual, but healing for “all.”



THROUGH EACH ARC, THE WHOLE

If, as we have said, the mental, emotional, physical, and spiritual aspects of life are all related, then why separate them as distinct parts of the medicine wheel? We do this because it is important to work on achieving health, positive change, and growth in all areas. If we focus on or become stuck in one aspect or direction, we lack wholeness in all aspects. Taking these elements apart and examining if we are in balance is important—as long as we put them back together again.

The mental. When we talk about mental health and illness, we often refer to psychiatric illness, but there is more to this aspect of the medicine wheel. When we contemplate the

mental aspect, do we mean *mind*? By mind, do we mean *brain*? Humanities philosophers have long attempted to distinguish between mind and brain—but the medicine wheel encourages us to think holistically. When asked to make decisions, Indians tend to quietly consider alternatives, to reflect on cultural understandings, traditions, and the ultimate consequences of their decisions. This is well represented in the “Seven Generations” philosophy that all decisions should reflect the impact of actions on seven generations to come.

The emotional. In the 1980s, it was common to speak of the left brain as rational or “cold hearted,” and the right brain as emotional or “warm hearted.” Later, we spoke of the pre-frontal cortex as the rational, planning part of the brain, while considering the mid-brain as the emotional, reptilian brain. With brain imaging we have learned that, while parts of the brain have certain functions, the whole brain must work in concert. So how does this brain science correlate to the medicine wheel? Reflecting on the emotional aspect, people may say they speak from their *hearts* and not their *heads*. Some refer to being “sick at heart,” which we interpret as emotional distress. People suffering from panic disorder (regarded by modern Western medicine as a disease of the *brain*) often think they are having a *heart* attack. The medicine wheel helps us resolve the dichotomy—head and heart act as one.

The physical. In discussing the mental and the emotional, haven’t we been talking about the physical, too? Where are the head and heart if not located in our physical bodies? The organs of the human body are related anatomically and physiologically. We know that when people have physical illnesses, they often have emotional, cognitive, and behavioral problems as well. We once thought that people became depressed only as a response to physical illness or pain; we now know that depression can be one of the early signs of a physical illness. We have eyes, ears, noses, tongues, and skin; yet, the interpretation of these physical organs and their accompanying diseases remains in the brain—a function of the mental. These interpretations are given meaning from our experiences, cultures, and religions (aspects of the mental, the spiritual, and the emotional), as well as physiology or pathophysiology. The circle continues ...

The spiritual. The words we use to communicate religious substance—spirit, soul, sacred, holy—have application in many aspects of the medicine wheel, yet are hard to define. For instance, when we talk of “high spirited” horses running in the meadow, we probably don’t mean that they are having a religious experience. Hospital charts once described patients as being in “good” or “poor spirits.” Unscientific, yes, but people knew what was meant. The word *soul* can similarly confuse, yet we understand when people are said to have “sold their souls.” As an idea, the spiritual may be difficult to pin down, but thanks to medical technology we can now view parts of the physical brain that are activated when people are in spiritual states—whether from prayer, meditation, or similar phenomena.

Just as a circle has no beginning and no end, so, too, the medicine wheel leads us from aspect to aspect, from one direction to the next, through seasons and cycles—a guide with ancient roots and modern relevance.

LEARNING CURVE: THE WHEEL AS GUIDE

Spending time in one or even all aspects of the medicine wheel does not indicate health. By genetics (nature) and experience (nurture), some aspects of the medicine wheel are more dominant than others. Some people choose to focus on thinking or the mental aspect and distance themselves from anything emotional. Some focus on the physical, telling us of every ache and pain they have, often in details we’d rather not know. Some focus on the spiritual, certain that their beliefs and practices are the only “right” ones. Life includes both wonder and tragedy, and we can become trapped in our areas of preference. Philosophies and belief systems can cause us to ignore facts. They can prevent us from being open to new information and perhaps more effective action.

Carl Jung, who first theorized the concept of psychological types, wrote that it is important to develop the non-preferred aspects of ourselves for wholeness and balance. It is good to ask people where they are stuck—where they are uncomfortable. It helps to picture ourselves as centered, in the middle of the wheel, the place where many American Indians believe the Creator is.

The medicine wheel can serve as a guide for living. It can help us nourish and develop different facets of our lives. Some use the medicine wheel as ceremony, meditation, and reflection; others use the medicine wheel as a tool for learning and assessment, with specific activities to develop balance in all aspects:

In the East, we can commit to ongoing learning. We can pursue accurate knowledge before making decisions and think about the consequences of our actions: *If we act in this way, what is the likely outcome?*

In the South, we can use journals and stories to express our feelings—positive and negative—so we better understand them. We can smile, laugh, and sing to lighten our moods. The goal is to “have” emotions and learn from them, not allow them to “have” us.

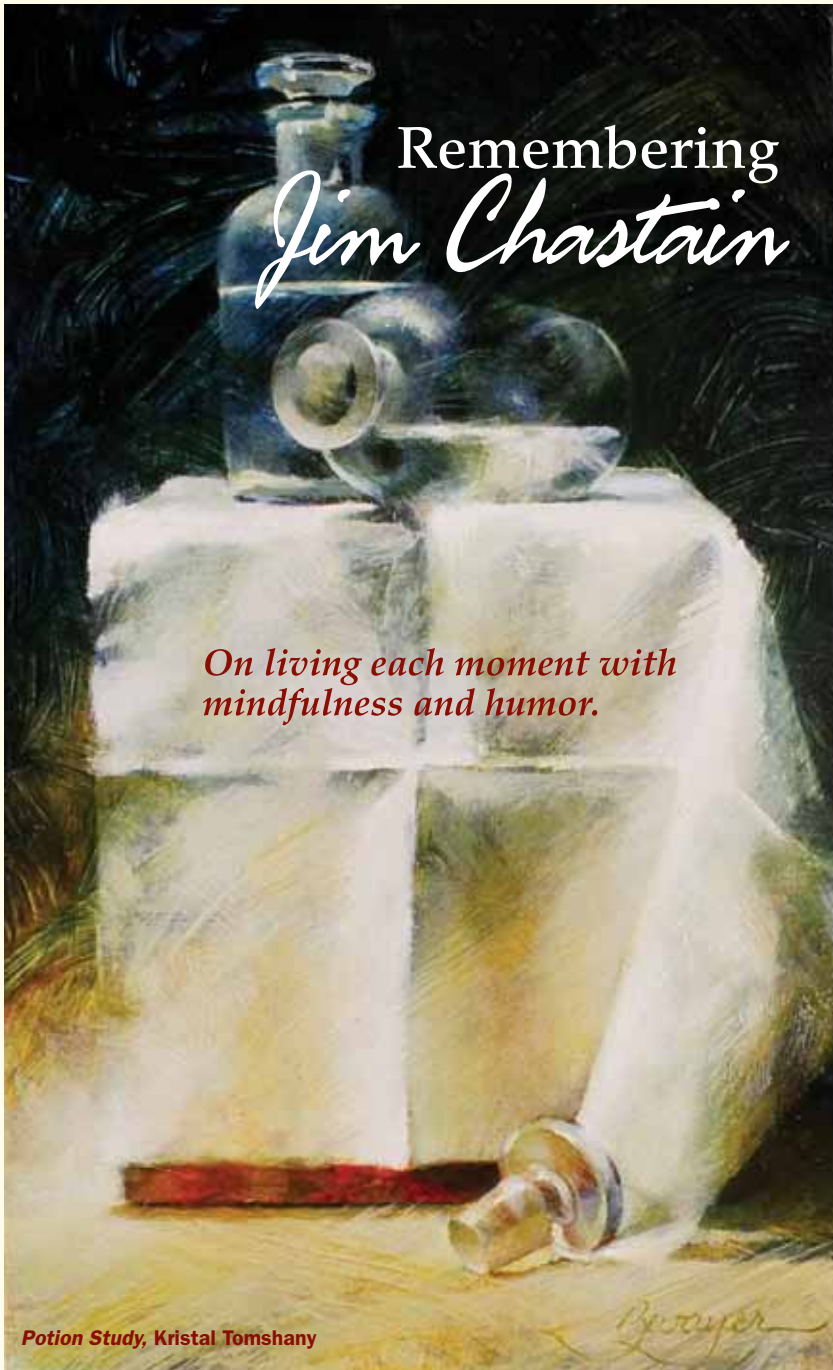
In the West, we can care for our bodies—as we American Indians are taught to care for mother earth. We rely on both for life. We can eat to live, not live to eat. We can engage in exercise that we enjoy, preferably in nature, and enjoy the peaceful benefits of rest and sleep.

In the North, we can be nurtured by the sacred places of our universe: beautiful mountains, oceans, and streams; sunsets and sunrises; stars and moon—all these give us a sense of place. An Indian elder once said, “We are part of all and all is part of us—and all is bigger than we can begin to imagine.”

Finally, we can determine to be “creators” of good—acting in kindness, honesty, justice, and compassion—for it is here that we are in the Center of the Medicine Wheel. ■

ANN DAPICE has taught and/or served as administrator at universities across the country. She is Director of Education and Research for T.K. Wolf, Inc. and Founder/Executive Director for the Institute of Values Inquiry. She serves on the Board of Directors for the National Indian Monument and Institute, American Indian Arts Association, and as a Commissioner for the Greater Tulsa Area Indian Commission. DANA TIGER is a member of the Muscogee “Creek” Nation. She is an inductee to the Oklahoma Women’s Hall of Fame, and founder of Legacy Cultural Learning Community, a youth and Elder arts organization. tigerartgallery.com

EXTRA: Find videos, interviews, photos and a virtual tour of the Big Horn Medicine Wheel in Wyoming, lesson plans, and more at: okhumanities.org/extra



Potion Study, Kristal Tomshany

Jim was a good friend ... a fun poet ... a gifted performer ... and very tough to lose. So, it will be impossible to contain all that he was, and did, into a few sentences that might make sense to someone who may not have known him. Along with everything listed above, Jim was also a strong soldier for the cause of poetry, film, and the arts in general, here in Oklahoma. Jim always had the ideas. But unlike many who do, he also made sure to carry them all the way through and into something real, useful, and beautiful.

In the end, he walked the long dark walk that we all fear the most. He did it with a good bit of grace and an incredible spirit right up to the end. And he left us with these poems that sometimes shock us with their humor, and often hit us between the eyes with their honesty—at times a painful honesty about dying ... but, more often, a profound honesty about living while we can.

—Nathan Brown, Oklahoma State Poet Laureate. Adapted from the preface of *Last Supper: Poems* by Jim Chastain. Preface and poems courtesy of Village Books Press: villagebookspress@yahoo.com

The Average Person

The average person
in my situation
lives two years, I'm told.

But they don't say how
the average person
in my situation
responds to such news.

Does he go out
on a spending spree,
book vacations
to Paris and Rome,
climb a mountain,
apologize to every person
he ever wronged,
or just curl up
in a fetal position
and watch soaps?

I'm not sure.
But here's what I did today.
I slept in.
I finished a good book.
I helped rake the leaves,
then cleaned up the dog shit
in the backyard.

—Jim Chastain
Antidotes and Home Remedies, 2008

All the World's a Stooge

I remember the name of the newest
member of my medical team, Dr. Curley,
by thinking of the three stooges.

He's no stooge, of course.
He's at the top of his game, death.
Even *60 Minutes* calls him to consult.

Still, when we discuss my condition,
I'm on the verge of laughter and tears,
knowing this surgical slapstick.

As we look at my scans, I ask,
"Is it bad?" And I wait for him to
smack his head and say, "soytenly!"

—Jim Chastain
Antidotes and Home Remedies, 2008

JIM CHASTAIN was an attorney, film critic, and beloved Oklahoma poet—and a friend of the OHC, serving on our state poet laureate nominations panel. He faced cancer with courage and humor.

Dirty Little Secret

The tear that rolled down
your cheek spoke volumes
and I suddenly heard
the words you refuse to say.
I'd sensed your loneliness,
your despair, the uncertainties
gathering over our future,
the broken bargain, that pact
we made long ago, once,
back then, when life wasn't so.

But the tear also told me
that you too are lost, unsure
where to go, except to plod on,
privately grieving our losses,
what has been, what will be
some day, not so far in the future.
I couldn't comfort you, then.
The tear wasn't meant to be shared.
As with so many dreams, I had
to let it go, my only gift to give.

—Jim Chastain
Antidotes and Home Remedies, 2008

One Night Stand

I remember their faces,
each cat scanner who violated me,
shoving a sudden hose
up my unsuspecting rectum.

They don't remember me though.
I was nothing more than the twelfth
or thirty-third victim that day.
They've moved on.

But I can't forget what happened,
what went on behind closed doors.
Take a deep breath, they'd say.
This may be a little cold.

Afterward they left me there,
humiliated and half-naked
with a souvenir towel.
Then they just walked away.

Later, in the hospital cafeteria,
I saw one of the culprits and blushed,
thinking that they could at least
have bought me dinner.

—Jim Chastain
Last Supper: Poems, 2012

KRISTAL TOMSHANY is an adjunct art instructor at Tulsa Community College. As a studio artist, she explores the flux between static, three-dimensional form and the gestural expression of energy. sorghumsentinel.org

Beginning of the End

We've broken the news
and made the calls.
We've sent out the emails
and stumbled through
the one-on-ones.

We've searched for joy,
beyond the despair,
but there are decisions
to make and sometimes
we disagree.

The kids seem stunned
as reality sinks in.
They're quiet
and they hug me more.
Today they skipped school.

This is the part
that no one talks about.
Even books and movies
gloss over it.
Even nurses look away.

—Jim Chastain
Last Supper: Poems, 2012

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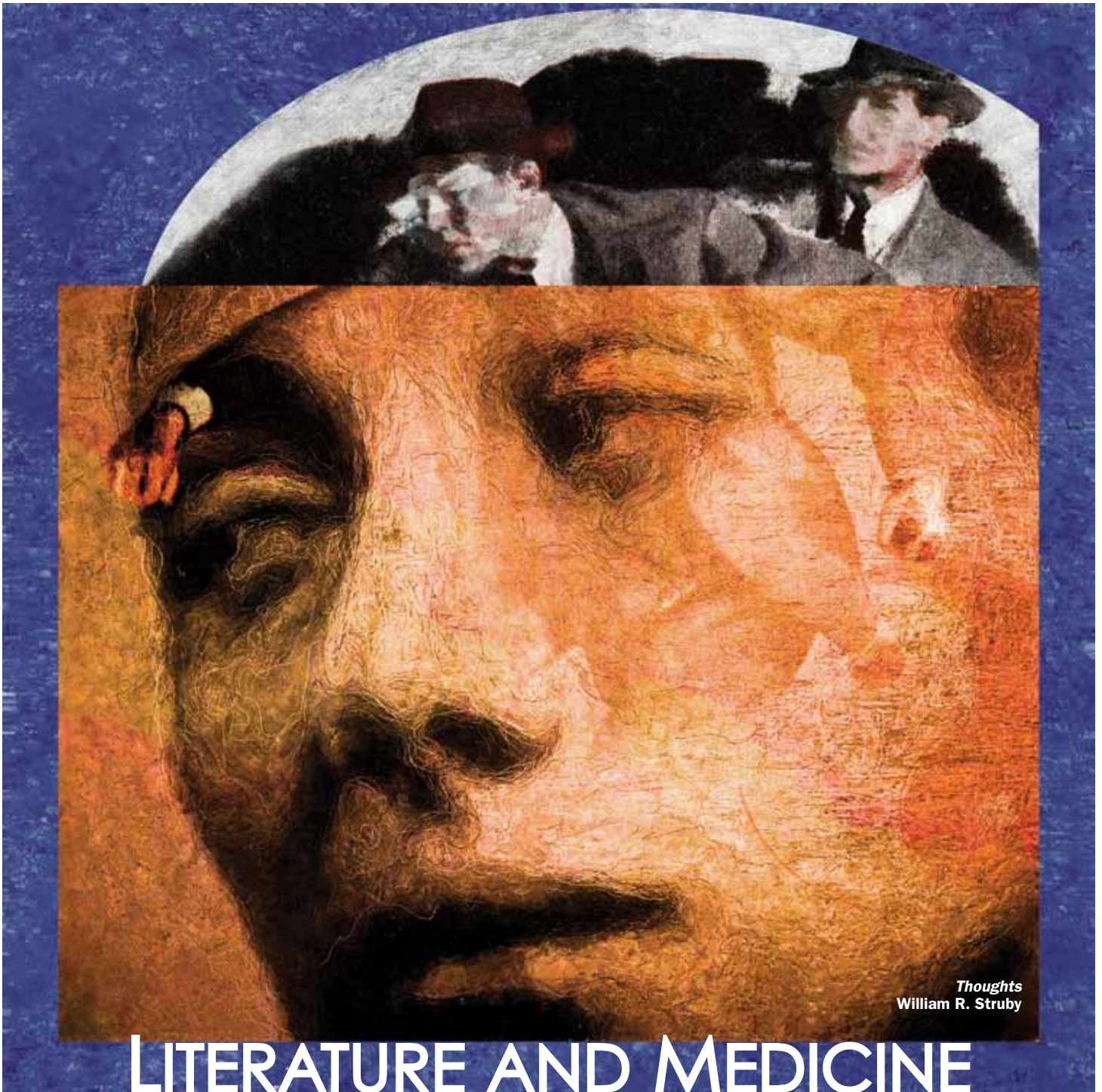
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Thoughts
William R. Struby

LITERATURE AND MEDICINE

A Path to Better Doctoring

By Jerry B. Vannatta and Ronald Schleifer

*Cultivating better doctors by
teaching the art of "story."*

Doctor Jerry Vannatta read Toni Morrison's novel *Beloved*—a story of heartbreak, memory, and the legacy of slavery—soon after it won the Pulitzer Prize for fiction. The prose profoundly affected him and his medical practice. Soon after reading the novel he had the following experience.



WILLIAM R. STRUBY combines images, paint, and collage in mixed media to evoke what he calls “the messy richness of life.” savagepop.com

In a return visit to my office after hospitalization, an elderly African American woman told me that she was having trouble affording her medications. I didn't get to know her in the hospital because she was primarily cared for by residents and medical students on my service, as I supervised. During the office visit, there was no meaningful connection between us. This lack of connection makes me so uncomfortable that I usually stop the interview and take a psychosocial history as an attempt to know the patient better—a process of gaining insight into who a person is aside from her disease. On this day, I did just that. I said, “I didn't get to know you very well while you were in the hospital. Tell me about yourself.”

She told me about having grown up in east Texas on a sharecropping farm. When she was fifteen, her father made her marry. She was in love with a sixteen-year-old, but was forced to marry a twenty-one-year-old man because he could provide a living. “He wasn't very good at making a living,” she said, “but he was sure good at making babies.” She had seventeen of them.

I thought at the time, *My goodness, that could have rolled right out of a novel*. She went on to say that, to make ends meet, she often walked two miles to a white man's house and two miles back to do domestic work. Sometimes the white man would give her a dozen eggs, and sometimes he would give her a two-gallon pail of milk to carry back to the family. She looked at me and said, “Doctor, have you ever carried a two-gallon pail of milk two miles?” In fact, I did grow up on a farm. I can remember carrying those galvanized pails of water around the farm to the chickens and what not, and I could see that wire handle cutting into her hand.

More importantly, I imagined her carrying this pail of milk on a dusty, rocky road, probably without very good shoes. As I thought about her feet, making this long journey, I began to think of the novel *Beloved*, which I had just read a few months earlier—at that time, the most remarkable novel I had ever read. *Beloved* is a disturbing story about slavery in America. The protagonist, Sethe, is running from slavery. She's very pregnant, about to deliver. She is tired, hiding under a bush, and a little white girl finds her. One of the striking things about that scene is her swollen, bleeding, infected feet. That image of Sethe's feet flashed in my memory. As in a flood, the emotions that I had felt reading the novel washed over me.

Remarkably, those emotions were available to me, facilitating my ability to connect with my patient; not that she was a slave, but in that moment her story about economic enslavement touched me deeply—a kind of empathy from vicarious experience rather than personal. The experience was dramatic and from that point we began to form a meaningful connection, rapidly problem solving her inability to buy her medications. At the end of the interaction, we stood to leave and a remarkable thing happened, something that usually doesn't happen in my practice—we embraced. She knew that a wonderful relationship had begun, and so did I.

This vignette was an epiphany—that the study of literature could be a powerful facilitator of the relationship between patient and physician. As an academic physician, I began exploring this relationship between literature and medicine, introducing the use of literary studies in my teaching with medical students and residents. Yearning to develop this nexus between literature and medicine into a formal academic offering, I approached Dr. Ronald Schleifer, professor of English, and together we created a curriculum and began teaching a course on “Literature and Medicine.” What follows is a bit of what we have learned over the ensuing fifteen years of teaching, writing, and doing research in this field.

Our students, some in medical school and others who have yet to enter, are by definition young and have limited life experiences. Performing as a physician requires dealing with patients of all age groups, cultures, religions, and political views. It requires connecting with people whom the student will have had no experience. Our theory is that literature—a poem, short story, novel, or memoir—can provide “vicarious experience,” and this experience, when reflected on, might make a significant difference when encountering a similar, very real patient.

The themes we explore—empathy, the patient-physician relationship, diagnosis, ethics, cross-cultural medicine, and many more—are dealt with only informally in medical school curriculum and never tested for in terms of competency. Analysis and discussion of literary narratives can fill this gap and, we believe, cultivate *better doctors*—physicians trained to listen for *the patient's story* and to use that knowledge to facilitate better diagnoses and, ultimately, better outcomes. To illustrate, let's look at a few examples of the medical themes and literary pieces we use to explore them.

"The Patient-Physician Relationship," our first theme, is important to every patient—interaction with the physician. We ask students to read a short story called "Old Doc Rivers" by the great American poet William Carlos Williams. The story's general practitioner is addicted to narcotics, uses alcohol to excess, and has an abrupt bedside manner. Still, he is a brilliant diagnostician and sees patients at times that are convenient for them. In exploring this complex individual, students are challenged to define the appropriate boundary between professional and personal life. Williams's story forces students to struggle with the fact that ethical virtues commonly conflict with one another, even in the same individual.

In Atul Gawande's "When Good Doctors Go Bad," students follow a surgeon who begins a brilliant career, but ends up doing more harm than good. Rather than centering on the patient as an important compass, the surgeon focuses instead on production and money. He begins to make mistakes, ignores them, as well as the suffering of patients, and ends up depressed with a failed career. This true story asks students to look at their own lives and personality traits—many of which are obsessive compulsive, much like the doctor in the story. We ask them to reflect on how they might be similar to this surgeon, how his errors could be avoided.

As an example of a good patient-physician relationship, we read "Epiphany" by Ferrol Sams. In this story, the doctor is caring for an alcoholic ex-convict with no insurance and little money. The story demonstrates a maxim also taught by poet William Carlos Williams: that the physician should stay interested in his patients by turning "stereotype" into "insight." The physician in "Epiphany" is interested in the ex-con because of his story; the doctor honors it and the stereotype of an ex-con drunk recedes. The doctor listens carefully to the man's narrative—who he is and why he's suffering, physically and mentally—and uses that insight to make an effective diagnosis. It is an opportunity to discuss how the patient's story, what we in medicine call the *History of Present Illness*, is equally as important as the biomedical story.

"Empathy," another theme, is an essential part of the patient-physician relationship. It's easy to have empathy for someone who is like us, but it requires work to be empathic with people we don't understand or, worse, don't like. The skill of empathizing with all patients requires diligent education, years of training, and habituation.

We believe that vicarious experience gained from good stories is one way of gaining some of this knowledge that young students lack. Within the "Empathy" theme we teach Toni Morrison's *Beloved*. The novel has no doctors, virtually no diseases per se, but plenty of suffering. For most students it is the first account of slavery they have read from the perspective of the slave. They are amazed at the difference in the novel's portrayal of slavery from what they learned in school—similar to the difference in the way diseases are experienced by patients from what young doctors learn in school. The book helps students explore putting themselves in the shoes of the other person, a step that must be taken to experience empathy.

The book evokes emotion in the reader—emotion we can use to show students how emotionless science is. The story the patient tells affects the way a doctor functions; it's not science, but it contains symptoms in the patient's own words, emotive content that can be used to not only diagnose but also understand what these symptoms mean to the patient, what we call the patient's *chief concern*. Facilitating the patient's chief concern is one of the most important functions of patient-physician interactions.

"Diagnosis" is at the fulcrum of activity in the medical profession. When we use the detective stories of Edgar Allan Poe ("The Murders in the Rue Morgue") and Arthur Conan Doyle ("The Resident Patient") to demonstrate the logic of diagnostic medicine, students are easily engaged. As it turns out, the logic of making a diagnosis is the same as the logic used by the detectives in these two stories, a process that most have not heard of—abduction. The process teaches the student (or detective) to focus carefully on certain "kinds" or categories of evidence. After discussion and reflection, students learn to use it on other stories, on "detective" television programs. Some become facile with this process in fairly short order. Abduction is one of the "schemes" that can be taught using literature and applied directly to the doctoring process. By learning a "scheme" of diagnosis, the student is not left to trial and error over many years to become a good diagnostician.

There are other issues the medical profession deals with frequently, but which are relegated to the "informal" curriculum, if not simply ignored. One such issue is violence; specifically spousal or intimate partner violence and sexual abuse. We assign two novels to explore these issues. Roddy Doyle's *The Woman Who Walked into Doors* is the story of Paula, a mother of three and wife to a man who beats her. She turns to alcohol and stays in the marriage, enduring severe physical and emotional trauma. For most of our students this is the first experience, even though vicarious, with family violence as the organizing principle. The prose is excellent and, like Morrison's novel on slavery, makes Paula's suffering impossible to ignore.

Dorothy Allison's *Bastard Out of Carolina* is also a difficult read because of the disturbing violence and suffering—childhood sexual and physical abuse by a stepfather. Students explore the cause of such behavior, the effects on the victim as well as the perpetrator, and store vivid memories and emotions of the scenes as they read them. One of our students revealed in follow-up interviews that he simply could not ignore the first abused spouse he encountered in the emergency department, when everyone else on the team was writing her off without actually discussing intimate partner violence with her. The rest of the team simply attended to the injuries. This is an excellent example of how the *chief complaint* (My face hurts.) and the *chief concern* (My husband beats me and I need someone to listen.) are fundamental to the patient-physician relationship.

The final theme that we cover in detail is "Aging, Death, and Dying." Students studying medicine are young; patients are getting older. A potential gap in communication exists based on age alone. Unless the student has experience with a grandparent or other older adult, they are shocked when they first encounter



When Sarah Dreams, Dennis R. Scott

someone who takes twice as long as they do to undress, or who cannot remember what it was they wanted to ask. Short stories and poems can provide vicarious experiences of aging.

In Flannery O'Connor's story "Everything That Rises Must Converge," we meet an elderly woman being cared for by her young son. The son feels he is better than she is—better educated, less rigid, and less bigoted. The story ends in tragedy with the mother having a stroke and the son feeling bad about his treatment of her. Like many of O'Connor's stories, the moral is somewhat ambiguous but sets up the reader to feel superior to the son who so mistreats his mother. Students gain insight into how poorly most young people understand aging, and how easy it is to be arrogant in relation to the elderly.

We also read poetry about aging and dying: "There's been a Death, in the Opposite House" by Emily Dickinson; "Do Not Go Gentle into That Good Night" by Dylan Thomas; "Talking to Grief" by Denise Levertov; and "What the Doctor Said" by Raymond Carver. Students soon realize that, to thoughtfully address mortality with a dying patient, they need to have done some thinking about their own mortality.

The Death of Ivan Ilych by Leo Tolstoy is timeless in its presentation of the dying person who has done none of this self-exploration. It helps us emphasize one of the most important issues in medicine: the patient's *chief concern* (Is my condition serious?). Physicians and caregivers in the novella ignore the dying man's chief concern, focusing instead on the symptom, abdominal pain. Ivan's story illustrates beautifully not only issues of mortality, death, and dying but also the difference between the doctor's agenda and the patient's agenda.

Medical education teaches students how to elicit a story that will most likely lead to a diagnosis. Getting to the diagnosis is important to the patient, too. However, the patient's *chief complaint* (why they came to the doctor) and *chief concern* (what they are worrying about) are different. This may be the most powerful contribution of literature in the education of the doctor—imparting the information and vicarious experience she needs to develop a strong relationship with the patient, develop empathy, honor the story, and finally attend to *both* paths of investigation: the chief complaint (the doctor's agenda) *and* the chief concern (the patient's agenda).

The connection between literature and medical practice is obvious: The better we are at apprehending stories, the better we will be at listening to and understanding the stories our patients tell us. The significance in using literature to teach medicine—or, more accurately, doctoring—is evident in feedback from students who have taken a literature course like ours and applied that knowledge in their clinical years of medical school.

One student remembered seeing a pediatrician perform a vaginal examination on a young fourteen-year-old girl. The procedure had not been explained well to the patient and it hurt. The doctor ignored the pain, attending only to getting the information she needed for the diagnosis. Our student remembered Dorothy Allison's novel about sexual abuse. Though not the same as the abuse in the novel, the situation with the young girl was similar enough that the student experienced deep empathy and felt committed to never do such an examination without careful discussion and attention to the patient's discomfort.

Another student related an experience in the emergency department with an abused spouse. The student was reminded of Paula in Roddy Doyle's novel and was unable to ignore her suffering.

Another student recalled seeing a patient who was a prison inmate. The patient was being tended by a resident who saw him stereotypically as a felon with ulcers. The student, reflecting on Ferrol Sams's story about the ex-con with alcoholism, decided to stay behind and connect a bit more with the patient after the resident had left the room.

These are only a few examples of how vicarious experience, gained from engaging with literature, aids the education of the physician. The humanities and literature provide understanding of the human condition—as essential to good doctoring as the science courses we use to understand disease.

Literature helps us understand the human beings we treat, and beckons us to attend to their suffering as well. ■

RONALD SCHLEIFER, Ph.D., is George Lynn Cross Research Professor of English and Adjunct Professor in Medicine at the University of Oklahoma. JERRY B. VANNATTA, M.D., is David Ross Boyd Professor of Medicine and John Flack Burton Professor of Humanities in Medicine at the University of Oklahoma. They co-authored *The Chief Concern of Medicine: The Integration of the Medical Humanities and Narrative Knowledge into Medical Practices* (The University of Michigan Press, 2013).

DENNIS R. SCOTT is a retired English teacher turned artist who also enjoys work as a writer, lyricist, poet, and craftsman. He resides in Tulsa, Oklahoma. etsy.com/ca/shop/TheArtManStore



Ennis Quadrangle, Patron Saint of Honne and Tatema. SARAH ATLEE's artwork has been exhibited across the U.S., including New York City, Santa Fe, Phoenix, Kansas City, and Oklahoma City. In 2007, she was among the first group of Oklahoma artists to participate in the Art 365 exhibition from Oklahoma Visual Arts Coalition. She resides in Austin, Texas. sarahatlee.com

*Ethics
and planning
can ease the anguish
of difficult choices.*

End-of-Life Decisions

EXERCISING YOUR RIGHT TO CHOOSE

By Philip J. Rettig, M.D.

Three young women are now so well known in the annals of biomedical ethics that mere mention of their surnames—Quinlan, Cruzan, Schiavo—evokes principles and precedents that changed the way we govern contemporary end-of-life issues. These young women never could have imagined that failure to document their wishes about future medical care, or to specify who should make choices for them if they became incapacitated, would trigger major paradigm shifts in both legal and ethical approaches to end-of-life decision making. Few would have expected these young women to consider such matters (which ideally should concern only the elderly, the chronically infirm, or the terminally ill)—for they were healthy.

And then they weren't.

Karen Ann Quinlan, age 21, was found unresponsive in bed at home after attending a party with friends in April 1975. She had stopped breathing and was resuscitated by EMTs after some fifteen minutes, then taken to a New Jersey hospital. There she failed to regain consciousness and after several months was believed to be in a persistent vegetative state (PVS), a condition marked by no purposeful movements, no meaningful speech, no apparent awareness of or response to the world around her, with all higher level brain functions shut down and only primitive brainstem functions supporting circulation, temperature control, and respiration. She was maintained on a ventilator and tube feedings in a hospital. In 1976, with no improvement in her condition, her parents, devout Catholics, asked that her father be named her legal guardian, that ventilator support be removed, and that “extraordinary means” to keep her alive cease. The New Jersey Supreme Court ruled on this petition in 1976.

Nancy Cruzan, age 25, was thrown from her car in January 1983 in a single-vehicle accident and landed facedown in a water-filled ditch. When found by EMTs, she had no heart rate or respirations but was resuscitated. Eventually she, too, was found to be in a PVS. Though able to breathe on her own, she was maintained on tube feedings without improvement. In 1986, her parents petitioned for a court order to allow discontinuation of her tube feedings, stating that she would not have wanted to continue living as a “vegetable” (as stated to her housemate, a year before the accident). The Missouri Supreme Court ruled in 1988 that there was insufficient evidence to know what Ms. Cruzan’s wishes would have been. The case was appealed to the U.S. Supreme Court, which issued a ruling in 1990.

Theresa “Terri” Schiavo, age 27, was at home in February 1990 when she had a cardiac arrest, possibly related to an electrolyte imbalance. She also was diagnosed as being in a PVS due to massive brain injury from lack of oxygen, and was maintained in nursing homes on tube feedings for years. Despite attempts at intensive physical and speech therapy and even temporary transfer to California for an experimental nerve stimulation therapy, she remained in a PVS without any objective improvement. In 1998, her husband sought to have her feeding tube removed to allow her to die, but her parents intervened legally. After lengthy court proceedings, the tube was transiently removed in 2001, only to be reinserted. After multiple petitions and hearings in various Florida courts, interventions by the Florida legislature and governor (enacting a patient-specific statute called “Terri’s Law” to mandate reinsertion of the feeding tube), and unprecedented federal legislation signed by President George W. Bush (enacting the Protection of Incapacitated Persons Act of 2005, which allows federal court review of “certain cases” like the suit initiated by Terri’s parents), her feeding tube was again removed in 2005. By this time, there had been five Federal lawsuits; “Terri’s Law” had been declared unconstitutional by the Florida Supreme Court; and the U.S. Supreme Court had refused to hear the case or to reverse lower court rulings four times.

PRECEDENTS

The New Jersey Supreme Court (*In re Quinlan*) ruled that, just as a competent adult has the right to refuse medical treatment based on the right to privacy, a guardian has the right to refuse treatment on behalf of an adult who is incompetent. The guardian should make decisions based on the patient’s specifically-stated wishes or, lacking such knowledge, based on what the patient would most likely choose for herself, given the surrogate’s best judgment of her values and beliefs. The court also endorsed the value of a hospital “ethics committee” to review the medical status of the patient. The court wrote presciently that judicial involvement in such cases should be minimized “not only because that would be a gratuitous encroachment upon the medical profession’s field of competence, but because it would be impossibly cumbersome.” This case represents the first judicial support for the right to request withdrawal of life-sustaining treatments by patients *or* their surrogates, and provided strong impetus for the development of hospital ethics committees.

Following this 1976 ruling, ventilatory support was withdrawn from Karen Ann Quinlan and she was able to breathe on her own. (It has been recognized since then that most patients in a PVS have intact brainstem function and are able to breathe on their own.) She finally died in 1985, after ten years in a PVS.

In *Cruzan v. Director, Missouri Department of Health*, the Missouri Supreme Court stated that “no person can assume that choice for an incompetent [to refuse life-sustaining treatment] in the absence of the formalities required under Missouri’s Living Will statutes” or in the absence of “clear and convincing inherently reliable evidence.” The U.S. Supreme Court upheld the Missouri decision in a 5 to 4 vote, in effect denying Nancy Cruzan’s parents’ petition to discontinue her feeding tube. However, the Court did recognize a Fourteenth Amendment “due process liberty interest” to refuse medical treatment (*including nutrition and hydration*), while still requiring “clear and convincing evidence” for a surrogate’s decision to withdraw or deny such care. This decision, for the first time, established a constitutional right to decline life-sustaining treatment in all U.S. states; additionally, it highlighted the benefit of having written preferences for end-of-life care in the form of a living will or advance directive as clear and convincing evidence of a patient’s wishes. It gave impetus to passage of the federal Patient Self-Determination Act in 1991, which requires hospitals and other inpatient health care facilities to give all patients, aged 18 years or over, information about the right to have an advance directive. The mandate has increased acceptance and use of these documents.

Nancy Cruzan’s parents petitioned the Missouri courts to rehear their case following these rulings and were able to then provide more “clear and convincing evidence” as to what treatment their daughter would have chosen. In December 1990, her feeding tube was removed with judicial authorization. She died within days, after almost eight years in a PVS.



Suffocation (detail), CORAZON WATKINS.
Quote reads: *Self is the only prison that can ever bind the soul.* Henry Van Dyke (from *The Poems of Henry Van Dyke*, The Scribner Press, 1920).

The multitude of court hearings and the quixotic Florida and Federal laws spawned by the Schiavo case provided no new legal precedents, shed no new light on ethical debates, and politicized discussion about end-of-life care for years. For months it was daily fodder for news on CNN, FOX News, and national networks, featuring demonstrators outside nursing homes, courts, and capitols or spotlighting ethical and legal media “experts” that provided more heat than light. It made painfully clear the conflicts that can arise among family members who disagree about appropriate care for a loved one who cannot speak for herself. It reinforced the need for one person to be authorized as the surrogate decision maker. (Michael Schiavo was Terri’s surrogate under Florida law—as spouse, not because she had so designated him in a living will or health-care-proxy document. Throughout the years of legal wrangling, the courts consistently recognized his right to make decisions on her behalf.) It also made clear that the legislative and executive branches are even less appropriate grounds for resolution of such disputes than the courts.

There is something unseemly about physician-legislators diagnosing a patient via the airwaves and news articles. Representative Barney Frank’s statement aptly characterized Congress’s actions: “We’re not doctors, we just play them on C-SPAN.” Nonetheless, there is a final important lesson from the Schiavo case: had Ms. Schiavo had an advance directive, the contention regarding her care might have been resolved much more quickly and easily.

Terri Schiavo finally had her feeding tube removed on March 18, 2005, and died thirteen days later. She had been in a PVS for more than fifteen years.

PRINCIPLES

What do the lives, and more so the deaths, of these three young women teach us? The simple answer is that it is a good idea to have an advance directive, to specify who should make medical decisions on our behalf in case of incapacitation, and to discuss with that surrogate and other loved ones what our values and desires might be in an end-of-life situation. Unfortunately, answers aren’t simple.

It is vital to understand not just the legal aspects of end-of-life care but also the ethical principles underlying the manner in which health care providers approach end-of-life decisions with their patients. The ethical basis for allowing patients to determine what treatment they accept or refuse is the principle

of *autonomy*. Its legal counterpart is found both in the right to privacy and the right to liberty. Autonomy is foundational to the right to give informed consent for clinical care and procedures, to consent to research involvement, and to accept or refuse end-of-life interventions such as CPR, ventilation, artificial hydration, or nutrition. Being autonomous means that a patient has the right to his or her body integrity and to decide what will be done to that body.

The right of a competent adult to refuse any or all treatment is sacrosanct. However, the right to autonomy is not limitless. Patient autonomy does not mean that a patient may *demand any and all* treatments.

Physicians also enjoy autonomy. This is not the “doctor knows best” paternalistic care of past generations. Rather, physician autonomy derives from the right and even the duty to be true to the additional ethical principles of beneficence, nonmaleficence, and justice. Although autonomy is often regarded as the preeminent principle guiding medical ethics, it is better considered as part of the whole of ethical practice.

Beneficence refers to the principle of “doing good”—acting in the best interests of the patient to cure disease, prevent illness, and alleviate pain and suffering. *Nonmaleficence* refers to the ancient dictum of *primum, non nocere*: first, do no harm. Harm can occur from not providing appropriate care, or from inappropriate or negligent care. *Justice* refers to the provision of care equally without discrimination and to the fair distribution of resources. In our current health care “system,” justice considerations are often ignored or demonized as “death panels.” The principle is misinterpreted as legitimizing the denial of care based on financial or insurance status. To be truly ethical, all these principles should underlie decisions about providing, withholding, or refusing end-of-life care.

PLANS

Every state citizen aged 18 years and older should consider completing an Oklahoma Advance Directive form. The approved template can be found in the Oklahoma Advance Directive Act as revised and amended in 2006. [Editor’s note: An informational video, FAQs, and downloadable forms are available online: <http://www.oumedicine.com/familymedicine/oklahoma-palliative-care-resource-center/advance-directives>]. This form allows competent adults to specify their wishes on types of care in four different scenarios: (1) a terminal condition that will result

in death within six months; (2) a persistent unconscious state; (3) an end-stage condition of incompetency or dependency for which treatment would be medically ineffective; and (4) “other conditions.” For each of these four conditions, the person can specify that they would want: (1) life-sustaining treatment, including artificially administered nutrition and hydration (ANH); (2) no treatment except ANH; (3) no treatment including no ANH.

The Oklahoma Advance Directive form covers a wider scope of conditions than that of many states, in that it includes “end-stage conditions” (for example, Alzheimer’s disease or other neurodegenerative conditions which will eventually render a patient incompetent) and the open-ended “other conditions” (for specific clinical scenarios, such as choices of care for a patient with traumatic quadriplegia). In Section II of the form, an adult can specify who he or she wants to be a Health Care Proxy. Ideally, this surrogate will be able to make specific decisions in end-of-life situations, based on intimate knowledge of the patient’s wishes and values. This is important because, under Oklahoma law, there is no legal hierarchy of surrogate decision makers. If an Oklahoman has no designated health care proxy or someone named with a durable power of attorney for health care decisions, that person’s spouse or parent or child has no more legal standing as a proxy than a cousin or distant acquaintance.

It is clearly better to have an advance directive than not, but the past two decades have shown that these are not panaceas. Only twenty to thirty percent of adults have completed an advance directive or living will. One large-scale study showed that in almost half of instances, patients’ advance directives were not followed; errors of both omission and commission were frequent. Even the Oklahoma form with four clinical scenarios lacks specificity for most end-of-life situations. Additionally, patients’ attitudes and desires can change, as can therapy options, over a period of possibly decades after completion of a form.

An additional tool has been in use in OU Medical Center since 2006: the Physician’s Orders for Life-Sustaining Treatment (POLST) form. This one-page detailed “menu” is completed by care provider and patient (or surrogate), and includes specifics on: resuscitation status (DNR); use of ventilators or other lung support; use/nonuse of antibiotics, blood products, dialysis; provision of artificial hydration/nutrition (feeding tube or intravenous); and provision of pain medications and other comfort care measures. The form is not a substitute for an advance directive, but provides details on agreed-upon parameters of end-of-life care for an appropriate patient. First introduced in Oregon in the mid-1990s, the POLST form is currently in use in a number of states; efforts are underway to extend its use in Oklahoma hospitals beyond OU Medical Center.

POLICY

This year the Oklahoma legislature passed a law entitled the “Nondiscrimination in Treatment Act” (HB 1403), which becomes effective November 1, 2013. Despite its innocuous title, the measure may adversely intrude into provider-patient decisions in end-of-life situations. The law permits patients or their legal surrogate to seek judicial intervention if life-preserving health

services are denied: (1) based on a view that “extending the life of an elderly, disabled, or terminally ill individual [is] of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill”; or (2) based on provider-patient disagreement about “the trade-off between extending the length of a patient’s life and risk of disability.”

This new law appears to allow a patient to demand any life-preserving treatment, regardless of the physician’s professional judgment as to its benefits or risks. It addresses a problem that hasn’t been shown to exist: namely, that patients are denied care in a discriminatory manner because of their age or terminal state. Some medical treatments that *could* be provided at end of life *should not* be provided because they are unethical (of no benefit and/or harmful), violating the principles of beneficence and nonmaleficence. Physicians have the ethical obligation to follow the patients’ expressed wishes, *but not* to provide care which is medically inappropriate.

A physician does not have the right to deny care that would benefit a patient, even one who is terminally ill. Conversely, a patient ethically does not have the right to demand care which is of no potential benefit and may in fact prolong suffering and dying rather than prolong life.

When disagreements on end-of-life care occur, the standard and preferred means to mediate such disputes is to involve the hospital’s ethics committee. The new Oklahoma law bypasses this mechanism and will inject the legal system into end-of-life care in a manner which likely will not serve patients’ best interests—and may potentially add to their pain and suffering with no benefit. The New Jersey Supreme Court, almost forty years ago, cautioned against the judiciary’s “gratuitous encroachment upon the medical profession’s field of competence,” a warning unheard and unheeded by the Oklahoma legislature in 2013.

Quinlan, Cruzan, Schiavo. The untimely medical catastrophes experienced by these three young women, and the legal precedents and ethical guidelines which developed as a consequence, have heightened awareness and established a greater necessity for end-of-life planning. Hopefully this legacy will bring informed and beneficial self-determination for Oklahomans in end-of-life care, rather than the potential worst-case consequence of the Nondiscrimination in Treatment Act: judicial “encroachment” that may well lead to multiple “Terri Schiavo” cases played out in Oklahoma courts and in the media, rather than resolved at the bedside or in a hospital conference room.

With compassion and cooperation, patient autonomy will continue to be balanced with physician beneficence, nonmaleficence, and justice toward all. ■

PHILIP J. RETTIG, M.D., is Professor of Pediatrics at the OU College of Medicine and has been involved with hospital ethics committees for nearly three decades. He currently serves as co-chairman of the OU Medical Center Ethics Committee and as course coordinator for the Clinical Ethics course for second-year students in the OU College of Medicine.

EXTRA! For more on advance directives, guidelines for end-of-life care, and legislative policies affecting care, visit: okhumanities.org/extra

Rabbit Punched

By Howard Faulkner

An Atheist's Guide to Living with Cancer
Introduction by Carla Walker, Editor

ART BY JOHN FOX

Topeka, Kansas, circa 1996. As a non-traditional student (collegespeak for “older”), Dr. Howard Faulkner was the first professor at Washburn University to present a speed bump in my straight-A-honors-student cruise toward graduation. I can't remember the precise grade he gave my initial essay for his American Lit. class, but anything less than an A would have had me in a dither. I marched myself into his office hours to find out, What gives? My recollection is fuzzy (it's been a few years or twelve since then), but the upshot was that I was editing myself too much. He counseled that good writing must balance brevity and style with the need to tell the reader enough—advice that stood me in good stead, as (little did either of us know) I would build a career on my tendency to edit.

In his class I learned to think critically and to appreciate poetry; in particular, to understand Emily Dickinson (all those dashes and capital letters!). As a student, I was in awe. He was a Fulbright Scholar who had traveled the world (summer sabbaticals in Paris, leaves of absence to teach in Macedonia, France, Bulgaria, and Morocco. Who does that?!). He was intellectual, well-read, utterly the English professor. Before his long tenure at Washburn, he did graduate teaching and completed a Ph.D. at the University of Oklahoma. And, of course, there were his own forays into writing and editing, including, with his colleague Virginia Pruitt, the correspondence of ground-breaking psychiatrist Karl Menninger.

I had only that one class with Dr. Faulkner and we didn't communicate for the dozen years after he sent me on my way with an anything-but-easy A. But I had the happy occasion to renew our acquaintance a year ago while in Topeka for an alumni awards event. My mentor and college adviser, Tom Averill, hosted a celebration dinner at his home and Dr. Faulkner was among my former professors who attended. It was a lovely evening of reminiscing and conversation.

I learned that weekend that Howard had been diagnosed with stage four kidney cancer; nevertheless, he looked well, was happy and full of vigor. His use of a cane and considerable graying, on both our parts, were the only visible differences from the dashing professor of memory. Shortly after that trip, I learned from a mutual friend that Howard was writing a blog on living with cancer.

What I found was anything but the typical “I have cancer, woe is me” narrative you would expect. He is a consummate storyteller. In addition to candid revelations of the day-to-day fight and costs—financial, physical, and emotional—of dealing with a terminal disease, there are stories about coming of age in a small Iowa town; the life-changing revelations he was forced to make to avoid the Vietnam draft; the weekends he spent in Tulsa and Oklahoma City in the late '60s, going house to house to encourage black voter registration. There is humor, too, and commentary, and opinions—plenty of opinions: film and book reviews, rants on politics, thoughts on the latest Supreme Court cases, and the importance of love and friendship as disease narrows life to home, doctors' visits, and the daily quandary, Can I stomach sushi or Kraft mac-n-cheese today? Now and again he includes a favorite poem and, ever the teacher, an explication (collegespeak for “explanation”) of its relevance to the season, his life, or the issues of the day.

When Howard agreed to our publishing blog excerpts, he had already outlived his initial prognosis. It's a year later and his entries are increasingly hopeful (as are we who care about him). I'm happy to report that he's facing each day with courage and determination and, at this writing, has just married his beloved partner, Mohamed, whose name you'll see mentioned, again and again.

So make yourself a cup of tea or pour a glass of wine, settle in, and savor a bit of narrative from one man's extraordinary life.

Saturday, January 28, 2012 Four reasons why I'm not afraid of death (which is not to say that I'm not afraid of dying). Reason #1: "I see dead people." Story City, Iowa, where I grew up, was a town of about 1600 inhabitants, most of them Norwegian and Lutheran. (Unfortunately, I can still recall of the odor from the semi-annual lutefisk and lefse dinners.) In my class, which roughly held steady at 33, there was an Anderson, Carlson, Johnson, Knutson, Larson, Matson, Nelson, Olson, Paulson, Peterson, Samson, and Thompson. My best friends were Bobby Knutson and Kathy Johnson. Kathy's cousin, Liz Larson, was the daughter of the owner of the local funeral home. The key word was "home," since the Larsons lived there. It was one of the biggest houses in town, and Kathy and I spent many happy afternoons there.

I still remember the layout of the house. When you entered, there was a formal staircase on the right that led to the second floor. To the left was a large room, sparsely furnished because when there were funerals in the house it would be filled with folding chairs for the service. Beyond that to the left was what we'd now call the family room with the TV. Behind the largest room were the dining room and the kitchen.

There were two rules for us kids: one, when a funeral was taking place, we had to stay outside. Since most Story Citians had funerals in one of the three Lutheran churches or the one Methodist church, this proscription wasn't very difficult. The other rule was that the room on the second floor, where Liz's father did the actual embalming and other preparations, was off limits. I'm sure we must have been tempted to sneak a peek or test whether the door was unlocked, though I don't remember that we ever did so.

But I've omitted one room. If, when you entered, you turned neither to the left nor right, there was in front of you the viewing room, where the dead lay so that others could view the body. During all the years that we played in that house, there were often bodies nicely laid out in this room. As kids we thought nothing of it. It seemed perfectly natural—not an object of fear or even curiosity, except when we might know the person who was lying there. That people died seemed just a part of the way things are.

Nearly 30 years later, I met Kathy again. She was returning to nursing and wanted to work with AIDS patients, this at a time when a diagnosis of AIDS meant almost certain death. Both of us agreed that our experience in the funeral home gave us a healthy perspective on death and its familiarity.

When I told this story to a good friend, she said that it would make a great short story. But my point was the opposite: there was no story there—no tension, no epiphany, just life in all its fullness and completeness.

Tuesday, January 31, 2012 Reason #2: I survived the AIDS epidemic, while so many of the people I cared about did not. Nearly thirty years ago, my undergraduate roommate—funny, smart, good-looking, young—was the first I knew who died. Rich had gone to San Francisco to join, he thought, the American Conservatory Theater. They ultimately didn't take him, and to survive he became a male prostitute. I visited him once in perhaps the most depressing trip I ever took. Rich lived in a fleabag hotel in the Tenderloin. The rooms had single, shadeless bulbs hanging from the ceiling. There was one toilet in the hallway on each floor. I peed in the sink in my room at night because I was afraid to go into the corridor. Rich and I barely saw each other, since he plied his trade at night and slept during the day. I never saw him again.

And there was Ken, whom I took to Paris for the last summer

of his life. And Jacques, who ran a Nicolas wine shop in Paris. When I came back to Paris one time, Jacques' partner said that he would be so happy to see me, that he'd been, for some reason, depressed. When Jacques and I met for dinner at one of my favorite restaurants in Paris, I knew instantly from his gaunt appearance what was wrong. And Gustavo—one year a gorgeous model in Paris, the next wasting away in his hospital bed. And too many more.

But it's about more than just survival. I know that I've been very lucky in my life. For 45 years, I taught literature and language—a career that I loved. Randall Jarrell once said that if he wasn't paid by others to teach, he'd pay to do so. I felt that way too, though I didn't say that aloud till the last year, since the administration might well have taken me at my word. How lucky to get paid to talk about things that you love! And lucky too that Karl Menninger ("long considered the elder statesman and dean of American psychiatry," as noted by *The New York Times*) was here in Topeka, a man who was still brilliant (if very cantankerous) into his nineties, which allowed me to produce four books of his letters and a monograph, as well as articles on literary subjects more closely related to my own field.

I was lucky in that two sisters, whom I never knew, endowed a summer sabbatical fund that enabled me to spend seven or eight summers in Paris. It seems that every fourth year I got restless and took a semester or, more often, a year off to teach abroad, first in Macedonia, then France, then Bulgaria, and finally Morocco. Those four years were some of the happiest and most interesting of my life. I learned how much I loved languages and how language opens the way to immersion in the culture.

And I've been very lucky in that for the last five years, I've loved and been loved despite what began as a very long-distance relationship for me and Mohamed. I want(ed) to live longer, of course. (The past tense seems depressingly fatalistic; the present tense perhaps naively optimistic.) I wanted many more years on a new page in my life. But even if that's not to be, I do know that I've had a happy and lucky life.

Thursday, February 2, 2012 Reason #3: I'm an atheist. A Muslim friend in Morocco was upset by the subtitle of the blog: *Why did I have to be so aggressive about it? Was this a guide only for atheists?* (I'm not sure that so far it's even much of a guide.) In part, the choice was a reaction to a specific event: I was watching my favorite morning show, *Up with Chris Hayes*. One of the panelists was a liberal black woman. I was nodding and agreeing with everything she said when the subject of the death of Christopher Hitchens came up. The panelist said that she didn't understand why atheists didn't just shut up and stop being so in-your-face about their lack of belief. She was a Christian, and ... On and on she went, and higher and higher went my blood pressure. She didn't see any reason why she shouldn't expound on her beliefs, but those atheists!

God, prayer, spirituality, heaven, hell—they have no purchase, either emotionally or intellectually. And I find that very comforting. Without God, the supposed stages of grieving can be ignored entirely. Anger? There's no one/nothing to be angry with. Bargaining? Ditto. There's no fruitless asking, "Why me?" No one will answer, and no answer would make sense.

Life takes meaning from its shape, and the idea of hell and, more so, of heaven are beyond my ken. What would eternal life even mean? As Wallace Stevens says in one of the most beautiful poems of the twentieth century, "Sunday Morning":

Is there no change of death in paradise?
Does ripe fruit never fall? Or do the boughs
Hang always heavy in that perfect sky,
.....
Alas, that they should wear our colors there, . . .

As Stevens writes in an earlier stanza, if the earth is all of paradise that we know:

The sky will be much friendlier than than now,
A part of labor and a part of pain,
And next in glory to enduring love,
Not this dividing and indifferent blue.

Amen!

Thursday, February 9, 2012 Reason #4: "Love calls us to things of this world," wrote Richard Wilbur. We have them for a while, and knowing that we won't have them forever provides a welcome rhythm to our lives. So reason #4 for not fearing death is that without that ending, life would have no meaning.

Steve Jobs, in his search for a spiritual lesson, said that he didn't want to think of life, like a computer, with an on/off switch. It's not the prettiest of metaphors, but there is that moment when the switch flips to "off." Perhaps more accurately, life is like a rheostat: in the "on" position, some moments are bright, others dim. I try as best I can to keep the light shining brightly. One of the frustrating aspects of cancer is that the disease and the chemo and the side effects often dim the lights when I'd like them bright. Eventually, though, there will be an ending, the switch will descend to the "off" position: "Put out the light and then put out the light" (*Othello*).

In my all-time favorite novel, *The Sound and the Fury*, Jason Compson is fond of cynical descriptions of the cycle of life. One is in Latin: *Non fui. Sum. Fui. Non sum.* (I was not. I am. I was. I am not.) His cynicism is sometimes amusing, but it's also destructive. If we think of that series, though, not as something to despair over but as simply the way it is, the sequence suggests the beginning, middle, and end of our journey. The world endured for millions of years before I was; it will endure when I am not.

Saturday, February 11, 2012 *Things you should not say to someone who's living with cancer.* I've discovered a variety of responses to my illness. The most surprising to me are people who I assume know, but who say nothing. Are they indifferent? Embarrassed? At the other extreme are those who ask extremely personal questions, which I'll usually answer for close friends. I'm happiest when people just want to discuss it matter-of-factly and move on. I realize that it's often difficult or awkward for the other person. Still, occasionally, there are people who say things that seem so strange or inappropriate that I have no idea how to respond. For example:

My dentist after a regular cleaning: "Do we even need to make another appointment?" The same dentist six months later when I did have another cleaning, explaining why I had to take a massive dose of antibiotics beforehand: "We're just being overly cautious, but when you kick (his word), it's more impressive if it says 'cancer' and not 'dental hygiene.'"

A secretary (Washburn still uses that designation) with tears in her eyes: "I'm sorry, it's just that you look awful. You look so much weaker than the last time I saw you." (If I didn't look awful before—and I wasn't aware that I did—I probably did afterwards.) The next time I saw her, she was smiling and said, "You look really

good." (Great. Stop there.) "You look so much better than the last time I saw you." (Good. Let's stop now.) "The last time you looked like you were at death's door." (Oh-oh. Too late.)

Tuesday, February 28, 2012 *Cancer, shmancer, abi gesund.* (Roughly, "Cancer, shmancer, as long as you're healthy.") On the one hand, the phrase is dark humor—ignorance or denial or defense. On the other, it's an accurate description of how my days go and how I react to what's going on. The cancer is there and it's doing whatever it is that cancers do. Cancer, shmancer—there's not much more to think about. Well, of course there is, but I can't really spend every day contemplating mortality.

I start each day with a handful of pills washed down with OJ, a bowl of cereal, and several cups of coffee. Then I have to wait for two to three hours before I can take the chemo. It's then that I have the most energy I'll have all day. I blog and do e-mails and watch *Morning Joe* or *Up with Chris Hayes*. Next comes showering, and suddenly I'm exhausted. Something I've done every morning for all of my adult life has become an ordeal. After the shower, I text Mohamed if he's at school, just to let him know I haven't fallen (and can't get up—or can't reach my drink, as we joke). Getting dressed in my uniform of sweats, t-shirt, and hoodie is also time consuming. I have to keep standing up and sitting down because I can't stand on one leg.

And then it's time to face the day ahead. What's always present is an awareness of whether this is a good day or one that's not so good. I know I'm going to take a nap or two. It's not a choice; suddenly my mind and body shut down. Much worse is the diarrhea, which is completely unpredictable, except that it's a constant threat. I love going out for lunch or dinner, but I always take an extra *Imodium* before I go and am aware of restroom locations in all restaurants. (Too much information?) Nothing is more debilitating than a day like yesterday when I didn't dare leave the house. One of my oldest friends called when I was napping, but I didn't have the energy to call back—and what was there to say except to recount my G-I troubles? Not exactly charming conversation. It's my "new normal," as they say. *Cancer, shmancer*—not much more I can do about that; *abi gesund*—now that's what really counts.

Friday, March 9, 2012 *We who were living are now dying / With a little patience.*—T.S. Eliot, "The Waste Land." For the moment, I feel as if I'm in a holding pattern or, to borrow a religious metaphor (not fair, I know, for an atheist), limbo. I feel pretty good, haven't changed too much physically, and am cheerful. As one of my friends from California asked yesterday, "Are you sure you're really sick?" And sometimes I'm not. Still, for someone who's always thought of himself as energetic and adventurous, the limitations are frustrating. I've cried only once in all of this (shed a tear, as my mother would've said, not sobbed). I was watching a rerun of *Anthony Bourdain: No Reservations*, this one set in Paris. I've spent so much time in France and feel so at home there that the thought that I'd never go back again caused some tears to trickle down my face.

The days here in limbo have settled into a routine. I don't get bored, and the days don't seem long. But I do feel as if I should be doing something more important or creative or meaningful. I don't know what that would be or where I'd get the energy to do it. What I'd really like is totally irrational: I'd like to know where on the trajectory of this disease, I am. I count the months. To paraphrase Eliot, we're all dying . . . with a little patience. Every one of us is on the same trajectory, and almost none of us knows where we are. If I knew, what would I do? I don't know.



Monday, April 2, 2012 Regret is an emotion I seem to lack. It's not that I haven't made (more than?) my share of stupid decisions, often costly (in all senses) ones. It's partly that I tend not to focus on the past—not that I don't have 60-plus years of wonderful memories that I often revisit. I don't feel regret, too, because it's a useless emotion; no amount of regret will change the past. I'm happy with who I am and with my life, so having regrets, wishing I'd done things differently implies that I'd like to be someone different.

A more biting critique of looking back occurs in Robert Frost's "The Road Not Taken." The poem is commonly reduced to something like a high school graduation speech: You're at a crossroads, be courageous and choose your own path, etc. But surely Frost wasn't as banal as that. He says explicitly in lines 9 and 10 that "the passing there / Had worn them [the paths] really about the same." So the speaker hasn't really made such a bold choice. But the key is the last stanza:

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I—
I took the one less traveled by,
And that has made all the difference.

The self-dramatizing speaker tells his narrative with a melodramatic sigh. And then his dramatic pause after the first "I" and its repetition. The reader can sense the self-pity, the catch in his voice. And what is this important "difference"? We know from such Frost poems as "Neither Out Far Nor In Deep" and "For Once, Then, Something" what Frost thinks about human powers of discernment, and it's not flattering.

So I hope to avoid regrets, self-dramatization, trémolos (Edith Piaf's word), and sighs in the blog while guarding the decades of great memories.

Wednesday, April 11, 2012 It's been exactly one year since a doctor told me that I had cancer—one moment at a few minutes till 11 a.m. when everything in my life changed. After I retired, I taught as an adjunct for the next year—classes of freshman composition. All the books and art from my old office had been shlepped home, and I was sharing an office with Josh, an old student, now a colleague and friend. This wing of the building had once been active with classrooms and professors' offices, but it had been turned into mostly administrative space, so generally felt deserted. Before my class, I went up to the second floor. The corridor was empty. My cell phone rang, and it was the doctor who had been treating me for nearly six months for a torn rotator cuff and bursitis. A few days before, he had said that I should have an MRI in case he had missed something, as indeed he had. He called to tell me that I had a tumor that had destroyed part of my left scapula. When I didn't react with anything but silence, he said, "You have cancer and you need to find a specialist immediately." He also asked that I keep him informed, but since he'd misdiagnosed me for so many months, I didn't really feel obligated.

In retrospect, I don't know what went through my mind. I know that I taught my class, and I think it was normal enough. And then on the way home, I told Mohamed. We had a few days of denial: the doctor hadn't done a biopsy, so how could he know that the tumor was malignant? Most of the next couple of weeks consisted of confusion and frustration. I never managed to talk to my primary doctor, whom I had considered a friend, each time being shunted to a nurse. Finally I was referred to Dr. Templeton, an orthopedic surgeon at KU Med. At that point, the assumption was that it was bone cancer. After about three weeks, I finally began the battery of tests. The last test was on a Friday afternoon. As we were leaving the Med Center, the phone rang. It was Dr. Templeton's nurse saying that she had some good news: although much of the scapula itself had been destroyed, the cancer hadn't

EXTRA: Read the full blog at: rabbitpunched.blogspot.com



PHOTOS: Howard and Mohamed (near left) at the 2012 Washburn Alumni Association Awards where, as Professor Emeritus of English, Howard was awarded the Col. John Ritchie Award for distinguished teaching. A clipping from *The Oklahoma Journal* (right), c. 1970, is captioned: "Old and young hold hands in rally for integration." As a graduate assistant at the Univ. of Oklahoma, Howard (wearing sunglasses) joins students and others in support of Oklahoma City sanitation workers in a march for job equality and other civil rights. "The photo was taken in front of the mayor's house," says Howard. "We had linked hands and were, of course, singing 'We Shall Overcome.'"

spread to the surrounding muscles and tissue. Good news was very welcome, even if it was short-lived. Saturday morning, Dr. Templeton called me at home. Again, I was totally unprepared for the call. She said that the last test had shown that the primary cancer was in the kidney and that it had metastasized to the femur, which needed immediate surgery, as well as the scapula and, to a lesser extent, to other bones. The only response that I remember is saying, "That's not good news." She agreed.

If everything had seemed to move in slow motion for the previous three weeks, events now moved extremely quickly. The surgery was scheduled and I was quickly admitted to the hospital. The day before we left for Kansas City, Mohamed and I were standing on the back deck and he asked me whether I was frightened. If I'm not very focused on the past, so, too, I'm not very good at thinking about the future, except in making immediate, practical decisions. I told Mohamed that no, I wasn't frightened. I think that if I imagined anything, I thought it would be like a hip replacement and I'd be home in a couple of days and walking normally in a couple of months.

Once at the Med Center, Dr. Templeton said she would do an embolization (I had to look it up). I have great faith in her as a surgeon, but she doesn't have the world's best bedside manner. She said, "We don't have to do it, but if we don't, chances are you'll never get up from the operating table." So the first day was the embolization, the second was the surgery. There were nine days in the hospital and seven weeks in the extremely constricting abduction brace. It's probably good that I couldn't foresee the future or I would have been really scared. Events happened so quickly that I thought only about what was happening day by day (or hour by hour). Even if I'd had the inclination, I had neither the energy nor the vision to think beyond the present.

So has passed the first year of knowingly living with cancer. I just have to keep saying to myself, *cancer, shmancer, abi gesund*. And I have to be thankful for all the love and affection that surrounds me.

Tuesday, April 17, 2012 Joanne, my most frequent commenter, suggested yesterday that perhaps my last blog, full of complaints, was less about complaining than about anger. But no. I've been very lucky. I've never known poverty or hunger. I had good parents who didn't pass on anything more than

garden-variety neuroses. Unlike anyone else in my family, I went to college and grad school, and had a good education and bright, funny, feisty friends. I spent 45 years in a career that I loved and that gave me unusual opportunities to live and teach in five countries on three different continents. I've got good doctors and a wonderful partner. So what's to complain? Friends have said, You didn't deserve this (the cancer). If I didn't "deserve" the cancer, does that mean I didn't deserve all the good things? We simply don't live in a world where fairness obtains. Our tragedy is that of Aeschylus, not Aristotle.

I'm not afraid of death. But dying—well, that's another matter. When, as the last few days, my right leg hurts and my left shoulder hurts even more, it's not that the discomfort has turned to pain (so far, I can suck it up). It's the fear of what is really going on and what it bodes for the future. And that scares the shit out of me.

(As I typed this, the *Today* show was on in the background, and a TV psychologist who specializes in anger management was asked, "Some people say that they never get angry. Is that possible?" You don't have to be clairvoyant to guess her answer. And, she continued, those who bottle it up suffer physical consequences. Damn! If only I'd yelled at a few more people, I could've avoided cancer. I guess I had it coming.)

Thursday, May 10, 2012 I always thought of my identity as composed of many traits: teacher, gay, left-wing Democrat, atheist, left-handed, adventurous . . . The cancer diagnosis seemed to change my whole sense of identity; it risked becoming my identity, making everything else of very tenuous importance. My whole life changed, both physically and psychologically. There was the operation and radiation. There were practical tasks: arranging doctor visits, re-arranging furniture, re-writing my will. There was a new realization of the loss of possibilities and of dignity (though that was low on the list). And behind it all was the prognosis—10 or 11 months for stage four kidney cancer.

But I've lived with the cancer diagnosis for over a year now, and somehow it's taken its place as just one more facet of who I am. It doesn't define me as it did for a while. One/you/I can't think about mortality all the time—not when there is so much that is interesting/heartening/discouraging/funny in the world.

Saturday, May 19, 2012

The Oven Bird
By Robert Frost, 1874–1963

There is a singer everyone has heard,
Loud, a mid-summer and a mid-wood bird,
Who makes the solid tree trunks sound again.
He says that leaves are old and that for flowers
Mid-summer is to spring as one to ten.
He says the early petal-fall is past
When pear and cherry bloom went down in showers
On sunny days a moment overcast;
And comes that other fall we name the fall.
He says the highway dust is over all.
The bird would cease and be as other birds
But that he knows in singing not to sing.
The question that he frames in all but words
Is what to make of a diminished thing.

Robert Frost's "The Oven Bird"—and especially the phrase "what to make of a diminished thing"—has been haunting me recently. The sonnet describes the loud songs of an oven bird who has, as the poem progresses, less and less reason to sing. In one startlingly original line, Frost uses a mathematical ratio ("Mid-summer is to spring as one to ten"), the world already diminished by ninety percent by mid-summer. But the oven bird continues, knowing "in singing not to sing" ("I sing because I'm happy. I sing because I'm free"—the traditional reasons for singing no longer apply to the bird). Its song becomes a question about the meaning of the diminished world. The bird is, of course, like Frost the poet (the "dark" Frost, not his public persona). Frost's poetry is an extended and various meditation (framed in words) on our diminished natural and personal world (his poetry rarely deals with the mediating social world). And for me over the last few months, that question has been my own: how to deal with a diminished world of possibilities and still keep, well, not singing (that would be frightening for everyone), but thinking, talking, writing.

I always taught "The Oven Bird" in the second half of the American Lit. survey. My modest ambition was to teach students that the basic unit of a poem is a sentence, not a line (students paused at the end of each line, whether it was end-stopped or not, and started the next as if it were the beginning of a new thought, often reducing the poem to nonsense) and that the poems we read consist of English words conveying a literal English meaning. *Does that mean a poem has one and only one meaning?* the students would ask. I hope not; otherwise, I'd have been out of a job.

As you can tell, I was always proud of my attempts to demystify deconstruction to students who had had trouble reading a sonnet and whom I had just told to be nothing if not literal. Ah well, as American writers from Emerson to Ellison, from Whitman to Fitzgerald have argued, consistency is overrated. And, like the oven bird, as you also can tell, while feeling that I live in a diminished world, I just keep talking and writing.

Monday, July 16, 2012 And so I've begun a new year—two days into year 68. The weekend was fun with visitors from Kansas City, and meals out, cards, texts, e-mails, and phone calls, including several from France (I'll admit that I've got an easy birthday date to remember, Bastille Day), and a beautiful pink gold watch from Mohamed.

I've always wondered whether teachers were more conscious of time passing than people in most other professions. Our lives are marked by the rhythm of semesters: four months of teaching, a month off, four months of teaching, three months off. Dusting off an old syllabus and adjusting the dates, ordering books, writing exams, and grading, grading, grading—these are all parts of a regular cycle. And we watch time pass as the gap between our age and that of our students keeps growing.

When I started teaching at the University of Oklahoma, I was 21—three years older than the traditional students. By the time I retired, the gap was nearly five decades; references and allusions that I had shared with students for many years fell completely flat. E. A. Robinson's poem "Richard Cory" was made into a song by what group, I'd ask. It wasn't just that no one knew, but that no one even knew who Simon and Garfunkel were. It's hard not to be aware of time's passing when you teach.

Still, even in a more diminished life, there are constant small markers of time. Every night, it's preparing the coffee so that I'll come downstairs to the smell of morning joe. Every three days it's writing the blog. Every month or so, it's inventorying the many bottles of pills to see which ones need re-ordering. Every three months it's the whole battery of tests: bloodwork, CT scans, a full-body x-ray, a bone-strengthening shot. The day of tests isn't painful or even particularly unpleasant, but it's long and tiring. It also costs the taxpayers \$22,000, \$12,000 of which is just for the shot.

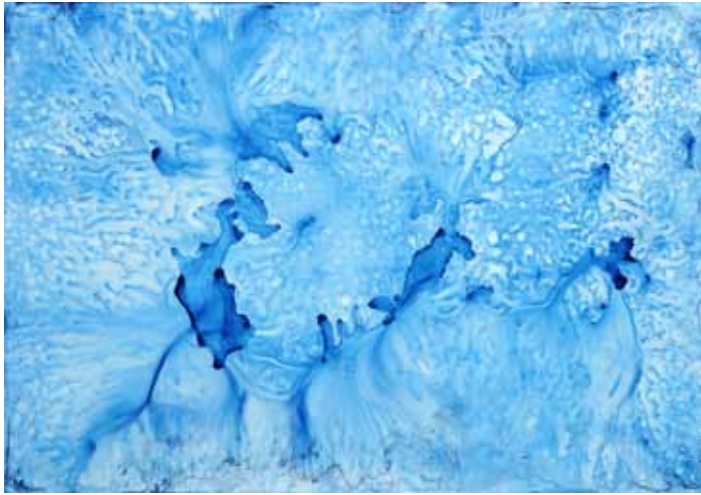
And every three months, the seasons change. The giant cottonwood tree in the back yard starts to lose its leaves early; already in the heat some of the leaves have fallen, but it hangs on to its last few leaves until winter is here. Every year I think of Shakespeare's sonnet, "That time of year thou mayst in me behold / When yellow leaves, or none, or few do hang . . ." and wonder about the sequence: shouldn't "few" logically come before "none"? In the late fall, the cottonwood is often full of blackbirds, and I think of Wallace Stevens's poem "Thirteen Ways of Looking at a Blackbird." Some, at least, of the poetry (and stories and novels) that I taught for so many years are etched in my mind.

Another day and week and season and year pass. I'll put on my new watch and hope that friends notice it so I can show it off, as it mechanically and indifferently ticks off the passing seconds.

Wednesday, February 13, 2013 It's been almost two years (the second year of which I wasn't supposed to be around to see) since the first telephone call with the word "cancer." We still haven't cried. Instead, we've followed the British slogan, "Keep calm and carry on." Mohamed has carried on with a full load of classes every semester, in addition to being my chauffeur, my therapist, my rock. I've carried on in large measure because of Mohamed's love and support. Life feels in many ways diminished because it is. But in more important ways, it's not diminished at all—and all because I'm not going through this alone but with a smart and loving partner. He makes it easy to keep calm and carry on, and together we continue to do so.

Tuesday, February 19, 2013 My mental health is okay. Even though my life is much more constrained than I had hoped, I don't get bored (sleeping so much probably helps), and I've got many good friends whose company always gives me a burst of energy. I've certainly got my share of neuroses, but luckily depression has never been one of them.

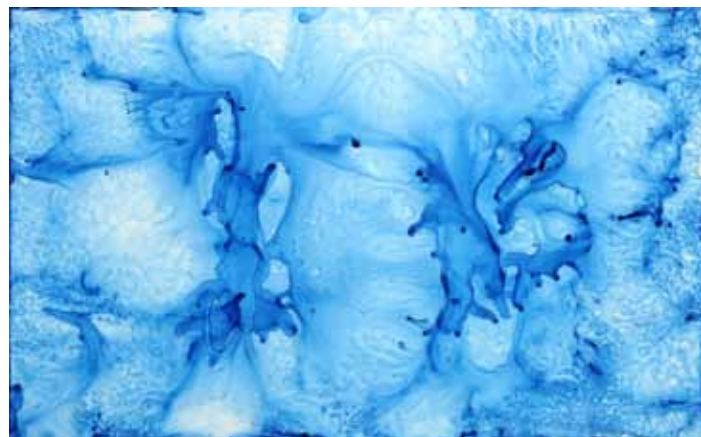
I'm also by nature not a brooder. It's not denial or avoidance; it's just my character. True, it's frustrating that food is an ordeal rather than a pleasure and that I'm not spending time lounging



on a beach in Mexico or planning a summer trip to France. But I'm much more likely to think about what I should read next (having just finished the very funny and very cynical *Vanity Fair*, I need another long book to immerse myself in) or when Liam is finally going to choose between Hope and Steffy on *The Bold and the Beautiful* than about what isn't happening in my life. You can see I have my priorities in order.

Tuesday, May 14, 2013 Late yesterday afternoon, we went out for drinks with our cute, young friend Sarah. The restaurant has a large patio and the afternoon was warm. Towards the end of our stay, the conversation turned to cancer, our reactions to the initial diagnosis, and our feelings now. I said that sometimes I feel a little strange, almost guilty (though that's much too strong) for being so seemingly healthy. The initial prognosis was so dire that everyone showed immediate concern: tears, lots of visits with casseroles and pies, a certain awkwardness. But it's been two years and I look and feel generally pretty healthy. I said aloud for the first time that what I really want is to live long enough to see Mohamed graduate. He's only fifteen hours from that goal, and my condition hasn't really changed for the last year, so that sounds somewhat melodramatic.

As we were having this cheerful conversation, suddenly five large buzzards or vultures, whichever we have in Kansas, appeared in the sky, lazily circling over the patio. If I believed in omens, this wouldn't have been encouraging. Sarah mentioned a culture that valorized vultures because they did the work that no one else wanted to do: they kept nature new. That made me think of one of my all-time favorite poems by Richard Wilbur, which makes exactly that point.



Still, Citizen Sparrow

By Richard Wilbur, *Collected Poems 1943-2004*

Still, citizen sparrow, this vulture which you call
Unnatural, let him but lumber again to air
Over the rotten office, let him bear
The carrion ballast up, and at the tall

Tip of the sky lie cruising. Then you'll see
That no more beautiful bird is in heaven's height,
No wider more placid wings, no watchfuller flight;
He shoulders nature there, the frightfully free,

The naked-headed one. Pardon him, you
Who dart in the orchard aisles, for it is he
Devours death, mocks mutability,
Has heart to make an end, keeps nature new.

Thinking of Noah, childheart, try to forget
How for so many bedlam hours his saw
Soured the song of birds with its wheezy gnaw,
And the slam of his hammer all the day beset

The people's ears. Forget that he could bear
To see the towns like coral under the keel,
And the fields so dismal deep. Try rather to feel
How high and weary it was, on the waters where

He rocked his only world, and everyone's.
Forgive the hero, you who would have died
Gladly with all you knew; he rode that tide
To Ararat; all men are Noah's sons.

The poem begins in the middle of a discussion between the speaker and a sparrow (hardly the most glamorous of birds), which has argued that what the vulture does is "unnatural." The speaker's three alliterative words of address are respectful enough and acknowledge that the vulture's ascent is less than graceful. But once the vulture is in the sky, the description of flight is one of praise for the vulture's watchfulness, its grace, its natural burden of renewing nature.

The turn comes in stanza four. Just as Wilbur has reversed our initial unfavorable opinion of the vulture, he shifts our perspective on Noah. Most readers begin thinking of Noah positively; but the focus here is on Noah building the ark, the "bedlam hours" when "his saw / Soured the song of birds with its wheezy gnaw." The sound of the lines is nearly as ugly as the sound of Noah's saw and hammer. Then, once the reader has had second thoughts about Noah, the point of view is modified again: Noah, like the vulture, is portrayed as one who has the heart to renew the world, to put death in perspective and mock mutability.

The vultures or buzzards that circled the patio last night weren't omens. They were beautiful birds "making lazy circles in the sky." "Wings spread wide, they scoured the landscape, ready to devour death and keep nature new. ■

JOHN FOX has exhibited widely in major cities across the country and his work is represented in private and corporate collections in the U.S. and abroad. He served as gallery director at Ohio State University and Southern Illinois University, and has taught fine arts at Ohio State University, Dartmouth College, Southern Illinois University, Los Angeles Harbor College, California State University at Long Beach, and the California Institute of the Arts. He resides in Los Angeles. johnfoxart.net

End Notes from the Editor

Doctor.
*The word for healer and wise man
throughout the universe.*
—*River Song, a.k.a. Melody Pond*

What's the craziest TV show you've ever tried to follow? The cheesiest storyline, one that's absolutely absurd and yet you can't stop watching.

For me, that show is *Doctor Who*.

It's a long-running science fiction series from the BBC. Space aliens, the Daleks, are out to take over the universe. These creatures-slash-robots look like a cross between a round top trash can and Mr. Potato Head. Cheesy. The Doctor, a Time Lord, travels through time and space to save civilizations, visit historical legends, and generally right the wrongs of the universe. Contrived. His mode of transportation is not a supersonic spaceship, but a cornflower-blue police telephone box, a British relic from the 1960s, known as the TARDIS. "It's bigger on the inside than on the outside," the narrator tells us during the opening credits, and somehow this flying telephone booth can touch down in any universe on any planet during any period in history. Absurd.

The show debuted in 1963 and ran through 1989. It reappeared in 2005 and retains a cult following. Online blogs report that it began as a family show,

using the premise of time travel to explore scientific ideas and significant moments in history.

Did you say history? Yep, the humanities. But wait, there's more.

Normally on Friday (in fact most nights) I'm watching public television instead of the local news. *Doctor Who* follows another PBS show on my watch list. The first several times I saw The Doctor step out of his telephone box and wave a glowing green screwdriver at a metal trash can that talked back, I thought, *Seesh, who writes this stuff?* And promptly changed the channel.

With nothing better to watch one Friday, I left it on. Surprise, surprise it had a decent plot. Over a number of episodes we visited Richard Nixon and Winston Churchill (and both men were in a pickle, let me tell you). We watched Apollo 11 and visited Vincent Van Gogh, whom we whisked to the future to see people admiring his art in a museum. Even the farfetched seemed crazy-interesting: Sharks swam down from the sky, ready to snap our necks but suddenly soothed by a woman's lullaby. People jailed in frozen animation, a sort of sci-fi debtors' prison, could be thawed to visit their families only

one day each year until the set number of years ran out, a universe where you'd hope for a long, long sentence.

The story skips back and forth, revisiting people and events, each time looking at things from a slightly different angle, a different point of view, someone else's interpretation. A lot like the humanities!

There you have it. A crazy-good yarn with relevance to our conversation about medicine and the humanities, because it reminds us that history and narrative can inform those two great and powerful forces—forces that can change, yes, and *save*, the world!

And if that isn't cheesy enough, how about a parting quote from our friend, The Doctor: "We're not fighting an alien invasion—we're leading a revolution!"

Lead on, Humanities Time Lords.
Lead on.

Carla Walker, Editor
carla@okhumanities.org



Next up: HUMOR | Winter 2014!

Do the humanities
have a sense of humor?
Find out in our next issue.
It'll be all funny business. Seriously.



See the Stars, Lenny; Dennis R. Scott



428 W. California Avenue, Suite 270
Oklahoma City, OK 73102
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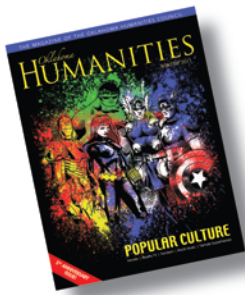
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EXTRA!

History of Medicine vs. Organic Chemistry

By Sarah Tracy | Fall 2013 | Vol. 6, Issue No. 3

For Discussion

1. What can the Tuskegee Experiment teach us about clinical trials and patients' rights? What kinds of information should be disclosed to patients before they are enrolled in a study?
2. Discuss other modern-day groups of people and diseases that have been overshadowed by stereotypes, such as AIDS which was initially diagnosed among the homosexual community, the lingering lack of health care for the poor, and women's rights in making health care choices.
3. Should medical researchers assume that all people are alike—or should ethnicity, income, and sex be factored into modern research? Are these issues a matter of science or ethics—or both?
4. What assumptions does society make about health care professionals: that they are objective in making diagnoses and administering care? That they are always truthful with patients and insurance companies? That they are too far removed from us—by higher education or income—to understand our problems? How do we impair the care we receive when we make assumptions about those who treat us?
5. What factors—social, economic, cultural, political—do you think contribute most to the breakdown of communications between health care providers and patients?

EXTRA! Reading

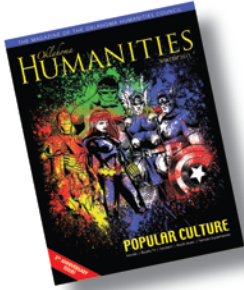
- Michael Bliss, *William Osler: A Life in Medicine* (Oxford University Press, 2007), a comprehensive biography on the physician credited with revolutionizing the practice of medicine in the twentieth century.
- William Osler, "A Note on the Teaching of the History of Medicine," *British Medical Journal*, Vol. 2, No. 2167 (July 12, 1902). Osler's short commentary on how he and his colleagues used the history of medicine in teaching students at Johns Hopkins Medical School. Online text available from U.S. National Library of Medicine: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2401327/>
- Elizabeth Blackwell, *Pioneer Work in Opening the Medical Profession to Women* (E.P. Dutton & Co., 1895). Blackwell's autobiography recounts sex discrimination and other barriers she overcame to become the first fully-qualified female physician in America. She reveals deep convictions about the ability of women and the need to build institutions and associations that would help them become health care professionals. Online text available from the Internet Archive: <http://archive.org/details/pioneerworkinop00blacgoog>
- Elizabeth Blackwell, Letter to Baroness Anne Isabella Milbanke Byron concerning women's rights and the education of women physicians, March 4, 1851. See photos of the letter in Blackwell's handwriting and read a short biographical sketch of Blackwell's life, work, and relationships, including her lifelong friendship with Florence Nightingale. American Memory archives, Library of Congress: [http://lcweb2.loc.gov/cgi-bin/query/r?ammem/mcc:@field\(DOCID+@lit\(mcc/065\)\)](http://lcweb2.loc.gov/cgi-bin/query/r?ammem/mcc:@field(DOCID+@lit(mcc/065)))
- "Better Living Through Lobotomy: What Can the History of Psychosurgery Tell Us About Medicine Today?" An interview with Elliot S. Valenstein, author of *Great and Desperate Cures: The Rise and Decline of Psychosurgery and Other Radical Treatments for Mental Illness* (Basic Books, 1986). Valenstein and interviewer Allison Xantha Miller (*Stay Free!* magazine) discuss psychosurgery pioneer Egas Moniz, the history of mental health treatments, and the use of lobotomy in the early- to mid-20th century. Read it online: <http://www.stayfreemagazine.org/archives/21/lobotomy.html>
(continued)

- James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment, New and Expanded Edition* (The Free Press, 1993). Edited book description from Amazon: “From 1932 to 1972, the United States Public Health Service conducted a non-therapeutic experiment involving over 400 black male sharecroppers infected with syphilis. Its purpose was to trace the evolution of the disease to learn how syphilis affected blacks. Instead of the powerful drugs required, they were given aspirin for their aches and pains. Health officials systematically deceived the men into believing they were patients in a government study of “bad blood.” At the end of this 40-year deathwatch, more than 100 men had died from syphilis or related complications. *Bad Blood* provides compelling answers to the question of how such a tragedy could have been allowed to occur. Tracing the evolution of medical ethics and decision making in bureaucracies, Jones attempted to show that the Tuskegee Study was not an aberration, but a logical outgrowth of race relations and medical practice in the United States. In the revised edition, Jones traces the tragic consequences of the Tuskegee Study over the last decade. A new introduction explains why the Tuskegee Study has become a symbol of black oppression and a metaphor for medical neglect, inspiring a prize-winning play, a *Nova* special, and a motion picture. A new concluding chapter shows how the black community’s wide-spread anger and distrust caused by the Tuskegee Study has hampered efforts to combat AIDS in the black community. *Bad Blood* was nominated for the Pulitzer Prize and was one of *The New York Times* 12 best books of the year.”

EXTRA! Links

- Watch an impressive YouTube video of James Jones’s lecture, “The Tuskegee Syphilis Experiment: A Tragedy of Race and Medicine,” delivered at the University of New Hampshire, April 2012. Jones discusses his discovery of the Tuskegee papers in the U.S. National Archives in 1970 (two years before AP reporter Jean Heller broke the story in the national press), his subsequent years of research, the arc of people and events that allowed Tuskegee to continue for 40 years, and his assistance in the class-action lawsuit brought against the U.S. government. Jones is a historian and Professor Emeritus, University of Arkansas. He was a Kennedy fellow in bioethics at Harvard University, a senior research fellow at the Kennedy Institute of Ethics at Georgetown University, and a former senior fellow at the National Endowment for the Humanities. YouTube video: <http://www.youtube.com/watch?v=WUExTIFaLE>
- Susan Reverby, *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy* (University of North Carolina Press, 2009). Companion website has photo galleries of Tuskegee documents, doctors, and participants, and links to resources on the Tuskegee Study. <http://www.examiningtuskegee.com/>
- NPR, “Remembering Tuskegee”: <http://www.npr.org/programs/morning/features/2002/jul/tuskegee/> Listen to a report from *Morning Edition*’s Alex Chadwick, read the transcript of President Bill Clinton’s formal apology to Tuskegee Study members, and link to CDC-sponsored information, including a website, timeline of events, and factsheet.
- U.S. National Library of Medicine, a division of the National Institutes of Health (NIH): Find digital archives, exhibits, photos, film, and more on the history of medicine (<http://www.nlm.nih.gov/hmd/index.html>). One gem among thousands is the exhibit *Changing the Face of Medicine*, exploring how women have influenced the practice of medicine. Includes a bio and photos of Elizabeth Blackwell: (<http://www.nlm.nih.gov/changingthefaceofmedicine>).
- Bioethics Resources on the Web from the National Institutes of Health: <http://bioethics.od.nih.gov/> Web links to information and issues in bioethics, including: cultural, diversity, and health disparities; genetics; biotechnology; public health ethics; and research ethics.
- The University of Oklahoma Medical Humanities Program: <http://www.ou.edu/honors/MedicalHumanities>

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EXTRA!

The American Indian Medicine Wheel: A Guide for Living By Ann Dapice (Lenape/Cherokee) | Fall 2013 | Vol. 6, Issue No. 3

For Discussion

1. Discuss the differences between mainstream U.S. medical practices and the holistic approach to healing represented in the medicine wheel. What differences would the *patient* encounter with the two? How would *practitioner* skills differ? How could the two approaches be integrated?
2. Have you or someone you know explored complementary or alternative (CAM) therapies (like the medicine wheel, herbal remedies, massage, meditation, etc.)? How difficult was it to find resources in comparison to mainstream health care?
3. Compare and contrast the *spiritual* values of the medicine wheel with those of other religious traditions. Which values intersect and how might they differ?
4. When taking a patient's history, should health care professionals incorporate questions about all aspects of the medicine wheel—including mental health, emotional health, and spiritual attitudes—in addition to asking about physical well-being? As a patient, would you welcome this more holistic approach?
5. Look through the photographs on the *Explore Big Horn Medicine Wheel* website [see [EXTRA! Links](#) below]. How does the Big Horn stone medicine wheel in Wyoming relate to the one discussed by author Ann Dapice? Does the medicine wheel philosophy benefit from having a physical representation or tie to a specific place?

EXTRA! Reading

- Jordan Pascale, "Alternative Methods Still Important to Native Healers," *Native Daughters* website, a project of University of Nebraska-Lincoln, exploring the historical, political, and cultural roles of Native American women. Article discusses historical and contemporary intersections between traditional tribal healing practices and Western medicine. Pascale notes: "Today, after generations of drastic and cultural changes, many Native Americans face epidemics of diabetes, alcoholism, and obesity. But some are countering the devastating health problems by merging the old ways with the new." Article also includes short videos of Rose Mesteth (Oglala Lakota) discussing the use of plants in American Indian healing traditions. [See [EXTRA! Links](#) below for additional resources from this website.]
<http://cojmc.unl.edu/nativedaughters/healers/alternative-methods-still-important-to-native-healers>
- Kelly Crow, "The New Medicine Men," *Oklahoma Today*, May/June 1999. Article discusses Oklahoma health care professionals of American Indian descent who are blending cutting-edge technology and research with ancient Native traditions and philosophy to provide better health care outcomes. Article quote from Dr. Everett Rhoades, the first Native American to oversee the Indian Health Service: "Physicians are taught to concentrate on abnormal physiology so much that we've nearly forgotten that wellness is more than an absence of illness; in reality, it's a tangible harmony in yourself."
<http://digital.library.okstate.edu/oktoday/1990s/1999/oktdv49n4.pdf#page=52>
- "Sacred Landscape," Program 203, *Wisdom of the Elders* website: Read the transcript and listen to audio of an August 2010 interview by Judy Bluehorse Skeleton (Nez Perce/Chickasaw/Cherokee) with Black Hills

(continued)

herbalists Marie Randall and Annie White Hat of the Teton Sioux. The women discuss the use of plants as part of their traditional knowledge and Native healing practices. Excerpt: "Over the past 200 years, the loss of traditional foods and medicines has had a devastating effect on the health of Native Americans across the continent. Many tribes are working to restore and protect their hunting, fishing and gathering places. As they restore their traditions, they regain their health." Transcript and audio (6:29 minutes): <http://wisdomoftheelders.org/2011/08/01/program-203-sacred-landscape>

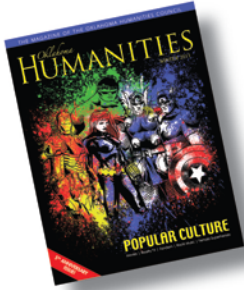
EXTRA! Links

- *Explore Big Horn Medicine Wheel*, website from Solar Observatories Group, Stanford University: Learn about stone medicine wheels and how they have been used by American Indian tribes to mark seasons and chart the stars. Site includes a virtual tour of the Big Horn Medicine Wheel in Wyoming, photos, activities, and more. <http://solar-center.stanford.edu/AO/bighorn-medwheel.html>
- "The Medicine Wheel," a three-part video series discussing historical interpretations and modern applications of the Lakota (Sioux) medicine wheel. Historical American Indian photographs are featured. Narrated by Dr. Donald K. Warne (Oglala Lakota), North Dakota State University.
 - Part 1: Video excerpt: "A difference between modern medicine and traditional medicine is that [in American Indian traditions] the person takes an active role in their own healing process by working with the medicine man; whereas, in modern medicine many people believe it is the doctor's responsibility to make them well." YouTube video (9:20 minutes): <http://www.youtube.com/watch?v=fIgrFHy463g>
 - Part 2: Discusses the four aspects of the medicine wheel, how they are interrelated, and how imbalances in one or more areas are manifested. Mentions Black Elk, the Oglala Lakota shaman and healer who survived the 1890 Wounded Knee Massacre, and his assertion that the Sacred Hoop (medicine wheel) was broken that day. YouTube video (8:47 minutes): <http://www.youtube.com/watch?v=tK-RdmQwlvI>
 - Part 3: Video excerpt: "The elders tell us to keep harmony within nature and within ourselves. The medicine wheel gives us directions for attaining this balance." Discusses how aspects of the medicine wheel influence human relationships. YouTube video (8:39 minutes): <http://www.youtube.com/watch?v=3HF1UBY2vjQ>
- *Native Daughters*, a website project of University of Nebraska-Lincoln: Download the *Native Daughters* Curriculum Guide and see pages 24-26 for lesson plans, resources, and links, including a *USA Today* article and video, "Native American Doctors Blend Modern Care, Medicine Men," by Felicia Fonseca and Heather Clark, Associated Press, September 2010. <http://cojmc.unl.edu/nativedaughters> [Click on Curriculum Guide in the right-hand corner of the website to download a pdf.]
- National Cancer Institute:
 - "An American Indian Physician: Dr. Judith Kaur, Warrior in the Fight Against Cancer," *Lifeline* video series. Dr. Kaur (Choctaw/Cherokee) discusses the misconceptions about American Indian health she encountered in medical school and her work through the Mayo Clinic to help the American Indian/Alaskan Native communities. "The emphasis is on health and wellness, not disease and dying," she says. "It's about finding that balance." YouTube video (6:32 minutes): <http://www.youtube.com/watch?v=xytz7uQFalo>
 - "Connecting Complementary and Alternative Medicine (CAM) and Traditional Native American Healing Practices," *Lifeline* video series. Dr. Jeffrey Henderson of the Black Hills Center for American Indian Health and Dr. Jeffrey White of the National Cancer Institute discuss cancer research, integrating complementary and alternative medicine in the Native American community, and how communication and cooperation are important for practitioners and patients. YouTube video (3:48 minutes): <http://www.youtube.com/watch?v=kN2NIIIE9VLg>

(continued)

- “Talking about Complementary and Alternative Medicine with Health Care Providers: A Workbook and Tips.” You can download and print this 15-page booklet, which has suggestions on talking with your doctor about complementary and alternative medicine (CAM), worksheets and diary pages to record your results, a glossary of CAM terms, and a list of CAM resources.
http://cam.cancer.gov/talking_about_cam.html?cid=ARcam_camnews

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EXTRA!

End-of-Life Decisions: Exercising Your Right to Choose

By Philip J. Rettig | Fall 2013 | Vol. 6, Issue No. 3

For Discussion

1. Under what circumstances would you *not* want to have life-support or cardiopulmonary resuscitation (CPR)? Would you want to have artificial feeding (via feeding tube or intravenously) withheld or withdrawn if you were in a persistent vegetative state with no realistic hope of ever “waking up”? If you were in the terminal stage of a fatal illness? If you suffered from advanced Alzheimer’s disease?
2. Which family member or trusted friend would you want to make decisions about your medical care if you were incapacitated?
3. Could you be an effective proxy for someone else if you had no knowledge of the person’s wishes when it came to end-of-life decisions?
4. Scholars who study ethics say there is no difference between *withholding* therapy and *withdrawing* therapy. Do you agree? If you were the health care proxy, would either choice be easier to make on behalf of an incapacitated patient?
5. What role do you think courts should have in deciding limits on end-of-life care?

EXTRA! Definition: Palliative Care

From the National Consensus Project for Quality Palliative Care, 2013: The definition of palliative care in the United States described by both the U.S. Department of Health and Human Services (HHS) Centers for Medicare & Medicaid Services (CMS) and the National Quality Forum (NQF) states:

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

EXTRA! Reading

- Thanh Huynh, et al, “[The Frequency and Cost of Treatment Perceived to be Futile in Critical Care](#),” *JAMA Internal Medicine*, published online September 9, 2013 (downloaded from <http://archinte.jamanetwork.com> on 09/18/2013). A short report on a study of critical care. Edited synopsis: “Physicians frequently perceive that they are providing futile treatment, and the cost is substantial. In the United States, critical care accounts

(continued)

for 20% of all health costs and 1% of the gross domestic product. Treatment that cannot achieve a patient's goals or that simply maintains a state such as ICU dependence or permanent coma is contrary to professional values, inappropriately uses health care resources, and creates moral distress. Nonetheless, the determination of futility is often value laden. Identifying and quantitating ICU treatment that is perceived as futile is a first step toward refocusing care on treatments that are more likely to benefit patients."

- Robert D. Truog and Douglas B. White, "[Futile Treatments in Intensive Care Units](#)," *JAMA Internal Medicine*, published online September 9, 2013 (downloaded from <http://archinte.jamanetwork.com> on 09/18/2013). JAMA Invited Commentary on the above article by Huynh, et al. These authors caution: "Making assessments about potentially inappropriate care is complex and requires multiple perspectives."
- Michael Ollove, "Oklahoma's 'Life-Preserving' Law Raises Questions for Doctors," *Stateline*, a nonpartisan, nonprofit news service of the Pew Charitable Trust, May 16, 2013. Article discusses new Oklahoma legislation whereby patients cannot be denied life-preserving treatments that they or their proxies request. <http://www.pewstates.org/projects/stateline/headlines/oklahomas-life-preserving-law-raises-questions-for-doctors-85899476549>
- Atul Gawande, "Letting Go," *The New Yorker*, August 2, 2010. In this lengthy article, Gawande asks, "What should medicine do when it can't save your life?" He discusses the soaring costs of health care as a threat to U.S. financial solvency and the ethical questions (like quality of life versus length of life) that arise with advancing science. http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande
- George J. Annas, "'Culture of Life' Politics at the Bedside—The Case of Terri Schiavo," *The New England Journal of Medicine*, Vol. 352, April 21, 2005. *NEJM* synopsis: "The parents of Terri Schiavo, a Florida woman who was in a persistent vegetative state, objected to her husband's decision to discontinue artificial nutrition, and a protracted legal battle ensued. The Florida courts ordered the removal of Schiavo's feeding tube to provide care consistent with her wishes. The judicial decisions in the Schiavo case were consistent with legal precedent, but the interference in the case by the legislative and executive branches of the Florida and U.S. governments was unprecedented." [Editor's note: As of September 2013, a Google search found pdfs of the article posted on a few university websites.]

EXTRA! Links

- From the American Medical Association:
 - *Principles of Medical Ethics* – Nine principles that define honorable behavior for a physician. <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page>
 - *Ethics Timeline* – Highlights major AMA decisions on issues such as: calling for increased representation among women and minority physicians; ensuring adequate protection of individuals used in human experimentation; opposing sex discrimination in medical institutions; and endorsing hospice care for the terminally ill. Go to <http://www.ama-assn.org> and click through the following path: About AMA » Our History » History of AMA Ethics » Ethics Timeline
- Oklahoma Palliative Care Resource Center, hosted by The University of Oklahoma College of Medicine, Department of Family and Preventive Medicine: Find articles, FAQs on advanced care planning, downloadable advance directive forms, and a comprehensive list of resource organizations. <http://www.oumedicine.com/familymedicine/oklahoma-palliative-care-resource-center/advance-directives>
- Senior Law Resource Center: Offers videos and line-by-line written guides on filling out the Oklahoma Advance Directive form, a video on end-of-life care and planning, information on durable powers of attorney, and helpful forms for collecting information. <http://www.senior-law.org>
- American Hospice Foundation: Under the "Advanced Care Planning" tab, link to "Medical Issues to be Considered in Advance Care Planning," an article by Cheryl Arenella that defines key medical terms and treatments that come to bear in advance planning and end-of-life care decisions. <https://www.americanhospice.org>
- Caring Connections: A program of the National Hospice and Palliative Care Organization, a national initiative to improve end-of-life care. Find free resources on caregiving, grief support, how to talk to physicians, pain management, locating hospice and long-term care, advance planning and documents, and a glossary of terms.

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The site has an informative brochure, "[Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-Of-Life Care](#)," that discusses: definitions of end-of-life and palliative care; the evolution of end-of-life care in the U.S. and how the Quinlan, Cruzan, and Schiavo cases helped shape public opinion and government policy; national efforts to improve care and increase awareness; and a timeline of pivotal events in the history of end-of-life care in America. <http://www.caringinfo.org>

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Original Investigation

The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care

Thanh N. Huynh, MD, MSHS; Eric C. Kleeerup, MD; Joshua F. Wiley, MA; Terrance D. Savitsky, MBA, MA, PhD; Diana Guse, MD; Bryan J. Garber, MD; Neil S. Wenger, MD, MPH

IMPORTANCE Physicians often perceive as futile intensive care interventions that prolong life without achieving an effect that the patient can appreciate as a benefit. The prevalence and cost of critical care perceived to be futile have not been prospectively quantified.

OBJECTIVE To quantify the prevalence and cost of treatment perceived to be futile in adult critical care.

DESIGN, SETTING, AND PARTICIPANTS To develop a common definition of futile care, we convened a focus group of clinicians who care for critically ill patients. On a daily basis for 3 months, we surveyed critical care specialists in 5 intensive care units (ICUs) at an academic health care system to identify patients whom the physicians believed were receiving futile treatment. Using a multivariate model, we identified patient and clinician characteristics associated with patients perceived to be receiving futile treatment. We estimated the total cost of futile treatment by summing the charges of each day of receiving perceived futile treatment and converting to costs.

MAIN OUTCOME AND MEASURE Prevalence of patients perceived to be receiving futile treatment.

RESULTS During a 3-month period, there were 6916 assessments by 36 critical care specialists of 1136 patients. Of these patients, 904 (80%) were never perceived to be receiving futile treatment, 98 (8.6%) were perceived as receiving probably futile treatment, 123 (11%) were perceived as receiving futile treatment, and 11 (1%) were perceived as receiving futile treatment only on the day they transitioned to palliative care. The patients with futile treatment assessments received 464 days of treatment perceived to be futile in critical care (range, 1-58 days), accounting for 6.7% of all assessed patient days in the 5 ICUs studied. Eighty-four of the 123 patients perceived as receiving futile treatment died before hospital discharge and 20 within 6 months of ICU care (6-month mortality rate of 85%), with survivors remaining in severely compromised health states. The cost of futile treatment in critical care was estimated at \$2.6 million.

CONCLUSIONS AND RELEVANCE In 1 health system, treatment in critical care that is perceived to be futile is common and the cost is substantial.

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← Invited Commentary

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Author Affiliations: Division of Pulmonary and Critical Care Medicine, Department of Medicine, David Geffen School of Medicine, University of California Los Angeles (Huynh, Kleeerup); Institute for Digital Research and Education, Department of Psychology, University of California Los Angeles (Wiley); RAND Health, Santa Monica, California (Savitsky, Wenger); Department of Medicine, David Geffen School of Medicine, University of California Los Angeles (Guse, Garber); Division of General Internal Medicine and Health Services Research, Department of Medicine, David Geffen School of Medicine, University of California Los Angeles (Wenger).

Corresponding Author: Thanh N. Huynh, MD, MSHS, Department of Medicine, Division of Pulmonary and Critical Care Medicine, Box 951690, 37-131 CHS, Los Angeles, CA 90095-1690 (thuyh@mednet.ucla.edu).

Advances in medicine enable critical care specialists to save lives as well as prolong dying. An admission to the intensive care unit (ICU) should be considered a therapeutic trial—aggressive critical care should transition to palliative care once it is clear that the treatment will not achieve an acceptable health state for the patient.^{1,2} However, intensive care interventions often sustain life under circumstances that will not achieve an outcome that patients can meaningfully appreciate. Such treatments are often perceived to be “futile” by health care providers.³ A survey of ICU physicians in Canada found that as many as 87% believed that futile treatment had been provided in their ICU in the past year.³ In a single-day cross-sectional study performed in Europe, 27% of ICU clinicians believed that they provided “inappropriate” care to at least 1 patient, and most of the inappropriate care was deemed such because it was excessive.⁴

In the United States, critical care accounts for 20% of all health costs and 1% of the gross national domestic product.^{5,6} Because approximately 20% of deaths in the United States occur during or shortly after a stay in the ICU, critical care is scrutinized for the provision of potentially futile resource-intensive treatment.^{2,7-9} However, information is lacking on the prospective identification of patients who are perceived as receiving futile treatment, factors associated with these perceptions, and the outcomes and costs of the care.

Treatment that cannot achieve a patient's goals or that simply maintains a state such as ICU dependence or permanent coma is contrary to professional values, inappropriately uses health care resources, and creates moral distress.^{3,10,11} Nonetheless, the determination of futility is often value laden. We convened a focus group of critical care physicians to establish reasons why treatment might be considered futile. Using these reasons, we surveyed critical care physicians daily during a 3-month period to identify patients whom they perceived to be receiving futile treatment.

Methods

The University of California Los Angeles (UCLA) institutional review board approved the study.

Focus Group

In a focus group, 13 physicians who care for critically ill patients discussed whether and how they provided treatment that they perceived as futile. Two clinicians (T.N.H. and N.S.W.) led the discussion, using open-ended questions. The group consisted of 3 surgeons, 1 anesthesiologist, 1 cardiologist, and 8 pulmonary critical care physicians. Participants were asked to describe patients for whom they had provided ICU treatment that they judged to be futile. They were asked what made them view the treatment as futile, how a case perceived to be futile differed from other cases, and when in the course of treatment they recognized the treatment as futile. Participants were asked to voice agreement or disagreement with whether they perceived specific treatments as futile and to classify the reason for treatment futility. Audiotapes of the discussion were

transcribed. When there was consensus, categories of futile treatment were identified.

Survey Instrument

On the basis of the discussion, we developed a questionnaire to identify patients whom physicians perceived as receiving futile treatment in critical care. For each ICU patient under the physician's care, a brief paper-and-pencil questionnaire asked whether the patient was receiving futile treatment, receiving probably futile treatment, or not receiving futile treatment. For patients judged to be receiving futile treatment, the physician was asked to select the reason(s) that the treatment was perceived to be futile from among the reasons derived from the focus group: burdens grossly outweigh benefits, patient will never survive outside an ICU, patient is permanently unconscious, treatment cannot achieve the patient's goals, or death is imminent. Physicians also could write in a reason. The questionnaire was piloted for 1 week to test ease of administration, wording, and content. On the basis of the pilot, an additional reason was added to identify patients who received futile treatment on the day that they transitioned to comfort care.

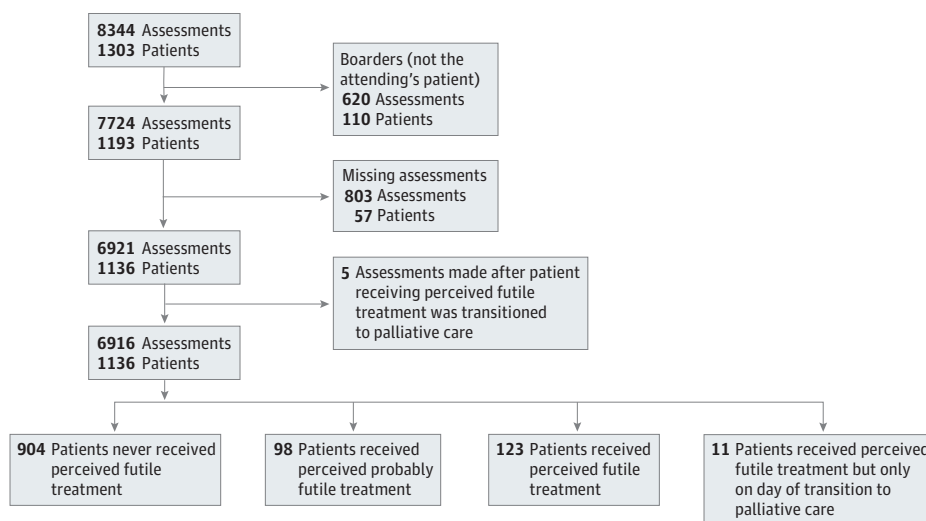
Administration of the Questionnaire

Every day from December 15, 2011, through March 15, 2012, 2 research assistants administered the questionnaire to each attending critical care specialist providing treatment in 5 ICUs in the health system: medical ICU (MICU), neurocritical care unit, cardiac care unit, cardiothoracic ICU, and an academic community hospital mixed-use ICU. The first 4 ICUs are located in 1 quaternary care hospital of an academic medical center. A fifth adult ICU (liver transplant ICU) at the hospital declined to participate. Each day, the research assistant prepopulated patients into the questionnaire for each ICU and approached the critical care physician for an assessment on each patient. Physicians provided assessments only for patients for whom they were responsible for direct patient care (patients “boarding” in the ICU were excluded). Clinicians provided informed consent and completed a questionnaire that asked about demographic characteristics and clinical experience. Patient and physician identifiers were removed before data were stored on encrypted drives.

Data Sources and Statistical Analysis

Patient demographic characteristics including age, sex, ethnicity and race, insurance, and zip code (used to compute distance from the hospital); source of admission; and Medicare Severity Diagnosis-Related Group (MS-DRG) weight were obtained from the hospital. Sources of admission included emergency department, outpatient setting, skilled nursing facility (SNF), long-term acute care (LTAC) facility, and transfer from an outside hospital (usually for a higher level of care). Distance from residence to the hospital was dichotomized at 20 miles (32 km). The MS-DRG weights, determined on the basis of the patients' diagnoses and the resources required during their hospitalization, were used as a measure of severity of illness. We subtracted the date of hospital admission from the date of the physician assessment to create the day of each physician assessment. Clinician characteristics including sex, race,

Figure. Patients and Assessments Included in the Study



and age were obtained from a questionnaire. Hospital and 6-month mortality rate were obtained from electronic medical records and publicly available death records.

Patients were categorized into 3 groups: patients for whom treatment was never perceived as futile, patients with at least 1 assessment that treatment was probably futile but no assessments of futile treatment, and patients with at least 1 assessment of futile treatment. Patients who were assessed as receiving futile treatment only on the day that they transitioned to comfort care were excluded from analysis. Hospital and 6-month mortality rate for the 3 patient groups were compared using analysis of variance. Bivariate differences between the 3 patient groups were evaluated for patient characteristics, ICU unit, and day of assessment using χ^2 tests and *t* tests, as appropriate. Analyses were performed using STATA software, version 12 (StataCorp).

We performed multivariate analysis with the assessment as the analytic unit using a multilevel ordered probit linear mixed effects model that included patient and clinician characteristics. The ordered probit mixed effects model assumes approximately equal effects of the predictors on moving from nonfutile to probably futile treatment and on moving from probably futile to futile treatment. Two sensitivity analyses were conducted by comparing nonfutile treatment assessments with combined probably futile and futile treatment assessments and comparing combined nonfutile and probably futile treatment assessments with futile treatment assessments, which suggested that the proportional hazards assumption was met. Because each assessment was cross-classified by patient and physician, random intercepts for both patients and physicians were included. Models were estimated using the MCMCglmm function in R, version 2.15.2 (R Foundation for Statistical Computing). An additional sensitivity analysis was conducted by using a multivariate 2-outcome model comparing nonfutile treatment assessments with combined probably futile and futile treatment assessments. We examined how accurately the model classified futile treatment assessments

by comparing the actual assessment with the predicted assessment with the highest probability. We present the average marginal change in a patient's probability of receiving each type of assessment for a 1-unit change in the predictor.

Cost Analyses

Daily and admission charges were obtained from the hospital financial decision support office. To evaluate the total charges for perceived futile treatment, we summed charges for each day that the patient was perceived to receive futile treatment and subsequent unassessed days until the end of the hospitalization (or 3 months after study conclusion, whichever came first). Charges for subsequent unassessed days were only included in the total charges if care on the last day that an assessment was made was perceived as futile. Cost was estimated using the most recent publicly available institution-specific cost-to-charge ratio.¹²

Results

During the 3-month study period, 36 critical care clinicians in 5 ICUs provided care to 1193 patients; these physicians did not treat 110 ICU "boarders." Eight hundred three assessments were not obtained because physicians were too busy or unavailable, resulting in 57 patients with no assessments (4.8%). Of 6921 daily assessments, 5 were omitted from analysis because they were made after a patient was transitioned to palliative care, leaving 6916 assessments of 1136 patients. Of these 1136 patients, physicians perceived that 904 never received futile treatment (80%), 98 received probably futile treatment (8.6%), and 123 received futile treatment (11%) (Figure). Eleven patients (1%) (who had 19 assessments) were perceived to have received futile treatment only on the day they were transitioned to comfort care. The resulting analytic sample includes 6897 assessments of 1125 patients. The 904 patients who received no futile treatment were assessed on 4487 days. The

Table 1. Description of All Intensive Care Unit (ICU) Patients Admitted During a 3-Month Period and Receipt of Perceived Futile Treatment^a

Characteristic	Never Received Futile Treatment (n = 904)	Received Probably Futile Treatment (n = 98)	P Value ^b	Received Futile Treatment (n = 123)	P Value ^b
Sex, No. (%)					
Male	486 (54)	58 (59)	.31	75 (61)	.13
Female	418 (46)	40 (41)		48 (39)	
Age, median (range), y	63 (15-98)	67 (21-99)	.009	67 (17-99)	.007
Race, No. (%)					
White	678 (75)	74 (67)	.91	87 (71)	.31
Asian	73 (8)	6 (6)		12 (10)	
Black	85 (9)	12 (12)		17 (14)	
Other	68 (8)	6 (6)		7 (6)	
Ethnicity, No. (%)					
Hispanic	155 (17)	17 (17)	.96	17 (14)	.35
Non-Hispanic	749 (83)	81 (83)		106 (86)	
Insurance, No. (%)					
Medicare	352 (39)	44 (45)	.25	52 (42)	.48
Medicaid	90 (10)	9 (9)	.85	15 (12)	.44
Private	117 (13)	13 (13)	.93	14 (11)	.63
HMO	291 (32)	26 (27)	.25	41 (33)	.80
Uninsured	54 (6)	6 (6)	.95	1 (1)	.02
Residence >20 miles (32 km) from hospital, No. (%)	395 (44)	47 (48)	.42	49 (40)	.42
Source of admission, No. (%)					
Outpatient setting	263 (29)	8 (8)	<.001	13 (11)	<.001
Transferred from outside hospital	89 (10)	16 (16)	.047	23 (19)	.003
Transferred from SNF/LTAC facility	21 (2)	8 (8)	.001	12 (10)	<.001
Emergency department	531 (59)	66 (67)	.10	75 (61)	.64
MS-DRG weight, median (range) ^{c,d}	2.6 (0.6-24.3)	4.7 (0.7-18)	.001	4.1 (0.8-18)	.003
Hospital length of stay, ^d median (range), d	8 (1-303)	18 (1-193)	<.001	15 (1-111) ^e	<.001
Type of ICU in which patient was evaluated, No. (%)					
Medical ICU	148 (16)	37 (38)	<.001	45 (37)	<.001
Neurocritical care unit	214 (23)	22 (22)	.79	27 (22)	.67
Cardiac care unit	127 (14)	5 (5)	.01	6 (5)	.004
Cardiothoracic ICU	231 (26)	10 (10)	.001	11 (9)	<.001
Academic community hospital mixed-use ICU	184 (20)	24 (24)	.34	34 (28)	.06

Abbreviations: HMO, health maintenance organization; LTAC, long-term acute care; MS-DRG, Medicare Severity Diagnosis-Related Group; SNF, skilled nursing facility.

^a Table excludes 11 patients who were assessed as receiving futile treatment only on the day of transition to palliative care.

^b Compared with patients who never received futile treatment.

^c Determined by MS-DRG and how many resources were required to treat that patient during that hospitalization.

^d Across all hospitalizations.

^e Because 1 patient was still hospitalized at the end of the study, n = 122.

98 patients who received probably futile treatment had 806 assessments of nonfutile treatment and 277 assessments of probably futile treatment. For the 123 patients who received futile treatment, there were 493 assessments of nonfutile treatment (37%), 370 assessments of probably futile treatment (28%), and 464 assessments of treatment perceived as futile (35%) (range, 1-58 days). Assessments of futile treatment accounted for 6.7% of all assessments.

Reasons Treatment Was Perceived as Futile

The most common reason treatment was perceived as futile was that the burdens grossly outweighed the benefits (58%). This reason was followed by treatment could never reach the patient's goals (51%), death was imminent (37%), and the patient would never be able to survive outside an ICU (36%).

Thirty percent of the patients were permanently unconscious. In 1 case, the patient had repeatedly required ICU admission for fluid overload because of extraordinary nonadherence to a regimen of diuretics and fluid restriction. Physicians usually perceived that a patient was receiving futile treatment for multiple reasons (eTable 1 in Supplement). For example, 8 patients had the following 4 reasons in combination: they were permanently unconscious, treatment could not achieve the patient's goals, burdens grossly outweighed benefits, and death was imminent.

Patient and Clinician Factors Related to Perceptions of Futile Treatment

The 1125 patients had a mean age of 62 years, 55% were male, 75% were white, and 17% were of Hispanic ethnicity. In bivar-

Table 2. Estimated Average Marginal Difference in Percent Probability of a Patient Being Perceived as Receiving No Futile Treatment, Probably Futile Treatment, and Futile Treatment

Characteristic	Mean (95% CI), % ^a			P Value
	No Futile Treatment	Probably Futile Treatment	Futile Treatment	
Patient sex				
Male	Ref	Ref	Ref	.02
Female	4.10 (0.22 to 7.58)	-1.60 (-2.92 to -0.05)	-2.50 (-4.64 to -0.13)	
Patient age, per decade	-2.57 (-3.84 to -1.31)	1.00 (0.51 to 1.51)	1.57 (0.79 to 2.35)	<.001
Patient race				
White	Ref	Ref	Ref	.94
Asian	0.16 (-6.30 to 7.10)	-0.15 (-2.62 to 2.61)	-0.01 (-4.00 to 4.12)	
African American	-6.06 (-13.03 to 0.24)	2.04 (-0.06 to 4.00)	4.02 (-0.26 to 9.00)	
Other	1.59 (-6.09 to 8.64)	-0.72 (-3.81 to 2.15)	-0.86 (-5.00 to 3.73)	
Patient ethnicity				
Non-Hispanic	Ref	Ref	Ref	.79
Hispanic	0.65 (-4.59 to 5.77)	-0.29 (-2.25 to 1.80)	-0.36 (-3.43 to 2.89)	
Insurance				
Medicare	Ref	Ref	Ref	.09
Medicaid	-6.42 (-14.36 to 1.21)	2.18 (-0.34 to 4.56)	4.24 (-0.76 to 9.86)	
Private	-3.45 (-10.54 to 3.01)	1.17 (-1.25 to 3.34)	2.28 (-2.03 to 6.96)	
HMO	-2.29 (-6.93 to 2.35)	0.85 (-0.94 to 2.52)	1.44 (-1.46 to 4.37)	
Uninsured	3.21 (-6.15 to 11.55)	-1.48 (-5.20 to 2.32)	-1.72 (-6.28 to 3.70)	
Patient residence >20 miles (32 km) from hospital	-1.81 (-6.22 to 2.12)	0.70 (-0.79 to 2.42)	1.11 (-1.32 to 3.83)	.41
Source of admission				
Emergency department	Ref	Ref	Ref	.01
Outpatient setting	5.87 (1.50 to 10.10)	-2.53 (-4.51 to -0.59)	-3.34 (-5.75 to -1.02)	
Transferred from outside hospital	-2.40 (-7.93 to 3.00)	0.86 (-1.17 to 2.78)	1.55 (-1.76 to 5.26)	
Transferred from SNF/LTAC facility	-15.07 (-23.83 to -7.26)	4.43 (2.42 to 6.38)	10.64 (4.61 to 17.38)	
MS-DRG weight	-0.05 (-0.33 to 0.26)	0.02 (-0.10 to 0.13)	0.03 (-0.16 to 0.20)	.77
Hospital day of futility assessment, weeks	-1.99 (-2.36 to -1.60)	0.78 (0.60 to 0.94)	1.21 (0.99 to 1.45)	<.001
Physician sex				
Male	Ref	Ref	Ref	.11
Female	-4.64 (-10.43 to 1.22)	1.75 (-0.44 to 3.90)	2.89 (-0.70 to 6.71)	
Physician age, per decade	-1.01 (-4.09 to 1.89)	0.39 (-0.77 to 1.57)	0.61 (-1.18 to 2.46)	.50
Physician race				
White	Ref	Ref	Ref	.28
Asian	2.83 (-2.73 to 7.91)	-1.12 (-3.16 to 1.03)	-1.71 (-4.76 to 1.71)	
Other	2.28 (-7.51 to 10.90)	-1.12 (-4.83 to 2.91)	-1.16 (-5.79 to 4.82)	
ICU type				
Medical ICU	Ref	Ref	Ref	.32
Neurocritical care unit	5.83 (-5.60 to 16.40)	-2.41 (-6.54 to 2.04)	-3.43 (-9.97 to 3.52)	
Cardiac care unit	14.15 (10.03 to 17.76)	-7.16 (-9.27 to -4.86)	-6.99 (-8.69 to -5.19)	
Cardiothoracic ICU	10.78 (4.25 to 16.65)	-4.99 (-8.17 to -2.01)	-5.80 (-9.00 to -2.73)	
Academic community hospital mixed-use ICU	0.62 (-4.43 to 5.42)	-0.27 (-2.23 to 1.61)	-0.35 (-3.26 to 2.77)	

Abbreviations: HMO, health maintenance organization; ICU, intensive care unit; LTAC, long-term acute care; MS-DRG, Medicare Severity Diagnosis-Related Group; ref, referent; SNF, skilled nursing facility.

^aQuantities greater than zero indicate a greater probability compared with the reference group.

iate comparisons, compared with patients who were never perceived as receiving futile treatment, patients perceived as receiving probably futile treatment and futile treatment were older; had higher MS-DRG weights; had longer lengths of stay; were more likely to be admitted from an outside hospital, SNF, or LTAC facility; and were more likely to have received care in

the MICU (Table 1). There were no differences by sex, race, ethnicity, or distance from the hospital.

The multilevel multivariate probit ordinal model (Table 2) correctly classified 91% of futility group assessments. Age was the strongest patient predictor; for each decade increase in age, the mean probability for patients to be perceived as receiving

Table 3. Survival During Hospitalization and up to 6 Months After Intensive Care Unit (ICU) Care

Patient Group	Death, No. (%) (N = 1136)	
	In-Hospital	Within 6 mo of ICU Care
Never received futile treatment (n = 904)	42 (4.6)	66 (7.3)
Received probably futile treatment (n = 98)	23 (23)	33 (34)
Received futile treatment (n = 123)	84 (68)	104 (85)
Futile treatment only on day transi- tioned to palliative care (n = 11)	9 (82)	11 (100)

futile treatment increased by 1.6% (95% CI, 0.79%-2.4%). The mean probability for females to be perceived as receiving futile treatment was 2.5% (95% CI, 0.13%-4.6%) lower than for males. There was no significant difference by race, Hispanic ethnicity, insurance, or MS-DRG weight. Compared with patients admitted from the emergency department, patients transferred from an SNF or LTAC facility were significantly more likely to be perceived as receiving futile treatment. No physician descriptor was a significant predictor of the perception of futile treatment, although patients treated in the MICU were significantly more likely to be perceived as receiving futile treatment than patients in the cardiac care unit or cardiothoracic ICU. Patient and physician random effects were both statistically significant, but the variation accounted for by patient factors was 10 times greater (patient factors, $\sigma^2 = 6.22$; physician factors, $\sigma^2 = 0.54$). Parameter estimates are provided in eTable 2 (in Supplement). The sensitivity analyses of the 2-outcome models did not significantly change the results (data not shown).

Patient Outcomes

As expected, the hospital and 6-month mortality rates were significantly higher for patients perceived as receiving futile and probably futile treatment compared with patients perceived as receiving no futile treatment ($P < .001$) (Table 3). Eighty-four of the 123 patients who were perceived as receiving futile treatment (68%) died before hospital discharge, and another 20 died within 6 months of ICU care (6-month mortality rate of 85%). Two patients were referred to hospice and lost to follow-up. One patient remains hospitalized, dependent on life-sustaining treatments. The remaining 16 patients perceived to have received futile treatment were discharged or transferred in severely compromised health states, with 10 patients placed in an LTAC facility maintained on life-sustaining treatment (Table 4).

Cost of Futile Treatment in the ICU

The mean cost for 1 day of treatment in the ICU that was perceived to be futile was \$4004. For the 123 patients categorized as receiving futile care, hospital costs (ICU and subsequent non-ICU days) for care perceived to be futile totaled \$2.6 million. The \$2.6 million cost of perceived futile care was 3.5% of the total hospital costs for the 1136 patients in the study.

Table 4. Outcome of Patients Who Were Perceived as Receiving Futile Treatment

Outcome	No. (n = 123)
Died	
During hospitalization	84
After hospital discharge and within 6 mo of intensive care unit stay	20
Total	104
Discharged home	
With hospice care, lost to follow-up	2
End-stage liver disease, not transplant candidate, flown internationally to die in patient's home country	1
Total	3
Discharged to long-term acute care hospital	
Severe cognitive impairment, bedridden, requiring mechanical ventilation and tube feeding	5
End-stage dementia, requiring tube feeding	2
Amyotrophic lateral sclerosis, unable to communicate, requiring mechanical ventilation and tube feeding	1
Anoxic brain injury, no meaningful communication, bedridden, requiring tube feeding	1
Persistent vegetative state, requiring mechanical ventilation	1
Total	10
Discharged to skilled nursing facility	
Severe cognitive impairment, bedridden, requiring tube feeding	2
Chronic disease, bedridden, requiring hemodialysis	1
Untreatable malignant neoplasm, bedridden	1
Total	4
Transferred to another hospital	
Extensive cancer refractory to chemotherapy, multiorgan failure	1
Total	1
Remained hospitalized	
Bedridden; nonresponsive; requiring mechanical ventilation, hemodialysis, and tube feeding	1
Total	1

Discussion

We prospectively identified patients perceived as receiving futile treatment in critical care to avoid post hoc bias in labeling patients receiving treatments that were only later judged to be inappropriate.^{13,14} In the critical care units that we studied, we found that treatment that is perceived by physicians to be futile is common: more than 1 in 10 patients received such treatment during their ICU stay. The outcomes of these patients were uniformly poor; two-thirds died during the hospitalization and 85% died within 6 months. "Survivors" of treatment perceived to be futile were often discharged in severely compromised health states that some might perceive to be worse than death, such as being permanently severely neurologically compromised and dependent on life-sustaining machines.¹⁵

The cost of perceived futile treatment, although sizeable, accounted for only a small percentage of critical care expenditures at the health system during the study period. Some have postulated an unclear economic impact of decreasing futile

treatment^{16,17}; beds freed up by avoiding futile treatment for 1 patient might be used to provide needed critical care to another patient, as well as other expensive treatments such as organ transplants. Luce and Rubenfeld¹⁷ argued that a reduction in critical care utilization at the end of life would not yield significant cost savings because the number of patients is small and the majority of ICU costs are fixed. Our findings show the substantial cost of perceived futile treatment in critical care.

Our multivariate model provides some insight into which patients were more likely to be perceived as receiving futile treatment. Physicians were more likely to assess patients admitted from an SNF or LTAC facility as receiving futile treatment, suggesting that patients whose health was already sufficiently compromised that they required nursing care were less likely to benefit from critical care. Perceived futile treatment was more common in the MICU. In our institution, patients admitted to the MICU are more likely to have complex medical problems not limited to 1 organ system or amenable to surgical correction (as in specialty ICUs). It is also common for patients not responding to critical care to be transferred to the MICU from other critical care units.

Our study has several limitations. We studied a single health system where resource-intensive treatment is known to be provided¹⁸; it is unclear whether our findings can be generalized. Also, 1 of the ICUs declined to participate. The responsible critical care physician designated futile treatment. There were no objective criteria; it is likely that the families of many patients would not have agreed with the physician's assessment. We quantitated only the frequency and economic costs of treatment perceived to be futile, whereas the

burdens to patients, families, and clinicians also deserve attention. The high mortality rate and severely compromised health states of patients assessed as receiving futile treatment provide our findings with some face validity. However, ratings of futile treatment may result in less aggressive treatment, thus yielding a self-fulfilling prophecy.¹⁹ Ratings of futile treatment inherently include subjective judgments, but the vast majority did include an objective outcome (eg, permanent coma) or a clinical assessment (eg, chance of survival or chance of improving to leave the ICU).

Another limitation is that the multivariate model showed that physician random effects were a significant predictor of futile treatment assessment, after patient characteristics were controlled for. These physician factors could not be identified in the present study and should be further explored. Patient factors, however, were much more strongly associated with assessments of perceived futile treatment than physician factors. Finally, because critical care physicians defined futile treatment, the findings raise the question of why they provided such care. Reasons might include lack of agreement by the family, lack of agreement within the clinical team, or a failure to address end-of-life issues. We were unable to characterize the reasons that treatment perceived as futile was provided.

In summary, in our health system, critical care physicians frequently perceive that they are providing futile treatment, and the cost is substantial. Identifying and quantitating ICU treatment that is perceived as futile is a first step toward refocusing care on treatments that are more likely to benefit patients.

ARTICLE INFORMATION

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Study concept and design: Huynh, Kleerup, Wenger.

Acquisition of data: Huynh, Guse, Wenger.

Analysis and interpretation of data: Huynh, Kleerup, Wiley, Savitsky, Garber, Wenger.

Drafting of the manuscript: Huynh, Kleerup, Wiley, Savitsky, Guse.

Critical revision of the manuscript for important intellectual content: Huynh, Kleerup, Savitsky, Garber, Wenger.

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Invited Commentary

Futile Treatments in Intensive Care Units

Robert D. Truog, MD; Douglas B. White, MD, MAS

The provision of treatments that are perceived to be futile is a major problem in the intensive care unit (ICU), leading to burdens for patients and families, as well as moral distress for caregivers. In this issue of *JAMA Internal Medicine*, Huynh and



Related article

colleagues¹ report on the perceptions of intensive care physicians about treatment perceived to be futile in 5 intensive care units at an academic health care system. They found that the physicians perceived that the treatment that they are providing is futile or probably futile up to 20% of the time. During a 3-month period, the cost of treatment perceived to be futile was estimated at \$2.6 million.

We agree that the perceptions of these critical care physicians are concerning. We urge caution, however, in the interpretation and application of the findings of Huynh et al.¹ With regard to the prevalence of potentially futile treatments, for example, the data were derived from the perceptions of a single physician making a single assessment about futility on each day the patient was in the ICU. We have no idea whether other critical care physicians would have agreed with this assessment, whether other physicians (eg, surgeons, subspecialists) would have concurred with this determination, what opinions other clinicians on the team (eg, nurses, social workers) held about the situation, or—most importantly—the views of the patient and family themselves. This mode of assessment stands in sharp contrast to current recommendations that futility assessments be based on an inclusive process that incorporates the perspectives of all stakeholders.²

With regard to cost, the authors estimated that the cost of the treatment that was perceived to be futile (ICU and subsequent non-ICU days) represented 3.5% of total hospital costs for the patients in the study. The relevant question, however, is how much money would be saved if these treatments were not provided. Others have shown, for example, that roughly 85% of the costs associated with ICU care are fixed costs that cannot be eliminated unless critical care beds are closed.³ On the basis of such findings, the true savings of not providing life-prolonging treatment to the patients in the study by Huynh et al¹ who were perceived as receiving futile care are almost certainly less than the amount calculated by the authors. These more modest potential savings should be compared with other potential targets for cost savings (eg, excessive imaging, laboratory testing, prescribing) before the decision is made to prioritize the elimination of potentially futile treatments. Such assessments are controversial and often have divisive effects on clinicians, patients, and families.

We offer 4 suggestions for how clinicians in critical care units should conceptualize and respond to requests for treatment that they judge to be futile or wrong. First, we believe that clinicians should generally avoid using the term *futile* to describe such treatment and instead use the term

potentially inappropriate. It is exceedingly rare for surrogates in ICUs to request treatments that are strictly futile (ie, stand *no chance* of achieving their intended goal). Instead, disputes generally arise from requests for treatments that stand at least some chance of accomplishing the patient's goal but for which the clinician believes that there are competing ethical considerations that may justify treatment refusal, such as the low likelihood of benefit or the high cost.

Second, from an ethical and legal standpoint, these disputes are often more complicated than they seem. Although in some cases clinicians may believe strongly that it would be wrong to administer the requested treatments, there is ongoing debate about the boundaries of acceptable practice near the end of life. Short of brain death, there are no criteria or rules to which clinicians can appeal to justify decisions to refuse life support, at least when those treatments hold even a small chance of achieving the patient's goals. Even within the medical profession, clinicians vary substantially in their attitudes and practices regarding what sorts of treatments should be provided near the end of life.⁴

An added ethical complexity in critical care is that incapacitated, critically ill patients are vulnerable in different ways than patients in other settings. For example, many critically ill patients are unable to speak for themselves, have no choice regarding who will treat them, and, because of their overwhelming illness, have limited ability to seek out alternative physicians. In contrast, in ambulatory practice and many other medical settings, patients have greater latitude in finding and choosing physicians who are willing to support their preferences.

Third, clinicians' initial response to requests for treatments that they believe are wrong should be to increase communication with the patient or the patient's surrogate rather than simply to refuse the request. Clinicians should provide emotional support, discuss the patient's prognosis, elicit the patient's values and preferences, explain principles of surrogate decision making, and discuss which treatment options fit with the patient's goals, including the option of a treatment plan focused on palliation. Clinicians should strive to understand the surrogate's perspective and to find a mutually agreeable treatment plan. Clinicians should also consider early involvement of expert consultants, such as palliative care clinicians, ethics consultants, or other individuals with expertise in conflict resolution. An important goal is to intervene early, before conflicts become entrenched and intractable. Empirical research suggests that the vast majority of disagreements can be resolved collaboratively through ongoing dialogue⁵ or with the help of expert consultants, such as ethics or palliative care clinicians.⁶

Fourth, if the conflict becomes intractable despite intensive communication, clinicians should pursue a fair process of dispute resolution rather than refusing unilaterally to

provide treatment. Clinicians also should not simply acquiesce to requests for treatments that they judge to be inappropriate and inconsistent with good medical practice. We agree with recommendations from the American Medical Association and the Society of Critical Care Medicine that a formal, stepwise approach be pursued to resolve conflicts.^{2,7} Important components of a fair process include seeking a second opinion from a qualified physician, case review by the hospital ethics committee, attempts to transfer the patient to another institution when such a transfer might be

appropriate, and informing surrogates of their right to seek judicial intervention.

In sum, although we fully agree with Huynh and colleagues¹ about the importance of treatment perceived to be futile in critical care, we urge caution in the way that their data are applied to understanding the prevalence and financial impact of such treatments. Making assessments about potentially inappropriate care is complex and requires multiple perspectives. When disputes arise despite sustained efforts to prevent them, a stepwise procedural approach to resolving conflicts is essential.

ARTICLE INFORMATION

Author Affiliations: Department of Global Health and Social Medicine, Harvard Medical School, Boston, Massachusetts (Truog); Department of Anaesthesia, Harvard Medical School, Boston, Massachusetts (Truog); Program on Ethics and Decision Making in Critical Illness, Department of Critical Care Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania (White).

Corresponding Author: Robert D. Truog, MD, Social Medicine and Anaesthesia, Harvard Medical School, 641 Huntington Ave, Boston, MA 02115 (robert.truog@childrens.harvard.edu).

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Caring Connections

Private Conversations and Public Discourse

THE IMPORTANCE OF CONSUMER ENGAGEMENT
IN END-OF-LIFE CARE



“MANKIND’S GREATEST GIFT, ALSO ITS GREATEST CURSE, IS THAT WE HAVE FREE CHOICE. WE CAN MAKE OUR CHOICES BUILT FROM LOVE OR FROM FEAR.”

ELISABETH KÜBLER-ROSS
ON DEATH AND DYING

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FOREWORD

In *Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care*, the National Hospice and Palliative Care Organization (NHPCO) interweaves the stories of Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo with the 40-year history of the end-of-life care movement in the United States. These three poignant stories exemplify the difficult issues that many patients and their families face when making decisions about care at the end of life.

These stories also underscore the chilling fact that, despite advances in medical care, many Americans still suffer from unnecessary pain, discomfort and inadequate care at the end of life. For almost two decades, the Robert Wood Johnson Foundation helped lead a national movement to improve end-of-life care in the United States. We supported a three-pronged strategy to change patients' and their families' experiences at the end of life by helping to 1) educate and empower patients, families and caregivers; 2) train nurses, doctors and other health care providers to deliver better end-of-life and palliative care; and 3) make higher quality end-of-life care available in health care institutions.

During that time, end-of-life care in the United States improved substantially and became part of the health care mainstream. Patients and their families now have more and better information to help them manage care at the end of life, including the Five Wishes living will. Palliative care has also improved, in both extent and quality—offering better pain management and support options for patients at any age and any stage of their illness, and their families.

We take pride in knowing that we've helped build the end-of-life and palliative care fields, and we are pleased that the National Hospice and Palliative Care Organization is continuing to lead and mobilize the movement for improved care at the end of life. As this important report explains so convincingly, still more work is necessary to meet the physical, emotional and spiritual needs of patients and their families. And I hope that other individuals and organizations will recognize this truth and join together to help ensure that patients and families facing the end of life are able to experience the best care and greatest compassion that we can offer. They deserve nothing less.



RISA LAVIZZO-MOUREY, MD
PRESIDENT & CEO
ROBERT WOOD JOHNSON FOUNDATION

INTRODUCTION

Everyone dies. It is inevitable. Yet talking about this experience, shared by all humankind, is often difficult. Patients, families and health care professionals alike hesitate to discuss dying and death. The reasons for avoiding the conversations are numerous and complex.

Americans are notoriously adept at denying death's inevitability. As members of a culture where youthfulness is accentuated, Americans have not been schooled in discussing issues associated with advanced illness, dying and grief.

Further, in some pockets of American cultures, merely talking about dying invites death to visit a patient or his/her family. Others may view discussions about dying as a sign of disrespect or insensitivity. And the historical pattern of health care inequities in the US complicates end-of-life care.

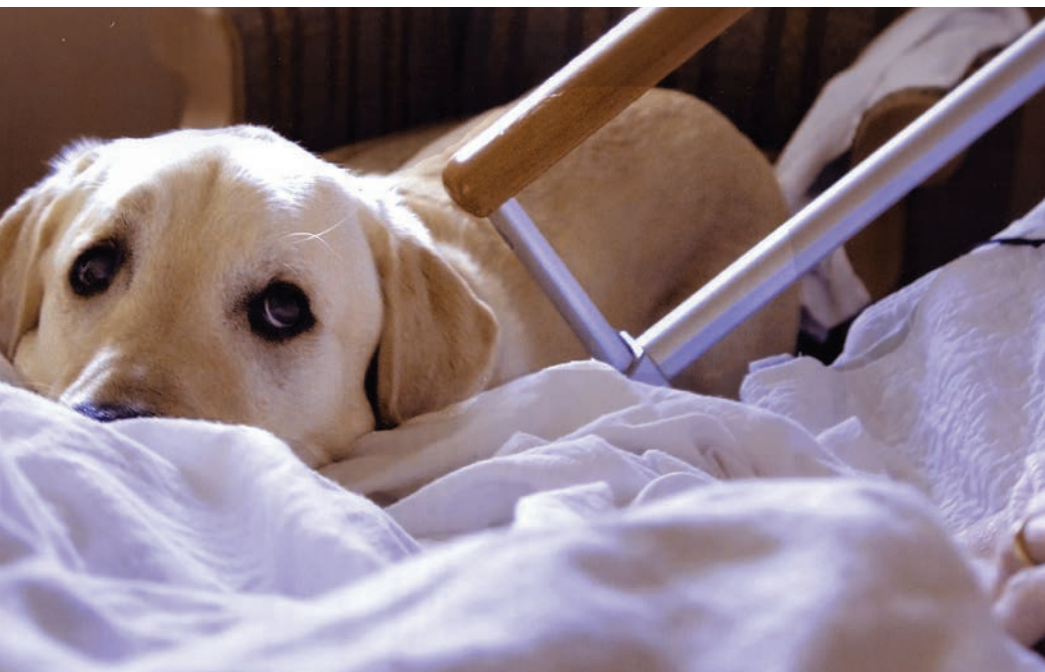
This discomfort—whether experienced as part of national consciousness or as a specific cultural norm—thwarts conversations between family members and between patients and clinicians about a person's wishes at the end of life. And it is exacerbated by the complex and somewhat fragmented culture of medicine in the U.S.

In the 1950s and 60s, when medical technology seemed to be breaking new barriers every day to save and extend lives, life extension “at all costs” became an accepted norm of medical practice. As an unintended consequence, the needs of the dying were often ignored.

Generations of physicians have been taught to see death as the enemy, as something not to surrender to, no matter what. With an ever-expanding arsenal of tests and treatments at their disposal, physicians walk a fine line between “not giving up on their

patients” and providing futile care. Many patients and their caregivers still rely on their doctors to decide what treatments to try and when, if ever, to acknowledge that the end of life is near. When clinicians stay unwaveringly intent on life-extending treatment, their conversations don't transition to ones that focus on “quality of life”—the very things that allow a patient with advanced illness to enjoy what life has to offer, whether it be spending time with family and friends, decreasing pain, or receiving needed emotional and spiritual support.

Advances have occurred over the past 40 years, as a growing group of consumers, health care providers, social change leaders, politicians, insurers, philanthropists and the media has worked to change public perceptions about dying and to improve the care and quality of life for those facing advanced illness, death and grief. This report explores many of these consumer engagement and public awareness efforts. Despite this progress, however, much



GENERATIONS OF PHYSICIANS HAVE BEEN TAUGHT TO SEE DEATH AS THE ENEMY, AS SOMETHING NOT TO SURRENDER TO, NO MATTER WHAT.

more work is needed to assure that all Americans are able to reliably receive high-quality care, in accordance with their preferences, as they confront illness and the end of life.

THE NEED FOR CHANGE

The convergence of several variables demands renewed attention to the quest to inform and engage consumers in end of life issues: the graying of America, continued lack of understanding of patient preferences at life's end, and a changing political climate in relation to health care.

Today, seven out of 10 Americans die from chronic disease. Data on the number of Americans living with advanced illness and needing care is also staggering—and will continue to confound health care delivery in the foreseeable future. Over the next 25 years, the number of Americans living with a chronic illness is expected to double with the aging of the baby boomers. By 2020, the number of people living with at least one chronic illness will increase to 157 million. Half of Americans still die in hospitals, despite numerous studies revealing a preference for dying at home.

The impact of these demographic statistics grows exponentially when caregivers are considered. One American in five provides care for another adult, often a family member. There are currently an estimated 44 million caregivers in the United

States—and, according to the U.S. Census Bureau, that number is expected to surge as today's baby boomers age. Studies show that caregivers are less healthy than those not involved in caring for others, and are at risk for compromising their own physical, psychological, spiritual and financial wellbeing.

The Agency for Healthcare Research and Quality (AHRQ) *Research in Action Issue 12: Advance Care Planning Preferences for Care at the End of Life* synthesized findings from AHRQ-sponsored studies on advance care planning in March 2003. Highlights of AHRQ research as quoted from the Research in Action website reveal that:

- Less than 50 percent of the severely or terminally ill patients studied had an advance directive in their medical record.
- Only 12 percent of patients with an advance directive had received input from their physician in its development.
- Between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.
- Language in advance directives was usually too nonspecific and general to provide clear instruction.
- Surrogates named in the advance directive often were not present to make decisions or were too emotionally overwhelmed to offer guidance.

These statistics are not just numbers; they represent real people

whose lives—and deaths—are impacted by the hard choices they make with loved ones and with their clinicians about their care. The heartbreaking stories of Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo exemplify the difficult issues that patients and families face when confronting illness and making decisions about care. We present their stories—and the importance of open dialogue on end-of-life issues—in this report.

The data compellingly suggests that in contemporary American society, issues surrounding death and dying are public health issues, requiring public response. Public discourse is often contentious as our nation grapples with topics such as the right to die and physician-aided suicide. This was obvious in the 1970s, 1980s and 1990s with the Quinlan, Cruzan and Schiavo cases. And the 'death panel' discussion that erupted in 2009 and 2010 preceding the passage of the Patient Protection and Affordable Care Act is evidence of how confusing our national dialogue on end-of-life issues remains.

The pervasive denial of death, combined with baby boomer demographics and ongoing changes as America's health care reform unfolds, means that the task of improving care for those in the last years of life remains one of society's biggest challenges. Renewed efforts need to be undertaken that normalize conversations, raise awareness and change behavior.

This report provides a retrospective glance at 40 years of public engagement in end-of-life issues and highlights these key points:

- In each decade, there have been individuals and situations that have elevated end-of-life issues to the forefront of popular culture and national attention.
- There is a common thread of responsibility—societal and individual—that runs through each decade.
- There is consensus among those working on these issues that

society has not yet reached the “tipping point” where attention to the final phase of life has become an integral part of all health care planning and decision-making in this country.

This report is a call to action, a rallying cry that encourages—and provides a framework for—a national agenda for consumer engagement in end-of-life issues. The information in this report is designed to serve as a catalyst for more individuals and organizations to assume the mantle

of responsibility for improving the way society cares for people in the final months and years of life.





END-OF-LIFE CARE EXTENDS BEYOND THE DEATH OF A LOVED ONE, AS FAMILY AND FRIENDS WORK THROUGH THE GRIEVING PROCESS.

WHAT IS END-OF-LIFE CARE?

As the nation's oldest and largest organization focused exclusively on end-of-life care, the National Hospice and Palliative Care Organization (NHPCO) in its efforts to lead and mobilize social change for improved care at the end of life, defines "end-of-life care" as:

Encompassing the interdisciplinary care and supportive services provided to seriously ill people and their family caregivers focused on alleviating suffering, facilitating end-of-life wishes, training family caregivers and providing support to the bereaved.

End-of-life care is a component of palliative care. NHPCO's Standards of Practice for Hospice Programs describe palliative care as:

Treatment that enhances comfort and improves the quality of an individual's life during the last phase of life. No specific therapy is excluded from consideration. The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual's needs must continue to be assessed and all treatment options explored and evaluated in the context of an individual's values and symptoms. The individual's choices

and decisions regarding care are paramount and must be followed.

In the United States, hospice and palliative care are recognized as the "gold standard" in the provision of end-of-life care. End-of-life care also extends beyond the death of a loved one, as family and friends work through the grieving process.

NO SINGLE LABEL FOR END-OF-LIFE CARE

End-of-life care isn't one single thing. It's offered by many types of providers, and it's offered in many different settings. The provision of end-of-life care varies and can "look" very different in communities across the country. In Florida, a person might receive services from a PACE program (Program for All-Inclusive Care for the Elderly) that is run by a hospice while, in another state, a person may find 25 hospices that all provide essentially the same services. Some hospitals have thriving palliative care teams or their own hospice

programs, while others discharge patients without any discussion about hospice or palliative care. Still other hospitals—and some hospices—have robust pediatric palliative care programs, while others have no staff formally trained to address the unique needs of dying children and their family caregivers. Care in skilled nursing facilities can also vary—one facility may have contracts with several local hospice and palliative care providers while another in the same community may rely solely on its own staff to serve dying residents.

“Where” end-of-life care is provided also varies, depending on the place the person calls “home.” For example, care might be provided in a patient’s or family member’s home, in a hospital or nursing home, in a VA or correctional facility, in a hospice residential facility, or for the homeless person, on the street or in a shelter.

ADVANCE CARE PLANNING

Yet, to adequately understand end-of-life care, one must look beyond the process of dying and include the process of identifying, discussing and documenting wishes for care during the last days, weeks or months of life. Ideally this process of advance care planning happens throughout a lifetime so that, in the event of a medical crisis, family caregivers and physicians can ensure that wishes are honored.

OVER THE NEXT 25 YEARS, THE NUMBER OF AMERICANS LIVING WITH A CHRONIC ILLNESS IS EXPECTED TO DOUBLE.

THE EVOLUTION OF END-OF-LIFE CARE IN THE UNITED STATES

Attention to end of life in the US began in the early 1970s when a group of committed individuals organized to start the nation’s first hospice. The Connecticut Hospice opened its doors in 1974, just seven years after Dame Cicely Saunders founded the first modern hospice outside of London. Since then, the growth of the hospice and palliative care movement has been unprecedented. Passage of the Medicare Hospice Benefit in 1982 as part of the Tax Equity and Fiscal Responsibility Act solidified the role of hospice as a provider of

end-of-life care; there are now more than 4,800 hospices providing care to an estimated 1.45 million patients annually. In 2006, the American Board of Medical Specialties approved subspecialty status for hospice and palliative medicine. 2009 data shows more than 2,800 physicians, 11,200 nurses and almost 400 nurse practitioners are now board certified in palliative care.

The SUPPORT study fueled the field of end-of-life care, prompting new research and spawning new programs that sought to improve

information on what patients and their families value when confronting advanced illness. The graphic on the following page illustrates the evolution of efforts within the context of important consumer/community engagement initiatives. Please visit www.nhpco.org to view a timeline that touches on factors in the past 40-plus years that have influenced public perception of end-of-life care. View an in-depth timeline of sentinel events from the 1970s through 2010 that have influenced public perceptions of end-of-life care in the Appendix of this report on page 34.

AVERAGE LENGTH OF SERVICE HAS DECREASED

The average number of days of care—or average length of service—for hospice patients decreased from 69.5 days in 2008 to 69.0 in 2009. While many patients receive hospice care for months approximately 34.4% of hospice patients received care for seven days or less—often an insufficient time for patients and families to benefit from the full scope of medical and psychosocial services that hospice care offers.

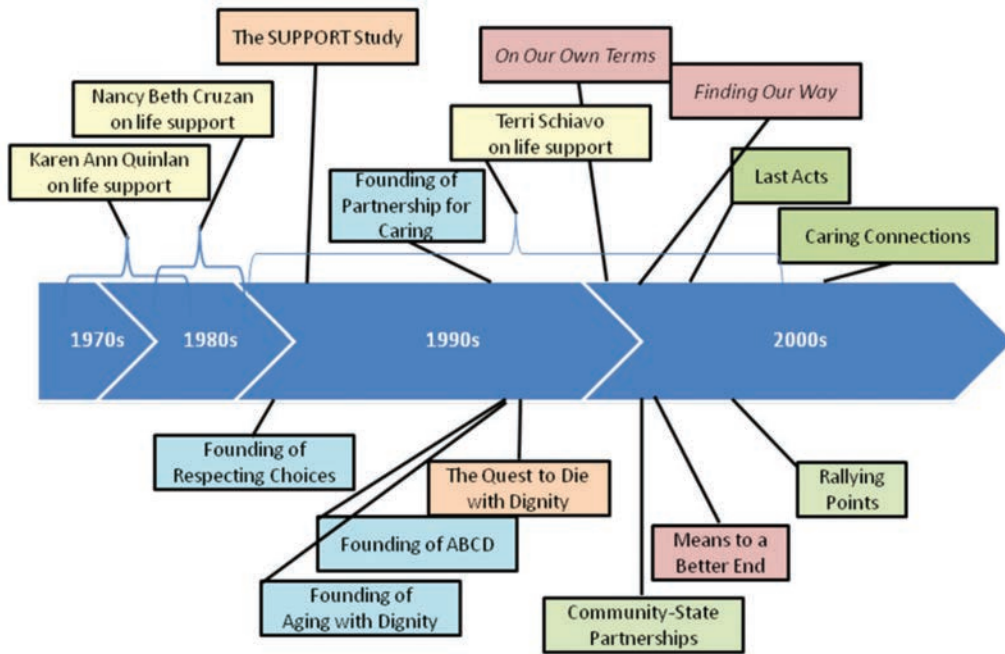
AGE AND GENDER

In 2009, people age 75 and older accounted for 53.8 percent of hospice patients. Overall, more women received care than men, with women accounting for 56.6 percent of patients. As the U.S. population ages, the number of Americans receiving hospice care will also increase.

TOP FIVE DIAGNOSES

It was once true that hospices served cancer patients almost exclusively—but those days are long since passed. Hospice is reaching out to care for people with a broader range of diagnoses, as NHPCO 2009 data show:

PRIMARY DIAGNOSIS	% OF HOSPICE PATIENTS
Cancer	40.1 percent
Debility Unspecified.....	13.1 percent
Heart Disease	11.5 percent
Dementia	11.2 percent
Lung Disease	8.2 percent



THE EVOLUTION OF END-OF-LIFE CARE IN THE UNITED STATES

- Sentinel events
- Organization
- Publication
- Research
- Grant-funded program

HOSPICE FACTS AND FIGURES

During this 40-year history, hospice has been the primary delivery mechanism for end-of-life care. As described by NHPCO's Caring Connections program, hospice care is predicated on the belief that each of us has the right to die pain-free and with grace, and that our loved ones should receive the necessary support to allow us to do so:

- Hospice focuses on caring, not curing—with care most often provided in the person's home.
- Hospice care also is provided in freestanding hospice centers, hospitals and nursing homes, and in other long-term care facilities.

- Hospice services are available to patients of any age, religion, race or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs and other managed care organizations.

NUMBER OF PATIENTS RECEIVING HOSPICE CARE IS GROWING

Between 2000 and 2009, the number of patients served by the nation's 4,800 hospices doubled. NHPCO estimates that 41.6 percent of all who die in the U.S. receive care from a hospice program.

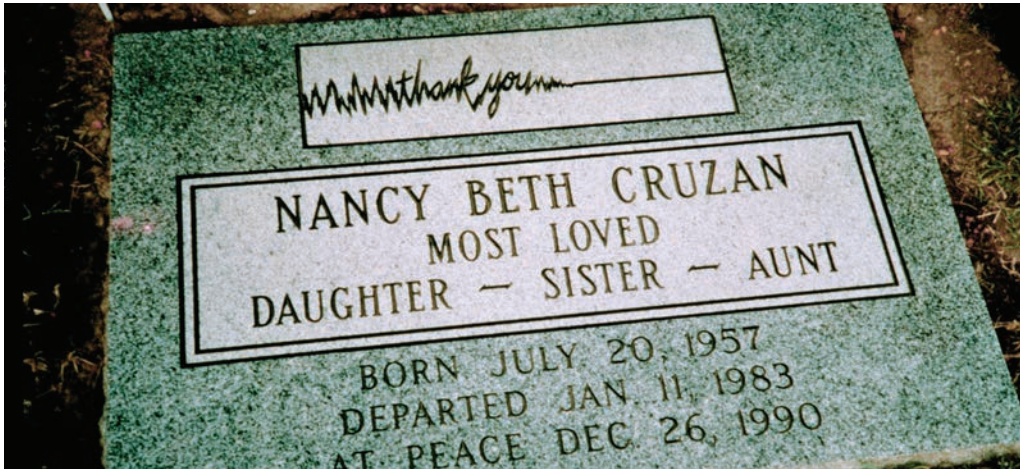
HOSPITAL-BASED PALLIATIVE CARE

In the late 1990s, leaders in the end-of-life care movement in the U.S. recognized a need to bring the best of what hospice had to offer to those who were dying in inpatient settings, giving rise to hospital-

based palliative care programs. The Center to Advance Palliative Care, (CAPC), a national organization dedicated to increasing the availability of quality palliative care services, reports that:

- The number of palliative care programs has doubled over the last six years. To date, there are approximately 1,300 hospitals with a palliative care program.
- Approximately 53 percent of all hospitals with more than 50 beds have a palliative care program.
- An estimated 58 percent of all children's hospitals have a palliative care program.

IN 1989, THE NANCY CRUZAN CASE WAS THE FIRST RIGHT-TO-DIE CASE TO REACH THE U.S. SUPREME COURT.



PUBLIC DISCOURSE ON END-OF-LIFE CARE: SHAPING OPINION, DRIVING POLICY

The growth in hospice and palliative care over the last 40 years has been punctuated with several events that highlight the need for public discourse, most notably the stories of three young women: Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo. Unwittingly, these three women were instrumental in shaping public opinion on the emotionally-charged and complex issue of the “right to die.”

As a result of their tragic deaths, they compelled our legal system to develop relevant laws to protect our rights and opened America’s eyes to the limitations of the law and the importance of documenting personal end-of-life preferences.

On the one hand, their stories are surprisingly similar. These young women were placed on artificial life support to prolong their lives

following either an accident or illness that left them permanently unconscious—or in a “persistent vegetative state.” After a period of time, each woman’s legal guardian sought to discontinue the medical intervention, engaging in legal battles to do what each felt their loved one would have wanted. What is different is the decade in which each case occurred—and the medical advancements, media

coverage and public perceptions at the time that impacted the course of the legal battles as well as each woman's final days.

1975: KAREN ANN QUINLAN

At the age of 21, Karen Ann Quinlan lost consciousness while at a party and was rushed to the emergency room of a local hospital in Newton, New Jersey. When her parents arrived on the scene, their daughter had lapsed into a coma and was placed on artificial life support—both a respirator and a nasogastric tube for artificial nutrition and hydration. After several months

unit; the 911 emergency system had been launched in 1968; and the first school program to train ambulance attendants in CPR had begun in 1969. What's more, medicine had only just named the condition to which Quinlan had fallen victim—the persistent vegetative state—in 1973.² The medical community and the American public were still very much enraptured by such advancements and wanted to do “everything possible.” No one was yet prepared to deal with the negative repercussions of these advancements.

Following a legal battle with Quinlan's physician and the state attorney general, the case was brought before

U.S. Congress established a President's Commission to examine the ethical issues arising from advancements in medicine and published two reports by 1983: *Defining Death and Deciding to Forego Life-Sustaining Treatment*. More notably, the California Legislature passed the nation's first living will law to protect a person's rights concerning his/her medical treatment. The first living will document was created in 1969 and was followed by three failed attempts to pass living will laws in Florida and California. It took the Quinlan case—and public interest in the issue—for the law to pass in California. While other states followed suit, state living

THE AMERICAN PUBLIC WANTED TO DO “EVERYTHING POSSIBLE.” NO ONE WAS PREPARED FOR THE NEGATIVE REPERCUSSIONS.

of waiting and hoping for a change in medical status, Quinlan's parents asked the hospital to turn off the respirator and allow their daughter to die in peace. The hospital refused, on the grounds that doing so was immoral. “You have to understand our position,” the hospital administrator told Quinlan's father, “in this hospital, we don't kill people.”¹

This was 1975—a time when advancements in the medical community were helping to save and extend lives. The first direct-current defibrillator had been invented in 1961, followed by the establishment of the first hospital coronary care

the New Jersey Supreme Court in 1976. The court ruled that Quinlan had a constitutional right to privacy that her father could exercise on her behalf. While the court granted him the right to discontinue all life support, Quinlan's father chose only to wean her off the respirator. To the medical community's surprise, she started breathing on her own. Quinlan lived on in a persistent vegetative state, kept alive with artificial nutrition and hydration, and died from pneumonia 10 years later.

The Quinlan case paved the way for several proactive steps in this still unfamiliar, uncharted territory. The

will laws varied in their provisions, resulting in a fragmented national ethos. In Missouri, for example, feeding tubes were excluded from medical technology considered medical treatment—the very issue that forced Nancy Cruzan's parents to wage a four-year legal battle.

1983: NANCY CRUZAN

In 1983, 25-year old Nancy Cruzan swerved off the road and was thrown from her car while en route to her parent's home in Carthage, Missouri. Paramedics found her with no vital signs, but they were

able to resuscitate her. By the time she reached the hospital, she had fallen into a deep coma. After several weeks of hospitalization, she was diagnosed, like Quinlan eight years before, as being in a persistent vegetative state. As a result of the accident, Cruzan had suffered anoxia, or lack of oxygen to the brain, that caused her bodily functions to shut down. She was placed on a respirator until hospital staff was able to get her to breathe on her own. Because she could not eat or drink, surgeons inserted a feeding tube.

For several years, her family waited in vain for any signs of recovery. Then, in 1986, they asked medical officials to remove her feeding tube after they jointly agreed that's what she would have wanted. The medical officials refused to comply unless a specific Order of the Courts of Missouri was furnished. The family's request was at odds with the Missouri living will law that had been enacted following the Quinlan case.

After battling with the medical establishment, the Cruzan case was brought before the Missouri Supreme Court in 1988. The Court found that unless Cruzan had left clear instruction or convincing evidence that she did not want a feeding tube, it could not be removed.

In 1989, the U.S. Supreme Court agreed to hear the case, marking the first right-to-die case to reach the hallowed chambers. The case generated national headlines and captured public attention for the next 18 months. On June 25, 1990, in a 5-4 decision, the Cruzan family lost the case: the federal court stated that the Missouri ruling did not violate the federal constitution and, "unless Nancy Cruzan had left clear and convincing evidence of her wish to remove the feeding tube, it had to stay in place." Ultimately, the Cruzan family prevailed when two witnesses came forward, testifying that Nancy had indeed expressed those wishes during conversations with each of them. On December 15, 1990, the tube was removed. Nancy Cruzan died 11 days later.

While the Cruzans were finishing their long journey of caring for Nancy, the ordeal of Terri Schiavo's family was just beginning.

1990: TERRI SCHIAVO

On the morning of February 25, 1990, 26-year-old Terri Schiavo collapsed in the hallway of her apartment in St. Petersburg, Florida. Her husband, Michael, dialed 911. By

the time the paramedics arrived, she was not breathing and had no pulse. They attempted to resuscitate her: she was defibrillated several times and was hospitalized, placed on a respirator and had a feeding tube inserted. The long period without oxygen led to profound brain injury that eventually, upon autopsy, was termed "anoxic-ischemic encephalopathy," a disorder characterized by a reduction in oxygen supply combined with reduced blood flow to the brain.

While Terri's medical condition turned out to be very similar to that of Nancy Cruzan's, the Schiavo family disagreed on what they perceived to be her true cognitive state and on whether she would have wanted her life prolonged through artificial means. Terri's husband believed she was in a permanent vegetative state and would not have wanted artificial means to prolong her life. Conversely, Terri's parents and siblings were convinced that she was in a "minimally conscious state" and that removing her life support was tantamount to murder. The ensuing initial legal battles between 1993 and 2000 involved the husband's role as legal guardian and his request, beginning in 1998, to remove Terri's life support.

"MAKE A LIVING WILL. TALK ABOUT IT. DEATH IS GOING TO HAPPEN TO EVERYBODY. WRITE IT DOWN. EVEN IF YOU WRITE IT ON A PIECE OF PAPER AT HOME AND HAVE YOUR FAMILY WITNESS IT, YOU NEED TO WRITE IT DOWN."

MICHAEL SCHIAVO



In 2000, the case changed dramatically when the media entered the picture: a lone reporter from the *St. Petersburg Times* was assigned to the case and seated in the courtroom. While Michael Schiavo's attorney objected to the reporter's presence, the judge ruled to permit the media coverage, absent of any case law to support doing otherwise. It is worth noting that the judge had offered an extended recess to allow both attorneys to research the issue, but both decided to proceed.³

With the advent of 24-hour cable television, the local story soon reached epic proportions, transforming a personal legal matter into national tabloid news. The coverage incited demonstrations among pro-life and disability rights activists and prompted politicians, including then-Florida Governor Jeb Bush and House Majority Leader Tom Delay,

to take unprecedented moves to pass legislation granting Terri's parents more time to argue their case.

In 2000, the judge ruled that Michael Schiavo could stop tube feeding Terri and allow her to die. Shortly after this decision, Michael had Terri moved from a nursing facility to Woodside, a residential facility operated by The Hospice of the Florida Suncoast (now Suncoast Hospice). On April 24, 2001, Terri's artificial nutrition and hydration was stopped—but not for long; Terri's parents filed a new lawsuit, leading to an emergency order to resume feeding.

In all, the Schiavo case involved 14 appeals and numerous motions, petitions and hearings in the Florida courts; five suits in federal district court; Florida legislation known as "Terri's Law" (later struck down by

the Supreme Court of Florida); and the fast-track passage of the federal law, "For the relief of the parents of Theresa Marie Schiavo," sponsored by House Majority Leader Tom Delay. Ultimately, the decision to discontinue life support fell back to the Florida courts, which ruled in favor of her husband. On March 18, 2005, Terri was disconnected from life support. She died on March 31.

During the final weeks of Schiavo's life, media attention to the story, fueled by around-the-clock protesters outside Woodside, resulted in unprecedented attention to the issue of advance care planning. During the week before Terri Schiavo's death, NHPCO received hundreds of phone calls each day – including more than 1,200 in a single day – as well as thousands of emails and web hits from people seeking advance directives."

¹ Colby, William H. (2006). *Unplugged*. New York: AMACOM. p. 97; ² *Ibid.*, p. 96; ³ *Ibid.*, p.18

NATIONAL ATTENTION TO HONORING END-OF-LIFE DECISIONS

In the early 1990s, leaders at the Robert Wood Johnson Foundation (RWJF) became alarmed that patients near the end of life were being subjected to high-tech and high-cost interventions that were ineffective and contrary to their preferences. With the goal of decreasing suffering, RWJF staff engaged leading medical researchers in the development and implementation of the *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)*. Prior to the 1995 publication of the *SUPPORT* study, research about end-of-life care preferences and treatment decisions was scarce.

The five-year study was conducted in two phases. The first phase focused on describing the prognoses and preferences of patients admitted to five major medical centers with one or more of nine life-threatening diagnoses. Phase I confirmed the hypothesis that a majority of patients received care that was ineffective and against the wishes of the patient and/or family. Phase I also revealed that physicians seldom consulted prognosis data or asked about preferences prior to determining the plan of care. Furthermore, Phase I showed that patients and their families were ill-equipped to understand their options or to

articulate their preferences. Using models for prognosis developed in Phase I, the second phase of the study evaluated the outcomes of three interventions designed to improve prognostication and communication about prognosis and preferences:

- Validated prognostic models were developed for each patient so that physicians could estimate the likelihood of severe disability or death.
- Specially-trained nurses talked with patients and their families to understand their wishes and relay them to the physicians and nurses involved in their care.
- Physicians received detailed written instructions about patients and families' wishes regarding treatment.

RWJF expected the three interventions to be effective in promoting quality of life and changing the landscape of end-of-life care in the United States. It was not to be. The interventions failed to achieve improvements in the timing of Do-Not-Resuscitate (DNR) orders; patient/family and physician agreement regarding DNR; reduction of time spent in the intensive care unit or on a ventilator; and pain management or resource use for patients with advanced illness.

However, the study was highly successful in illuminating the need for changes in social and professional norms and priorities. The results of *SUPPORT* raised the salience of end-of-life care issues among health care providers, employers and funders and catalyzed more than a decade of initiatives to improve end-of-life care.

These initiatives took many different forms, capitalizing on existing leverage points and approaching improvement from several angles.

The overarching goals were to:

- Understand consumer concerns and increase awareness of options for care and control;
- Build a supportive environment—legally and culturally—for patient-focused, value-directed care;
- Increase clinical capacity for quality end-of-life care (e.g., train more clinicians to address the unique clinical and non-clinical issues of care at the end of life); and
- Develop successful models for delivery of high quality end-of-life care.

Many of the initiatives focused directly on consumer outreach, education and/or engagement, while others included consumer-directed components.



AMERICANS FROM DIVERSE BACKGROUNDS SAY THEY WANT THE SAME THING: A HUMANE, COMPASSIONATE PROCESS FOR DYING.



LEARNING WHAT CONSUMERS WANT AND NEED

The *Quest to Die with Dignity: an Analysis of Americans' Values, Opinions and Attitudes Concerning End-of-Life Care* was funded by RWJF and published in 1997. Researchers gathered information via focus groups involving 385 people who were not necessarily sick or dying and follow-up interviews with people who were terminally ill or had experienced the recent death of a loved one. The report's authors commented on the "remarkable degree" to which participants of different ages, races and cultural backgrounds shared the same opinions, values, fears, beliefs and hopes about end-of-life care and dying. Focus group participants:

- Feared they would die connected to tubes and machines, in direct contrast to their desire for a natural death, surrounded by family or loved ones;
- Had little or no confidence that the current health care system

- could or would support them in dying how they wished;
- Believed that planning for their care at the end of life was important, but they preferred to avoid talking about it;
- Did not "want to be a burden"—family concerns drove their decisions about care at the end of life.

The report concluded that, "Americans from diverse backgrounds say they want the same thing: a humane, compassionate process for dying that allows them as much control as possible over what happens at the end of their lives."

From the *Quest to Die with Dignity* study came 10 suggestions for improving the process of dying in America. Seven of these addressed advance care planning, recommending:

- Increased public dialogue to motivate advance care planning;
- Facilitation of communication between physicians and consum-

- ers to improve the doctor-patient relationship and develop a shared language for discussions;
- Provision of information to help consumers make more responsible care decisions;
- Development of better advance directive documents that address the range of options consumers may face when dying;
- Physician training to acknowledge and act on wishes expressed by family members;
- Possible use of incentives, such as lower insurance premiums, to motivate more Americans to put their wishes into writing;
- Respect for cultural and religious values and practices surrounding death and dying.

Many consumer outreach initiatives developed in subsequent years addressed these suggestions.



PARTICIPANTS FEARED THEY WOULD DIE CONNECTED TO TUBES AND MACHINES, IN CONTRAST TO THEIR DESIRE FOR A NATURAL DEATH, SURROUNDED BY FAMILY OR LOVED ONES.



“THE ULTIMATE LESSON ALL OF US HAVE TO LEARN IS UNCONDITIONAL LOVE, WHICH INCLUDES NOT ONLY OTHERS, BUT OURSELVES AS WELL. ”

ELISABETH KÜBLER-ROSS
ON DEATH AND DYING

CONSUMER OUTREACH, EDUCATION AND ENGAGEMENT

Some of the earliest efforts to empower consumers to shape and demand better end-of-life care started at the national level. Americans for Better Care of the Dying (ABCD) was founded as an independent non-profit “consumer membership” organization in 1997 in Washington, D.C. with a goal of assuring quality end-of-life care.

The organization aimed to build momentum for reform; explore new methods and systems for delivering care; and shape public policy through evidence-based understanding. ABCD recruited consumers to join a grassroots effort to improve care by bringing pressure on policymakers and health care provider organizations. Leaders of the organization also published a consumer guide to end-of-life issues, *A Handbook for Mortals*. Ultimately, the organization struggled to obtain adequate financial support from

consumer members and other funders and, as a result, the ABCD board of directors closed the organization in 2007.

In 1998, Partnership for Caring: America’s Voices for the Dying (PFC) was founded in Washington, D.C. PFC evolved from an organization called “Choice in Dying” and focused on facilitating advance care planning through completion of living wills and/or health care surrogate designations. The partnership brought together representatives of organizations and initiatives across the country. Of particular note was the partnership with the American Bar Association’s (ABA) Committee on Elder Affairs. With ABA’s help, PFC published a yearly summary of state legislation affecting advance care planning and ranked each state’s efforts based on how well the laws supported consumer choice and delivery of preference-based health care.

In April 1999, RWJF established a national program office at PFC for its national initiative, Last Acts. The Last Acts initiative brought together a national-level coalition of more than 800 health and consumer groups to (1) improve communication and decision-making for consumers about their own deaths, (2) change the culture of health care institutions and (3) change American culture and attitudes toward death. In an effort to ensure the sustainability of Last Acts at the conclusion of RWJF’s funding commitment, PFC and Last Acts became the Last Acts Partnership. When the organization closed in 2004, the majority of its assets were acquired by the National Hospice and Palliative Care Organization (NHPCO) and, with funding from RWJF, Caring Connections was born.

One of the most visible Last Acts initiatives was the report, Means



IN 2004, WITH
FUNDING FROM
THE ROBERT
WOOD JOHNSON
FOUNDATION,
*CARING
CONNECTIONS*
WAS BORN.

to a Better End (MTBE), which was published in November 2002. Designed to “...spark public discussion about the state of dying in America...”, the report rated 50 states and the District of Columbia on eight criteria affecting end-of-life care and showed that, for the most part, care was mediocre. It also highlighted the lack of data available on other criteria that significantly affect access to quality care for the dying.

By profiling end-of-life care strengths and weaknesses, the MTBE report provided both the impetus and a framework for improvement. In addition, it was unique in targeting

designed to help people articulate their preferences for end-of-life care in the context of five specific elements of care – health care decisions, medical treatment, physical comfort, social interactions and messages to family. The popular Five Wishes document, which meets the legal requirements for living wills in 42 states, is now available in 23 languages, with more than 12 million copies in circulation across the nation.

While the national campaigns and initiatives brought together key partners and crafted consistent messages for consumers, health care is controlled primarily at the state

private partnerships composed of providers, academic institutions, insurers and policy makers in 23 states from 1999-2003. The program had four primary goals: to remove barriers to good end-of-life care; to develop policies and implement practices that promote excellence; to create public understanding about care choices; and to monitor the impact of these efforts.

Nearly all the projects that received funding from CSP engaged their communities or states through focus groups, forums, community discussions and surveys. The most successful projects focused on community education of target

HEALTH CARE IS CONTROLLED PRIMARILY AT THE STATE LEVEL AND ULTIMATELY DELIVERED AT THE LOCAL LEVEL.

a public rather than professional audience. The breadth of coverage about MTBE in national publications and newspapers suggests that it helped raise public awareness about the salient issues surrounding end-of-life care.

Aging with Dignity also formed in the late 1990s, with the primary purpose to “affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life.” In 1997, the organization published the Five Wishes living will, the first “user-friendly” living will

level and ultimately delivered at the local level. Consequently, state-level initiatives began that were dedicated to reaching consumers where they live by changing social norms and public policy, as well as increasing discussions between consumers and their health care providers.

The Community State Partnerships to Improve End-of-Life Care (CSP), a national program of RWJF based at The Center for Practical Bioethics (formally the Midwest Bioethics Center) in Kansas City, Missouri, provided grant funding and technical assistance to public-

audiences that were “primed” to receive it, such as older individuals and current or future caregivers (mostly women age 40 and older). Examples of successful initiatives included:

- The Utah-based Dialogue in Action project, which brought together small groups of health care professionals and consumers to share end-of-life care experiences and discuss systematic improvement;
- Educational training on the Medicare Hospice Benefit for Minnesota-based insurance counselors; and

- Educational training on end-of-life care for all of Kansas' county agricultural agents—a central source of information in rural counties.

Many of the CSP projects discovered that local community coalitions, whose members understood the norms and values of local consumers, were essential in identifying and reaching an audience that could be engaged in change efforts. These local groups performed best when they identified with a larger effort and when they could rally around a state or national event. Events provided coalitions with a reason to meet, a focus for their work and momentum for growth, as well as credible information to share and tools for action.

Other influential activities included national media events and local

coalitions that engaged individuals in social change efforts. In September 2000, the four-part public television series, *On Our Own Terms (OOOT)*, was broadcast nationwide and examined the cultural, medical, ethical and spiritual aspects of death and dying in America. The series was directed by Bill and Judith Moyers of Public Affairs Television, Inc., and was funded by grants from RWJF, the Fetzer Institute, the Nathan Cummings Foundation, the Kohlberg Foundation, Inc., the Laurance S. Rockefeller Fund and Mutual of America Life Insurance Company. As RWJF stated in a January 1999 press release, the series was intended to show the progress and problems in delivering high-quality end-of-life care and to “give the public the language and opportunity to talk about an issue that too often remains taboo.”

In conjunction with the OOOT series, Last Acts conducted a year-long outreach campaign to connect public television stations, health care professionals and institutions, civic organizations, community-based groups and individuals and to encourage them to use this series to catalyze dialogue and community action on end-of-life issues. Local coalitions were intended to be the workhorses of the outreach and were furnished with a range of OOOT tools and materials to help: a leadership guide; community awards for public television station community outreach; a leadership-training videoconference; a discussion guide for individuals, families and groups; a website; and an electronic outreach newsletter.

In addition, a multi-faceted project, *Finding Our Way: Living with*





COMMUNITY COALITIONS WERE ESSENTIAL IN IDENTIFYING AND REACHING AN AUDIENCE THAT COULD BE ENGAGED.

Dying in America (FOW), was conducted between 2000 and 2002. It included a 15-part newspaper series, community outreach via local coalitions, and Internet-based learning. The newspaper series, published in fall of 2001, was designed to educate consumers about issues and opportunities for managing care at the end of life. The community outreach initiative, which started in the late spring of 2001 and continued into 2002, sought to increase the series' readership as well as its impact on readers. To evaluate the project, surveys and interviews were conducted to assess the project's success, access, satisfaction, outreach and impact. Newspaper editors, local end-of-life coalition leaders and readers/consumers were all included in this evaluation process.

Following these two successful local community outreach programs, RWJF announced the Rallying Points (RP) initiative. Designed as an adjunct to Last Acts and

directed by Partnership for Caring, Rallying Points aimed to mobilize improvement of end-of-life care at the grassroots community level, building on 305 local and state coalitions that had participated in OOOT outreach. The two primary goals of the RP initiative were to maximize the number of coalitions whose projects were having sustainable impact on their communities (i.e., meaningful projects) and to bring as many coalitions as possible along a trajectory of readiness to conduct similar projects.

Three regional resource centers, each with expertise in one or more areas critical to coalition function, were identified and charged with providing core technical assistance to coalitions in assigned states. Alta Consulting was engaged to develop the National Resource Center on Diversity (NRCD) that would provide information, materials and technical assistance nationally to Last Acts partners and RP coalitions.

One of the most significant conclusions that emerged from the evaluation of these earlier initiatives was the importance of utilizing both national and state-level programs and networks for stimulating and encouraging work in local communities. Projects provided individuals and coalitions with a sense of commitment and belonging to a "broader movement" and an impetus to continue in the face of challenges. For example, individuals and coalitions felt that they could learn from each other via networking and that they could gain momentum from their desire not to let "the movement" down. The sense of community generated optimism that the movement as a whole could make a difference.

CARING CONNECTIONS

These valuable insights were the impetus behind NHPCO's development of the national consumer-engagement program, Caring Connections, which RWJF funded from 2004 to 2009. Caring Connections provides free resources and information to help people make decisions about end-of-life care and services before a crisis occurs. It designs national campaigns that bring together community, state and national partners working to improve end-of-life care.

At its inception, Caring Connections re-energized coalitions that had developed as part of the Rallying Points initiative. Drawing on the lessons learned by Rallying Points that local and state-level coalitions have few resources and need help focusing on specific activities, Caring Connections improved upon traditional approaches to consumer engagement. It provided coalitions with practical strategies for fundraising and communications, detailed action plans, robust mechanisms to share their work, and opportunities to participate in national initiatives/campaigns. In designing Caring Connections,

NHPCO also took note of the challenges its predecessors faced when engaging consumers in end-of-life issues and set forth to emphasize positive messages in consumer communications about what can be done.

Caring Connections leveraged the power of multiple national voices by providing a small number of simple messages on which to focus. It capitalized on basic advertising principles that suggest that the more times people hear the same message, particularly if it comes through different media and seemingly different sources, the more likely they are to believe it and act on it.

Caring Connections is designed to be a collaborator, striving to “connect” the many organizations that offer consumer information and services with consumers who can benefit from the information. Such organizations include the National Alliance for Hispanic Health and the National Association of Social Workers, among many others. In addition, Caring Connections supports hospices and other community organizations in their outreach efforts at the local level.

In all of its collaborative work, however, the informed, engaged consumer is always at the center of the Caring Connections logic model—a model that was inspired by Liz Kirkman, a hospice volunteer who integrated her commitment to hospice and advance care planning into her daily life (see the sidebar on page 24, “The Engaged Consumer”). Thinking about Liz, Caring Connections focuses on helping consumers:

- Become aware of and connected to one or more elements of the network;
- Get desired information;
- Become prepared to deal with end-of-life experiences;
- Understand and exercise options for care at the end of life;
- Become a resource for friends and family;
- Participate in advocacy for better end-of-life care.

Caring Connections offers an array of consumer engagement programs and activities that build awareness, provide resources, prompt conversations, and improve diversity. A brief overview of Caring Connections activities follows and a detailed list of Caring Connections resources is in the addendum.



LIZ KIRKMAN: THE ENGAGED CONSUMER

Liz Kirkman, a hospice volunteer who worked at The Hospice of the Florida Suncoast (now Suncoast Hospice), was the inspiration behind the Caring Connections model of the “informed, engaged consumer.”

Liz not only volunteered with hospice patients and their families, but she also raised money for the Suncoast program, participated in the speaker’s bureau, trained her dog to be a pet therapist for hospice patients and literally carried a copy of advance directives around her neck as a way of starting conversations with people about the importance of making their wishes known. Liz wasn’t just informed about end-of-life care—she actively worked to ensure that people understood their options and the importance of planning before a crisis.

BUILDING AWARENESS

The “LIVE” Campaign and Its Partners: The *It’s About How You LIVE* community engagement campaign, developed in 2005, provides a unified message that compels consumers to take responsibility and action to improve end-of-life care. Hospices, end-of-life coalitions and other health care organizations joined the LIVE Campaign and, by 2008, 770 LIVE partners had received information, resources and/or support and facilitated dialogue in their communities about the need for improved end-of-life care.

Colby Book Tour: In 2006, Caring Connections launched a national book tour in partnership with NHPCO Senior Fellow Bill Colby, the attorney for Nancy Cruzan’s family and author of a *Long Goodbye... The Deaths of Nancy Cruzan* and *Unplugged: Reclaiming Our Right to Die*

in America. Through this tour, Colby promoted the LIVE campaign and advance care planning in 99 events nationwide—reaching over 15,000 individuals.

“THE CARING CONNECTIONS PROGRAM IS A PERFECT EXAMPLE OF THE ADAGE ‘THINK GLOBALLY, ACT LOCALLY.’ THE GRASSROOTS ENERGY FROM THIS CREATIVE, WELL-EXECUTED INITIATIVE HELPED TO SPARK TENS OF THOUSANDS OF CONVERSATIONS ACROSS THE COUNTRY—THAT, TO ME, IS RESPONSIBILITY IN ACTION.”

BILL COLBY



PROVIDING RESOURCES

Caring Connections Customer Service Center and Helpline:

A comprehensive consumer service center with a toll-free telephone HelpLine began in 2005 to respond to inquiries regarding all aspects of end-of-life care. Many consumers, like Joan in the sidebar below, also call because they are afraid or confused or simply need a compassionate, listening ear.

CARING CONNECTIONS HELPLINE: QUELLING FEAR, CLARIFYING HOSPICE

Joan is the youngest daughter in a large family. She called the Caring Connections Helpline in the spring of 2009 because she had just accompanied her father to the doctor and, during the visit, the doctor mentioned hospice. This scared her. She felt “hospice” had a negative meaning. Caring Connections staff spent 35 minutes talking with Joan, clarifying what hospice could offer, what values underlay the service, how it is paid for, and how it could help her dad and their whole family. By the end of the call, Joan was thankful for the information, and noted that it had “brought hospice into perspective” for her.

Caring Connections website:

The Caring Connections website (www.caringinfo.org) provides educational materials and offers consumers and health care professionals contact information for local hospices, as well as information on advance care planning, caregiving, serious illness and grief. More than 54 Caring Connections brochures plus advance directive forms for all 50 states and the District of Columbia can be downloaded from the site free of charge.

PROMPTING ADVANCE CARE PLANNING CONVERSATIONS

- Eleven publications covering various issues surrounding advance care planning are available through Caring Connections—plus bilingual guides in Spanish/English and Mandarin Chinese/English.
- The Advance Care Planning Awareness Ribbon was created, and a promotional campaign was launched on March 31, 2006 in honor of the one-year anniversary of Terri Schiavo’s death. The campaign encourages people to wear a white ribbon to increase awareness about end-of-life discussions and makes available for purchase the *It’s About How You LIVE* lapel pins and informational lapel-pin cards.
- Caring Connections distributes advance care planning

information and advance directive forms—and has provided over 1.3 million free advance directive forms since its inception in 2004.

- In July 2009, Google Health launched a program for users to download and store advance directive documents securely online. Google Health selected Caring Connections as the sole founding partner in this new initiative. (www.google.com/intl/en/health/advance-directive.html)
- The first annual National Healthcare Decisions Day took place on April 16, 2008 and has continued each year since. Caring Connections staff provides support for this grassroots effort and hosts the National Healthcare Decisions Day website (www.nationalhealthcaredecisionsday.org).

REDUCING DISPARITIES

Focus Groups:

Caring Connections conducted focus groups in various cities nationwide in 2006-2007 to identify areas of need in underserved populations and determine compelling messaging strategies and resources for consumer groups representing African American, Chinese American, Latino, parents of seriously ill children, parents grieving the loss of a child, and developmentally disabled individuals.

Outreach Guides:

Five outreach guides were developed to help hospices, coalitions and others seeking to expand access to end-of-life care for African Americans, Chinese and Latino populations as well as pediatric patients and those with disabilities.

Bilingual Materials:

Caring Connections developed multiple bilingual and culturally-relevant resources on a variety of end-of-life topics in Spanish/English and Mandarin Chinese/English. It also created bilingual Spanish/English educational materials specifically for parents of seriously ill children or parents of children who are grieving.

Spanish and Multilingual HelpLines:

Caring Connections developed Cuidado con Cariño, a toll-free Spanish HelpLine that offered

information and resources for people living with or caring for someone with a serious illness. With strong feedback indicating the need for translations in additional languages, the Spanish HelpLine transitioned to a “Multilingual Line,” with staff responding to calls in over 200 languages.

Pediatric Resources:

In addition to the Pediatric Outreach Guide and multilingual pediatric resources, Caring Connections collaborated to create Partnering for Children, a campaign that focuses on community engagement, creating a virtual resource library, and conducting national media outreach.

Guide providing hospices and coalitions with specific ideas and resources to reach out to faith communities. It partnered with the Duke Institute on Care at the End of Life and Project Compassion to create *The Unbroken Circle: A Toolkit for Congregations Around Illness, End of Life and Grief*.

- Caring Connections developed the *It's About How You LIVE—At Work* campaign to help employers support employees who are living with a serious illness, caregiving, or grieving. The cornerstone of the campaign is the *It's About How You LIVE—At Work: An Employer's Guide to Work-Life Programs and Policies*. The initiative also includes consumer brochures related to end-of-life issues in the workplace and a guide to help hospices reach out to local businesses.

REACHING OUT

- In 2008, Caring Connections published the *It's About How You LIVE—In Faith* Outreach



Cuidando con Cariño:
1-877-658-8896

¿Está usted cuidando a un ser querido seriamente enfermo?
¿Tiene alguna pregunta acerca de la aflicción y de dónde buscar ayuda al respecto?
¿Tiene alguna pregunta acerca de los servicios ofrecidos por los hospicios y los cuidados a los enfermos terminales?

"Cuidando con Cariño" es una Línea de Ayuda gratuita que ofrece información y recursos destinada a personas que viven o cuidan a alguien aquejado de una enfermedad severa. Nuestro personal bilingüe puede: Responder a preguntas acerca de la aflicción, cuidados, directivas anticipadas y otros temas y servicios a enfermos en fase terminal. Pueden identificarse un hospicio o programa de cuidados paliativos en su comunidad, escuchar con ánimo compasivo y de colaboración y enviar por correo postal hojas de datos y folletos.



SINCE 2004, MORE THAN 1.3 MILLION FREE ADVANCE DIRECTIVES HAVE BEEN DISTRIBUTED BY CARING CONNECTIONS.



FURTHER EDUCATION IS CRUCIAL TO IMPROVE UNDERSTANDING, ACCEPTANCE AND PRACTICE OF ADVANCE CARE PLANNING.

CONSUMER ENGAGEMENT AND HEALTH CARE REFORM

In March 2010, Congress passed H.R. 3590, the Patient Protection and Affordable Care Act, which President Obama subsequently signed into law. For more than a year, the end-of-life community was on the edge of its collective seat, watching the political process that consumed health care reform. When the dust settled, hospice advocates celebrated gains such as approval for demonstration projects to test innovative approaches for hospice patients to concurrently receive hospice and other Medicare-covered services, and provisions that allow children enrolled in Medicaid or the Children's Health Insurance Plan to receive hospice services without foregoing curative treatment related to a terminal illness. NHPCO was in the center of

discussions advocating for service delivery approaches that supported the real-life needs of patients and families. It encouraged development of "Advanced Illness Transitional Care Management and Planning" demonstrations projects, which assure that there is a seamless continuum of care and that conversations about transitioning to palliative care are explored throughout the disease trajectory.

The health care debate also revealed that many Americans feel passionate about care at the end of life. This was demonstrated by the media frenzy that resulted from an advance care planning provision in the 2009 House version of the health care reform legislation that would have reimbursed physicians

for the time they spent talking with patients about advance care planning. Social networking sites condemned federally created "death panels" and "rationed care," which quickly spread to major media outlets, the halls of Capitol Hill, and community assembly halls where the nation's legislators hosted public meetings about health care reform. It's clear from the furor that erupted over misperceptions of "death panels" with discussions about end-of-life preferences that further education is crucial to improve understanding, acceptance and practice of advance care planning as a process to determine and communicate wishes to receive or withhold life-prolonging treatments.

A CALL TO ACTION

As the new health care reform law is implemented, it's abundantly apparent that, as a nation, we must take some important steps if we are to change society's approach to serious illness, death and dying. Presented here as "needs," the following are suggested ways that individuals, communities and organizations can assume responsibility for meeting the concerns of those at the end of life:

1. Individuals need to talk about their wishes for care at the end of life with family members, friends and care providers and then document their wishes in writing to better assure that their wishes will be honored;
2. Health care providers need to initiate honest, timely and culturally-relevant discussions about the burdens and benefits of treatment options in the last stages of an illness to assist patients in making informed decisions;
3. Communities need to work together, providing care and support to seriously ill people and their family caregivers to ensure that no one dies alone or in pain;
4. Health care payors need to understand the importance of a continuum of care that would ensure that patients have access to the highest quality care regardless of where they are in the course of an illness. This continuum begins with the introduction of palliative care at the onset of advanced illness while a patient is still pursuing curative treatments to ensure that distressing symptoms and emotional care are addressed promptly, and the ratio of curative and palliative care can be adjusted throughout the illness;
5. Policy makers need to eliminate barriers that prevent timely access to hospice and palliative care;

6. Employers need to support their staff who are living with a serious illness, caring for a loved one or grieving a loss;
7. Researchers need to study end-of-life issues such as the efficacy of life-sustaining and palliative care therapies and the impact of grief on the workplace;
8. The media needs to explore ways to demystify dying and conversations about end-of-life issues in order to normalize the experience for the general public.

No single organization can fully articulate the needs of those living with, or caring for someone, with a serious illness. The needs listed above are an amalgamation of 40-plus years of working with hospices, end-of-life coalitions, funders, policy makers, regulators and individuals working to make the end-of-life experience better for those who face it today, tomorrow and in the years to come.

AS A NATION, WE MUST TAKE SOME IMPORTANT STEPS IF WE ARE TO CHANGE SOCIETY'S APPROACH TO SERIOUS ILLNESS, DEATH AND DYING.





THE NEED FOR ADDITIONAL SUPPORT

Despite the tremendous work that has been accomplished to change society's approach to serious illness, death and dying, much more needs to be done – and funding is required to do it. NHPCO has identified specific needs and programs that are worthy of consideration by funders of all types who are interested in continuing to improve end-of-life care in the United States:

1. Individuals need to talk about their wishes for care at the end of life with family members, friends and care providers and then document their wishes in writing.
 - Produce and disseminate advance care planning decision tools. Funding is needed to develop decision-making tools that “walk” individuals and families through the advance care planning process, including resuscitation, intubation, health care surrogacy, hospice and other “options” or decision points that comprise the advance care planning process. These tools could be used by physicians and other health providers, faith communities, senior service providers and case managers as well as families.
2. Health care providers need to initiate honest, timely and culturally-relevant discussions about the burdens and benefits of treatment options in the last stages of an illness.
 - Bring interdisciplinary, palliative care training to medical and social service providers to ensure professionals know how and when to talk about end-of-life care options.
 - Translate end-of-life care informational materials into languages other than English. Caring Connections has developed culturally-relevant and language-specific materials in Spanish and Mandarin Chinese. However, additional funding is needed to meet consumer requests for resources in other languages.

3. Communities need to work together, providing care and support to seriously ill people and their family caregivers to ensure that no one dies alone or in pain.
 - Educate faith, cultural and other community leaders. Consumers often rely on their faith communities and social networks to support them when facing the end of life, death and grief. Funding is needed to disseminate forces and train faith and other leaders to meet the needs of their community members.
4. Health care payors need to understand the importance of a continuum of care that would ensure patients have access to the highest quality care regardless of where they are in the course of an illness. This continuum begins with the introduction of palliative care while a patient is still pursuing curative treatments to ensure that distressing symptoms and emotional care are addressed promptly, and the ratio of curative and palliative care can be adjusted throughout the illness.
 - Fund the development of an Advanced Illness Transitional Care Management and Planning demonstration. Demonstration projects would provide people who have serious illness access to palliative care services, end-of-life care planning, counseling, discussions regarding supportive services and care planning delivered by a hospice team prior to eligibility for the Medicare hospice benefit. This information will enable patients and their families to make informed choices from among care options, improve the quality of the care they receive, reduce needless suffering and select the most effective care. It may also encourage patients to elect the Medicare hospice benefit earlier.
5. Policy makers need to eliminate barriers that prevent timely access to hospice and palliative care.
 - Educate policy experts on the current barriers to accessing palliative and hospice care and potential solutions. End-of-life issues are complex and involve clinical, legal and financial considerations. Policy makers need evidence-based information to guide their thinking. Funding is needed to teach grassroots advocates how to communicate the efficacy of innovative models with policy makers. One such innovative model is the Transitional Care Model (TCM). Under this model, an interdisciplinary team member meets with someone who is hospitalized and his family to coordinate his care. The team member continues to meet with the patient at his home.
6. Employers need to support employees who are living with a serious illness, caring for a loved one or grieving a loss.
 - Expand the *It's About How You LIVE—At Work* Initiative. Funding is needed to expand the *It's About How you LIVE—At Work* Initiative to help more employers improve their understanding of how to assist employees who are juggling work responsibilities with family caregiving tasks.
 - Determine the impact of grief in the workplace. Fund a national study to quantify the costs of grief in relation to employee productivity, health and behavioral health care expenditures and the cost of rehiring employees who quit or are fired because of grief-related issues.

7. Researchers need to study end-of-life issues such as the efficacy of life-sustaining and palliative care therapies and the impact of grief on the workplace.
 8. The media need to explore ways to demystify dying and conversations about end-of-life issues in order to normalize the experience for the general public.
- Evaluate TCM and other models of “concurrent care” to determine outcomes, actual costs and cost savings. Funding is needed to support a national research agenda that evaluates access to palliative care, quality of care and cost implications of innovate models of service delivery.
 - Repeat national polls on American attitudes about and understanding of end-of-life care issues. Funding is needed to develop and disseminate national data that reflects current perceptions and misperceptions and will help inform the outreach initiatives of stakeholders.
 - Gather and implement a national education, outreach, marketing and social media campaign so that all Americans understand how to access quality palliative, chronic and end-of-life care, in accordance with their care needs, in a timely manner. Build upon the success of Caring Connections, National Healthcare Decisions Day and other grassroots, nationally-coordinated efforts to educate the public about advance care planning, hospice, palliative care, grief and pediatric palliative care.

Of all the nationally-focused grant-funded initiatives and special organizations formed since the late 1990s, only a few are still active. The Center to Advance Palliative Care, the EPEC Project (Education on Palliative and End-of-Life Care), End-of-Life Nursing Education Consortium (ELNEC), and Caring Connections are the four significant initiatives that have sustained the core elements of their grant-funded work. Despite the tremendous outcomes achieved by all of these initiatives and organizations, more work must be done to continue the progress of the last 40 years. We need only look to the misinformation and widespread fear of “death panels” that captured our country’s attention during the 2009-2010 health care reform debate as testament to this.

Caring Connections is seeking partners to help accomplish these targeted goals. Rigorous approaches to public awareness of and engagement in issues related to end-of-life care are essential if American society is to advance beyond the heartbreaking encounters with the medical and legal arenas experienced by the Quinlan, Cruzan and Schiavo families ...and by families today who privately endure the sadness that results when the wishes of those who are dying go unknown or unacknowledged. Public awareness and engagement are vital steps toward the greater goal of creating a world where individuals and families facing serious illness, death and grief will experience the best that humankind can offer.

CARING CONNECTIONS RESOURCES

The resources under each topic can be found on the Caring Connections website – www.CaringInfo.org. Most are listed under resources or brochures and the rest are under the Community section.

CARING CONNECTIONS

Advance care planning, caregiving, serious illness, grief, community outreach and workplace

- www.caringinfo.org
- caringinfo@nhpco.org
- HelpLine: 800-658-8898
- Multilingual Line: 877.658.8896

ADVANCE DIRECTIVES/ ADVANCE CARE PLANNING

- Artificial Nutrition and Hydration at the End of Life
- Communicating End-of-Life Wishes
- Conversations Before the Crisis
- End-of-Life Decisions
- If You or Someone You Love is Very Ill...Ask Tough Questions
- Leaving a Legacy
- Saying Goodbye
- Understanding Advance Directives
- You Have Filled Out Your Advance Directive. Now What?

Websites

- National Healthcare Decisions Day: www.nationalhealthcaredecisionsday.org
- The Physicians Orders for Life-Sustaining Treatment Paradigm: www.polst.org

CAREGIVING

- End-of-Life Caregiving Booklet How to Support Someone Caring for Another

Websites

- Family Caregiver Alliance: www.caregiver.org

- Johnson & Johnson Strength for Caring: www.strengthforcaring.com
- Lotsa Helping Hands: www.lotsahelpinghands.org

COMMUNITY OUTREACH

- Community Outreach: Guides and Resources

Websites

- Project Compassion: www.project-compassion.org

END-OF-LIFE CARE

- Hospice Care and the Medicare Hospice Benefit
- Hospice Care: A Consumer's Guide to Selecting a Hospice Program
- Hospice Volunteers: Helping People LIVE
- How Can Palliative Care Help Me?
- The Dying Process-A Guide for Family Caregivers
- What is Hospice?
- What is Palliative Care?

Websites

- Center to Advance Palliative Care: www.getpalliativecare.org

END-OF-LIFE FOUNDATIONS AND RESEARCH

- Epidemiology of Dying and End-of-Life Experience: www.edeledata.org
- The National Hospice Foundation: www.nationalhospicefoundation.org
- The Robert Wood Johnson Foundation: www.rwjf.org

GRIEF

- Supporting Someone Who is Grieving
- There is no Wrong or Right Way to Grieve After a Loss

PAIN

- How to Manage Your Pain
- Using Narcotics Safely

PEDIATRIC

- Helping Children Cope with the Loss of a Loved One
- Talking to Your Child's Doctor: When Your Child Has a Serious Illness
- Talking With Your Child About His or Her Illness
- When a Child Dies: A Guide for Family and Friends
- When Your Child is in Pain

Websites

- Children's Hospice and Palliative Care Coalition: www.childrenshospice.org
- Partnering for Children: www.partneringforchildren.org
- Partnership for Parents: www.partnershipforparents.org

PROFESSIONAL RESOURCES

- A Guide for Clinicians
- Advice for Physicians Caring for Dying Patients
- Hospice Patient Rights
- Palliative Care: Information and Resources for Healthcare Professionals

Websites

- Center to Advance Palliative Care: www.capc.org

- Hospice and Palliative Nurses Association: www.hpna.org

SERIOUS ILLNESS

- Living with Serious Illness
- When Someone you Care About is Seriously Ill

SPIRITUALITY

- Offering Spiritual Support for Family or Friends

SPANISH/ENGLISH BILINGUAL RESOURCES

- Aflicción por una pérdida—*Grief and Loss* in Spanish/English
- Apoyo para el cuidador—*How to Support Someone Caring for Another* in Spanish/English
- Cuidado Paliativo o Cuidado de Hospice—*Hospice and Palliative Care* in Spanish/English
- Las etapas en los finales de la vida - Phases at the End of Life in Spanish/English
- Mis deseos a la atención de mi Salud: Medicas o Directivas Anticipadas—*Advance Directives: My Wishes for Medical Attention* in Spanish/English

PEDIATRIC SPANISH/ENGLISH BILINGUAL RESOURCES

- Como Ayudar a los Niños a Afrontar la Muerte de un ser Querido—*Helping Children Cope with the Death of a Loved One* in Spanish/English
- Cuando Muere un Niño: Un Guía Para Familia y Amigos—*When a Child Dies: A Guide for Family and Friends* in Spanish/English
- Cuando Su Hijo Tiene Dolor—*When Your Child is in Pain* in Spanish/English
- Hablando Con Su Hijo Sobre Su Enfermedad—*Talking With Your Child About His or Her Illness* in Spanish/English

- Hablando Con el Médico Sobre Su Hijo: Cuando Su Niño—*Talking to Your Child's Doctor: When Your Child Has a Serious Illness* in Spanish/English

Websites

- Padres con Padres:
www.padresconpadres.com

MANDARIN CHINESE/ENGLISH BILINGUAL RESOURCES

- Hospice Care
- Palliative Care
- There is No Wrong or Right Way to Grieve After a Loss
- Understanding Advance Directives
- Understanding the Dying Process

Websites

- Chinese American Coalition for Compassionate Care: www.caccc-usa.org

WORKPLACE

- A Guide for Working Caregivers
- Helping Employees Cope After a Critical Incident
- It's About How You LIVE—at Work: An Employer's Guide to Work-Life Programs and Policies
- Supporting Someone Who is Grieving
- When a Co-Worker Dies
- When an Employee Dies
- When an Employee is Seriously Ill
- When an Employee Suffers a Loss

END-OF-LIFE CARE IN AMERICA:

PIVOTAL EVENTS

This timeline touches on factors in the last 40-plus years that have influenced public perception about end-of-life care, including several key elements, events and programs that will be explored in-depth in subsequent pages.

1967: Dame Cicely Saunders founds the first modern hospice—St. Christopher’s Hospice – outside of London.

1969: Dr. Elisabeth Kübler-Ross publishes *On Death and Dying*.

1972: Kübler-Ross testifies at the first national death-with-dignity hearings, entitled “Death With Dignity: An Inquiry into Related Public Issues”, which are conducted by the U.S. Senate Special Committee on Aging.

1974: The Connecticut Hospice cares for the first U.S. hospice patient.

1974: The first hospice legislation is introduced to provide federal funds for hospice programs. However, the legislation is not enacted.

1975: Karen Ann Quinlan, age 21, falls into a coma following a drug overdose and is placed on artificial life support, including a respirator and a nasogastric tube for artificial nutrition and hydration.

1976: The New Jersey Supreme Court rules that Quinlan has a constitutional right to privacy that her father can exercise on her behalf. Her father exercises this right by having her slowly weaned from the respirator. She lives in a persistent vegetative state for another ten years.

1976: California becomes the first state to enact legislation allowing individuals to complete advance directives that outline care they do and do not want to receive should they become unable to make or communicate their health care decisions.

1978: A U.S. Department of Health, Education and Welfare task force reports that hospice is a valuable delivery system, worthy of federal support.

1979: The Health Care Financing Administration (now The Centers for Medicare and Medicaid Services or CMS) initiates demonstration programs at 26 hospices to assess the cost effectiveness of hospice care and to help determine the essential characteristics of a hospice organization, including the services to be provided.

1980: The W.K. Kellogg Foundation awards a grant to the Joint Commission on Accreditation of Hospitals (now the Joint Commission) to develop standards for hospice accreditation.

1981: Hospices begin caring for patients who have a new disease called Gay Related Immune Deficiency, later renamed the Acquired Immune Deficiency Syndrome (AIDS).

1982: Congress includes a provision to create a Medicare Hospice Benefit in the Tax Equity and Fiscal Responsibility Act of 1982, with a 1986 sunset provision.

1983: Nancy Cruzan, age 25, has a feeding tube surgically implanted to provide long-term care for her following a car accident that leaves her in a permanent vegetative state.

1984: The Joint Commission initiates hospice accreditation.

1986: Congress makes permanent the Medicare Hospice Benefit, giving states the option of including hospice in their Medicaid programs. Hospice care also becomes available to terminally ill nursing home residents.

1986: Cruzan’s family petitions in Missouri court to have her feeding tube removed, although removal is prohibited under Missouri law.

1988: The Missouri Supreme Court rules that Cruzan’s feeding tube cannot be removed without clear instruction or convincing evidence that she did not want a feeding tube.

1989: The U.S. Supreme Court agrees to hear the Cruzan case.

1990: Terri Schiavo, age 27, experiences respiratory and cardiac arrest leading to a persistent vegetative state and is hospitalized with a feeding tube inserted.

1990: In a 5-4 decision, the Supreme Court rules against the Cruzan family, stating that the Missouri ruling did not violate the federal constitution, and, “unless Nancy Cruzan had left clear and convincing evidence of her wish to remove the feeding tube, it had to stay in place.”

1990: Following testimony from two witnesses that Cruzan had expressed wishes not to be kept alive artificially, her feeding tube is removed, and she dies 11 days later.

1991: The Patient Self Determination Act is enacted, requiring health care institutions to provide education and information about advance care directives.

1991: The Commission on the Future Structure of Veterans Health Care releases a report recommending inclusion of hospice care in the veteran’s benefit package.

1993: Schiavo’s husband and parents initiate legal battles to determine who can make her medical decisions and ultimately whether artificial nutrition and hydration can be stopped.

1995: The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) Hospice Benefit is implemented on June 1, 1995. It mirrors the Medicare Hospice Benefit in conditions of participation and reimbursement.

1995: The Physician Orders for Life-Sustaining Treatment (POLST) form, an out-of-hospital Do-Not-Resuscitate (DNR) order is released for use in Oregon.

1995: *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)* is published—showing the barriers to patient/physician communication about end-of-life care exist in even the best hospitals.

1995: The Robert Wood Johnson Foundation (RWJF) launches Last Acts, a national campaign to improve care at the end of life.

1996: Major grant makers, including the RWJF and Soros Foundation, invest significantly in research, program initiatives, public forums and conferences to transform the culture of dying and improve care at the end of life.

1996: RWJF funds *Promoting Excellence in End-of-life Care* to identify, promote and institutionalize care practices that allow seriously ill people and their families to experience physical, psychological, spiritual and emotional comfort at the end of life.

1997: The American Medical Association begins development and dissemination of the RWJF-funded Education on Palliative and End-of-Life Care (EPEC) core curriculum.

1997: Congress passes legislation barring taxpayer dollars from financing physician-assisted suicide. The U.S. Supreme Court rules that mentally competent terminally ill people do not have a constitutional right to physician-assisted suicide, leaving the issue up to the states. Oregon voters affirm the right to physician-assisted suicide by passing for the second time its “Death with Dignity Act.”

1997: RWJF funds the *Community-State Partnerships to Improve End-of-life Care*.

1997: The American Health Decisions publishes *The Quest to Die with Dignity: An Analysis of Americans’ Values, Opinions and Attitudes Concerning End-of-Life Care*.

1997: Americans for Better Care of the Dying (ABCD) is founded.

1997: Aging with Dignity publishes *Five Wishes*, a “consumer friendly” advance care planning document encompassing medical and non-medical wishes for care at the end of life.

1998: A consumer advocacy group, Choice in Dying, is renamed *Partnership for Caring: America’s Voices for the Dying* and becomes the program office for *Last Acts*, a program of RWJF.

1998: The Annenberg Center for Health Sciences and the National Hospice Foundation releases *Care Beyond Cure: Physician Education in End-of-Life Care*.

1999: RWJF funds the Center to Advance Palliative Care (CAPC) at the Mount Sinai School of Medicine.

2000: The Duke Institute on Care at the End of Life is established.

2000: RWJF funds the End-of-Life Nursing Education Consortium (ELNEC) project, a national education initiative to improve palliative care.

2000: The PBS series *On Our Own Terms: Moyers on Dying in America* is the focus of national education and engagement programs, generating record viewership for a PBS series.

2000: Schiavo is admitted to The Hospice of the Florida Suncoast (now Suncoast Hospice) following a court ruling that permits her husband Michael to stop the artificial nutrition and hydration.

2001: The Children’s Project on Palliative/Hospice Services releases *A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions*.

2002: The Institute of Medicine releases *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*.

2002: The Department of Veterans Affairs launches a program to increase veterans’ access to hospice and palliative services while providing educational opportunities for clinicians in veterans’ health care facilities.

2002: RWJF’s *Last Acts* campaign launches *Rallying Points*, an initiative to support local community efforts to improve care and caring near the end of life.

2002: A Federal court upholds Oregon’s law that permits physician-assisted suicide.

2003: The U.S. Health Services Resource Administration releases *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS* at The White House Conference on Palliative Care and the HIV/AIDS Global Pandemic.

2004: Hospice reaches the million-person mark, with more than one million Americans receiving hospice care.

2004: The National Consensus Project, a consortium of palliative care and hospice organizations, publishes the *Clinical Practice Guidelines for Quality Palliative Care*.

2004: NHPCO creates the consumer-engagement initiative, *Caring Connections*, after receiving an RWJF grant to advance public understanding and awareness of end-of-life care.

2005: NHPCO’s *Caring Connections* launches the comprehensive, national campaign, “It’s About How You LIVE.”

2005: Schiavo’s parents lose their long and very public legal battle to keep Schiavo alive artificially, and her husband directs hospice staff to cease artificial nutrition and hydration. Schiavo dies 13 days later.

2005: The Department of Veterans Affairs releases the report, *VA Transforms End-of-Life Care for Veterans*.

2007: The National Quality Forum releases *A National Framework for Palliative and Hospice Care Quality Measurement and Reporting*.

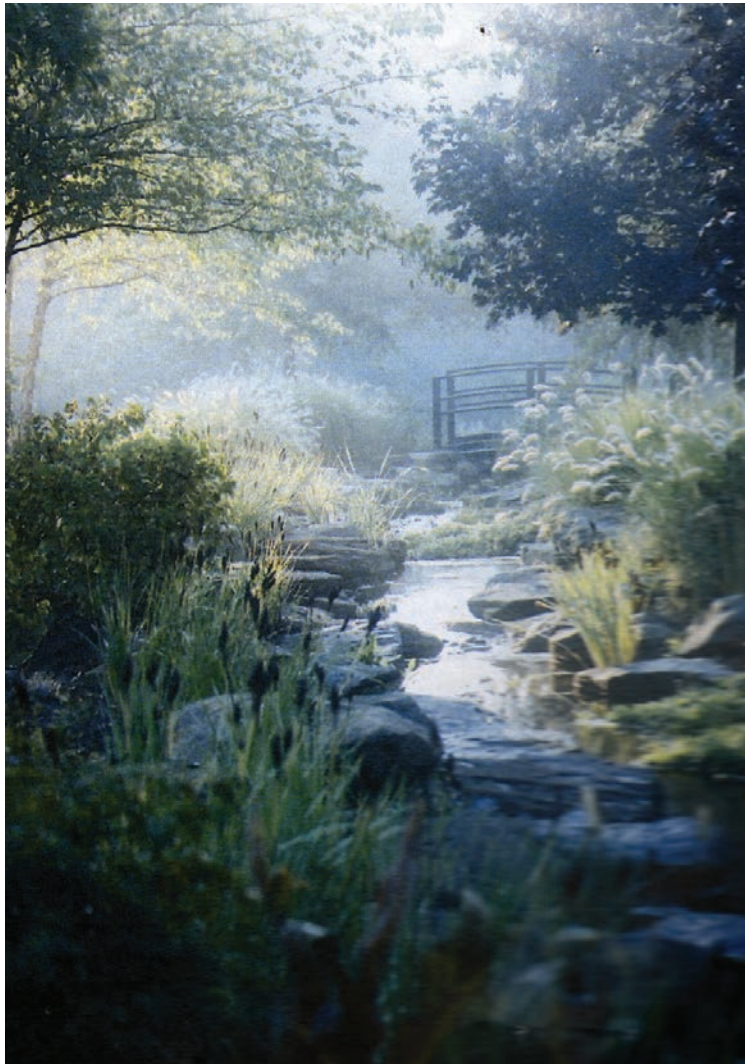
2008: The inaugural National Healthcare Decisions Day is held on April 16.

2009: NHPCO announces that a record number of volunteers—estimated at 550,000—contributed their time in service to hospice patients in 2008.

2009: NHPCO publishes *The Standards of Practice for Pediatric Palliative Care and Hospice*, along with the companion publication *Facts and Figures on Pediatric Palliative and Hospice Care in America*.

2009: NHPCO’s *Caring Connections* and Google Health partner to allow people to access advance directives online.

2009: NHPCO publishes *Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings*.



Caring Connections

The logo for Caring Connections features a stylized purple flower or leaf design inside a circular frame. The text "Caring Connections" is written in a purple, cursive font, with the logo partially overlapping the word "Caring".

HELPLINE: 800.658.8898
MULTILINGUAL LINE: 877.658.8896

WWW.CARINGINFO.ORG
CARINGINFO@NHPCO.ORG

WRITTEN BY: [KATHERINE BRANDT, MS](#), NHPCO, SENIOR VICE PRESIDENT, OFFICE OF EDUCATION AND ENGAGEMENT | [MELANIE ABIJAOUDE](#), NHPCO, CARING CONNECTIONS MANAGER | [SUE CANUTESON, MA](#), NHPCO, EDITOR | [JON RADULOVIC, MA](#), NHPCO, VICE PRESIDENT, COMMUNICATIONS | [MELANIE MERRIMAN, PHD, MBA](#), TOUCHSTONE CONSULTING

EDITED BY: [JAIMIE KELLEY](#), COMMUNICATIONS CONSULTANT, RWJF | [SARAH MELTZER, MPA, CFRE](#), NHPCO, DEVELOPMENT ASSOCIATE DIRECTOR | [CHRISTIN \(COCO\) O'SHAUGHNESSY, MSW](#), NHPCO, CONSUMER PROGRAMS AND SERVICES DIRECTOR | [GWYNN SULLIVAN, RN, MSN](#), NHPCO, DIRECTOR, ACCESS | [JEANNE TWOHIG, MPA](#), TWOHIG CONSULTING | [EMIL ZUBERBUELER](#), NHPCO, DIRECTOR, NATIONAL VETERANS PROGRAM

FOREWORD BY [RISA LAVIZZO-MOUREY](#), PRESIDENT AND CEO OF THE ROBERT WOOD JOHNSON FOUNDATION

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