

# HOSPICE Management Advisor™

Reimbursement • Palliative Care • Risk Management • Best Practices

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## Need to cut \$1.3 million from budget? It can be done

*Use invoices, timesheets, and benchmarks to find savings*

A \$1.3 million cut in an annual budget is no easy feat, but management at Horizon Home Care & Hospice in Brown Deer, WI, was able to make the cut without affecting quality or requiring across the board staff layoffs.

The agency, which provides hospice, home health, private duty, and meals on wheels services, cares for more than 2,500 patients daily but had to find a way to cut costs when Medicare reimbursement was cut by 5% in January for home health.

“At this time the significant reimbursement cuts from Medicare and Medicaid affect only home health, so our focus was on home health but we looked for cost savings throughout the entire agency,” explains **Mary Haynor**, president and chief executive officer of the agency. It makes sense to improve cost-effectiveness and efficiency in hospice now, because

### ExECut IVE SummArY

Medicare reimbursement reductions have hit the home health industry harder than the hospice industry at this time, but agencies with both services are leading the way to find cost-cutting strategies that save money and maintain quality. The key to success is to dig deep into your finances to identify all areas of savings, even small ones.

- Use benchmark studies to evaluate how you are doing financially to identify areas of potential savings and to bolster your decision to make changes.
- Be ready to tackle the “sacred cows” or habits of practice that are followed because “we’ve always done it this way.”
- Understand that you can’t implement all changes immediately. Set a time-frame that gives everyone time to give support to the changes.
- Communicate changes and reasons for the changes frequently in many formats to employees.

the same reimbursement challenges will affect hospice in the future, she adds.

With a philosophy that the agency can't spend more than it takes in, Haynor and her management staff combed through all of the expenses of the agency. "We identified 50 different areas in which we could become more efficient and cut costs," she says. "We did eliminate 4 manager positions through attrition and did not replace them," she says. It was possible to divide the case-loads among other managers, she adds. The one layoff was a receptionist whose position was eliminated, she says.

"It wasn't easy but we evaluated every single expense of the agency," says Haynor. "Nothing was sacred and we found ways to save on cell phones, mileage, some benefits, drugs, and staff

pay," she says. (For details on cost reduction strategies, see story on page 100.)

"There is never an advantage to defer looking at your costs," says **Walter Borginis III**, CPA, MBA, executive vice president of finance & administration and chief financial officer for VNA of Greater Philadelphia, PA. "You must be proactive and I'm an advocate of using benchmarks to evaluate our performance," he says. Some hospice managers are reluctant to use benchmarks because they believe their programs are very different from others, he admits. "I think we are all more similar than different, and if you do have a service that is different, just recognize that your costs may appear higher due to a specific service," he suggests. "The most important thing is to review your costs, trends in costs, and industry benchmarks to monitor how you are doing."

Once you have compared your costs to industry benchmarks, the challenge is determining why costs are higher, says Borginis. "Hospices are struggling with new payment systems and many managers don't know where costs are," he admits. "Go to your staff and ask them why they think some costs may be high," he suggests.

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**Editorial Questions**  
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#### use of aides examined

National Hospice and Palliative Care Organization's benchmark report revealed that his agency orders more home health aide hours than most hospices, says Borginis. The finding led to development of some changes and tools used by schedulers and clinicians that resulted in a savings of about \$400,000 between the end of September 2010 and May 2011. (See story use of aides on page 100.) We were automatically ordering 7 days a week of home health aides for every patient and had been doing so for years," he says. This practice was a "sacred cow" that no one had questioned so it became a habit, he adds.

Another area that is often overlooked, as a place to cut costs is indirect costs, such as lease expense or legal or accounting fees, says Borginis. "People think of indirect costs as fixed, but you can always renegotiate contracts and should do so on a regular basis," he recommends. "Don't let contracts automatically renew because they usually have a built-in increase," he warns. With property values and office space rentals declining in many areas, you may be in a good position to negotiate a new rental agreement, he suggests.

Don't forget to evaluate back office efficiencies on a regular basis as a way to improve financial

efficiency, suggests **Michael Horsley, BS, RPT**, owner and administrator of All Coast Therapy Services in Lady Lake, FL. By monitoring every aspect of the back office's performance including accounts receivables days, claims returned for corrections, and underpaid claims, you can pinpoint the areas in which you can improve, he says. "Sometimes poor back office performance is a lack of training and sometimes it is inadequate monitoring," he admits. You have to monitor on a weekly and monthly basis to identify potential problems before they become difficult to address, he adds.

Although staffing costs are a significant portion of any agency's budget, Horsley warns against cutting staff as a first step to address financial challenges. "If there is a drop in revenue, the first step is to check with marketing and evaluate your competitors," he recommends. "Find out if this is a long-term or short-term situation," he says. If it appears to be short term, look for ways to cut costs in other areas, without cutting staff. "If your first reaction is to cut staff, especially non-clinical staff, you may end up overworking the remaining staff as census increases," he says. "If you overload the back office staff, you increase the risk for billing mistakes that may cost your agency more revenue," he explains.

Because Horsley's agency is in Florida, he sees a major seasonal fluctuation in business every year. "We plan for the fluctuation by scheduling some jobs, such as archiving medical charts, for the off-season," he says. "This ensures that staff members are productive and working efficiently no matter how many patients we may have at the time."

## Be aware of public perception

Layoffs at your agency might also create a negative impression in the community, points out **Borginis**. "Not only do you want to maintain the capacity to expand, especially if your downturn is seasonal or short-term, but your competitors might use the fact that you have laid off people to gain a competitive advantage," he points out. Even if you do have to restructure staff, or reduce positions in some areas, be sure you can always accept new patients so the community and your referral sources maintain confidence in your ability to provide care, he suggests.

Timing changes throughout the agency is also important, suggests **Borginis**. "Don't wait until you are in trouble," he warns. Evaluate the need for changes carefully and be reasonable about how

quickly you can make the changes, he suggests. Some items can be changed quickly but realize that many changes require your clinical staff to be on board with you, he says. "You can't do everything right away, so be flexible on your timeframe," he says.

The key to getting everyone on board with changes, big and small, is communication, says **Haynor**. There is no such thing as too much communication, she points out. An added challenge is the nature of agencies that provide care to patients in their homes, she admits. "We don't see all of our employees every day so they do feel isolated," she says. "Also, we have to remember that managers who are involved in identifying and implementing the changes are spending hours and hours of discussion to which most employees are not privy," she points out. Because the general announcement of changes is often the first time employees become aware of the need for changes, it is important to include explanation of why the changes are being made, and how much time and effort went into identifying changes that are good for the agency with no impact on quality care, she adds.

Even though **Haynor** and her managers spent many hours communicating with staff at meetings and through e-mail and newsletters, there were still employees who needed additional information. "One nurse was convinced that our efforts were targeted at senior staff nurses who had the highest salaries, even though our changes affected all employees equally, and no clinicians were laid off," she says. "Any change is scary and people are so busy that they don't always hear the full message the first time," she says. "They hear the pieces of information that impact them the most and they miss the big picture." ■

## SOur CES

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# Small amounts add up to big savings

*Timesheets and invoices reveal opportunities*

When the money is flowing you don't always look closely at what you spend," admits **Mary Haynor**, president and chief executive officer of Horizon Home Care & Hospice in Brown Deer, WI, an agency that cut \$1.3 million out of the annual budget in early 2010. "It is hard, time-consuming work to evaluate all of your costs but when you do, you see how the little things add up," she admits.

"I looked at every one of our 560 employees' timesheets," says Haynor. "It was enlightening." She found employees receiving on-call pay who were never called and office employee overtime pay that steadily crept up over the years. "We eliminated on-call pay for the employees we don't call and we set a policy that we don't pay overtime for our office staff," she says. "It was amazing that we eliminated overtime and the work is still getting done."

One of the more creative strategies to control employee costs was to adjust the benefit guidelines for part-time employees. "We have always offered full benefits to part-time workers who are at a least ½ of a full-time employee position," she says. "But, 2 part-time employees cost more in benefits, taxes, and paid time off than 1 full-time employee so we had to find an incentive for our part-time employees to work more hours," she says. Now, an employee must work 7/10ths of a full-time schedule to qualify for benefits. "We not only needed to control benefit costs, but we really needed them to work more hours so we did not have to hire more full-time employees to cover the increasing number of patients we were seeing," she adds. She estimates that the increase in part-time employees hours worked translated to 10 fewer clinicians that the agency needed to hire. She says, "This worked out to be a win-win for employees and the agency."

Benefit levels for all employees were evaluated and the agency discovered that it was paying more than the market for extended illness, says Haynor. "The market pays 66 2/3% of salary for extended illness and we were paying 80%," she says. The benefit was adjusted to reflect the market standard, she says.

Another bold step Haynor's agency has taken is to announce that annual pay raises will be held

until the agency exceeds budget projections, says Haynor. "No one was thrilled to hear this decision but we've explained the challenges we're facing and people understand," she says. "The whole process has made employees more aware of costs and we get suggestions from them for more cost savings."

To get a handle on every expense of the agency while they were identifying potential cost savings, Haynor set a policy that all invoices had to be co-signed by her. "I literally looked at everything we spent," she says. Having an extra pair of eyes looking at each invoice that was automatically signed for many years led to some cost savings no one might have considered, she says. "In our employee kitchen we always provided plastic forks, spoons, and knives for employees to use as they ate their meals," she says. "We were spending \$1,000 on items that employees now bring with their lunches from home. It isn't a huge amount but reducing these small, unnecessary expenses can add up." ■

## Automatic use of aides increases costs

*Tools manage use of staff vs. contractors*

But this is how we've always done it." Whenever you hear this phrase, take a close look at the process to which it refers. The staff at Visiting Nurse Association of Greater Philadelphia did and the close look resulted in a process change that resulted in a \$400,000 savings over an 8-month period.

"We noticed that we were higher than the norm for home health aide days per patient according to the National Hospice and Palliative Care Organization benchmark survey," says **Josh Sullivan**, business manager of hospice services for the agency. After questioning staff members about the use of home health aides, Sullivan discovered that it was routine to order home health aides 7 days a week for all patients. "This was a practice that had been in place for years, and no one had evaluated it before," he explains.

After researching the industry standards for use of home health aides, a list of questions was developed to determine the appropriate level of use of aides for the nurses, says Sullivan. The hospice director worked with the nurses to explain the

need for a change and to show that not all patients required 7 days a week of aides to produce the same outcome, he says. “We did get pushback from nurses because they were concerned about quality of care and they saw a decrease in aide days as a decrease in quality.” By basing their protocol on national standards and by evaluating each patient on a case-by-case basis, managers were able to demonstrate that quality of care would not be affected, he adds. “We did proceed slowly because we didn’t want to immediately cut back on aides for patients who already had them for 7 days a week,” he admits. “We were sensitive to their needs and met with patients and their families before any changes occurred.”

Another side effect of the evaluation of the use of aides was the discovery that many of the aides scheduled to work were contract employees, says Sullivan. “Schedulers were calling contract personnel before employees in many cases,” he says. Although scheduling contractors was easier in some cases than working out employee schedules, it was not cost-effective, he says. The problem with

contractors was a minimum charge they required and a lack of monitoring of their hours, he says. “We can schedule an employee for 1 hour and they work 1 hour, but a contractor might work, and charge us 2-8 hours, regardless of what we scheduled,” he says.

“I developed a scheduling tool that enables schedulers to easily see what employees are available and how many contractors are being used,” explains Sullivan. “We now have a firm rule that you can’t go over a certain number of contractors in a month,” he says. The contractors that are approved by the hospice have all agreed to work in 1-hour increments and not to charge for more unless scheduled for more, he says.

“We also hired some more aides to our staff to make sure we could meet our patients’ needs,” says Sullivan. Although there is an expense to hiring and training new staff members, it is worth the investment because you know that the aides are trained, motivated, and able to provide the quality care your hospice expects, he adds. ■

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## Final Wage Index Changes Increase Fy 2012 Payments by 2.5%

*Goal to improve patient access, quality of care*

Hospices serving people with Medicare will see a 2.5% increase in their Medicare payments for fiscal year (FY) 2012, according to a final regulation released July 29, 2011, by the Centers for Medicare & Medicaid Services (CMS). Hospices also are called upon to begin reporting on the quality of care received by Medicare patients as a result of this final regulation.

The estimated hospice payments are the net result of a 3% increase in the “hospital market basket,” an indicator of industry-related price increases, offset by an estimated 0.5% decrease in payments to hospices due to updated wage index data and the third year of CMS’ 7-year phase-out of a wage index budget neutrality adjustment factor (BNAF).

The final rule also implements Affordable Care Act requirements, including a hospice quality reporting program, and clarifies previously

adopted policies on hospice face-to-face certifications, said **Jonathan Blum**, deputy administrator and director of CMS’ Center for Medicare. “These payment and policy changes and additional attention to quality will work to encourage better coordination of hospice benefits and fair payments to Medicare hospice providers.”

### Final rule details

This final rule continues the BNAF phase-out, now in its third year. The BNAF was implemented in 1997, when the former Health Care Financing Administration (HCFA), now CMS, moved from an outdated wage index to a more current and accurate method for determining hospice payments. To minimize disruption to services during the transition, a special budget neutrality adjustment was applied. In FY 2010 rulemaking, CMS adopted a schedule to phase out the BNAF over 7 years, reducing it by 10% in FY 2010, 15% in FY 2011, and successive 15% reductions from FY 2012 through FY 2016.

The final rule revises how CMS calculates each hospice’s yearly aggregate cap. Federal law requires that CMS impose a limit on the aggregate Medicare payments a hospice provider receives annually. CMS calculates each hospice’s aggregate

cap by multiplying the number of patients served by the hospice in a cap year by a cap amount. Medicare payments made to a hospice during the cap year that exceed the hospice's aggregate cap must be refunded to Medicare.

In this final rule, CMS will:

- Change the way it counts hospice patients for the 2012 cap accounting year and beyond. The final policy for counting the number of Medicare hospice beneficiaries in care for a given cap year calculates the cap based on the number of days of care the patient received in that cap year for each hospice. This rule also finalized that the new counting method be applied to past cap years in certain instances.
- Allow hospice providers who do not want a change in their patient counting method to elect to continue using the current method.
- Allow any hospice physician to perform the face-to-face encounter regardless of whether that same physician recertifies the patient's terminal illness and composes the recertification narrative.
- Implement a hospice quality reporting program, which includes a timeframe for reporting, as required by section 3004 of the Affordable Care Act. The measures that are being adopted in this final rule for the FY 2014 program are one measure endorsed by the National Quality Forum related to pain management and one structural measure that assesses whether a hospice administers a Quality Assessment and Performance Improvement (QAPI) program that contains at least three indicators related to patient care.

As finalized, hospices will be required to begin collecting quality data in October 2012, and will submit the data in 2013; hospices also may voluntarily begin collecting data on the QAPI measure in October 2011 for submission in 2012. Hospices failing to report quality data in 2013 will have their market basket update reduced by 2 percentage points in FY 2014.

Information on the final hospice wage index payment and policy changes can be found on a new web portal, [www.healthcare.gov](http://www.healthcare.gov), made available by the U.S. Department of Health and Human Services. A link to the final rule, which will be published in the *Federal Register* on Aug. 4, 2011, along with accompanying documents, will be available at: [www.ofr.gov/OFRUpload/OFRData/2011-19488\\_PI.pdf](http://www.ofr.gov/OFRUpload/OFRData/2011-19488_PI.pdf) or [www.federalregister.gov/inspection.aspx](http://www.federalregister.gov/inspection.aspx). ■

## Q&A: OIG on Medicare Hospice Care

*Investigating fraud, waste, and abuse*

The goal of hospice care is to help terminally ill beneficiaries continue life with minimal disruption and to support beneficiaries' families and caregivers throughout the entire process. It includes pain control, symptom management, and counseling for patients and their families in an effort to make the last days of a patient's life as comfortable as possible. Clearly, this type of care is both important and personal, yet hospice care in the Medicare program does not escape the problems of fraud, waste, and abuse. The following Q&A highlights this issue and the Office of Inspector General's (OIG) efforts to eliminate it.

### What is the Medicare hospice benefit?

To be eligible for Medicare hospice care, a beneficiary must be entitled to Part A of Medicare and be certified as having a terminal illness with a life expectancy of 6 months or less. The hospice care may be provided in various settings, including the home or a nursing facility. This care is palliative, improving quality of life, rather than curative, curing the illness.

### What is the status of the Medicare hospice benefit?

Medicare is paying more and more each year for hospice care. Between 2005 and 2009, hospice payments increased 53%. Payments for hospice care in nursing facilities rose even faster: nearly a 70% increase over the same years.

There are also more hospices providing care to Medicare beneficiaries, and an ever greater percentage are for-profit hospices. In 2009, more than half of Medicare hospices (56%) were for-profit, up from 13% in 1992.

In addition, there are compliance issues with hospice claims and Medicare requirements. Eighty-two percent of hospice claims for patients residing in nursing facilities did not meet Medicare coverage requirements in 2009, totaling \$1.8 billion. Sixty-three percent of Medicare hospice claims did not meet the plan-of-care guidelines, which state that hospices must establish a plan of care for each patient describing what is supposed to be done, by whom, at what time, and for what purpose.

Also, OIG found that in 46% of all hospices

surveyed, health deficiencies were cited most often in regard to patient care quality and planning.

### **Why are some hospices seeking out nursing facility residents?**

A recent OIG report (see article, below) found that hundreds of hospices had more than two-thirds of their patients residing in nursing facilities in 2009. These “high-percentage hospices” typically served patients who required less complex care than other patients, but required hospice care for longer periods. By serving patients for longer periods, these hospices billed Medicare more per patient, on average, which can mean larger profits. The numbers reflect this; compared to the overall pool of hospices, high-percentage hospices are more likely to be for-profit.

### **What does OIG recommend to address this issue?**

This report shows that the current payment structure provides incentives for hospices to seek out patients in nursing facilities, who often receive less complex care but receive it for longer periods. Accordingly, OIG recommends that the Centers for Medicare & Medicaid Services (CMS):

- monitor hospices that depend heavily on nursing facility residents and
- reduce Medicare payments for hospice care provided in nursing facilities.

CMS concurred with these recommendations.

For more information, visit <http://oig.hhs.gov/oei/reports/oei-02-10-00070.asp> for the full report.

### **What other work has OIG done related to hospice care?**

OIG’s work in the hospice care area is not new. For example, in 1999, OIG issued compliance guidance for hospices. In 2001, an advisory opinion was posted concerning a payment arrangement between a Medicare-certified hospice and certain nursing facilities for services provided to residents of such facilities who are eligible both for Medicaid and Medicare hospice benefits (“dually eligibles”).

Earlier this year, OIG published an audit regarding Medicare hospice payments made by the Massachusetts Executive Office of Health and Human Services, pointing out various errors totaling \$1.7 million in overpayments.

Also, several enforcement actions have been related to hospices. Examples are highlighted below:

- SouthernCare Inc., an Alabama-based company, and its shareholders allegedly submitted

false claims to the Government for hospice patients who were not eligible for such care. In 2009, SouthernCare Inc. agreed to pay a total of \$24.7 million to settle allegations and enter into a corporate integrity agreement (CIA) with OIG.

- Roberto Ruiz, MD, and his company, Southwest Internal Medicine Group, PC, entered into an integrity agreement with OIG in 2009 to resolve charges of submitting false claims to Medicare for hospice services. The agreement requires written policies, employee education, and annual audits. He also paid \$525,000 to resolve his civil liability.

- In 2008, Solaris Hospice, Inc., formerly Home Hospice of North Texas, and its two owners agreed to pay \$500,000 plus interest to resolve allegations that Solaris submitted improper claims for hospice-related items and services. The improper claims included, for example, alleged misrepresentation to Medicare of the medical conditions of patients to ensure that they would be or continue to be hospice patients. Also, Solaris Healthcare, the parent company of Solaris, agreed to enter a 5-year CIA with OIG.

### **What does OIG plan to do from here?**

OIG will continue to monitor hospice care in the Medicare program and take action against those who break the rules. OIG also has some forthcoming reports planned, including:

- investigating the business relationships between high-percentage hospices and nursing facilities and the way hospice services are marketed and
- assessing the appropriateness of hospices’ general inpatient care claims and hospice patients’ drug claims under Part D. ■

## **medicare Hospices that Focus on Nursing Facility r esidents**

*Less complex care for longer periods of time*

**M**edicare spending on hospice care for nursing facility residents has grown nearly 70% since 2005. Additionally, hundreds of hospices had a high percentage of their patients residing in nursing facilities, and most of these hospices were for-profit.

Compared to hospices nationwide, these high-percentage hospices received more Medicare payments and served beneficiaries who spent more time in care. High percentage hospices typically enrolled patients whose diagnoses required less complex care and who already lived in nursing facilities before they elected hospice care.

Medicare currently pays hospices the same rate for care provided in nursing facilities as it does for care provided in other settings, such as private homes. Unlike private homes, nursing facilities are staffed with professional caregivers and are often paid by third-party payers. These facilities are required to provide personal care services, which are similar to hospice aide services that are paid for under the hospice benefit.

Some hospices may be seeking beneficiaries with particular characteristics, including those with conditions associated with longer but less complex care. Such beneficiaries are often found in nursing facilities. By serving these beneficiaries for longer periods, the hospices receive more Medicare payments, which can contribute to larger profits.

OIG recommends that CMS: 1) monitor hospices that depend heavily on nursing facility residents and 2) modify the payment system for hospice care in nursing facilities. CMS concurred with both recommendations. It also agreed that the current payment structure may provide incentives for hospices to seek out beneficiaries in nursing facilities, who often receive longer but less complex care. ■

## Study examines trends for medicare patients at EOL

*More time is spent in the ICU*

**A** new study from the Dartmouth Atlas Project seems to indicate the “report card” for Medicare patients at the end of their lives is a mixed bag of pluses and minuses. On the positive side, the study, “Trends and Variations in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness,” showed that Medicare beneficiaries with severe chronic illness spent fewer days in the hospital at the end of life in 2007 than they did in 2003, and that they were less likely to die in a hospital and more likely to receive hospice

care. On the other hand, they were more likely to be treated by 10 or more doctors in the last 6 months of life in 2007 (36.1%) than they were in 2003 (30.8%), and the average number of intensive care days increased to 3.8 from 3.5.

“The fact that these patients are spending less time in the hospital is connected with the fact that they are spending more time in hospice,” notes lead author **David Goodman, MD, MS**, the co-principal investigator of Dartmouth Atlas of Health Care, professor of pediatrics and of health policy, and director, Center for Health Policy Research, at the Dartmouth Institute for Health Policy and Clinical Practice. “But the fact remains that these are the two domains where patients receive higher-intensity care, and there were more ICU days. And it’s not just the ones left in the hospital who are sicker patients; there are more numbers of ICU days across the entire population of those who died, so there is a real increase of ICU care in this population. Patients certainly spend less time on general hospital wards, but they spend more time on the ICU.”

Goodman says the medical profession is uncertain as to why this is, and adds, “This is not true for every hospital. It’s fascinating that there are some hospitals where their change is in parallel with this study, while others have defied this general trend.”

In other words, he continues, it is not the “destiny” of any specific facility to have these patients spend more time in the ICU. “I think one of the important factors that tend to shape the local experience is how local health care systems invest — and what they invest in,” says Goodman. “Places that make relatively greater investment into ICU units can be providing valuable care for certain patients, but they can have unintended consequences as well.”

### Patients prefer less intensive care

One of those “unintended consequences,” says Goodman, is lower patient satisfaction at a difficult time in their lives. “For this report, one of the major findings is that patients near the end of life on average strongly prefer to spend as much time as they can in a home-like environment,” he says. “Many spend time in the ICU when it is not their preference — but that preference is not often elicited or legitimized by health care systems that have tremendous resources available for curative care and then assume the patient wants that applied to them, even in situations where the likelihood of

their returning to the life they once knew is nil.”

In earlier research, notes Goodman, “We studied the relationship of intensity of care and the HCAPS rating, and patients’ perception of hospital experience and quality of care, and it really showed a negative correlation — patients were most unhappy in places where care was of the highest intensity. Also, many research studies look at what happens in patients at the end of life in terms of decision quality — whether their preferences are followed by caregivers, even when those preferences are clearly articulated.” What did he glean from that research? “We have a long way to go,” he says.

Intensity of care has a lot of physical consequences as well, says Goodman. “Sometimes a patient will be in the ICU and we will not only save their life, but create the opportunity for that patient to acquire an HAI, or the clinician may give the patient more cytotoxic chemotherapy, which can lead to pneumonia. These are fragile patients, and sometimes intensity can tip them over the edge.”

### **trends must be reversed**

Goodman says that for things to improve in hospitals, health systems and providers must “unlearn” certain assumptions. “In places that have grown their population of physicians and sub-specialists, that is the capacity that gets used,” he explains.

“I am a trained physician,” he continues. “The classic way we think of ourselves is that our job is to gather as much information as we can about the patient and their condition; we have knowledge of treatments, we learn about the patient’s condition, and we make a recommendation.”

But that common role of making recommendations does not work today, says Goodman, and it won’t in the future — particularly for very sick patients. “It assumes we understand all of the care options, and often we don’t,” he asserts.

What’s more, Goodman continues, there is no

correlation between intensity of care and measures of technical quality. “When you spend many more days in a hospital ICU, you see many different doctors, but the quality of care tends to be lower,” he observes. “We think that’s because care becomes disordered. There are more handoffs, and more chances for missed communication.”

In addition, he says, electronic medical records (EMRs) do not solve that problem. “EMRs rarely extend to full care, especially in chronic care facilities,” Goodman asserts.

### **Reduce spending, improve quality**

Another implication of the study’s findings is that “providers can look for insights into potential savings they can achieve through improved care of chronic illness that allows patients to remain safely out of the hospital,” asserted **Risa Lavizzo-Mourey, MD, MBA**, president and CEO of the Robert Wood Johnson Foundation, a long-time funder of the Dartmouth Atlas Project, in a statement released to accompany the study’s publication.

Goodman agrees. “We shouldn’t be surprised we’re spending more money on health care than any other developed country in the world, but there might be opportunities to do a better job with less money, particularly when some patients get expensive care they do not want,” he says. “There are opportunities for accomplishing greater efficiencies thoughtfully. I’m not talking surgery with dull tools, but crafting our models of care and reimbursements so we can deliver higher quality for less cost.”

End-of-life care, he continues, is one place where we know if patients get palliative care services early in the care of chronic illness, they have a much better experience. “They generally have a lower intensity of care, which saves money, and at least in cancer care, there are studies that show they actually live longer,” says Goodman. ■

## **SOur CES**

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## **Discussion of EOL Care Helps Patients, Families**

*Pre-op conversations assure family*

**F**or patients with severe heart failure, an implanted mechanical pump known as a Left Ventricular Assist Device (LVAD) can

be a life-sustaining treatment. Even though the technology involves risks, few patients and their families tend to talk explicitly about the “what ifs” before surgery takes place. In the June issue of *Mayo Clinic Proceedings*, a team of Mayo Clinic researchers found that careful discussions at the bedside about patients’ end-of-life preferences brought relief to families and eased subsequent medical care.

“Previous studies have looked at the ethics of LVAD surgery and the role of patient and family members when it comes to turning the device off,” says lead author **Keith Swetz, MD**, an internist and specialist in palliative medicine. “But these are complex patients, and many things can happen. To our knowledge, this was the first study to investigate how to help patients and families to be proactive in decision-making before patients’ quality of life is compromised.”

The study looked at 19 patients dependent on LVAD as a long-term survival strategy rather than as a “bridge” to a heart transplant. Among them, 13 patients and their families discussed advanced care wishes with a palliative care team that included physicians and social workers. The study found the conversations provided guidance when adverse events occurred, such as when a patient fell after surgery and suffered brain damage. The study also found LVAD patients often presumed family members were aware of their end-of-life wishes, when, in fact, spouses and children were grateful to be guided in a conversation.

The study affirms the effectiveness of palliative care discussions before LVAD surgery and provides guidelines for clinicians and hospitals about how to address end-of-life decision-making. “It can be a tough conversation for families to have but we found it didn’t cause stress or loss of hope,” Swetz says. “Instead, having the conversation brought relief and was ultimately reassuring for families and patients.” ■

## r ESOur CES

For more information about Left Ventricular Assist Device (LVAD), visit:  
• The **mayo Clinic web site**: [www.mayoclinic.com/health/lvad/MY01077](http://www.mayoclinic.com/health/lvad/MY01077).  
• YouTube: A video titled “**Palliative medicine for Preparedness Planning in Patients r eceiving LVAD as Destination t herapy**” from Keith Swetz, MD, is available at [www.youtube.com/watch?v=EYwUVCyToL0](http://www.youtube.com/watch?v=EYwUVCyToL0).

# Age appropriate language essential for pediatric patients

*Let the child dictate conversations*

*[Editor’s note: This is the second of a two-part series that looks at communicating with patients who have difficulty communicating. Last month, we looked at innovative and proven strategies to communicate with patients who have dementia. This month, tips and strategies for communicating with pediatric patients, and their families, are offered.]*

Caring for children in any segment of health care presents special challenges because your care extends not only to the child who is the patient, but also to all members of the family. Hospice staff members are accustomed to providing family support for all patients but pediatric patients and their families require specific skills not normally associated with hospice care.

“The biggest challenge is cultural,” says **Kathy Perko, MS, PNP, CPON**, director of the Bridges Palliative Care program at Doernbecher Children’s Hospital in Portland, OR. An 85-year-old at the end of life is acceptable and understood, but a 12-year-old in hospice care is not as easy to understand, she explains. “When the child is dying of a genetic disease, we are also working with parents who are dealing with the guilt of passing the disease on to the child,” she adds.

Hospice nurses working with pediatric patients find themselves in the position of teaching parents and family members how to interact with the child, says Perko. “They must model best practices for family members because this is not a situation they’ve faced before.”

One way to teach family members how to talk with the patient and to read their symptoms is to conduct all assessments out loud, suggests Perko. A nurse assessing pain might comment on the wrinkled brow or slight grimace and state the last time pain medication was used. She can then give pain medicine and notice, out loud, that the grimace or wrinkles are gone so the pain must be lessened, she explains. “Let parents see what you do and talk through your thought process so they can better understand their child’s condition,” she adds.

Be sure to find out what the family and child

know about the child's condition before starting care, suggests **Marion Taylor**, RN, MSN, CPNP, director of Kid's Path at Hospice and Palliative Care of Greensboro in Greensboro, NC. "Have a private conversation with the parents to find out what they know and what the child knows," she says. Sometimes parents have not told the child, or siblings, that he or she is dying, so the nurse needs to know this upfront, she explains. "When we encounter this situation, we tell parents that we will not introduce the topic of death until they are ready, but if the child asks us directly, we will not lie," she adds. "We advise the parents to talk to the child and we offer support and advice on how to tell the child or the other children in the family." Although parents are reluctant to talk with children about death, the reality is that the child is ready before the parent, she adds.

When talking with pediatric hospice patients or their siblings, let the child dictate how much he or she wants to talk, suggests Perko. "Children will only talk about death as long as they can handle it. Your patient may ask a question or two about death, then stop and ask if you want to play Nintendo," she says. "When the child changes the subject, stop the conversation but be ready to pick it up again when the child shows interest."

Age appropriate language is key to all communications with a pediatric patient, parents, and siblings, says Perko. "If the family uses the phrase "pass on" instead of "die" and the child is old enough to have heard and understood the phrase, it can be used," she says. Be careful, however, of using phrases such as "he went to sleep" or "we lost ..." especially when talking with siblings because younger children might ask when their brother might awake, or when they can look for him, she explains. "We never use those phrases in pediatrics."

Incorporate play into communications with

patients or their siblings whenever possible, suggests Taylor. "This is effective if the patient or sibling is non-verbal, or if you want to establish rapport," she says. Puppet play is one way to hold conversations, or you can talk while you work on a puzzle, she suggests. "Drawing is another good way to communicate so I always keep a pad of paper and markers with me," she adds.

With siblings, remember that children grieve differently, says Perko. "When a 3-year-old patient died, his sister was a kindergartner and grieved as a kindergartner," she says. "When she was in high school, she grieved for him again because as she was preparing applications for college she realized that her brother never got to go to college," she says. Preparing parents for different types of grief at different times of the siblings' lives is an important role for hospice staff, she adds.

Hospice nurses who don't normally care for pediatric patients are often apprehensive when they have a child as a patient, admits Perko. To alleviate some concern, two nurses can share the care of the child so they can each talk to the other for support, she suggests. "I always tell nurses they can take care of a pediatric patient," she says. "Although the patient is a child, compassion is compassion, and hospice nurses are great at showing compassion." ■

## Pediatric Pain Trials Get Novel Approaches

*No more pain in study than in standard care*

Researchers say there need to be more clinical trials examining the safety and effectiveness of pain medications used with children, which are too often administered based on information from adult trials.

### SOur CES

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### COMING IN FUTURE MONTHS

- Do your press releases result in media coverage?
- Staff training strategies that work
- Tips to improve access to hospice
- How cultural differences affect pain assessment

Gary Walco, PhD, director of pain medicine at Seattle Children's Hospital, says extrapolating from adult clinical data doesn't provide assurance that pain medications are safe for children.

Children often metabolize drugs differently, and there is the possibility that medications, especially those used long-term, may affect development.

Despite the need for pediatric pain trials, Walco says there have been obstacles to conducting them, including a lack of consistent guidance. Now, as a result of a 2009 conference involving the FDA and pediatric pain experts, that obstacle may be overcome.

"A paper has been written that lays out all of these issues so that when [pharmaceutical companies] come to the FDA, they could say, 'Look at this paper, it's peer-reviewed, that's your road map,'" Walco says.

He says the paper is scheduled to be published later this year.

## No greater pain

One ethical issue Walco says is important in conducting a pain trial for children is the idea that pediatric participants cannot be disadvantaged as a function of being in the trial. "That means they can't endure any more clinical pain than they would in standard clinical care," he says.

Walco says it is possible to design trials that meet this requirement. For example, in an opioid-sparing trial, patients have ready access to an opioid such as morphine to treat pain. In addition, they would take a study drug or placebo. The effectiveness of the study drug would be measured not by how much pain the child reported, but by how much morphine had to be used to minimize pain vs. the amount used with placebo.

## Long-term effects

Walco says other issues IRBs should consider when reviewing pediatric pain studies include:

- Children participating should get some direct benefit from the study.
- Physical and emotional pain should be prevented as much as possible and effectively treated when unavoidable. Physical pain and distress must be monitored appropriately.
- Painful procedures such as blood sampling should be minimized.
- Walco says that in general, pediatric analgesic trials should be conducted in pediatric facili-

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ties, because they're most attuned to the needs of children.

He says consent and assent procedures are generally the same as they are for other pediatric trials.

Walco says it's important for pain trials to look not just at the immediate effects of using pain medication, but at the long-term impact, including any effects on the development of children.

"Especially if you're talking about some of the medications that are going to be used for more recurrent and chronic pain, where you're using them over time," he says. "How likely are negative side effects to occur? What is the magnitude of their occurrence? How long might they last?"

Even with the new guidelines for pediatric pain trials, Walco says obstacles remain, including finding enough patients to study. He and other pain experts are starting an international research collaborative to create multi-site analgesic trials for children. So far, 55 centers around the world have expressed interest.

"We hope by setting up a research consortium to do these trials and getting centers on board, they will be more likely to get done," he says. ■