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Language and cultural differences affect pain assessments

Take care not to over- or under-treat pain

Bilingual staff, cultural diversity education, and community presentations designed for specific populations are efforts that hospices throughout the country have implemented to increase access and improve care to hospice patients of all backgrounds. (See “Reaching varied cultural groups requires education of staff, community,” *Hospice Management Advisor*, March 2010, page 25.)

Although respecting traditions and customs of a different culture are important, the most critical aspect of providing hospice care is pain management, and that is not always optimal for minority patients, says **Mary Curry Narayan, MSN, RN, HHCNS-BC**, a clinical education and transcultural nurse specialist and owner, Narayan Associates in Vienna, VA. “Nurses are taught that pain levels are whatever the patient says they are,” she says. “This means that we under-treat pain for people who grew up in a culture that values stoicism and views admission of pain as weakness,” she explains. For this reason, nurses need to understand the culture of their patient and use other cues to evaluate pain in addition to the

EXECUTIVE SUMMARY

Accurately assessing a patient’s pain is no easy task, and language or cultural differences increase the difficulty. A nurse’s own biases and learned behavior can lead to misinterpretation of the patient’s description or visual cues. This misinterpretation can result in over- or under-treating the pain.

- Educate staff members about different cultural or religious groups in your service area.
- Ask patients and family members to offer guidance about beliefs regarding pain.
- Recognize pain from cues other than self-reporting.
- Understand the limitations of pain assessment tools and how they can be interpreted differently by different cultures.

patient's report of pain, she adds.

"If the patient says there is no pain but there is a grimace or a tight look about the face, the nurse should explore more carefully," suggests Narayan. Questions that don't ask the patient to admit pain are a good tactic to use with patients who have learned to minimize pain, she says. These questions include:

- Can you do the same activities you've always been able to do?
- Do you sleep and eat as well as you did last month?
- Are you uncomfortable?
- Did the medicine make you more comfortable?
- Are you able to sit up (or walk) more easily after taking the medicine?

Other cultures may be more expressive about

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Editorial Questions
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pain, so a careful assessment also is needed to establish the correct level of pain medication, says Narayan. "Pain is what the patient perceives, but a nurse must be careful not to over-medicate someone just because her beliefs lead her to interpret the expressive patient's pain as extreme," she says. Asking the same questions asked of the stoic patient will help assess the patient's discomfort and the effect of pain on his or her life, she adds. "Always start with the lowest effective dose of medication and work up to higher doses," she says.

The first step to correctly assessing a patient's pain when the patient is from a different culture is to evaluate your own cultural and learned bias regarding pain, suggests **Kenneth J. Doka**, PhD, professor of gerontology at the Graduate School of The College of New Rochelle in New York, and senior consultant to the Hospice Foundation of America. "If you understand your own beliefs about pain, and how your culture affected those beliefs, you'll be less likely to view someone else's reaction to pain as inappropriate or frustrating," he adds. (For self-assessment questions, see page 111.) "If you are using an interpreter to communicate with the patient, talk with the interpreter to determine his or her own biases as well," he suggests.

It is important to avoid stereotypes and biases when assessing pain, agrees **Hank Willner**, MD, medical consultant for Hospice Foundation of America and hospice medical director and palliative care consultant for Capital Caring in Falls Church, VA. The best advice for a pain assessment is to listen more than talk, he says. "Have empathy for the patient in pain and be curious about what the discomfort represents," he suggests. For example, does the pain prevent the patient from doing a favorite activity? If so, talk about finding a way to help the patient return to that activity, he suggests. After listening to the patient's description of the pain, explain your own perception of what you think the patient described, he recommends. "Acknowledge that everyone describes pain differently and let the patient know you want to make sure you understand his or her description."

Know limits of assessment tools

Different languages and cultures may make standard pain assessment tools ineffective, says Narayan. "The Western culture is very quantitative so we rely on numbered scales, but other cultures do not," she says. For example, some Native Americans may choose a favorite or sacred number

on a pain scale as opposed to a number that actually reflects their pain, she says. (For tips on other ways to assess pain, see page 112.)

Different languages may also affect the validity of a pain assessment, points out Narayan. “Not all languages have a word for pain and interpreters may not be able to accurately describe the patient’s pain,” she says. When using a pain scale, be sure it has been validated for translation into other languages,” she says. “I like the Brief Pain Inventory developed by M.D. Anderson,” she says. (See resources, below.)

If you discover that your patient is from a different culture than you, don’t be afraid to ask questions of the patient and the family to learn what is acceptable in their culture, says **Jennifer Carlson**, director of operations for Amedisys Hospice of Sweetwater in Sweetwater, TN. “I once had a patient who was a Buddhist monk and I not only had to rely upon a translator but I could not touch him,” she says. “I did know the patient was a Buddhist monk before I arrived at the home, so I spent time with the other monks asking what was appropriate,” she says. By explaining that she did not want to offend the patient or the monks

SOURCES/RESOURCES

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Resources:

- **The Brief Pain Inventory** can be found at www.mdanderson.org, select “departments and divisions,” then choose “symptom research” and “symptom assessment tools.” (There is no cost for use of the tool in clinical practice.)
- **The Hospice Foundation of America** has developed “Addressing Cultural Diversity in Hospice Care,” a free on-line webinar that looks at how and why different cultures may or may not utilize hospice. This tutorial aims to prepare and equip hospice organizations, and its providers and volunteers, with strategies and information to meet the needs of culturally diverse patients and loved ones. Go to www.hospicefoundation.org, under “professional education” select “hospice information center CE’s” and then choose “Addressing Cultural Diversity” on the right navigational bar.

who provided the actual care, she was able to ensure the monk received the proper care from the other monks. “I assessed the patient’s symptoms and explained how to care for him to the other monks,” she explains. “I observed as they provided the care.”

Be sure to educate your staff about cultural diversity and especially about the specific cultural groups that are served by your hospice, says Carlson. Although every patient and family is different, even within the same cultural group, hospice staff members are better able to assess the patient if they understand some of the cultural differences upfront, she says. (See resources, below left, for staff education webinar information.)

Another facet of the person’s culture that plays an important part in the care hospice provides are other people who influence the patient, suggests Willner. “Some American Indians want a shaman, medicine man, or faith healer to be present,” he says. In some cases, the patient wants permission from the shaman to accept the Western health treatment, he explains. “In all cases, be sensitive to the patient’s beliefs and follow the patient’s wishes as to how treatment should proceed,” he adds.

Remember that culture does not just refer to a different country, says Carlson. “In eastern Tennessee, we see patients whose religious beliefs are that pain is a test of their belief,” she explains. Because these patients believe that a strong faith and prayer can relieve their pain, visits from a hospice chaplain can provide additional support that might help the patient accept other forms of pain management, she suggests.

Always be prepared for patients to refuse treatment for pain as part of their cultural beliefs, says Carlson. “We can listen and make sure they know we have options to control their pain, but it is ultimately the patient’s decision, even if we see they are in pain,” she says. “This is their journey, not ours.” ■

How to assess your own beliefs about pain

Questions uncover biases

Understanding your own cultural beliefs and biases about pain is an important first step in accurately assessing a hospice patient’s pain levels, says **Mary Curry Narayan**, MSN, RN, HHCNS-BC, a clinical education and transcultural

nurse specialist and owner, Narayan Associates in Vienna, VA and author of “Culture’s Effects on Pain Assessment and Management.”¹

Narayan suggests that hospice staff use the following self-assessment questions to determine their own cultural norms concerning pain:

1. **When you were a child, how did those who cared for you react when you were in pain?**
 - How did they expect you to behave when you had a minor injury?
 - How did they encourage you to cope when you had severe pain?
 - How did they encourage you to behave during an injection or procedure?
2. **When those who cared for you as a child were in pain, how did they react?**
 - What words did they use to describe the pain?
 - How did they cope with their pain?
 - Do you tend to follow their example?
3. **Consider a painful experience you’ve had as an adult (for example, childbirth, a fracture, a procedure).**
 - How did you express (or not express) your pain?
 - Did the pain cause you fear? What were you afraid of?
 - How did you cope with the pain?
 - How did you want others to react while you were in pain?
4. **Have you ever felt “uncomfortable” with the way a patient was reacting (or not reacting) to pain?**
 - What did the patient do that concerned you?
 - Why did you feel that way?
5. **Do you have “feelings” (make value judgments) about patients in pain who:**
 - behave more stoically or expressively than you would in a similar situation?
 - ask for pain medicine frequently or not often enough?
 - choose treatments you don’t believe are effective or with which you are unfamiliar?
 - belong to a cultural group (ethnic, linguistic, religious, socioeconomic) different from your own?
6. **Do you tend to feel certain reactions to pain are “right” or “wrong”? Why? What about these reactions makes them seem right or wrong?**
 - Are some expressions or verbalizations of pain “right” or “wrong”?
 - Are some descriptions of pain “right” or “wrong”?
 - Are some treatments for pain “right” or “wrong”? ■

REFERENCE

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Tailor pain tools to patient

Understand beliefs that affect assessment

Language and cultural beliefs can affect the accuracy of pain assessment tools regularly used by hospice staff members, says **Hank Willner**, MD, medical consultant for Hospice Foundation of America and hospice medical director and palliative care consultant for Capital Caring in Falls Church, VA. Interpretation of visual and numeric scales may differ according to culture, he explains.

Even though a smiling face may mean no pain to the clinician, a smiling face may indicate embarrassment to some people, says Willner. Before relying upon a scale that uses faces, first show the faces to patients and then ask what the facial expression means to them, he suggests. “This will give you more information about how the patient interprets the scale,” he says.

When using a numeric scale, find a way to define the numbers to which patients can relate, suggests Willner. “For example, say that a particular number is pain like a toothache, a stabbing knife or a needle,” he says. For women who have had children, describe the highest number as labor or if the person has had kidney stones, use that pain as the highest level, he says. “Converting pain into a number is a conceptual challenge for most people, so using definitions that both patient and clinician can understand improves communication,” he says.

Nurses should also talk to patients about their views of pain to better understand how the patient expresses pain, says Willner. Ask patients what they think causes their pain, how the pain affects their lives, and what they hope for in terms of relief from the clinician, he says. Ask the patient what has already been done to control pain, how well it worked, and why the patient does not think it worked, he says. “This information will help the nurse not only determine the best way to approach pain control, but also to evaluate which approaches the patient is most likely to accept,” he adds.

“Many cultures believe in the healing or com-

forting effects of teas, herbs, touch therapy or acupuncture,” points out **Mary Curry Narayan**, MSN, RN, HHCNS-BC, a clinical education and transcultural nurse specialist and owner, Narayan Associates in Vienna, VA. If the patient believes these treatments will work, they may be an effective addition to more traditional medicine, she says. “If the non-traditional treatment is not medically contraindicated, I encourage them to do what makes them comfortable.”

If medication is prescribed, be sure you prescribe it in a way that enables the patient to take it as prescribed, suggests Narayan. “Some cultures associate different colors with different meanings such as bad or good,” she says. “If blue is a negative color for my patient, I prescribe the medication in a different dose that results in a different color pill,” she says. One blue pill versus two yellow pills that equal the same dose can improve compliance and improve pain management, she points out.

If the patient’s upbringing has taught stoicism or refusal to take pain medicine until pain is excruciating, you can help the patient by instructing patient and family to take the pain medication on schedule, says **Jennifer Carlson**, director of operations for Amedisys Hospice of Sweetwater in Sweetwater, TN. “If you know the patient is in pain but doesn’t want to have to ask family members for pain medication, you can make it routine.” She adds, “This means the patient doesn’t have to explain himself to family members because ‘the nurse said it has to be taken this way.’” ■

Awards to honor palliative, EOL care

7 recognized as Circle of Life honorees

The Circle of Life Award celebrates programs across the nation that has made great strides in palliative and end-of-life care. This is the 12th year for the Circle of Life Award.

Circle of Life nominations were received and reviewed by a selection committee that included leaders from medicine, nursing, social work, and health administration. The committee visited programs that respect patient goals and preferences, provide comprehensive care, acknowledge and address the family or caregivers’ concerns and needs, and build systems and mechanisms of sup-

port that will ensure that the programs continue. The programs selected serve as innovative models for other communities.

Three programs that expand the reach of palliative and end-of-life care will be recognized as the 2011 recipients of the Circle of Life Award: Celebrating Innovation in Palliative and End-of-Life Care, along with four others that will be awarded Citations of Honor.

The programs share overriding themes of compassion, dedication, and collaboration. **Gilchrist Hospice Care in Hunt Valley, MD**, has successfully integrated palliative care across hospital, hospice services, physician groups, patient homes, and long-term care and assisted living facilities. **St. John Providence Health System in Detroit** has hardwired palliative care into every service and educated staff, so that no matter where an individual enters the system, they are evaluated for palliative care needs. The **Center for Hospice & Palliative Care in Cheektowaga, NY**, provides an extensive care continuum and a sophisticated palliative care institute, with strong emphasis on collaboration, physician leadership, and clinical research.

Each of these innovative programs recently received a Circle of Life Award at a ceremony in San Diego.

“A patient needing palliative or end-of-life care faces difficult challenges that must be addressed with skill and unique expertise,” said AHA president and CEO, **Richard Umbdenstock**, FACHE. “These winners exemplify what the health care field is striving for: compassionate care for patients and families at all times. These innovative programs serve as guiding lights for others on this path.”

Citations of Honor were awarded to:

- **Dartmouth-Hitchcock Medical Center in Lebanon, NH**, in recognition of its strong commitment to inpatient and outpatient palliative care, regional focus, and end-of-life and palliative care research and education;

- **John H Stroger Jr. Hospital of Cook County in Chicago** for its commitment to treating a diverse population with complex needs, including helping dying immigrant patients fulfill wishes to return to home countries;

- **St. Mary’s Healthcare System in Athens, GA**, for embedding palliative care throughout the hospital and a culture change on the community level;

- **University of Pittsburgh Medical Center in Pittsburgh**, for providing close to seamless palliative care delivery and working to spread palliative

care across the entire 18-hospital system.

The 2011 awards are supported, in part, by the California HealthCare Foundation, based in Oakland, CA, and the Archstone Foundation in Long Beach, CA. Major sponsors are the American Hospital Association, the Catholic Health Association, National Consensus Project for Quality Palliative Care, and the National Hospice and Palliative Care Organization & National Hospice Foundation. The American Academy of Hospice and Palliative Medicine and the National Association of Social Workers are Circle of Life cosponsors. The Circle of Life Award is a program administered by the Health Research & Educational Trust.

For more information on the Circle of Life Awards, visit www.aha.org/circleoflife. ■

In-home visits reduce utilization for elderly

Program generates 195% ROI

A program that sends geriatricians and nurse practitioners into the homes of high-risk, frail elderly patients has resulted in a 195% return on investment (ROI) for Fallon Community Health Plan in Worcester, MA.

The Home Run Program began in 2009 after the health plan and Fallon Clinic looked for ways to reduce health care utilization for Medicare Advantage members.

“The health plan and the clinic share risk for the care of these patients,” says **Patricia Zinkus, RN, CCM**, director of case management. “We focused on the rising medical costs and the increase in the aging population.”

Participants in the program might have multiple chronic conditions, including depression and other issues that put them at risk for complications and hospitalizations. Many of the members who are in the program have difficulty getting to their primary care physician regularly or have sought care in the emergency department when acute symptoms have occurred.

“We know that a small percentage of members are responsible for the majority of health care costs,” Zinkus says. “Our goal is to improve the functional status and quality of life for frail, homebound, or those members with chronic progressive conditions in our Medicare Advantage population

and to reduce preventable hospital admissions, readmissions, and emergency room visits.”

Members in the program receive monthly in-home visits from a nurse practitioner who assesses their needs; helps them follow their care plan; and arranges for needed health care, equipment, and services. A geriatrician from Fallon Clinic visits the members periodically and when the nurse practitioner recommends it.

The health plan used a predictive modeling program to identify Medicare Advantage members at highest risk for health care utilization or hospital admissions. The target of the program is 150 members, **Susan Legacy, RN**, senior manager, case management says. “It vacillates as some members transition into hospice or other programs. We try to keep it close to 150,” Legacy says. “We used a predictive modeling tool after initially utilizing claims data. Because of the lag between the time the members use the services and the time we receive the claim, we missed opportunities to make a difference.”

The clinical staff of the Home Run Program reviewed the files of members identified by predictive modeling and referrals from various providers to determine if there were any common denominators that interventions could address. They determined that most of the people identified had experienced a significant functional decline as the result of a fall or an illness. Some had a limited ability to participate in activities of daily living and were not able to get out of the house and socialize at their previous level of function, Legacy says.

The health plan has a contract with a local visiting nurse agency that supplies the nurse practitioners who make the home visits, Zinkus says. “This program does not take the place of the patient’s primary care physician,” she says. “The health plan, the nurse practitioner, and the geriatrician at the clinic all work in collaboration with the primary care physician.”

When a member is identified for the program, the health plan’s program support coordinator refers the member to the clinic’s geriatrician, who reviews the medical record and determines eligibility. A letter is sent to eligible members explaining the program and outlining the benefits.

The support coordinator follows up and schedules an appointment for the nurse practitioner to visit the member in the home and conduct a comprehensive assessment. “The nurse practitioner is able to see the home environment and can determine if patients understand their medication regimen or if they need additional teaching,” Zinkus

says. “They can see safety issues in the home or anything else that can lead to an adverse event.”

For example, the nurse practitioner can determine if patients with heart failure have scales to check their weight every day and if their pantry and refrigerator are stocked with high sodium foods. They can help patients make appointments with their primary care provider, arrange for additional home care services, or set up medication reminder systems if needed.

After the initial visit, depending on the needs of the member, the nurse practitioner makes monthly or bi-monthly follow-up visits. The nurses call in a Fallon geriatrician for a home visit when they think it’s warranted by the patient’s condition. Program participants can call the Home Run Program or the after-hours line at any time for assistance.

As an adjunct to the home visits, the health plan developed the Home Run Club, a monthly event for participants in the Home Run Program. The events are at Summit Elder Care, a senior center where the health plan operates the PACE (Program for All-Inclusive Care for the Elderly). The health plan arranges for a speaker, refreshments, and fun activities, and it provides transportation for members who need it. Zinkus says, “This is a way for the seniors to get out of the house and interact with peers,” she says. “We feel that the socialization piece of the program is crucial to its success.”

A social worker from Fallon Community Health Plan runs the program, and it’s often attended by members of the health plan’s case team. Often the members will ask a question about their health, and this question gives the staff an opportunity to educate the members or suggest that they call their doctors.

Patients may remain in the program until they experience a major life change such as moving into a skilled nursing facility or a hospice, or until they receive care from PACE. Patients whose condition stabilizes to the point that they no longer need home visits are transitioned to telephonic case management. They receive regular outreach calls from the health plan’s case managers for at least three months.

“One of the other successes of the program is that we have been able to help people transition to the appropriate level of care,” Zinkus says. “If the members really need hospice care or the nurse practitioner determines that they can’t live safely at home, the geriatrician can visit the home and sit down with the family and discuss alternative means of care.” ■

Palliative care hardwired into hospital system

Care consultations part of all aspects of care

Palliative care isn’t just for hospice patients — it is also used to manage the symptoms of those with chronic or advanced illnesses. One hospital system in Michigan has brought palliative care into all aspects of hospital care for all patients. The efforts of St. John Providence Health System to develop a screening tool for palliative care needs has earned it a spot as one of the recipients of the American Hospital Association’s Circle of Life Award — Celebrating Innovation in Palliative and End-of-Life Care.

The health system has integrated palliative care into all aspects of care. “This was a leadership-driven initiative,” says **Elizabeth DiStefano**, RN, BSN, coordinator of palliative care services for St. John Providence Health System, Warren, MI. “I didn’t have to spend time trying to talk anyone into it. Anything they can do for us, executive leadership is really supportive of the program. That’s really unique — oftentimes people have problems with their leadership, but this was something we needed to provide to the patients,” she says.

St. John first introduced palliative care consultations in its hospitals in 2005, but there was no standard in place to identify prospective patients. To solve this issue, St. John partnered with Duke University’s Institute on Care at the End of Life to improve the screening process for palliative care needs and develop criteria that all physicians in the system could follow.

Palliative care triggers

“We partnered with Duke to increase access to quality palliative care with increase in attention to spiritual needs,” DiStefano says. “We had five objectives: to screen for palliative care needs, to fully integrate spiritual care with palliative care, educate all associates on basic palliative care, engage the faith community, and institute a culture change for these efforts.”

From the collaboration came a trigger tool that medical staff could use to screen patients for palliative care that was pilot-tested in the ICU of St. John Hospital and Medical Center in Detroit, the system’s largest hospital. “It was a larger tool that we did. It became cumbersome and lengthy, so we use the top nine triggers from our tool,” DiStefano

says. “Now, all patients are screened for palliative care needs upon admission, and after five days if they are still in the hospital.”

Palliative care triggers include:

- code status changed to DNR;
- conflict about stopping/starting life-prolonging treatment;
- goals of care or code status discussion needed and/or surrogate or proxy distressed about decision-making;
- uncontrolled symptoms that interfere with quality of life;
- marked decrease in functional status/ADLs in last 60 days;
- considering PEG tube placement;
- admitted from extended care facility with ADL dependence or chronic care needs.

The palliative care process involves more than just physicians — according to DiStefano, St. John’s palliative teams comprise a nurse practitioner, social worker, and chaplain for a multidisciplinary approach for the patient and his or her family. “We don’t just care for the patient — we care for the whole family,” she says. “We look at the dynamics, and we look at their needs and if they need spiritual care. The multidisciplinary approach is helpful to the families as well. They have the time to spend with the team to work out the care and what kind of care they want to receive. The team can have those difficult discussions with the family. If they want to see a spiritual care provider daily, they can have daily rounds with chaplains and clinicians.

“I would say that it’s an extra layer of support for the patients,” DiStefano continues. “Doctors find it very helpful because it saves them time and they don’t have to do difficult family meetings. They have found it to be very valuable. We called it value-added care — the value that has been added is an extra team member in there.”

However, DiStefano says, attending physicians were initially reluctant to order palliative care consultations. “When we rolled it out, there were issues that were going on,” DiStefano says. “Staff education has been very helpful, and the culture has

changed over time. Speaking with doctors about it one on one has been helpful, and having the support of the medical executive team has been key.”

Response has been ‘overwhelming’

In fact, the system has had “mass education from housekeeping staff to the CEOs” on palliative care, according to DiStefano. “We have annual training days and ask staff members to become champions and train four or five other associates,” she says.

Response from the community on the program has been “overwhelming,” DiStefano says. “I wrote an article about the program for a newspaper for seniors — a little old lady [patient] brought the paper with her to the doctor and said she wanted that kind of care. We have phone calls from the community all the time in support of the program. When people make comments like ‘Where have you been?’ ... it’s good feedback from the community.”

“We are always willing to share information with other health systems — we want to improve the field of palliative care,” DiStefano explains. “We want others to learn from our lessons and what we’ve done. We want to help other programs improve.” ■

Palliative care model meets goals of health care reform

All of the accountable care principles that are integrated into the Affordable Care Act (ACA) require a clinical approach to the sickest, most complex, and costliest patients, says Diane E. Meier, MD, FACP, director of the Center to Advance Palliative Care at the Mount Sinai School of Medicine in New York City, because they all begin to move the system away from the fee-for-service model.

“Health care groups, providers, hospitals and multiphysician practice groups will need to function in an environment that involves various forms of capitation, where payment is linked to quality and not quantity of care,” she says.

Palliative care is one of very few interventions that has repeatedly been shown to save money by improving the quality of care, Meier says. “It

SOURCE

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doesn't save money by rationing care, but by helping to avoid preventable crises," she says.

For this reason, says Meier, the new delivery and payment models called for in health reform have the potential to "enormously increase" attention to access and capacity for palliative care in Medicaid. "It's not explicitly called for in the law, but I don't see how any of these models can survive without it," she says.

A missed opportunity

The ACA's failure to mandate that palliative care be included in accountable care organizations (ACOs) was a "missed opportunity," says **R. Sean Morrison, MD**, a professor of geriatrics and palliative medicine at Mount Sinai School of Medicine in New York City.

"Within ACOs, it's going to be the 5% to 10% of the seriously ill patients that will account for the majority of health care spending," he says.

Including palliative care teams within the ACOs would ensure that a vulnerable population would receive the best quality care, says Morrison, and would also ensure that ACOs would be sustainable moving forward. "One of the things that states should be cognizant of is to make sure that ACOs and Medicaid medical homes include palliative care," he says.

Morrison says the "last untouched frontier" where palliative care has not been developed is long-term care facilities such as assisted living and nursing homes. "Right now, many Medicaid regulations are designed to encourage a system where seriously ill patients from nursing homes are transferred back and forth to hospitals to receive unwanted and unnecessary interventions, then sent back to the nursing home," he says.

For this reason, says Morrison, palliative care needs to be developed for the dually eligible elderly and disabled population residing in nursing homes. "This is a generalizable model that really meets the goals of health care reform," says Morrison. "It improves quality and reduces costs at the same time."

Barriers still exist

Morrison notes that only 60% of U.S. hospitals have some sort of palliative care program currently. "We need to move to fully integrating this into the fabric of our health care institutions," he says. "If we can do that, we improve care for our most vulnerable and costly population. We also

have more dollars to go around."

One key barrier is reimbursement, says Morrison, as the physician and nurse practitioner are the only providers on the palliative care team who are currently reimbursed. "The other barrier is a workforce issue," he says. "It is a relatively new specialty. There need to be training opportunities for health care professionals to enter the field."

There is currently a cap on the number of graduate medical education trainees, he explains, and since palliative care is a new specialty, there are no new open training slots.

Some providers wrongly believe that palliative care is the same as end-of-life care, says Morrison, when in fact it's provided at the same time as disease-directed and curative treatments. Due to that misconception, he says, many patients are never referred.

"If I was a Medicaid director, I wouldn't want any of my beneficiaries being cared for in a hospital that doesn't have a palliative care program," says Morrison. "State Medicaid directors can have a huge role in promoting education on palliative care for practitioners, as part of licensing requirements, for example."

Meier notes that Medicaid redesign laws were recently passed to require hospitals, home care agencies, assisted living facilities, and nursing homes to ensure access to palliative care in New York state, adding that almost all payers who participate in Medicaid also participate with other payers such as Medicare and commercial insurance.

"By saying, 'If you want to participate in Medicaid, you must assure access to this kind of care for patients,' it's the same thing as saying that every health care institution needs to do this," she says.

Meier adds that the budget crisis was a key motivator for the legislation. "Everybody knows we are in a cost crisis," she says. "That has a way of overcoming a lot of barriers that ordinarily would prevent this kind of law from passing." ■

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Data collection comes to palliative care

Late to the game, it is figuring out the rules

Palliative care was only recognized as a specialty 5 years ago by the American College of Graduate Medical Education. Because of its newness, those working in the specialty are still learning how to effectively collect data and make use of the information once they have collected it. Even once they have decided that data collection is a good idea — and not all of those who work in the specialty are there yet — they often rely on measurements and tools that seem sensible, but lack evidence that they are actually appropriate.¹

Amy Abernethy, MD, associate professor of medicine and director of the Duke Cancer Care Research Program at Duke University in Durham, NC, has worked on figuring out what data are of value in palliative care. In an article published this month in *Current Oncology Reports*,² she and her peers looked at what data are collected and how they can affect “quality, value, and research within a palliative care organization.” Without data, she notes, the specialty can’t demonstrate its value and won’t survive.

A number of problems have to be addressed, she says. First, most of what is commonly collected in palliative care is from medical documentation, which Abernethy notes “isn’t discreet and can’t help you do the kind of predictive modeling you need to affect care. Plus, this is a distressing time, and data collection can be repulsive to both patient and family. I think, too, that those who go into palliative care aren’t into data collection as much as they are into caring for their patients. They are just not number wonks.”

While palliative care and hospice are good at using patient and family satisfaction tools to see how they are doing, says Abernethy, the environment is what she calls “data naïve.” There are attempts by many organizations to improve

SOURCE

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things. Specifically noted in Abernethy’s paper is the Center to Advance Palliative Care (www.capc.org), which has a variety of tools and articles available (for a list of suggested data points suggested for collection by CAPC, see box, below). Among the types of data to collect, Abernethy and her coauthors name process data, such as patient demographics, where care is delivered, and referral sources, and outcomes data that quantify the impact of care delivered on patients and their families.

Once you figure out what to collect, you have to determine the best way to collect it. “This is a poorly reimbursed and time-intensive specialty,” Abernethy says. “You have to make people more likely to participate.” Putting more data collection at the point of care and making the collection systems more streamlined and easier to use could encourage more providers to engage in data collection. “We can use electronic pens, iPads, or other tablets, and find ways to run algorithms in the background so that if you put in some incorrect data, you can be prompted quickly to correct it so that you don’t have to go back to the patient or family and repeat something.”

Suggested data points for palliative care

- Patient demographics: age, gender, race/ethnicity
- Consultation diagnosis
- Referring service and/or referring MD
- Admission date
- Discharge date
- Consultation date
- Disposition: inpatient death vs. discharge
- Consultation volume
- Disease distribution: cancer vs. non-cancer
- Location of consult
- Age distribution
- Consults by referring service or physician
- Length of stay
- Length of stay outliers: admission-consultation > 30 days or consultation-death > 30 days
- Origin of admission: direct to palliative care (hospice or non-hospice), ED, ICU, ward
- Type of inpatient unit: fixed bed unit (average daily census, average % occupancy) or swing bed unit (average daily census)

Source: Center to Advance Palliative Care



One leg up that Abernethy has on others is that there is a consortium of palliative care organizations in North Carolina that have agreed upon what data to collect and how to expand on that if desired. “If someone wants to do a study on difficulty swallowing, they can add something to the electronic form we have already created. They don’t have to create a complete new form,” she says. The state now has a single large data pool, too, which can help the individual organizations monitor their quality and outcomes compared to their peers.

There is no question that those working in palliative care are dedicated, but Abernethy says even the most dedicated providers can learn from data how to be more effective. One example uncovered in North Carolina was that African-American patients were more likely to suffer from constipation than other patients. “We don’t really know why — it could be that people are afraid of being culturally insensitive and so we treat them differently when asking questions. Or perhaps they have some cultural sensitivity around discussing it with us. Or it could be an issue about their medication.” Just knowing, though, allows an organization to create initiatives to treat the problem.

The consortium also learned from data collection that they were taking care of a much larger number of heart failure patients than they knew. “Once we found that out, we figured that they might have some special needs we could address, that we might have some workforce issues to deal with to handle their needs. We know now to ask certain questions. Before we collected the data, though, we didn’t know it. It wasn’t something we noticed off hand.”

There will undoubtedly be more pressure on palliative care to prove its worth using data as time goes on. Meanwhile, Abernethy says that the data they collect can be used to improve care for patients and also to market palliative care services. “They can say they think about evidence-based practice.” ■

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ICDs result in adverse events at end of life

Policies for deactivation needed in hospice

Although implantable cardioverter-defibrillators (ICDs) improve survival in patients at risk for recurrent, sustained ventricular tachycardia or fibrillation, the device can add to a patient’s discomfort at the end of life. (See “Are you talking to patients about deactivation of their ICDs?” *Hospice Management Advisor*, June 2010, page 61.)

Unless deactivated, ICDs may deliver unwanted shocks to terminally ill patients near the time of death. A study in the *American Journal of Hospice and Palliative Care* evaluates the adverse events that result in continued activation of the device.¹ In addition to determining the frequency and nature of adverse experiences with ICDs, hospice programs were surveyed to determine preventive measures taken.

Forty-two of 50 hospices in Oregon participated in the study. A total of 36 respondents had cared for a patient with an ICD in the preceding 4 years. The average number of patients with ICDs per program increased from 2.2 in 2005 and 2006 to 3.6 in 2007 and 2008. Of the 36 programs that had cared for a patient with an ICD, 31 reported having some kind of adverse experience.

Adverse events ranged from unwanted shocks delivered (64%), patient/family distress related to the decision to deactivate the ICD (47%), and time delay in ICD deactivation (42%). Only 16 (38%) programs had policies for managing ICDs and only

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19 (43%) routinely screened new patients for ICDs.

As patients near the end of their lives, receiving defibrillating shocks may no longer be consistent with their goals of care and hospices should routinely screen patients for ICDs and proactively adopt policies to manage them. ■

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Accurate life expectancy prediction possible

Scoring system helps clinicians recommend care

A new scoring system that can more accurately predict the life expectancy of a patient with advanced cancer in terms of “days,” “weeks,” and “months” is described in an article published in *BMJ*.¹

This information is significant for clinicians as they evaluate appropriate care for terminally ill cancer patients. Current survival predictions based on clinicians’ opinions are often unreliable, over-optimistic, and subjective, according to the authors. Researchers at St George’s University of London developed a scoring system for patients with advanced cancer in different care settings that was as good or better than clinicians’ best predictions.

The researchers evaluated 1,018 patients with advanced incurable cancer who no longer received treatment, and were recently referred to palliative care services across the United Kingdom. To predict patients’ remaining life expectancy in “days” (0-13 days), “weeks” (14-55 days), or “months” (more than 55 days), the team developed two prognostic scores (PiPS-A and PiPS-B) by using a combination of clinical and laboratory variables and compared these with actual survival and clinicians’ predictions.

They found that both scores were at least as accurate as a clinician’s estimate but PiPS-B, which required a blood test, proved to be significantly more precise than an individual doctor’s or nurse’s prediction.

According to the authors, this study is the first to benchmark a prognostic scoring system against

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current best practice, but further validation work is required before recommending the scales to be used in routine clinical practice. ■

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