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IN THIS ISSUE

- Building inpatient hospice presents challenges cover
- Capital campaign takes extra effort 39
- Families want privacy incorporated into inpatient hospice 40
- When do physicians discuss EOL options? 41
- Job satisfaction of home health care workers tied to safety. 43
- **Journal Reviews:** Guideline for physician interaction with families; checklist for palliative care; minority Medicare beneficiaries with heart failure less likely to receive hospice; do parents of children with terminal cancer consider hastening death? 44-47
- Children with brain tumors present challenges 47
- **News Briefs:** Advance directive service available; Webinar covers grief counseling. 47-48

Feasibility, financing, and design are keys to success of inpatient hospice

Detailed planning required before ground breaking

What am I doing? I'm a nurse. What do I know about building a hospice facility?

This question has popped into **Pat Stropko-O'Leary's** mind quite often in the past two years as Hospice of Medina (OH) County, has moved closer to having its own building to house a 16-bed inpatient program along with administrative offices for the home health and home hospice services offered by the agency.

As executive director of the agency, Stropko-O'Leary has overseen efforts to raise funds, purchase land, design the facility, and build it.

"In 2000, our board members developed a strategic plan to expand our services," she explains. A bereavement center was established and a home health service for patients who don't yet meet hospice eligibility requirements was developed as two ways to meet unmet needs in the community, Stropko-O'Leary says. "We also began to look at offering inpatient hospice services because there was no inpatient service in our area, and it is not easy for family members to travel great distances to see a loved one at the end of their life," she says.

Although the feasibility study for inpatient hospice initially showed

EXECUTIVE SUMMARY

If a feasibility study shows a need for an inpatient hospice in your area, the hospice manager and board need to handle tasks that are not typical.

- Launch a capital building campaign that will solicit larger contributions that most hospices solicit for programs and services.
- Obtain financing to handle costs not covered by fundraising.
- Educate financiers about the specific needs of hospice.
- Work with an architect and contractors to ensure that building regulations are met.
- Learn how to manage and staff a 24-hour, seven-day-a-week inpatient facility.

enough support for a 10-bed unit, board members were not convinced that the study justified the financial commitment a building required, says Stropko-O'Leary. The logical next step was to find a way to offer the service and gain experience in managing an inpatient unit without the hospice owning its own building.

"In 2003, we leased space in an assisted living facility to set up an eight-bed hospice unit," she says. During the seven years, the inpatient unit operated at close to 100% capacity. "We gained valuable experience, solidified our ideas about what we wanted in our own building, and proved that there is a need for the service in our community."

Groundbreaking for Hospice of Medina County inpatient facility occurred 10 years after the strategic plan called for expansion of services,

but this delay is not unusual, says **Jim Faulkner**, AIA, NCARB, LEED AP, president of Dayton, OH-based Matrix Architects, an architectural firm that specializes in hospices. "Fear of the unknown is the biggest challenge to overcome to get a hospice inpatient facility built," he says. "Board members and hospice leadership often don't have any experience with major capital fundraising campaigns, construction of a health care facility, or staffing a 24-hour inpatient program."

When consulting with a hospice that is considering an inpatient facility, Faulkner advises board members to move forward if a feasibility study indicates a need for the facility. "In most cases, construction costs never go down, so each year the project is delayed, the costs will go up," he points out.

Waiting was a smart move

For Hospice of Medina, waiting until 2010 to break ground actually helped financially, says Stropko-O'Leary. "We were estimating that our initial 12-bed design would cost \$10 million to build, but when we received bids on the project, they were lower than we expected, so we are building a 16-bed project for less than we planned to pay for a 12-bed facility," she says. The lower costs for construction are attributable to the economy and the competition among builders and building supply companies, as well as the competitive bidding process the hospice used, Stropko-O'Leary says.

"We had to bid the project on an open-bid process because of the low-interest loan we are using from the U.S. Dept. of Agriculture's Rural Development Program [www.rurdev.usda.gov]," she says. The loan, along with funds raised through the hospice's capital campaign and money saved by the hospice since 2000 for this project, will pay for the building. All administrative offices, along with the bereavement center and inpatient unit, will move to the new building, Stropko-O'Leary reports. The cost of current leases for the administrative offices, inpatient unit, and bereavement center are three-fourths of the total cost of the monthly mortgage payments, so the hospice is not looking at a significant increase in monthly expenses for space, she points out. (For more tips on financing a facility, see p. 39.)

Incorporating administrative offices and other services into the same building is a way to maximize use of your investment, but be sure the facility doesn't look like an office building, suggests Faulkner. "An inpatient hospice facility should

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-

have a homelike look both inside and outside,” he says.

While a more institutional look might be less expensive to build, fewer patients and families will choose that type of environment, he says. “Our buildings look like residential homes with dormers, hipped roofs, bump-outs, brick, and stone,” Faulkner says. “We also like to build on sites that are in residential neighborhoods because family members have places to walk, backyard gardens in which to relax, and a quiet place with less traffic than a commercial area.”

Inside the facility, spaces should continue the homelike look, suggests Faulkner. “Space in a hospice facility is used differently than other health care facilities,” he says. Rooms must be large enough to accommodate family members, space for family members to spend the night must be available, and small areas throughout the facility should be available for family members to sit when they are not in the patient’s room, Faulkner says. **(For other ideas on hospice design, see p. 40.)**

There will be unexpected challenges, warns Stropko-O’Leary. The hospice was able to purchase a beautiful piece of land that borders a state park, but the state Department of Transportation (DOT) would not allow the hospice to build a driveway from the highway, she says. “We are on a corner, and the DOT rules state that a corner piece of property must use the side street, not a state highway, for access,” Stropko-O’Leary says.

Although the hospice appealed the decision, highway access was not allowed. “We wanted highway access because it means cutting down or damaging fewer trees,” she says. Because the hospice is building their facility as an energy-efficient, environmentally friendly building, the goal has been to remove as few trees as possible. “We can make the driveway from the side street work, and we will just replant trees when we are finished construction,” Stropko-O’Leary says. ■

Outside experts can help with capital campaign

Educate community, bankers about hospice

One of the biggest challenges encountered by hospice administrators and board members who want to build an inpatient facility is funding the project, says **Jim Faulkner**, AIA, NCARB, LEED AP, president of Dayton, OH-based Matrix Architects, an architectural firm that specializes in hospice.

“Many hospices have relied upon smaller, event-oriented fundraising efforts,” explains Faulkner. Although grass-roots, word-of-mouth fundraising is effective for supporting many hospice programs, a 12-bed inpatient unit will cost between \$5 million and \$10 million, he says.

“To raise this amount of money, a hospice needs a well-coordinated capital gift campaign that solicits specific individuals or companies for sizeable gifts,” Faulkner says. “If a hospice does not have this expertise on staff or on the board, a professional fundraiser should be considered.” Faulkner recommends networking with other hospice managers at conferences and meetings to find good fundraisers for hospice. *(Editor’s note: The Association of Fundraising Professionals, at www.afpnet.org, also can serve as a resource.)*

The current economy will affect your ability to raise funds, so be realistic, warns **Pat Stropko-O’Leary**, executive director of Hospice of Medina County in Medina, OH. “We’ve always received great support from our community, so when we started our capital campaign, we set a goal of raising \$5 million to cover half of the anticipated cost of the building,” she says. “We did receive some large gifts from unexpected sources, but we soon realized that we were not realistic about what we would raise.”

Setting the goal at \$2.2 million was more realistic. When the hospice broke ground in March 2010, almost half of the money had been raised. “The campaign will continue throughout the building of the facility to raise the remainder of the money to pay construction expenses,” Stropko-O’Leary adds.

When you are contacting local companies about support for the facility, don’t forget in-kind donations, suggests Faulkner. “A building supply company or a subcontractor might donate a certain amount of supplies or labor rather than cash,” he

says. “One project we handled received a donation of \$300,000 worth of brick and stone from a local company.”

Although you might not have the architectural or fundraising expertise for the project locally, work with local banks for financing, suggests Stropko-O’Leary. “We solicited loan proposals from local banks and are using a combination of loans from a local bank and a low-interest government loan from the U.S. Dept. of Agriculture’s (USDA’s) Rural Development Program [www.rurdev.usda.gov],” she says. “We learned that we qualified for the USDA loan from one of the local bankers.”

Be prepared to educate people about hospice when you submit your loan request, warns Stropko-O’Leary. “We were the first hospice to apply for a loan with the bank, so the person assessing the viability of our business plan for the facility tried to compare our business to nursing homes,” she says. Because the design of the hospice’s building included administrative offices for the home health agency, the home care hospice service, in addition to the inpatient facility, the assessor focused on the number of offices compared to the number of inpatient beds, Stropko-O’Leary says.

“He kept saying that having 24 offices to support 16 beds did not make sense,” she says. “We had to explain that the 24 offices were not just to support the beds, but also to support all of the home-based patients, the bereavement center, our fundraising, our counseling, and all of the other community outreach services we offer.”

Unlike a nursing home or hospital, most of the hospice’s patient care takes place out of the building, because they see most patients in their own homes. That is something most loan officers don’t understand, she says. ■

Homelike design appeals to patients and families

Ask staff members for input

“It should look like Grandma’s house.” This is how **Jim Faulkner**, AIA, NCARB, LEED AP, president of Dayton, OH-based Matrix Architects, an architectural firm that specializes in hospice, describes the ideally designed inpatient hospice facility.

“People want to feel comfortable with their

surroundings, and the best way to make them feel comfortable is to make the building similar to a home,” he says.

Designing a hospice inpatient facility requires attention to items that are different from other health care facilities, says Faulkner. “People use an inpatient hospice facility differently than a nursing home or hospital,” he points out. “Family members will stay with their loved ones 24 hours a day when they are dying, and the facility has to be able to handle an influx of additional people.”

Versatility for the facility begins in the parking lot, says Faulkner. You have to design the parking lot with a specific number of parking places according to local regulations and anticipated, normal, use of the facility, he says. However, what happens if several patients are at the end of life at the same time, and multiple families are at the facility? “We design driveways wider than normal to handle overflow parking when needed,” Faulkner says.

Patient rooms must be larger than most health care rooms, says Faulkner. “More family members want to be involved in care at the end, so the rooms have to accommodate additional people providing care,” he says. “If possible, we design a small sitting area with a pullout sofa and sometimes a small second room can be built adjacent to the patient room.” These are expensive options, but some hospices opt for them to provide privacy to the patients and their families.

Another way to provide a private, quiet area for families to use is to build a number of “nooks and crannies” throughout the facility, suggests Faulkner. “Small sitting areas, counseling rooms, libraries, or bereavement rooms that resemble living rooms, all offer places for family members to gather,” he says.

Even the kitchen in an inpatient hospice facility is different, points out **Pat Stropko-O’Leary**, executive director of Hospice of Medina (OH) County. “Hospital and nursing home kitchens serve meals at scheduled times of the day, but our kitchen has to make food available to family members throughout all hours,” Stropko-O’Leary says. “We have to stock and staff it so that we can fix a sandwich or chicken soup or other comfort foods that family members want, any time of the day.”

Stropko-O’Leary’s staff had the advantage of operating an inpatient unit within an assisted living facility’s building before designing their own building. “We asked staff members for input, and we got a lot of good ideas,” she says. While the assisted living facilities had doorways opening

onto outside patios from the rooms, staff members were concerned about security in a building with that many doors to the outside and a building that contains narcotics and other drugs. “Our inpatient hospice rooms face a beautiful, wooded park so we want them to enjoy the outdoors, but we opted for floor-to-ceiling windows rather than doors to the outside,” Stropko-O’Leary says.

A children’s counseling room and a library for families to use were two other ideas implemented from staff suggestions, she says. “Our inpatient staff also insisted on no carpeting in the unit,” Stropko-O’Leary says. This suggestion went against the architect and hospice leadership’s intention to make the building as warm and home-like as possible, but the nurses explained the difficulty keeping the carpet clean and unstained from blood, she says. “Our architects came up with another option. They found a durable, bacteriostatic carpet that would be easy to clean and disinfect,” Stropko-O’Leary says. “The nurses were happy with the solution.”

There was one employee suggestion that did not go far in the approval process because it didn’t fit the mission of the project, Stropko-O’Leary admits. “One staff member wanted us to include a fitness area with showers and changing rooms so staff members could work out before going home or before starting work,” she says. ■

CANCER study: Physicians and end-of-life discussions

Physicians don’t discuss EOL within guidelines

Most physicians reported in a national survey that they would discuss end-of-life options with a terminally ill patient only when there were no more treatments to offer that patient, not when the patient still was feeling well, according to a study published online in *CANCER*, a peer-reviewed journal of the American Cancer Society.¹

Based on other studies that suggest cancer patients receive a lot of aggressive care at the end of life, and through their own experiences treating cancer patients, the designers of the study were “suspicious that doctors might not be talking about end-of-life issues,” Nancy L. Keating, MD, MPH, an author of the study and a member of the Department of Health Care Policy, Harvard Medical School, Boston, and the Division

of General Internal Medicine, Department of Medicine, Brigham and Women’s Hospital, both in Boston.

Also, the researchers took a cue from other literature, which suggests that many patients really don’t know how sick they are, she says. “We were quite surprised to find such low rates of discussion of some of these end-of-life issues in patients [who] had a life expectancy of four to six months,” Keating notes.

National end-of-life guidelines usually recommend that such end-of-life discussions take place when a patient has less than a year to live, she explains.

The researchers, Keating says, believe there are two possible explanations: One is that physicians aren’t aware of these national guidelines; the other is that they are aware of the guidelines but disagree with them. It is possible, she says, that physicians often decide on their own that their patients aren’t ready to discuss the end of life, or they believe that patients won’t take the prognosis or discussion well, and as a result they will lose hope and give up.

“I personally think that patients have a right to have these discussions early, when they’re really able to and capable of [understanding],” Keating says. “But there aren’t, and there haven’t been, excellent studies randomizing people to hearing about [these matters] early or late to know what happens.”

Difficult conversations are, well, difficult

One explanation for why physicians don’t have end-of-life discussions with their patients is that these are difficult conversations to have, Keating says.

“Unfortunately, we didn’t know what our results would be to have follow-up questions on that, so we can’t tell you anymore about that,” Keating says. “We need more research to try to find out why doctors aren’t having these discussions.”

Keating suggests that the best guess for why they aren’t having these discussions is that doctors tend to focus on treatment. One finding from the survey was that 66% of physicians surveyed discussed prognosis early, or when the patient had four to six months to live. “So, we said, are doctors using this as an opportunity to have other discussions about hospice and DNR status, etc.?” she says. “And in fact, there were no differences in the rates of doctors discussing these other things who did or did not discuss prognosis early, which leads us to think that the prognosis is a discussion that the doctors use as an opportunity to discuss treatment.”

“They might say, ‘Well, the average person might live for six months with your condition; but if we treat you with this drug, the average person

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-

will live for eight months,” Keating says.

Because most of the doctors indicated they would not discuss end-of-life options with the patient unless there were no more treatments to offer, Keating takes issue with that approach. “In patients with metastatic disease, what does it really mean that there are no more treatments to offer? I mean, none of the treatments are curative in the cancers that were studying, or pretty much none. So, most of these patients really do have relatively few options, and I think they may not be understanding that any treatment for them is not going to be curative.”

Often, when these conversations are delayed, Keating says that in her experience, the patient receives chemotherapy, then the patient becomes sick from chemotherapy and goes to the hospital, where he or she is intubated due to pneumonia. Keating maintains that “if the patient really understood their prognosis, they might not want that.” (For story on why physicians have later conversations about end-of-life care, see story, below. For story on timing of the discussion, see below right.)

REFERENCE

1. Keating NL, Landrum MB, Rogers SO Jr., et al. Physician factors associated with discussions about end-of-life care. *CANCER* 2010; 116:998-1,006. ■

Physicians are trained to treat

The real culprit for why physician conversations with patients about end-of-life care occur later rather than sooner is that physicians in medical schools primarily are trained to treat rather than talk, but that appears to be changing.

“I think, by and large, doctors are trained to treat patients, and to make patients better, to cure patients. And we’ve traditionally had very little training and experience in focusing on improving

the quality of death,” says Nancy L. Keating, MD, MPH, an author of a recently published study on physician discussions with patients on end-of-life care.¹ “And I think a lot of doctors feel like they’ve failed, if they can’t cure someone or can’t continue treating someone,” says Keating, a member of the Department of Health Care Policy, Harvard Medical School, Boston, and the Division of General Internal Medicine, Department of Medicine, Brigham and Women’s Hospital, both in Boston.

20% go to ICU in last month

Keating notes that about 20% of patients in the Medicare population are admitted to the ICU in the last month of life. “I think there’s lots of evidence out there that many patients get lots and lots of courses of chemotherapy at the end of life,” she says. “Many patients are getting new chemotherapy within 30 days of death, and all of these things suggest that we really are possibly being too aggressive with the way that we’re treating people.”

An encouraging sign related to this issue is that many medical schools now have structured classes on communication covering topics such as end-of-life options. Also, the survey found that more recently trained doctors were more likely to have end-of-life discussions with their patients, Keating notes.

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1. Keating NL, Landrum MB, Rogers SO Jr., et al. Physician factors associated with discussions about end-of-life care. *CANCER* 2010; 116:998-1,006. ■

Timing of discussion is sensitive to patients

End-of-life discussions can begin when someone is diagnosed with a life-limiting illness, says James A. Tulsky, MD, director of the Palliative Care Center at Duke University Medical Center, in Durham, NC.

“Part of it is, it’s very important to find out what the patient wants,” he says. “You know, if you look at surveys of patients, they have very different preferences for when they want to talk about this. Some people say, ‘As soon as I get diagnosed with metastatic disease, for example, I want to have a discussion about end of life.’ Other people will say, ‘Only when I am a few weeks away from death do I want to have a discussion about end of life.’”

Physicians are increasingly trained to ask

patients questions and to listen to their answers.

“One of the things that we train people to do is to ask patients and to say to somebody, ‘One of the things I would like to talk with you about is decisions you would face in the future, concerns about the future. Is now a good time to talk about this? Would you like to hear about prognosis? Would you like to hear what we expect to happen with this illness, or would you rather not? People will [sometimes] say, ‘I’m not ready to talk about that right now.’ And then that’s their choice,” Tulsy says. ■

Improve retention: Make safety a priority

Job satisfaction related to safety

Why should a home health manager pay close attention to employee safety? Not only are there legal and ethical reasons to do so, but employees who feel safe in their work environment are more likely to remain in their job.

“As home health nurses grow older, it becomes more important to make sure that they are satisfied with their jobs and stay with the agency, because it is difficult to replace their experience and knowledge,” points out **Robyn R.M. Gershon, MHS, DrPH**, associate dean of research resources and professor at the Mailman School of Public Health at Columbia University in New York City. High turnover is not only expensive, but it also can create more dissatisfaction among employees, as other staff members are asked to cover more patients, she says.

What the research says

One study shows a negative correlation between threatened verbal or physical abuse, environmental exposures to cigarette smoke or unhealthy homes, and household job-related risks to job satisfaction and retention, Gershon says.¹ Other issues that home health employees identify as issues in the job, such as transportation and travel, or the type of work that is done, do not present a significant correlation to retention. “It is clear that violence, or the potential for violence, are issues that affect the employee’s plan to stay with the agency,” says Gershon. If an agency can develop safety policies that are specific to home health and ensure that all employees understand that the agency takes their safety seriously, the opportunity to retain employees increases, she says.

Be sure your policies address the process to

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report a safety issue, the actions that are taken after a safety incident or report, and the options for resolving the safety issue, says Gershon. Safety policies should address a range of issues, including infection control and personal security, she adds.

Just developing policies is not enough to reassure employees, suggests **Norma R. Anderson, RN, MSN, CNL**, nurse educator at the University of San Francisco School of Nursing and author of “Safe in the city,” a study of workplace danger in home health.² “Safety policies and protocols needs to be reinforced through yearly safety training classes and daily reminders that safety is important,” Anderson says. “A continuous focus on employee safety makes employees feel valued.” (For information on how to handle a report of a safety issue, see story, below. For more on the safety of employees who work in the home, see “‘Safety comes first’ should be more than slogan,” *Hospice Management Advisor*, March 2010, p. 30.)

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How to address report of a safety issue

Take report seriously; document follow-up

Ensuring employee safety requires more than a set of policies and procedures. It requires immediate action and thorough investigation once an employee reports an unsafe situation, says

Robert W. Markette Jr., an attorney with Gilliland & Markette in Indianapolis.

Take each report seriously, says Markette.

Although the issue might seem minor, be aware that most cases of violence in home health were preceded by warning signs that the home health employee didn't report or didn't view as serious, he explains.

Make sure that employees know that they don't have to stay in the home if they feel threatened, says Markette. "If the patient or a member of the patient's family yells at the employee or threatens them in any way, they should leave and let their manager talk to the family," he says.

There are gray areas in which some home health nurses use their own judgment, admits Markette. "Some patients with dementia will threaten others, curse, or yell, and the behavior is related to the disease," he says. "Older, more experienced nurses will often take the behavior in stride, but younger nurses or aides may not be prepared to handle the situation."

Regardless of the situation, once an employee reports that he or she doesn't feel safe, a manager must investigate, says Markette. "If there is violence or a threat of violence, suspend service while you investigate," he suggests. "After the investigation, a manager and another person from the agency should visit the family."

The agency should always send two people to meet with the family, with one person having the authority to make decisions and the other person as a witness to the meeting. The purpose of the meeting is to identify the issue, outline the results of the investigation, and discuss the actions that will be taken to resolve the issue. The employee involved in the report should not be present, says Markette.

"All of these points should be included in a letter that will be given to the family," he says.

A family member or the patient must sign a form acknowledging receipt of the letter, Markette adds.

In some cases, the agency might ask a family to fix unsafe conditions in the home, make sure that family members or friends who threatened or made the employee feel unsafe are not at the home when the employee is there, or confine a dog during the employee's visit, says Markette. "If the family and patient agree to the conditions, resume service," he says.

There might be cases in which patients or family members don't want certain employees based upon race or gender, and that preference prompted the threatening language, says Markette. "An agency cannot assign employees based upon race or gender," he emphasizes. If the family or patient insists upon certain gender or race, then the agency will have to

SOURCE & RESOURCE

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discharge the patient, based on the family's unwillingness to provide a safe environment, he adds.

Dementia patients can present challenges, but Markette suggests that the agency try to assign more experienced nurses to them if there is no real potential for violence. "If you do make a staffing change after an investigation, be sure to point out to the employee who filed the complaint that it is not a reflection on the employee's performance; it is related to being able to serve the patient," he suggests.

If the patient and family don't address the issues outlined in the letter, it is appropriate to send another letter informing them that due to their inaction, your agency must discharge the patient, says Markette. Although agency managers are reluctant to appear to abandon a patient, it is acceptable to discharge a patient when there is clear evidence and documentation that providing care places the home health employee in a potentially dangerous situation, he says.

Finally, after the report has been investigated and issues have been resolved, be sure to communicate with the employee who initiated the complaint, says Markette. "Explain the process and the results thoroughly, so that the employee knows the complaint was taken seriously." ■



JOURNAL REVIEWS

Relationships explored for patients, caregivers

Association issues paper to explore ethics

The American College of Physicians (ACP) has issued a position paper to guide ethical relationships among patients, physicians, and caregivers.

The *Journal of General Internal Medicine* has published “Family caregivers, patients, and physicians: Ethical guidance to optimize relationships.”¹ The text and an online appendix of resources to help physicians manage relationships with patients and caregivers are available at www.acponline.org/running_practice/ethics/issues/policy. The article is listed under “Individual position papers.”

The paper defines caregivers as relatives, partners, friends, and neighbors of patients who assist with activities of daily living and complex health care needs. It outlines four primary principles for physicians, who might face ethical challenges collaborating with patients and caregivers while preserving the primacy of the patient-physician relationship:

- Respect for the patient’s dignity, rights, and values should guide all patient-physician-caregiver interactions.
- Effective communication and physician accessibility are fundamental to supporting the patient and family caregiver.
- The physician should recognize the value of family caregivers as a source of continuity regarding the patient’s medical and psychosocial history and facilitate the intellectual and emotional transition to the end stage of serious chronic illness.
- When the caregiver is a health care professional, the physician should draw appropriate boundaries to ensure that the caregiver is not expected to function in a professional capacity in relation to the patient and that the caregiver receives appropriate support, referrals, and services.

Although hospice and palliative care address the impact of illness on patients and families, the authors wrote, historically the patient-physician relationship has focused on the patient’s rights and interests with less attention to the patient’s experience within the context of family and social relationships, according to the authors. “Contemporary bioethics with its emphasis on patient autonomy and confidentiality has supported this model but is beginning to recognize the need for a family-centered approach,” the authors add.

REFERENCE

1. Mitnick S, Leffler C, and Hood VL, for the American College of Physicians Ethics and Human Rights Committee. Family caregivers, patients, and physicians: Ethical guidance to optimize relationships. *J Gen Intern Med* 2010. Doi 10.1007/s11606-009-1206-3. ▼

Checklist published for in-home palliative care

A study by Spanish researchers presents new information for palliative care teams that administer sedation to patients at home.¹ Their findings prove that palliative sedation does not hasten death among terminally ill patients.

The researchers reviewed medical records for 370 patients in palliative home care. Researchers looked at situations where caregivers used different types of drugs to relieve intolerable suffering of end-of-life cancer patients. Among the 370 patients in the study, 245 (66%) died at home, and 125 (34%) died in a hospital or hospice.

As a result of their research, the research team developed a standard checklist for in-home palliative care patients. This treatment checklist can be used to evaluate the frequency and efficacy of palliative sedation on cancer patients dying at home.

The checklist covers items that should be addressed in the clinical assessment and preparation of the patient for palliative sedation. Specific guidelines for administration of sedation, as well as monitoring of the patient and family, are included.

REFERENCE

1. Alonso-Babarro A, Varela-Cerdeira M, Torres-Vigil I, et al. At-home palliative sedation for end-of-life cancer patients. *J Palliative Med* 2010. Doi: 10.1177/0269216309359996. ▼

Minorities with heart failure less likely to use hospice

Study targets Blacks and Hispanics

Black and Hispanic Medicare beneficiaries with heart failure appear less likely to receive hospice care than white patients with the same condition, according to a report in the March 8 issue of *Archives of Internal Medicine*.

“Underuse of hospice care is well documented, especially among racial and ethnic minorities,” the authors wrote. “Racial and ethnic differences in patients who use hospice care have been found across a spectrum of patients with cancer diagnoses and may be more pronounced in patients with

noncancer diagnoses.” (For more on this topic, see package of stories in the March 2010 issue of *Hospice Management Advisor*, beginning on p. 25.)

Heart failure affects nearly 5 million people in the United States. Advanced heart disease is the second most common hospice diagnosis, accounting for about 12% of all hospice enrollees.

Medicare population studied

Jane L. Givens, MD, MSCE, of the Hebrew SeniorLife Institute for Aging Research, Beth Israel Deaconess Medical Center, Boston, and colleagues studied a national sample of 98,258 Medicare beneficiaries age 66 or older who had a diagnosis of heart failure. None of the participants was enrolled in hospice at the beginning of the study, in 2000. Over the next year, of the beneficiaries who entered hospice care, 18.2% did so because of heart failure. In unadjusted analyses, black and Hispanic patients were less likely than white patients to enter hospice care. The association persisted after adjusting for other factors, including income, urban location, severity of heart failure, and co-occurring illnesses. When compared with whites, black patients and Hispanic patients had lower odds of receiving hospice care.

“In addition to sociodemographic, clinical, and geographic characteristics, cultural beliefs and values may contribute to differences between blacks and whites in end-of-life care and hospice use,” the authors wrote. “For example, compared with whites, blacks are less likely to complete advance directives, have less favorable beliefs about hospice care, opt for more aggressive treatments and are more likely to have spiritual beliefs that conflict with the goals of palliative treatment.

“In addition, lack of trust between patients and physicians may be more pronounced for ethnic minorities and may contribute to ethnic differences in hospice entry,” the authors conclude. “It is not clear how many of these differences reflect access issues as opposed to considered patient preferences.” ▼

Parents weigh whether to hasten death

A survey of parents who had a child die of cancer found that one in eight considered hastening their child’s death, a deliberation influenced by the amount of pain the child experienced during the last month of life, report researchers at Minneapolis-based Dana-Farber Cancer Institute in the March issue of *Archives*

of *Pediatrics & Adolescent Medicine*.

The study, the first to explore this area, suggests that many parents worry that their children will suffer from uncontrollable pain, and that some parents might consider that an early death would be preferable. The researchers say the findings underscore the importance of managing patients’ pain and of communicating with parents about the tools available for easing progressive pain.

“The problem is that conversations about these family worries may not always happen,” said senior author Joanne Wolfe, MD, MPH, division chief of pediatric palliative care at Dana-Farber and director of palliative care at Children’s Hospital Boston. “Parents may not have the opportunity to express these feelings and considerations, and as clinicians, we may not be adequately enabling sufficient opportunity for them to talk about their concerns.”

Wolfe, along with first author Veronica Dussel, MD, MPH, a Dana-Farber research fellow, undertook the research to gain an understanding of why some parents would consider a measure as extreme as intentionally ending a child’s life. The researchers interviewed 141 parents of children who had died of cancer and were treated at Dana-Farber, Children’s Hospital, or Children’s Hospitals and Clinics of St. Paul and Minneapolis.

Parents questioned twice

The scientists queried parents about their behaviors and feelings leading up to their child’s death and at the time the survey was conducted, which was a year or more after the death. The parents also were presented with hypothetical vignettes involving a terminally ill child with uncontrolled excruciating pain or who was in an irreversible coma.

One in eight (13%) of parents had considered asking caregivers about the possibility of ending their child’s life, though only 9% reported having such a discussion. Five parents (4%) had requested that their child’s death be hastened, and three parents said it had been carried out, using morphine. Wolfe commented, however, that “this may not reflect what actually happened, because morphine is used in increasing doses to manage worsening pain without the intent or the effect of ending life.”

In response to the hypothetical vignettes, 50% of parents said they endorsed hastening death in situations of uncontrollable pain or if the child was in an irreversible coma. Parents were 40% more likely to approve hastening death for a child experiencing extreme pain than for a terminally ill child in a coma.

Wolfe said it is important to keep the findings in perspective. Only five parents reported having talked about hastening their child's death, and 19 said they considered it. Wolfe said it is her experience that parents are comforted by having conversations about pain management and that most are reassured by knowing what will be done to ease their child's suffering.

"We've come a long way, because we have a good palliative and supportive care program for children with cancer," said Wolfe, who also is an assistant professor of pediatrics at Harvard Medical School. But she acknowledged, "I can never promise that their child will be pain-free. We still have quite a way to go in figuring out the best way to ease suffering at the end of life." The gap exists in part, Wolfe said, because this area is not given high priority for research funding agencies. ■

End-of-life experiences of children with brain tumors

Parents and clinicians caring for children with brain tumors might experience significant challenges near the end of life due to the neurologic deterioration that often occurs in these patients, according to a study in the March issue of *Archives of Pediatrics & Adolescent Medicine*.

Shayna Zelcer, MD, FRCPC, staff physician, hematology/oncology of Children's Hospital, London Health Sciences Center, Ontario, Canada, and colleagues conducted a qualitative analysis of focus group interviews involving 25 parents of 17 children who had died of brain tumors.

The analysis identified three primary themes. The first was that parents described their child's dying path as characterized by progressive neurologic deterioration. Loss of communication ability was a key turning point, and parents coped by striving to maintain normality and finding strength through hope and the resilience of their child. The second theme identified common parental struggles: balancing competing responsibilities and talking with their children about death. The third theme was that parents who wanted their child to die at home faced barriers, including inadequate symptom control, financial and practical hardships, and a lack of community support.

"We hope this report will increase the awareness of health care professionals concerning the

challenges these families face and the need for anticipatory guidance and education of patients and families early in the course of illness," the authors conclude. ■

NEWS BRIEFS

Company offers advance directive services

Embark Health, Daytona Beach, FL, now offers an online solution to help people plan for end-of-life health care decisions. The company's Advance Directive Solution (ADS) offers an opportunity to subscribe to a service that helps them set up their advance directive, communicates with health care providers to ensure that the document is on medical charts when needed, and informs caregivers and family members of the terms of the advance directive and location of the document.

A percentage of the \$85 enrollment fee is donated to a health care-related charity. The enrollment fee and subsequent renewal fees of \$32.50 per year provide the following services:

- 24/7 online and telephonic support;
- three levels of quality checks to ensure that the advance directive is completed clearly and correctly;
- multiple communication channels with health care providers to transmit the advance directive to the health care team when it is needed;
- legal counsel in the event of a dispute;
- education for the member's Circle of Care: health care team, family, and health care agent, so they are fully informed about the location of the advance directive and its terms.

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- How to turn your staff into a sales force

Although completion of the advance directive does not require legal guidance or consultation with a health care firm, Embark Health representatives point out that only one in five people complete an advance directive, and many of those people just file it away in their home without communicating its contents or location to people who need to know about it.

“We are dedicated to making advance directives valid, clear, up-to-date, and accessible when needed, so that the family and the health care agent know the patient’s decisions before a crisis occurs,” said **Michael Brouthers**, chief executive of Embark Health. For more information about the Advance Directive Solution, go to www.embarkhealth.com/ADS, or call (800) 944-0451. ▼

Webinars address grief counseling for children

The Hospice Foundation of America (HFA) offers webinars on helping children and adolescents cope with grief and loss.

The webinars look at lessons learned from extensive research into the issue, emerging trends on the horizon, and how hospices and other health and community organizations can use bereavement camps and other strategies to help grieving children. HFA’s live online webinar series includes:

- **Bereaved Children and Adolescents: Lessons from Research** on Wednesday, April 14, 1 to 2:30 p.m. Eastern Time.

- **Grieving Children and Adolescents: The Role of Internet Support** on Tuesday, June 15, 1 to 2:30 p.m. Eastern Time.

Cost of the live webinars are \$100 per program for organizations and \$35 for an individual. If an organization wants access to all three of the programs in this series, the fee is \$250, which allows access to both the live webcasts and an archived online program for one year past the live webinar, with unlimited CEs (1.5 hours) available for a wide range of professions. This fee includes access to the first program of the series that occurred in February: Bereavement Camps for Kids: Benefits and Challenges. Continuing education credit is included for individuals. For more information, go to www.hospicefoundation.org, choose “Professional Education” and select “webinar series,” or call (800) 854-3402. ■

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