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## Improve hospice staff skills on being compassionate presence for patients

*Ohio experts create training curriculum*

**H**ospice nursing work is different from the typical health care experience, but how often has it become rote and driven by schedules and regulatory tensions?

An Ohio hospice initiated a research project that teaches hospice staff how to become more fully present and engaged in patient care, resulting in more satisfying hospice staff-patient experiences.

Participants who received the compassionate presence training reported significantly improved purpose and meaning and reliance on inner resources than before the training, says **Sharon Stout-Shaffer**, PhD, RN, an associate professor at Capital University in Bexley, OH. Stout-Shaffer was involved with the research project.

The idea for the project came from a hospice nurse. When **Ruth Frankenfield**, RN, MS, CNS, a staff nurse at HomeReach Hospice in Columbus, OH, found herself questioning the lack of spirituality in her daily work, she asked her director for permission to conduct a research project on the topic.

"I was interested in doing work around enhancing spiritual care amongst staff with our patients," Frankenfield says.

Frankenfield teamed up with **Kate Dean-Haidet**, RN, MSN, CS, a psychotherapist in private practice in Pataskala, OH, and a graduate student at the Ohio State University Comparative Studies Department.

"It was a serendipitous meeting with Kate," Frankenfield recalls. "She had just started doing work at Ohio State in comparative studies and had expressed a keen interest in spirituality and the death and dying process."

The result was a research project about what would work best in helping staff understand their own spirituality and be more present and active in engaging patients from a spiritual perspective, she says.

"We pulled together key people at the hospice to serve on an advisory board and began to develop our definition in terms and concepts

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that would be key to the content," Frankenfield says.

The result was six weekly sessions of 90 minutes duration, designed for groups of eight to 12 people. All participants were voluntary, and the only criteria was that they be a hospice staff member directly involved with hospice or family care, Frankenfield says.

"So we worked with managers to figure out how they could spare those individuals from their care for each of those 1.5 hours for six weeks," she says. "That was a major concern for us, and in any hospice setting that would be a concern."

The project has involved three groups and a total of 32 participants, Frankenfield says.

After Frankenfield and colleagues presented the project and its results at the Ohio Hospice & Palliative Care Organization 2005 annual conference, held Nov. 9-11, 2005, they were approached by other hospice staff interested in replicating the program.

"They were very excited and enthused and hopeful about being able to integrate a program such as this," Frankenfield says. "There's a lot of hunger on behalf of staff providing hospice care."

Each participant received a notebook with handouts at the weekly sessions, and each was organized around a theme, Dean-Haidet says.

"There was a glossary of terms and a reference sheet in the back," Dean-Haidet says. "There was a practice journal given to the participants because this program is really predicated on the assumption that practice is involved in being compassionately present."

Each class had an experiential component that participants could practice at home during the week as time allowed, and they would write down their experience in the journal, Dean-Haidet says.

The weekly journal would give participants a question to answer.

For example, one question was, "How did your practice of meditation and participation in this group affect your ability to be present to yourself, patients, and families?"

Among the answers written in journals were these:

"I've become more present when I give baths, like appreciating the sound of water in the basin when I wring the washcloth, the look on the patient's face, their breathing pattern, mine, and I realize how much I receive through the giving," a home health aide wrote.

"I am seeing that I am learning from this class how to quiet myself, center, release tension. I also realize I've been a rabbit jumping quickly into and out of activities for a long time. I was centered before a visit Wednesday. I'm not sure if my presence made a difference to the patient/family, but it kept me from being totally drained during and after the visit," wrote a hospice nurse.

Participants were tested before and after the six sessions on their awareness and spirituality, based on four dimensions, Dean-Haidet says:

- spirituality as an integrating or unifying dimension of need;
- spirituality manifested through meaning and purpose in life;
- awareness of inner resources;
- meaning, strength, and transcendence.

While the data from the journals provided a qualitative way to look at the participants' experiences, the Spiritual Assessment Scale, developed by Judy Howden, provided quantitative data with measures of pre- and post-changes in

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the participants' spirituality, based on how they completed the test, Stout-Shaffer says.

The scale had 28 questions that participants answered, she says.

The pre-training data showed that participants rated themselves fairly high on the spiritual dimensions measured. Then the post-training data showed that they had significant improvements on eight dimensions, Stout-Shaffer explains.

"It was a little surprising that we would see that much difference at the end of a six-week program," Stout-Shaffer notes.

"What the results were telling us was that participation and the ability to go through the exercises and process did create a change at a significant level in quite a few categories on the scale," Stout-Shaffer says. "For people who are interested in this kind of experience, this does suggest a pretty powerful intervention."

It's unclear whether the positive results would apply to a hospice orientation program that included this training, Stout-Shaffer says.

The program has six themes, which are carried out over the six sessions. They are as follows:

- Creating sacred space:

This session could also be called centering and compassionate presence, Dean-Haidet says.

"In this session, we talk about what kind of definitions there are of spirituality," Dean-Haidet says. "We tried each week to create this kind of space where people would feel comfortable discussing their experiences with spirituality in a nonjudgmental way."

Each session had some kind of relaxation experiential where they engaged in stretching, imagery, or breathing exercises, followed by discussion of that week's theme.

Hospice staff already understands compassionate presence, but they may not always be able to manifest it, Dean-Haidet says.

- Compassionate presence, mindfulness, conscious intent:

The advisory board had spent a couple of hours discussing how to define spirituality, finally choosing the term "compassionate presence," Frankenfield says.

"It's one thing for us as individuals to be with patients and families and pay them attention and do good clinical work and be present emotionally," Frankenfield says. "But it takes it to a whole new level when you have an awareness of this person beyond how you see them physically and emotionally."

This session covered mindful meditation, building on the first week's focus on centering meditation, Dean-Haidet says.

"Centering meditation is a way to find an inner reference of calm and peace, using a repetitive kind of anchor," Dean-Haidet says. "Mindfulness, on the other hand, is a kind of meditation where you're open to anything that comes through consciousness with attention to the flow of moment-to-moment experiencing in the present."

- Compassionate presence and inner resources:

"We talked about what are the inner resources of the healer, and this was different for everyone," Dean-Haidet says. "People mentioned many different things, including family, church, nature, prayer, and music was mentioned a lot."

The session included a discussion of what hospice staff needs to do to refuel and renew themselves, and how to expand that repertoire of approaches, including using meditation, Dean-Haidet says.

- Meaning and purpose; service as a spiritual path:

"We talked about the life of a healer and how healing as a profession can be a spiritual path," Dean-Haidet says. "We talked about how they can see meaning occurring in their work."

There were many stories told in this session, and participants discussed questions about values, principles, beliefs that guide one's life and life's work, and how these involve caring for hospice patients, she says.

One story a participant told was how she was taking care of a 13-year-old girl who was dying. When the nurse came to change the IV bag, the nurse just sat there with her because she really didn't know what to do and there were no words she could use to express what she felt, Dean-Haidet recalls.

"The girl took her hand and started singing with her, and in some way it was like the patient was ministering healing to the nurse, so this was very meaningful to the nurse," Dean-Haidet says. "There were dozens of stories like this told throughout the group."

- Transformation and transcendence:

"In this session we talked about times when you were able to go beyond the usual limits of ego and achieve something of integration with a larger reality," Dean-Haidet says. "So

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people had stories about transcending personal trouble.”

The participants discussed their crises and illnesses or those of their family members, she adds.

“We talked about meditation as a way to transcend non-ego consciousness, being able to go beyond separate sense of self to a greater sense of self,” Dean-Haidet says.

- Integrating compassionate presence skills into practice:

The sixth session showed participants how to integrate the skills they had learned into their hospice work.

“We talked about barriers to being present, which sometimes involves just listening or being with someone,” Dean-Haidet says. “We talked about things that might facilitate that, and we talked about the psychosocial spiritual stages of dying.”

The big issue hospice staff faced was their own perception that they didn’t have time to do spiritual care with patients, Frankenfield notes.

“This was a typical reaction on all levels,” she says. “How do you slow yourself down and almost sit with a person in a whole new way.”

While the training is for hospice staff, the benefits could extend to hospice patients and families, Frankenfield and Dean-Haidet say.

“This training is really focused on the staff, and what we’re hoping is that as they learn these things and become more present that this spills over into the family,” Dean-Haidet says. “We would like to eventually study the effects that being involved in a group like this has in patient care.” ■

## Special Report: Improving Diversity in Hospice Care

# Extensive program for increasing minority access to care

*Outreach committees are key to program*

*[Editor’s note: In this issue of Hospice Management Advisor, there is the second part of a two part series about how hospices lack diversity in their staff and patients and what can be done about it. The February, 2006, issue contains a cover story about how hospices still lack diversity in patients and staff. In this issue, there are articles about how the Hospice of Western Reserve in Cleveland, OH, has improved access and diversity and how hospices can do more to connect with minority communities.]*

**B**ased in Cleveland, OH, Hospice of Western Reserve has long recognized the need for its hospice program to represent its community’s diversity in staff and patients.

In 1992, the hospice formed a staff diversity committee that worked with consultants and devised a mission statement and objectives, says **Shareefah Sabur**, MNO, director of planning and evaluation.

“One of our objectives was to review policies and procedures to make sure they were not biased,” Sabur says. “We also came up with educational activities.”

In the last five years, the hospice’s minority admissions have fluctuated in the 20 percent range, while nationally, minority admissions are less than 14 percent, Sabur says.

The hospice serves a five-county area that includes Cleveland, which has a majority minority population, Sabur says.

The adjacent counties are predominantly white, so the overall percentage of minority admissions reflects the hospice's service area, she notes.

However, the diversity program encompasses much more than race, Sabur says.

"We look at religious diversity, and we've made initiatives for the Jewish population," Sabur says.

Also, the Cleveland area has seen a major shift in culture as more individuals have moved to the region from Vietnam, Russia, Croatia, and the Mideast, says **Bridget Montana**, MS, APRN, MBA, chief operating officer.

"We look at how we can impact our practice and create programs to serve different populations," Montana says. "From a human resource perspective, we are hiring staff that represents different diverse populations."

Two areas within the hospice's reach are densely populated with Hispanic families, including people from Mexico and Puerto Rico, Montana notes.

"One organization we work with trains Hispanic individuals as nursing assistants with plans to be trained as nurses," Montana says. "We've hired several nursing assistants and work with them as they work toward their nursing degrees."

All of these nursing assistants are bilingual and work and live in the hospice's western service area, she adds.

The hospice also has incorporated cultural sensitivity into its orientation and staff education, Montana says.

In the last few years, the hospice has used an interpretation service that has interpreters representing 150 languages. These interpreters can be on the telephone with the family and patients while hospice workers are in the home, Montana adds.

"We keep a database with volunteer and staff information about the different languages they speak," Sabur says.

Hospice managers also have met with an African American nursing association and the Greater Cleveland Nursing Association to promote hospice work.

"A lot of people are interested in hospice work through word-by-mouth," Sabur says. "The more minority staff we hire the more we can attract because you have someone who can advocate the organization within those pockets of people."

## NHPCO toolkit lists benefits to increasing cultural proficiency

*Employee satisfaction may be increased*

**T**he National Hospice & Palliative Care Organization (NHPCO) of Alexandria, VA, offers this sample preview of its diversity toolkit, which will be published next year:

Benefits to be gained from increased cultural proficiency:

- Enhanced comfort with care by patients and families and a willingness to discuss and receive services, because care providers either look like them or have an openness to accommodate someone who is different from the provider.
- Increased proficiency by providers to deliver services as they discover a frame of reference and opportunities to explore diverse populations and how those communities wish to receive end-of-life care.
- Improved community relationships and opportunities to form strategic partnerships as the perception by the community evolves from "they" to "us" through collaborative ventures.
- Increased satisfaction by employees and volunteers as they recognize that they work at an organization whose board, governance, and leadership reflect policies embracing multiple cultures and celebrating diversity.
- Enhanced diversity of the workforce, as hospice and palliative care organizations proactively seek to recruit employees and volunteers who more accurately reflect the diversity of their communities.
- Preparing all employees and volunteers to deliver care and services in a manner that fits the needs of each patient and family.

Another strategy the hospice has employed involves the formation of an African American Outreach Committee, whose job is to get more information about hospice into the African American community.

"Our goal was to change and address some of the myths in the community," says **Valerie Ridgeway**, BA, community relations and pub-

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lic policy coordinator with Hospice of Western Reserve.

The outreach committee was formed 3.5 years ago, Ridgeway says.

The committee identified the people who are trusted most within the community, including those in the faith community, physicians, and others and asked them to serve in an advisory capacity, Ridgeway explains.

The committee has 20 people, including representatives from long-term care facilities, a media person, and representatives from various churches, a funeral home, medical facilities, other health care agencies, and the city of Cleveland, she says.

"The idea is for the members to give us inroads into their sphere or domain of influence," Ridgeway says. "So if we have someone who is in the congregation of a large church, we expect them to help us get on the church's agenda."

For example, the hospice was able to speak during a Sunday morning service at one area church because of a committee representative, Ridgeway notes.

Each committee meeting has an educational component with a speaker, and topics have included palliative care, with detailed descrip-

tions of pain management and a discussion of hospice myths, Ridgeway says.

For instance, one myth was that people have to leave their homes to receive hospice care, because people often think of the hospice's residential house, Ridgeway notes.

"I often get an 'Oh-ow,' when I say our residential facility takes care of 42 people a day, but we have 1,000 patients in the community," Ridgeway says.

"I encourage the committee to take on the role of ambassador and go back to their different organizations and present the same information they've learned," she says.

The committee's other work has included distributing hospice fliers to African American church congregations and looking for African American volunteers.

"There's a whole movement of getting information out through the barber shops and hair dressing salons, where people go to talk, and hopefully we can do that this year," Ridgeway says.

"One other thing we do is email the committee a listing of staff openings so they can in turn share these with their organization or group," Ridgeway adds.

A remaining challenge is for the hospice to become more fully integrated in multicultural communities, Montana says.

"We're better educated and have staff on board who have helped with the different communities, but it doesn't always work to go in with education and communication and tell people what to do," Montana says.

"There's a sense in the community that you need to be a part of them and know their churches and schools and who they are as a community."

This philosophy goes back to Hospice of Western Reserve's roots, Montana says.

"We started by creating satellite offices that put us in the community," she says. "It helped us go to the next level."

The key to expansion in multicultural communities is similar.

"You start with someone in that community and connect with them and build a relationship and then work from that relationship," Sabur says. "We continue to push forward because we know there still are other groups we have not been able to reach yet."

Diversity work never ends, Sabur notes.

"Even as we reach more people we still are challenged to keep our staff very sensitive, so that's ongoing training, as well," Sabur says. ■

# Hospices can do more to improve access to diverse communities

*King's death highlights problem*

The controversy surrounding Coretta Scott King's recent death at a Mexican alternative care clinic known for promoting unorthodox cancer treatments obscured a fact that hit home for hospices: the renowned widow of Martin Luther King, Jr., had chosen to attempt a cure for her advanced ovarian cancer in her last days rather than seek hospice care.

Her decision may not be as unusual as it seems, especially among African Americans at the end of life, according to research.

One study of African Americans and their views of hospice care showed that they were oriented toward desiring every treatment that's available and curative care, rather than palliative and hospice care, says **Dona Reese**, PhD, MSW, assistant professor in the school of social work at the University of Arkansas in Fayetteville, AR.

There are many historical and cultural reasons for this attitude, but hospices partly are responsible because they don't work hard enough at becoming culturally competent, Reese notes.

"It's important for hospices to change themselves to have services that are culturally appropriate," Reese says.

"There are practice models available that will help hospices become culturally competent and which will help them reach out to diverse communities," Reese says. "But hospices have not generally implemented these models."

Reese conducted a study last fall to find out what barriers existed within hospices, preventing them from providing culturally competent services.

She found that the problems chiefly are due to these five factors:

1. There's no funding for the staff to provide community outreach.
2. There are too few applications to hospice from diverse professionals. According to NHPCO statistics, the percentage of physicians who are minorities in the U.S. is 7 percent, while the percentage of nurses who are minorities is 3 percent.
3. Hospices provide no funding for development of culturally competent services.

4. Hospice staff lack knowledge about diverse cultures, and this can lead to stereotyping.

5. Some staff are not aware of what cultural groups in their community are not being served.

"Right now, I'm working on a project on how to address those five major barriers," Greene says.

The National Hospice & Palliative Care Organization (NHPCO) of Alexandria, VA, has made it a priority to improve access to hospice care among minorities, says Fay A. Burrs, RN, BSN, director of access and diversity.

NHPCO assembled a task force on improving hospice access to care among minorities nearly 20 years ago, Burrs says.

The organization has addressed the issue at annual conferences and at town hall meetings since the early 1990s, she adds.

"In 2004, the strategic plan of NHPCO made access and quality the two major arms by which it would address the issue of hospice care in America, because the two are intricately connected," Burrs says. "You cannot have true access to care without it being quality care, and if you have quality care, but some people don't have access, it's still missing components."

One result of NHPCO's work is a diversity toolkit, which will be published within the next year. (See chart on examples of outreach, p. 29.)

NHPCO addresses the benefits that can be gained from increased cultural proficiency in the toolkit, as well as ideas to consider when recruiting a diverse workforce. (see chart on benefits of improving access to diverse communities, p. 32.)

Access issues exist for Hispanic, Asian, and other communities, as well. In some states, such as Minnesota, state hospice organizations have taken the lead in improving access for minority communities. In others, like California, dedicated individuals and hospice organizations have been the leaders.

Despite California's diverse Asian communities, there have remained barriers to hospice care among Chinese Americans and other Asian Americans, says **Sandy Chen Stokes**, RN, PHN, MSN, a public health nurse and a consultant in end-of-life care, who lives in Shingle Springs, CA. Stokes works with the California Coalition for Compassionate Care and has spearheaded efforts to form the Chinese End-of-Life Coalition based in Sacramento, CA.

While the younger generation of Asian Americans is comfortable with the concept of hospice, it remains a new idea to older Asian

## Here are some examples of how to reach minority communities

### *NHPCO offers these tips*

The National Hospice & Palliative Care Organization (NHPCO) of Alexandria, VA, offers these strategies for improving outreach in minority communities, which are included in a sample preview of NHPCO's diversity toolkit, which will be published next year:

Some examples of where assets can be found:

- Clergy and faith communities;
- Faith communities may represent excellent sources of talents, gifts, and skills;
- Knowledgeable community, political, or civic leaders; grassroots activists;
- Local merchants and community stores;
- Beauty and barber shops, pharmacists, Librarians;
- Recreation facilities, such as YMCA/YWCA;
- Community-based organizations;
- Sororities and fraternities;
- Rotary and other civic organizations; senior centers;
- Health and human services providers, governmental agencies;
- Specialist physician groups (e.g., cardiology practice);
- Professional organizations and associations that are active in the community;
- Media and communications, such as newspapers and radio;
- Funding sources, schools, and academic institutions;
- Partnerships or consortiums, hospice and home care data, and organizations.

Americans, who never saw anything like it when they were growing up overseas, Stokes says.

Older Chinese Americans may believe that talking about cancer could make a patient's condition worse and hasten their death, Stokes says.

"We have a high percentage of patients who sign-up with hospice, but unfortunately they don't know what they've signed up for," Stokes says. "They might not know they have cancer and are dying because the family keeps it from them."

Many Asian Americans believe that if they don't tell their loved one about the diagnosis then the person will suffer less, Stokes adds.

The key is to educate health care professionals and the Asian community about hospice care, and that is part of the mission of the coalitions, Stokes says.

"We'd like to increase education for the Chinese community through media outreach," she says. "With one-on-one education, people may not want to talk about it, but if we provide the information through the newspaper, radio, or television, then it's not talking with them specifically, so it's okay."

The Chinese coalition's three major goals are as follows:

1. Advertising in the Chinese community: While Stokes worked as a consultant for the California Coalition, she initiated the translation of end-of-life articles into Chinese and worked with the local media to reach Chinese doctors and family caregivers to discuss end-of-life care.

2. Educating providers: Stokes has spoken before groups of doctors about end-of-life care in the Chinese community, and she has attended committee meetings and held presentations on the topic.

3. Training Chinese volunteers: The American Cancer Society started a Chinese unit for home visits. "We go to a Chinese person's home and visit," Stokes says. "We accompany them and support the family, as well."

Hospice Minnesota formed the Opening Doors Project to provide multicultural resources and to bring interested hospices together for brainstorming and educational sessions, says **Barbara Greene**, MPH, multicultural and diversity consultant with Custom Health Consultants of St. Paul, MN. Greene has worked with Hospice Minnesota as program director for the Opening Doors Project.

"For the last three years, we've done quite a bit of training in terms of seminars, workshops, and portions of state-wide conferences," Greene says.

Some resources and materials promoting diversity are available at the organization's Web site: [www.hospicemn.org](http://www.hospicemn.org).

For instance, since one of Minnesota's multicultural populations is the Hmong community, there is a two-page pamphlet on communicating and understanding Hmong patients.

The pamphlet lists some basic Hmong words and their pronunciation, as well as some communication suggestions for health care workers. One

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example is the suggestion to “Ask who the decision maker or spokesperson is for the family. Identify the best way to reach this individual, if an interpreter is needed, or if the family has other important communication needs.”

Another suggestion is: “Referring to oncoming death is not well received. Preferred communications include, ‘To help your mother feel better’ or ‘To make your father more comfortable.’ Referring to oncoming death is perceived as inviting the death of a loved one.” ■

## Loss of vision does not mean loss of independence

*Medical care, adaptive aides can help*

**H**ome health nurses see it all of the time—patients don’t want to lose their independence so they don’t tell anyone if they experience changes in their mobility, memory or vision. If your patient has problems with vision, there are things that can be done to help him or her maintain independence and handle the vision loss safely.

“Admitting that you are losing your vision has

a tremendous impact psychologically on any person,” points out **Priscilla Rogers**, PhD, a vision rehabilitation consultant in Mooresburg, TN. “There are techniques and adaptive equipment that allow a person with vision loss to continue living independently,” she says.

There are several different types of vision loss and it is important to diagnose the correct reason for the loss to best identify the assistance your patient needs, says Rogers. “No one should assume that a patient’s loss of vision means that they can’t do anything for themselves,” she adds.

The first step in helping a home health patient with vision loss is to identify the problem, even if the patient won’t admit it. “Look for changes in the patient’s behavior,” suggests **Alberta L. Orr**, MSW, program manager of the National Aging Program of the American Foundation for the Blind in New York. “If the person stops doing his or her favorite activity, such as knitting, watching television, reading, or playing cards, it might be due to trouble seeing well enough to do these things,” she says.

Orr and Rogers suggest a vision component for all initial patient assessments any time that a nurse believes there may be a change in a patient’s vision. “Once the type of loss is identified, the patient should be referred to a physician for evaluation and treatment, and environmental changes or adaptive equipment can be used to help the patient manage their daily lives,” says Orr.

The most common types of vision loss in older people are central field loss, which is found in patients with macular degeneration; peripheral field loss, which is found in patients with glaucoma and hemianopia, a condition that is caused by a stroke; and overall blurring, which is caused by cataracts and diabetic retinopathy.

Once the problem has been identified, there are a number of techniques to help patients, says Rogers. “There are therapists who specialize in vision rehabilitation and they can provide a wealth of information to patients and their families,” she says. There is also federal funding for vision rehabilitation as part of Title VII, Chapter 2 of the Rehabilitation Act, often referred to as the “Older Blind Program,” that provides training to older people with vision loss, she points out. Each state agency that is responsible for the aging has information about the program, she adds.

### ***Environmental changes help***

There are also simple things that a home health nurse can teach patients and their families to help maintain independence, points out Orr. “Increase

lighting in the home by adding lamps throughout the house," she suggests. "We need four times more light as we age than we do in our 20s and, at age 85, we need 10 times more light to see at the same level as we did when we were younger," she says.

Better lighting doesn't mean only increasing the wattage of light bulbs. "Light that comes from different sources, such as an overhead, a floor lamp, and a table lamp, that provides light directly on the area in which I'm working or reading is more effective," says Orr. "Incandescent light is best, and using light bulbs that are described as 'daylight' are good since natural light is best," she says. Use the highest wattage that is recommended by the lamp manufacturer but don't exceed the recommendation, she warns. "Fluorescent lights are problematic because they do flicker, and halogen lights get hot so I don't recommend them," she adds.

In addition to improving light in the home, look for ways to provide contrast to better distinguish everyday items. "If the patient has trouble identifying items on a dinner table, use a dark plate on a light background so it is easy to find the plate, and use contrasting towels and bath mats in the bathroom to easily distinguish the sink and toilet," she says.

Cooking is a major safety concern for older patients with vision loss but there are ways to handle this activity as well, says Rogers. "Larger or contrasting markings for the on and off positions on the stove can be used. Patients can be taught to keep pot handles turned inward, measuring cups can be more clearly marked, a tomato slicer that is just pushed down on the tomato can be used in place of a knife, and pouring devices that signal when a cup is full can be used," she says.

Because a patient is embarrassed or frightened to admit vision loss, approach the issue carefully, suggests Orr. "Ask non-threatening questions and be specific," she says. "I notice that you have difficulty reading that paper" or similar questions can lead to a discussion, she explains. "Nurses need to trust their observations and their judgment because many patients won't admit a problem, even when it is obvious," she says.

Nurses can also bring an item that might adapt the patient's home and say, "Some of my other patients find it helpful when I mark their measuring cups for them," or a similar statement, says Orr. Organizing cabinets or drawers, labeling them with large print, changing a tablecloth, or replacing light bulbs might be a simple first step to get a patient to talk about vision difficulties, she adds.

While ophthalmologists can diagnose and treat the medical conditions that cause vision loss, it is

often up to the family and home health provider to find ways to help the patient retain as much independence as possible in the home, points out Rogers. "When a doctor says that he or she has done all that's possible, patients don't realize that there are things that can be done beyond medical treatment to help them make the most of their remaining vision. That's why home health nurses' observations and assessments are so important." ■

## Caregivers benefit from education and support

*Sessions with hospice nurses improve coping skills*

For many patients dying of cancer, home is where they want to spend the last weeks of their lives. Their caregivers—often spouses, life partners or children—may be willing to give whatever care their loved one needs, but can find themselves overwhelmed, unsure, and at risk for depression and other health problems themselves.

"In today's health care system, patients simply don't have the option of being hospitalized for long periods, including at the end of life. And most patients tell you they want to be able to die comfortably at home in their own beds," says **Susan McMillan**, PhD, RN, FAAN, a professor at University of South Florida College of Nursing. "But that can only happen if we adequately prepare family members to provide extensive care for their loved ones at home."

McMillan recently completed a study in which caregivers were given supportive educational intervention by veteran hospice nurses in an effort to measure what effect that would have on the caregivers.

McMillan says people taking care of dying cancer patients at home significantly benefited from the interventions, in which they were taught how to cope with distressing patient symptoms. She knew of the COPE (creativity, optimism, planning, and expert information) model developed by Peter Houts, PhD, described in "The American College of Physicians Home Care Guide for Cancer," and was sure it could be modified to benefit those caring for terminal cancer patients at home. The COPE approach, on which McMillan based her project, includes clearly defining a problem, gathering expert information

about it, brainstorming a range of solutions, devising a plan, anticipating potential obstacles, adjusting the plan accordingly, implementing the plan, and evaluating the results.

COPE was provided to family caregivers of hospice patients with cancer over a seven- to nine-day period, and outcomes were compared with hospice care alone and hospice care plus emotional support.

### ***More become caregivers every year***

At any one time, as many as 52 million Americans assist family members with an illness or disability, including many who provide extensive care for relatives with cancer. That figure is expected to grow as the population ages.

Previous studies have shown highly stressed family caregivers are at higher risk for depression, health problems, and increased death rates.

"There has been little prior data to describe which caregivers are at greatest risk for distress and which interventions are likely to relieve that distress," according to McMillan. "We found that caregivers benefited from even a small number of sessions with the interventionists, above and beyond the benefits gained from hospice care alone."

Family caregivers are central to end-of-life care because they offer emotional support, help with activities of daily living and medications, and communicate with the patient's health care team about his or her condition. Yet, caregivers—many of whom are elderly spouses with their own health problems—may experience significant strain and anxiety from taking care of seriously ill patients, McMillan says.

With cancer patients, there are some symptoms that are nearly universal, and so three of those—pain, dyspnea, and constipation—were selected as the symptoms that caregivers would receive support for. Hospice nurses visited caregivers and patients three times, and during the visits focused on identifying, accepting, and managing the sometimes distressing symptoms.

"The nurses worked with the caregivers during those visits on managing the symptoms using the patient as the model," says McMillan.

Another component to the study was a set series of visits in which the nurse did not address symptom management, but talked at length with the care-

giver about his or her relationship with the patient.

"The 'friendly visit' was designed for the nurse to spend time with the caregiver and to talk about specific topics that we gave the intervener to use, such as 'How did you meet [the patient]?' or 'How long have you known the person?' It's more focused on being supportive of the caregiver, not on managing the patient's symptoms."

McMillan says the results of her study indicate that the addition of COPE intervention for the caregiver was crucial for the caregiver. Researchers compared the group of patients and caregivers who were receiving standard hospice care alone with those who were receiving hospice care along with supportive visits for the caregivers.

With intervention, McMillan says, the caregiver's quality of life increased, while the burdens from caregiving and caregiver distress were significantly reduced.

"Their distress at the patients' symptoms lessened with intervention," she says. "Part of it has to do with the ability to accept and manage the symptoms and the feeling of self-efficacy. They felt more in control, better able to manage the symptoms and accept, and not be so distressed about [the symptoms]."

While at first she was disappointed to see that the intensity of patients' symptoms did not decrease with educational intervention for their caregivers, McMillan was pleased to note that there was a decrease in patients' distress about their symptoms.

"Initially it distressed me that their symptoms did not decrease in intensity, but then these are cancer patients within days or weeks of death, so it is to be expected that their symptoms would not decrease in intensity," she points out.

McMillan says the findings of the hospice intervention study are "immediately translatable" to the bedside of end-of-life hospice patients, regardless of what they are dying of.

"Usually, when you talk about studies of intervention, you need additional research and confirmation, but this is something that can only help," McMillan explains. "There's no hazard to it, and no need to not use it immediately in other patients."

Patients with end-stage heart disease, chronic obstructive pulmonary disease or dementia are populations for which hospice support and education intervention should be expanded, McMillan

## ***COMING IN FUTURE MONTHS***

■ Build a professional education toolkit

■ Improve access and outcomes for CHF patients

■ Follow these strategies to improve quality

and her colleagues recommend. Their findings on benefits to caregivers appeared on-line Dec. 2, 2005, in *Cancer*, the journal of the American Cancer Society, and in the January 2006 print issue.

### ***Creative approach to HIPAA concerns***

In designing her study, McMillan avoided potential ethical and privacy issues by teaming with the hospice and hiring its staff, making them employees of the study.

“When you come from the university in to the hospice, where you don’t belong, it can be iffy whether you can get a sample or not,” she explains. “We overcame that by hiring the staff, reimbursing the hospice for the staff we used. Only hospice staff participated [in the interventions and sample gathering].”

The nurses retained their positions with the hospice for purposes of raises and promotions. The precaution of making the hospice nurses employees of the study provided reassurance to the hospice that only hospice nurses would be gathering data, thereby reassuring the hospice that researchers would not interfere with patients; it also ensured that patients could expect that the nurses calling on them would be the hospice nurses they were used to. ■

### ***Resources***

- McMillan S, Small B, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer*. On-line, December 2005, at [www.cancer.org](http://www.cancer.org).
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