

Medicine  Health  
RHODE ISLAND

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SPECIAL ISSUE: HOSPICE

# What's in a Name???

GOOD - authentic, honest, just, kind, pleasant, skillful, valid

NEIGHBOR - friend, near

ALLIANCE - affiliation, association, marriage, relationship

CORPORATION - company, business establishment

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# COMMENTARIES

## CURING LAWYERS [APRIL FOOL'S]

The word “lawyer” derives from the Saxon word, “layer,” which still means the same thing in English, namely layer. The uncovering (or the opposite) of “truth” was seen as a covering (or uncovering) through layers, in order to get at the truth. The Anglo derivation is a bit different. Lawyer is descended from the Anglo word, “lyre,” which was used in music, as in lyrical speech.

The evolution of lawyers is unclear. There are references to lawyers in some Egyptian papyri, which reside in the British Museum. These have not been fully translated, and refer to people who were fed to various wild beasts in order to argue with the gods for better weather conditions. The Greeks used lawyers to publicly debate, for entertainment at times, but also to argue points of law. The public debates evolved into the gladiator games of Rome, and then, as the intellectual component declined, into Bill O'Reilly. Shakespeare's famous line, “First kill the lawyers!” may have derived from the incident in medieval England, where the symbolic relationship between lawyers and layers was made real when a reigning feudal lord used the lawyers in his domain to form actual layers in the foundation of the famous Church of the Wandering Tongue, built on a bog on the Lancashire downs. And to this day lawyers have a special role in modern American life, just as they have a special location in Dante's world.

However, only with the development of the DSM IV-WD has the medical world recognized that being a lawyer is, like being autistic, not a choice but a disorder.

Aristotle, in what may have been the first localization exercise in clinical neurology, placed the seat of the soul in the pineal gland. Thomas Willis, of Circle of Willis fame, concurred, and no evidence has accrued in the several centuries subsequent to these pronouncements to counter this opinion.

In a seminal study (Cronan J, Tung G. Pineal calcification and lawyers. *Shadows, J Roentgenology and Ethics*. 1957;43:35-98) two radiologists performed a retrospective study, looking at skull x-rays, comparing lawyers and non-lawyers who were age-matched (all were male) for pineal calcification. They determined that the odds ratio for a lawyer to have pineal calcification was 3.7 (sd 1.0) greater than that of a male control,  $p=.00001$ . Their hypothesis was that a calcified pineal, suggesting a reduced activity of the soul, would correlate positively with being a lawyer. This was, in fact, borne out. Confirmatory studies were later published.

A parallel study, performed by neurologists, asked a related question. They opined that while the association between lawyers and pineal calcification appeared to be true, it could not be determined whether pineal calcification led to becoming a lawyer, or the opposite. Fahr's disease, an idiopathic mineralizing disorder affecting the basal ganglia but also the pineal, was thought to be a possible way to answer the question. Since Fahr's disease is presumably genetic, and can be seen in children, it seemed like a natural approach. The Fahr's data indicate that pineal mineralization leads to a 10-fold increase in the likelihood of becoming a lawyer. Physiological studies have also demonstrated differences between lawyers and non-lawyers. In a now classic study, a closed circuit TV EEG and a variety of measures of autonomic function were obtained on middle-aged men who were asked a series of questions. Some were emotionally neutral, while others made comments considered upsetting to the person under evaluation. Lawyers failed to show any response on either EEG or on autonomic measures, in 78% of questions, in contrast to the controls who typically had changes in both that were far from subtle. In fact, the most discriminating stimulus was 94% sensitive and 98% specific to lawyers. During the question-

ing a lab tech, not seemingly involved in the study, came into the room, asked the subject his name, and then said, “I've dreadful news for you. You'll have to stop this test. I just got a call that your mother died.” Failure to show a response to this question virtually always predicted being a lawyer. The only two other subjects who did not respond to this were either deaf or did not understand English.

Recent MRI studies have buttressed other reports. Routine awake studies have shown diminished metabolic activity in the pineal region of lawyers versus non-lawyers, even when the pineal was neither calcified nor mineralized.

The next, and most important, question then became: can something be done about it? Can these poor people with calcified pineals and poorly or non-functional souls be reclaimed? Friedman and Friehs, after approval by a special ethics committee at the NIH (chaired by William Bennett, and Henry Kissinger, began a trial of **deep pineal stimulation (DPS)** for the treatment of pineal insufficiency as manifest by being a lawyer. Using strict DSM IV-WD criteria, patients have been randomized to active or sham treatment. Our preliminary results are positive but too premature to reveal to the public. We do know that one of our subjects has applied to medical school. Another subject, who thought he received a placebo, evidently decided to sue us but a bizarre and unique stimulator malfunction rendered that decision irrelevant.

We stand on the edge of a new era, and hope that, even though we might not be able to cure this dreadful disease, we may be able to keep it safely contained and tolerable.

— JOSEPH H. FRIEDMAN, MD

# OH DEATH, WHERE IS THY DEFINITION?

Every age has its unique roster of end-of-life medical anxieties. Ask an average American adult to identify his greatest medical foreboding, say in 1960, and he might declare that he fears most being abandoned to die in some impersonal institution or be left to experience endless pain unrelieved by medication.

A millennium ago, however, the dominant fear was different. At a time when medicine could offer little more than some suppression of pain, many dying ones feared that they had not prepared themselves spiritually for an afterlife.

By the early years of the 18<sup>th</sup> Century, a new anxiety had arisen in the thinking of many in western Europe. It was the fear that they might sink into unconsciousness and, because of ignorance, indifference or avarice, might then be buried while still alive. Widespread anxiety over premature burial arose particularly during episodes of civil unrest, wars and epidemics, when hastily arranged mass burials were common events.

The worries over premature burial became so pervasive in France and England that a number of preventive measures were undertaken.

Efforts were first made to extend the interval between the time when death was declared and the time of the interment, thus providing an extended interlude when the body remained above ground and was available for periodic inspection. The likelihood of a hurried burial arranged by a relative bedazzled by the prospect of an inheritance was therefore diminished. Specially constructed buildings, called mortuaries, were set aside where the unsealed coffins rested upon biers in well-illuminated rooms for a few days, thus allowing hourly inspection of the putative corpses by a mortician expressly hired for the purpose. Furthermore, in such establishments, the coffins were equipped with bells which could be rung by someone surfacing from a deep coma.

More apprehensive Europeans insisted that their coffins be outfitted with air-breathing pipes extending from the interior of the coffin to the surface, and that strings be attached to a surface bell should they awaken after entombment.

In most jurisdictions, death was declared by clergy, by coroners or by a close relative. Many now demanded that physicians be required to certify death through personal inspection; but more important, that the medical profession now seek out the most reliable physiological standards for ascertaining death. I. Bruhler, an eminent 18<sup>th</sup> Century French physician, recognized that the medical profession possessed no definitive test for death and that its currently employed diagnostic signs, except for putrefaction, were inconclusive. Accordingly, then, and until the medical profession could declare a consensus on an objective sign of death, he expected that these public anxieties would continue unabated.

Inevitably the medical profession had to confront a crucial question: Was death an event initiated by divine decision irrespective of earthbound physiological dynamics? Or, alternatively, did living organisms function [and then cease to function] according to verifiable rules of nature? If indeed there were such rules, then there was merit in Galileo's premise that the great book of nature was written in the language of mathematics.

Widespread anxiety that some might return from the dead had some basis in fact. Physicians had noted that drowned

persons, declared dead, were occasionally revived by strenuous chest compression. This prompted groups of physicians in Venice, Amsterdam, London and other cities to form groups [called Humane Societies] expressly instructed in the art of resuscitating those who, typically because of drowning, had ceased to breathe. Cessation of respiration could no longer be deemed a criterion of death.

The first decade of the 19<sup>th</sup> century witnessed legislation such as France's Civil Code of 1803, which mandated that physicians be required to certify, by whatever tests were deemed suitable, that a person was dead. Increasingly the determination of death was given over to physicians who used whatever measures were then recognized [including such criteria as unresponsive coma, lack of ocular papillary reaction to light, lack of response to pain and/or rigor mortis].

The ambiguity in defining death was finally resolved when a French physician, Rene Laennec [1781-1826], devised a tubular apparatus [now called a stethoscope], in 1819, for the amplification of cardiac sounds. And so, by the late 19<sup>th</sup> Century, death became identified as the concurrent cessation of both heart beat and respiration in an unresponsive patient. The emotional clamor over premature burial, if not totally eliminated, had substantially diminished [but see note below]. That fear still lingered and could be readily activated by the gothic literature of writers such as Edgar Allen Poe. In his macabre tale, "The Premature Burial," are such phrases as: "The unendurable oppression of the lungs, the stifling fumes of the damp earth, the clinging to the death garments, the rigid embrace of the narrow house, the blackness of the absolute night, the silence like a sea that overwhelms, the unseen but palpable presence of the Conquering Worm..."

Each age has its own roster of anxieties concerning events at the termination of life. And today's apprehensions? Marc Alexander, a legal scholar, believes that "a surfeit of medical technology" has yielded an entirely new tapestry of anxieties for critically ill individuals: "Life-prolonging technology creates the danger that an overbroad test for life signs will cause the physician to treat a corpse as a living person." The reality that medical sciences of the 1970s can indeed keep the patient's heart and lungs functioning, by extracorporeal means, prompted the government to redefine, yet again, the definition of death. Committees, including physicians, basic scientists, clergy, ethicists and concerned citizens finally agreed upon a new definition of death which declared that the cessation of physiological activity of certain segments of the central nervous system, as determined by electroencephalography, shall now be recognized as the criterion of death.

The definition of death has come a long ways from those medieval days when the absence of condensed moisture on a mirror, held over the patient's mouth, was the declared criterion of death.

**Note:** Brief news item in *Providence Journal*, January 27, 2005: Raleigh, NC. "Man found alive in morgue."

– STANLEY M. ARONSON, MD

# THE EARLY YEARS OF HOSPICE CARE IN RHODE ISLAND

STANLEY M. ARONSON, MD

The hospice concept of care is now a widely accepted mode of management for the terminally ill of Rhode Island. It entered this state, however, through the vestries of our clergy rather than by way of conventional medical channels.

The word, hospice—as a place of shelter for the weary traveler on a long journey or pilgrimage—is old. But the concept of hospice, as a place [or mode of humane caring] expressly for the dedicated management of the terminally ill, is relatively new. The design and logistics of a patient-centered, compassionate facility for the dying—those without reasonable hope of cure—originated in England when Dr. Cicely Saunders established her unique inpatient program at St. Christopher's Hospice in June of 1967. It evolved in recognition of the reality that standard inpatient facilities, designed solely to sustain life, were ill-equipped to confront the emotional, social and biophysical needs of the dying patient. Saunders never doubted the earnest and caring qualities of her medical colleagues; but she contended that their agenda, and the mission of the institutions under their management, were directed to the fighting of death and were not therefore designed to acknowledge that there are times when conventional therapies were no longer effective, and indeed may even have been transformed into inhuman interventions.

The novel idea of a medical institution where the patient and his/her family are in charge, where the physician exerts an important but secondary role and where the conscious objective is palliation rather than cure, was first cautiously attempted by Dr. Saunders at St. Joseph's Hospice in South London. It then spread as an institutional credo to St. Christopher's, in 1967, where it became a model for other like-minded institutions in England and abroad.

Hospice reached the Western Hemisphere via Canada. The first coordinated hospice program in the United States was jointly initiated in 1974 by the Rev.

Edward Dobihal, chaplain to Yale University, and Florence Wald, Dean of the Yale School of Nursing. Working with physicians from Yale's medical school, they established both a home-care program and a free-standing hospice facility in Branford, Connecticut.

A group of concerned Rhode Islanders independently convened in 1974 to explore ways of easing the terminal weeks and days of dying patients. This informal group called itself the **Thanatology Associates in Rhode Island [TARI]**. It consisted of Rev. Ken Wentzel, a Congregational minister from Kingston, RI; Ralph Redding, MD, an internist from Pawtucket; Michael Scala, MD, an orthopedic surgeon from Providence; Gene Knott, PhD, a clinical psychologist from Kingston; two nurses from Pawtucket Memorial Hospital [Marion Humphrey, who later became Hospice Care's first staff nurse, and Barbara Wright]; and Rev. Charles Baldwin, Chaplain to Brown University. The initial leadership of TARI was provided by Rev. Wentzel, who had just returned from a sabbatical leave in London, where he had worked as a visiting chaplain at St. Christopher's Hospice.

Yet another group was gathering in Providence, beginning in January of 1974, to determine how the hospice concept might be implemented locally. This small group met periodically at the Barrington home of Irving Kronenberg, then Executive Director of the Jewish Home for the Aged of Rhode Island. Other participants included Marilyn Schlossberg, a social worker from the Miriam Hospital; Rabbi Les Gutterman of Temple Beth El; Rev. Ray Gibson, senior minister of the Central Congregational Church, Providence; Norma Kronenberg; Bruno Borenstein, MD, a Providence oncologist; and Rev. Charles Baldwin.

Still another cluster of concerned people were meeting on the campus of Brown University, in late 1974, to ex-

plore the merit and feasibility of introducing hospice concepts within the didactic curriculum of Brown's medical school. This group consisted of Drs. Scala and Redding and Rev. Baldwin, meeting regularly with Brown's dean of medicine to design and implement a weekly elective program for first and second year medical students. Dr. Sidney Cobb, Professor of Community Medicine, was instrumental in insisting that hospice and palliative care, particularly pain management, must be an indispensable component of undergraduate medical education. A series of seminars called, "Death and Dying" was assembled with a volunteer faculty consisted of Drs. Scala, Redding, Cobb, McDuff, Borenstein, and Aronson as well as members of the clergy including Rev. Duane Parker, recently recruited to lead Interfaith Health Care Ministries, shortly to become New England's largest hospital chaplaincy training program. A surprisingly large number of medical [and pre-medical] students registered for this program; and the format and mission of this course on death and dying was shared with deans of other American medical schools through national meetings on medical education.

Rev. Baldwin, a moral leader on Brown's campus since his appointment as University Chaplain in 1958 and a prominent participant in the civil rights movement of the 1960s, had actively participated in all of these various formative hospice groups and naturally assumed its leadership as the independent study groups in Providence, Kingston, and Pawtucket coalesced to create a single entity. By 1975 there was a consensus that Rhode Island was ready to accept an ongoing hospice program.

On March 27, 1976, Hospice Care of Rhode Island was formally established, with the following incorporators: Rev. Baldwin [as its first president]; Rev. Ray Gibson; Ralph Redding, MD; Irving Kronenberg; and Marilyn Schlossberg. Joining them in the inaugural Board were: Sidney Cobb,

MD, Charles Edwards, Rev. George Frappier, Rabbi Leslie Gutterman, William Harvey, Margaret MacColl Johnson, Minerva King, Rev. Duane Parker, Jane Pretat, Eleanor Slater, and Rev. Ken Wentzel.

Acceptance by the medical profession was slow. Bruno Borenstein, MD, observed: "To most doctors, hospice represented a whimsical, pseudo-religious voluntaristic thing without real shape, without real substance or form."

The early years of **Hospice Care of Rhode Island [HCRI]**, when it was initially administered by volunteers, were fraught with more setbacks than successes as it struggled through a succession of temporary offices, financial crises, interpersonal travails, interagency disputes, contradictory regulations and bureaucratic reversals. There were times, in these early years, when the agency survived solely through the benefaction of such philanthropic individuals as Bernard Bell, Rosalie Fain and Adelaide Nicholson. By 1978 the need for fulltime leadership became inescapable and Robert J. Canny, formerly director of chaplaincy programs for the Catholic hospitals of southern Connecticut, was then recruited as HCRI's first Executive Director. Marion Humphrey was appointed as chief of nursing and Esther D'Orsi was chosen to be director of the HCRI volunteer program.

In November of 1982, HCRI was licensed as a Home Health Agency and in February of 1983 both Medicaid and Medicare began to reimburse it, thus providing the agency with a measure of financial security.

Following the death of Bob Canny, David Rehm was appointed Executive Director in July, 1987, and the agency moved to more spacious quarters on the Butler Hospital campus. In November of 1989 the previously independent

hospice program of Washington County and the Island Hospice program merged with HCRI to form a statewide agency, the largest but not the only hospice agency in the state.

In June of 1992, Hospice Care of Rhode Island moved into its new quarters at 169 George Street, Pawtucket. In July, 1993, HCRI established its inpatient hospice unit, a specially constructed ten-bed facility called the Philip Hultar Inpatient Center.

In October, 1999, Analee Wulfkuhle was elected as President and CEO of Hospice Care of Rhode Island. The succession of Board presidents/chairs have been: Rev. Charles Baldwin, James Byers, Stanley Aronson, MD, Arthur Robbins, George Miller, and Jeffrey Chase-Lubitz. Medical Directors

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### ACCEPTANCE BY THE MEDICAL PROFESSION WAS SLOW.

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of Hospice Care have included Bruno Borenstein, MD, Henry McDuff, MD, and currently, Ed Martin, MD.

The agency has grown steadily in its 28 years as a health care facility incorporated in the State of Rhode Island. In the early years, only patients with advanced cancer were accepted; but by 1997 patients with stroke, dementia and other organic disorders, no longer amenable to therapy, were being accepted.

In 2001, the agency's name was expanded to **Home & Hospice Care of Rhode Island [HHCRI]** to reflect this diversity of patients receiving palliative care as well as traditional hospice care.

Table 1 summarizes the considerable growth in the numbers of patients and average daily census.

By autumn of 2004 nearly 300

Rhode Islanders were lovingly nursed by HHCRI's nurses and nursing aides [about 200], physicians [5], clergy [5], pharmacists and volunteers [about 150]. The Agency, now statewide, maintains offices in Pawtucket, Providence, and Wakefield.

Home & Hospice Care of Rhode Island began its life as a volunteer enterprise. And volunteers continue to fulfill a crucial role in the hospice program. These willing Rhode Islanders have undergone extensive training, learning that patient care is no longer the sole responsibility of physicians but may involve numerous other health workers, clergy, the patient's family and earnest volunteers. Of the many lessons learned by the volunteers, the most enduring one is this: Help one struggling person to reach some peace of mind, even for a few fleeting days, and you will have enriched the world.

HHCRI now maintains contracts with six hospitals and 75 nursing homes within Rhode Island. On the average day in 2005 it provided comprehensive care for about 291 terminally ill persons, whether in the hospital, the nursing home or the patient's private residence. And, since its formal inception in 1978, the agency has provided hospice care to over 15, 000 terminally ill Rhode Islanders.

Before he died in 1986, Robert Canny, Home & Hospice Care's first director, wrote: "In some ways the beginning of Hospice seems a long time ago - in other ways, only yesterday. My years with hospice have been a labor of love, as we went about giving life to a dream. There were many problems to solve, and obstacles to overcome. Hospice was a challenge to the traditional health care system. Over and over, questions surfaced about its very viability. We had to learn how to work with the complicated reimbursement system, the Federal and State legislation processes, as well as the regulatory and certification programs, while shaping a very special kind of program."

*Stanley M. Aronson, MD Former Deim of Brown Medical School, is Editor Emerins of this Journal.*

**CORESPONDENCE**  
Stanley M. Aronson, MD  
e-mail: smamd@cox.net

**Table 1  
Hospice Care Statistics**

	1983	1986	1989	1993	2004
Number patients	88	310	440	890	2,066
Average daily census	21	31	78	98	252

# RULES TO USE AND RULES TO LOSE FOR PAIN MANAGEMENT IN THE LONG-TERM CARE SETTING

JOAN M. TENO, MD, MS, AND THERESE ROCHON, RNP, BC-PCM, MSN

Over the past decade, Rhode Island (RI) has become a bellwether state in the care of older, frail persons. In 1989, RI was 26<sup>th</sup> in the nation with about one in five persons dying in a nursing home. In 2001, RI was ranked 2<sup>nd</sup> with nearly 38% of the non-traumatic deaths occurring in a nursing home. Many of these deaths occurred only days after discharge from the acute care hospital.

Research at Brown University, Center for Gerontology and Health Care, reveals opportunities to improve pain management in the long term care setting. Bernabei and colleagues found that one in four persons with daily cancer pain did not have any analgesic medicine prescribed.<sup>1</sup> In RI, examination of pain assessments (from the Minimum Data Set) in 2000 revealed a 42.2% rate of persistent pain. As many as 83% of nursing home residents experience pain that impairs their mobility, results in depression, and diminishes quality of life.<sup>1-14</sup> Often, complaints of pain are not recognized<sup>2,7</sup> or treated.<sup>1,2,15-17</sup>

There are barriers to pain management in nursing homes. (Table 1) When a patient moves from the hospital to a nursing home, s/he often loses his/her primary care provider. Often, too, information gets lost in the transfer. More than one in five families report that health care providers did not know enough about the new resident's medical history. Additionally, there is an increased risk of medical errors with these transitions. Nursing homes often are faced with inadequate staffing, resulting in inconsistent nursing. Because many residents cannot voice their concerns, nursing home staff must recognize the behavioral changes (e.g., grimacing, rubbing an area, or other subtle changes) that may indicate pain. In nonverbal persons, an astute clinician must carefully interpret discomfort in persons with dementia.

A second concern with inadequate

staffing is an inability to assess the patient on a timely basis for the use of breakthrough medications and frequent dosing with short-acting medications. Prescribing long-acting opiates for the opiate-naïve person may seem to be a time-saving measure but without titration first with a short-acting opiate, substantial risks may result. Older persons with impaired renal clearance, decreased protein binding of drugs, and cognitive impairment may be at higher risk of adverse drug reactions and side effects. Once an adverse reaction such as sedation has occurred, many family members are afraid to try other medications, leaving the resident in pain. Family members should be informed that tolerance to some of these effects (e.g., nausea, sedation) develops. The desired pain relief involves selecting the medication that is best suited for that individual. Because of the difficulties of enrolling frail, older persons into clinical trials, the evidence base for the efficacy and rate of adverse drug reactions with newer medications is largely based on information derived from healthier, younger persons. Health care providers should be cautious in the use of new medications given that the true rate of adverse drug reactions is only learned after the drugs have been used in this older, frail population.

The challenge is to insure competent, compassionate, and coordinated care for frail residents in nursing homes. Fortunately, several excellent guidelines provide recommendations for

pain management in this setting (e.g., American Geriatrics Society (AGS),<sup>18</sup> American Medical Directors' Association (AMDA),<sup>19</sup> American College of Rheumatology (ACR),<sup>20</sup> American Pain Society (APS) Guidelines).<sup>21</sup>

The approach to pain management of Mrs. C., an 83 year-old woman with congestive heart failure, renal insufficiency, and knee pain will illustrate the application of these guidelines.

**Rule # 1:** Do a complete pain assessment.

The key to pain management is the recognition and diagnosis of pain. A complete pain assessment should characterize the pain, its location, radiation, what makes it better, what worsens it, and how the pain affects function, sleep, mood, and appetite. Also, determine what pharmacologic and non-pharmacologic treatment has helped or caused adverse reaction. Nearly 2/3<sup>rd</sup> of nursing home residents can use at least one pain assessment tool to report on their level of discomfort.<sup>22</sup> In the case of persons with cognitive impairment, questions should be in the present tense.

Listen to the nursing home resident and his/her family. Pain is a subjective sensation and a cardinal rule of pain management is to believe the resident's report. In the case of persons with advanced cognitive impairment, families can tell you the resident's non-

**Table 1. Barriers to Pain Management in the Long Term Care Setting**

1. Transition to a nursing home often involves loss of the primary care provider, discontinuity of medical information, and a higher risk of medical errors.
2. Inadequate staffing.
3. Nursing home residents are often unable to report or fully characterize their pain.
4. Nursing home residents are at an increased risk of adverse drug reactions.
5. Information on newer pain medications is often based upon their use in younger, healthier persons.

verbal signs of pain.

Pertinent positive findings in Mrs. M's pain history

- Pain that is rated 4/10 on the 0-10 numeric pain rating scale
- Worse on walking
- Wakes up at night with knee pain
- No redness or swelling of her knee
- History of **Peptic Ulcer Disease PUD** – No history of coronary artery disease
- Currently on no pain medications

**Assessment:** Moderate pain impacting on Mrs. M's quality of life.

**Decision point:** What is the best treatment?

**Rule # 2:** Use the **AGS and AMDA guidelines, or the World Health Organization (WHO) Step Ladder** to approach pharmacologic management of pain.

**Rule # 3:** Always use a non-pharmacologic treatment first.

**Rule # 4:** Reassess whether you are achieving specified goals with minimal side effects.

Because of the risk of gastro-intestinal side effects from **non-steroidal anti-inflammatory drugs (NSAID)**s in the nursing home population, acetaminophen remains the first line medication for pain management in nursing homes. The WHO approach to pain management in persons with

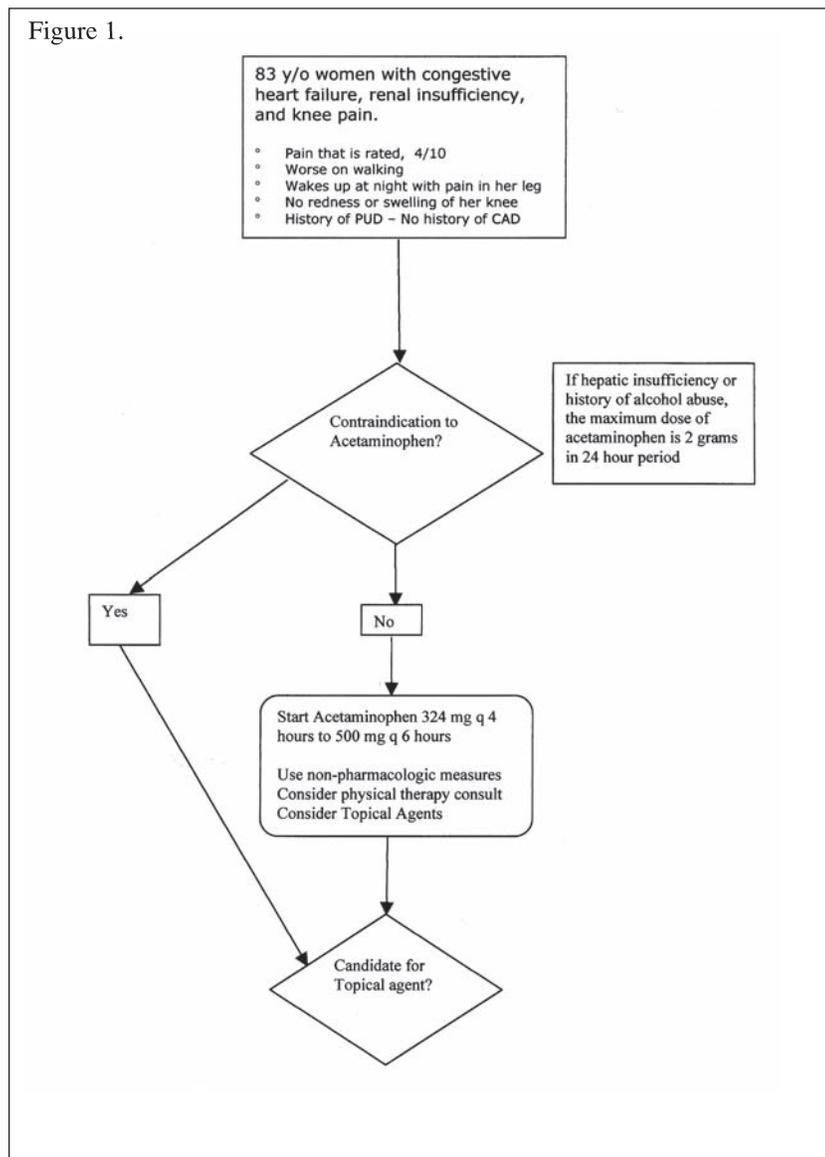
cancer provides guidance for the approach to non-cancer pain. For Mrs. M, we recommend a step I WHO agent or non-opiate medication—specifically, acetaminophen, given its safer side effect profile, with the following caveats: Acetaminophen should be used with caution in persons with significant history of liver disease or alcohol abuse, and the maximum dosage of 4 grams/day should be reduced by 50% to 75% (generally, less than 2 grams/day). An algorithm approach to the management of Mrs. M is presented in Figure 1.

Non-pharmacologic interventions (music therapy, distraction, massage, use of heat or cold, etc.) help. This can be as simple as instructing the nursing home resident to listen to a favorite CD with headphones while waiting for the effect of pain medication. Music may relate to the gate control theory of pain by modulating the release of neurotransmitters.<sup>23</sup> It redirects the focus of attention from the pain to a pleasant stimulus. Research showed that listening to music is effective in reducing pain associated with arthritis and cancer.

The adage “start low, and go slow” holds for the adjustment of pharmacologic treatment. Part of the reassessment is whether pre-specified goals are being achieved. Goals should be formulated for the resident's preferred level of pain, function and improvements in mood and sleep. All drug treatments have potentially adverse reactions. Thus, it is unrealistic to set a goal of being pain-free. Rather, the goal should be to reduce pain, so that it does not harm sleep and function. An additional goal is to minimize the risk of adverse reactions, and when there is an unacceptable side effect, to choose an alternative treatment.

As shown in Figure 1, Mrs. M has moderate pain affecting her quality of life. Initial recommendations for Mrs. M would be the use of acetaminophen in conjunction with non-pharmacological interventions. Exercise is an important intervention for older persons suffering from osteoarthritis. A consistent finding across studies examining exercise in the management of osteoarthritis is that exercise lessens pain and improves function.<sup>24</sup> A recent

Figure 1.



clinical practice guideline developed by the American Geriatric Society provides information on screening persons for participation in, and the design of, an exercise program for persons with osteoarthritis. A physical therapist could help design a program to maximize function. As noted, non-pharmacological interventions such as heat, distraction, etc. should be offered to Mrs. M.

If Mrs. M has mild to moderate pain after receiving a maximal dose of acetaminophen, consideration should then be given to adding a topical medication such as Capsaicin, topical methyl salicylate, topical non-steroidal anti-inflammatory drug, or counterirritants. These have been shown to provide moderate pain relief. One study by Mason and Moore<sup>25</sup> showed that while the treatment with salicylates was efficacious, the benefit diminished after 4 weeks. There is no study about the effect of topical NSAIDs after 4 weeks. Capsaicin has been effective for both musculoskeletal pain and neuropathic pain. It can be used as adjunct or alone. One side-effect is skin irritation. Capsaicin must be started at lowest concentration and then slowly titrated.

There are three options for persons in which these first line conservative treatments fail. Figure 1 lists the key pros and cons with the use of non-steroidal anti-inflammatory agents, tramadol, and opiates. Key to successful pain management is the use of individualized medication trials. The American Geriatric Society Clinical Practice Guidelines<sup>18</sup> on the management of persistent pain cautioned against the use of NSAIDs in the long term care setting because of the risk of gastrointestinal side effects and hemorrhage. Risk factors for upper gastrointestinal adverse events include: 1) age 65 and older; 2) co-morbid medical conditions; 3) concurrent use of oral glucocorticoids; 4) anticoagulant use; 5) history of peptic ulcer disease; and 6) history of gastrointestinal bleeding.<sup>20</sup> Evidence suggests that the nonselective COXII inhibitors both decrease risk of gastrointestinal bleeding and increase the risk of a cardiac or cerebral event.

Because of the risk of cardiac events, Rofecoxib was recently removed from the market. Whether the other two nonselective COXII inhibitors have a similar risk has not been adequately studied. Physicians should exercise prudence in the use of nonselective COXII inhibitors in persons with increased risk factors for coronary artery disease.

Mrs. M has two gastrointestinal risk factors precluding the use of NSAIDs. Three of the most pertinent guidelines recommend the use of misoprostol, high dose famotidine or omeprazole with NSAIDs. Another hazard is whether the nursing home resident is at risk of developing renal failure from the NSAID. Persons with known renal insufficiency, hypertension, congestive heart failure, and the concomitant use of diuretics and angiotensin-converting enzyme inhibitors are at an increased risk of renal failure following the use of NSAIDs. AMDA and AGS guidelines do not recommend the long term use of NSAIDs.

Tramadol is a synthetic opioid agonist that binds to the u-opioid receptor and inhibits the reuptake of

serotonin and norepinephrine. Unlike opiates, tramadol is reported to have a low potential for abuse or addiction. Tramadol provides comparable analgesic effect to either acetaminophen and codeine or aspirin and codeine. One in four persons stopped tramadol because of an adverse reaction. This was nearly twice the rate (12%) for acetaminophen with codeine. A limiting adverse reaction with tramadol is nausea, occurring in about one in ten older persons. Slow titration (i.e., 50 mg increase every 3 days) minimizes the development of adverse side effects such as nausea, dizziness, vertigo and vomiting.

If Mrs. M did not tolerate tramadol or NSAIDs, there is now wider acceptance to offer opiates in older persons with moderate to severe pain. If her health status warrants, consideration should be given to surgical treatment. In the case of Mrs. M, burdened by constant pain that wakes her from sleep, the use of round the clock opiates may be recommended. Long-term use of opiates in the cancer population has shown that adequate relief can be provided to the majority of cancer patients; addiction is rare among those

**Table 2. Guidelines for the Use of Opioid Therapy for Chronic, Non-malignant Pain**

1. A single practitioner is in charge.
2. History of prior substance abuse or severe character disorder is a relative contraindication.
3. If health status of the patient allows, establish the diagnosis.
4. Previous trials found that non-opiate and non-medical treatments have not resulted in pre-specified goals.
5. The nursing home resident is informed of the risks (physical dependence, possible cognitive impairment especially when used in combination with other sedatives or hypnotics)
6. Set treatment goals and initial dose adjustment phase of up to 8 weeks. Remember the adage, "start low, go slow."
7. Limited trial that stabilizes the pain with short-acting agents prior to any conversion to long-acting preparations.
8. Failure to achieve at least partial pain relief at relatively low initial doses of opiates in non-tolerant persons should prompt reassessment of the use of opiates.
9. Patient is seen monthly to reassess the efficacy of treatment and there is documentation in the medical record of pain severity, pain relief, function, side effects, and any aberrant behavior.
10. Request for dose escalation should prompt a reassessment of the patient's status.

Table modified from Portenoy<sup>26</sup> and Ballantyne and Mao<sup>27</sup>

without a history to substance abuse.<sup>26</sup>

Table 2 summarizes and modifies guidelines for the nursing home environment. Surprisingly, the literature on long-term use of opiates is confined to surveys and case studies. Most of these studies have used only moderate dosages of opiates – up to 195 mg of morphine or morphine equivalents a day. An important concern with the use of higher doses is that long-term use of opiates can be associated with abnormal pain sensitivity similar in mechanism to neuropathic pain.<sup>27</sup> Whether there is a ceiling dose of opiates (potentially, 180 mg of morphine or morphine equivalents per 24 hour period) in chronic non-malignant pain is controversial. Future research is needed to understand the long term safety of opiates. Key to treatment is that medications are titrated carefully and side effects are

carefully monitored. While there are important concerns with the long term opiates, such concerns do not justify the under-treatment of pain.

### RULES TO LOSE

#### RULE TO LOSE # 1: USE OF FETANYL PATCH AS FIRST-LINE AGENT

The use of the fentanyl patch as a first-line agent is a common error based on our clinical experience. The 25 ug fentanyl patch has a long half life and variability in its equivalency with morphine, from 45 mg to 134 mg in a 24-hour period. For an opiate-naïve patient, this dose can result in sedation and respiratory depression. For this reason, the fentanyl patch is not recommended in an opiate-naïve patient. While there is evidence that fentanyl suppresses chronic pain,<sup>28</sup> its pharmacokinetics is based upon studies

in a healthier population. The time to maximal concentration from the time of initiation is 18 hours, with the recommended titration interval 72 hours. These characteristics make the fentanyl patch a poor choice for opiate-naïve patients or persons with acute pain.

#### RULE TO LOSE # 2: IF THE PATIENT GROWS CONFUSED, BLAME THE OPIATE AND DISCONTINUE IT.

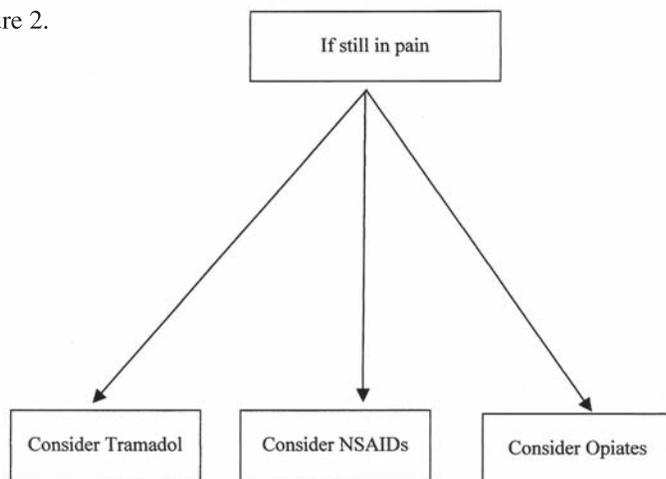
Confusion or sedation may occur at the initiation of opiate therapy or with rapid dose escalation. However, do not attribute all changes in mental status to opiate usage. The onset of confusion for a person receiving opiates merits a careful review of the patient's entire medical condition, which should include the start of other medications, the presence of an infection, changes in the resident's oxygenation status, the presence of a fecal impaction, the presence of hypercalcemia, hypoglycemia, or hyponatremia. Discontinuing an opiate without tapering the dose may result in a potentially life threatening withdrawal syndrome. Rather, consider either reducing the dose or shift to a different opiate, and seek an explanation for the confusion or delirium.

### CONCLUSION

Important opportunities exist in improving pain management in long-term care patients. Acetaminophen and topical agents should be considered as first agents or adjuvants because of their low risk of side effects. If these fail, you will need to undertake careful individualized drug trials. If the patient develops a side effect, another trial should not be abandoned. Increasingly, opiates are being used for non-malignant pain in the nursing home setting. While research is needed to assess their long-term safety, published surveys suggest that opiates may improve pain and function in a younger population. Such findings warrant careful trials of opiates if patients have moderate-severe pain harming their quality of life.

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Figure 2.



<b>Pros</b> <ul style="list-style-type: none"> <li>Believed Not addictive</li> <li>Not treated as a control substance</li> <li>Effective for moderate pain</li> </ul>	<b>Pros</b> <ul style="list-style-type: none"> <li>Anti-inflammatory</li> <li>Does not have reported risk of stroke and CAD as reported with COXII</li> </ul>	<b>Pros</b> <ul style="list-style-type: none"> <li>Long history of use in persons with cancer providing effective pain relief for moderate to severe pain</li> <li>Alternate dosing preparations, including long acting agents</li> <li>Tolerance develops to many of side effects except for constipation</li> </ul>
<b>Cons</b> <ul style="list-style-type: none"> <li>Potential to lower seizure threshold</li> <li>Dose and timing of administration adjusted in renal failure</li> <li>Concern with use in persons with depression</li> <li>Has maximum or ceiling dose</li> <li>Frequent nausea and vomiting</li> </ul>	<b>Cons</b> <ul style="list-style-type: none"> <li>GI side effects, including risk of GI hemorrhage</li> <li>May worsen renal insufficiency</li> <li>Has maximum or ceiling effect</li> </ul>	<b>Cons</b> <ul style="list-style-type: none"> <li>Concerns with addiction</li> <li>Constipation</li> <li>May rarely produce respiratory depression</li> <li>Nausea and vomiting with beginning of opiates</li> <li>Lethargy and mental status changes with initiation</li> </ul>

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Joan M. Teno, MD, MS, is Professor of Community Health and Medicine, Brown Medical School, and Associate Medical Director, Home & Hospice Care of Rhode Island.

Therese Rochon, RNP, BC-PCM, MSN, MA, is a Research Nurse, Brown Medical School, and Palliative Care Consultant, Home & Hospice Care of Rhode Island.

## CORRESPONDENCE:

Joan Teno, MD  
Brown Medical School  
2 Stimson Ave.  
Providence, RI 02912  
Phone: (401) 863-9627

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# A PASTORAL PERSPECTIVE ON DEATH AND THOSE WHO SURVIVE

DAVID A. AMES, DMIN

I retired as the Episcopal Chaplain at Brown University at the end of the 2002-2003 academic year. Although I continue to do some volunteer teaching in the Brown Medical School I have not had as much opportunity to help students understand concerns about death and dying as I used to have. However, I have been serving in a parish (St. Martin's Church in Providence) and have stood by the bedside along with family members of a few people during the final stages of their lives. And during the past two years I have officiated at 24 services for the burial of the dead.

When you see so much death, you are prone to ask, What does it mean to die? When I was at Brown, a student who knew she had only a certain time to live was open in discussing her disease and impending death. Laura was twenty-one and lived with **cystic fibrosis (CF)**. It is fatal, with a median survival age in the early 30s. Laura had been in and out of the hospital so many times that she considered herself a resident. "It's like my hotel," she said. In a tape-recorded diary of the last two years of her life with CF, Laura said she started college "by telling everyone about it [CF] and I realized — oh, my God, they don't care. Everyone's a freshman and everyone is going through their own stuff, and they don't need to hear, in depth, about my stuff." Laura's story aired on National Public Radio on "All Things Considered." She had received a lung transplant, after which her body experienced mild rejection. She said, "The last year of my life has taught me not to depend on anything. When you've had a transplant, one minute you can feel fine and the next, you're in the hospital. . . . I don't really count on anything anymore; I just go with the flow. I think that's okay." Laura knew the transient nature of life and she often struggled against considerable odds to make the most of it.

In another instance, I was referred to a man whose wife was dying

of cancer. I went to see him and his family at their house and heard a recitation of the patient's illness from the time of diagnosis two years earlier until the present when she was lying unconscious in medical intensive care at a local hospital. We talked about the patient and what was important to her. She was a wife, mother and a friend of many people. She enjoyed travel, shopping, decorating, and had many interests. I visited the patient in the hospital and prayed with her family for strength and courage, for those responsible for her care, and for God's blessing during this time of suffering and grief.

A few weeks later, when it became clear that the patient could no longer live, we gathered at the bedside as the ventilator and IV fluids were withdrawn. Within a few minutes the patient died.

An outpouring of grief and sadness followed, feelings of things left undone that would never be accomplished, and some relief and satisfaction that a few happy experiences did in fact happen before the illness took over. During many months that followed her death, the family continued to reassess their relationships, their personal lives, and eventually came to terms with their own directions. Some of this adjustment was painful; it was also necessary.

A hospital chaplain said that when she meets a dying patient she is meeting that person at a time when they are often coming to terms with their whole life's story. She enters a relationship near the end of that person's history. In telling their story, in assessing their life, they come to terms with their inner spirit. They can learn to accept life's limits and sustain a sense of hope even in the face of death. For religious communities, hope is an integral part of faith. This element of hope was certainly present in Laura's experience, and I trust it was also present in experiences of the patient in the situation just cited.

Every person's understanding and experience is unique. Dr. Ned Cas-

sem, a Jesuit priest and formerly Chief of Psychiatry at the Massachusetts General Hospital, has spoken about palliation and spiritual suffering. In a talk at Butler Hospital several years ago, he said he asks patients several questions. Among them are these: How do you live ill? Do you have a faith in God or a power beyond yourself? Are you part of a community of believers? What sort of person is God? Is your God compassionate, caring, merciful, forgiving; or is your God judgmental, vengeful, angry, punitive? What is communication like with God and others? What about doubt? What doubts do you have? What is God's position on your illness? How do you view death? Is there anything after death?

These are difficult questions. They are also critical for us to reflect on while we still have that ability. They are questions not always addressed in end-of-life planning. Physicians are not trained to raise these concerns with their patients, and they are sometimes reluctant to inquire about pastoral support. They may ask family members about the need for a chaplain or social worker, but more often this area is left entirely to the family to work out for themselves.

When I realized how many deaths were occurring in the parish during a relatively brief period of time, I organized a bereavement support group. Several people responded and we met twice monthly for two years. One person had lost a young child, another a retired spouse, another a brother, another a parent, and another a spouse barely in middle age. In our meetings we shared stories, stories about the deceased person and what was important to her/him, stories about the stress of dealing with estate issues, stories about personal feelings of despair and loss.

In coping with loss and in helping others to cope with their feelings, I am mindful of several things. One is to encourage them to keep as informed as possible and share important information with others

who need to know or who can help. Communication with family, friends, and relatives is important. It is also important to give yourself permission to take all the time you need to process what is happening and what you are experiencing. Issues of loss, and grieving the death of another take time and effort.

Ritual is also important. Several years ago when a family I knew was killed in an airplane crash, the 2nd grade children used their classmate's empty chair as a focus of their grief. They wrote messages, drew pictures, and decorated the chair as a way of expressing their feelings and honoring their friend and classmate. Doing something in an active way that memorializes others is helpful.

Make a conscious distinction between grief and mourning. They are not the same. "Grief is a fear, a dread an apprehension that the structure of values that sustain a person's life will be destroyed." Generally, we work through grief by traversing stages of emotional release, depression or isolation. We may even have physical symptoms of distress like aches and pains, or experience a sense of panic, guilt, hostility, anger or resentment, and find ourselves unable to return to usual activities. Gradually, however, we move toward a renewed sense of hope and a reaffirmation of reality.

Mourning, however, is different. It remains with us for the rest of our lives. The relationship we had with the person who died is part of our identity. It remains with us as part of our self-understanding. Mourning is about remembering and celebrating the importance of our relationships, filled with memories of shared times, including occasions filled with joy and laughter.

To provide a social climate that addresses the pastoral and spiritual needs of patients, and not to hesitate from asking the difficult questions about death, is critical for relating to patients during their final weeks and days of life. Perhaps we need to reclaim that older ideal of medical practice prior to the advent of our ever-burgeoning technology, "To cure, sometimes; to help, often; to comfort, always."

I conclude this pastoral perspec-

tive with a magnificent poem by Walt Whitman that addresses what it means to be in relationship with a dying person.

*"To One Shortly to Die"*

*From all the rest I single out you, having a message for you:*

*You are to die—Let others tell you what they please, I cannot prevaricate, I am exact and merciless, but I love you—There is no escape for you.*

*Softly I lay my right hand upon you—you just feel it, I do not argue—I bend my head close, and half envelop it, I sit quietly by—I remain faithful,*

*I am more than nurse, more than parent or neighbor, I absolve you from all except yourself, spiritual, bodily—that is eternal—you yourself will surely escape,*

*The corpse you will leave will be but excrementitious.*

*The sun bursts through in unlooked-for directions!*

*Strong thoughts fill you, and confidence—you smile!*

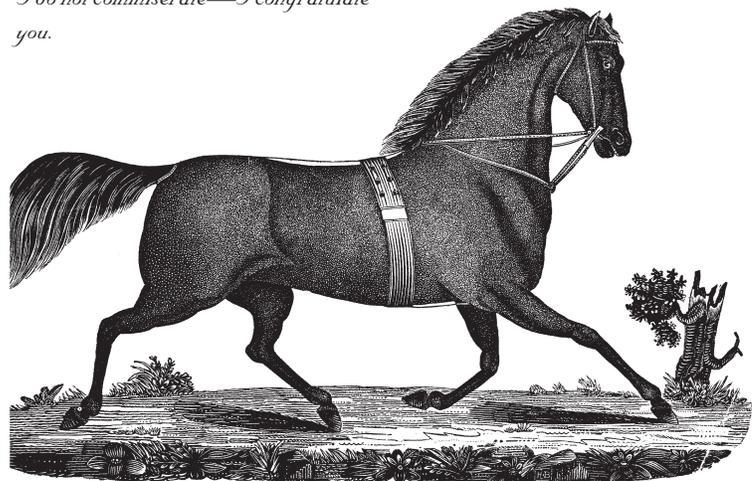
*You forget you are sick, as I forget you are sick,*

*You do not see the medicines—you do not mind the weeping friends—*

*I am with you,*

*I exclude others from you—there is nothing to be commiserated,*

*I do not commiserate—I congratulate you.*



*David A. Ames, DMin, is Clinical Assistant Professor of Community Health, Brown Medical School.*

#### **CORRESPONDENCE:**

Rev David A. Ames  
St. Martin's Church  
50 Orchard Ave.  
Providence, RI 02906  
Phone: (401)751-2141  
Fax: (401) 751-0038  
E-mail: [David\\_Ames@brown.edu](mailto:David_Ames@brown.edu)

# BARRIERS TO HOSPICE: ACCESS DELAYED, ACCESS DENIED

EDWARD W. MARTIN, MD

Hospice is an interdisciplinary team approach to the care of terminally ill patients and their families. Hospice addresses psychological and spiritual issues as well as the physical needs of the patients. Hospice can provide a mix of services that includes symptom management as well as emotional and spiritual support to the terminally ill patient and family. When access to hospice care is delayed or denied, a valuable opportunity to improve the quality of life for that patient and family is lost.

Delayed referral to hospice care prevents patients and families from receiving these services. When patients are referred late in their illness, they may only receive services for their final days or hours of life even though they had been eligible for, and may have benefited from, hospice care weeks or months earlier. Barriers to timely access to hospice care stem from various sources: patient and family attitudes, health system factors, and physician behaviors.

## PATIENT BARRIERS

Death as a topic often creates discomfort, so few people discuss end-of-life care.

Advance directives can address this barrier. An advance directive allows the patient to designate a decision-maker who will make health care decisions in the event that s/he cannot make those decisions at a later date. The process of completing an advance directive encourages patients to discuss with family and friends their goals and values in the event of a life-threatening or terminal illness. Thus, the person designated as the agent is in a much better position to make decisions consonant with the patient's wishes.

In Rhode Island, the Attorney General's Task Force on End-of-Life Care has revised the Durable Power of Attorney for Health Care form to make it more user-friendly and accessible to

patients with a limited understanding of legal or health care terminology.

The form has specific questions about preferences for artificial nutrition, hydration and life support in a number of different clinical situations. These clinical scenarios prompt the patient to confront these issues and discuss them with their agent.

The Durable Power of Attorney for Health Care certification process was also changed: now one notary can witness the document for validation, in lieu of two witnesses. These revisions sought to facilitate the creation of properly executed advance directives and to encourage Rhode Islanders to discuss end-of-life care preferences with family and loved ones. The new form can be downloaded from the Rhode Island Attorney General's web site [www.riag.ri.gov/reports/index.php/](http://www.riag.ri.gov/reports/index.php/).

Research has shown that most patients want to complete an advance directive and are not deterred by the potentially disturbing nature of the topic.<sup>1</sup> In fact, patients perceived the lack of physician initiative as a much greater barrier.<sup>1</sup> Physicians can play a crucial role by initiating discussions about end-of-life care with patients and encouraging them to complete an advance directive.

While an advance directive is helpful for identifying patient preferences, its execution is only a first step in addressing problems with access to hospice. Lack of consideration of patient preferences regarding end-of-life care can and does interfere with timely access to hospice, but there are other patient-related barriers, including lack of knowledge, reluctance, overly optimistic perspectives, and ignorance about hospice.

Another barrier stems from patient misunderstandings about end-of-life care.<sup>2</sup> Educational efforts may be required before patients can make informed choices regarding end-of-life care. Patients may be misinformed or

not informed regarding assisted suicide, euthanasia, double effect, and refusal or withdrawal of treatment.<sup>2</sup> Completion of an advance directive without additional education is not enough to bridge this knowledge gap. Individuals who had completed an advance directive did not appear to be more knowledgeable about these issues than those without advance directives.

Although patients could obtain information about end-of-life-care from their physicians, they may be reluctant to do so. For example, patients with advanced lung disease were no more likely to want to discuss end-of-life care with their physicians than those who were less seriously ill.<sup>3</sup> Given this, the discussion of end-of-life care cannot wait until the patient brings it up, but must be initiated by the physician if the discussion is to progress in a timely way.

Patients in general are found to be overly optimistic in estimating their prognosis. Accordingly, they prefer more aggressive treatments if they believe they have a life-expectancy of greater than 6 months.<sup>4</sup> These patients are less likely to choose comfort-focused care such as hospice. In these patients, it should be stressed, the more aggressive treatment did not improve the survival interval.<sup>4</sup>

Finally, patients and families were often unaware of the services that hospice offered at the time they agreed to begin hospice care.<sup>5</sup> Efforts to educate patients and their families about the range of hospice benefits could assist in improving timely access to hospice.

## SYSTEM BARRIERS

Health systems also influence the timeliness of referral to hospice. It is not unusual to hear the problem of access to hospice blamed on managed care. Surprisingly, research has reported just the opposite finding. Areas of the country with greater managed care enrollment showed a greater use of

### **Table 1. HOSPICE SERVICES**

- 1) Hospice staff can assist with some of the time-consuming burdens for the family such as obtaining medication refills. They can take on some of the personal care duties such as bathing and dressing, allowing the family to spend more time being a spouse, son or daughter and less time being a caregiver.
- 2) Hospice support is available 24/7. Patients and families can call with questions and concerns and if needed, a nurse will visit any time of day or night.
- 3) Medicare, Medicaid and most insurers fully cover hospice care.
- 4) Medications to control symptoms related to the terminal illness will be provided by hospice. This would include pain medications as well as medications needed to control other symptoms.

hospice,<sup>6</sup> and Medicare beneficiaries in managed care had longer lengths of stay in hospice than patients in fee-for-service systems.<sup>7</sup>

Within the hospital, the availability of hospital beds and hospice services influence access to hospice. In one study patients who wanted to die at home were no more likely to die at home than those patients who wanted to die in the hospital.<sup>8</sup> Patients were more likely to die in the hospital in areas with greater numbers and utilization of hospital beds, and more likely to die at home in areas with greater hospice availability and use.<sup>9</sup>

One of the biggest barriers to hospice access has been aggressive oversight by Medicare fiscal intermediaries. Congress created the Medicare Hospice Benefit in 1983 to facilitate access to hospice services for Medicare beneficiaries. This represented a new approach to care at the end-of-life and was a striking alternative to dying in the intensive care unit. Hospice grew in the following years but still served primarily cancer patients when the National Hospice Organization developed admission guidelines for non-cancer diagnoses.<sup>10</sup> The guidelines were developed to assist hospice programs in evaluating and admitting terminally ill patients with diseases such as dementia, heart disease and cirrhosis. Medicare then adopted the guidelines to review the eligibility of non-cancer patients for hospice.<sup>11</sup> Although the guidelines were initially developed to improve and expand ac-

cess to hospice, Medicare used them retrospectively to judge the validity of the hospice admission. Patients who died within six months of admission could be retrospectively denied because they failed to meet the written criteria at the time of admission.

The situation worsened as the federal office of the inspector general's Operation Restore Trust began an extensive review of hospice programs for fraud and abuse.<sup>12</sup> The intensive review efforts by Medicare led to the denial of millions of dollars of hospice care on

the grounds that some of the patients had not died quickly enough, and so were not terminally ill.<sup>13</sup> The federal agencies had taken the position that patients were being referred too early to hospice, but a study by Christakis and Escare reported that the median survival of Medicare patients admitted to hospice was only 36 days.<sup>14</sup> This information did not deter Medicare from looking for patients who may have died more slowly than their doctors had initially predicted.

The regulations do not require that death must occur in six months. A physician may certify a patient for hospice when it is determined that the prognosis is six months or less if the disease proceeds as expected.<sup>15</sup> Some patients may die more slowly than originally predicted. Congress addressed this issue by extending the benefit beyond six months. In fact, no limit was placed on the amount of time a patient could be on hospice.

Across the country, length of stay on hospice declined as hospice programs were faced with financial penalties because some of their patients died too slowly. Rhode Island, however, had the shortest length of stay in the country, 13.7 days.<sup>16</sup> Half of the patients admit-

### **Table 2. HOSPICE STAFF**

- 1) A nurse will visit the patient regularly, coordinate care and services needed by the patient, evaluate and help manage symptoms, educate the patient and family on what to expect as the illness progresses, keep in close contact with the physician, and support the patient and family throughout the dying process.
- 2) A certified nursing assistant may provide personal care such as bathing and dressing.
- 3) A social worker may provide counseling to the patient, family and children, assist with practical matters such as funeral and burial arrangements, insurance and financial issues, preparation of an advance directive, and help identify community resources.
- 4) A chaplain is available to provide spiritual support and counseling to the patient and family.
- 5) Bereavement staff are available to provide support and counseling to the family following the death of the patient.
- 6) Volunteers are available to support the patient and family and be an additional resource to the family, staying with the patient while the caregiver runs an errand or takes a break.

ted to hospice in Rhode Island died within two weeks of admission.

Medicare has softened their stance on this issue. A Medicare Memo from summer, 2003, stated that physicians should not fear sanctions from Medicare because their patients survived longer than predicted.<sup>17</sup> "CMS recognizes that making medical prognostication of life expectancy is not always an exact science. Thus, physicians need not be concerned. There is no risk to a physician about certifying an individual for hospice care that he or she believes to be terminally ill."<sup>17</sup> The memo outlines the benefits of hospice, noting that patients with terminal illnesses other than cancer are appropriate recipients.

### PHYSICIAN BARRIERS

Physicians are often unaware that they were contributing to a delay in referral to hospice,<sup>18</sup> but they often play a role in decreased access to hospice.

Physician factors have been shown to influence hospice length of stay, specifically, physicians who were more accurate in estimating prognosis referred earlier than physicians who were less accurate.<sup>19</sup> Given this, one might expect that oncologists would refer cancer patients earlier than primary care physicians. Surprisingly, the same study found the opposite to be true: general internists and geriatricians were more likely to refer to hospice earlier than oncologists. Many cancer patients are given chemotherapy in the final three months of life even when the cancer is considered to be unresponsive to chemotherapy.<sup>20</sup>

Hospice Medicare guidelines require that a physician certify that the patient has a prognosis of six months or less if the illness proceeds as expected. Physicians cited the difficulty of making that determination as the greatest barrier to hospice referral. However, few physicians were aware of the guidelines adopted by Medicare to assist physicians in determining prognosis in non-cancer patients.<sup>21</sup> These guidelines can be accessed at the Home and Hospice Care of Rhode Island Web Site (HHCRI.org) by following the links to LMRP's (Local Medical Review Policies).

Physicians often initiate the discus-

sion of hospice with patients but do not offer the patient and family sufficient information about hospice services.<sup>5</sup> The following tables summarize some basic information about hospice that physicians can give patients and families. Hospice staff can provide the patient and family with additional information and answer questions regarding the services.

Barriers to hospice care can delay or prevent terminally ill patients and families from accessing hospice services in a timely way. Physicians can reduce these barriers. Physicians currently initiate discussions regarding hospice and end-of-life care options. Providing just a few brief details about the specific services of hospice could help. Accessing hospice in a timely way can maximize the chance that the patient and family will receive the maximal benefit from hospice.

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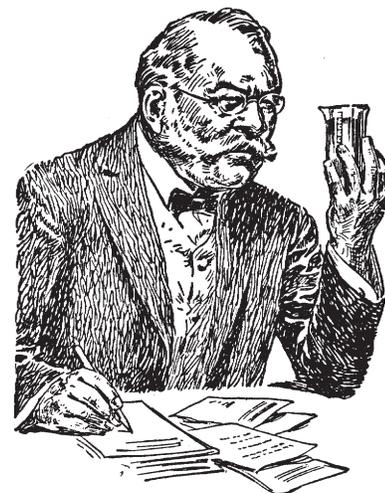
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*Edward W. Martin, MD, is Medical Director, Home & Hospice Care of Rhode Island and Clinical Assistant Professor of Medicine, Brown Medical School.*

### CORRESPONDENCE:

Edward W. Martin, MD  
Home & Hospice Care of RI  
169 George St.  
Pawtucket, RI 02860  
Phone: (401) 351-5570  
Fax: (401) 351-2813





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# WHAT IS THE OCEAN STATE ETHICS NETWORK?

JAY M. BARUCH, MD

A breakfast meeting took place at the Brown University Faculty Club on February 6, 2003. The goal was to establish a regional ethics network. We hoped ten or so individuals would take time from their schedules to exchange ideas on how to improve the practice of clinical ethics in the region. However, the “intimate” discussion included approximately forty people. The enthusiastic response proved that participants on **hospital ethics committees (HECs)** in Rhode Island believed there was a need for a collaborative forum for persons challenged with the task of delivering ethical healthcare. Once agreement was reached on the concept, the group faced practical questions relating to identity, function, and implementation: What is an ethics network? How could an ethics network serve the state of Rhode Island? What should be its focus? How would it sustain itself? Who are its members?

This paper will focus on the evolution of the 160-member **Ocean State Ethics Network (OSEN)**, its activities, and future roles for this group on both a state and local level.

## WHAT IS AN ETHICS NETWORK?

Ethics networks exist in various guises throughout the United States. They may exist on a statewide level, or serve a particular region.<sup>1-9</sup> They vary in the number of affiliated hospitals and the formality or laxity of their connections. Some networks exist in rural or sparsely populated

areas, where individuals with ethics training may be limited. In this context, an ethics network may serve as a regional repository, letting HECs in member institutions draw on experts. Others develop in response to specific needs as healthcare institutions address ethical issues in their communities. Some networks, such as OSEN, get willed into existence as a means for inter-institutional communication between HECs.

HECs generally concentrate on three tasks: case consultation, education, and policy formation.<sup>1</sup>

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### “IDEALLY, HECs PROVIDE A MORAL COMMUNITY IN THE HIERARCHICAL HOSPITAL STRUCTURE...”

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<sup>2</sup>The HEC is a **Joint Committee on Accreditation of Health Care Organizations (JCAHO)**-mandated hospital committee: hospitals must have a mechanism in place for resolving ethical issues involving patient care and organizational practices. These committees are required to meet on a quarterly basis, but differ in their focus, level of activity, and authority within each institution.

Ideally, HECs provide a moral community in the hospital, a “safe space” where multiple parties can reflect on their own moral beliefs as well as the beliefs of others. Often, HECs must first help the involved parties identify the nature or source of the moral problem. Clarification

of the moral dilemma is essential before the issues at hand can be placed within an ethical framework. However, persons participating on hospital ethics committees may not have the necessary training or tools for these endeavors.

Formal and informal surveys of HECs within Rhode Island revealed organizations functioning at varying degrees of sophistication. When we mailed invitations to the initial meeting, we asked the contact persons of the HECs to answer a short survey to get a sense of the regional baseline. Coincidentally, Bill Kirkpatrick, from The Miriam Hospital’s ethics committee, had already initiated a survey of HECs in Rhode Island. Some met monthly, others met quarterly; some didn’t engage much in clinical consultation service; some participated in the education of the larger hospital community, others didn’t feel comfortable undertaking such a role. Nevertheless, practically all the HECs at the meeting were in a state of change, confronting problems, or undergoing self-examination. More importantly, some HECs were dealing with similar issues, or had experiences that were useful to others, except the infrastructure wasn’t in place to encourage communication between committees.

At its inception, the overarching goal of OSEN was to enable HECs in Rhode Island to come together, educate one another, and take back to their institutions a richer understanding of the practice of clinical ethics. However, by

necessity we broadened the scope. Our education symposia attracted non-members of HECs. Now, OSEN provides a platform that is open to all individuals engaged in the moral act of caring for others.

### STRUCTURE

Would the ethics network be a formal or an ad-hoc organization? Should there be an executive committee, officers, etc, or should the group evolve naturally? There were cogent arguments for the need for structure. But there was a consensus that the group should be allowed to grow naturally over the next year. During this inchoate phase, Dr. Jay Baruch and Donna Goodnow, the coordinator at the Center for Biomedical Ethics, Brown Medical School, assumed responsibility as “point people.” OSEN now has a 10-person Board of Directors; representation includes physicians, nurses, administrators, a librarian, ethicists, and a lawyer.

How often should the group meet? To start, members met quarterly. The meeting included an education component, lasting for 2 hours from 8am-10am. We established a listserv, hoping to spur on-going dialogue between formal meetings. At the moment, it serves primarily to disseminate information about OSEN events, but we hope it will serve as a vehicle to share ideas.

### REPRESENTATION

The network was established primarily for individuals involved in ethics consultation at regional hospitals, as well as for people involved in ethics education. However, there were many people involved in healthcare who should have a voice in such an ongoing

project. Information about symposia were posted on the listserv, and members were encouraged to post flyers in their hospitals and to advertise through word-of-mouth. Medical students were informed of the events.

Each education session attracted people interested in the particular topic. Our first session, “Barriers to Advanced Directives,” drew persons involved in end-of-life care not working or practicing in hospitals. In this fashion, each event has broadened the diversity of the participants.

### ETHICS NETWORK AND EDUCATION

The group decided that education would be the first objective of the network. Such an agenda would serve HEC members by establishing a basic fund of knowledge on issues relevant to the clinical practice of ethics consultation. It would also begin to establish the network as a resource for the healthcare community. These sessions were not supposed to be purely didactic; time was set aside for open discussion.

The first educational session (March 31, 2003) focused on barriers, myths, and misconceptions surrounding advanced directives. The panelists included Maureen Glynn, Assistant Attorney General; Dr. Joan Teno, Professor of Community Health and Medicine and a principal investigator in the **Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)**; and Mary Callahan-Cimini, Executive Director, Aging 2000.

On May 6, 2003, Bill Kirkpatrick, Director of Clinical Social Work for Lifespan Academic Medical Center, presented preliminary

results from his “Ethics Committee Benchmarking Project,” a survey of HECs at fourteen hospitals in Rhode Island and Massachusetts. During the dialogue, three immediate needs were identified: ethics consultation; medical futility; and brain death.

At the next symposium (June 26, 2003) “Ethics Consultation: Nuts and Bolts,” Dr. Jay Baruch provided a brief, overview on the process of ethics consultation, discussing the aim of clinical ethics consultation, the nature of “ethics expertise,” the essential elements of ethics consultations, the different models of ethics consultation, and pitfalls that can undermine a consult. Following the talk, representatives from three HECs presented two cases: one consultation that went well, and one that went poorly.

At “Medical Futility: Clarity or Confusion?” (October 2, 2003) discussants focused on the discord when the core conflict over “futility” involves differences in personal values and goals. This session also raised the importance of institutional futility policies. These cases can generate intense emotional volatility from all sides; a coherent, transparent process ensures that cases will be addressed in a similar objective manner.

The Rhode Island Ethics Network joined with the New England Organ Bank for “Dead, or Dead Enough,” (December 4, 2003). The Organ Bank sought to promote **non-heart-beat cadaver donation (NHBCD)** in Rhode Island. Cardiac death may appear straightforward, but when tied to organ donation poses areas for ethical inquiry. For example, after what minimal interval from the moment the heart

stops can death be declared? Does that equal death of brain tissue? Can end-of-life care, withdrawal of medical treatment, and respect for the dying be separated from the organ procurement process? What is the role of ethics committees in hospital NCHBD protocols? Dr. Stephen T. Mernoff, Medical Director, Neurorehabilitation Program, Rehabilitation Hospital of Rhode Island, reviewed brain death criteria. Paul E. Morrissey, MD, Assistant Medical Director, New England Organ Bank, and chief of transplantation surgery at Rhode Island Hospital, spoke on organ transplantation in Rhode Island.

At "Negotiating Moral Differences: When Doctors and Nurses Disagree" (March 4, 2004), Cynthia Padula, PhD, RN, CS, Lynn Pasquerella, PhD, and Sheri Smith, PhD, explored the dynamic between doctors and nurses, how their roles inform their perception and reaction to ethical problems, and strategies for improvement.

In "Limitations of Surrogate Decision-making: A Modern Day Dax" (June 3, 2004), Tom Bledsoe, MD, the acting director of the Center for Biomedical Ethics at Brown Medical School, discussed the case of a man badly burned in a fire. The man, estranged from his family, had not designated anyone to speak on his behalf. He was heavily sedated and incapable of making decisions. The patient's chances for a good functional recovery were promising, but required a number of surgical procedures followed by extensive physical and occupational therapy. Representatives of area HECs addressed salient aspects of this case; e.g., 1) What counts as due diligence in information-gathering when families provide a "substituted

judgment" on the patient's behalf? How does a health care provider access this process? 2) To what extent does a patient's history (of substance abuse) put him at risk for negative bias? 3) How do surrogates and clinicians apply a patient's previously expressed wishes to an actual situation? 4) Is it ever appropriate to just treat according to what the clinician believes would be in the patient's best interest? 5) What is the relevance of prognosis in substituted judgment?

### **IMMEDIATE GOALS OF THE OCEAN STATE ETHICS NETWORK**

The OSEN will potentially serve as a public, non-partisan forum that brings together many individuals involved in health care who may otherwise trudge alone through moral dilemmas. It will raise the sophistication of HECs in Rhode Island, develop standards, and encourage individuals from different institutions and backgrounds to talk and learn from each other.

The future of OSEN will depend upon continued interest and funding. The listserv includes over 160 members, from a range of academic and professional disciplines. With a basic infrastructure in place, we are exploring funding opportunities. For the moment, OSEN has a home with the Center for Biomedical Ethics at Brown Medical School, through which we have been grateful to receive funding for the educational events, as well as administrative and clerical support.

Brown Medical School lent credibility to the network in the development phase in several respects: Ed Beiser, JD, PhD, then-Director of Brown Medical School's Center

for Biomedical Ethics, pledged the Center's support; and Dr Richard Besdine, Acting Dean of Brown Medical School, eloquently validated the importance of this project and the value of clinical ethics during his introductory remarks at the first meeting.

We recently received a mini-grant from the Rhode Island Foundation, which will allow us to expand our educational scope and invite experts from outside Rhode Island to participate in OSEN events. We're exploring other funding opportunities and contemplating institutional and individual dues.

The educational agenda will evolve along with the needs of OSEN's members. Nurturing the growth of HECs will always be the driving purpose of the network. That process includes educating developing ethics committees or new members of established committees, as well as providing resources and advice to existing HECs so they can mature and become comfortable with the many complex tasks expected of them. Through educational events we hope to foster this notion of a "moral space," and perhaps, by extrapolation, generate an ambient ethical climate that will permeate healthcare institutions in Rhode Island and promote the identification, analysis, and comprehension of moral dilemmas as a healthy part of clinical practice.

We will continue these quarterly education symposium, approved for physician CME, nurse CEU, and social work CEU (pending) credit. We hope to stage smaller education sessions targeted at specific groups.

Through the listserv we hope individuals will engage in an on-

going dialogue, share information (examples of futility policies, for instance) and present difficult cases. Our website will include information from the education symposia, a listing of future forums presented by OSEN as well as other related events throughout the state, medical ethics topics, citations of interesting articles, and a directory of members. Thanks to the work of Tovah Reis, Medical Library Coordinator at Brown University, individuals will be able to use this website to search the medical ethics literature. We hope the web site will eventually develop into an on-line journal for patients and their families.

#### POSSIBLE FUTURE ROLES

Ethics networks aren't limited to education functions. Depending on its growth, organizational credibility, and acceptance by institutions within Rhode Island, OSEN can serve as a resource for consultation or mediation. A growing literature advocates the role of extramural ethics consultation, especially in cases where patients (or families) have lost trust in the healthcare providers or the institution.<sup>3</sup> A neutral, third-party can often mediate a resolution by asking questions that were not raised, or explaining the medical facts and options in a different manner, or getting the stakeholders to concentrate on the issues.<sup>4</sup>

Extramural ethics consultation or committees have proven worthy in those environments that may not have ethics committees. HECs usually address in-patient moral issues. However, clinical ethics isn't limited to hospitals or in-patient units. Collaboration between National Kidney Foundation of Kansas and Western Missouri and Midwest

Bioethics Center has resulted in a multi-disciplinary ethics committee that provided consultations and organized educational seminars focused on patients with end-stage renal disease.<sup>5</sup> Long term care facilities, group homes, home care agencies, hospice, organizations that provide psychiatric care may also benefit. (As of this writing, there are preliminary discussions between OSEN and Home and Hospice of Rhode Island)

There exist opportunities for community outreach as well; for example, providing a forum on end-of-life issues and advance directives with nursing home residents or senior citizens, or hosting a dialogue on cultural issues in health care with the ethnic communities in the state.

The Ocean State Ethics Network has the capacity to serve a large community. What started as an organization of HECs has expanded because there appears to be a pressing need for this type of forum that brings together diverse individuals involved in the moral act of caring for patients.

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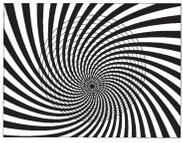
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*Jay Baruch, MD, is Clinical Assistant Professor of Emergency Medicine, Brown Medical School, on the Faculty, Center for Biomedical Ethics, Brown Medical School, and Director, Ocean State Ethics Network.*

#### CORRESPONDENCE:

Jay Baruch, MD  
Department of Emergency Medicine  
Memorial Hospital of Rhode Island  
Brewster St.  
Pawtucket, RI 02860  
Phone: (401) 729-2419  
e-mail: [Jay\\_Baruch@Brown.edu](mailto:Jay_Baruch@Brown.edu)



# IMAGES IN MEDICINE

## NEUROCYSTICERCOSIS

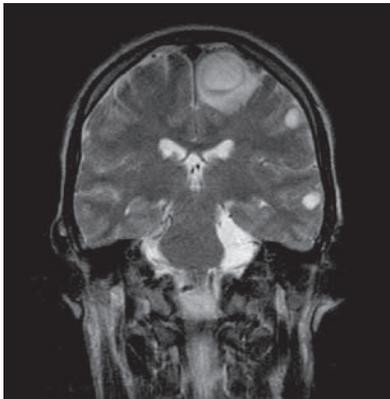


FIGURE 1.

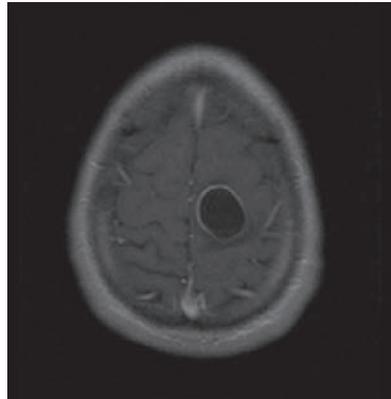


FIGURE 2.

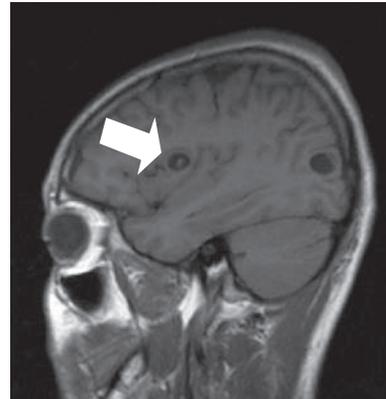


FIGURE 3.

A 28-year old Guatemalan man noted the sudden-onset of jerking movements of his right arm and leg. These lasted about 30 seconds and were followed by severe weakness of his right arm and leg, headache and blurry vision. A similar episode without associated weakness occurred three years earlier. He had had headaches and right arm tremors for the past three years. On physical exam, he had extreme weakness in his right proximal leg and mild weakness in his right arm. Sensory exam was normal. MRI of the brain showed multiple cysts throughout the brain parenchyma and the subarachnoid space. A large cystic lesion measuring 2.2 x 2.5 cm, with surrounding vasogenic edema and mild focal mass effect in the parietal lobe was noted on the T2 coronal image (Figure 1) and T1 axial image (Figure 2). A cyst with a central focus of increased T1 intensity was noted on the sagittal image (Figure 3). Based on the clinico-epidemiologic findings and the MRI, the patient was thought to have neurocysticercosis.

Neurocysticercosis is the most common cause of adult-onset seizures in developing countries. Infection is acquired by ingestion of infective eggs of the tapeworm *Taenia solium*. Neurocysticercosis results from parasitic invasion of the nervous system. Treatment of neurocysticercosis with the antiparasitic drugs praziquantel or albendazole is based on parasite load, viability and symptoms. Surgery is reserved for cases of obstructive hydrocephalus secondary to neurocysticercosis. Corticosteroids are frequently used to decrease neurological symptoms due to the vasogenic edema of degenerating cysts or encephalitis. Anti-epileptic medications are usually needed to control seizures and analgesics are used for headaches.

The patient's serology, including Western blot, was positive for *T. solium* antibody. He was treated with albendazole and maintained on phenytoin and prednisone. The latter was gradually tapered over 6 months, and the patient has had no further seizures in 7 months.

-BRENDA R. SCHLAEN, MD, SHADABA ASAD, MD,  
AND MARGUERITE A. NEILL, MD

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### Correspondence:

Brenda R. Schlaen, MD  
e-mail: brenschlaen@yahoo.com

*Brenda R. Schlaen, MD, is a resident in the Brown Medical School Family Medicine Program, Memorial Hospital, Brown Medical School. Shadaba Asad, MD, is a Fellow in Infectious Diseases, Memorial Hospital, Brown Medical School. Marguerite A. Neill, MD, is Professor of Medicine, Brown Medical School.*



## CHANGES IN SOURCES OF HEALTH CARE COVERAGE IN RHODE ISLAND

JAY S. BUECHNER, PHD

In recent years, the economic slow-down relative to the expansion experienced during the 1990s has generated concern that an increasing number of Americans will lose coverage for health care. Studies at the national and local levels have focused on both the growing number of uninsured persons<sup>1,2</sup> and the increasing disparities in the rates of coverage based on income, race and ethnicity, and other socioeconomic characteristics.<sup>3,4</sup> One of these studies has also presented national data on the sources of health care coverage during this period, showing a significant shift from employer-based private coverage to government-provided coverage.<sup>4</sup> This report employs survey data to examine trends in the source of health care coverage in the Rhode Island population from 1997 to 2003.

### METHODS

The **Behavioral Risk Factor Surveillance System (BRFSS)** is a national telephone survey of randomly selected non-institutionalized adults ages 18 and older that live in households with land-line telephones. The BRFSS monitors key health risk behaviors, participation in health screening, and access to health care. It is administered in all 50 states and four US territories with funding and methodological specifications provided by the Centers for Disease Control and Prevention (CDC).<sup>5</sup> Rhode Island has participated in the BRFSS since 1984; a professional survey organization conducts the annual survey under contract to the Rhode Island Department of Health. During the period 1997-2003, the number of persons responding to the survey ranged between 1,842 (in 1997) and 4,120 (in 2001). For analyses involving subgroups based on age, income, and race and ethnicity, data were aggregated over two-year periods in order to obtain sufficient sample size for reliable results. All proportions are weighted to adjust for the sample design and patterns of non-response.

The BRFSS includes basic questions on health insurance coverage. This analysis included an initial screening question for health coverage of any kind, a verification question for those who initially report no coverage,

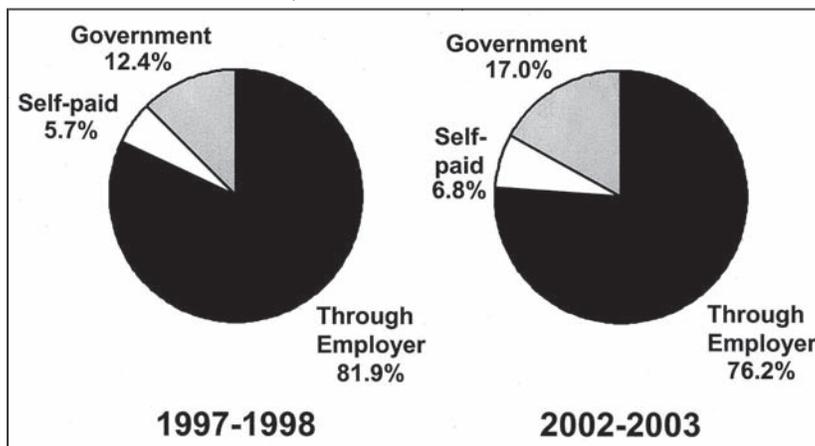


Figure 1. Source of health care coverage for persons ages 18-64, Rhode Island, 1997-1998 and 2002-2003.

and questions for those with coverage who identify their particular type of health plan or program. For those with coverage, the indicated types of coverage were grouped into the following sources "Employer," "Self-paid," and "Government." Respondents ages 65 and older and those with coverage who did not specify the type were excluded from the analysis.

### RESULTS

During the period 1997-2003, the proportion of working age adults (ages

18-64) without health care coverage ("uninsured") fell from 10.3% in 1997 to 8.1% in 2001, then rose in 2002 and 2003 so that in the latter year the proportion uninsured (10.4%) was nearly identical to that for 1997. However, in 2002-2003, the distribution of sources of coverage for the insured population was noticeably different from the distribution in 1997-1998. (Figure 1) Fewer insured persons obtained their coverage through their employers or their family members' employers and more insured persons obtained their coverage through

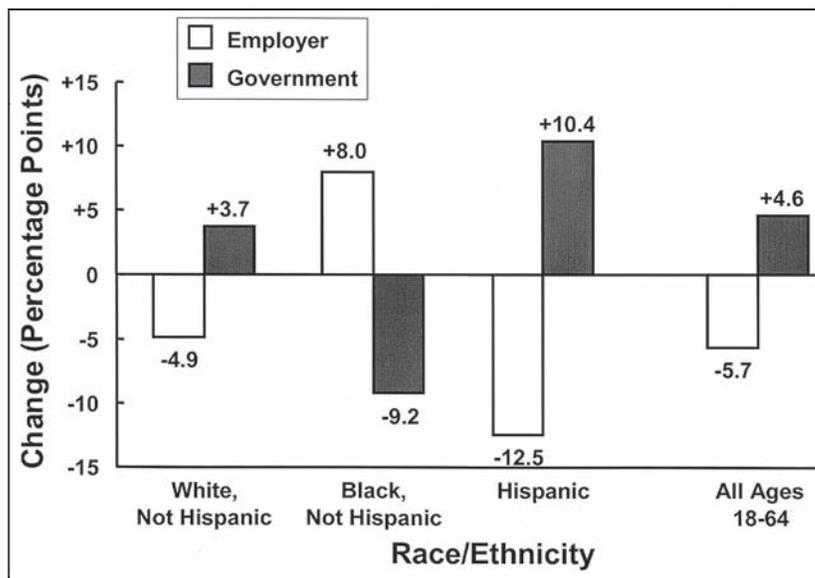


Figure 2. Changes in source of health care coverage for persons ages 18-64 from 1997-1998 to 2002-2003, by race and ethnicity, Rhode Island.

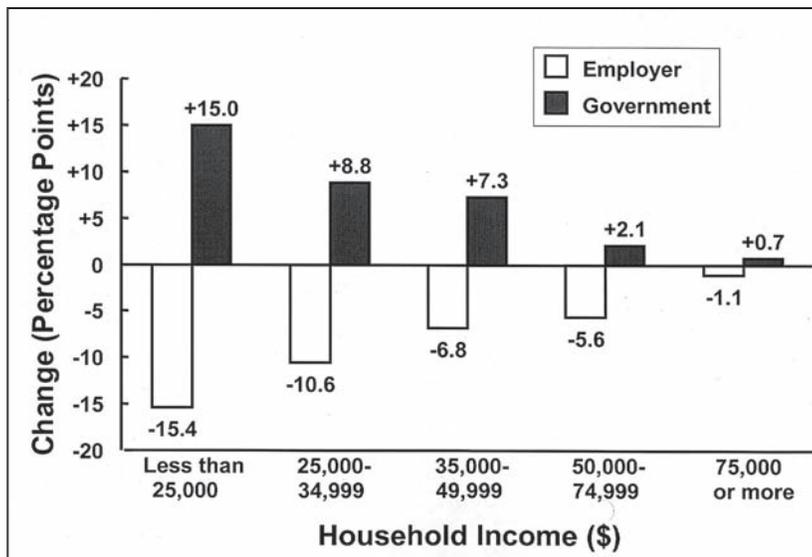


Figure 3. Changes in source of health care coverage for persons ages 18-64 from 1997-1998 to 2002-2003, by household income, Rhode Island.

government programs.

The replacement of employer-based coverage with government provided coverage during the period from 1997-8 to 2002-3 was most extreme among specific subgroups of the Rhode Island population defined by race and ethnicity, income, and age. The pattern by race and ethnicity was particularly complex. For non-Hispanic Whites, employer-based coverage eroded by 4.9 percentage points, and government programs grew by 3.7 points, with both changes slightly smaller than the corresponding changes for the working age population as a whole. (Figure 2) The Hispanic population showed a substantially larger movement from employer-based coverage to government-provided coverage. The non-Hispanic Black population was the only group investigated that showed movement in the opposite direction, i.e., growth in employer-based coverage and decline in government program participation.

The patterns of change across income and age groups were more straightforward. For all groups there was replacement of employer coverage by government programs. By income (Figure 3), the largest shift from employer-based coverage to government-provided coverage was in the lowest income group, and the smallest shift was among those earning \$75,000 or more. By age (Figure 4), the magnitude of the shift decreased from the youngest working-age adults to the oldest.

#### DISCUSSION

Since the mid-1990s, the percentage of the Rhode Island working-age population without health coverage has varied within a relatively narrow margin,

first decreasing until the end of the decade, then increasing after 2001. These incremental changes have masked more substantial trends in the source of health coverage for working-age adults. During this period, the proportion of those who are insured who receive employer-based coverage has fallen from 82% to 76%, and the proportion covered by government programs has increased from just over 12% to 17%, representing an expansion in government coverage by more than one-third over a period of about six years. Among young adults, persons with low incomes, and Hispanics, the magnitude of this change was especially large.

If employer-based coverage continues to erode under the pressures of increasing health plan premiums, it

is unlikely that government programs will continue to expand to offset such declines. Medicaid, the largest government program that provides coverage to working-age persons, is facing budgetary constraints at both the federal and state levels. Other government programs are limited in their impact, focusing on disabled adults, children with special health care needs, etc. Without a reversal of the trend in employer-based coverage, the likely result is an increasing number of uninsured among our working-age population, both nationally and in Rhode Island.

Jay S. Buechner, PhD, is Chief, Office of Health Statistics, and Clinical Assistant Professor of Community Health, Brown Medical School.

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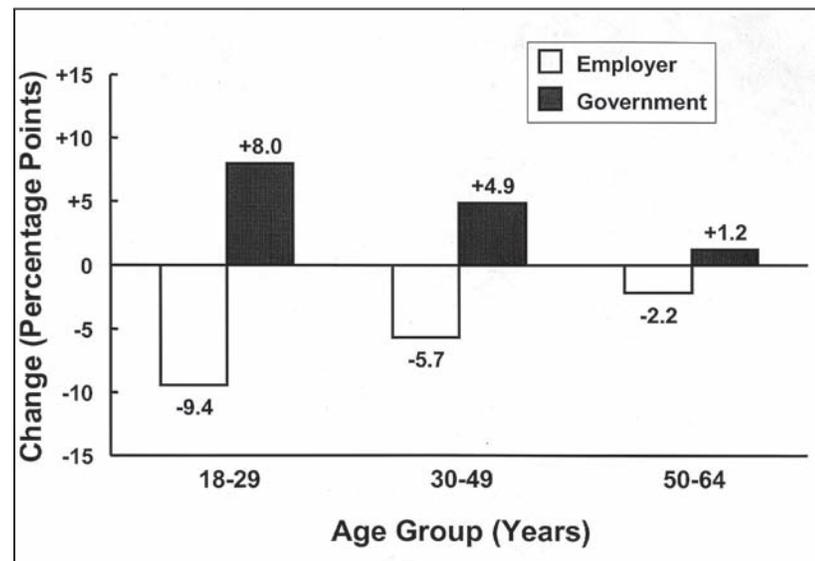
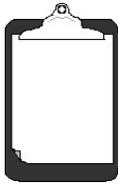


Figure 4. Changes in source of health care coverage for persons ages 18-64 from 1997-1998 to 2002-2003, by age group, Rhode Island.



## OSTEOPOROSIS: MISSED OPPORTUNITIES FOR DIAGNOSIS AND TREATMENT IN RHODE ISLAND

NANCY SUTTON, MS, RD, DEBORAH PEARLMAN, PHD,  
GEETHA GOPALAKRISHNAN, MD, AND DIANE CALLAHAN, BS, RN

### US SURGEON GENERAL RESPONDS TO THE BURDEN OF OSTEOPOROSIS

The *United States (US) Surgeon General's Report on Bone Health and Osteoporosis* recommends prevention, timely diagnosis, and appropriate treatment of osteoporosis throughout the lifespan, focusing on women and high-risk men of all races, ethnicities, and income levels. An estimated 44 million Americans suffer from osteoporosis or osteopenia, resulting in an estimated 1.5 million bone fractures each year.<sup>1,2</sup>

*Osteoporosis* is a disease characterized by low bone mass and the deterioration of bone structure. As a result, bones become weak and fragile increasing the risk of fracture.

*Osteopenia* is term used to identify a person with low bone mass, but not as low as osteoporosis. As a result, bones are weaker and more fragile than normal, healthy bone with some increase in the risk of fracture.<sup>1</sup> Low bone mass is the term used in this article when referring to both osteoporosis and osteopenia.

### WHY SHOULD HEALTH CARE PROVIDERS DISCUSS OSTEOPOROSIS WITH THEIR PATIENTS?

In the United States, osteopenia/osteoporosis remains under diagnosed and undertreated.<sup>1,3,4,5</sup> Perhaps as many as one in two American women with osteopenia/osteoporosis remain undiagnosed.<sup>3,6</sup>

**Low bone mass (LBM)** is a problem for people of all races and ethnicities. For example, national data show that 72% of Asian, 59% of Hispanic, and 40% of non-Hispanic black women ages 50 and older have LBM, defined as osteoporosis or osteopenia. (Table 1).<sup>7</sup>In addition,

33% of those with osteopenia or osteoporosis are men.<sup>7</sup>

Osteoporosis causes about 300,000 hip fractures, 700,000 spinal fractures, and 250,000 wrist fractures annually in the United States.<sup>2</sup> Fractures are often debilitating, deadly, and costly. About one in four hip fractures among people ages 50 and older is followed by death within one year of the fracture. Of those who live longer, about one in three require long-term nursing home care.<sup>2</sup> Rhode Island spends an estimated \$60 million per year on hospital and nursing home costs associated with osteoporosis-related fractures.<sup>2</sup>

### DEFINING BONE LOSS

A **bone mineral density (BMD)** test remains the best predictor of osteoporotic fractures to date:<sup>8</sup>

Osteoporosis: BMD t-score: -2.5 or less  
Osteopenia: BMD t-score: -1.0 to -2.5

One standard deviation below the mean BMD of young women (t-score) is associated with a relative risk of 2.6 for hip fracture and 2.4 for vertebral fracture.<sup>9</sup> Siris *et al.* assert that fracture risk exists not only for patients with osteoporosis, but also for those with osteopenia.<sup>10</sup> In one study of 149,000 postmenopausal women, 82% of those who presented with fractures had a t-score greater than -2.5.<sup>10</sup>

### GUIDELINES

There is a strong consensus in the United States that all women ages 65 and older should receive a BMD test routinely. The medical community is also close to consensus that post-menopausal women under age 65 who are at increased risk for osteoporotic fracture should receive a BMD test routinely, (Table 2).<sup>8,11,12</sup> BMD testing is also recommended by the International Society for Clinical Densitometry for all men ages 70 and

older, and all men under age 70 who present with fragility fractures or who are at increased risk for osteoporotic fracture.<sup>12</sup>

National guidelines promote routine patient education for osteoporosis prevention and select medication use for high-risk individuals.<sup>8,12</sup> Approved options for the treatment and prevention of osteoporosis include calcium, vitamin D, estrogen replacement, alendronate, risidronate, raloxifene, calcitonin, and teriparatide.<sup>2</sup>

## RHODE ISLAND STATISTICS

### *BURDEN*

An estimated 172,600 men and women in Rhode Island (RI) ages 50 and older have osteopenia or osteoporosis.<sup>7</sup> As expected, the majority of Rhode Islanders at risk are postmenopausal women (Table 3), but about one-third are men. (Estimates of the prevalence of low bone mass in Rhode Island are not presently available by race and ethnicity.)

### *Screening*

In 2003, 63% of Rhode Island women ages 65 and older (the group at highest risk of LBM) reported that a health care provider ever recommended BMD testing.<sup>13</sup>

### *Counseling*

In 2003, 63% of Rhode Island women and 10% of Rhode Island men ages 50 and older reported that a health care provider had ever discussed the risk of osteoporosis with them.<sup>13</sup> Nearly half of the women ages 50 and older (51%) but only 12% of men in this age group reported that a doctor, nurse, or other health care professional had ever spoken to them about calcium in the diet.<sup>13</sup>

## DISCUSSION

### *Missed Opportunities*

Despite a strong national consensus that women ages 65 and older should receive a BMD test, one in three Rhode Island women in this age group did not recall a health care provider ever recommending it. Most women in this age group (93%) had visited a health care provider in the past 12 months for routine medical care. Thus, in more than 20,000 recent encounters for routine medical care, health care providers missed an opportunity to recommend an essential test. Many opportunities to counsel patients about osteoporosis were also missed. One-third of Rhode

Island women ages 50 and older reported never having been counselled about osteoporosis despite a recent encounter for routine health care (totalling about 50,000 visits). Even more women had no recollection of discussing dietary counselling with a health care provider despite a recent medical encounter (totalling about 70,000 visits).

Health care providers often play a key role in behaviour change. Patient counselling about osteoporosis, its prevention, detection, and management, may lead to lifestyle change and timely diagnosis and treatment. Messages relevant to osteoporosis are relevant to the prevention and control of obesity, arthritis, cancer, diabetes, and cardiovascular illnesses.<sup>14,15,16</sup>

- ⊙ Eat a balanced diet with attention to calcium-rich foods.
- ⊙ Get regular, weight-bearing exercise.
- ⊙ Don't smoke; don't drink to excess.

### *Men*

Although most recent data estimate that 25% of men ages 50 and older will have an osteoporotic fracture in their lifetimes, few men receive education about this chronic and debilitating disease, or treatment for it.<sup>7,17</sup> Among older Rhode Islanders, men are far less likely than women to report that a health care provider had ever discussed osteoporosis or dietary calcium with them, and this despite significant smoking histories in a majority of Rhode Island men ages 50 and older (68%).

### *Limitations*

Rhode Island data for this brief were generated by the Rhode Island **Behavioral Risk Factor Surveillance System (BRFSS)**. This statewide random-digit-dial telephone survey collects information on a wide variety of health issues from Rhode Island adults 18 years of age and older. Limitations of the BRFSS should be considered when interpreting BRFSS results. First, persons who do not have a telephone cannot participate in the BRFSS. Second, the BRFSS is less likely to survey people of low income than others. Third, all data are based on self-report from respondents. Some individuals may have difficulty remembering counseling and testing.

## CONCLUSIONS

Despite the limitations of the BRFSS, the data in this brief demonstrate considerable room for improvement in the routine health care of older Rhode Islanders. Based on the findings presented here, the Rhode Island Osteoporosis Program remains strongly committed to working

collaboratively with the Rhode Island Osteoporosis Coalition on public and professional education, surveillance, and advocacy to improve the health of Rhode Islanders.

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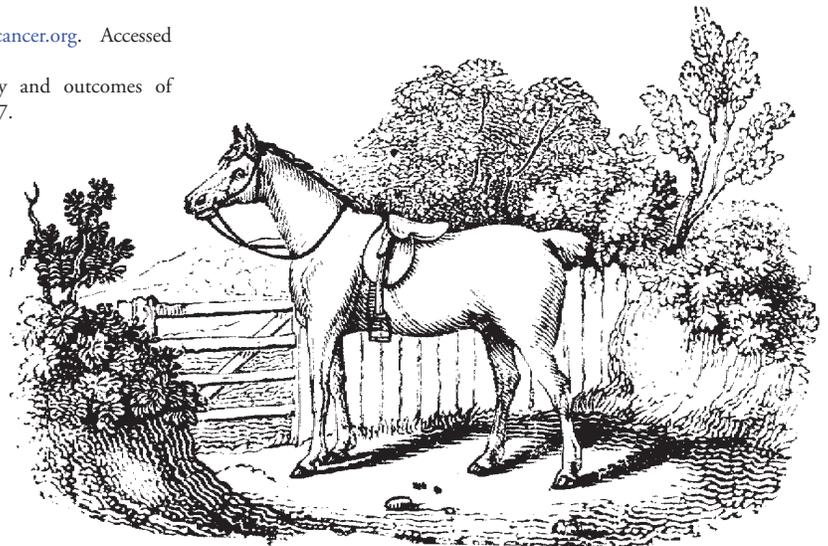
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*Nancy Sutton, MS, RD, is Public Health Nutritionist, Office of Women's Health, Division of Disease Control and Prevention, Rhode Island Department of Health.*

*Deborah Pearlman, PhD is Assistant Professor Research, Department of Community Health, Brown Medical School, and Senior Epidemiologist, Cancer Control and Obesity Prevention Programs, Division of Disease Prevention and Control, Rhode Island Department of Health.*

*Geetha Gopalakrishnan, MD, is Clinical Assistant Professor, Department of Medicine, Brown Medical School, and Clinical Staff Physician, Hallett Center for Diabetes and Endocrinology, Rhode Island Hospital.*

*Diane Callahan, BS, RN, is a Research Nurse at the Hallett Center for Diabetes and Endocrinology, Rhode Island Hospital.*





## POINT OF VIEW

# TIME STRESSES IN THE LIVES OF PHYSICIANS

MELVIN HERSHKOWITZ, MD

In May, 2004, sixty-two years after I entered New York University School of Medicine in 1942, I retired from the Voluntary Clinical Faculty in the Department of Medicine at the Brown Medical School. Since then, I have had ample time to reflect on my careers in private practice in New York City and Washington, DC, on my military service, as a Captain and Commanding Officer of the Medical Detachment of the 27th Infantry Regiment in Occupied Japan after WWII, and on my academic and administrative medicine experiences in four different medical schools before coming to Brown. Now, as an elderly but intact retired doctor looking back on the gratifications and negative aspects of the past decades, it is clear that a serious problem, which I will call Time Stress, was a frequent counterweight to the many positive factors which give meaning and value to doctors' careers. This essay does not discuss the many gratifications which come in one form or another to all physicians: intellectual stimulation, service to patients, teaching medical students and house officers, interactions with colleagues, and contributions to the community at large bring their own intrinsic rewards. However, alongside all of these, Time Stress was for me, and is still, an ineluctable fact of daily life for medical students, residents, and older physicians in varying specialties.

I define Time Stress as the dilemma of how to meet not only the regularly scheduled, but the often intrusive, unexpected professional responsibilities of a doctor, while trying to participate in other aspects of daily life, including time with spouse and family, pursuit of avocational interests in music, film, theatre, art, sports, politics and travel, and taking an active role in community affairs. When these circumstances collide, the stage is set for both acute and chronic turmoil and discontent. I encountered these situations with great frequency during my years in solo private practice as a general internist, and can report with some regret that I never found a way to achieve a tran-

quill sense of balance between the demands of work and the leisure activities I so intensely desired. Some medical specialties offer less exposure to Time Stress than family practice, ob-gyn, internal medicine, pediatrics and surgery. Rarely do radiologists, pathologists and dermatologists need to respond to unexpected calls on their special skills, but the managed care revolution has increased the burdens for even these less vulnerable physicians.

Time Stress is ubiquitous in medical school, since students must learn an entirely new language, in addition to enormous amounts of factual information. The burdens of such intense learning are unrelenting and onerous, and students cope by forming study groups, study partners, and resorting to acronyms to shorten time and space in describing laboratory tests, physical examinations, diagnoses, and therapy. A cursory examination of any medical chart will confirm this. This writer has a paperback book of Medical Abbreviations, the first edition of which, in 1983, contained 1700 abbreviations. Ten years later, the revised edition contained 8600 abbreviations. One can only imagine what a 2005 Edition might contain. These abbreviations, a response to Time Stress, are often conveniences at the expense of clarity and safety. Chosen at random, my initials, MH, may mean malignant hypertension, malignant hyperthermia, marital history, menstrual history, mental health, or moist heat. The initials LO-LOTF once described a "little old lady on the floor", who had fallen at home with a fractured femur. Such hazardous pathways of compressed expression may save time in medical records, but may add to the subsequent dangers and delays of misinterpretation and erroneous decisions. Once again, Time Stress intrudes within the demanding atmosphere of academic ambition and patient care.

Early and late long hours, large patient loads, morning report, ward rounds, and night call with inter-

rupted sleep comprise a smoldering Time Stress cocktail which must be imbibed by all students and residents, with varying levels of dysfunctional results. Even with the recent restrictions on total work hours for house staff, the demands of these often traumatic years can be staggering, and leave little time for personal and family life. These circumstances were humorously but seriously described by Dr. Perri Klass in *A Not Entirely Benign Procedure*, describing her four years at Harvard Medical School (G.P. Putnam's Sons, 1987). More seriously, and more ominously, Dr. Samuel Shem's *House of God* (Richard Marek Publishers, 1978) addressed the Time Stresses endured by a group of six PGY-1 interns at a major Harvard teaching hospital in Boston. All six were cynical and dysfunctional, and one committed suicide. Samuel Shem is the nom de plume of Dr. Steve Bergman, a distinguished psychiatrist. *House of God* has become a cult book for medical students, mostly because of its irreverent style and raunchy sexual humor, but its more serious message is highly visible.

The managed care revolution has added yet another massive Time Stress burden to physicians in solo practice, in office-based groups, and in hospital-based affiliations. The overwhelming and often irrational documentation requirements imposed by insurers and governmental agencies affect all physicians who care for patients. The cruelties of managed care are highly visible in the time stress background of needing to see large numbers of patients on a compressed schedule, little time spent with each patient, in order to attain a reasonable (not affluent) income to meet the expenses of office staff salaries and benefits, malpractice insurance and taxes. Patients are the innocent victims of this depersonalized system, sitting unattended for long intervals in isolated examination rooms, waiting for the speedy entrance (and exit) of their doctor, who is trying to cope with their needs and concerns

in an atmosphere which is inhumane and inimical to both. This scenario is capable of destroying the doctor-patient relationship, and has already done so on many occasions. Hospital-based physicians in an academic medical school affiliation, who need to see patients to achieve their compensation levels, while also conducting clinical research for publication and academic promotion, and simultaneously trying to teach medical students, residents, and specialty fellows, are subject to severe debilitating Time Stress. I have seen their grave discontent when their objectives cannot be met, and I have also seen the uncompensated teaching obligation cast aside in order to meet their other obligations. This has been visible to, and injurious to, the medical students in attendance.

I grew up in New York City. My mother was a pianist and music teacher. My father, an ENT surgeon, one of the first Diplomates in that specialty, graduated from medical school in 1921. He was afflicted with Otosclerosis, which had a major negative effect on his social activities, but not his professional accomplishments. My horizons were enlarged at Horace Mann School and Columbia before medical school. You may already sense that as a young man, I had wide exposure to so many interesting areas of sports, literature, politics, film, music, food and theatre, resulted in 41 subsequent years of intermittent frustration, tension and turmoil as a doctor, when I was unable to pursue those many interests. I was not able to resolve the stressful situation of competing claims on my available time. As a general internist in solo practice, 1950-1971, in academic and administrative medicine, 1971-1980, and again in solo practice, 1980-1991, I encountered frequent exposure to sudden unforeseen professional obligations which intruded on my time with family, friends and recreational activities. Some doctors achieve an inner peace in such circumstances. They come to terms with their omissions and sacrifices, and reach a tranquility which always eluded me. I was never very good at accomplishing that. In contrast, my father, the oldest of eight brothers and sisters, and the patriarch of his family, lived a far more contented life. His family and his ENT practice were pre-eminent in his universe. His recreational horizons were limited by his otosclerosis, and in one

sense, contributed to his contentment, since his leisure pursuits were minimal, and he did not miss what he knew he could not enjoy. I knew that our Friday night theatre visits, when he could not hear the dialogue or music, were gestures of his affection for and devotion to my mother. He had a level of inner contentment and satisfaction which I could never reach in all the years we were doctors together, from the time of my graduation from New York University School of Medicine in 1945 to his death in 1988 at age 93. He practiced in his office until age 86, when most of his patients had pre-deceased him, and his siblings were old, sick, or dead. Life held little interest for him after that, and his last years were a sad decline. Ironically, had he shared my own interests, agitation and discontents, his final years might have been better.

A illustrative event took place on a Saturday afternoon in 1966 in Madison Square Garden. My son Paul was a guard and Captain of his high school basketball team. They had a game as a preliminary to a Knicks game. I went to the game with much anticipation, as Paul's proud father. At the start of the second half, a man sitting a few rows behind me had an epileptic seizure. By the time I reached him, the seizure was over, but his post-ictal state required additional observation. I helped the ushers take him to the Madison Square Garden medical department office in the basement, reported to the doctor on duty there, and helped arrange his transportation home and after-care. By the time I returned to the game, there was only one minute to play. I had missed the entire second half. Paul's team lost, but he scored 22 points to lead his team. I was full of anger, and global resentment at having missed half the game, and Paul's good performance, in a situation I could not control. My distress lingered for a long time, and only slowly dissipated as time passed. Later, I received two nice action pictures of Paul, dribbling and shooting during the game. Now, at age 82, I look at them occasionally with a lingering mixture of admiration and retrograde frustration. Paul is now a rotund 56 and his athletic days are long over. This brief event, trivial as it may seem, epitomized for me the frustrations and disappointments which many doctors must face and resolve, one way or another, in their personal and professional lives.

Every physician must seek and find an individual solution to this dilemma of Time Stress. It may involve serious deprivation and sacrifice, and may not be easy.

I often find myself humming the lyrics of Rudy Vallee's old song:

*My Time Is Your Time,  
Your Time Is My Time,  
There's No Time Like Our Time,  
And No one Like You.*

Only the first line was applicable to much of my life to date.

*Melvin Hershkowitz, MD, is Clinical Assistant Professor of Medicine, Emeritus, Brown Medical School.*

#### **CORRESPONDENCE:**

e-mail: DrMel23@cox.net



# A PHYSICIAN'S LEXICON

## THE COLORFUL WORDS OF MEDICINE, PART II

Last month's Physician's Lexicon began an etymological inquiry into medical terminology, of Greek and Latin derivation, portraying color. This column will complete the spectrum, at least of the principal hues.

The Greek word for blue, *kyanos*, has given rise to the English word, cyanide [because of its bluish hue], cyanogen, cyanosis and cyanhemoglobin. The Latin equivalent, *caeruleus*, literally sky-blue, is from the Latin, *caelum*, meaning sky, as in words such as celestial or ceiling. *Caeruleus* also appears in medical terms such as cerulean and *locus ceruleus*. The Latin, *lividus*, meaning blue [or sometimes leaden-blue] is the origin of the words lividity and livor mortis. The Greek word, *glaukos*, means blue-green as in the adjective *glaucous* or *glaucoma*.

The Greek word for green, *chloros*, appears in modern words and

names such as chlorophyll, chloromycetin, chlorosis, chlorine [coined by Humphrey Davy] and Chloe. The Latin for green, *viridis*, appears in numerous English words including verdant, verdigris and viridity. There are, however, numerous Latin words also beginning with *vir-* but conveying strikingly different meanings [eg, *virilis*, meaning manly; *virgo*, meaning maiden-like; and *virus*, meaning poison] and their English descendants [virulent, virilent and virtuous] can be confusing.

The Greek word for red, *erythros*, is seen in currently used words such as erythema, erysipelas, erythrocyte, erythralgia and erythromycin. The Latin equivalents are *rufus* and *ruber*. Derivative words include bilirubin, rufus, rubella, rubeola, rubefacient, rubidium, ruby and rubric.

The Greek, *chryseus*, meaning golden, appears in such con-

temporary words as chrysalis and chrysanthemum. The Latin counterpart is *aureus*, as in words such as aureomycin, aurora, orpiment, oriole and El Dorado.

Silver has its verbal roots in both Greek and Latin. The Greek, *argyros*, has its current representation in argyrol, argentophile and argyria. The Latin equivalent is *argentum*, which forms the roots for words such as Argentine, Argo, litharge and Pelargonium.

The Greek word for color, *chroma*, is found virtually unchanged in the Latin, *chromaticus*, both forming such current words as chromatin, metachromasia, chromium, chromatography and chromosome. And the word, spectrum, meaning an array of colors ordered in accordance with their wave-lengths, is derived from the Latin, *specere*, meaning to look at, as in words such as speculum, speculate, spectacles, spectroscopy and species.

-STANLEY M. ARONSON, MD



RHODE ISLAND DEPARTMENT OF HEALTH  
DAVID GIFFORD, MD, MPH,  
ACTING DIRECTOR OF HEALTH

## VITAL STATISTICS

EDITED BY ROBERTA A. CHEVOYA, STATE REGISTRAR

### Rhode Island Monthly Vital Statistics Report

Provisional Occurrence Data  
from the  
Division of Vital Records

Underlying Cause of Death	Reporting Period			
	April 2004	12 Months Ending with April 2004		
	Number (a)	Number (a)	Rates (b)	YPLL (c)
Diseases of the Heart	214	3,010	281.4	4,466.5
Malignant Neoplasms	182	2,403	224.6	7,651.0
Cerebrovascular Diseases	35	533	49.8	897.5
Injuries (Accident/Suicide/Homicide)	25	468	43.7	7,227.0
COPD	44	521	48.7	452.5

Vital Events	Reporting Period		
	October 2004	12 Months Ending with October 2004	
	Number	Number	Rates
Live Births	912	13736	12.8*
Deaths	827	10073	9.4*
Infant Deaths	(9)	(78)	5.7#
Neonatal deaths	(8)	(64)	4.7#
Marriages	1009	8393	7.8*
Divorces	296	3,220	3.0*
Induced Terminations	394	5,459	397.4#
Spontaneous Fetal Deaths	95	1,134	82.6#
Under 20 weeks gestation	(91)	(1,058)	77.0#
20+ weeks gestation	(4)	(76)	5.5#

(a) Cause of death statistics were derived from the underlying cause of death reported by physicians on death certificates.

(b) Rates per 100,000 estimated population of 1,069,725

(c) Years of Potential Life Lost (YPLL)

Note: Totals represent vital events which occurred in Rhode Island for the reporting periods listed above. Monthly provisional totals should be analyzed with caution because the numbers may be small and subject to seasonal variation.

\* Rates per 1,000 estimated population

# Rates per 1,000 live births

### NINETY YEARS AGO, APRIL 1915

An Editorial praised the recent “official communication” from the US Department of Agriculture on “the proper labeling of medicinal preparations.” The communiqué banned the words, cure, remedy, infallible, certain, reliable – unless “actually capable of fulfilling the promises made for it. It pronounced the phrase, widely recommended, “subject to doubt.” It objected to certain names, like Kidney Pills, Blood Purifier, Nerve Tonic, because of “the suggestion which they carry.” It found testimonials “valueless,” cautioning: “A remedy advertised as a cure for seasickness is fortified by testimonials of persons who have made a sea passage without suffering the pangs of that disease, but they may have had an unusually smooth trip and would not have been sick anyway.” Furthermore, the Editorial praised the *Providence Journal*, which had banned “objectionable” medical advertising: “[It] is certainly entitled to a great deal of credit, for it must mean a serious financial loss.”

A second Editorial criticized several physicians for asking a surgeon to use “Twilight Sleep” instead of anesthesia. “McClure’s and The Cosmopolitan have vied with each other in their sensational advertising of this fake...” Promoters claimed Twilight Sleep was “detoxicated morphin [sic],” though analysts said it was essentially morphin [sic].

Edward Burt, MD, in “The Clinical Recognition and Treatment of Some Common Deformities of the Foot, pointed to “weak foot” as the most common deformity. “It occurs from childhood to old age and is responsible for most of the painful and disabled feet seen by the physician.”

### FIFTY YEARS AGO, APRIL 1955

The Journal reprinted “The Clinical Problem of Aseptic Meningitis,” the talk Derek Denny-Brown, James Jackson Putnam Professor of Neurology, Harvard Medical School, gave at the 108<sup>th</sup> annual meeting of the Providence Medical Association.

Jesse P. Eddy, 3<sup>rd</sup>, MD, FACS, In “Bilateral Adrenalectomy and Oophorectomy in the Treatment of Recurrent Carcinoma of the Breast,” noted that he had performed the procedure on 8 patients since 1953. Of the first 7, 2 died.

Edwin O. Hirsch, MD, discussed the case of a 19 year-old man with acute lymphatic leukemia in “The

Problem of Platelet Transfusion.”

In “Ruptured Lumbar Intervertebral Disk Syndrome Caused by Metastatic Cancer,” David LaFia, MD, discussed the case of a 57 year-old woman who complained of right sciatica. Twenty years earlier, she had had a total hysterectomy, but physicians noted no malignancy. Her treatment was a bilateral lumbosacral laminectomy.

An Editorial, “We’ve Done Our Children Wrong,” supported Dr. Henry Utter, who argued against “...the continual despoiling of the few open spaces left to us in Providence.” Officials had seized “the best part of Davis Park” for the Veterans’ Administration Hospital.

### TWENTY-FIVE YEARS AGO, APRIL 1980

Manuscripts were abbreviated versions of papers presented at a symposium on “Life Stress and Depression.” Robert Westlake gave the Introduction. Presenters included Louis I. Hochheiser, MD (“Stress Effects of Changing Roles and Work Events on Mid-Life”); Jack C. Westman, MD (“Family Stress and the Physician”); Paula J. Clayton, MD (“Clinical Insights into Normal Grief”); Myrna M. Weissman, PhD, and Jerome K. Myers, PhD (“The Magnitude of Depression in the Community”); Herbert C. Modlin, MD (“Management of Suicidal Behavior”).

In the Dean’s Message, “Some Problems Facing Medical Education in the Decade Ahead,” Stanley M. Aronson, MD, elaborated on those problems; e.g., the quality of future physicians, the supply of future faculty, the role of physicians in educating patients, the costs of health care.

**FORTHCOMING**

*Medicine & Health/Rhode Island*

*May 2005*

**Autism**

*Guest Editor:*

*Joseph J. Hallett, MD*

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