



“Suffering from a terminal illness involved four different sources of pain: physical, emotional, spiritual and social.”

—Cicely Saunders



Understanding Total Pain

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No -- this article is not about professional wrestling, your kid brother, or what the nurses think about the

medical director. The concept of total pain is the basis for the hospice approach to caring for people at the end of life.

Dr. Cicely Saunders is an English physician who developed the concept of treating total pain. (She began her career as a nurse, then became a social worker and finally a physician. If she could have squeezed in religious training she could have been a hospice team on her own.) She put forth that suffering from a terminal illness involved four different sources of pain: physical, emotional, spiritual, and social.

Physical symptoms are perhaps the most obvious and most thought of causes of suffering, but the others are equally important. All four sources of pain can worsen each of the others or, if improved, help lessen the others. For example, uncontrolled physical symptoms can cause depression, anxiety and affect personality. Relieving those symptoms can do a lot to improve people emotionally and socially.

Loss of social relationships (work, contacts outside of the home, hobbies, independence) cause stresses that lead to physical symptoms, faith issues, and depression. Financial issues can do the same and are very common.

Spiritual issues about “why me?” the afterlife, the quality of one’s life, one’s relationship (or lack of) with God can frustrate attempts to treat other sources of pain. Pain medicine may be less effective until spiritual issues are addressed. Some patients can feel they are being punished or tested and won’t take medicine to counteract what seems to be God’s intent.

Emotional pain such as anxiety or depression can degrade social relationships, spiritual beliefs, and negatively impact physical symptoms.

If you only treat one type of pain, a patient and caregiver are unlikely to achieve the best possible quality at the end of their life. Consider the core members of the hospice team and you will note that the concept of total pain is the foundation of our patient care: social worker, spiritual care counselor, nurse, and physician. They each have their area of expertise but they interconnect in a complimentary fashion to provide more relief of suffering than any one team member could do on their own.



Paying for End of Life Care

Educating your patients

Many of your patients are certainly wondering how they will pay for the rising costs of health care. Concerns over these costs are shared not only by elected officials but by almost every family across the country. Many baby boomers are providing care for their aging parents just as they are facing their own health care issues.

Yet, for more than 25 years, the Medicare Hospice Benefit has provided a model for financing end-of-life

care that can bring great relief and support to families during one of life’s most difficult times.

This benefit covers virtually all aspects of hospice care with little out-of-pocket expense to the patient or family. As a result, the financial burdens often associated with caring for a terminally-ill patient are lifted.

Hospice care also offers supports to the loved ones of the patient; this brings an added level of relief to

continued on back

Physicians Report High Level of Involvement in Palliative Care

A significant majority of physicians who treat large numbers of hospitalized patients with advanced disease report that they are highly involved in palliative care and feel comfortable managing many of the symptoms that frequently occur with this group of patients. This is according to a study published in the March 2009 edition of the *Journal of Palliative Medicine*.

Researchers interviewed 74 physicians who regularly treat patients at New York Presbyterian Hospital. One group of physicians (n=50) had previously referred one or more patients to the hospital's inpatient Palliative Care Consult Service (PCCS), while the other group (n=24) had never referred a patient to the PCCS.

From the interviews, investigators hoped to determine:

- Physicians' involvement and comfort levels with delivering palliative care in a hospital setting
- Which barriers prevented physicians from referring patients to the PCCS
- Physicians' attitudes toward palliative care

Key Findings

There were several similarities in comfort level reported by both referring and non-referring physicians:

- Both groups reported that they are directly involved in providing palliative care for seriously ill patients.
- Both also indicated that they are comfortable managing most of the symptoms that their patients experience.
- Both groups of physicians were less involved and less comfortable in managing delirium and addressing existential and spiritual concerns.

However, the major difference between the two groups regarding involvement and comfort level centered around dealing with end-of-life issues. Referring physicians were more involved and comfortable with discussing end-of-life care and hospice care with patients and their families. They also reported more involvement and a higher comfort level with coordinating meetings with dying patients and their families.

Perceived Barriers

Referring physicians most frequently reported the following barriers: referring and non-referring physicians:

- Patients' and/or families' perceived unrealistic expectations regarding disease prognosis (84%)
- Inability to prognosticate (32%)
- Unfamiliarity with palliative care consult team (24%)

The most common barriers reported by non-referring physicians were:

- Unfamiliarity with palliative care consult team (50%)
- Patients' and/or families' perceived unrealistic expectations regarding

disease prognosis (42%)

Researchers conclude that coordinators of the inpatient palliative care service could take several steps to increase the number of physician referrals. For example, they could offer consults for dealing with specific symptoms such as delirium and spiritual issues, produce brochures or conduct presentations to introduce the PCCS to all physicians in the hospital, and work directly with physicians "...to understand what role the service could play in helping to address the barrier of patients' and families' unrealistic expectations."

Source: "Identifying Factors Affecting Utilization of an Inpatient Palliative Care Service: A Physician Survey," Journal of Palliative Medicine; February 2009; 12(3):231-237. Snow CE, Varela BR, et al; Division of Geriatrics, Weill Medical College of Cornell University, Weill Cornell Medical Center; New York, New York.

Physician Attitudes Toward Palliative Care

- 50% of referring physicians and 58% of non-referring physicians stated that they had not been adequately trained in palliative care.
- 50% of referrers and 75% of non-referrers expressed the belief that "All physicians should be expert" at managing physical/psychological symptoms for seriously ill patients.
- 80% of referrers and 79% of non-referrers did not believe that most of the physicians they know are expert in managing physical/psychological symptoms. Only about one-third of each group considered themselves to be expert in management of these symptoms.
- 66% of referrers and 57% of non-referrers found providing end-of-life care satisfying.
- 94% of referrers and 96% of non-referrers believe that patients can benefit from a multi-disciplinary approach to treatment.
- Most physicians agreed that palliative care can coexist with oncology/medical therapeutics without undermining existing relationships between patient and physician.
- 29% of non-referring physicians disagreed with the statement that palliative care is best coordinated by a palliative care specialist, compared with 8% of referring physicians. *Physician Attitudes Toward Palliative Care*

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CONGRESSIONAL HOSPICE CHAMPIONS SEND LETTER TO PRESIDENT OBAMA URGING ACTION TO STOP FUNDING CUTS.

171 Members Sign Hospice Letter to Protect Access to High-Quality & Compassionate End-of-Life Care

(Alexandria, Va) – A bipartisan group of 171 Members of the U.S. House of Representatives sent a letter to President Barack Obama showing their support to protect access to high-quality end-of-life care for the 1.4 million patients, and their families, who depend on hospice each year. In the letter, lawmakers urged the President to stop cuts to the Medicare hospice benefit scheduled to begin on October 1, 2009, which threaten to jeopardize the compassionate care the nation's hospices provide to the dying.

The letter was spearheaded by Representatives Chris Van Hollen (D-MD) and Ginny Brown-Waite (R-FL). A similar bipartisan letter is also gathering signatures in the U.S. Senate.

Over the past year, the National Hospice and Palliative Care Organization, the Alliance for Care at the End of Life, and thousands of Hospice Advocates from across the country have been working to overturn a 2008 rule issued by the Centers for Medicare and Medicaid Services under the direction of the Bush Administration. The rule eliminates a key component of the Medicare hospice benefit known as the budget neutrality adjustment factor (BNAF).

President Obama and Congress approved a moratorium on the hospice funding cuts earlier this year, but it expires on September 30, 2009. Without action by the Administration and

Congress, hospice reimbursements through Medicare will be reduced by 3.1 percent in fiscal year 2010, leaving hospice programs nationwide, particularly smaller and rural ones, facing cutbacks in services and possible closure.

“In a year when lawmakers are looking for answers when it comes to health care reform, hospice is part of the solution. It is a model for the expansion of high-quality and cost-efficient health care, and protecting patient access to hospice should be a national priority. This bipartisan letter demonstrates that President Obama has Congressional support to permanently put a stop to the devastating hospice funding cuts looming before us,” said J. Donald Schumacher, president and CEO of NHPCO.

Hospice is a proven Medicare cost saver. In 2007, an independent, Robert Wood Johnson Foundation-funded study by Duke University found that hospice reduced Medicare costs by \$2,300 per patient, amounting to more than \$2 billion in savings per year.

Considered to be the model of high-quality care at the end of life, hospice involves a team-oriented approach to care that includes expert medical attention, pain and symptom management, and emotional and spiritual support. Research from NHPCO shows that 98 percent of families served by hospice are willing to

recommend its care and services to others.

“There are few segments of the health care industry that receive such high marks from family caregivers, provides dignity and compassion, and saves the federal government money,” Schumacher added.

In April, more than 700 hospice providers from across the country visited their Representatives and Senators urging them



Mark Murray, President & CEO of the Center for Hospice and Palliative Care (CHAPC) and Don Schumacher, President & CEO of the National Hospice and Palliative Care Organization, Washington, DC, take a moment during Schumacher's June 17 visit to CHAPC.

to protect hospice as part of NHPCO's annual Capitol Hill Day. In addition to the meetings in Washington, D.C., thousands of phone calls were made through NHPCO's first Virtual Hill Day. Grassroots advocacy efforts will continue as the hospice community turns its efforts towards gaining support for the Senate letter.

Currently, no Indiana representatives have signed on to either letter.



On June 17, Don Schumacher, President & CEO of the National Hospice and Palliative Care Organization, Washington, DC, presented to CHAPC staff and area healthcare executives about end of life care and health care reform.

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Paying For End of Life Care (Continued)

the dying person, knowing their loved ones are being cared for as well.

Hospice is paid for through the Medicare Hospice Benefit, Medicaid Hospice Benefit, and most private insurers. In addition, most private health plans and Medicaid in 47 States and the District of Columbia cover hospice services. If a person does not have coverage through Medicare, Medicaid or a private insurance company, hospices will work with the person and their family to ensure needed services can be provided.

Medicare covers these hospice services and pays nearly all of their costs:

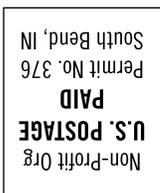
- Doctor services
- Nursing care
- Medical equipment (like wheelchairs or walkers)
- Medical supplies (like bandages and catheters)
- Drugs for symptom control and pain relief
- Short-term care in the hospital, including respite and inpatient for pain and symptom management
- Home health aide and homemaker services

- Physical and occupational therapy
- Speech therapy
- Social work services
- Dietary counseling
- Grief support

Medicare will still pay for covered benefits for any health problems that aren't related to a terminal illness.

Hospice and palliative care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Families making end-of-life decisions for a loved one need compassion and support, not financial worries. The Medicare Hospice Benefit helps alleviate these concerns.

For more information, contact The Center for Hospice and Palliative Care, Inc. at 800-413-9083. This information is provided by the National Hospice and Palliative Care Organization and The Center for Hospice and Palliative Care.



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