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Combined palliative care and medical care in hospice's future?

'Hospices are as close or as far as they want to be'

For the past 20 years, hospices have operated under the Hospice Medicare Benefit model — people get sick and exhaust their curative options, and a hospice is there waiting to take care of them. Hospices, like other health care providers, are situated on a continuum that patients move along as they navigate the health care system.

So much for the present. The future of hospice is shaping up to be quite different from a static point on a line that patients travel while moving from one provider type to the next. Instead, hospices may well be the agent moving along the continuum to meet patients where palliative care services are needed.

The latest development in the movement to provide combined palliative and curative care is a report issued by Promoting Excellence, a national program office of the Princeton, NJ-based Robert Wood Johnson Foundation. Promoting Excellence researchers did a study tracking the financial performance of hospice programs that have been offering concurrent care on a limited basis. They learned that those who finance health care, such as Medicare, could reap savings in reduced emergency room visits, hospital length of stay, and overall patient cost by adding palliative care to the treatment plan of patients diagnosed with potentially fatal diseases.

Concurrent care consumes fewer resources

"Our goal is to improve access to hospice and to provide quality care, but in the process of looking at concurrent care we tracked utilization of resources and we are noticing that [hospice programs that provide concurrent care] are consuming fewer resources," says **Ira Byock, MD**, director of Promoting Excellence and director of The Palliative Care Service in Missoula, MT.

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Promoting Excellence, which has provided \$15 million in grants and technical support to innovative programs that promote improved care for the dying, conducted a study in 2002 at seven sites to measure the financial implications of combining palliative care with medical intervention. Following are summaries of what the researchers discovered at three of the sites:

Lower hospitalization costs

- **The Hospice of Michigan and the University of Michigan Comprehensive Cancer Center.**

This Detroit-based program, which provides hospice care to patients who receive cancer treatment, recorded fewer emergency room visits and lower hospitalization costs than other programs. Compared with patients receiving only cancer treatments, patients receiving both palliative care and cancer therapy had fewer emergency room visits per patient (0.8 vs. 1.07), fewer hospital

admissions per patient (1.65 vs. 1.83), and shorter hospital stays per patient (7.7 vs. 9.9 days).

Average hospitalization costs for patients receiving only cancer care were \$13,126 per patient, compared with \$8,974 for those receiving both cancer care and hospice care. Average total costs for patients receiving only cancer treatments were \$19,790 per patient, compared with \$12,682 for those receiving both forms of care.

- **The Kaiser Hospice and Home Health.**

This Downey, CA, hospice program provides hospice care along with curative and restorative care to patients with congestive heart failure, respiratory disease, and cancer. Most patients have as much as a year to live. A team of physicians, social workers, nurses, and aides makes home visits to patients, develops treatment goals, and provides care. In addition, the team provides respite care and emotional and social support to the family. The goal of the program is to prevent unnecessary hospitalizations and to allow patients to die at home, if possible.

Patients reported higher satisfaction

Based on a two-year comparative study involving 300 patients who died, patients who were in the program reported higher satisfaction with the care they received compared to a control group. More than 87% of the program patients died at home, compared with less than 57% of the control group patients. The average daily cost for a patient in the palliative care program was \$62, compared with \$133 for a patient receiving usual care. Total per-patient costs for those in the program were 45% lower than for those receiving usual care (\$7,990 vs. \$14,570).

- **The Lillian and Benjamin Hertzberg Palliative Care Institute at Mt. Sinai Medical Center.**

By allowing palliative care nurses and physicians to consult with hospital providers, this program netted more \$750,000 in hospital length of stay savings.

The New York City-based program provides a team of nurses and physicians that advise hospital providers on pain management and consult with family members regarding decisions concerning life-sustaining care. Aside from showing symptom improvement among patients experiencing pain, nausea, and breathing problems, cost savings from palliative care were \$757,555 for those patients who stayed more than 14 days

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Editor: **Eric Resultan**, (770) 329-9684, (eric_resultan@msn.com).

Vice President/Group Publisher: **Donald R. Johnston**, (404) 262-5439, (don.johnston@ahcpub.com).

Editorial Group Head: **Glen Harris**, (404) 262-5461, (glen.harris@ahcpub.com).

Managing Editor: **Robin Mason**, (404) 262-5517, (robin.mason@ahcpub.com).

Production Editor: **Brent Winter**.

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Editorial Questions

For questions or comments, call **Glen Harris** at (404) 262-5461.

in the hospital and \$455,936 for those who stayed more than 28 days.

“Preliminary study findings as cautiously interpreted suggest that earlier introduction of hospice care improves quality of life and caregiver burden and potentially reduces cost,” says **John Finn**, MD, medical director for the Hospice of Michigan (HOM) and lead author of an upcoming paper that discusses HOM’s three-year research project.

While Finn is optimistic about the financial benefit that may be attached to concurrent care, he says larger demonstration projects would be necessary to definitively declare that concurrent care was cost-effective.

“If these demonstration projects show improved access, reduced caregiver burden, and reduced cost, then we would have hit a home run,” Finn adds.

Byock echoed Finn’s call for demonstration projects and urged the hospice industry to take the lead in designing and developing demonstrations, rather than placing the blame on the Centers for Medicare & Medicaid Services, federal lawmakers, and private insurers for standing in the way of progress. Hospices are in a position to prove the value of combined medical treatment and palliative care to payers.

“Hospices are as close to or as far from making [concurrent care] a reality as they want to be,” Byock says.

‘The revenue streams will come’

Are the road signs signaling a new direction for hospices? Byock, a 16-year provider of hospice care and a well-regarded hospice expert, seems to think so. More importantly, he says individual hospices should start adopting changes to their business model so that they can begin to offer concurrent care even in the absence of reimbursement.

“I truly believe the revenue streams will come,” he says.

The idea of combining palliative care and curative care has been pushed for years by the hospice industry. Advocates have argued that payers should find a way to finance hospices’ foray into providing care alongside physicians trying to fend off life-threatening illnesses. Their efforts have had limited success.

Byock, however, suggests a new approach: entrepreneurship. Like companies looking to expand their customer base, hospices should

approach concurrent care as a product they are trying to promote to consumers.

If hospices expect the combination of palliative care and medical intervention to change the way the health care industry cares for the dying, it would be reasonable to expect hospice itself to change, as well. The current hospice business model will have to change in order to adjust to the “new patient.”

“If they don’t do it, someone else will,” says Byock. “Hospitals, nursing homes, residential care facilities, even the Marriott Corporation will provide these services. Hospices need to be bold and courageous, just like in the early ‘80s.”

To borrow a business phrase, hospices need to be “first to market” if the industry intends to remain a leader in the provision of palliative care. This requires hospice to take on some risk by providing concurrent care to payers who are willing to study its benefits. It likely means hospices will have to provide concurrent care absent any reimbursement.

Patients don’t want to forgo curative care

Still, Byock says it’s sound business and good health care. Hospices, he says, would be responding to consumer demands. Specifically, he says patients have said that while they believe hospice care is valuable, the reason most of them elected hospice in the latter stages of their illness was because they didn’t want to give up the care they were already receiving.

In the end, a bold hospice industry would be speeding up the shift in consumer demand. Once consumers begin to expect concurrent care, payers will find a way to finance the growing demand. “Any shift creates winners and losers,” Byock says.

How the shift in practice will shape up is anyone’s guess. But hospices will certainly have to implement a number of programmatic and cultural changes to implement a system that bridges medical intervention with hospice care.

“It will be a dramatic change for hospices,” Finn says.

At Hospice of Michigan, Finn observed cultural hurdles that both hospice staff and non-hospice personnel had to overcome. For example, treating physicians were wary of hospice staff. There was a fear that hospice workers would try to convince patients to give up treatment.

“To address this and related issues, meetings were initiated early on by the project director and

investigators, the hospice medical director, and billing departments within the participating institutions and offices," Finn wrote. "We assured the oncologists that the project would not impact their ability to provide care and receive compensation for their services."

Finn and researchers encountered challenges in integrating oncology treatment and hospice care among participating different professional cultures, including a comprehensive cancer center, hospital-based cancer centers, and private oncology offices.

"Despite our efforts in the project to create a seamless transition from standard medical care to palliative care, the two models do not meld easily," Finn wrote.

The culture clashes led to patients receiving conflicting messages. For instance, a cancer patient may have been encouraged by an oncology clinic nurse to eat more to keep up her strength. The hospice nurse, on the other hand, told family to accept waning appetite as part of the natural disease process.

Palliative care coordinators bridge the gap

To prevent conflicting messages and miscommunication, HOM assigned a hospice worker to the position of palliative care coordinator, whose role was to bring the two perspectives together. The responsibility to provide education and promote understanding of the dueling perspectives went both ways, meaning the palliative care coordinator directed his or her efforts to colleagues as well as to non-hospice workers. For example, hospice staff were taught how differentiate treatment toxicities from the natural progression of disease.

Palliative care coordinators were given further training in the discipline of oncology, which was later conveyed to the hospice staff. According to Finn, the training proved to be invaluable. In fact, there were several documented episodes of hospice field staff circumventing visits to the emergency room after identifying and reporting early symptoms to attending physicians.

On the non-hospice side, the palliative care coordinator gave suggestions to clinic or office staff on how to discuss palliative matters more tactfully and realistically than might have been customary practice.

"Over time, the participating oncologists became more accepting of, and even came to prefer, this type of comprehensive palliative care to conventional oncology care," Finn wrote. ■

Concurrent care makes good business sense

Facilitating provision of full hospice care

Twenty years ago, hospices broke into the Medicare market with the Hospice Medicare benefit, a bold move by many hospices to elect a per diem payment for care of a patient whose cost of care could exceed the total of per diem payments.

Some 15 years later, payers suggested something similar to physicians. They called it capitation, but most doctors found the risk too much to stomach. Hospices in the early 1980s were pioneers in taking on risk, a fact that often is overlooked these days.

Nevertheless, the industry's foray into risk transformed the hospice industry from a collection of small volunteer organizations to a sector that takes in nearly \$4 billion annually from Medicare. Once again, however, hospice must consider another risky proposition.

For years, hospices have been saying they needed earlier access to patients with terminal illness to provide the full benefit of hospice care and to succeed financially. Experts suggested modifying the terminal illness certification to allow earlier referrals and perhaps revamping how hospices are reimbursed.

Combine hospice care with curative efforts

While these may be things that should be done, hospices should consider taking the same kind of bold steps they took 20 years ago to advance the practice of combining hospice care with curative efforts.

Why, you may ask? Because it makes good business sense, and it improves the quality of care at the end of life, says **Ira Byock**, MD, director of Promoting Excellence, a national program office of The Robert Wood Johnson Foundation, and director of The Palliative Care Service in Missoula, MT.

Surveys and anecdotal research have shown that patients and their families generally agree with the principle of hospice care, but they shunned hospice until it was too late to reap the full benefit of hospice care because they didn't want to give up the care they were already receiving.

If hospices were to take this customer information to heart, they would realize that many potential hospice patients are lost because hospices were unable to offer a product that suits the customer.

“Hospice needs to expand its service products,” says Byock.

What he means is that if consumers are asking end-of-life care providers — which means hospices or any other organizations providing that care — to provide palliative care sooner in the disease process without requiring patients to give up the care they are already receiving, then hospices must find a way to offer that product.

“We need to ask ourselves if we are going to provide these services,” Byock adds. “If we don’t do it, someone else will.”

Finding a partner

Under today’s current reimbursement rules and regulations, hospices cannot be reimbursed for care that falls outside the terminal illness certification. Larger hospices that have the resources to underwrite the cost of care that is not reimbursed may be able to offer palliative care services to patients who have yet to qualify for the benefit.

This requires finding a partner in the community — which is easier said than done. Most hospitals and physicians don’t want to be bothered with proposals to partner with a hospice. Byock advises going further up the health care food chain to insurers or any other organizations that bear the financial risk of underwriting the cost of health care. Among the list of potential partners are:

- the dominant private insurer within a market or region;
- a safety net health system, such as a rural health system;
- globally budgeted health systems.

A 2002 report issued by Promoting Excellence cited a project involving the Department of Veteran’s Affairs (VA), which operates a safety net system that provides health care to veterans of all military branches.

The VA Greater Los Angeles Health Care System implemented a palliative care model with disease-condition-specific elements for poor-prognosis veterans with lung cancer, congestive heart failure, and chronic obstructive pulmonary disease. The program centered around a nurse

case manager who educated enrolled patients and families regarding decision-making and symptom self-management, provided continuity and coordination of care, and served as the hub of an interdisciplinary palliative care team that helped manage patients’ psychosocial and spiritual needs.

The program introduced palliative care soon after diagnosis, worked closely with hospices and other home-based services, and eased the transition into hospice care. In the final month of their lives, Pathways of Caring patients had total health care costs of \$10,248, compared with \$18,853 for a retrospectively matched control group, with most of the savings resulting from reduced hospital costs.

Assuming that evidence of improved access, improved quality of care, and greater financial efficiency is borne out in similar studies conducted by entrepreneurial hospices, hospices that implement this model of care would not only have satisfied patients’ request for combined hospice and medical care, but payers’ demand for the same.

Don’t forget anti-kickback laws

In all the excitement to bring a promising hospice model to market, hospices must remember that unless Medicare relaxes the rules as part of a demonstration project, any partnership must follow Medicare’s rules and regulations. If a hospice has an agreement with another health care provider, such as a physician group, to provide palliative care to non-hospice patients, it must navigate anti-kickback laws.

An Office of Inspector General (OIG) advisory to a Florida hospice in 1999 offers some guidance in this area. In the advisory, which applies specifically to the hospice that sought OIG’s guidance, the OIG said the hospice could provide free services as long as it was not doing so in exchange for future referrals and as long as it made the distinction between the free services it provided to its non-hospice patients and the core services it provided to hospice patients, such as labeling the free services as a community service that is nonexclusive to the physician practice.

Based on the 1999 OIG advisory, palliative care-related services a hospice could provide without reimbursement to non-hospice patients include:

- friendship and visitation;
- transportation;

- assistance with writing and reading correspondence;
- running errands;
- food preparation;
- respite care for the family or caregiver.

The other option is to devise a demonstration program that sets aside pesky rules and regulations in order to investigate promising ways to deliver publicly funded health care. ■

Hospice Trends

‘Simultaneous care’ may be in hospice’s future

Don't force patients to make the terrible choice

By **Larry Beresford**

A report issued late last year by the Robert Wood Johnson Foundation’s Promoting Excellence national program office in Missoula, MT, highlights some provocative new directions for end-of-life care policy and financing. Drawn from the experience of palliative care demonstration projects funded by Promoting Excellence between 1998 and 2001, the report suggests that improving quality and access to appropriate end-of-life care can also generate cost efficiencies for the health care system. One of its most provocative themes is a concept called simultaneous care.

This concept has huge implications for the future of hospice. Simultaneous care means offering seriously ill patients the compassionate support of hospice or palliative care while they are still pursuing “aggressive” curative, disease-modifying, or even experimental treatments. The simultaneous approach can address patients’ needs for support, symptom management, and whole-person care while acquainting them with the palliative care team and its philosophy. That relationship has the potential for easing the patient’s eventual transition from active treatment to a strictly comfort-oriented approach such as hospice when that becomes appropriate.

The concept of simultaneous care increasingly turns up in the palliative medicine literature and

in public statements by end-of-life leaders such as Promoting Excellence director Ira Byock, MD; Diane Meier, MD, of the Center to Advance Palliative Care (CAPC) in New York City; and even Donald Schumacher, the new president of the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA. This concept holds the potential to dramatically alter some of hospice professionals’ most basic and cherished assumptions about the demarcation between cure and care.

But it does not alter what is perhaps the cornerstone of the hospice movement: restoring patient autonomy — meeting the seriously ill patient where he or she is and addressing care needs as defined by the patient.

Medicare’s current hospice regulatory structure poses barriers to the provision of simultaneous care by hospices, because only clinically appropriate, terminally ill patients should be enrolled on the benefit. However, some hospice agencies have gotten around those barriers by developing corporately segregated palliative care programs.

An even greater barrier is the ingrained hospice belief that seriously ill patients must “give up” curative treatments before they can qualify for the psychosocial/spiritual support and relief of suffering that are hospice’s stock in trade.

Hospices prevented from sharing expertise

This divide is known as the “terrible choice” and is one of the primary reasons why stays in hospice care have gotten so short in recent years — as well as why new models of non-hospice palliative care are springing up in hospitals from coast to coast. The terrible choice prevents many seriously ill patients with significant palliative care needs from taking advantage of hospice because they are not willing to give up the pursuit of a cure.

But that also prevents hospices from sharing their expertise in symptom management, whole-person care, anticipatory grief support, life-transition management, and counseling with patients who truly need these services from the moment of diagnosis of a life-limiting illness.

In the view of simultaneous care advocates, it is neither realistic nor fair to expect patients and families confronting a life-limiting illness to do all of the hard work of giving up aggressive treatments before they can take advantage of the support of hospice — not when the best resources for

helping them work through those issues are on the hospice team itself.

The Promoting Excellence report, *Financial Implications of Promoting Excellence in End-of-Life Care* (available at www.promotingexcellence.org) profiles seven demonstration project grantees that attempted to provide simultaneous aggressive and palliative care for specific patient populations including cancer patients, children, people with AIDS, veterans, and enrollees on a Blue Cross case management program. (I was primary author and site visit researcher for this report, although it mainly reflects the vision of Byock and his staff at Promoting Excellence.)

Saving money by averting crises

While cost data from these innovative, leanly funded projects are sketchy, they nevertheless are suggestive in terms of the potential for palliative care to generate cost savings by preventing or managing medical crises and thereby forestalling emergency room visits and hospitalizations.

“They achieved these results by coordinating care and facilitating communication between patients, families, and providers; by enhancing patients’ autonomy and sense of personal control; and by assisting patients with advanced care planning and treatment decision-making that reflected their personal values and preferences,” the report states.

In other words, the simultaneous care demonstrations offered the best of hospice care to patients who had longer to live than the typical hospice patient and weren’t ready to give up active treatment. “Comprehensive hospice care at its best is the gold standard for end-of-life care in America and it also provided a benchmark for the Promoting Excellence projects,” the report notes.

In several instances, hospice agencies were actively involved as partners in the Promoting Excellence projects’ provision of simultaneous care. However, their experience also demonstrated that under the current reimbursement system, financing hospice care at the same time as active treatment is difficult. Ultimately, changes

in the funding of hospice care may be needed to institutionalize the simultaneous approach.

The best way for hospice professionals to begin to understand what simultaneous care means for the practice of hospice is to go back to the profession’s historical focus on the patient and on “what is in the best interest of the patient — as defined by the patient,” Meier observes. “We may disagree with some of the decisions these patients make, but whose life is it? Very few patients want to give up on active treatment. Both doctors and patients, understandably, want appropriate life-prolongation. We shoot ourselves in the foot by insisting on the forced choice,” she says.

It is also important to recognize that semantics can cloud understanding the implications of simultaneous care. Hospice care is palliative care, the most intensive and specialized form of palliative care, although other palliative care models

are now attempting, with varying degrees of success, to move “upstream” and offer similar kinds of support for seriously ill patients from the point of diagnosis.

There is also the distinction between hospice agencies and their primary income stream, which is the Medicare hospice benefit. Increasingly, hospices themselves are providing

palliative radiation, chemotherapy, and other intensive treatments when those are desired by the hospice patient or the treating physician and when such treatments have the potential to enhance comfort. At times, calling the treatment palliative may just be a euphemism or a form of psychological palliation for patients who aren’t quite ready to let go.

Palliative care can support search for a cure

Simultaneous care, on the other hand, explicitly acknowledges that the seriously ill patient is still fighting for a cure. For such patients, the support of palliative care can help them explore their treatment goals and preferences in a non-judgmental atmosphere while having their symptoms and side effects managed by experts — without requiring them to give up treatment before they can be considered for such support. In the case of

“We may disagree with some of the decisions these patients make, but whose life is it? Both doctors and patients, understandably, want appropriate life-prolongation. We shoot ourselves in the foot by insisting on the forced choice.”

treatments that are no longer offering much benefit, palliative counseling might make it easier for the patient to reach the inevitable conclusion sooner to let go and focus instead on comfort and goodbyes.

For one of the Promoting Excellence demonstration projects based at the Ireland Cancer Center in Cleveland, the results of simultaneous care were dramatic. Project Safe Conduct brought a team from Hospice of the Western Reserve into Ireland Cancer Center to provide integrated, concurrent support to advanced lung cancer patients who were still receiving treatments at the center. The proportion of patients who ended up on the hospice benefit increased under this project from 13% to 80%, while their median length of hospice stay increased from just three to 30 days, compared with the center's lung cancer patients prior to Project Safe Conduct.

Even the NHPCO, long-standing defender of the Medicare Hospice Benefit, is exploring how simultaneous care models might be integrated into the field. Hospice has clearly influenced the overall culture of dying in America during its three-decade history, Schumacher observes. "But you can't legislate psychology, and the human tendency is to hold onto chemotherapy until you're truly ready to let go," with the result that most patients choose hospice too late.

Demonstrations and other opportunities

"If we can offer these patients the opportunity to have a reasonable and purposeful discussion of what the therapies mean to them, I believe that patients eventually will choose hospice sooner in the disease progression," giving up aggressive treatments that aren't helping them.

In the current regulatory environment, Schumacher says, "I think you need to be very careful only to admit patients onto the hospice benefit who meet the criteria [for a terminal prognosis]. I would agree that a patient seeking aggressive, curative therapy is not hospice-appropriate at this time."

However, NHPCO has developed a public policy proposal that would permit Medicare-certified hospices to provide and be reimbursed for interdisciplinary palliative care consultations for patients who are not hospice-appropriate. NHPCO's Public Policy Steering Committee also is exploring a proposal for regional demonstration projects that could test simultaneous care models. "What those demonstrations would

look like is still to be determined, but we believe they have the potential to save money and bring patients into hospice sooner," Schumacher says.

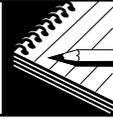
Other ways for hospices to begin to explore the potential and the implications of simultaneous care include collaborating with hospitals in the development of hospital-based palliative care programs, as described in the joint NHPCO-CAPC monograph, "Hospital-Hospice Partnerships in Palliative Care" (accessible at www.capc.org/content/165/). There are also opportunities to expand the role of the hospice medical director in physician relations and to establish more effective professional relationships with physician offices and medical groups. Hospices can conduct their own mini-demonstration projects by working with a single medical group to test models of simultaneous care, Schumacher suggests.

Precedents for simultaneous care

The simultaneous approach is not without precedent for American hospices. A number of specialized AIDS hospice teams in the 1980s experimented with simultaneous models that would be more palatable to the relatively young AIDS population. Pediatric hospice experts point out that parents of terminally ill children are unlikely to give up active treatment as a condition of enrolling them in hospice care. As a result, pediatric hospice programs have tended to relax that requirement. The new emphasis on simultaneous care suggests that these kinds of modifications aimed at expanding hospice access are appropriate for all patients with life-threatening illnesses.

Otherwise, as medical treatment continues to advance, the "terrible choice" will loom ever larger as a barrier to hospice referrals. Increasingly, end-of-life care providers will be dealing with patients who are not going to be cured but who may live for years with their illness. For such patients, extending their life span with adequate quality of life may be a good thing, not just "delaying the inevitable." If hospices can't find ways to get involved in caring for such patients, they are in danger of being left on the outside looking in.

(Editor's note: Larry Beresford is a health care journalist who specializes in hospice issues. He is author of The Hospice Handbook: A Complete Guide.) ■



Be aware of family limitations

Culture, depth of loss must be understood

By **Robin McMahon**, LCSW, BCD
Senior Advisor for Grief and Loss
The Hospices of the National Capital Region
Fairfax, VA

(Editor's note: This is the final installment of a series on understanding the family dynamic and addressing its challenges. Last month, columnist Robin McMahon focused on defining a family at end of life.)

The term "cultural diversity" is often narrowly viewed as religion, socioeconomic status, and/or ethnicity. Indeed, these characteristics of the family will affect how members relate to one another and "outsiders" such as health care workers. However, other factors such as communication styles, the hierarchy of the family, and customs and beliefs about caregiving, dying, and death are equally important components of each family's unique culture.

Whether biology, intimacy, or both are requisite for family membership, families are generally multigenerational as well. This added wrinkle of age and corresponding history adds further complexity to a family's relationships, attitudes, and communication.

One family, two branches

Mary's family typifies both the complexities and the richness of working with a multigenerational, two-family culture. Mary was 37 years old when she was diagnosed with a brain tumor. By the time she became a hospice patient six months later, she had profound memory loss and difficulty with balance. In other words, she needed 24-hour supervision and care. The family consisted of her spouse, Jed, and their two adolescent children, as well as the couples' respective parents and siblings.

Mary's parents and siblings had lived in the same small town all their lives. Jed's parents were missionaries who had traveled all over the world.

Mary and Jed's home was at least a four-hour drive away from the nearest relative. Over the next two years, in spite of the differing backgrounds and beliefs of the two families and their extended families, Mary lived at home until her last six weeks of life.

Mary's family of origin practiced great closeness and openness in communication. Her parents' mission in life when she became ill was to make any adjustments needed to help care for their child. Jed's parents, on the other hand, were stoic and practical. In their minds, keeping Mary at home was a burden beyond what Jed and the children should bear. Jed's grandmothers had lived out their days in a nursing home, and that solution suited Jed's parents the best.

Part of the hospice social worker's role with this family was to listen to each branch of the family and affirm each person's perspective on the situation. As Jed's and Mary's families rotated through their caregiving stints, the social worker also helped Jed process the various messages he was receiving from both sides. The nurse and certified nursing assistant on the team worked with differing caregiving styles and affirmed the quality of care that each provided while helping to establish consistency from caregiver to caregiver. The chaplain who was "not needed" when Jed's parents were in residence was a supportive presence, especially with the spiritual questions of parents who would survive their child.

A tome could be written about this challenging yet loyal family. Suffice it to say that the hospice team's most effective intervention was the effort to meet each individual where he or she was and to respect their diverse opinions on how to cope with the situation. Helping Jed to respect all points of view was the key to his handling of this family ordeal.

Resources and limitations

Addressing the resources and limitations of a family that has a dying member involves recognizing the strengths and weaknesses of individuals and of the collective family unit. When considering the resources and limitations of a family, the following questions should be considered:

- What are the family members' previous experiences with caregiving, death, and illness?
- How much diversity exists in perspectives and beliefs about death and dying?
- Is there consistency among family members

about communicating difficult subjects, or is the family divided in subgroups that either communicate or practice stoicism?

- What are the financial resources or time factors that allow even distribution of care responsibilities — or that place the burden on a select few?

- What other life issues and crises are occurring for the various family members?

Rather than simply deciding what the problems and resources of the family may be, it is essential that the hospice team begin communication with individual family members about what they perceive to be their assets and challenges in coping with the situation.

Lack of money may be a problem in one family, while inexperience in caregiving may be a source of apprehension in another. Hospice team members can overcome deficits by helping family members identify these challenges and creatively explore resources within the parameter of hospice services, the larger community, and their own support networks. Hospice staff and volunteers also can remind family members of strengths they possess and model for them ways to affirm the other members of the family. For a complex family with differing opinions and resources, a family meeting facilitated by hospice staff can reinforce the family's common ground — love and concern for the patient — while defusing some of the areas of conflict.

Nature and meaning of loss of a loved one

The nature and meaning of the loss are important for hospice staff to recognize. Each family member's caregiving role and reaction to a dying loved one will be unique based on the life cycle of the family, what other losses are occurring as a result of this death, the course of the patient's illness, and the roles both the patient and the various family members have held in the family. Questions relevant to the nature and meaning of the loss include:

- Who is the dying person, and what roles does that person fulfill for the collective family and in relation to each of the members?

- Is this a matriarch who is dying in old age and who was still the glue that held the family together, or is it a young child whose death forces individuals to question their faith, confront their mortality, and wonder why not them?

- Are there dependents that relied on the dying individual for care, financial support, or a home?

Does the death of a loved one leave them wondering who will care for them now?

- Is the dying process witnessed by the family one that is frightening or overwhelming because of the care involved or unfamiliarity with illness and death?

- Will the patient die at home, or is a home death unacceptable for some reason? And what will the consequences be after the death in terms of the bereavement experienced by those who survive?

Engage individuals in discussion about death

It is beneficial for the members of the hospice team to try to engage each family member in a discussion of what this impending death means to them. A simple question such as "What is this like for you?" allows individuals to describe how they are being affected by verbalizing what is most difficult, frightening, frustrating, or surprising for them. Often, the professional outside the family is the safest person in whom to confide these thoughts and feelings.

Each hospice clinician possesses discipline-specific expertise to provide support as individuals struggle to find solutions for practical problems such as housing or finances, deal with role stresses such as hands-on care questions, and find spiritual and emotional comfort for their grief. Awareness of all of the permutations of family dynamics in end-of-life care would be the ideal for expert hospice nurses, social workers, nursing assistants, chaplains, and volunteers.

This article has mentioned only a fraction of the family factors that affect how those concerned cope with a dying loved one. Even the most seasoned hospice clinician will not have been exposed to every possible family dynamic.

A more realistic and beneficial expertise, then, is the ability to respect each individual as unique and to recognize the diversity of perspectives within a given familial unit. The art of the hospice practitioner is ease in demonstrating hospice's philosophy of caring for all who are affected by the approaching death so a wounded family member does not perceive that "hospice" is taking sides when individuals clash. Qualities of compassion, dedication, and respect that draw nurses, social workers, nursing assistants, chaplains, volunteers, and other front-line staff to hospice also enable them to make a difference in working with even the most complicated families. ■

Seminar takes sensitivity into homes of clients

Home staff must respect customs, religious beliefs

A culturally insensitive remark to the grandchild of a patient not only resulted in the home care nurse being thrown out of the home, but also resulted in a major change in the way the home care and hospice program of Catholic Health Service (CHS) of Long Island addressed cultural differences between patients and employees.

Although the remark was bad enough, the worst part of the situation was the fact that the nurse was clueless about why the fuss was being made and refused to apologize to the family, says **Keith Kertland**, president and chief executive officer of CHS Home Care and Hospice in Hauppauge, NY.

In the three years since the incident, CHS Home Care has implemented a one-day cultural sensitivity seminar that all 450 employees are required to attend and has added members of the minorities represented in the community to the board, he says. "We are also translating patient information into more languages and developing a resource book that identifies cultural issues that home care employees are likely to encounter," Kertland adds.

While home care agencies have studied the need to address language barriers, there is more to consider than just language when your patients have a different cultural background, points out **Mary Jo Clark**, RN, BSN, MSA, home care management consultant for RBC Limited, a management consulting firm in Staatsburg, NY. "Sometimes, your nonverbal communication can offend," she says. For example, in many Asian cultures, direct eye contact is disrespectful, she points out.

The need for cultural competence is growing, Clark says. "It is no longer just the metropolitan areas that have a variety of cultures," she notes. With resettlement of refugees from different parts of the world, even smaller towns and rural areas

Cultural Diversity Resources

• **The Henry Ford Health System Multicultural Resource Guide** contains background, family, social, food, spiritual, and health practice information on more than 20 cultural, racial, and religious groups. Copies of the book can be purchased for \$29.95. For more information or to order the book, contact Karen Giovannini at (313) 874-3766 or kwierci1@hfhs.org.

• **Language Line Services**, One Lower Ragsdale Drive, Building 2, Monterey, CA 93940. Telephone: (800) 752-0093, ext. 441. E-mail: prodinfo@languageline.com. Web site: www.languageline.com. Provides over-the-phone interpretation and document translation services in more than 140 languages. Interpreters are available 24 hours a day, 7 days a week, 365 days per year. A variety of subscription plans are available depending on how much time is needed per month. ■

have people with different languages and customs, she adds.

It is even more important for home care employees to be aware of cultural differences than hospital employees, says **Ann Hutchinson**, RN, BSN, clinical supervisor of the Downriver Office of Henry Ford Home Health in Lincoln Park, MI. "In the hospital, patients surrender themselves to the hospital routine because they are the guests of the hospital," she says. "In home care, we are guests in the patients' homes, so we need to respect their customs," she explains.

In addition to cultural competence seminars that all employees must attend, Henry Ford Home Care employees take a cultural competence exam each year, Hutchinson says. The exam follows a review of the health system's *Multicultural Resource Guide* (see resource box, above) that contains detailed descriptions of different customs, beliefs, religions, and practices for more than 20 different groups, she says.

Language barriers are handled in a variety of ways. "We use family members, staff members, or Language Line," Hutchinson says. (See resource box, above.) "Our branch office has a

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number of Hispanic patients, so all of our staff members have learned some rudimentary Spanish," she adds.

It's important to find out if there is a language barrier when the referral is first received, Hutchinson says. "This gives you time to make arrangements before the first visit."

During the initial referral, you should ask not only about language but about religion and nationality as well, Clark points out. "Although you can't put every patient in a box and expect them to act exactly like everyone else with the same language, religion, or nationality, you can research the traditional customs prior to the first visit so you won't be surprised," she says. For example, an Asian family may expect the nurse to remove her shoes and wear slippers, she points out. "The nurse should be prepared for this so that her reaction doesn't offend the family," she adds.

Understanding different beliefs also improves communication, Kertland points out. "One of our hospice nurses wanted to report a Muslim family to adult protective service because they had the patient lying on a mattress on the floor rather than a bed," he says. "It wasn't abuse. Muslims believe that you should be close to the earth and facing Mecca when dying, so the family was following their religious practice," he says.

Culture-related questions are raised at case conferences, Hutchinson says. "In addition to reviewing the patient's progress, we take the opportunity to discuss cultural issues that may have arisen during the visits so we can all learn from them" she says.

"In the Arab culture, it is rude to expose the soles of the feet," she says. "This presents a problem when the nurse is conducting a diabetic foot exam." Situations like this rely on the development of a trusting relationship so that the nurse can explain the rationale for the exam and make sure it is conducted in a private place, she adds.

Hiring employees from the same populations as your patients also will help your agency, Clark points out. "Although you won't always be able to assign only Jamaican nurses to Jamaican patients, just having the diversity on staff will help everyone learn more about different cultures," she says. Be sure you hire staff members who are open to experiencing new things, no matter what their backgrounds are, she adds.

Although hiring aides and nurses is a challenge all by itself, Clark suggests that home care agencies work with local community and religious

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groups to promote their own agency as an employer and talk about the need for aides and nurses.

As you evaluate your agency's ability to provide care to patients of different cultures and backgrounds, be sure not to forget about the different backgrounds of your own employees, Hutchinson says. "The easiest way to make sure we are respectful of our patients' differences is to make sure we respect our colleagues' differences," she says.

Even with resource guides, research, and preparation before the first visit, sometimes the best way to make sure you don't offend patients and their families is to ask what their preferences are, Hutchinson says. "Not every family has the same beliefs that other people of the same background have. When we ask their preferences, we show that we are aware of differences and want to respect the family's customs." ■

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