

HOSPICE Management ADVISOR

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FEBRUARY
2001

VOL. 6, NO. 2
(pages 13-24)

Rural hospice challenge: Bring services into underserved communities

Volunteers and technology are keys to keeping rural patients home

Traveling 60 miles to reach patients in the most remote places is a way of life for hospice workers in rural areas. But the challenge of bringing hospice care to rural patients only begins to describe the obstacles hospices face in non-urban areas.

Despite the Homeric efforts of nurses who travel from one corner of a sparsely inhabited county to another, many rural residents remain out of reach because coverage areas of hospices there do not overlap. The same community resources available in metropolitan areas are absent in rural settings, and many rural communities are a collection of tight-knit, homogeneous residents who are often resistant to accepting help from outsiders.

“In some counties there are literally no medical services,” says **Wendy Hournbuckle**, RN, hospice coordinator for Jamestown (ND) Hospital Hospice.

People living in rural communities make up about one-fourth of the country’s population, but geographical distances, isolation, and poverty inhibit their access to high-quality medical care.

As the country faces a boom in the elderly population, those who provide end-of-life care are trying to figure out how to overcome these obstacles. End-of-life organizations and hospices in rural communities are trying to find ways to improve access to medical care, shore up community resources, understand cultural belief systems, and meet the needs of caregivers.

For the past year, Matters of Life and Death in Bismarck, ND, a Robert Wood Johnson-funded organization studying rural end-of-life care, says hospices have been a major focus of their research.

“We believe the holistic approach of hospices will allow dying patients in these areas to stay at home, rather than having them live outside their community in a nursing facility or hospital,” says **Theresa Frohlich**,

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project coordinator of Matters of Life and Death, which is spearheaded by the North Dakota Medical Association. “But what we’re finding is that hospice services are fragmented throughout the state.”

Expand volunteer programs

A few rural hospices are increasing their volunteer staffing to try to address the shortage of hospice care. Some are expanding coverage areas by recruiting volunteers who live in the underserved areas.

Hournbuckle also says rural hospices should expand their volunteer programs and provide proper training to people in living underserved areas so they can overcome the barriers some communities would place on outside caregivers.

Any program that gives volunteers an expanded role in patient care requires an intense volunteer training program. Volunteers should be educated in the following elements of hospice care:

- **The dying process.** Teach volunteers the signs and symptoms associated with the last hours of life so they can communicate this information to the family. This communication can prevent unnecessary grief over what might be considered suffering when instead the symptoms should be seen as a natural and inevitable prelude to death.

- **Types of terminal illness.** Volunteers should be aware of the kinds of diseases they will face, as well as the symptoms associated with these diseases.

- **Communication techniques.** Volunteers must be versed in how to talk about death with patients and must have sufficient listening skills to better gauge the needs of patients and families.

- **Psychosocial aspects of death.** Understanding spiritual matters, for example, will help volunteers engage patients in matters of religion in hopes of revealing a patient’s spiritual needs. Other psychosocial topics include family relationships and emotions surrounding one’s pending death.

- **Hands-on caregiving.** Because volunteers in rural communities will be providing the bulk of care, they need to be trained in assisting patients in activities of daily living, including brushing their teeth, combing their hair, and using the bathroom.

Training also allows hospice volunteer coordinators to assess volunteers’ ability to handle

expanded duties, as well as helping to determine whether a prospective volunteer has unresolved bereavement issues that need to be addressed before being assigned a patient.

Still, volunteers may be difficult to recruit, given society’s inability to talk about death. If finding volunteers in small communities is a challenge, then technology may provide some solutions.

“Hospices might want to consider telemedicine,” says Hournbuckle.

Telemedicine is an emerging technology for hospices. Hospices in Michigan and Kansas are studying telemedicine to determine where it might be best applied, including rural communities, where nurses and other hospice workers have difficulty maintaining face-to-face interactions. In addition to patient exams, telemedicine is commonly used to interpret electrocardiography, echocardiography, X-rays, and magnetic resonance imaging between remote sites.

A team of pain specialists in Kansas City, KS, uses the extensive and well-established telemedicine system of the University of Kansas Medical School to consult with patients and practitioners in communities as far as 400 miles away.

Preventing a 300-mile trip

“We have telemedicine sites in 35 locations around the state, all linked to the medical center through interactive television systems,” explains **Robert Twillman**, PhD, a clinical psychologist who chairs the Kansas Cancer Pain Initiative. A team of three pain experts, including Twillman; Teresa Long, MD, who is board-certified in internal medicine, psychiatry, and hospice and palliative care; and Melanie Simpson, RN, BSN, OCN, pain management nurse/coordinator of the center’s pain service, consults on an as-needed basis. In the past three years, the team has advised 15 to 20 patients, some of whom “would have had to travel 200 to 300 miles to see a true pain expert in person,” Twillman notes.

Typically, the patient’s local physician will schedule the telemedicine appointment and then fax the patient’s records. The pain experts meet via video with the patient and a health care provider and make recommendations about prescriptions and non-pharmacological interventions. “Many times, the physicians are pretty certain about what is happening, but they consult with us to confirm that they’re doing the

right thing — and they usually are,” Twillman notes.

Since May 1997, Kendallwood, a hospice in Kansas City, MO, has been using telemedicine to keep more frequent contact with their at-home patients. Called “telehospice,” the Kendallwood program is being used by 20% of the agency’s patients, mostly those living in rural areas.

“As we worked together, I saw that they had a significant rural background,” explains **Gary Doolittle**, MD, Kendallwood’s medical director and director for telemedicine services at the University of Kansas Medical School. “They were being paid a per diem by Medicare. As a result, it’s a large expense to visit patients in terms of nursing time and windshield time.”

Videophone permits 24-hour hospice access

Kendallwood’s telehospice program uses a videophone, telephone, and existing phone lines at home with caregivers in an office. The hospice version allows patients 24-hour access to doctors, nurses, social workers, and chaplains within the hospice.

The videophone — a small television screen with a camera eye mounted above it — is connected to a telephone and placed on a table or desktop. The unit is small enough to be moved throughout a patient’s home to allow hospice workers flexibility in viewing patients.

Once installed, the patient and hospice worker can call each other by simply dialing the phone and pressing telephone keypad buttons as prompted by an on-screen menu to establish a video connection. Receiving a videophone call requires the same process. The videophone allows each party to zoom in on the other party, pull back, or change the screen angle by tilting the screen.

Telemedicine is an appropriate service for all hospice patients, says **Maria Hoffman**, RN, BSN, the patient care coordinator at Kendallwood. Its use goes beyond the clinical applications for which most health care organizations are using the technology.

Doolittle says hospices that want to implement telemedicine should take the following steps:

- **Training.** Staff should become thoroughly familiar with the technology, because any hint of staff unfamiliarity with the technology will undermine the training of patients. Doolittle recommends applying the technology to office operations to get staff accustomed to it, such

as setting the videophones up for meetings with remote staff.

- **Identify key staff.** Single out staff from each discipline who will champion telehospice. These staff members should be those who are excited about the new technology and who will push its implementation and act as consultants for other staff who have questions.

- **Target rural patients.** While telemedicine is an appropriate service for all hospice patients, Doolittle says patients in rural settings are particularly well-suited for telehospice.

While telemedicine offers technological innovation, improving rural hospice care also requires innovation on more basic levels. One of the challenges is providing support services to rural patients despite not having a network of community resources readily available. For instance, patients in metropolitan areas have access to meal programs that provide hot meals to home-bound patients.

Churches can play expanded role

Hournbuckle says churches can serve as a key resource for hospices in rural communities where churches often are central institutions in the lives of residents. Aside from being a place of worship, a church is often a center of community functions. Because of this, church members might be willing to expand their role in helping neighbors cope during a difficult time by providing volunteers to cook and deliver meals, help caregivers keep up with housework, and provide respite care.

For Jamestown hospice, one unlikely ally is the county agricultural extension office. More known for providing assistance in farming matters, the local agricultural extension office in Jamestown also serves as a place to get end-of-life care information. County residents can go to their local offices to get written information about hospice and palliative care, Hournbuckle says.

In the effort to increase access to hospice care in rural areas, there doesn’t seem to be a single simple formula. Instead, a patchwork of innovation and technology is needed. But the goal remains the same: bringing hospice care directly into the underserved communities, rather than having workers travel long distances to provide the needed care.

“The closer we bring the services to the patient’s home, access is going to improve,” Hournbuckle says. ■

Use cost accounting to boost hospice efficiency

Cost report is first step toward cost accounting

You've spent hours preparing this year's cost report. Once it has been submitted to the Health Care Financing Administration, you breathe a sigh of relief and put the process behind you. But your cost report should not be seen as a mere exercise in federal busywork. While not a perfect or even a detailed picture of a hospice's costs, cost reports should be perceived as a tool for judging an organization's efficiency rather than a chore heaped on it by HCFA.

"Hospices were one of the only providers that haven't had to do cost reports," says **Lisa Spoden**, president of Strategic Healthcare, a hospice consulting firm based in Columbus, IN. "It has actually hurt them. Hospices have been telling payers that their reimbursement wasn't covering costs, but why should any payer just take their word for it?"

In the long term, cost reports will yield benchmarks hospices can use to compare their costs to other hospices. In the short run, their first cost report provides a snapshot of how a hospice spends its money, from pharmacy costs to administrative services to nursing care. **(For details of what should be included in a cost report, see list, p. 17.)**

A detailed examination of the numbers contained a cost report can reveal how much a hospice is spending in each category per day. The total of all categories represents how much a hospice is spending per day. That total can be compared to the hospice's current per diem reimbursement.

In order to determine cost per day, simply take the total from each cost center and divide this by the number of days of care. While this may seem like a rudimentary tool to be used in the complex task of cost accounting, some hospices may be surprised by the result. Because so many hospices have ignored costs in the past, a cost report can reveal aberrant numbers that may prompt a closer look at how money is spent in each cost center. For example, a high total figure or cost per day figure may be evident in the durable medical equipment category. This allows the hospice's leadership to focus on that specific area to reduce costs in it.

Still, the cost report itself can provide only a limited amount of information, says **Andrew Reed**, CPA, president of Multiview Inc., an accounting software firm that has developed programs to help hospices complete their cost reports.

One of the ways the hospice cost report falls short of being a complete picture of how a hospice spends its money is that it's unable to link operational data with financial data, says Reed. Also, the cost centers listed in the hospice cost report bear too much resemblance to home health care, adds **Teresa Craig**, CPA, chief executive officer of Hospice Systems Inc., in Largo FL, which also sells cost reporting software for hospices.

If hospices want to get full use of the numbers they collect for the cost report, they need to do a complete cost analysis beyond the cost centers listed in the cost report. For example, a sound financial analysis should include not only a hospice's cost per day, but also cost per day by discipline, patient, or disease, none of which are required by the cost report. The only way to achieve that level of financial detail is to implement more elaborate accounting systems, says Reed.

Brush up on your ABCs

One accounting method, activity-based cost accounting (ABC), does just that by looking at cost as an element of a process rather than as an individual item that chips away at the bottom line. ABC requires hospices to determine the individual parts of a process, which allows them to look at the cost of that process from several perspectives, says **Stephen Jessup**, CPA, president of Jessup & Richmond, a Battle Creek, MI-based postacute consulting firm.

Traditional cost accounting can distort cost information because it requires you to assume that most costs are the result of direct patient care and ignores money spent on nonclinical processes. For example, a home visit is made up of a number of activities — planning and scheduling, coordination between disciplines, travel, the actual visit by a nurse or aide, and documentation.

Under ABC, providers must shed their perception of a visit or patient day as a product and instead think of them as processes that are made up of a number of activities, each with an associated cost. By doing this, they can account for the

vast cost differences in similar visits, draw a more accurate picture of how resources are used, and begin to make decisions about how each process can be improved from both a cost and quality perspective. Because activities are like building blocks in a process, they can be broken down and reassembled to offer different cost perspectives.

From a strategic standpoint, providers generally have three ways to improve their bottom line: raise prices, boost referrals, or reduce costs. Cost is the area over which hospices have the most control. That's because prices are generally payer-driven, and referrals, while influenced by provider marketing, are primarily facility- or physician-controlled. The best way to manage costs is to identify processes and improve on them rather than simply cutting positions or programs to reduce costs.

In order to implement ABC, Jessup recommends following these steps:

- **Management must commit to better costing.**

Before ABC can be implemented, there must be management commitment to the process. This must occur at the highest level of the organization. Without leadership buy-in, it will be difficult to justify the time spent scrutinizing activities and to make the necessary changes in inefficient processes that ABC uncovers.

- **Identify activities and resources.**

Determine what is involved in a given process. For example, a visit is made up of a number of activities, such as nursing, travel, and medical equipment. In general, you'll need to identify resources — the pool of costs that make up activities. This requires going back to staff or department heads and conducting interviews to find out how employees fill their days.

Follow these guidelines when identifying resources:

- **Focus on the most expensive products.**

Hospice providers' products typically have a high ratio of overhead and personnel costs to total costs. Link these expensive products and service lines to diagnoses or episodes of care.

- **Focus on resources that have significantly varied rates of consumption by product and product type.** For example, therapy is a resource that varies from one diagnosis to the next or from one episode of care to the next.

- **Focus on resources that have demand patterns that don't correlate to traditional allocation measures,** such as direct labor, documentation, and billing. In other words, examine resources

What to Include in Your Cost Analysis

Here is a snapshot of items that can be included in a cost report:

General Services

- Capital-related — buildings and fixtures
- Capital-related — movable equipment
- Plant operations and maintenance
- Transportation — staff
- Volunteer services coordination
- Administrative and general

Inpatient Care Services

- Inpatient — general care
- Inpatient — physician services
- Inpatient — respite care
- Inpatient — physicians, respite care
- Medical social services, inpatient

Visiting Services

- Physician services
- Nursing care
- Speech therapy
- Medical social services
- Occupational therapy
- Spiritual counseling
- Dietary counseling
- Other counseling
- Home health aide
- Homemakers
- Other visiting services

Other Hospice Service Costs

- Drugs and biologicals
- Durable medical equipment/oxygen
- Patient transportation
- Imaging services
- Lab and diagnostic
- Medical supplies
- Outpatient services, including emergency room services
- Infusion therapy
- Radiation therapy
- Other

Non-reimbursable Services

- Bereavement program costs
- Volunteer program costs
- Fundraising
- Other program costs

needed to treat a diagnosis or episode of care that are not traditionally measured by current cost-accounting methods.

Some cost items will still be missed. ABC does not account for every penny, but rather draws a broad picture of how a hospice spends its money. An attempt to be too precise will only bog down the process and require more resources to complete.

- **Assign costs.** This is a simple concept with complex hurdles. Much of the cost information you'll need can be found in employees' salaries and benefits. Beyond that, you'll need to determine other cost items, such as medical equipment, drugs, office space, and whatever other costs your organization incurs. Each of these costs will play a role in one or all of the various processes a provider performs, such as determining how much of a

Choose compliance officer from hospice leaders

Study current policies and follow OIG standards

The vast majority of hospices are small organizations that spend most of their resources providing care to their patients. Administration is thin, and their budgets don't allow for additional administrative staff. So when Medicare's Office of Inspector General (OIG) strongly suggests hospices implement a compliance program, complete with a compliance officer, does this mean small hospices have to sacrifice a clinical position to fill an administrative one?

Even the OIG recognizes the burden an added administrative position places on hospices, especially small and medium-sized ones. While the agency stresses the importance of having a compliance officer within the organization, it has said the position can be added to the job responsibility of an existing position.

But which person in your organization is in the best position to assume this important responsibility? Ideally, hospices want to appoint a compliance officer who is among the organization's leaders and has direct access to the top administrator and the board of directors, says **Mickey Pope**, RN, BSN, corporate compliance officer for Hospice of the Bluegrass in Lexington, KY.

People in charge of quality management, risk management, or data management are good

nurse's salary and benefits should be assigned to a visit or to documentation.

"The problem is that when you get hundreds of people in an organization, it gets fairly complex," Jessup says. "There is a lot of number-crunching going on, but the concept is quite simple."

In assigning costs under ABC, providers will have to abandon the notions of direct and indirect costs. ABC holds that all costs are indirect. For instance, nursing costs are traditionally seen as direct costs. ABC, however, holds that nursing costs can be divided among several activities, such as patient care, documentation, and travel. When assigning costs, providers will find additional costs that they had not associated with patient care in the past, such as administration and billing. ■

candidates for the post, says Pope, who is also the director of quality assurance.

"It seemed logical to make me the compliance officer, because I report directly to the president, and I can also bypass the president and go directly to the board," Pope says.

People in the positions mentioned above bring a broad perspective of hospice to the position, monitor problems within the organization, and have experience in implementing change when needed, adds Pope.

Hospices shouldn't make the mistake of making people with accounting backgrounds the heads of compliance programs, says **David Queen**, JD, a Baltimore-based attorney who handles fraud cases for home health and hospice providers. While accounting skills are valuable, they represent a small portion of overall job responsibilities. Instead, Queen says, compliance chiefs should have a human relations background and management skills.

"You need someone who is able to interact with both employees and upper management," Queen says.

Whether full-time or part-time, the primary responsibilities of the compliance officer should include:

- **monitoring implementation of the compliance program;**
- **certifying that employees have received, read, and understood the standards of conduct;**
- **developing the education and training programs to ensure staff are knowledgeable of not only organizational policies but state and federal standards as well;**

- **investigating and acting on matters related to compliance, such as suspected violations.**

Once a hospice has tapped one of its administrative staff to assume the position of compliance officer, that person becomes the organization's leader for implementation of a compliance program. And this is no small task.

Pope identifies the following steps a compliance officer must complete or oversee:

- **Become educated in OIG's compliance guidelines.**
- **Assemble a compliance committee composed of key members of the organization, including the vice president of clinical services, director of finance, human resources, and the administrator.**
- **Inform the board of directors of the hospice compliance program plan, and keep the board updated on progress.**
- **Educate staff with a series of inservices that inform them about the policies within the compliance program and assure them that the policies are not the result of current problems and that no one is the target of fraud and abuse scrutiny.**

Avail yourself of OIG's guidance

All of the above points are part of an overall plan to implement a compliance program. One important point not mentioned above is the development of policies and procedures that will illustrate how a hospice approaches potential fraud and abuse. The hospice compliance officer should consult the OIG's guidance, which can be found at the OIG's Web site at www.oig.gov.

Among the key elements the OIG looks for in a compliance program elements are:

- **development and implementation of effective training and education programs;**
- **development and maintenance of effective lines of communication;**
- **enforcement of standards through well-publicized disciplinary guidelines;**
- **use of audits and other evaluation techniques to monitor compliance;**
- **development of procedures to respond to detected offenses and initiate corrective action.**

Compliance officers must spearhead a hospicewide effort to review current policies and procedures, compare them to OIG guidance, and adjust, change, or add policies to ensure the program mirrors OIG's expectations.

"We came up with a whole list of policies that needed to be amended," Pope notes.

Hospices might consider using the compliance guidance as a checklist so as to ensure every standard is met. Important standards include the following:

- Are the standards of conduct applicable to all affected employees and independent contractors?
- Do the standards of conduct articulate the hospice's commitment to comply with all federal, state, and private insurer standards, with an emphasis on preventing fraud and abuse?
- Are the standards of conduct distributed to all employees?
- Do policies and procedures require proper/timely documentation of the specific clinical factors that qualify a patient for the Medicare Hospice Benefit?
- Has the hospice created an oversight mechanism to ensure that the terminal illness of a Medicare beneficiary is verified?
- Do written policies and procedures require that before a patient is admitted for hospice services, the hospice physician and attending physician thoroughly review and certify the admitting diagnosis and prognosis?
- Does the hospice take all reasonable steps to ensure that the written plan of care is established and maintained for each individual who receives hospice care?
- Does the hospice monitor and evaluate its resource allocation regularly to identify and resolve problems with the utilization of services, facilities, and personnel?
- Has the hospice implemented policies and procedures to identify, assess, and rectify problems associated with the appropriateness of interdisciplinary group services and the level of services being provided?
- When a nursing home resident elects the Medicare Hospice Benefit, do the hospice and nursing home jointly establish a coordinated plan of care that reflects the hospice philosophy and is based on an assessment of the individual's needs and unique living situation in the nursing home?
- Do the policies and procedures require that all of the hospice's contracts and arrangements with actual or potential referral sources be reviewed carefully for compliance with all applicable statutes and regulations?

The above standards only represent a fraction of the standards the OIG has established for hospice compliance programs. Reviewing policies and creating new ones is a time-consuming process. Pope says Hospice of the Bluegrass started its program implementation in November 1999

and had it completed for employee education by June 2000.

“It takes so much time and follow-up,” says Pope. “You really have to give it most of your attention.”

In the eyes of the federal government, a compliance program brings numerous benefits to its users, not the least of which is the ability to identify weaknesses in internal systems and management. Those who have effective compliance programs in place will have, in the opinion of federal officials:

- safeguards that will identify and prevent illegal or unethical behavior;
- a view of expected employee and contractor behavior relating to fraud and abuse;
- a document that demonstrates to the government and public that the hospice is committed to honest provider and corporate conduct.

Putting the plan in motion

Once the standards have been met and policies established, it's time to begin educating workers about their roles in keeping the organization compliant.

Training sessions should be spearheaded by the compliance officer who must highlight the hospice's compliance program, summarizing fraud and abuse laws, federal health care program requirements, claim development and submission processes, and patient rights. Training should not be limited to hospice employees, but should include physicians contractors and other agents.

Based on the home health compliance program guidelines, the OIG is likely to recommend that hospices require a minimum number of educational hours per year as a condition of employment. It may also recommend that an employee's failure to attend training should lead to disciplinary action, including termination.

There should be an open line of communication between employees and the compliance officer. The OIG may suggest that written confidentiality and nonretaliation policies be developed to encourage employees to report potential fraud. The process of communication needs to be clear among employees to prevent confusion when reporting potential fraud. These lines of communication can take several forms, such as hotlines, e-mails, written memos, and suggestions boxes, to name a few.

An effective compliance program will include clear disciplinary guidelines for officers, managers,

and employees who violate policies and standards of conduct. The OIG says compliance programs for all health care settings need to set forth the degrees of disciplinary action and ensure that workers are aware of the consequences of illegal or unethical behavior.

There should be an ongoing evaluation process to ensure compliance. The OIG suggests performing regular audits by internal or external examiners who have an expertise in state and federal health care program requirements. According to past guidelines, OIG has recommended that the minimum scope of audits include laws governing kickback arrangements, physician self-referral, claim development and submission, reimbursement, cost reporting, and marketing.

Procedures for investigating suspected abuse should take into account the possibility that a single incident may be indicative of a systematic problem. Procedures may include bringing in outside counsel, auditors, or other health care experts to assist in the investigation. The compliance officer also is responsible for reporting misconduct to the proper authorities along with evidence uncovered during the internal investigation. The reporting of misconduct will be considered a mitigating factor in OIG's determination of administrative sanctions. ■

Class facilitates dying at home

Teaching patients and families what to expect

The challenges of caring for the dying at home are well-known — caregivers overwhelmed by the emotional burden of watching a loved one die, inundated by the responsibilities of meeting their everyday needs and preparing them for the inevitable.

The problem is that most caregivers are ill-prepared for the task. Because death is a subject not often talked about, family members of dying patients aren't aware of their loved ones' wishes or how to spot the telltale signs that death is near. The harsh reality is that most are unprepared for the challenges of caregiving.

“Families need to know they have options,” says **Audrey Cochran**, MSN, PHN, CNS, RN, CS, CCN, a clinical specialist in gerontological nursing.

As a way to address the lack of information available to dying patients and their caregivers, Cochran teaches a course at Bakersfield (CA) Community College called “Dying at Home.” The three-hour course helps terminally ill people and their families prepare for death in the home. Through videotapes and guest speakers, Cochran shows participants what to expect and steers people away from assisted suicide.

“I try to affirm that death is another part in the process of life,” she says.

Her class covers the following topics:

- societal attitudes about death;
- understanding depression and malnutrition and spotting true signs of death;
- physical changes that occur just prior to death;
- living wills and durable power of attorney;
- making funeral arrangements;
- avoiding calling 911 when the patient is close to dying;
- spiritual and emotional support.

Unfortunately, Cochran says, her class is never well-attended. She says this is because she lacks funds to publicize the class, and society’s attitudes toward death make it difficult for people to talk about it.

“In theory, it’s a great idea, but without publicity, people won’t come,” she says.

But she believes hospices should try to do similar classes in their own communities because they have the resources and experts.

Study shows caregivers lack training

Studies of caregivers certainly point to their need for information. A recent study in New York City illustrated the challenges caregivers face. Approximately one million people in New York City are family caregivers, and most have received little or no training from health care professionals to provide the complex care needed.

Researchers conducted a random telephone survey of New York City caregivers, which was representative of the city’s overall population. The survey found that nearly 60% of caregivers reported that they received no training from health care professionals for essential care responsibilities, such as bathing, feeding, or moving a patient from bed to a chair. While these tasks may appear simple, they can be extremely difficult to perform when a patient is ill or disabled.

The study was funded by the United Hospital Fund and the Visiting Nurse Service (VNS) of

New York. In July, the fund, in partnership with VNS, published the findings in a special report titled *A Survey of Family Caregivers in New York City: Findings and Implications for the Health Care System*. ■

News From the End of Life

Physicians know more about palliative care

The American health care system is undergoing a change in the way it cares for critically ill and dying patients. Palliative care is now more widely understood and practiced than ever before, according to the Last Acts coalition on end-of-life care.

“I graduated from medical school 14 years ago, and the word ‘palliative’ wasn’t even on the radar screen, but it is now recognized as cutting-edge care. I think that’s quite encouraging,” said **Joseph Fins**, MD, director of medical ethics and associate professor of Medicine at New York Weill Cornell Medical Center of New York Presbyterian Hospital during a Nov. 13 conference call with journalists, which was sponsored by Last Acts.

Legions of physicians are receiving training in palliative care, and expectations for better palliative care are also rising because of new exam questions for licensing of internists, new pain management standards required in hospitals, and new state laws allowing physicians to prescribe effective pain medication, Fins said.

There is even hope that restrictive Medicare and Medicaid regulations may be changed to improve access to palliative care. **Joel Cantor**, MD, professor of public policy and director of the Center for State Health Policy at Rutgers University, said the Medicare hospice benefit has come under recent scrutiny by the General Accounting Office (GAO) and the Senate Special Committee on Aging.

“Medicare’s focus on acute medical needs and curative care is becoming more widely acknowledged as a barrier to palliative care for the chronically ill and dying,” Cantor said. ▼

Spiritual matters take precedence

Religion, communication, and control take precedence over physical symptoms and functioning at the end of life for some terminally ill patients, Yale researchers suggest in a new book, which examines the complex issues surrounding death and dying.

“Our review proposes that quality of life is dynamic at the end of life and the components that make up quality of life may shift, making some more important than others, depending on how close one is to death,” says **Elizabeth Bradley**, assistant professor in the department of epidemiology and public health at Yale School of Medicine in New Haven, CT.

The research results are published as a chapter in *Focus on the End of Life: Scientific and Social Issues* by M. Powell Lawton. The book is part of a series by the Annual Review of Gerontology and Geriatrics, which examines and appraises current progress in research, clinical practice, and program development across disciplines from psychology, biology, and medicine to social issues and public policy.

The volume brings together the latest research on issues around death and dying, life’s attributes as it nears death, planning and preparation for death, and care and intervention-related issues.

“By focusing on quality of life at the end of life, the book re-orient us to the life, rather than the death, of terminally ill individuals,” says Bradley. “Our chapter highlights some of the components of quality of life, such as religiosity, communication, and control, that have been less studied than physical symptoms and functioning, but may be particularly important as death becomes imminent.”

In the chapter, Bradley and her colleagues note that much of the literature concerning religiousness and spirituality in the end of life implies that religious beliefs provide comfort, meaning, a

sense of continuity, and a better quality of life for terminally ill individuals. In fact, recent efforts in the United States to improve the care of the dying invariably call for increased attention to the spiritual needs of patients.

“Efforts to provide answers to fundamental questions surrounding quality of life can help further shape clinical practice and research to benefit terminally ill patients and their families in the future,” said Bradley. ▼

Pain study: Family expectations high

Most physicians and nurses believe a recent jump in family reports of pain was due in part to increased family expectations for pain management, according to a study published in the December issue of the *Journal of Palliative Medicine*.

Researchers at Oregon Health Sciences University (OHSU) believe they have explained why family reports of pain increased in dying hospitalized patients in late 1997. The OHSU Center for Ethics in Health Care surveyed physicians and nurses about their opinions regarding the observed increase. Most respondents (79%) thought that more than one factor was at work in explaining this worrisome change.

According to the research, the vast majority (96%) of physicians and nurses believe the jump in family reports of pain was partly the result of higher family expectations for pain management. Respondents reported that other significant factors included decreased physician prescribing of pain medications (66%) and reduced nurse administration of pain medication (59%). In addition, those respondents who thought physicians were more conservative in prescribing pain medications suggested the two main reasons were fear of investigation by the Board of Medical Examiners and the Drug Enforcement Administration.

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“While this study does provide important information, it can only be considered one piece of an incomplete puzzle,” says **Susan Hickman**, PhD, a senior research associate with the Center for Ethics in Health Care and lead author of the study. “We must continue to investigate the increase in family reports of pain and explore the reasons behind it. We also must make efforts to ensure that dying patients are receiving the pain medication they need.”

This latest study follows a string of studies that showed disturbing increases in reported pain among dying patients. The increase in reports of pain was identified in a prior study conducted by OHSU’s center for ethics. Families of hospitalized patients in Oregon reported a jump in moderate and severe pain levels for their dying loved ones in late 1997. In late 1996 and early 1997, 33% of families reported that their loved one had experienced moderate or severe pain in the last week of life. In late 1997, this rate increased to 57%. This increase occurred in dying hospitalized patients only, not in those dying at home or in long-term care facilities.

“While Oregon is considered a national leader in pain management, the information obtained in this study reveals that there is more work to be done,” says **Susan Tolle**, MD, director of OHSU’s Center for Ethics in Health Care and co-author of the study. “Our earlier findings indicated more pain in dying hospitalized patients. In this study, we learned that less pain medication administration was a partial contributor. We need to work on understanding the reasons behind reduced physician prescribing and decreased nurse administration to assure quality care for all dying patients.” ▼

Most Kevorkian patients were depressed

Most of the people who asked Jack Kevorkian, MD, to assist them in suicide were not dying of terminal illness, but instead lacked family support and suffered from depression, says a new study. It suggests that the retired pathologist acted callously by facilitating the suicides of patients who were not able to make rational decisions.

For the past two years, Kevorkian has spent his time in a small prison cell in Jackson, MI, where he

is serving a 10- to 15-year sentence for a second-degree murder conviction that resulted from an assisted suicide that was broadcast on the TV show *60 Minutes*.

The image of Kevorkian as a strange but good-hearted crusader differs from his practices, say the study’s authors, which include the Oakland County, MI, medical examiner, **L.J. Dragovic**, MD. The results of the study were published in the *New England Journal of Medicine*.

“There has been a major discrepancy between what the public saw and what he actually did,” Dragovic says. “They never really got to see who this man was.”

Dragovic and his co-authors studied the autopsies and medical examiners’ files in all 69 suicides in which Kevorkian assisted in Oakland County. Kevorkian is thought to have assisted in 21 more suicides in other counties, but the authors felt data from those areas might be inconsistent.

The study found the following:

Hospice Management Advisor™ (ISSN# 1087-0288) is published monthly by American Health Consultants®, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Application to mail at periodical rates is pending at Atlanta, GA 30304. POSTMASTER: Send address changes to **Hospice Management Advisor™**, P.O. Box 740059, Atlanta, GA 30374.

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Editorial Questions

For questions or comments, call **Lee Reinauer** at (404) 262-5460.

- Seventy-five percent of those assisted by Kevorkian otherwise would have lived for at least six more months.
- Seventy-two percent of them had recent declines in health, such as a new symptom or slightly more pain, that may have clouded their judgement.
- Sixty-seven percent were divorced, widowed, or had never been married, a strong indication they had no social or family support.
- Only 35% of them were in pain.
- Five people had no evidence of disease, suggesting mental distress drove them to Kevorkian.
- Seventy-one percent were women.

The authors then compared Kevorkian's assisted suicides with those in Oregon and Washington state, where assisted suicide has been permitted. In those states, most patients who committed assisted suicides had been expected to die within six months, and most were male. The two states prohibited assisted suicide in patients with depression or recent declines in health, saying both factors impaired the ability to make a rational decision about death.

One of the authors, **Donna Cohen**, PhD, professor of aging and mental health at the University of South Florida in Tampa, says the contrast between Kevorkian's patients and those in Oregon and Washington demonstrates the importance of having a comprehensive system in place to deal with assisted suicide.

"He became a model for what might happen without guidelines and practice," she says. "This confirms what many had suspected, which is that a single man who was a messenger for the right to die wasn't employing clinical safeguards. He wasn't protecting vulnerable patients, many of whom were women." ▼

JCAHO award honors PI improvement efforts

The Oakbrook Terrace, IL-based Joint Commission on Accreditation of Healthcare Organizations (JCAHO) created the Ernest A. Codman Award in 1996 to recognize health care organizations for achievements in the use of process and outcome measures to improve performance and care. Codman has been regarded as the father of outcomes measurement in health care.

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Awards are given in a number of organization categories, including home care, a category that includes hospice and home medical equipment. In order to be eligible, an organization must hold a status of Accreditation with Recommendations for Improvement or better.

A home health agency also must have been surveyed under the home care standards in its most recent JCAHO survey.

An application form for the award will be available on the JCAHO Web site beginning in early 2001. The entry fee is \$295. An evaluation committee of national experts in performance measurement will judge entries. Finalists are subject to an on-site visit conducted by a JCAHO surveyor and office staff member who review the organization's work and validate the information in the application.

Based on the application and the on-site review, the evaluation committee makes recommendations for awards to the executive committee of JCAHO's board of commissioners. Winners are notified in August and honored in October at an awards program in Chicago.

For more information on the Ernest A. Codman Award, call JCAHO at (630) 792-5000 or visit the organization's Web site at www.jcaho.org. ■