

HOSPICE Management

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Next new hospice product could be palliative care consulting

Provision of medical advice can help reach nontraditional patients

Palliative care consulting is much the same as other types of consultations in health care. In general, consultation is a type of service in which one provider seeks the opinion or advice of another provider regarding evaluation or management of a specific problem.

Under Medicare Part B, physicians request the opinion of specialists to ensure accurate diagnosis and proper treatment. This does not mean patient care is transferred to the consultant. Medicare has specific rules regarding consultation between physicians, including the requirement that the request for consultation and the reason for the request be documented in the medical record. The opinion and any investigations or services ordered or performed also must be documented.

Documentation aside, the consultant examines the patient and gives advice to the provider managing the patient's care.

Palliative care consultation services offer physicians and hospital staff the opportunity to consider end-of-life care options for their patients.

Palliative care consultations normally focus on the following:

- pain and symptom control;
- discharge planning and continuity of care;
- decision-making at the end of life;
- psychosocial issues involving patients and families;
- ethical issues.

Palliative care consultation services can take various forms, such as when the hospice medical director is the sole provider of the service. In some settings, palliative care consultation is interdisciplinary, including such team members as physicians, nurses, social workers, chaplains, or psychologists.

Hospice of the Bluegrass in Lexington, KY, operates an interdisciplinary palliative care consulting practice. According to administrator **Gretchen M. Brown**, the creation of a consulting team fits with the organization's mission.

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"It's our mission to serve the terminally ill, but there are some terminally ill patients we don't get — those in intensive care units, for example," Brown says. "When we started this, we thought it would help our length of stay and help bring in more patients."

In Hospice of the Bluegrass' consulting practice, the hospice medical director is the consulting physician, and the hospice bills the consultation services under Medicare Part B. Palliative care consultation works like any other attending physician/consulting physician relationship. An attending physician requests the opinion and advice of the hospice medical director, who also may call upon interdisciplinary team members for input.

The hospice does not take over medical management of the patient unless the attending physician approves the transfer of care. The consulting physician does, however, provide follow-up communication to the attending physician in

the form of phone calls, letters, and copies of clinical notes.

While there is reimbursement for consulting services, it is not a service line hospices should launch to increase revenue. Reimbursement for consultation is not remarkable, experts say. Instead, Brown sees the cost associated with palliative care consulting as part of the cost of doing business. Palliative care consulting is critical to the hospice's mission to serve dying patients no matter where they are, she says.

"This is an area in which we have expertise," Brown says. "Hospitals are starting their own palliative care centers. We can provide the expertise, or we can let hospitals do it."

Know the customer

If a hospice expects palliative care consulting to generate revenue or help increase access for patients, hospice executives and staff should understand what their intended customers expect.

While each physician is different, and each community varies in its level of familiarity with palliative care, there are general areas in which physicians and hospital staff are looking for help. These include:

- **Advice on physical and psychological issues surrounding end-of-life care.**

Typically, physicians will seek assistance in four domains:

- pain and non-pain symptom assessment and management;
- assistance in making difficult decisions, usually about continued use or withdrawal of technological treatments such as feeding tubes, dialysis, or ventilators;
- assistance in planning for the most appropriate care setting and level of care to meet patient and family goals for end-of-life care;
- providing psychological support to patients, families, and the health care team.

- **A clear statement of the hospice's goals under palliative care consultation.**

After a detailed discussion of the patient's history and family support structure, requesters of palliative care consultations will expect a hospice to describe its goals for the consultation and how it fits with the goals of the physician, the patient, and his or her family. Patients and family may have concerns regarding the consultation. You should explain your goals in an easily understood fashion.

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Editorial Questions

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

- **Advice or assistance in engaging the patient and family regarding the patient's current medical condition.**

Like most people, physicians are not adept at discussing the topic of dying. While they can talk about clinical matters, they often need help discussing treatment options outside the realm of curative medicine. They will expect hospice consultants to provide information and advice to patients and their families, taking into account cultural and psychosocial issues.

Patients may have a difficult time understanding why a consultation is necessary, or they may have preconceived ideas that contribute to a negative attitude toward hospice and palliative care. Physicians will need help emphasizing the positive aspects of palliative care, such as improving quality of life through pain relief, symptom control, and restoration of functional capacities.

Serving the broader community

On a larger scale, hospices can be palliative care consultants to the entire community, using the consultation team to educate the public and health care professionals. Hospices can approach specific sectors in their own community in the following ways:

- **Physicians:** One of the hurdles hospices face in getting physicians to refer patients earlier is the perception that the physician would be letting go of the patient. Hospices need to get across the message that hospice care is still physician-directed. Perhaps physicians in a hospice provider's community are unaware of hospice's physician-directed interdisciplinary team approach. Hospices need to explain to physicians who have referral potential that the hospice team approach calls for the patient's physician to take a lead role and work with the hospice medical director, nurses, social workers, counselors or chaplains, and other health care professionals.

Hospices should start with hospital medical staff meetings to educate physicians about hospice and palliative care. Another educational device is a newsletter aimed at physicians that explains the principles of hospice care, including the value of palliative care.

It's also a good idea to stress dialogue between physicians and end-of-life care promoters, either through educational efforts, such as pain management guidelines, or a toll-free hotline. While a single hospice cannot influence the curriculum of a medical school or nursing school, it can

influence the habits of the clinicians with whom its works.

- **Community:** If the idea behind educating physicians is to increase the number of referrals, then hospices should educate the public so hospice will be considered when it becomes appropriate.

Hospices can accomplish this by visiting various groups within the community. Hospice leaders should identify community groups that would benefit from a presentation about hospice, such as nursing homes, community centers for the elderly, or local chapters of AARP.

Talk to a population that has had little exposure to death and dying: teen-agers. Religion classes in churches, synagogues, and schools are ideal platforms for end-of-life discussions.

The end result is that teen-agers share the discussion with their parents and get them thinking about end-of-life issues and how they want their parents to be treated.

No matter the group, hospice supporters should try to facilitate end-of-life discussions. For instance, audience members should be encouraged to talk about their experiences with the deaths of friends and relatives. This not only gets the audience to think about issues they haven't considered, but it also gives providers a glimpse of the public's impression of end-of-life care.

As people begin to contemplate end-of-life care, hospices should encourage the audience to think about advance care planning and should offer audience members assistance in developing a statement of how they want to be treated in the last few weeks of their lives.

- **Managed care organizations:** As managed care becomes more prevalent in some markets, contracting with managed care organizations (MCOs) becomes more important. Like physicians, nurses, and the general public, MCOs need a dose of education, as well.

However, the message to MCOs will be slightly different from the one given to the two previous audiences. Hospices will want to stress their place and value in the health care continuum.

- **Public forums:** Ask the public to share their experiences, both good and bad. Videotape this testimony and show it to health care providers to raise their awareness of problems within end-of-life care.

- **Pain management guidelines:** Develop pain management guidelines and a curriculum on pain management to be used in medical schools and nursing programs. The curriculum should be designed to help educate a new crop of health

care professionals regarding the value of palliative care.

- **Continuing education:** Develop a continuing education program on palliative care and interdisciplinary pain management. Design this program to address working clinicians who were trained in an era when greater emphasis was placed on curative techniques.

- **Toll-free help line for clinicians:** Establish a help line to encourage telephone consultation for clinicians who are experiencing difficulty managing their patients' symptoms, such as nausea and pain. Give clinicians access to a palliative care specialist to answer their pain management questions.

- **Long-term care facility workshops:** Conduct educational workshops for residents and staff at long-term care facilities. For instance, a workshop specifically for residents and their families may be helpful. The resident/family workshop can

include educational programs and discussions of end-of-life issues. Residents should be exposed to advance care planning issues and be given assistance in developing a directive for the kind of care they want to receive during the final stage of life. Instruct participants and their families to follow up with their area hospice for additional information.

- **Community workshops:** In addition to nursing home workshops, hospices can target service groups for community workshops. Like the long-term care workshops, the community workshops should facilitate an open discussion about end-of-life issues and advance care planning.

The above strategies represent elaborate, well-planned efforts to affect public opinion and behavior. If these programs are successful, it will be in large part to the concerted effort of the community of providers that contributed to their implementation. ■

Hospice Trends

Storytelling rewards both sides of conversation

Teller and listener reap its benefits

By **Eric Resultan**

Editor, *Hospice Management Advisor*

The older I get, the more sentimental I become. I look at my own children and wonder if they will value my life-defining stories, or whether they'll simply suffer through them, as I have done with some of my parents' own stories.

One of my earliest recollections includes my mom's *Coming to America* tale. She told the story to my brother and me as if Emma Lazarus had penned "Give me your tired, your poor, your huddled masses..." right after seeing a certain young Filipino nurse arrive in Philadelphia in 1960. "I had only \$20 in my pocket, and I didn't speak the language very well," she told her impressionable sons.

As the years went by, Mom dragged the story out time and again to remind us of her humble beginnings in order to shame two ungrateful children into accepting the things they had, or to

prod an underachiever ("Surely a boy who has been given everything can do better than someone who started from nothing") into better work habits. It seemed, though, that with each retelling, she had less money in her pocket when she stepped off the airplane. By the time I packed off for college, the embellishments bordered on the ridiculous: "All I had was the lint in my pockets, and I used it to knit myself a sweater that kept me warm during my first winter there."

OK, maybe I'm guilty of a little hyperbole.

In truth, I have come to realize the value of those stories, both to the storyteller and the listener. And while my mother is alive and well, I imagine the benefit she receives from telling these stories is similar to that received by terminally ill patients when they are asked to tell their life stories: It reminds them that their life has value. For this reason, storytelling should be a part of the care that hospice patients receive. It helps dying patients move past the debilitating emotions that hinder a high-quality death. Storytelling helps the hospice patient see his or her life in a positive light and brings families closer.

When people reminisce and tell stories, they find common ground with others and engage in a social process that promotes a sense of well-being. In the hospice setting, storytelling can help the dying patient feel empowered by focusing on positive life experiences.

The value of storytelling lies in the way it creates an opportunity for social support from family

and friends. As people get older, they have fewer opportunities to feel supported by family and friends. The same can be said for the dying, who often feel isolated and angry.

As a result, self-esteem is diminished because of the lack of support. Self-esteem is even more dramatically affected in dying elderly patients. For example, men of retirement age often have lower self-esteem because they feel their life has lost meaning. If a terminal illness is thrown into the mix, the patient's ability to achieve a meaningful death can be hampered by the perception that his or her life has lost meaning and that friends and family are providing less support.

The goal of hospice workers is to help patients wade out of the sea of negative emotions and get to a place where they can begin addressing their social and spiritual needs. In the book *I Remember When*, authors **Howard Thorsheim** and **Bruce Roberts** list five ways that storytelling promotes life affirmation and helps patients along the road to a positive accounting of their lives:

1. Provides a sense of belonging. Telling stories helps people feel closer to their families and community.

2. Makes the patient's name known to others and others' names known to the patient. Storytelling promotes an emotional connection between people who otherwise would be strangers. It can help hospice workers break through walls and nurture a familiarity that precedes trust.

3. Establishes a sense of caring. Sharing stories promotes a closeness among individuals through sharing details of one's life and perceiving that others are listening and interested.

4. Sets up care. Story listening is a skill that sets the stage for giving care, while storytelling fosters trust that allows one to be cared for.

5. Provides an opportunity to ask for help. A story can often give the listener clues as to which emotions a person is struggling with and how to help the person handle them.

But convincing a patient to reveal intimate details of their life is not a simple task. The patient must place trust in the caregiver — trust not only that the caregiver will keep confidence, but that the patient's efforts to share will be received favorably by the listener. If the patient believes the story is of little significance to the listener, the listener can cause the patient to retreat and make future storytelling more difficult.

Listening is a skill that few people master.

Fortunately, most people possess the skills to become good listeners. According to Thorsheim and Roberts' book, aspects of good listening include the following skills:

- **Develop good eye contact.** Look at the speaker when he or she is sharing a life experience.

- **Ask open questions.** Ask for more details through simple open-ended questions. For example, "Can you tell me more about that?" Asking for more details adds weight to the importance of the speaker's story.

- **Paraphrase what the speaker is saying.** In your own words, offer a quick summary of what the speaker just told you. This shows the speaker you are interested in his or her story and promotes sharing of additional details.

- **Reflect the speaker's feelings.** Saying something like, "That must have made you happy," shows the speaker you understand the emotions he or she experienced.

- **Know when to keep quiet.** Allow the speaker to tell his or her story without interruption. For example, don't start in with a story of your own until the speaker has finished.

- **Respect the speaker's experience.** Don't belittle what the speaker did just because you would have done it differently.

- **Concentrate on what the speaker is saying.** If you are going to find common ground with the speaker, you will need to think about what is being said. If necessary, ask questions that would make the story more interesting.

Practice listening skills

Listening exercises can take place during team meetings or inservice programs. Bring an object that has a story behind it — pocket lint, for example.

Break up into pairs and take turns telling the story behind the objects that each has brought. The exercise begins with the listener asking the speaker about the object. The speaker then responds with a short answer that does not offer much detail, simulating reluctance to open up. People have two minutes to tell their story.

The listener not only learns to ask more questions, paraphrasing when appropriate, but also to concentrate on what the speaker is saying so as to keep the conversation going. The exercise should last about 20 minutes, with the two participants switching roles afterward.

It has been a while since my mother last recounted her immigration experience. In fact,

I have probably told the story more often than she has. But if I know her as well as I think I do, it's only a matter of time before my children will get to hear it, or some version of it. "Hey Dad, did you know that lola [Filipino for 'grandmother'] came to this country in a raft she paddled all by herself?"

No, son, I didn't. I can't wait for her to tell me that one. ■

One in five terminally ill Americans dies in an ICU

ICUs not prepared for end-of-life issues

Although most Americans say they would prefer a low-tech approach to death, the opposite is happening, with more than 20% of terminally ill patients dying in intensive care, according to an article in the March issue of *Critical Care Medicine*, the journal of the Society of Critical Care Medicine.

"This is the first study to provide national scale to the often discussed end-of-life public health issue," says **Derek C. Angus**, MD, MPH, professor of critical care medicine and vice chair of research in the department of critical care medicine at the University of Pittsburgh School of Medicine.

"Previously there were no reliable estimates of the magnitude of this situation."

In light of their findings, the researchers are concerned that hospitals and intensive care units (ICUs) are not prepared to deliver end-of-life care to the over-65 population, which is rapidly increasing.

The researchers analyzed hospital discharge data from 1999 for six states — Florida, Massachusetts, New Jersey, New York, Virginia, and Washington — and the National Death Index to estimate the use of critical care at the end of life.

The researchers found that of the 552,157 deaths they were studying, 38.3% occurred in the hospital, and 22.4% occurred following ICU admission. Nationally projected, this means more than half a million Americans die annually following ICU admission.

End-of-life ICU use was highest (43%) among infants, ranged from 18% to 26% among older children and adults, and fell to 14% for people

older than 85 years.

Additionally, the researchers found that terminally ill ICU patients had an average length of stay of 12.9 days, at a cost of \$24,541. Non-ICU hospitalization of the terminally ill had an average stay of 8.9 days, at a cost of \$8,548.

Nine of 10 Americans say they would prefer to die at home; however, 20% die after receiving the most technologically advanced care available. This contradiction may be explained by the uncertainty surrounding time-of-death predictions, which is particularly true in acute-care settings where advanced technology is used to prolong life.

The number of Americans who are older than age 65 is expected to double by the year 2030, putting a great deal of stress on ICUs. The researchers recommended a systemwide expansion in ICU care for dying patients unless the health care system pursues an alternative approach.

"Intensive care plays a major role in end-of-life care in the United States," says Angus, who also is director of the CRISMA Laboratory at the University of Pittsburgh School of Medicine. "We have an enormous social and medical imperative to take very seriously our efforts to make sure critical care is only provided when appropriate and provided in a way that has all the elements of compassion and humanism necessary to treat and manage end-of-life care with dignity."

Angus recommends improving prediction models, which help reduce ICU admission at the end of life for patients with a poor prognosis. He suggests critical care physicians partner with referring physicians to consider risk prevention models before admitting terminally ill patients who cannot benefit from critical care.

"Even with excellent prediction models, we will still admit patients at high risk of dying because they also have a good chance of survival," says Angus. "There will still be a large, irreducible number of patients who die in intensive care. This means we have to carefully consider providing and promoting good end-of-life care in the ICU."

Angus says it is difficult for patients, families, and physicians to strike a balance between not wanting to die and not wanting to die badly.

"Some groups of patients are less likely to die in the ICU than others," says Angus. "For instance, HIV/AIDS patients and cancer patients use the ICU less often at the end of life, presumably because they have more clearly established guidelines for

their end-of-life care. However, other groups who end up in the ICU at the end of life may do so without forewarning or forethought. Better awareness of what ICU care can offer, and better a priori discussions between patients and their health care providers, might promote more efficient use of intensive care services."

The author of an accompanying editorial in the journal says the study may mark a new beginning for research on the subject. "Along with some other recent data demonstrating interventions for improving the quality of end-of-life care in the ICU, the data from Angus et al provide the basis for a new era in ICU end-of-life care — one in which we move from simple descriptive studies to acknowledging the magnitude of the problem and developing specific, practical interventions aimed at enhancing the quality of care received by dying patients and their loved ones," says **Mitchell M. Levy, MD**. Levy is professor of medicine at Brown University in Providence, RI. "It is time to move our understanding of the barriers to quality end of life care 'from the bench to the bedside' and make our care for those dying in the ICU — something that is inevitable for almost 20% of Americans — more humane and compassionate and of the highest quality."

Research for the study was supported by a grant from The Robert Wood Johnson Foundation of Princeton, NJ. ■

Expand your agency by forming partnerships

Relationships expand referral base and services

(Editor's note: This is the first of a two-part series that looks at innovative approaches to patient care and expansion of services by home health agencies. This month's article describes partnerships that are designed both to increase referral bases and enhance home health services. Next month's issue will examine the proactive approach of two agencies that have found a way to offer a more holistic approach to patient care.)

As the population ages and the needs of seniors change, home health managers are looking for ways to make their services more applicable to today's senior population. One way to expand services and increase the visibility of

your home health agency is to form partnerships or other types of relationships with other organizations in the community.

On one end of the spectrum of new ways to serve seniors is Elant in Goshen, NY, a senior health care and housing solution that combines a variety of housing options, such as independent living units, assisted living facilities, adult homes, and traditional skilled nursing facilities, with community health services such as home care in several New York locations. Clients who join the system at the independent living stage receive services as needed and move into other housing settings as their health and needs dictate, says **Susan Schulmerich, RN, MS, MBA**, vice president of community health services for Elant.

Keeping patients at home

"Home health is integrated throughout the system because it is appropriate for an organization that is managing the health needs of its clients to use home health to keep clients in the most independent setting appropriate for them," Schulmerich says. "Home health can provide services that range from assistance with baths and hair washing to preparation of meals, to care for acute needs such as stroke recovery or wound care," she says. "The goal is to provide the level of support clients need to stay in their home," she adds.

Even when the home health agency and the assisted living facility aren't part of the same corporation, it is a natural fit for the two types of organizations to work together, Schulmerich explains.

It's much easier for private-duty agencies to establish partnerships with assisted living facilities because rules related to anti-kickback statutes don't apply, says **Karon Austin, MPA, RN, CHCE**, a home care consultant and owner of Healthcare Concepts in Avon, CO.

"During my 21 years as an owner of a private-duty home care company, I was able to establish several relationships with assisted living facilities," Austin says. Her arrangements actually specified her agency as the preferred provider when the assisted living facility needed to refer to a home care agency. While Medicare-certified agencies are unable to establish the same type of formal agreement, there are a number of ways that all home care agencies can establish relationships, she explains.

"One of the services we provided to our

assisted living facility partners was a monthly educational program in which we provided speakers on a variety of topics of interest to the facility's clients," says Austin. "We would present topics on health issues such as osteoporosis and on Medicare coverage topics, such as benefits for wheelchairs, canes, or other durable medical equipment," she says. "We also provided cholesterol screenings and coordinated annual health fairs," she adds.

Speakers volunteer to teach future patients

Speakers for the educational programs and the health fairs can be a mix of agency nurses with expertise in certain areas, representatives from vendors such as durable medical equipment providers, and medical personnel such as podiatrists or dentists from the local area. "We never charged the clients for the seminars, and we never paid fees to any of the speakers," says Austin. There was, however, never a lack of willing volunteers to speak, especially when local health care providers and physicians learned about the program and saw it as an excellent way to establish a connection with an audience that would most likely need their services at some point, she adds.

Before finalizing any agreement to provide health fairs or educational programs at an assisted living facility, be sure to have an attorney review the agreement for violations of state and federal anti-kickback regulations, suggests **John Gilliland**, an Indianapolis-based attorney.

Basically, a home health agency cannot promise a free service such as an educational program in exchange for a promise of referrals, he explains. The laws differ from state to state, with some state regulations being even tougher than federal regulations, so each agency needs to have its agreements evaluated, Gilliland says.

It also is important to make sure the assisted living facility has a policy that gives preference to patient choice when choosing a home care agency, and that the facility follows its policy. This gives a Medicare-certified home health agency an extra measure of protection against charges of kickback violations, he says.

The Visiting Nurse Association (VNA) of Central Connecticut has relationships with assisted living facilities through an entirely different arrangement. The agency's partnership began with the University of Connecticut as a way to enhance community nursing training for student

nurses and to continue care for patients once they no longer had a need for acute care home health, says **Karen Reid**, RN, BSN, director of public health services for the agency.

The home health agency and the nursing school developed CareLink, a program that uses student nurses to follow VNA patients with chronic problems once they are discharged from VNA care for their acute episodes. "There is no charge to the clients for the care," says Reid. The students make the home care visits, perform assessments and evaluations, and monitor the patients' condition under the supervision of both the nursing school and a VNA employee who serves as a liaison for the program, she says.

Students who work with the 200 patients in the CareLink program are excellent representatives of home health, says Reid. "In addition to providing much-appreciated monitoring of chronic conditions, the students are taught to assess changes in a patient's condition that might signal a need for more acute home health services," she says.

Look for evidence of high-quality care

A key to any successful partnership is to ensure that both organizations have the same goals and philosophies, says Austin. "I recommend that a home health agency tour the organization with which the partnership is being discussed," she says. Austin looks for evidence of high-quality care, concerned staff members, and a clear definition of appropriate residents if she is looking at an assisted living facility.

"I want to make sure that the assisted living facility makes referrals to nursing homes or other facilities when it is appropriate, rather than keeping clients in inappropriate settings," Austin says. This also protects her staff, because they know the type of clients with whom they will be dealing and won't encounter surprise clients who require a much higher level of care than expected, she adds.

Working with assisted living facilities may be a first step in establishing a relationship with another senior care organization, points out Austin. New Medicare regulations in 2003 included a directive for a demonstration project that further evaluates the definition of "homebound" and its application to adult day care, she says. "This type of change will open up entire new avenues for home health to explore," she adds. ■

'Cash & Counseling' leads to more home care

Program participants direct own services

An evaluation of Arkansas' Medicaid Cash & Counseling program, in which enrollees direct their own personal care services, indicates that people in the program are much more likely to receive such services than are those who were eligible for services but had to get them in the usual way.

Because Cash & Counseling enrollees were less likely to use nursing homes, health care costs ultimately were lower, even though better access to care led to higher overall costs for personal care under the consumer-directed program.

Cash & Counseling programs in Arkansas, Florida, and New Jersey have been funded by the Robert Wood Johnson Foundation in Princeton, NJ, as demonstrations of the concept of giving Medicaid enrollees who qualify for personal care an allowance and a high degree of freedom in choosing personal care assistants and managing their personal care needs.

Cash & Counseling national demonstration director **Kevin Mahoney**, who leads the program from the Boston College Graduate School of Social Work, says those who organized the demonstrations knew consumers would benefit if they could make their own choices about how their personal care needs are met. "But we weren't so sure what would happen to Medicaid costs," he adds. "We're thrilled to discover that under Cash & Counseling, consumers can get more personal care services at no more cost to Medicaid."

The latest of the demonstrations to be evaluated compared the level and cost of personal care services provided through consumer- and agency-directed approaches.

An earlier look at the Arkansas program found that it greatly improved quality of life, reduced unmet needs for care, and did not compromise patients' health or safety.

Not enough agency workers

The current study found that home care agencies in Arkansas delivered only two-thirds of the personal care services to which consumers were entitled, with some consumers receiving no services at all. This was partly because of a

shortage of personal care workers, the study found. More consumers who hired their own personal care assistants were able to receive services in the evenings and on weekends.

The differential in the amount of services provided resulted in the consumer-directed care approach costing more than \$2,000 more than the agency model in both the first and second years after enrollment. By the second year after enrollment, however, these higher personal care expenditures were offset by reductions in expenditures on nursing home care and other Medicaid services.

The evaluation team was led by **Randall Brown**, a Mathematica Policy Research senior fellow in Princeton, NJ, and professor at Rutgers University. His report notes that states are increasingly interested in improving the well-being of beneficiaries who are eligible for personal care services by allowing them to plan and direct their own care. Advocates for consumer-directed care contend that individuals, rather than agencies, are best suited to make decisions about the care they receive and the workers they hire.

"However," the report cautions, "critics are concerned that consumers might misuse the funds intended for their care, receive inadequate care, or use a cash benefit to pay family members to provide care once provided by them for free. States are wary that the program might raise total Medicaid costs."

The IndependentChoices program in Arkansas was open to adults at least 18 years old who were otherwise eligible for personal care services under the state's Medicaid plan. Some 11% of personal care services users (2,008 beneficiaries) enrolled in the demonstration between December 1998 and April 2001. Control group members continued relying on agency services, or, if newly eligible for Medicaid personal care, received a list of home care agencies to contact for first-time services.

Helping patients develop plans

Treatment group members were contacted by a counselor to help them develop written plans for spending their allowance. Such plans could include hiring workers (excluding spouses or representatives) and purchasing other services or goods related to their needs, such as supplies, assistive devices, and home modifications. Counselors also monitored satisfaction, safety, and use of funds.

Brown says the evaluation team found the

program greatly increased the likelihood that beneficiaries received paid assistance. Elderly community residents in IndependentChoices were much more likely than those in the control group to receive paid assistance during their two most recent weeks at home before an evaluation interview nine months into the program. The difference for nonelderly beneficiaries was even larger.

“The lack of any paid assistance among control group members was striking,” Brown writes in his *Health Affairs* web-exclusive evaluation report, “particularly among new applicants — those who were not receiving publicly funded home care services when they enrolled in the demonstration (about a quarter of the sample). Fifty-one percent of new applicants in the control group, compared with only 8.1% of new applicants in the treatment group, did not have a paid caregiver nine months after enrollment, despite being eligible for personal care services. Among those receiving publicly funded home care at enrollment, the treatment-control difference in the percentage of consumers without paid assistance at nine months was statistically significant but much smaller (5.1% for treatments vs. 13.7% for controls).

“Among treatment group members, about two-thirds hired family members, and most others hired friends or acquaintances. A minority of those hired lived with the treatment group member,” he explains.

IndependentChoices was found to expand the provision of care during hours that agencies didn’t operate and also affected the way that nonelderly people met their personal assistance needs.

Control group received less care

Medicaid expenditures were larger for the treatment group, because the control group received a smaller-than-expected share of the services authorized for them. Control group members received much less care than was authorized, resulting in annual Medicaid personal care services spending per sample member that was almost twice as high for the treatment group as for the control group during the first year after enrollment.

Brown says lower long-term care costs for treatment group members suggest that Cash & Counseling enables consumers to substitute personal care services at home for other, more costly

services, particularly those provided in nursing facilities.

While it is not clear how much the Arkansas results can be generalized because other programs have varying features that could affect the outcome, Brown says the findings for IndependentChoices are clear: “The program greatly increased consumers’ access to care and ability to purchase needed equipment and supplies. However, the results raise two issues that could concern policy makers:

- Paid care could substitute for previously unpaid care.
- Consumer direction could raise Medicaid spending.”

According to Brown, some people question why enrollees should be allowed to pay family members for care they should be expected to provide without compensation.

“It’s a reasonable concern,” he says, “but the truth is that families are providing 80% of care, even if a patient gets agency care. These are benefits that patients are entitled to, and I think it is shortsighted to worry too much about whether patients are paying family members for care they should [receive].”

System has failed

The reason Medicaid expenditures for personal care services went up in the demonstration, he adds, is that the traditional system has failed, and patients were unable to get the services they needed and were entitled to — perhaps because agencies are stretched too thin and there are no workers available. Even if they are hiring relatives, he says, they are receiving the services they need under IndependentChoices. And increases in personal care services costs pay off in lower costs elsewhere in the health care system, Brown says.

“You can provide much better care and relieve a burden on families, although costs are up; but that is offset by savings in nursing home costs,” he notes. “In 27 years of evaluating public programs, I have almost never seen one this successful. This is a program that seems to benefit everyone. There are no losers. We can’t find a downside, and we looked very hard because we have no ax to grind and are not trying to promote this or any other particular program.”

Brown and his colleagues conclude that Arkansas’ experience demonstrates that states can design a Cash & Counseling program that

meets recipients' needs better at no greater cost per month of service than costs historically incurred under the traditional agency approach.

"Even if total costs for personal care services are higher than they would have been as a result of the improved access to care or induced demand, they appear to be offset by reduced need for long-term care services," the report says. "The better the traditional agency model is at meeting authorized needs, the greater the likelihood of immediate savings from a Cash & Counseling alternative. The worse the agency model performs, the greater the likelihood that spending will increase initially under the Cash & Counseling model, but the greater the need for this option to ensure adequate access to home care as an alternative to higher-cost Medicaid services, especially nursing home care."

Program wins award

The Arkansas program won the Council of State Governments 2003 Innovations Award, granted in recognition of innovations in state government.

The U.S. Department of Health and Human Services (HHS) has taken action to help more states develop consumer-directed services along the lines of a Cash & Counseling program. The department's Independence Plus waiver program, introduced in 2002, established a process for states to obtain authorization to operate such programs. In the fall of 2003, the Centers for Medicare & Medicaid Services awarded \$5.4 million in Independence Plus grants to 12 states to support such efforts.

In addition, President Bush has proposed changes to the Medicaid program that the administration says would give states more flexibility to implement programs such as this without obtaining permission from HHS. ■

HIPAA Q&A

[Editor's note: This column addresses specific questions related to Health Insurance Portability and Accountability Act (HIPAA) implementation. If you have HIPAA-related questions, please send them to Sheryl Jackson, Thomson American Health Consultants, P.O. Box 740056, Atlanta, GA 30374. Fax: (404) 262-5447. E-mail: sherylsjmjackson@cs.com]

Question: Does the HIPAA security rule prohibit transmission of protected health information (PHI) by e-mail?

Answer: No. "The security rule requires covered entities to address the security of electronic transmission of PHI," says **Robert W. Markette, Jr.**, an Indianapolis-based attorney. Depending upon a covered entity's perception of the threat, the home care agency may decide to implement encryption or some other security feature, he says. However, encryption is not a required standard, he adds.

"In the comments on the security rule, the Department of Health and Human Services [HHS] stated that one of the reasons they were not requiring encryption was the prevalent use of e-mail by rural providers to communicate with patients," Markette says. These comments from HHS recognize that PHI will be transmitted by e-mail, he adds.

Question: Are health organizations responsible for the protection of unsolicited e-mails sent by patients?

Answer: Once a home care agency comes into possession of electronic PHI, such as e-mail from a patient, the organization must protect it, Markette explains. "However, the agency is not responsible for the security of the information as it is transmitted from patient to the entity," he adds.

Question: If an employee, other than field staff, works out of his or her home, either full-time or part-time (e.g., during maternity leave, on weekends or evenings, or as part of a telecommuting job description), do the HIPAA security regulations apply? If so, how do we ensure compliance?

Answer: If the employee is working at home with PHI, then the security regulations do apply, according to Markette. Compliance will depend upon a number of factors:

- Does the employee access PHI remotely?
- Does the employee maintain PHI on her home PC?
- Who in the home can access that PC?

"If the employee is accessing PHI remotely, I would recommend at least evaluating the security of PHI in transit," says Markette. "If you have concerns about the security of that transmission, you might consider steps to increase the security," he suggests. There are numerous technologies that could work in this environment, and each entity will need to assess the risks and

determine an appropriate operating procedure, he adds. You also may want to establish password-protected access if other people have access to the employee's computer. ■

News From the End of Life

CMS tightens rules for processing claims

The Centers for Medicare & Medicaid Services (CMS) has published an educational article explaining the changes to the Health Insurance Portability and Accountability Act (HIPAA) claims processing requirements that will take effect on July 6, 2004. The changes affect all health care providers that bill Medicare fiscal intermediaries.

Medicare will now require certain data elements that are not needed for payment of Medicare claims but are required by HIPAA. Data that Medicare previously allowed but that are not permitted by HIPAA will result in claims rejection. Also, data that Medicare now edits only for syntax will be edited for content and will result in claims rejections if the data are not valid.

Examples of changes that can result in claims rejections after July 6 include:

— For all home health claims, all line items must contain a date or dates of service for each revenue code, or it will be rejected.

— Any claims that are not inpatient claims containing Covered Days (QTY Segment) will be rejected.

To view the article and for links to more technical documents related to the change, go to www.cms.hhs.gov/medlearn/matters/mmarticles/2004/MM3031.pdf. ▼

Upcoming hospice educational events

• The First National Conference on Pediatric Palliative and Hospice Care will be held Nov. 12-14 at the Hyatt Regency Dearborn, Dearborn, MI. This conference will comprise approximately two and a

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half days of plenary and concurrent sessions. It is jointly sponsored by the National Hospice and Palliative Care Organization and the Michigan Hospice and Palliative Care Organization.

Areas of emphasis include neonatal and pediatric pain and symptom management, spiritual needs, the role of advocacy, innovative collaborations, effective communication, bereavement, staff education, and research projects.

• The National Hospice and Palliative Care Organization offers frequent audio conferences. Upcoming topics are:

— May 13, "Updates in Pediatric Pain Control";

— May 25, "Your Fiscal Intermediary and You";

— June 10, "Palliative Approaches in End-Stage Respiratory Disease";

— June 22, "General Inpatient Care."

For further information on these sessions, see: www.nhpc.org/templates/1/homepage.cfm. ■

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