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## CMS evaluates hospice cap changes to offer options

*Managers should monitor cap deficit risk monthly*

After two district courts struck down the Centers for Medicare and Medicaid Services' (CMS) regulations for calculating hospice caps, CMS issued an unprecedented rule that allowed all hospices with appropriately filed hospice cap repayment demand appeals to avoid going to court.

"This ruling is a big deal," says **Carel T. Hedlund**, principal, Ober Kaler Attorneys at Law, in Baltimore, MD. (See resource box on page 63 for link to rule.) "If a hospice has a repayment demand based on exceeding the cap and has taken the appropriate steps to file an appeal, the cases go back to the CMS Intermediaries to be recalculated using the patient-by-patient proportional methodology," she explains. Losing judgments in two different district courts was a major blow to CMS and suggested that as other cases reached district courts, similar decisions

### EXECUTIVE SUMMARY

In response to two district courts declaring the method of calculating hospice caps invalid, the Centers for Medicare and Medicaid Services (CMS) issued a rule that sent appeals back to intermediaries to recalculate repayment demands using the patient-by-patient proportional methodology. The ruling preceded inclusion of revisions to the methodology included in the Proposed Hospice Wage Index for FY2012. Experts interviewed by *Hospice Management Advisor* point out several steps managers should take to reduce the risk of a cap deficit.

- Review the proposed rule and provide input to CMS;
- Monitor cap deficits or surpluses on a monthly basis to change business strategy when needed;
- Develop a well-balanced patient mix of short- and long-term lengths of stay to minimize the risk of exceeding the cap.

would be made to enjoin CMS from calculating hospice caps with the methodology currently used, she says. CMS has also included a proposal included in the 2012 Wage Index that allows a hospice to choose between the patient-by-patient proportional methodology and the current methodology to calculate their hospice cap, she adds. (See resource box on page 63 for link to proposed rule.)

The hospice cap was introduced in 1983, but appeals of the repayment demands did not occur regularly until about 5 years ago, points out Hedlund. The cap was established to limit the amount of Medicare payments a hospice receives in a fiscal year. Simply described, the cap is determined by multiplying the number of beneficiaries in an individual hospice by the fiscal year's cap

amount, which is adjusted each year by CMS, she explains. "I don't know if the repayment demands were not high enough to justify appeals prior to the 2005 fiscal year, or if hospices just did not consider it worthwhile to appeal," she says. "I do know that around 2005 we saw lengths of stay increasing as hospices provided care for longer term patients with a wide range of diagnoses, rather than the typical short-stay cancer patients," she explains. A longer length of stay does increase a hospice's risk of exceeding the hospice cap, especially if the hospice's case mix does not include enough short-term patients to offset the long-term stays, she adds.

**Kyle Terry**, MBA, consultant and principal at Hospice CAP Consultants in Owasso, OK, learned everything he knows about hospice cap repayment demands the hard way. When working as an administrator for two different hospices, he faced hospice cap deficits of \$1.5 million and \$800,000. Although the hospices were responsible for repayment demands for previous years, Terry was able to implement business strategies that prevented the hospices from continuing to accrue cap deficits on an ongoing basis. "I was able to eliminate the \$1.5 million deficit in 12 months and the \$800,000 deficit in 9 months," says Terry.

Even with the CMS ruling, hospices must pay close attention to their hospice cap exposure and hospice managers need to understand how the cap works, says Terry. "I hate to tell clients that if they've received one repayment demand letter, they will get a second and it will probably be for more money," he says. Because the repayment demands are for fiscal years that ended 2 years earlier, it is likely that the hospice did nothing to adjust the case-mix to address cap deficits for the year between the year addressed in the first repayment demand and the current year, he says. For example, a hospice manager won't receive a repayment demand letter for FY2009 until FY2011, he explains. "If the hospice manager wasn't monitoring cap exposure in FY2010 and addressing issues contributing to the cap deficit, the hospice will almost always receive a repayment demand for FY2010," he says.

Although the key to reducing hospice cap deficits is to monitor cap deficit exposure on a monthly basis, the first step is to understand the issues that can increase your hospice's risk, suggests Terry. "The larger the number of hospices in a single market, the greater the risk of exceeding the cap amount," he says. Competition increases awareness of the hospice benefit, improves edu-

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cation about the benefits of earlier admission to hospice, and encourages longer lengths of stay as hospices seek patients who have a wide range of diagnoses, he explains.

The first step to take when a repayment demand letter is received is to compare the list of beneficiaries included in the calculation to your own information, says Terry. Sometimes a patient whose benefit period started in one fiscal year but continued into the next year is counted as a full patient for the first year, he says. In other cases, a hospice may not realize that a patient received care from another hospice during the year and that adjusts how the cap is calculated, he adds. "I've had clients who immediately ask about the lawsuits filed by other hospices challenging the calculation methodology, but I've found that for most hospices the repayment amount is usually accurate, and if it's based on incorrect information, the intermediaries are willing to listen and adjust if needed," he says.

If you do believe your repayment demand is not accurate, you have 180 days to file an appeal, says Hedlund. "The CMS ruling automatically sends any appeals back to intermediaries for recalculation if the appeal was filed appropriately," she says. For that reason, hospices that receive repayment demands should make sure they file their appeals in a timely manner to ensure their cap is calculated in a proportionate manner, she adds. "However, before you file the appeal, make sure the new calculation is appropriate for your hospice," she says. "Some hospices, based on case-mix, may prefer the current calculation," she adds. The only way to know which method is best is to evaluate your data and conduct your own calculation, she says.

Once you've addressed the immediate concern of the first repayment demand letter, take a look at the fiscal year following the year addressed by the letter, suggests Terry. "There's nothing you can do to change the hospice cap deficit for that year because it is in the past, but you can get an idea of how much you might be asked to repay," he says. "Some of my clients were able to plan ahead to set aside extra funds or make financial arrangements for loans to repay CMS when the demand letter arrived," he says. The analysis also gives hospice managers a good picture of the issues that contributed to the hospice cap deficit, he adds. This analysis enables the hospice management team to make changes to their business strategy to avoid or minimize cap deficits in the current and future years, he adds. (For tips on avoiding cap deficits, see article, right.)

In addition to making sure the hospice cap and each hospice's individual risk of exceeding the cap is understood, managers also should review the proposed changes to hospice cap calculation carefully, suggests Hedlund. She adds, "Comment on the proposed changes included in the proposed Hospice Wage Index during the 60-day comment period so CMS has your input on cap calculations." ■

## SOURCES/RESOURCES

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- To see the **April 14, 2011 CMS Ruling** related to hospice cap appeals based on validity of calculation methodology, go to [www.cms.gov/Rulings/downloads/CMS1355R.pdf](http://www.cms.gov/Rulings/downloads/CMS1355R.pdf).
- To see the **proposed Hospice Wage Index for 2012**, which includes changes to the hospice cap calculation methodology, go to [www.cms.hhs.gov/hospice](http://www.cms.hhs.gov/hospice), select "Hospice Regulations and Notices" on the left navigational bar, then choose "CMS-1355-P." Comments can be made until early July.

## A good balancing act reduces risk

*Avoid cap deficits by managing case-mix*

**B**alancing your case-mix to avoid hospice cap deficits doesn't mean discharging patients or admitting patients who don't meet hospice criteria, warns **Kyle Terry**, MBA, consultant and principal at Hospice CAP Consultants in Owasso, OK. "Although a balance of short- and long-term patients is the best strategy to minimize your risk of receiving a repayment demand letter from CMS based upon the hospice cap, it is important to follow admission criteria guidelines issued by CMS," he says.

After you've evaluated your cap deficit risk, look at the types of patients you typically admit and at your referral sources, Terry suggests. "Then, look at where your marketers are going," he says. "Generally, oncologists will refer shorter term patients and family practitioners will refer longer term patients, many of whom may be in

nursing homes,” he explains. To ensure a balanced case-mix, make sure your marketers are visiting all types of referral sources, he adds.

Monitor your admissions on a monthly basis with a focus on how your patient mix affects your cap deficit or surplus, says Terry. “By watching on a monthly basis, you have an opportunity to make changes and redirect marketers in a timely manner,” he says.

Tricks such as not filing a claim with CMS until after the start of a new fiscal year won’t work, warns Terry. “The calculations are not based upon the date the claim is received, they are based upon the dates on which services were provided,” he says.

Staff members, not just marketers, should be included in discussions about the need for a variety of patients, says Terry. “Staff members are sources of referrals also because their friends and families are likely to choose the hospice because they know someone who works there,” he says. “I was always very open with my staff about the reality of the hospice cap and how we could work together to avoid repayment demands.” ■

## Use behavior not vital signs to assess pain

*Tool focuses on non-communicative patients*

**H**ow is your pain today? On a scale of 1 to 10, how would you rate your pain? Are you comfortable today? Did the medication lessen your pain? All of these questions are typical methods for physicians and nurses to assess the effectiveness of pain control methods. They work well for most patients, but what do you do when the patient cannot communicate?

“We have a lot of pain assessment tools available for newborn patients but there is no tool that addresses pain in non-communicative adults,” says **Deborah Bortle**, MS, BSN, CHPN, director of quality compliance at Hospice of Lancaster County in Lancaster, PA. Although hospice nurses use observation of various patient responses to assess pain in patients who could not communicate, there has been no standardized method for the process, she says. The need for a proven, standardized tool was the reason her hospice chose to participate in a study of a new tool being developed by researchers at University of Maryland

Medical Center.

Initial results for the Multidimensional Objective Pain Assessment Tool (MOPAT) do show that pain control is more effective when assessment of pain and evaluation of pain control methods are standardized,<sup>1</sup> says lead researcher **Deborah McGuire**, PhD, RN, FAAN, professor and director of the Developing Center of Excellence in Palliative Care Research and Oncology Graduate Program at the University of Maryland School of Nursing in Baltimore, MD. The tool is a result of four research projects conducted in several locations over many years, she says. The forms enable nurses and other providers to score behavioral and physiological indicators or signs from the patient, she explains.

Focus groups helped researchers gather information about how nurses assessed pain in non-communicative patients in one of the first projects, explains McGuire. “After the focus groups, we took the Post Anesthesia Care Unit Behavioral Pain Rating Scale (PACU BPRS), a pain tool designed for inpatient post-surgical patients, and modified it to reflect input from hospice nurses,” she says. Behaviors such as restlessness, tense muscles, frowning or grimacing, and patient sounds along with physiological signs such as blood pressure, heart rate, respirations, and diaphoresis were evaluated as indicators of pain.

At this time, researchers are waiting on data from their final test of MOPAT in a larger sample of both hospital and hospice inpatient settings before releasing the tool, as some preliminary

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### EXECUTIVE SUMMARY

Pain control is an important part of palliative and hospice care, but clinicians face special challenges when assessing pain levels of patients who cannot communicate. Although tools for newborns are available, they don’t translate well to adult, elderly patients who cannot communicate. Researchers at the University of Maryland are in the process of testing a tool developed specifically for adults who cannot communicate.

- A standardized tool improves communication from one clinician to another by making sure they all use the same indicators to assess pain.
  - In hospice, behavioral signs such as noises, muscle reactions, and restlessness are best indicators.
  - Physiological reactions such as heart rate or blood pressure are not reliable indicators of pain for hospice patients.
-

## SOURCES

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results may help some people enhance their own pain assessment methods. Although nurses often rely upon physiological symptoms to indicate pain level in non-communicative patients, reliability was more consistent for the behavioral signs, says **Karen S. Kaiser**, PhD, RN-BC, CHPN, AOCN, clinical practice coordinator at the University of Maryland Medical Center, adjunct associate professor University of Maryland School of Nursing, and co-author of the study. “We were not surprised at this finding,” she says. “We know chronic pain in hospice patients does not produce changes in vital signs,” she says. The fragile condition of hospice patients and the medications they take reduce the fluctuations in blood pressure, heart rate, and other vital signs, she adds.

“Nurses don’t use numbers to evaluate symptoms of pain, they use ‘none, mild, moderate, or severe’ to rank the intensity of behavioral signs,” says Bortle. “The nurses then write a narrative describing the symptoms,” she says. The narrative focuses on the behaviors exhibited by the patient, such as restlessness, tensed muscles, or sounds when moved, she adds. The tool is used to assess pain before and after intervention for pain, she says.

When testing the MOPAT for the study, Bortle’s nurses only used the tool in the inpatient hospice unit, but nurses who make home visits are now using it, she says. A one-hour CD developed by the hospice teaches nurses how and when to use the tool, she says. “At first, nurses did not want another form to handle, but once they became accustomed to the form they liked how easy it was to use,” she says. At this time, use of the tool for home-based patients is voluntary, she adds.

A standardized form enables nurses and other providers to better communicate levels of pain and effectiveness of different interventions, points out Bortle. “When everyone is assessing the same behaviors as signs of pain, we improve our communication with each other and are able to improve patient care,” she explains.

Researchers expect the final data and the release of the tool to occur this summer. ■

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## Old dogs teach new tricks at this hospice

*Pet therapy enhances patient care*

**D**ogs are a natural addition to a kid’s camp, especially a grief camp offered by a hospice. Not only are therapy dogs part of the camp held each year by the Hospice of South Georgia in Valdosta, GA, but policies and procedures related to therapy animals were put in place so adults could enjoy pet visits when the hospice designed its inpatient unit, which opened in 2007.

“Therapy dogs were part of the inpatient program from the beginning,” explains **Amanda Patterson**, executive director of the hospice. “Stroking a dog’s fur or just having a dog lay its head on a lap, calms and soothes patients,” she says. The policies do allow a patient’s personal pet to visit if a friend or family member stays with the pet, but the majority of pet visits in the inpatient unit are made by therapy dogs, she says.

“It is important that we recognize the relationship between patients and pets, but personal pets and therapy pets must be clean, controlled by a handler, and the handler must sign a waiver form signifying that he or she assumes responsibility for the pet,” says Patterson. “Patients must also give their permission for a pet to visit,” she adds. A personal pet may only visit its owner, while therapy animals may visit any patient who wants a visit, she says.

“We have a dog that visits the hospice house every other Sunday,” says **Della Perkins**, the hospice volunteer coordinator who oversees the therapy animal program. The dog and her handler

go from room to room to visit patients who have agreed to a visit. Another dog is at the hospice house every Wednesday to greet family members as they visit, she says. "Family members are under a lot of stress and having a dog greet them puts them at ease," she explains.

The program consists of five volunteer handlers and their dogs but there are specific requirements for a dog and handler to participate in the program, explains Perkins. "The dogs must go through a training program and be certified by Therapy Dogs Inc.," she says. "Therapy Dogs Inc. has excellent guidelines that describe the handler's responsibilities and requirements for the dog," she says. For example, guidelines require the dog to be clean, up-to-date on all vaccinations, and to have their nails clipped, she says. Their certification ensures that the handler and dog have passed tests and are ready to handle visits in the hospice, she adds. (See resource box below for information on Therapy Dogs Inc.)

The handlers and dogs have their own volunteer personnel files that contain proof of training, testing, and certification, points out Patterson. "We also keep a copy of the dog's vaccination record," she adds. The "human" volunteer's record also includes proof that he or she has undergone the hospice's required orientation and volunteer training, she says.

At the hospice's annual grief camp, Camp Lean on Me, dogs get to spend 3 days with children who have recently lost a family member, says Perkins. "The kids throw balls for the dogs to chase, pet the dogs, and bond with them," she says. "We occasionally have a child tell us that he or she is afraid of dogs so we let the handlers know about the child's fear and they watch to make sure the child feels safe," she says. Often, the child's fear of the dogs at the camp is gone at some point during the weekend, she adds.

Although the effect of a dog's visit can easily be

seen on most patients' faces, one patient experience stands out in Perkins' memory. When a dog went to visit a woman who was not responsive to conversation from family or staff, the staff member placed the woman's hand on the dog's head, she says. "She became very calm and left her hand on the dog's head," she says. Simple contact with the dog was beneficial for this patient." ■

## Can ethics and economics share common ground?

*Palliative care is one example of overlap*

Hospital ethics committees sometimes find they are drawn into local cases that reflect national debates over health care costs and policies. These debates might surface when there are conflicts between family and hospital providers over continuing life-sustaining treatment, including nutritional support and ventilator care. But adding health care costs to the mix can make the situation more complicated.

The high expense of most life-sustaining treatment also contributes to health care inequities and disparities, experts say.

"We have vast health care disparity domestically as well as globally," says Norman Daniels, PhD, Mary B. Saltonstall professor of population ethics and professor of ethics and population health at the Harvard School of Public Health in Boston.

"The main barrier has been in financing services," Daniels adds. "So if people do not have insurance coverage, then some kinds of services in hospitals that are not emergency-based are not available to them."

Health care providers and researchers usually are aware of medical costs even when cost savings is not a priority in patient care. It might not be enough in a costly health care environment to think only about outcomes and quality of care, experts say.

For this reason, palliative care researchers at Mount Sinai School of Medicine in New York City, have conducted studies about the cost of palliative care medicine, says Diane E. Meier, MD, director of the Center to Advance Palliative Care (CAPC) at Mount Sinai School of Medicine in New York City. "We studied the costs because from a pragmatic standpoint in this kind of fiscal environment in health care, there was no way

## SOURCES/RESOURCES

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- **Della Perkins**, Volunteer Coordinator, Hospice of South Georgia, Valdosta, GA. Telephone: (229) 671-8375; e-mail: della.perkins@sgmc.org.
- **Therapy Dogs Inc.**, P.O. Box 20227, Cheyenne WY 82003. Telephone: (877) 843-7364 or (307) 432-0272; fax: (307) 638-2079; e-mail: therapy-dogsinc@qwestoffice.net; web site: www.therapydogs.com. The web site includes guidelines for pets and handlers that can be incorporated into hospice policies and procedures.

we could make the argument that palliative care should be a core component of every hospital and nursing home and every doctor's and nurse's training unless we could make a business case for it," Meier says.

Hospital ethics committees need to focus on whether a palliative care program is promoting ethically good care, and not on the program's cost savings, says **Robert M. Arnold, MD**, Leo H. Kreep chair in patient care and chief of the Section of Palliative Care and Medical Ethics at the University of Pittsburgh (PA). "The fact that palliative care programs can save money may be a reason why it's easier for them to get funded in this tough economic time, but from an ethics point of view, this shouldn't fall into the equation," Arnold adds.

**R. Sean Morrison, MD**, director of the National Palliative Care Research Center and a Hermann Merkin professor of palliative care, a professor of geriatrics and medicine, and vice-chair for research, all at Mount Sinai School of Medicine, says, "Palliative care teams take on care of patients with serious or life-threatening illness in their families, and our approach is to improve their quality of life while they live with a serious illness." Morrison and Meier were authors of a recent study on palliative care and cost savings.<sup>1</sup>

"We address distressing symptoms such as pain and communicate about difficult topics while matching treatment to goals," Morrison says.

However, in the current economic environment, it is also important to find out if palliative care treatment costs hospitals and the health care system more than standard treatment, or if there is a cost savings, he adds. (See article on palliative care and biomedical ethics, page 68.)

"We looked at those patients who received palliative care and compared those to patients who received usual care, and the findings were fairly dramatic," Morrison says. "The cost was less for patients treated by palliative care teams."

The study found that Medicaid patients facing serious or life-threatening illnesses who received palliative care had \$6,900 less in hospital costs during a given admission than a similar group of patients who received usual care.<sup>1</sup>

The Medicaid study builds on Morrison's previous research, including a 2008 study that showed that patients seen by palliative care teams had a net savings of \$1,696 in direct costs per admission.<sup>2</sup>

The 2008 study looked at eight hospitals across the United States. The patients' health care costs

were paid by all different payers, Meier says. "For this latest study we concentrated on New York state because the state has a terrible Medicaid crisis due to reduced income tax revenues, increasing numbers of people in poverty, increasing Medicaid needs, and the continually rising costs of health care," he explains.

"We hoped to contribute to that dialogue involving finding the least restrictive, least harmful alternative ways of improving quality while avoiding unnecessary spending," she says. "Part of the reason Medicaid patients end up in the hospital is because there is no safety net for them."

These patients often lack family members who can stay home from work to care for them, and they cannot afford private pay assistance. "Their problems are a direct result of poverty and social inequity, and it's related to poverty, not the fault of the health care system," Meier says. "This is why I was not optimistic that we would show the same kind of cost savings impact with a Medicaid population."

Yet, that's precisely what happened. The cost savings were remarkable, she says. The reduced costs of patients seen by palliative care teams included \$4,098 less in hospital costs per admission for patients discharged alive and \$7,563 less for patients who died in the hospital. Investigators estimated the reductions in Medicaid hospital spending could range from \$84 million to \$252 million annually if every hospital with 150 or more beds had a palliative care team.<sup>2</sup>

## SOURCES

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“The question people ask is ‘Why?’” Morrison says. “The answer is that the patients that palliative care teams take care of are the sickest patients in hospitals.”

They consist of 5% of the general population, and they utilize 50% of health care costs, he adds. “These patients are very complex, so palliative care teams focus on those with special needs,” he says. “They sit down with patients and families and talk about what their values and goals are and what they hope to accomplish.”

For that reason, palliative care patients are less likely to die in intensive care units (ICUs), spend less time in ICUs, and are more likely to receive hospice referrals.

Once members of the palliative care team understand what their patient wants, they can match treatment to the patient’s goals. It’s a patient-centered model that improves efficiency and reduces unwanted and non-beneficial treatments, all of which helps streamline costs, Morrison explains. “One of the things palliative care teams do is sit down with patients and help them go through the benefits and burdens of particular treatments, depending on their goals,” he adds. ■

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# Palliative care model fits biomed ethics principles

*Side benefit: It brings cost savings*

Some of the core principles of medical ethics are patient determination, doing good for patients, and doing justice. These also are some of the chief attributes of palliative care, experts say.

“I view palliative care as applied medical ethics,” says **Diane E. Meier, MD**, director of the Center to Advance Palliative Care (CAPC) at Mount Sinai School of Medicine in New York City. “Palliative care is medical ethics operationalized at the bedside. My interest in palliative care grew out of my interest and work in medical ethics.”

The modern U.S. health care system has become so fragmented that patients are viewed in the system as a series of organs and diseases with a different specialist for each one, Meier says. “The patient as a person is no longer the focus of the health care system, so it’s very difficult to honor the core principles of medical ethics when health care is approached in this very narrow, organ-disease-driven manner,” she says.

The best way to influence this culture might be to show health care providers a different way of approaching the care of patients by beginning with trying to understand who the patient is and what they hope the medical profession can accomplish for them, Meier suggests.

“We can help patients and families develop a care plan and set of goals that are achievable with reasonable expectation of benefits and that are matched to what is most important to this patient and family,” she adds. “This is what palliative care embodies, an approach in which patient self-determination is at the core.”

The fact that palliative care saves hospitals and health care systems money is incidental to its goals. Meier says that palliative care advocates do not design or try to advance access to palliative care because of any concern about saving money. The drive behind palliative care is a desire to rekindle the originating impulses of the medical profession and making patient care center stage. “Cost savings was an unexpected consequence,” Meier says.

Hospital systems do care about the cost savings. This unplanned benefit has been an important reason why there has been a recent and rapid growth of palliative care programs nationwide, experts say.

**R. Sean Morrison, MD**, director of the National Palliative Care Research Center and a Hermann Merkin professor of palliative care, a professor of geriatrics and medicine, and vice-chair for research, all at Mount Sinai School of Medicine, says, “There is a reluctance in health care right now to embark on any new program that is going to cost the system a lot more money, even if it’s the right thing to do. Hospital budgets and health care budgets are stretched so tight there’s no room in the system for something new, even if it improves quality. That’s an unfortunate statement of where we are now.”

Between 2000 and 2008, the number of palliative care programs in U.S. hospitals increased from 658 to 1,486, a 125.8% increase. This increase means 58.5% of hospitals with 50 or more beds

now have a palliative care program, according to CAPC.

Prior to the 21st century, palliative care had very limited availability in the United States. It was an option delivered primarily through hospice care and was available to patients living at home.

With palliative care programs, there's a win-win on all counts because investigations including a study Meier and Morrison recently published show that palliative care can accomplish both quality and cost-savings.<sup>1</sup>

From a biomedical ethics perspective, the cost savings is immaterial, but from a pragmatic viewpoint, it matters. "Palliative care teams effectively improve quality of life, reduce symptoms, and improve satisfaction with the health care system," Morrison says. "They can do this and at the same time be fiscally responsible."

From an ethical perspective it's important to draw distinctions between what palliative care accomplishes and what it is intended to do, says **Haavi Morreim, JD, PhD**, a professor in the Department of Internal Medicine, College of Medicine, University of Tennessee Health Science Center in Memphis.

"The focus of good quality palliative care is to enhance the quality of life of the patient," Morreim says. "And if the patient is mortally ill, then its purpose is to enhance the quality of the dying process."

Saving money is not the goal, but it is a noticed side effect of good quality palliative care, she adds. "Another side effect is there have been some studies that show people live longer on palliative care," Morreim says.

Palliative care help to put ethics committee education and goals into action in the areas of conversations of inappropriate treatments and end of life issues, notes **Robert M. Arnold, MD**, Leo H. Krep chair in patient care and chief of the section of palliative care and medical ethics at the University of Pittsburgh (PA). The palliative care model is very helpful to ethics committees because they provide clinicians who can focus on patients, elicit patients' goals and values, and then provide the best possible care to people who have life-threatening illnesses, he adds. "As mediators, palliative care teams have good communications skills and can operationalize many ethical concepts in helping patients," Arnold says. "You have to have basic competencies in medical ethics to do a good job in palliative care."

The goal of palliative care is to elucidate the patient's goals and make sure the treatment a

patient receives matches those goals. These goals also overlap with what ethics committees want to see happen in the clinical arena, he says. "Many palliative care committees have multidisciplinary teams, and the ethics committee can say, 'Can we get involved to help you work together, provide education, communication, informal consults?'" Arnold suggests. "Many palliative care teams have multidisciplinary teams meeting once a month, and ethics committee members can go to these meetings."

Hospital ethics committees could view their health systems' palliative care programs as a role model for how health care providers can adhere to biomedical ethics principles, Meier says. "Pontificating on those values is not a good way of teaching," she adds. "You need to show people how to implement and apply those values at the bedside, and that's what palliative care teams do; these are their central principles of work."

Palliative care teams might seek out members of hospital ethics committees to work with them and coordinate educational efforts. In certain types of cases, palliative care teams and ethics committees might collaborate. "A lot of what hospital ethics teams have done overlaps with palliative care," Morrison says. "They are consulted when there are unclear goals of care and conflicts arise; they are called in to mediate that conflict."

Ethics committees and palliative care teams can work well together because there is much less reason for conflict when providers help patients and families articulate their goals of care, he adds.

Morreim notes that one idea palliative care advocates and ethics committees have been working on involves encouraging providers involved in the care of long-term intensive care unit patients to have standard team and family meetings.

"As soon as it looks like the patient will be in intensive care for more than a few days, this person will encourage early communication and a sit-down meeting with the family and main people providing the care," Morreim says. "This is not for the purposes of making drastic decisions, but is to make sure everybody is on the same page." ■

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## Caregivers continue to experience distress

By Linda L. Chlan, RN, PhD, School of Nursing, University of Minnesota

**Synopsis:** Caregivers of the chronically critically ill report restrictions on personal and social aspects of their lives, they continue to be distressed by problematic patient behaviors, and they are most distressed by their loved ones' continued reports of pain and discomfort up to 6 months post-ICU discharge.

**Source:** Choi J, Donahoe M, Zullo T, et al. Caregivers of the chronically critically ill after discharge from the intensive care unit: Six month's experience. *Am J Crit Care* 2011;20:12-23.

Chronically critically ill" patients are projected to increase in number over the next 10 years.<sup>1</sup> Little is known about their caregivers and how patient recovery influences these experiences over time.

Choi and colleagues enrolled 203 caregiver-patient dyads to describe lifestyle restrictions and distress, and to explore how these experiences are influenced by patient characteristics over time. A longitudinal survey design followed participants at 1 month and 6 months post-ICU discharge; 69 dyads remained in the study at 6 months. Feeling overwhelmed was the most common reason caregivers withdrew. Caregivers were employed white females between the ages of 31 and 70, were either a spouse or an adult child. Patients were 59% female, with a median age of 58.5 years, and had spent 25.5 days in the ICU with 23.5 of those receiving mechanical ventilation. Most (58%) had been weaned from ventilatory support at ICU discharge, with 74% weaned 1 month after discharge. No patients were discharged directly to home; most (52%) returned home by 6 months, 29% at 1 month; 19% had not returned home at 6 months. Many patients (64%) had not returned to their pre-ICU functional status level at 6 months.

Caregivers provided an evaluation of the patient's functional status using the Health

Assessment Questionnaire (HAC) prior to ICU admission, at ICU discharge, and at 1 and 6 months post-ICU discharge. The Changes in Role Function (CRF) scale was used to measure perceived lifestyle restrictions. Caregiver distress was measured using an 18-item subscale modified from the Revised Memory and Behavior Problems Check-list. Lifestyle restrictions were highest for visiting with friends, restrictions in hobbies, and recreation at 1 month. Overall, lifestyle restrictions significantly decreased from 1 month (23) to 6 months (19.4;  $P = 0.003$ ), although 35% of caregivers continued to report restrictions at 6 months. There was no difference in caregiver distress from 1 month to 6 months (8.9 to 7.9, respectively;  $P = 0.32$ ). The number of perceived patient problem behaviors did not differ from 1 to 6 months (6.2 to 5.0;  $P = 0.06$ ). Some problematic behaviors occurred more frequently at the 6-month period including: waking up others at night, comments related to feeling like a failure or having no worthwhile accomplishments, comments about death of self or others, having nightmares, and engaging in behaviors that are potentially dangerous to self or others. There was no difference in these problematic behaviors based on the location of the patients (home or facility) or in their functional status. Caregivers of patients who never returned home by 6 months and who did not regain similar functional status as prior to their ICU admission reported the highest lifestyle restrictions. Caregiver distress did not differ by patients' disposition or functional status. Caregivers were most distressed by the patients' continued pain or discomfort at 1 and 6 months post-ICU discharge.

### ■ COMMENTARY

Given the projected number of chronically critically ill patients by 2020 (600,000 patients per year),<sup>1</sup> there will be more family members in the years to come feeling strained when it comes to caregiving roles. As reported in this study, there does not seem to be less distress for caregivers even when their loved ones are not being cared for in the home. There may be need for a variety of services to support caregivers, particularly in those who are employed outside of the home. It is important for clinicians to realize that caregivers and patients continue to face significant challenges long after they are discharged from the ICU. Clinicians must examine their practice to ensure interventions are being implemented that minimize or prevent functional status decline. Life does not

miraculously return to “normal” once a chronically critically ill patient is discharged from the ICU.

An important finding from this study is the continued distress caregivers feel from problematic behaviors regardless of whether the patient is living at home or in a care facility. Further, there are ongoing symptom-management issues for these patients related to pain, discomfort, and impaired functional status. Patients in this study continued to experience functional status decrements, including muscle weakness, which emphasizes the necessity for care processes that minimize the severity or reduce the impact of weakness due to immobility. Prolonged periods of immobility are extremely detrimental not only to patients but also to their caregivers.

Only 34% of the enrolled dyads remained in the study, which limits the generalizability of these findings. Further, there was no direct assessment of patients’ functional status, which limits the findings’ reliability. Despite these limitations, this study highlights the need for clinicians to be keenly aware of the needs and challenges family members face in providing care to those patients who are in the increasing group of the chronically critically ill. ■

#### REFERENCE

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## Where the nation stands on end-of-life care

The National Hospice and Palliative Care Organization (NHPCO) has published a report about end-of-life care, emphasizing the importance of more personal and private discussions about the topic.

“Private Conversations and Public Discourse:

## RESOURCE

To encourage private conversations about end-of-life care, access: • **“Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care”** is available as a free download at the Caring Connections web site at [CaringInfo.org](http://CaringInfo.org). Click on the report’s title link, which is underlined in the top right corner of the home page.

The Importance of Consumer Engagement in End-of-Life Care” is a call to action, NHPCO says. It provides a framework and national agenda for consumer engagement in end-of-life issues.

The report details specific areas to address, including the following:

- Individuals need to talk about and document their wishes for care at the end of life.
- Health care providers need to initiate honest, timely, and culturally relevant discussions with those for whom they are caring.
- Policymakers need to eliminate barriers that prevent timely access to hospice and palliative care.
- Employers need to support staff who are living with a serious illness or are caregivers or grieving.
- The media needs to explore ways to demystify dying and help normalize the experience for the general public.

The report highlights the stories of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo. All three women died after prolonged life-sustaining treatment, and in each case their treatment and eventual deaths brought national media attention to end-of-life decisions and advanced directives.

The report was written and published by NHPCO’s Caring Connections, the organization’s consumer engagement initiative that provides free information on care, caregiving, and community

### COMING IN FUTURE MONTHS

- Are you ready to report your quality measures?
- Expand your volunteer base by recruiting GenYs
- Pediatric palliative care best practices
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engagement. Funding for the report was provided by the Robert Wood Johnson Foundation of Princeton, NJ.

Death issues are sometimes ignored and other times become part of polarized debate in American society. One example is the anger generated in the summer of 2009 over the rumors of death panels dictating American health care decisions under health care reform. More education and open discussions are needed, according to NHPCO.

Caring Connections, launched in 2004 through Robert Wood Johnson Foundation funding, works to support these important efforts. The report details real and perceived barriers in people seeking quality care when facing a serious or life-limiting illness. For example, there is the common misconception that a patient and doctor have “given up” when they elect hospice. Studies of hospice and palliative care have shown that these types of care can improve quality of life and family caregiver satisfaction. There are even some cases in which patients live longer than if more conventional treatments were chosen. ■

## CDC report identifies health disparities

Americans’ differences in income, race/ethnicity, gender, and other social attributes make a difference in how likely they are to be healthy, sick, or die prematurely, according to a news release issued on a report by the Centers for Disease Control and Prevention (CDC).

The report, titled “CDC Health Disparities and Inequalities Report — United States, 2011” is the first of a series of consolidated assessments and is designed to highlight health disparities by sex, race and ethnicity, income, education, disability status, and other social characteristics, according to the CDC news release.

State-level estimates in 2007, for instance, indicate that low-income residents report five to 11 fewer healthy days per month than do high-income residents, the report says. It also says men are nearly four times more likely than women to commit suicide, that adolescent birth rates for Hispanics and non-Hispanic blacks are three and 2.5 times higher respectively than those of whites, and that the prevalence of binge drinking is higher in people with higher incomes. ■

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