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## Health care disparities continue among minorities, the poor, says HHS

*Reports are first national effort to measure quality of U.S. health care*

African-American and low-income U.S. residents are more likely to die from cancer, less likely to be insured, and less likely to have usual sources of health care than white and higher-income Americans, recent reports from the U.S. Department of Health and Human Services indicate.

According to the first *National Healthcare Disparities Report*,<sup>1</sup> issued in December 2003 by the Agency for Healthcare Research and Quality (AHRQ), Americans generally receive exceptional quality in health care, but some socioeconomic, racial, ethnic, and geographic differences exist.

Among the report's key findings:

- Most Americans have access to public or private health insurance, but poor people and some minorities are less likely to be insured. Those same populations, if insured, are more likely to have public insurance.
- People of lower socioeconomic status (SES) and blacks have higher death rates for all cancers combined.
- Hispanics and American Indians or Alaska natives are less likely to have their cholesterol checked.
- People of lower SES and some minorities are less likely to have a usual source of care.
- Rates of admissions for conditions that usually are treatable with ambulatory care are generally higher for people who live in low-income areas compared with those who live in high-income areas.

On the other hand, some of the data on the studied "priority" populations indicate they have better outcomes in some areas than the general population:

- Asians and Pacific Islanders, American Indians/Alaskan natives, and Hispanics have a lower death rate from all cancers.
- Blacks have higher rates of Pap smears and blood pressure monitoring and lower rates of postoperative hip fractures compared to whites.
- Black and Hispanic patients are more likely to report that their

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health care provider usually asks about medications prescribed by other doctors.

• Hispanics, Asians, and Pacific Islanders have lower rates of hospitalization from influenza.

“The data in these reports provide an important message for the nation — we are making progress in enhancing health care quality and access, but we can do more and we need to do more,” says **Carolyn M. Clancy**, AHRQ’s

director. “The first editions of these reports, and those that follow, are an important key to meeting that challenge.”

The report, and its companion, the AHRQ’s *National Healthcare Quality Report*,<sup>1</sup> were mandated by the federal Healthcare Quality and Research Act of 1999 (now section 903(a)(6) of the Public Health Service Act). The law requires AHRQ to develop two annual reports: a *National Healthcare Quality Report* and a *National Healthcare Disparities Report*.

The quality report evaluates the quality of the health care available to and accessed by Americans overall. The disparities report is designed to track “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations.”

The framework for evaluating both the quality of health care overall, and for disparities in health care, was developed with input from the Institute of Medicine (IOM), the reports’ authors note.

According to the disparity report’s executive summary, both reports were released simultaneously because both should be taken together as an indication of the overall level of quality in health care in the United States.

The disparities report evaluates the quality of health care experienced by “priority populations” compared to the U.S. population overall. The report’s defined priority populations include:

- women;
- children;
- the elderly;
- racial and ethnic minority groups;
- low-income groups;
- residents of rural areas;
- individuals with special health care needs, specifically children with special needs, the disabled, people in need of long-term care, and people requiring end-of-life care.

Then, the report examines the following aspects of the care received by the priority populations:

- **effectiveness** — care based on scientific knowledge; is it provided to all patients who could benefit and not provided to patients unlikely to benefit;
- **safety** — care that avoids injuring patients through care intended to benefit them;
- **timeliness** — care that reduces delays in use of care;
- **patient centeredness** — care that is respectful and responsive to the individual needs, preferences, and values of patients;
- **equity** — care that encompasses the need for health care systems to provide care that does not

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## Editorial Questions

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vary in quality because of personal characteristics (such as gender, ethnicity, geographic location, and SES).

Both reports are supposed to serve as an annual comprehensive snapshot of the performance of our health care system, its strengths, and areas that should serve as a focal point for future improvement, the authors note. The performance measures underlying the two reports will be used to monitor the nation's progress toward improved health care delivery.

A key challenge in developing the report, however, was defining what constituted a "disparity" in care with the population as a whole. Recent federal reports have come up with a number of different ways of looking at disparities in care. For example, in pursuit of its overarching goal of eliminating health disparities, *Healthy People 2010*<sup>2</sup> considers all differences in its measures as evidence of disparities.

At the other end of the spectrum, a recent report by the IOM, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*,<sup>3</sup> defined health care disparities as differences that remain after taking into account patient needs and preferences and the availability of health care; notably, after an exhaustive literature review, the IOM report concluded that no study ever conducted has met this most rigorous definition of disparities. Still others associate health care disparities with adverse health outcomes, personal responsibility, or provider prejudice.

In the absence of consensus on the definition of disparities, the authors note, AHRQ report will focus on presenting stand-alone facts. Where researchers find variation among populations, this variation simply will be described as a "difference," the report states. By allowing the data to speak for themselves, it continues, there is no implication that these differences result in adverse health outcomes or imply prejudice in any way.

Some health quality advocates, however, are not pleased with the overall focus of the reports and on the broadened focus on variations among populations without examining possible causes.

"Recognizing that the health care disparities identified in the Institute of Medicine's landmark report, *Unequal Treatment*, still very much exist, we are perplexed that these two reports appear to shift the focus away from eliminating healthcare disparities," says **Roland W. Maxey**, MD, PhD, president of the National Medical Association (NMA) in Washington, DC, a professional society for physicians of African descent. "The new focus

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has as its premise, [the need to] 'increase health care quality for all' with emphasis on eliminating health disparities based on race or ethnicity all but disappearing."

Although the new focus may be well intentioned, Maxey says, it is not the most appropriate course to follow when so many Americans, because of their race or ethnicity, do not receive the same level of health care as the majority population.

The IOM report was very clear that some disparities in access to care and in health outcomes could only be attributable to racial or ethnic biases, Maxey tells *Medical Ethics Advisor*.

By emphasizing a goal of "quality for all," the AHRQ report ignores the fact that not all Americans are starting from the same place, he adds.

"Some populations, historically, have not had access to care, have not had good experiences with health care, some do not even know how to get health information or apply it to their lives," he explains. "Not everyone is going to be able to pull themselves up by their bootstraps. So, just providing that opportunity is not enough."

The reports' focus, he fears, indicates that funding specifically dedicated to outreach in at-risk populations may be in danger, and the NMA will work to ensure that does not happen.

"We at the NMA, however, commend the effort [at examining the existence of disparities] and we look forward to working with all of those of good will in redirecting how the report is used to create a blueprint for eliminating health care disparities and addressing the IOM's findings," he said.

Both of the AHRQ's reports are available for download on-line at: [www.qualitytools.ahrq.gov](http://www.qualitytools.ahrq.gov).

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## Examining choice to cease mechanical ventilation

### *Perception of patient's wishes forms decision*

Rather than age or severity of illness, the strongest determinants of the withdrawal of ventilation in critically ill patients are often the physician's perception that the patient preferred not to use life support or had a low chance of survival in the intensive care unit, a recent study<sup>1</sup> by the Canadian Critical Care Trials Group and the Level of Care Study Investigators has found.

Decisions about withdrawal of life support are among the most complex and difficult choices faced by critical care physicians and families of patients, says **Maurene A. Harvey**, RN, MPH, FCCM, a critical care nurse educator and past president of the Des Plaines, IL-based Society of Critical Care Medicine.

In the study, researchers evaluated adults receiving mechanical ventilation in 15 intensive care units in the United States and Canada. They recorded baseline physiological characteristics, daily Multiple Organ Dysfunction (MOD) scores, the patient's decision-making ability, the types of life support administered, any use of do-not-resuscitate orders, the physician's prediction of the patient's status, and the physician's perceptions of the patient's preferences about the use of life support.

They then examined the relationship between all of the separate factors and the withdrawal of mechanical ventilation. Of the 851 patients in the study, 539 (63.3%) were successfully weaned from the ventilator, 146 (17.2%) died while receiving mechanical ventilation, and 166 (19.5%) had mechanical ventilation withdrawn.

The need for isotropes or vasopressors was associated with the withdrawal of the ventilator, as were the physician's prediction that the patient's likelihood of survival in the intensive care unit was less than 10%, the physician's prediction that future cognitive function would be severely impaired and the physician's perception that the patient did not want life support used.

"I think the researchers found it surprising that the severity of the patient's illness and the MOD scores didn't affect the decision," Harvey says. "Not that they felt it wasn't good that the physicians did take the patient's and family's wishes into account, but that it indicates an evolution of our understanding of the issues."

Research into end-of-life issues in intensive care is a young science, notes **Mitchell Levy**, MD, FCCM, director of the medical intensive care unit (ICU) at Brown University and Rhode Island Hospital in Providence.

"We don't know a lot about how people die in critical care — that is, what that experience is like," Levy explains. "As we begin to look at things like whether these patients have a 'good death,' we are starting to look at the factors influencing death in the ICU."

Recent studies indicate that approximately 90% of deaths in the ICU are preceded by withdrawal of life support of some kind, almost double the percentage reported in studies as recent as five years ago, he adds.

Therefore, the researchers felt it important to look at factors influencing the withdrawal of life support — particularly mechanical ventilation.

### ***Discerning appropriate level of care***

Historically, in critical care, clinicians have used all available interventions at their disposal to treat patients, and, conventional wisdom would hold that decisions would largely be based on clinical criteria, such as age or severity of illness, the study's authors note.

But in recent years, clinicians, ethicists, and patient advocates have questioned the use of advanced interventions in so many cases, urging more judgment about which patients would be likely to benefit, Harvey adds.

Making these determinations is very difficult with critically ill patients. The illness and injuries they have, and the treatments available to use, are very complex and difficult to explain to family members. And not all patients may react in the same manner to available treatments. Patient and family perceptions about quality of life, and their subsequent wishes regarding treatment, may differ significantly from patient to patient.

Clinicians must evaluate complicated sets of data about each patient's condition, convey this complicated information to the patient and/or family members, and then help them come to decisions about how to proceed.

Ideally, the physician will delineate the available choices and options for treatment, provide information about the possible outcomes of each course, and then help the patient or family member make a decision that is consistent with their values and wishes.

In the old days, it was “cure at all costs,” Harvey says. With move toward more patient autonomy and decision making, the pendulum sometimes swings too far, with family members of critically ill patients faced with decisions that they find overwhelming and unprepared for.

The challenge for critical care practitioners now is to determine how to provide patients and families the appropriate context for making such decisions.

“More than any other area, in critical care, you really have to blend the science and the art of medicine,” Harvey explains. “In the past, we tended to do research on critical care medicine and focus on the science of different interventions. It thrills me to see researchers finally focusing on the art. We keep pushing the envelope in science, about how we can help people survive things they never would have survived 10 years ago. We keep pushing that envelope; but at the same time, we need to keep pushing the envelope of our ethical discourse as well — to make sure we keep developing our experience and judgments.”

### ***Need for better info on patient wishes***

The study indicates that physicians are making clinical determinations about the patient’s condition and prognosis and then using that information in conjunction with what information they have about the patient’s wishes, Levy says.

The bad news is that previous studies have indicated that, when physicians try to guess about a patient’s wishes at the end of life, they frequently are wrong. Studies of family members indicate they are often no better at guessing correctly about what measures a relative would or would not want, he adds.

“If we had a lot of confidence that physicians could reliably predict a patient’s wishes, then this would be very good news,” Levy says. “But that is not the case.”

Most people still do not enter an intensive care unit with documented advance care plans in place, and family and caregivers often have no information about what the person would have wanted.

In general, people do not discuss their wishes with family members because they either feel that

their relatives’ opinions mirror their own or because they are uncomfortable talking about death, Levy says.

The public and clinicians need to become more comfortable discussing death — even when death is not imminent. In particular, health care providers should initiate conversations about advance planning with patients when they are diagnosed with chronic conditions, he adds.

### ***ICU stays***

Harvey also highlighted the study authors’ comparison of the outcomes of their patients with published outcomes of critical care patients treated in intensive care units a decade ago. The patients in the current study who remained on the ventilator were the ones most likely to survive in the intensive care unit. Ten years ago, patients were more likely to remain on a ventilator until dying in the ICU.

“I think this indicates our decision making is getting better,” she adds. “We are not just pushing all the time. We are more likely to bring up the discussion [about terminating ventilation] early rather than late, instead of just keeping on until everything fails.”

As further evidence of this, she points out that patients in the study who received vasopressors or isotropes were more likely to have ventilator support withdrawn.

Patients with lung disease, who are on ventilators, can do well if they have strong hearts that can compensate and help increase blood oxygenation. However, patients with lung disease, or lung injury, who also have cardiac problems, frequently are too ill to improve and derive much benefit from mechanical ventilation.

“One of the worst combinations you can have in critical care is a patient with lung disease on a ventilator who also has a bad heart,” she notes. “The [use of medications to support blood pressure and cardiac function] related to withdrawal of ventilation indicates that they were making decisions appropriately, step by step, deciding each day — is this level of care appropriate for this patient at this time?”

Although patients or their surrogate decision makers may want to try intensive interventions at first, hoping for the best, once the patient’s condition worsens past a certain point, they may decide such interventions are not appropriate — and that is reflected in the current study’s information, Harvey notes.

## SOURCE

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It's important for more research to be done into the "art" of critical care, so that best practices and ethical decision-making skills can be developed, Harvey says.

"We all have our clinical experience to draw from, and you need experience," she says. "But you also need solid research like this to back it up."

### Reference

1. Cook D, Ricker G, Marshall J, et al. Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *N Engl J Med* 2003; 349:1,123-1,132.

### For more information

- **The Society of Critical Care Medicine (SCCM)** has published guidelines for withdrawal of ventilator support. They are available on the society's web site at [www.sccm.org](http://www.sccm.org). Click on the heading "Professional Resources" and the subheading "Guidelines" to find them.

SCCM also has several patient information pamphlets available for download. These pamphlets are designed to explain different aspects of critical care and intensive care units to patients and families. They also are available on the SCCM web site under the heading "Patient and Family Resources." ■

## Bioterrorism program may harm public trust

*Plan may complicate vaccination campaigns*

Public health officials should carefully evaluate the reasons for low rates of participation of health care workers in Phase 1 of the federal Smallpox Preparedness Plan before expanding the vaccination campaign if they hope to preserve the public's trust in vaccination campaigns as a viable public health measure, a group of ethicists from the University of Pennsylvania warn.

In a paper published in the Fall 2003 edition of the *American Journal of Bioethics*, **Pamela Sankar**, PhD, and colleagues from the University of

Pennsylvania Center for Bioethics and the Children's Hospital of Philadelphia argued that the federal plan is missing some key elements necessary to encourage targeted populations to participate and these issues must be addressed both in order to make the plan successful and to ensure public trust in future public health initiatives.

"Foreign intelligence reports that identified the United States as the potential target of a bioterrorist attack were cited by the government as justification for the unprecedented speed of the development and implementation of the CDC's [Center for Disease Control and Prevention's] Smallpox Vaccination Program," the authors wrote. "Passing time has demonstrated that this haste was unnecessary, as there has been no attack on the United States population or elsewhere. Passing time has also shown that we should be grateful the program was unnecessary because people chose not to trust the government's plan for protecting them."

As of this summer, only roughly 10% of the estimated 440,000 targeted hospital personnel had consented to receive the vaccine during Phase 1 of the program.

Sankar and colleagues cited a number of factors as the likely reasons for the unexpectedly low participation:

- **Health risks associated with the vaccine**

The smallpox vaccine is a live-virus vaccine that carries a risk of transmission of the virus, vaccinia, to close contacts. There also is a high risk of health complications for people who are immunocompromised or have other health conditions.

Prior to implementing the vaccine program, the CDC developed a comprehensive screening program designed to weed out personnel who were likely to experience an adverse reaction (estimates indicated that the current vaccine would be contraindicated in one in five Americans). The agency also developed guidelines for the covering of the vaccine site in vaccinated health care workers to prevent transmission to patients and close contacts.

However, Sankar and colleagues argued, the screening programs were not extensively tested in small groups prior to the large-scale implementation of the vaccination campaign, and some people who received the vaccine experienced unforeseen health problems.

Although the overall incidence of adverse events was within expected parameters, previously unknown adverse events emerged. In March 2003, public health authorities reported a possible increased incidence of cardiac inflammation and

ischemic cardiac disease among recently vaccinated individuals.

- **Liability and risk to patients**

Throughout the preparation and launch of the smallpox plan, media reports indicated that health care providers were concerned both about the risk of transmission to patients and the liability they might face if they accidentally transmitted vaccinia.

In addition, they questioned whether they would be compensated in the event they experienced an adverse reaction to the vaccine and were unable to work.

These concerns were not rapidly and comprehensively addressed, leading to widespread mistrust of the vaccination campaign, the authors stated.

Federal legislation that released the manufacturers of the vaccine from any liability associated with the vaccine's side effects was passed while the vaccination campaign planning was in its infancy; yet, by contrast, legislation to protect vaccine recipients was not passed until the program already was under way.

Because of this, some unions requested that their members refrain from participation until liability and safety concerns had been addressed.

### ***Health campaigns need public trust***

The federal government's slow response in addressing these issues hurt participation in the smallpox program because those asked to participate did not trust the campaign's leadership and direction, the authors argued.

This, in turn, could hurt future federal public health initiatives.

Participation in public health campaigns, particularly vaccination campaigns relies on maintaining public trust and confidence in the process, the authors stated.

The lack of participation in Phase 1 of the smallpox plan also may have a larger impact on other vaccination campaigns — particularly those targeting the public at large — because of the specific population involved in this effort, says **Peter H. Meyers, JD**, professor of clinical law at the George Washington University School of Law in Washington, DC, and director of the law school's Vaccine Injury Clinic.

"What is so interesting here is that it is the medical establishment here who is saying, 'We don't trust the vaccine. We don't see the need for it. We don't want to be involved with it,'" he tells *Medical Ethics Advisor*. "There is a very big debate

in this country, and in many countries, about the dangers and risks and benefits of vaccines. And there is a lot of concern about public mistrust of vaccination. And a lot of doctors and health care professionals always say the mistrust is the result of the public getting misinformation, going to the Internet and getting scare stories and misinformation, and that if the public had all the information about the risks and benefits of vaccination, then they would choose to be vaccinated. But that has not been the case with this program."

### ***Bioterrorism complicates decision making***

But preparing for a potential terrorist attack with a weaponized infectious agent is much different than implementing a typical large-scale vaccination program, and such efforts should be judged differently, argues **Ronald Blanck, DO**, president of the University of North Texas Health Science Center in Fort Worth, former U.S. Army Surgeon General, and head of the Army Medical Command.

Even a nominal threat of a bioterrorist event merits some pre-activity response. And when public health officials were informed that there was information an attack was possible, they had no way of knowing whether the country needed to be prepared for an attack the next day or the next year.

A multisite release of weaponized smallpox has the potential to cause massive mortality and morbidity nationwide, and a plan that involves having a set number of health care workers pre-immunized so that they would be able to quickly and safely care for those affected is a prudent protective measure, says Blanck.

"Given the reasonable assumption that an attack is possible, then I think it would be ethical behavior, particularly as health care workers, to do two things: one to minimize the threat, which you do that by immunizing a certain group. If a certain group is immunized, they can immunize the rest after a release, and, all of a sudden, you have reduced the threat of an severe outbreak to near zero," he says. "And the second obligation public health officials have is to avoid causing as much distress, illness and morbidity as possible. How do you do that? By limiting those who are immunized to health care workers, not immunizing the whole population — particularly since we know that with smallpox, you can be immunized after exposure — but immunizing a select number."

Blanck agrees that some elements of the federal

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plan could have been handled differently — particularly concerns about liability. But now that liability issues have been resolved, health officials should do more to communicate the essential facts and benefits of the program, he adds.

“I must admit that I don’t think these concerns have been well answered yet,” he says. “The CDC and the feds should have really gone to bat and really clearly and articulately laid out the liability protection. However, it is my belief that mostly that has been done and there is no reason for not getting [the vaccine] now.”

Blanck also says that new methods for preventing vaccine transmission from vaccinated health care workers have not been well publicized and

that federal officials need to make more of an effort to ensure that health care workers nationwide know that they can reliably prevent transmission to patients and to contacts, he adds.

Public health officials need to be more proactive and forthcoming and, perhaps, initiate “traveling road shows” to lay out the true pros and cons of participation in the program, and to provide as much background information as possible about what the threat is and why they think the smallpox plan is necessary, he says.

“At this point, the number of health care workers who have not stepped up and said, ‘Hey this is our responsibility,’ particularly with the things we have seen, is disappointing,” Blanck says. “I’m not convinced that it is enough to really do what we want. We haven’t assured a suitable protected group to respond in the event of a release. I would still like to see more participation.”

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## Voluntary dehydration as end-of-life option?

*Study reports on caregiver experience*

Studies of terminally ill patients indicate that a small number of them want the option of physician-assisted suicide (PAS) or other means of controlling the manner in which they die. Yet with PAS legal in only one state, most will not have that option.

Voluntary refusal of food and hydration has been proposed as an alternative to PAS that would allow patients to hasten their deaths if they want, without violating the law. But many clinicians and caregivers fear that such decisions will result in prolonged, severe suffering for patients choosing to do so.

However, a recent study<sup>1</sup> performed by researchers in Oregon indicates that a significant number of people do choose to do this and do not suffer a prolonged, difficult death as a result.

The researchers mailed a questionnaire to all nurses employed by hospice programs in Oregon, asking whether they had ever cared for a patient

choosing to refuse food and hydration and, if so, to report information about the most recent patient to do so.

They received 307 responses from the 429 questionnaires mailed and 102 of the respondents (33%) reported that in the previous four years they had cared for a patient who deliberately hastened death by voluntary refusal of food and fluids (VRFF).

The nurses reported a number of reasons given by patients for their choice: because they were ready to die, saw continued existence as pointless, and considered their quality of life poor. Eighty-five percent of the patients died within 15 days after stopping food and fluids. On a scale from zero (a very bad death) to nine (a very good death) the median score for the quality of these deaths, according to the nurses’ reports was an eight.

Compared to patients who chose PAS (which is legal in Oregon) during the same time period, the patients choosing to refuse food and fluids were typically older, less likely to want to control the circumstances of their death, and less likely to be evaluated by a mental health professional.

“Some patients do make this choice and health care providers need to be able to advise them about the consequences of the choices and continue to care for them,” says **Linda Ganzini**, MD, professor of psychiatry at Oregon Health and Science

University School of Medicine, director of the Palliative Care Fellowship at the Portland Veterans Affairs Medical Center, and the lead author of the study report. "Our study demonstrated, somewhat counterintuitively, that patients did not suffer intolerable discomfort with this choice, had good deaths, and died within two weeks."

## **Ethical issues**

During the debate over the passage of Oregon's Death with Dignity Act, which legalized PAS in that state, many ethicists drew a bright line between withholding and withdrawing treatment from terminally ill patients — which is universally considered acceptable — and physician-assisted suicide, which many ethicists consider unacceptable, Ganzini says.

Voluntary refusal of food and fluids occupies sort of a middle position between withdrawal or withholding of treatment at the patient's request and PAS, she continues. VRFF involves a deliberate decision by the patient to hasten death and still requires physicians and other caregivers to continue to provide care to the patient.

"VRFF shares some characteristics with each of these other types of choices and forces us to re-examine our thinking about the bright line," she says.

Both the recent study and other studies of PAS highlight the continued need for clinicians to expand their knowledge of how to provide good care at the end of life, Ganzini adds.

"Palliative and hospice care has focused on control of symptoms, spiritual concerns and the family's needs," she explains. "But our data suggest that there is a group of patients for whom the most important goal is remaining in control and not being dependent on other people. We need to do a better job of recognizing these people and helping them plan for the end of life."

Although their research found a number of reports of patients choosing VRFF, not much is known nationwide about how many patients choose to do this.

In Oregon, the state, health systems, and public health officials have conducted several different educational initiatives focusing on patient needs and rights at the end of life. So terminally ill patients there may be more proactive in deciding they want to hasten their death, and they may be more inclined to be open about such decisions, Ganzini says.

Because there are no other studies of the

experiences of patients choosing VRFF, the data obtained from the Oregon study cannot reliably be generalized nationwide.

"Patients can choose VRFF without ever discussing it with their family or care providers," she says. "In addition, loss of appetite is common enough in patients with terminal illness that patients can hide their motives."

It may even be difficult to determine which patients are deliberately stopping food and hydration with the goal of hastening death, and which are simply not eating or drinking because of loss of appetite or difficulty swallowing, both of which are common at the end of life, says **J. Andrew Billings**, MD, head of the Palliative Care Service at Massachusetts General Hospital in Boston.

"Despite how this survey was described, I suspect that there may be some overlap in the study between simply choosing to stop eating and drinking, which is quite rare in my practice, vs. stopping because of loss of appetite, thirst, poor energy, difficulty or pain with swallowing, mouth sores, etc.," he explains. "At the same time, these patients may choose not to start or to discontinue nutritional or fluid support."

However, the important information provided by the Oregon study is that the caregivers reported that patients choosing VRFF did not seem to suffer, he says.

"Regardless of the reason, the terminally ill patients who do stop eating or drinking or reduce their intake below levels consistent with survival — while typically in rather debilitated states — and who do not get fluid replacement, seem to die peacefully and comfortably, as reported by this study and others," Billings says.

For patients who are not eating or drinking, it's important that clinicians provide an appropriate medical evaluation and instruction to family and other professional caregivers about how to provide supportive care, he notes.

"This involves an explanation of what can be expected, teasing out concerns the family may have, and interpreting bodily changes and providing reassurance that they are doing what the patient truly wanted," Billings says. "The patient can benefit from good mouth care to prevent or minimize thirst and, if necessary, analgesics and sedation for comfort."

## **Physician support essential**

VRFF commonly has been discussed in palliative care circles, although it is believed to be very

uncommon, Billings says. Symptoms associated with dehydration or poor nutritional intake are an extremely common topic in the clinical literature and at professional meetings.

"Most palliative care texts have a chapter on this topic and it was first described in the literature as an alternative to physician-assisted suicide or euthanasia, and thus as a way for patients to have their way without involving physicians," Billings explains. "But patient abandonment seems a risk. I think palliative care clinicians should be involved to evaluate the patient and family, assure patient comfort and guideline the family through the process. This sort of procedure should be done with medical supervision in case there are disagreeable symptoms and also to reassure the family, who may misinterpret pre-terminal changes as distress or just be frightened by the dying process. Likewise, in a nursing home or other institutional setting, the staff typically need supervision and support when a patient is dying."

That being said, it's also essential to determine whether this is truly what the patient wants, he and Ganzini add.

When a patient expresses a desire to hasten death, it's important that clinicians examine these requests closely and try to determine the cause.

"Most [dying] patients hint at wanting to speed up the process and most frank requests for it, once examined more closely, do not turn out to be persistent requests for assistance in dying more quickly," he says. "The meaning of the request needs to be explored rather than just taken at face value. Common reasons, including poorly treated pain or disagreeable symptoms, depression, delirium, a feeling that they are a burden to others, a loss of dignity, overall frustration, a feeling of meaninglessness, etc.; practically all of these problems can be addressed and satisfactorily alleviated. We noted only two patients in the first 500 or so seen in our hospice program who had a persistent desire to hasten death after receiving an appropriate evaluation and treatment, which included psychosocial and spiritual support."

Ganzini agrees that it is important for patients who express a desire to hasten death — by whatever means — to receive appropriate evaluations of their physical and mental health. The Oregon survey respondents indicated that patients choosing VRRF were much less likely to have been evaluated by a mental health professional. Patients choosing PAS in Oregon must undergo such an evaluation under state law.

Although she believes that some patients do

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indeed choose VRRF for acceptable reasons, it is important that they be screened for depression.

"All of the patients covered by our study were in hospice and should have access to a hospice social worker who would have skills necessary to assess for depression," she notes. "Whether a depressed person in the final weeks of life should be prevented from deciding to stop food and fluids is more difficult. Some depression treatments take many weeks to be effective."

Research like the Oregon study is helpful because it helps clinicians learn more about how to help patients at the end of life, says Billings. More research is needed to better understand why patients make such choices and how to help them reach the end of their lives without suffering.

"I think we can learn a great deal about the dying experience, partly by attending to the small subset of patients who wish to hasten their deaths, regardless of the methods they consider or actually employ," he says. "Why do so many patients cling to life when they are terribly debilitated and often quite uncomfortable, while others wish to die? What is the nature of the suffering of the latter group, and what allows other to choose to live as long as possible, sometimes in dreadful circumstances, and what should we do to help both groups?"

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## Additional Reading

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# AHA releases guidelines on fair billing and collection

*Government asked to clarify Medicare regulations*

On Dec. 17, the American Hospital Association (AHA) announced it would provide guidelines for hospitals on billing and collection practices to ensure that poor patients and patients who lack health insurance are treated in a “fair-and-balanced” manner.

“Providing the patients and communities we serve with quality health care is our top priority,” AHA president **Dick Davidson** said in a statement accompanying the release of the guidance. “Hospitals see every day the stark reality that not all patients have insurance to help cover the cost of their care. In the absence of health care coverage for all, we are working on a number of ways to assist these patients and to ensure that hospitals are there when their communities need them.”

The new AHA guidelines stipulate that hospitals should:

- help patients with payment for their hospital care by helping them qualify for existing coverage options, and communicating more effectively about available payment programs;
- ensure that hospital policies are applied accurately and consistently;
- make care more affordable for patients with limited means;
- implement fair and balanced billing and collection practices.

As part of this effort at improving hospital billing practices, however, the AHA also is urging the federal government to clarify Medicare regulations that many hospitals perceive as a barrier to providing discounted services to indigent patients.

Medicare regulations require hospitals and other providers to maintain a uniform list of established charges for each product and service provided. Medicare bases its payments to

hospitals on these rates, but it and other third-party payers typically negotiate discounts for goods and services provided to their members.

However, Medicare regulations and most third-party payer contracts stipulate that charging different rates for the same services is fraudulent. So, while covered patients pay for goods and services at a discount of the established charge — many providers have interpreted the regulations to mean that uninsured patients must be charged the full amount.

In a Dec. 16 letter to Health and Human Services (HHS) Secretary Tommy Thompson, Davidson urged that Medicare regulations be re-examined.

“Hospitals believe that patients of limited means should not have to pay full charges simply because they have no coverage,” he wrote. “But federal Medicare regulations, as written today, constitute a string of barriers that discourage hospitals from reducing charges or forgiving debt for these patients without potentially running afoul of the law.”

In the letter, the AHA asked HHS to:

- work through the Centers for Medicare & Medicaid Services and the Office of the Inspector General (OIG) to develop safe-harbor protection for discounting or waiving charges for collections for patients of limited means who are unable to pay their hospital bills. Hospital programs that fall within the safe harbor would be protected from challenges to their payments and from OIG enforcement actions.

- institute an advisory opinion process that would allow hospitals to seek and receive binding regulatory guidance on a timely basis;
- create a panel of hospitals and others involved in this issue to explore solutions to the existing regulatory barriers and prevent new ones from developing. The panel could also develop new tools, processes, and resources that would enable hospitals to create new and innovative programs to meet the needs of patients with limited means.

Copies of the letter and the new AHA guidelines for hospitals are available on the AHA web site at [www.aha.org](http://www.aha.org). ■

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5. A key concern for health care workers considering vaccination against smallpox has been:
  - A. fears of transmission of vaccinia to patients and close contacts.
  - B. a potential for liability for adverse events associated with transmission or vaccination of others.
  - C. a potential for side effects.
  - D. all of the above
6. According to our article, what percentage of terminally ill hospice patients nationwide choose or consider voluntary refusal of food and fluids?
  - A. 10%
  - B. Fewer than 5%
  - C. 15%
  - D. Unknown
7. According to our article, what reason does the AHA cite as a factor complicating hospital efforts to offer discounts to indigent patients?
  - A. Lack of trained billing staff
  - B. Need for collecting outstanding debts in order to remain open
  - C. Medicare regulations prohibiting different charges for the same service
  - D. None of the above
8. According to the article, which factor was *not* a primary determinant of withdrawal of mechanical ventilation in anticipation of a patient's death?
  - A. Physician perception of the patient's wishes
  - B. Likelihood that the patient would survive
  - C. Patient's age
  - D. None of the above

**Answers: 5-D; 6-D; 7-C; 8-C.**

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