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Outreach efforts pay off for award-winning hospice

Programs expand services beyond traditional audiences

Working outside the box to provide services that don't always fit the definition of home health or hospice is a trademark of Kansas City Hospice and Palliative Care in Kansas City, MO. The hospice's innovative approach to meeting community needs is one of the reasons it was one of three programs honored with a 2010 American Hospital Association Circle of Life Award. (See resource box for information on award.)

Three programs that focus on reaching non-traditional hospice audiences were cited as reasons for the hospice's recognition: an outreach program for the African-American community, outpatient services and consultations in community oncology clinic, and a counseling program for community members whose grief exceeds hospice parameters.

Increasing the number of African-American patients from less than 8% to almost 14% in fewer than two years is the result of the minority outreach program at Kansas City Hospice and Palliative Care. "It was harder than I thought it would be to get this program going, but I've learned a

EXECUTIVE SUMMARY

Kansas City Hospice and Palliative Care in Kansas City, MO, won a Circle of Life Award from the American Hospital Association for outstanding service to the community. The hospice has expanded services beyond the normal scope of hospice care to meet community needs in three major areas:

- Outreach efforts to minority populations have increased admission of African-American patients from less than 8% to almost 14% in less than two years.
- Palliative care physicians working alongside oncologists in a community oncology clinic introduce the concept of palliative and hospice care to patients who still ARE undergoing active treatment.
- Mental health services that pick up where hospice counseling stops help seniors in the community deal with depression and other grief-related illnesses.

lot in the process,” says **Brenda Sanders**, LOM, minority community outreach liaison and educator for the hospice.

“When we started the program, I went to all of the obvious places to market the service,” she says. Churches, social service organizations, hospitals, clinics, physicians, and local universities were the first places she went to offer to speak to members or students, she says. “I found that healthcare people needed the most education about hospice and what it can offer,” she says.

She also found that churches, a central focus of many African-American communities, were more difficult to approach than she realized. “They don’t know where I fit into their agenda,” she explains. “I like to say that everyone wants to go to heaven, but no one wants to die.”

Prayer groups, some Sunday school classes, and

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Editorial Questions

For questions or comments, call Joy Daughtery Dickinson at (229) 551-9195.

prayer breakfasts were the groups to which she presented the most, she says.

Understanding the cultural beliefs that lead people to avoid talking about hospice is important in an outreach effort, Sanders says. “Family is important, so it is critical to point out that hospice is not planning to replace any member of the family. Instead we are there to help, to give respite, and to support,” she says. “I emphasize that I know they want the best quality of life for their family member and hospice services can reduce pain and increase comfort.”

Her marketing efforts don’t stop at community presentations. “I also appear on various local radio shows and write a column about grief, depression, and mental health issues for the local newspaper,” says Sanders. “I also speak with African American physicians because they have the same misperceptions about hospice as the general African American population,” she says. Many African-Americans believe that hospice care is less than adequate and hospice patients are lonely and in pain at the time of death.¹ She adds, “They appreciate finding out the resources that are available to their patients.”

Other one-on-one conversations that Sanders finds effective are with managers of assisted living and skilled nursing facilities. “Personal conversations take time and energy, but it is the best way to develop relationships that result in referrals,” she adds.

Presence in oncology clinic spurs service

Talking with oncology patients about the benefits of palliative care and hospice can be difficult, time-consuming conversations, but physicians at Kansas City Hospice and Palliative Care have the opportunity to do so at a community cancer clinic.

Ann Allegre, MD, director of medical programs at the hospice, says, “We were approached by physicians from a large oncology group about an opportunity to offer palliative care services to their patients early in their treatment for cancer.”

Allegre and another hospice physician are in the oncologists’ clinic one afternoon each week to meet with patients and provide palliative care consultations. “I see about two to three patients each week,” she says. “I’ve had mixed results with the patients I see.”

Some patients are open to the idea of palliative medicine, but others are more focused on active treatment and not ready to think about other possibilities, she says. “Patients who are receiving

SOURCE/RESOURCE

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The American Hospital Association (AHA) Circle of Life Award honors innovative programs in palliative and end-of-life care. A selection committee that includes leaders from medicine, nursing, social work, and health administration reviews nominations. For more information about the award, go to www.aha.org/circleoflife.

their second or third type of treatment are more open to palliative care discussions than patients undergoing their first round of treatment,” says Allegre. Patients who agree to talk with Allegre generally are open about their concerns and appreciate her discussion of end-of-life issues as well as palliative care, she says. “I’ve helped families complete do-not-resuscitate orders as well as advanced directives,” she says. Allegre has also referred patients and their families to the hospice’s home palliative care team when appropriate.

Although the ultimate goal of the program is to get patients admitted into hospice care sooner rather than later, Allegre measures success in smaller steps. “We’ve had a number of patients from the oncology clinic that have entered our hospice program as a result of meeting us in the clinic, but we are still trying to encourage earlier admission,” she says.

There are several challenges as well as benefits to working in the oncology clinic, says Allegre. “It is helpful to be in the clinic because patients and family members are more comfortable meeting me at a location with which they are familiar,” she explains. “They also appreciate having someone to talk with about issues that are not always easy to discuss with their oncologist.”

Physician perceptions are a challenge, admits Allegre. “Old habits die hard, and oncologists have bonded with their patients in a long-term fight against cancer,” she explains. “It is difficult for a physician to say that it might be time to stop active treatment.”

Allegre’s presence in the clinic helps physicians because she can talk directly with them to get their opinions and talk through options for the family. “We can make sure we are saying the same thing to the family, and I can handle the difficult part of the conversation if they prefer,” she adds.

Mental health program focus: depression

Talking with seniors about depression as a result of their losses is another difficult conversation handled by the staff of Passages, the hospice’s community counseling program.

“I started the program in 2006 after I noticed that a large number of our patients in hospice care had actually been suffering from undiagnosed and untreated depression for many years,” says **Stevie Shuchart**, LCSW, LCSW, CSW-G, director of the program. “These seniors just assumed that depression was a normal part of growing older, and they were not likely to seek help.”

Offering the counseling services was a natural extension of the grief and bereavement counseling provided by the agency, says Shuchart. “Hospice grief counseling is limited to 13 months for Medicare reimbursement, but there are families that require a longer period of time to address their grief as well as any depression that they were experiencing before their loved one’s death,” she says. Reaching out to people who have not been associated with the hospice also makes sense because it is one way to demonstrate the full range of services a hospice can provide, she adds.

Shuchart’s services are billed to her clients’ insurance coverage or Medicare if they are covered for mental health counseling. “Because the hospice is a not-for-profit and does offer free care, I can see patients who cannot pay,” she adds.

Community presentations on grief as well as end-of-life issues are one source of referrals for Passages and the hospice, says Shuchart. “I’ve also developed good relationships with several assisted living and skilled nursing facilities,” she says.

Seniors are her largest audience because, as a group, they experience more loss, says Shuchart. “There are the obvious losses of a spouse, a sibling, or a good friend, but there are also secondary losses that are not as apparent as a cause of depression,” she says. “Being told that they can’t drive themselves anymore is a huge loss, especially for men, that often causes depression.”

Other losses that contribute to depression include losing a long-time home when seniors can no longer live on their own or losing social groups when the move takes them to another area, she adds.

Although she describes her program as “a work in progress,” Shuchart says that any hospice planning to offer a non-traditional mental health program should be prepared to spend time

marketing it, often on a one-on-one basis. “This is not a typical program offered by hospice, so it does take time to get the word out,” she says. “The good news is that I’ve now had enough clients that word-of-mouth marketing is bringing me new clients.”

REFERENCE

1. Taxis JC. Attitudes, values, and questions of African Americans regarding participation in hospice programs. *J Hospice Pall Nurs* 2006;8:77-85. ■

Technology helps hospices meet QAPI requirements

EMR software produces timely reports

Twenty-one months after quality assessment and performance improvement (QAPI) requirements became part of the Hospice Conditions of Participation, quality improvement managers are reporting that the transition has gone smoothly when electronic medical records (EMRs) and staff education are integrated.

“Our hospice has used electronic records for billing purposes since 1994, and our field staff began documenting electronically in 2005, so our staff was familiar with the technology,” says **Maria Lawson**, MS, senior systems analyst for Gilchrist Hospice Care in Hunt Valley, MD. (See p. 125 for tips on implementing new technology.) Because information that is useful for quality improvement (QI) already was being collected, the agency developed protocols and tweaked the assessment forms to readily identify key areas for QAPI.

As case managers conduct the comprehensive assessment of new patients, the information is entered using a tablet PC, says Lawson. “We read the requirements for QAPI regularly as well as the other requirements for information we must collect for billing purposes and update the forms to reflect changes, but the process for nurses to enter the data remains the same,” she explains.

Members of the quality improvement team, comprised of representatives from different areas of the hospice, review monthly statistics from the report generated from the electronic records system and identify areas to focus upon for improvement, says Lawson. “Members of the senior leadership team and the director of qual-

ity set specific goals for the hospice based upon team recommendations,” she says. Once these goals are set, managers talk about the focus and steps to improve performance in staff meetings, Lawson explains. “Everyone in the hospice is involved in quality improvement, and it is a continuous process in our hospice,” she says.

Use of electronic records to capture information is valuable because you can obtain reports in a timely manner, Lawson points out. An “outcome” report based on information on all charts can be produced quickly with electronic records, she says. “We are monitoring falls, infections, and turnaround time to see new patients,” Lawson says. “Prior to use of electronic records for our field staff, we had to manually calculate results.” A report from electronic records can produce the information more quickly, enabling managers and QI team members to address issues, revise QI activities, or follow up on problems more effectively, she adds.

QAPI projects do not have to be related to clinical issues, Lawson emphasizes. The use of electronic records throughout the hospice enables staff members to track information in all areas, including staff credentials, she says. “One of our goals was to have 100% of all clinical leaders certified in their hospice specialty by the end of the fiscal year,” Lawson explains. This type of goal required a simple data tool that collected the information and generated a report that enabled managers to track progress of the certifications, she says. It is a straightforward, measurable goal that does improve patient care because it improves the knowledge and skills of the people overseeing the

EXECUTIVE SUMMARY

Documentation of quality improvement efforts at hospices represented a big change in process for many hospices when quality assessment and performance improvement (QAPI) requirements became part of the Hospice Conditions of Participation in 2009. After almost two years, hospices report that meeting QAPI requirements is much easier when the right tools are available.

- Be sure the technology you purchase for electronic medical record (EMR) documentation and generation of reports fits your hospice needs.
- Choose laptops or tablet PCs that your staff can easily use and carry on visits.
- Include staff members from all areas in the review and evaluation of software as well as hardware.
- Provided extensive training prior to implementation to allay concerns and ensure proper use of the programs.

SOURCES

For more information about use of electronic records for quality assessment and process improvement, contact:

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provision of care, Lawson adds.

The staff at VNA of Western Pennsylvania in Butler is looking at falls and pain for their QI initiatives. Nurses use laptops to document visits in the home, and the assessment forms have been developed to capture additional information on these two areas, says **Carol Arthur**, RN, CCM, QI coordinator for the agency. “We’ve developed specific profile forms that standardize the way information is collected,” Arthur says. “We also collect information from on-call triage nurses that identify issues that show up nights and weekends.”

Reports generated from the electronic records produced by field nurses and triage nurses are used to identify trends, she points out. “If it looks like we are having more calls about pain at night, or if nurses are reporting more falls, I look at specific data to see specific causes or trends,” Arthur adds. “Our hospice staff started using laptops and standardized assessment forms about 10 years ago, so they were accustomed to completing an array of forms.” This meant that the transition to QAPI was not a problem for the hospice, she says. Staff members just needed to make sure the forms collected data they needed to meet requirements, Arthur says.

Even though nurses had been completing standard profiles on their laptops, there was a need to update forms and re-educate nurses, she says. “We talked about QAPI and explained why we were changing some forms, but emphasized that it was a good thing for the hospice,” she says.

Constant evaluation of forms, reports, and data is necessary for a good quality program in a hospice, says Arthur. “We are always looking for ways to improve the forms, not only to improve the data we collect, but also to make the forms simple and easy to complete for the nurses,” she says. ■

Choose technology for ease of use, versatility

Include staff in selection of devices

When the leadership team at Gilchrist Hospice Care in Hunt Valley, MD, decided to have all field clinicians document their visits electronically, several types of technology were evaluated.

“We chose to use a tablet PC rather than a laptop computer because it is lighter, easier to handle, and offers different options for entering data,” says **Maria Lawson**, MS, senior systems analyst for the hospice. “It looks like a clipboard and offers the user an opportunity to use a stylus or a keyboard to enter data.”

The device was chosen after three devices were evaluated by a committee comprised of clinical and non-clinical, and technologically savvy and non-technological staff members, Lawson says. “The clinicians voted on the device we chose due to its weight, battery life, and durability,” she says.

In addition to the equipment itself, it’s important to carefully evaluate the software you purchase, says Lawson. “We did a lot of shopping and worked our way down to two providers,” she says. “We had each vendor give a full demonstration to the entire clinical management team.”

The team was made up of managers from all areas of the hospice, and they were encouraged to ask a lot of questions during the demonstration, she adds.

Training was mandatory for all employees, says Lawson. “Even staff members who were comfortable using computers had to go through the training because they were not familiar with the documentation software,” she says. Using a tablet PC with a touchscreen is different than a traditional keyboard and computer, she says. Staff members attended a four-hour training session on the use of the tablet that was scheduled during the day and for which they were paid, Lawson says. “We gave everyone tablets to take home and told them to play with them,” she says. “By letting employees get accustomed to playing solitaire, drawing with the stylus, and handle non-clinical tasks on the tablet at first, it was easier for them to learn how to use the software. No one had used a tablet before, so we wanted them to be comfortable with it before we taught the software.”

Training for use of the software and forms required for documentation was held for four

hours, five days each week, says Lawson. “From experience, we knew that four hours is the maximum length of time someone can pay attention when we are introducing something completely new,” she explains. By breaking the training into half-days, employees were able to retain what they learned from day to day and still see patients for half of a day, Lawson adds.

When purchasing laptops or tablets, be prepared for some devices to need service, she suggests. “We keep four or five extra tablets in our office to switch out with clinicians who have devices that need service,” Lawson says. “We purchased service agreements for all of our tablets, but we need the backups so clinicians can continue to document visits even if their tablet is in for repair.”

Although there were some clinicians who were reluctant to switch to electronic documentation, everyone is dependent on it now, she says. “Even the nurses who were not happy with the use of tablets at first are the nurses that are most concerned about how long they have to be without their tablets when we service the devices or update their software,” Lawson says. ■

Veterans have unique needs at EOL

VA/NHPCO program to be specific to vets

It's not unusual for soldiers who have returned from war never to discuss the war with their families or friends, which creates an aura of mystery or a sense that their loved ones somehow cannot fully understand them now that they have returned to civilian life.

What might be surprising is that often those very soldiers who attempt to shield themselves or others from their wartime experiences may re-experience the associated emotions — pain, fear, guilt, helplessness, etc. — at the end of life (EOL), according to **Deborah Grassman**, ARNP, nurse practitioner at Bay Pines VA Medical Center in St. Petersburg, FL, who has been with the Veterans Administration (VA) for 26 years and has been the director of the hospice program at the VA for 15 years.

Grassman was a plenary presentation speaker on “Wounded Warriors: Their Last Battle” at the recent 11th Clinical Team Conference and Pediatric Intensive, “Performing in the Key of E: Excellence in Interdisciplinary Care” sponsored by the

National Hospice and Palliative Care Organization (NHPCO).

Because soldiers, particularly those who have seen combat, often have unique needs at the end of life, the VA and the NHPCO have teamed up to offer a program available to all hospices that has been developed to meet these special needs of America's veterans. The program can be accessed at www.WeHonorVeterans.org which, at press time, was scheduled to open in October. It is designed to address the following: military history checklist; veteran benefits and the VA organizational structure; recognition ceremonies; veteran-to-veteran programs; outreach materials; and staff and volunteer training modules.

Contrasts from different wars

Veterans might experience different trauma, depending on how they were received by the public after returning to the United States. In World War II, “everyone was involved in this war effort,” Grassman noted.

For example, the Red Cross and other organizations would send pictures to soldiers overseas so that they would know that they were supported. “Also, there was no television coverage in World War II for the most part,” she said. “Therefore, that meant that war could be glamorized; the American public could be shielded from the brutality of war, which fostered a lot of unity for the war. Also, the mission was pretty clear and largely undisputed in World War II, especially after Pearl Harbor.”

World War II soldiers returned to the United States as victors. Because transportation was not as advanced at that time, “it took a while for them to get home, so there was time . . . to externalize some of those war stories that they had experienced,” Grassman said.

By contrast, the Korean War is often called the “forgotten war” and was officially only a “conflict” or a “police action,” she said. “I think those labels reflect how we often tend to minimize . . . what our Korean War veterans have gone through,” Grassman explained.

In Vietnam, due to television coverage, Americans “were no longer shielded from the brutality of war,” said Grassman, noting that it was “a very political war” about which the country was divided. Therefore, when Vietnam veterans returned, it was to quite a different reception than World War II vets received.

“You think about how our soldiers from

Vietnam were being treated,” Grassman said. “How did we meet and greet them when they came back?” Sometimes they were greeted as “baby killers” or simply as “murderers” by war protesters.

Although all wars involve brutality, one of the challenges with any veterans’ death is complicated by whether they have caused harm, in addition to whether they have been harmed, she said. The fighting in Vietnam was more face-to-face, and the enemy was hard to determine.

Grassman said that as a result, it is easy to understand that a Vietnam veteran’s memories like this “can sometimes complicate their peaceful dying.”

Post-traumatic stress syndrome

Post-traumatic stress syndrome (PTSD) can be diagnosed in anyone who has had exposure to a traumatic event that is experienced with fear, horror, or a sense of helplessness, Grassman said. Bad memories of war often lead veterans to do “what most of us would do, which is to avoid any thought, any memory, any trigger that . . . would cause them to have these memories,” she said.

According to the Diagnostic and Statistical Manual (DSM-IV), there are many criteria, or symptoms, of PTSD. The three major categories are:

- The “traumatic is persistently re-experienced.”
- The person avoids associated trauma. For example, a veteran hears a balloon pop at a party, which reminds him or her of the war, so that individual never goes to parties again.
- There are persistent symptoms of increased arousal, such as irritability or outbursts of anger, difficulty concentrating, etc.

According to Grassman’s presentation, “some resources say that the single most influential risk [factor for PTSD] is having killed. This complicates EOL care.”

“You see, it is one thing to have witnessed trauma; it is another thing to have caused trauma,” she said. “That is a deeper level of traumatization . . . That is the injury that sometimes surfaces as people come to the end of their lives.”

Some research suggests that one-third of Vietnam veterans suffer from PTSD, but 60% do not report it, Grassman said.

“PTSD is a mental, emotional, social, spiritual, moral, familial, intergenerational injury,” Grassman writes in her presentation. “Healing requires interventions that address all dimensions of suffer-

ing.”

With all the veterans that Grassman has dealt with in her years with the VA, she told the audience that they tend to “sort out” into three combat response trajectories:

- integration (healing from the war);
- apparent integration (delayed-onset PTSD; subclinical PTSD; latent PTSD);
- incomplete integration (PTSD).

With trajectory one, the combat trauma is “successfully integrated.” Among the comments she has heard from veterans who fall into this category are:

“I’ve faced death before in the war. I’m not afraid of death anymore.”

“I must have been spared for a purpose.”

“I faced death before, and every day since has been a gift.”

With the third trajectory, Grassman says that she has heard the following comments from veterans or family members of veterans:

“Most of my brother remained in Vietnam.”

“I didn’t know the person who came back.”

“I lost my soul in Vietnam.”

“90% of me died in that war.”

According to Grassman’s presentation, one of the main criteria for PTSD is “estrangement from others,” along with suspicion and lack of trust; alcohol use; anxiety; agitation; unfulfilled longing for the life not lived.”

Don’t push for stories

Grassman suggests that in working with patients at the end of life, it is “very important that we do not push people to tell their stories.”

She noted that providers can inadvertently “do damage when we don’t know” how to respond with an appropriate emotional environment.

Regarding intervention, Grassman suggested not asking someone, “Are you a veteran?” “The reason I don’t want you to ask it that way, there are some veterans who don’t think they’re veterans. They think veterans are only people who have been in combat [or] only those [who] have used the VA,” she told the audience. “Ask the question instead, ‘Have you ever served in the military?’”

Another step is to identify those among volunteers at a particular hospice or other facility who might be veterans themselves, and assign those volunteers to the patients who are veterans. “There is a camaraderie that forms very, very quickly,” she said.

“We need to affirm the feeling aspect of their death experience, especially the tears and the fears, which the military culture taught them to disdain,” she said. “We need to anticipate that they might under-report their physical and emotional pain and fear. We need to thank them for serving our country and giving us our freedom. And there are a lot of ways you can do that.” ■

MDs perspective on EOL spiritual care

Meshing spiritual with science

In addressing spiritual care for their patients at the end of life, physicians often face the challenge of how to mesh the spiritual concerns with objective science, which is a challenge that sometimes results in a “significant disconnect” with patients, said **Rabbi Barry M. Kinzbrunner, MD.**

Kinzbrunner, who is senior vice president and chief medical officer of Vitas Innovative Hospice Care in Miami, was a speaker at the recent 11th Clinical Team Conference and Pediatric Intensive Care sponsored by the National Hospice and Palliative Care Organization.

Because pain can be psychosocial, spiritual, as well as physical, to illustrate all the contributors to “total pain,” Kinzbrunner, who is trained as an oncologist, offered The Portenoy Model, published in 1988 in the *CA: A Cancer Journal for Clinicians*.¹ One of the major contributors to suffering at the end of life, according to that model, is fear of death, along with other contributors, such as loss of work, physician disabilities, and financial concerns.

The word “spiritual,” he noted, is derived from the Latin “spiritus,” meaning breath. However, trying to define spiritual care can be difficult. For example, he said, a literature review uncovered 92 definitions of spirituality, with seven “definitional themes,” including:

- “relationship to a higher power or reality greater than self;
- “not of the self;
- “transcendence or connectedness unrelated to belief in a higher being;
- “not of the material world;
- “meaning and purpose in life;
- “life force of the person; integrating aspects of the person;
- “summative definitions that combined multiple themes.”²

In other definitions of spirituality, he noted that religion is seen, in some sense, as a subset of spirituality.

He explained that in the guidelines on chaplaincy and spiritual care in the National Health Service Scotland that “spiritual care is not necessarily religious. Religious care, at its best, should always be spiritual.”³

“One does not necessarily exclude the other,” Kinzbrunner says.

In a study of palliative care physicians and spirituality by Seccareccia and Brown, the study found, according to Kinzbrunner’s presentation, that “physicians described spirituality as a multidimensional construct that may involve:

- a search for meaning and purpose;
- a sense of connectedness;
- a relations to a higher being or power;
- transcendence.”⁴

The study also found that “spirituality is different than religion,” he said, with the study suggesting that “religious patients often were described as experiencing distress related to what they perceived as punishment from God.”

Another finding, according to the presentation, was that “the authors conclude that the impact of a physician’s personal spirituality on practice and practice on spirituality were inextricably woven together.”⁴

What makes this work?

The message from this study’s findings, according to Kinzbrunner, is that “physicians have to be spiritual, as well, to make this work; if there is no spirituality by the [physician], then it’s very hard for the patient to express” spiritual/religious concerns.

Kinzbrunner also noted that the latest Pew research showed that 90% of Americans believe in and pray to a higher power. However, in one study by Curlin et al, 66% of physicians say that in treating patients, they do not consider “what would God want me to do.”⁵

In a 2009 study by Fitchett et al on physician’s experience and satisfaction with chaplains, of the 1,102 physicians surveyed, the respondents identified themselves as 59% Christian; 16% Jewish; 14% other; and 10% no religious affiliation. However, 41% of respondents agreed with the statement, “My whole approach to life is based on my religion.” Also, 50% of respondents believed it was appropriate to pray with patients, Kinzbrunner notes.⁶

Kinzbrunner explained that in a 1999 study by Ehman et al, 51% of 177 respondent patients in a pulmonary outpatient clinic identified themselves as “religious,” while 90% responded that they believed that prayer may sometimes influence recovery from an illness.⁷

In a 2008 study by Jacobs et al, it was found that “57.4% of the public and 19.5% of the professionals believe that divine intervention could save a person when physicians believe treatment is futile.”⁸

“More than half of the public believes in a miracle,” according to that study, Kinzbrunner noted. “The public is more often looking for a miracle than the people taking care of them, and that, to me, speaks volumes.”

A 2007 study by Balboni et al found that 88% of 230 patients “considered religion to be at least somewhat important,” according to Kinzbrunner’s presentation.⁹ Also, “spiritual support by religious communities or the medical system was significantly associated with patient quality of life,” with 47% reporting “spiritual needs minimally or not met by [the] religious community”; while 72% reporting “spiritual needs minimally or not met by [the] medical community.” Another finding of the Balboni study was that “religiousness was significantly associated with wanting all measures to extend life.”

Americans are “much more tolerant of cultural diversity than religious diversity,” Kinzbrunner suggested. “I think what’s beginning to happen in this country is that if you’re religious, what you want must be wrong,” he said. He also noted that just as we tend to think outside the box on how to provide patient care to those with cultural diversity, we should try to do the same for those with religious diversity.

Another study by Balboni et al on the impact of spiritual care on the perception of the quality of medical care and quality of life near death “shows you how important spiritual care is,” Kinzbrunner said.¹⁰ So, even for people who are not religious, spiritual care is important at the end of life, and it requires the participation of the entire health care team, including physicians, he said.

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How to partner with your faith community

Help in meeting spiritual needs

Jeanne S. Twohig, MPA, senior advisor, Duke Institute on Care at the End of Life, unabashedly asserted that there is a crisis in our country as to the quality of the vision for our health care futures.

Twohig, who noted the Durham, NC-based institute with which she is affiliated is housed in the divinity school vs. the medical school at Duke University, is a program developer focused on how to build better systems and better delivery of spiritual care. The goal is to design more rigorous systems as health care facilities strive to offer quality palliative care to patients.

Twohig, speaking at the National Hospice and Palliative Care Organization’s (NHPCO) 11th Clinical Team Conference and Pediatric Intensive, noted that there are now 77 million baby boomers, or those born between 1946 and 1964, with the oldest boomers at 64 and the youngest at 46.

“Our country is getting older,” noted Twohig, who explained that it is the “oldest of the old” demographic group that is growing at the most rapid pace. For example, she noted

that in 2000 there were 85,000 centenarians, but by 2050, it is projected that there will be 850,000 centenarians.

Another aspect of the aging is that women typically outlive their companions, leading to the question of who will care for the traditional caregivers. Fewer people will be contributing to Social Security, she said, which leads to the question, “Who is going to care for us, and how is it that we want to be cared for?”

What patients want at EOL

Twohig referenced the 2000 study in *The Journal of the American Medical Association* by another Duke researcher, Steinhauer et al, regarding the “attributes rated as important by more than 70% of patients but not physicians,” which included:

- “be mentally aware;
- “be at peace with God;
- “not be a burden to family;
- “be able to help others;
- “pray;
- “have funeral arrangements planned;
- “not be a burden to society;
- “feel one’s life is complete.”¹

According to Twohig, “Faith communities are natural allies, and providers of palliative care need alliances with community spiritual providers.” Such alliances are a well-organized way to engage with a community as a whole, she said.

Spirituality is important to people, Twohig said, although we live in what is largely a medicalized society, or what she calls the DMZ, or the “divinity-medical zone.” She noted that there are many cultural issues associated with this DMZ, as well as “tremendous” role confusion, since physicians historically have not been trained in meeting spiritual needs. Even now, courses on spiritual care are not routinely taught in the divinity school or the medical schools, Twohig says.

Other challenges to providing quality spiritual care include quality “measurement issues” and a “fragmented notion of what spirituality is,” she said.

Twohig said her goal is to develop new ways to meet the spiritual needs of this “tsunami of baby boomers” that is coming, to rethink the ways to provide care, because “the way we are doing it is insufficient.” And because, she said, “boomers are not quiet about getting their needs met,”

there is likely to be a coming demand for better spiritual care.

The recommendations from the February 2009 Consensus Conference on Improving the Quality of Spiritual Care as a Dimension of Palliative Care include the suggestion that spirituality should be considered a “vital sign,” just like any other physical vital sign. “That gets at the question: ‘Are you at peace?’” Twohig said.

Another target for improving the quality of spiritual care is at the point the discharge plan is developed, she said. Twohig asks, if the patient has had spiritual care as an inpatient, how can that plan of care be carried to the outpatient setting? Furthermore, she asked, what is a way to unite the inpatient and outpatient delivery systems and the community?

The answer might be found with the faith community, or community religious and spiritual leaders. Twohig said that some of the reasons hospices and palliative care teams should reach out to the faith community in their areas is answered by the fact that eight out of 10 people identify with a particular faith community. A faith community is a naturally occurring community, she said, and there is often good communication within such networks.

“Faith leaders need the skills that hospices have,” because while community clergy tend to be comfortable with formal rituals, i.e., delivering the funeral sermon, they are not as comfortable with the “end-of-life conversations,” Twohig said.

There is an opportunity to leverage what hospice now offers by linking with the faith community, she said.

“Hospice is a movement as much as a type of health care delivery . . . The power of one becomes exponential in all this,” Twohig said.

With the growing immigrant community in the United States, there are times when a patient might not choose to share with a hospital chaplain. With the changing face of America, there might be some belief systems that “may not yet have been embraced by chaplaincy,” she said.

The point of reaching out to the faith community in a hospice/palliative care service area is this, she said: “What it is really about is embracing that patient.”

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For caregiver, death at home is less trauma

ICU deaths carry risk for grief disorder

Cancer patients who die in the hospital or an intensive care unit (ICU) have worse quality of life at the end-of-life, compared to patients who die at home with hospice services, and their caregivers are at higher risk for developing psychiatric illnesses during bereavement, according to a study by researchers at Dana-Farber Cancer Institute in Boston.¹

One striking finding of the study was that bereaved caregivers of patients who died in an ICU were five times more likely to be diagnosed with post-traumatic stress disorder (PTSD) compared with caregivers of patients who died at home with hospice services.

In addition, families and loved ones of patients who died in the hospital, though not in an ICU, were at higher risk of developing prolonged grief disorder (PGD), an intense and disabling form of grief that lasts more than six months.

The authors noted that most cancer patients would prefer to spend their last days at home. However, they said, 36% die in a hospital and 8% die in an ICU, and they might be subjected to invasive and painful procedures at the end of life.

The report contains findings from a prospective, longitudinal study of advanced cancer patients recruited at seven cancer centers from 2002 to 2008. Patients and caregivers — primarily family members — were interviewed at the beginning of the study. Their medical charts were reviewed at that point and after the patients died, on average 4.5 months later. Within two weeks of the death, researchers interviewed the caregiver most closely involved with the patient's care during the last week of life. They interviewed the caregiver again six months later.

After analyzing the data on 342 patient-caregiver pairs, the investigators found that patients who had died in the hospital or an ICU experienced more physical and emotional distress and worse quality of life than those dying at home.

Among the caregivers, they determined that four of 19 caregivers (21%) of patients dying in an ICU developed PTSD, compared with six of 137 (4.4%) when death occurred in the home/hospice setting.

A similar elevated risk of prolonged grief disorder was found in caregivers when patients died in the hospital, but not in an ICU.

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Palliative Care Act is law in New York

A bill recently signed into law in New York state will require a patient's health care provider to provide information and counseling to that patient on palliative care, prognosis, and end-of-life options, once the patient is diagnosed with a terminal illness.

If the provider determines that a patient lacks decision-making capacity, the provider must give that information — orally or in writing — to the patient's surrogate.

Compassion & Choices drafted and sponsored the act, according to Compassion & Choices President **Barbara Coombs Lee**. The legislation was opposed in New York by the New York Medical Society; however, no representative of that organization was available to speak to AHC Media, publisher of *Hospice Management Advisor*.

Lee says this is the second state in which this type of law has been passed, with California being the first in 2008. Compassion and Choices has sponsored the Death with Dignity Acts in Oregon and Washington and fought for its passage through the Montana courts, Lee says that leaders with Compassion and Choices realized that most people aren't aware of the end-of-life options they legally have in the "other 50 states of the union." ■

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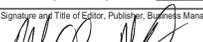
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