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Consumer-directed health plans: What they may mean for hospice

You will need well-informed consumers

There's a new health care insurance game in town. And unlike other permutations of managed care, consumer-directed health plans give more purchasing power to consumers — and not their employers. This new model assumes that if consumers have more choices, the right financial incentives, and appropriate information, they will be better informed and more prudent users of care.

They also will spend less, proponents of consumer-directed plans say, which would ease some of the pressure of rising health care costs and offer employers a little relief from annual double-digit percentage increases. Generally, the plans give money for health care directly to employees, who then make their own choices about how to spend — or save — that money.

For now, consumer-directed health plans represent only a small portion of the marketplace. Their impact on the American health care landscape will only be known over time. The same holds true for the impact on hospice and end-of-life care.

"It's an evolving product line," says **Steven Gardner**, a health care consultant who advises the National Hospice and Palliative Care Organization in Alexandria, VA. "No one can be sure how it will evolve, since the market is so new."

According to those familiar with consumer-directed health plans, hospices with consumer-directed health plans in their market should not fear exclusion. By the same token, they should not dismiss these plans as benign entities, either.

According to a health care consulting group, a number of large employers have taken an interest in consumer-directed health plans, and some plan to change their health care benefits to include this new form of managed care in hopes of reversing the continuing increases in the cost of health care coverage. (See related story, p. 99.)

As with most things new, caution is prudent. Yet, hospices also can

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look at the emergence of consumer-directed health plans as an opportunity, says **Donald Sacco**, chief strategist for My Health Bank, a Portland, OR-based provider of software and consulting services to consumer-directed health plans.

The frugal consumer

Consumer-directed health plans are based on the theory that if consumers have to pay a significant amount of money from their own pocket, then the perceived value of a visit to the doctor is more than it would be under a \$10 copayment plan. From a hospice perspective, this could mean that a consumer who has accumulated money in an account and is suddenly faced with a potentially life-limiting illness could opt for palliative care sooner than traditional health insurance currently allows. Because the money is the consumer's to spend, there are no restrictions on the health care services the consumer elects.

That's how the theory goes, anyway. But the theory assumes that those making choices are:

- able to identify their interests;
- completely informed about the possible courses of action and their consequences;
- sensitive to differences among alternatives;
- able to make decisions that maximize their interests.

The linchpin, of course, is information. According to the AARP in Washington, DC, you can't just assume people will choose what will best benefit them. To ensure consumers make the best choices for themselves, you must have an effective way to give them health care information.

The same can be said for hospices. If hospices expect consumers to choose hospice care appropriately under this new payment method, the industry and individual hospices must do a better job of not only telling plan beneficiaries what hospice is but why it's a wise choice.

Selling hospice to the public

Therein lies the opportunity, says Sacco. "Hospices were persistent with their message when they convinced Medicare that hospice care should be reimbursed," Sacco adds. "I don't see why that same persistence can't be applied to consumers."

Reaching consumers requires not only a strong message, but a campaign that addresses consumers' concerns and an understanding of the challenges facing them.

Within consumer-directed health plans, consumers face challenges related to both the initial decisions they must make and the ongoing day-to-day choices they make while seeking care. These challenges include:

- understanding information about options;
- identifying information relevant to their own situation;
- knowing the factors to consider in making a choice;
- integrating that information into choices, including differentially weighting factors and making trade-offs among factors;
- understanding the implications of choice for personal financial and health risks and considering those risks when making choices.

Although consumers face most of these challenges in more traditional health coverage options, the stakes — both personal and financial — are potentially far greater.

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

Vice President/Group Publisher: **Brenda Mooney**, (404) 262-5403, (brenda.mooney@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.

The AARP cites a number of provider challenges. While these challenges are general, hospices can address the same concerns as they begin their education of consumer-directed health plan beneficiaries. The challenges include:

- **Helping consumers understand their risks and make choices that protect against events that are not currently salient.**

Hospices must help consumers understand the risk of not considering end-of-life care options, even when the consumer is in good health and not facing chronic or long-term illness.

- **Helping people make trade-offs and decisions that will enable them to achieve their goals.**

Hospices can help advance the message that day-to-day choices about health care may have financial and health consequences, including decisions about: when to seek care; selecting providers; spending the personal spending account vs. saving funds for a future serious illness; and seeking care once the account is exhausted.

- **Helping consumers make good choices on a day-to-day basis about when it is necessary to seek care and assisting them in making good choices about the kinds of care they need.**

A longstanding hurdle for hospice has been the need to convince payers, physicians, and patients that hospice offers its greatest benefit when accessed early. The challenge of conveying this message about when to seek hospice care will spill over to beneficiaries of consumer-directed health plans.

- **Giving consumers complete and relevant information that helps them integrate all important factors, including quality and cost information, into the selection of providers.**

Recently, the hospice industry has collected data regarding the cost-effectiveness and advantages of hospice care. Hospices must find a way to merge data with anecdotal information to help consumers see the benefits of hospice.

- **Helping people make choices that will allow them to better forecast and then balance current wants with possible future needs, and assisting them in understanding the meaning or potential impact of the risks they are assuming.**

Perhaps the tallest order of them all: to open a dialogue on end-of-life issues. The challenge here is to get consumers to talk about death and how they want to be treated during this final stage of life.

The challenges listed above represent opportunities — the chance to promote hospice care to a

new market. Yet, this doesn't represent a great departure from the challenges and opportunities hospices face with their traditional payers. With Medicare, for example, patients still must be encouraged to raise the question of hospice with their physician, and physicians must be educated about the appropriate time to certify a patient as terminally ill.

Failure to educate beneficiaries of consumer-directed health plans will likely have consequences as the market grows and evolves. For now, the model involves consumers choosing from a menu of health plans, each with varying types of coverage. Chances are that hospice care, as with most managed care health plans, is an included benefit. Therefore, the consequence of having poorly informed patients will be much the same as it is with today's stable of payers: late referrals or no referrals at all.

What if consumer-directed health plans evolve to become a boutique of health care services, where plan beneficiaries pick and choose the type of services they want given a budget of money to spend? The consequence is far more drastic. Rather than losing referrals, hospices will lose access to patients.

For now, Sacco doesn't see consumer-directed health plans, as a whole, moving in that direction, although some could emerge to test the boundaries of the marketplace. Whatever the future holds for consumer-directed health plans, Sacco advises hospices to continue trying to convince the public that hospice is a worthwhile health care expense and experience.

"When it comes right down to it," he says, "even if you're talking about Medicare, the real trick is to convince the patient and family to accept hospice." ■

Consumer-driven plans expect rapid growth

Consumer is primary purchaser

It seems every new decade brings another twist to financing health care. Over the past 30 years, terms such as managed care, diagnosis-related groups, and capitation have become part of the health care industry lexicon. Now come "consumer-directed health plans." Only time will tell whether the latest variation of managed care will

stick, but based on employers' early reaction, it could be here for a while.

A survey by Mercer Human Resources Consulting in Chicago found that 29% of large companies (those with 20,000 employees or more) were likely to offer the option of a consumer-directed health plan to their employees within the next two years.

What are consumer-directed health plans? And why are they poised to become the next big thing in health care?

The answer to both questions starts with the consumer. A generation of Americans has known only a health care system in which insurers pay for much of the care delivered by providers. For many, minimal copayments of \$5 to \$15 have been the only out-of-pocket expense they've known. That means millions of health care consumers place a low value on health care services. If a \$10 copayment is all one has to pay for services that may cost 10 times that amount, the consumer has no incentive to keep costs down.

Giving consumers the purse strings

Consumer-directed health plans were born out of the belief that if consumers held the purse strings, they would have an incentive to spend health care-related money more wisely. If consumers have more choices, the right financial incentives, and appropriate information, the theory goes, then they will be better informed and more prudent users of care.

Employers have been struggling to rein in double-digit annual percentage increases in health insurance costs. Rising costs have put a dent in their profits and have contributed to a faltering economy.

To say the least, the atmosphere is ripe for change. That change, say advocates of consumer-directed health plans, involves shifting economic pressure from employers to consumers. If consumers must not only choose their health coverage but also pay for it, they will be more cautious about their health care spending.

With this shift in economic pressure, consumers must gather the requisite information about providers and services to make the same kinds of decisions about health plans that their employers have for years. Consumers in these plans face challenges both in the initial decisions they must make and in the ongoing day-to-day choices they make while seeking care. These challenges include:

- understanding information about options;
- identifying information relevant to one's personal situation;
- knowing the factors to consider in a choice;
- integrating that information into choices, including differentially weighting factors and making trade-offs among factors;
- understanding the implications of choice for personal financial and health risks and considering those risks when making choices.

Consumer-directed health plans are as varied as the number of consumer-directed health plans in the marketplace. According to **Donald Sacco**, chief strategist for My Health Bank, a Portland, OR-based provider of software and consulting services to consumer-directed health plans, there are three basic components of consumer-directed health plans:

1. Self-service: This can range from simply choosing from a stable of available health plans to on-line services that allow the consumer to make appointments.

2. Financial component: Consumer-directed health plans administer cash accounts and flexible spending accounts that consumers place their money into to pay for future health care expenditures.

3. Education: Self-service plans must make information available to consumers to foster sound decision-making.

Consumer-directed health plans are actually a spectrum of models along a continuum, beginning with simple and traditional co-insurance plan designs and moving toward true defined contributions or vouchers, according to the AARP in Washington, DC. The most common type of consumer-directed health plan combines high-deductible health insurance — typically \$1,000 to \$2,500 — with an employer-paid account designed to meet part, but usually not all, of that deductible.

The terms "consumer-directed" and "defined contribution" are often used interchangeably, but they are not synonymous. "Consumer-directed" refers to a health plan design feature, and "defined contribution" is better thought of as a kind of contribution strategy. In consumer-directed plans, employees typically have more financial responsibility for the choices they make and are more actively engaged in benefit selection and network design. In defined-contribution plans, employers give employees fixed amounts of cash for health insurance, and employees shoulder any costs above the fixed amounts.

The AARP notes the existence of three types of consumer-directed health plans:

1. Health reimbursement arrangements (HRAs). In these plans, personal spending accounts are established for each employee, and employees may draw upon the accounts for their health care needs. When their accounts are depleted, the employees pay out of pocket until they reach annual deductible amounts, at which time traditional major medical policies (or other insurance arrangements) go into effect.

2. Employee-designed benefits and networks. Employees in this model establish their own networks and design their benefit packages by selecting specific doctors and benefits. They bear the financial risk of their choices. Thus, if the doctors selected charge higher prices, employees will incur greater expenses. Likewise, if employees require benefits not selected, they will have to pay out of pocket when they need such services. This model requires individuals to construct networks consisting of 19 physicians representing the range of specialties patients are likely to require.

3. Customized packages. Employees select from among various networks and benefit packages that have been predetermined by their employers. Employees may choose from broader or narrower networks and richer or less comprehensive benefits. Most of the major managed care insurers (e.g., Aetna, Humana, CIGNA) have begun to offer this model, sometimes combined with HRAs and tiered networks (e.g., PPOs or HMOs) that vary by price.

Models 1 and 2 require fixed contributions in order to work properly; Model 3 does not necessarily require this contribution strategy.

Aetna offers HRA plan

Aetna offers an insurance plan that pays claims only after a \$1,250 deductible is met. Employers who bring their workers to Aetna's self-service plan help out by contributing \$250 a year to a special account, known as a health reimbursement or personal savings account. Consumers use this money to pay for any doctor, hospital, or medical service they choose. Unlike Aetna's own managed care plans, there are no preapprovals or referrals required.

All this means a consumer is given \$250 of his employer's money and then the consumer required to spend the next \$1,000 out of his or her own pocket. The only restriction on how the consumer spends the \$1,250 is that the money

must be spent on medical care. These deductibles and limits don't apply to preventive care, such as physicals and well-baby care. These services are covered by the insurance plan from the start.

Once the deductible is met, the consumer is then covered by the insurance plan, which is a PPO. At this stage, the consumer faces a copayment of 10% for any care provided by one of the PPO doctors or hospitals (30% if the consumer uses an out-of-network provider). There's a \$1,500 annual cap on copayments.

Any money left in the account at the end of the year can be rolled over to the following year.

Budgeting for day-to-day health services

The Destiny Health Plan of Bethesda, MD, offers an example of the HRA model. The plan provides insurance coverage for the higher-cost, lower-frequency services that are less controllable. In addition, it offers a way to budget and plan for day-to-day services. The approach, Destiny says on its web site, is a "common sense insurance solution [that] gives our members incentives to manage their healthcare costs intelligently; it also allows us to offer the control, affordability, value and flexibility not available with conventional health plans."

Here is how it works. The insured benefits are structured to protect members during those times when they clearly need insurance, which are divided into three distinct components:

- hospital and surgery benefit;
- chronic medication benefit;
- personal medical fund (PMF) Safety Net.

Contributions to the PMF are made monthly, and any remaining balance may be carried forward to the next year. Also, members may withdraw the cash when they leave the plan.

The PMF Safety Net is a mechanism that reduces beneficiary risk for day-to-day expenses, recognizing that even day-to-day expenses can accumulate to a costly level. Specifically, Destiny has established annual threshold levels. Beyond these levels, the PMF Safety Net provides further insurance to protect the member against unexpected and potentially cost-prohibitive events. Once a member's cumulative day-to-day claims exceed his or her annual threshold, the member becomes eligible for insurance benefits.

By integrating the PMF Safety Net and insured benefits, Destiny Health says it has created a comprehensive health plan that covers all areas.

Most day-to-day health care costs are generally within the member's control, says Destiny. Like all consumer-directed health plans, the reimbursement arrangement gives members the freedom to choose any provider without a referral. Like traditional managed care, the health plan has a network of providers that have agreed to discounted fee schedules. These discounts are applied to benefits paid through members' personal medical funds. ■

Hospice Trends

Despite all the talk, demo projects are rare

Valuable lessons are going unlearned

By **Larry Beresford**

Even though hospice care touches the lives of more than 800,000 Americans with life-threatening illnesses and their families per year, many critics have questioned the dominant payment mechanism for such care, the Medicare Hospice Benefit, which was implemented 20 years ago this November.

Some have challenged provisions of the Medicare benefit, such as its eligibility threshold of six months or less to live and its tendency to force a "terrible choice" on vulnerable patients, which can have the result of blocking access for people in need of the only large-scale health benefit explicitly designed for end-of-life care. Some have even suggested that the benefit is fatally flawed and in need of replacement by new models of palliative care.

Others in the hospice community want flexibility to experiment with adjustments to the benefit that could permit hospice providers to meet more of the needs of patients who may not be eligible, appropriate, ready for, or open to hospice care as currently defined by Medicare. They point to untenably short lengths of stay in hospice as proof of the need for alternative approaches that would allow more patients to access hospice care sooner.

In fact, a number of seminal reports on end-of-life care in recent years have called for hospice

demonstration projects. These could involve testing in the following areas:

- alternative definitions of eligibility;
- different payment mechanisms, such as variable rate levels for patients of differing acuity or length of stay;
- funding for high-cost outliers;
- disease-specific case management models;
- special approaches for children or other patients with special needs;
- concurrent or simultaneous care approaches (see "Hospice Trends" in *Hospice Management Advisor*, April 2003, p. 42);
- palliative care consultation benefits (see "Hospice Trends" in *HMA*, August 2003, p. 89).

But where are the hospice demonstration projects that have been recommended in these policy reports? Where are the federally funded experiments that could generate empirical answers to the concerns that have been raised about the hospice benefit?

Need for adjustment?

In its 1998 report, the Committee on the Medicare Hospice Benefit and End-of-Life Care of the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, concluded after a year of deliberations that the Medicare Hospice Benefit as it existed was "fundamentally well designed" and mainly just needed to be better utilized by providers. But the committee also recommended testing other eligibility criteria, along with examining the impact of alternative payment methodologies and disease-specific case management models. One of its most urgent recommendations was to explore alternatives to the six-month prognosis.

In March, a report titled *Access to Hospice Care: Expanding Boundaries, Overcoming Barriers* was released by the Hastings Center and the National Hospice Work Group. The report recommended that Congress approve demonstration projects to improve access to hospice care. These demonstration projects would advance hospice access for patients who don't yet qualify for traditional hospice care and would promote access to hospice's end-of-life competencies for other patients through new community partnerships, such as with PACE projects.

Last September, in a briefing held at the U.S. Senate, the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care initiative called for federal demonstration projects to

more thoroughly test and analyze some of the exciting preliminary results emerging from the 22 Promoting Excellence grantees — often on shoe-string research budgets.

According to Promoting Excellence Program Officer **Ira Byock**, MD, these demonstration projects showed that it is possible to increase access to and quality of end-of-life care without increasing overall costs. They also successfully introduced hospice or hospice-like services earlier in the disease trajectory for patients still receiving life-prolonging therapies.

“Demonstration projects are a means to an end — a wonderful way of expanding the realm of what is possible,” Byock says. “They explore the feasibility and acceptability of new ways of doing business. They expand health service delivery models. I think there are critical issues from both a public health and a hospice business perspective that need to be tested.”

The public health issues are related to access to care as well as the efficient use of health care resources, he says. “But there are also great business opportunities for hospices to open new markets and reach new populations of patients.” This could include safety-net systems, children, patients with HIV or end-stage renal disease, cancer patients on experimental therapies, and other groups that hospices historically have had a difficult time reaching, he says. Hospices can either complain about the structural access barriers that stand in their way or build new models to overcome those barriers, Byock adds.

So where are they?

So where are these hospice demonstrations that so many have called for? Some critics have questioned whether the U.S. hospice community is truly open to testing new approaches that could lead to significant changes in the Medicare benefit.

Even recognizing that the current regulatory and reimbursement structure has produced the extremely short lengths of stay now challenging many hospices, some in hospice may feel that the devil they know is preferable to opening a legislative Pandora’s Box that could alter the fundamental terms of end-of-life care in unexpected ways — perhaps even replacing hospice with a new provider type.

If the legislative process opens up the definition of hospice care to reconsideration, would

other constituencies rush in with their own counterproposals? Also, are America’s hospices prepared to deal with the ambiguities of caring for patients still receiving aggressive therapies or unwilling to commit to a purely palliative approach?

Among those who doubt the eagerness of hospices to experiment with solutions to the identified access barriers is **Joanne Lynn**, MD, of the Washington Home Center for Palliative Care Studies in Washington, DC. Lynn is the author of another end-of-life policy proposal called “MediCaring” (www.medicaring.org/). Lynn currently is working with U.S. Rep. James Oberstar (D-MN) on a bill titled “Living Well with Fatal Chronic Illness Act of 2003,” which contains some of Lynn’s ideas for end-of-life demonstration projects. Also, she’s working with the District of Columbia Medicaid office on a home- and community-based waiver program for medically complex patients.

Lynn doesn’t see much in the works in terms of hospice demonstrations, and, as a result, hospices may not have the research data they will need to develop to meet new opportunities or challenges. She says she wonders if the hospice community is suspicious of policy research, not to mention innovation and demonstration projects, because of fears that these endeavors could threaten hospice’s current dominant line of business.

“People are very concerned to preserve what they’ve already got, rather than putting the best interests of patients first, which clearly would mean trying out other models as quickly as we can,” she says. “Out of such experimentation might come all kinds of insights and innovations. Some may be contrary to the short-term interests of hospice per se but might be better for patients and families in the long run.

“Is there a better model [than the hospice benefit] that would serve more people with life-threatening illness or integrate better with the rest of the health care system? I’d say there’s a good chance that there is.”

Clearing the decks

Those who say the hospice community is reluctant to test alternative models of access or care may have misunderstood the industry’s careful approach to policy change, suggests **Donald Schumacher**, PsyD, president and CEO of the NHPCO. Hospice advocates have been busy in recent years seeking rate adjustments to the

Medicare Hospice Benefit and pushing for the Centers for Medicare & Medicaid Services to release long-awaited revisions of the Medicare Conditions of Participation and to address other regulatory concerns, even drafting a hospice palliative care consultation benefit.

With many of those issues — along with the prescription drug benefit in Congress — finally making their way toward resolution, the NHPCO has set the stage to move on its current top priority: hospice demonstration projects. “Now that we have cleared the decks, this is our next stage,” Schumacher says.

NHPCO working toward legislative proposal

The Legislative Subcommittee of the NHPCO’s Public Policy Steering Committee has catalogued and is about to start reviewing the various models that have been offered for hospice demonstration projects, with the aim of pulling together a specific legislative proposal before the end of the year.

“We are in the process of developing specific initiatives to test different eligibility models and services in a number of different care settings. There is a range of topics we want to test, and we’re now in the midst of developing the enabling legislation,” Schumacher says.

NHPCO’s aim is to present Congress with a comprehensive list of ideas to be tested and approaches for testing them, including eligibility strategies and payment mechanisms.

“We take seriously our charge to increase access for patients and families,” Schumacher says. “If we are going to approach this issue, we think it needs to be comprehensive and far-reaching. We don’t want to reinvent the wheel, but rather improve what we have now.”

The goal for these proposals would be to find ways for existing hospice programs to serve more patients in different ways and for longer periods of time.

The NHPCO would like to see quick action on its demonstration package, although that may not happen, especially if Congress decides to take a breather on health care issues after wrestling with the prescription drug benefit this year. Even if the NHPCO produces draft legislative language before the end of this year, Congress may not take up hospice’s proposal until 2005 or later.

Allowing for time to write implementing regulations, award contracts, test the demonstration

models, and analyze the data, it could be a long time before any of these experiments generate meaningful answers and new directions.

Can America’s health care system and hospice industry — or dying patients and their families — wait that long?

[Editor’s note: A variety of end-of-life care demonstration projects funded by Promoting Excellence in End-of-Life Care will be profiled at the National Hospice and Palliative Care Organization Management and Leadership Conference, to be held Sept. 6-9 in Phoenix. A seven-session track titled “New Models, New Markets” will highlight results, replicable models, and business opportunities, and will address how to move hospice care upstream.

“Hospice Trends” columnist Larry Beresford will be covering the NHPCO conference for HMA. If you’d like to arrange to speak to him in Phoenix to share your questions, ideas, and suggestions for future columns, contact him in advance at (510) 536-3048 or at larryberesford@hotmail.com.] ■

NEJM: Some hospice patients hasten own death

Study surveyed nurses to obtain data

A *New England Journal of Medicine*-published study suggests that patients who refuse food or fluids hasten their own demise. The article, titled “Nurses’ Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death,” provoked a strong response from the hospice community, which feared that hospices would be seen as helping patients commit suicide.

The study, which appears in the *NEJM*’s July 24 issue, received significant media attention.

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, issued the following comment to its members so they could respond to local media:

“It is important to recognize that a very small percentage of hospice patients have reportedly made this choice to forgo food and fluid to hasten death. The media may be focused on somewhat sensational headlines about hospice patients hastening their own death, but this is an inaccurate representation of the research done in this study.

“During the time period covered in the questionnaire, between 40,000 and 48,000 individuals

NHPCO's talking points on *NEJM* article

The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, has issued a list of talking points hospices can use when discussing the *New England Journal of Medicine*-published study on Oregon patients who died after refusing food and water.

The NHPCO talking points include the following points:

- Hospice supports a patient's right to choose care or refuse unwanted medical treatment.
- A patient who elects hospice care may often stop curative treatments and allow the illness to follow a natural progression leading to death.
- Hospice is committed to honoring patient autonomy and places the wishes of the patient at the center of care.
- Through proper education and support, hospices prepare patients and families for the journey they can expect to experience. An understanding that hospice will address fears and concerns brings comfort to all those whom hospice serves.
- Hospice utilizes an interdisciplinary team

with life-limiting illness died with hospice care in Oregon. The report that appeared in *NEJM* identified 102 persons who elected voluntary refusal of food and fluid within the four-year period examined in the study. Additionally, 55 patients who elected assisted suicide were identified.

"Ann Jackson, executive director of the Oregon Hospice Association and a researcher on the project, points out that the data does not pretend to accurately determine the occurrence of either assisted suicide or voluntary refusal of food and fluid. The study was developed to examine differences among patients in Oregon who elected PAS (patient-assisted suicide) and VREF (voluntarily refuse food and fluids). It is important to put this study into the proper context."

In his interview with HealthDay, a web-based news source, **Stephen Connor**, NHPCO vice president of research, development and finance, was quoted as saying, "This is really very rare. I've been in the field 25 years, and I only can remember one case in the hospice programs that I've worked with."

of health care professionals and trained volunteers to address symptom control, pain management, and emotional and spiritual support tailored to the patient's needs and wishes.

- More than 885,000 patients were served by the nation's 3,200 hospice providers in 2002.
- A very, very small number of hospice patients actually make the choice to stop food and fluids to hasten their own death.
- Every year, more than 10,000 people die with hospice care in Oregon. The study revealed only 102 hospice patients who made the choice to stop eating and drinking.
- The nutritional and hydration needs of patients actively dying are different from the needs of persons in good health. As death nears, the body begins to "shut down," and food and fluid requirements decrease.
- In discussing nutritional needs of patients, NHPCO's Standards of Practice for Hospice Programs say, "the interdisciplinary team assesses the patient's nutritional needs and implements nutritional care as desired by the patient and family." The nutritional and hydration needs of a patient are carefully assessed and discussed with each patient and adjusted according to each patient's preference and needs. ■

William Lamers, MD, medical consultant to Hospice Foundation of America, estimated in remarks made to the Associated Press that he had treated only 50 such patients in over 30 years of hospice practice.

"A core value of the hospice philosophy of care centers on honoring the needs and wishes of patients living with life-limiting illness and their families," the NHPCO said. "NHPCO supports a patient's right to choose hospice and palliative care and a patient's right to refuse unwanted medical intervention, including the provision of artificially supplied hydration and nutrition.

"For 30 years, hospice has been providing quality end-of-life care to Americans coping with life-limiting illness. Hospice providers work with the patient and family to explore the range of concerns and fears they may have and to develop a unique care plan that addresses these concerns and honors the specific choices and wishes of the patient. Through education and support, hospices strive to serve the patient

and family in a compassionate manner reflecting high-quality medical care.

“NHPCO has already heard from a provider member who received a call from the wife of one of their hospice patients who is in the process of actively dying. She read the AP story [about the *NEJM* study] in her local newspaper and was concerned that the situation applied to her husband. The hospice was able to explain that this was not the case with her husband, that his illness was following a natural course and he was receiving complete care in honor with his wishes and that he was free of pain.”

The study’s researchers surveyed hospice nurses in Oregon regarding patients who made the choice to stop eating and drinking in order to hasten death. In 2001, questionnaires were mailed to nurses employed by all 50 Medicare-certified home hospice programs in the state, as well as two hospices in neighboring states that provide services for patients in Oregon. A total of 429 nurses received the questionnaire. Seventy-two percent of the nurses surveyed responded; among those nurses, 33% (102 respondents) reported that in the previous four years they had cared for a patient who elected to forgo food and fluids with the intention of hastening death.

Nurses reported that these patients “chose to stop eating and drinking because they were ready to die, saw continued existence as pointless, and considered their quality of life poor.” Survey results indicate that 85% of these patients died within 15 days after stopping food and fluids. The quality of death among these patients, as rated by the responding nurses, was eight on a scale of zero (a very bad death) to nine (a very good death.)

The study said 31% of the patients in the reported cases were in their 80s or older. The most common diagnosis was cancer, which was found in 61% of the cases identified. Cardiopulmonary disease accounted for 16%, neurological disease accounted for 23%, 7% were coded as “other,” and 1% reported missing data.

The study was designed to compare the data regarding these hospice patients with hospice patients who hastened death by means of legalized physician-assisted suicide during the same period. The conclusion of this study states: “On the basis of reports by nurses, patients in hospice care who voluntarily choose to refuse food and fluids are elderly, no longer find meaning in living, and usually die a ‘good’ death within two weeks after stopping food and fluids.” ■

Hospice served 15% more patients last year

NHPCO says 885,000 served in 2002

In 2002, more than 885,000 Americans living with a life-limiting illness were served by the nation’s hospice providers, according to data collected by the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA. This represents an increase of almost 15% over the estimated 775,000 patients served in 2001.

The median length of stay in hospice in 2002 rose to 26 days, up from 20.5 days in 2001; the mean rose from 48 to 51 days. This represents the first increase in length of stay since 1999. Levels had remained constant for the past three years.

Most Americans prefer to die at home

This increase reflects a growing understanding of the importance hospice care has for Americans making choices about their health care at the end of life, the NHPCO said in a statement. The NHPCO’s data demonstrate that when patients are properly informed about the option of hospice care, hospice is the choice they often make.

“Research has consistently shown that almost 80% of Americans — if facing a life-limiting illness — would prefer to remain in their homes, free of pain, surrounded by family and loved ones,” said **J. Donald Schumacher**, PsyD, president and CEO of the NHPCO. “Hospice makes this happen. It’s important that people understand that hospice focuses on living fully up until the end of life.”

The NHPCO reports that some of the confusion surrounding eligibility and length of service is being cleared away, but more education is needed regarding physician prognoses. Specifically, physicians and patients still need to understand that as long as the patient meets eligibility requirements, hospice services are available for as long as necessary, even though a patient may outlive his or her physician’s original prognosis.

Another misconception is that hospice serves only aging cancer patients. Hospice services can benefit people at any age and with any life-limiting condition. Hospice patients with cancer diagnoses accounted for approximately 53% of patients in 2001. Care providers are becoming more accomplished at serving patients facing a wide range of serious illnesses. ■

Need to find money for a new program?

Look for grants that fit your mission

You've got a great idea for a new program, but you don't have the cash to cover the start-up expenses or maintain the program while you build it. There may be grant money with your name on it — you just have to use the right approach.

"We are not a big agency with a fundraising staff or grant-writers on the payroll, but when I heard about a National Family Caregiver Grant that was available through our local Area Agency on Aging [AAA], I decided to apply for the funds for a program I wanted to start," says **Jeff Crowley**, MSPA, executive director of Serve Link Home Care in Trenton, MO. "I started by making inquiries to see how much money was available and if we were entering the process too late," he says. "When I discovered that there was a reasonable amount of money and that there was plenty of time, I decided to apply," he adds.

Opportunities for partnering explored

Serve Link was awarded \$40,000 for the first year to fund a caregiver support program that includes an emergency personal response system for patients in the agency's rural nine-county area. In addition to the 36 families with a personal emergency response system, 12 other families are receiving respite care, with home health aides visiting once per week for three hours at a time, says Crowley.

Part of Crowley's initial conversations with other community organizations was also to explore opportunities for partnering on the program. "Not only did I want other organizations to make referrals to our programs, but I wanted to work with the local retired senior volunteer program to recruit volunteer installers," he says.

Before actually writing the grant application, Crowley also did some internal marketing to make sure his staff were supportive of the program and

to see what ideas they had. "Most staff members, especially the clinical staff, were excited because a personal response system, as well as caregiver support, would be a great benefit for our patients," he says. The only concern came from the financial people, who realized that a different system for tracking costs and income for the program would be needed to meet the accounting requirements for the grant, he adds.

The Caregiver Support Network designed by Crowley and funded by the grant includes five components:

- emergency personal response system;
- respite care;
- caregiver training;
- electronic information and support through an interactive web site;
- outreach education.

Focus application on products, services

Your grant application needs to contain a full description of your program that clearly shows how your program meets the objectives of the grant program, Crowley says. "Focus on products and services," he suggests. "It is much easier to explain personal response systems and respite care than the web site services," he says. "Outreach education is also important in the first year of a program to find customers and develop a referral base," he adds.

You also need to include a realistic budget. "My program required the hiring of a part-time coordinator to conduct the outreach education seminars and to oversee the Lifeline and respite care programs," says Crowley. Other expenses included cost of the personal response systems; reimbursement of mileage and meals for the volunteer installers; and salaries of the home health aides who provide respite care.

"This particular grant does not require a co-pay from the patient or caregiver, but we are asked to send letters soliciting contributions to the program," says Crowley.

Whatever funds are contributed are included in the income for the caregiver program and reported to the AAA.

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You will have reporting requirements with your grant, Crowley points out. In addition to whatever monthly or quarterly budget reports you may have, be sure to develop an ongoing relationship with the agency overseeing the grant, he suggests. "Once you are out of the competitive bid process, you become partners with the organization," he says. "We will talk with our AAA representative at least once a week to make sure we are proactive in verifying a caregiver's eligibility for the program or addressing any questions the organization may have," he adds.

A benefit to regular communication for Serve Link was a call from AAA to let Crowley know that additional funds were available halfway through his first program year. Because the grant organization was comfortable with the way Serve Link's program was run and knew how valuable the service was, the extra funds were granted to support the Lifeline program, says Crowley.

Make realistic funding requests

One way to improve your grant application's chances for success is to be realistic and reasonable in your requests, says Crowley. "Our AAA serves 18 counties, of which I serve only nine, which includes only a third of the population in the entire 18-county area," he points out. For this reason, Crowley asked for a proportionate amount of money for his program. "I believe that my application was attractive because I didn't come in and ask for 80% or more of the funds for a small part of their service area," he says.

A big question to ask yourself as you design a program for which you are submitting a grant application is, "Can I sustain the program in its second year?" Be honest as you evaluate the chance of a grant funding extension, Crowley says. Be prepared to work with a smaller budget for the second year, he adds. "In conversations with AAA, we've already been told that the emergency personal response systems and respite care are likely to be funded, but not the web site," he says.

One way to stretch grant dollars is to refrain from allocating a lot of expenses to the program, says Crowley. "We purchased the computer used by the caregiver program outright with agency funds rather than allocating the cost to the grant monies," he says. Not only does this make book-keeping simpler; it also demonstrates the home health agency's willingness to target grant expenditures toward services provided to clients, he adds.

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Finding grant opportunities is fairly simple, says Crowley. "I don't spend my time on the Internet searching for grants, but state agencies as well as health and educational foundations regularly send out public notices," he says. Also, networking with others on community foundation boards and in health care associations and home health agencies will alert you to grant opportunities, he adds. The key to finding a good fit is to make sure you know the mission of the organization providing the grant and make sure that mission is congruent with your agency's mission, he says.

Crowley's positive experience with his first grant application means this won't be his last. "I will pursue other grants to fund new programs, but we are a small agency, so we can only handle one start-up program at a time," he says. ■

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