End-of-Life Pain/Hospice & Palliative Care

Hospice, end-of-life care and palliative care are often used interchangeably, but there are differences in what each of these terms means.

One common component is that they employ efforts to control pain, and that these efforts are not intended to cure an underlying disease or condition.

End-of-life care describes the comprehensive process of attending to the overall needs of a dying patient. Although end-of-life care is often administered in an acute care setting, palliative care is increasingly being used to deliver high-quality, cost-effective care at the end-of-life within the confines of a patient's home or a hospice. Ultimately, end-of-life care strives to preserve patient dignity at the end-of-life by providing pain and symptom control.[1]

The National Hospice and Palliative Care Organization (NHPCO) describes hospice in the following way: Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the person's needs and wishes. Support is provided to the person's loved ones as well.[2]

- The focus of hospice relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.
- Hospice focuses on caring, not curing and, in most cases, care is provided in the person's home.
- Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race, or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Hospice is defined by Medicare as "care for individuals whose physician certifies that they have less than 6 months to live if the disease runs its normal course." The focus is on comfort and not extension of life.[3]

In the hospice setting, the majority of patients are older adults, many with advanced cancer. One of the priorities of hospice is to assure safe and comfortable dying and although pain outcomes are better in hospice than non-hospice settings, there remains considerable variation. Patients in hospice still die with poorly controlled pain.[4]

What is Palliative Care?

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with lifethreatening illness, through the prevention and relief of suffering by means of early identification and impeccable

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assessment and treatment of pain and other problems, physical, psychosocial and spiritual. A person can receive palliative care at any time during an illness, and does not have to be at the end of their life.[5]

According to WHO, Palliative Care:[5]

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Facts

- The NHPCO estimates that in 2012, approximately 1.5 to 1.6 million patients received services from hospice.[6]
- NHPCO estimates that approximately 1,113,000 deaths occurred in the U.S. while under the care of hospice.[6]
- The majority (66.0%) of hospice patient care was provided the patient's place of residence, including private home, nursing home or residential facility.[6]
- Annually, more than 1.6 million residents receive care in nearly 18,000 U.S. nursing homes. Given that most residents are adults 65 years of age or older and have high chronic disease burden, at least 30% of Americans die in the nursing home setting. This has led to increasing availability of hospice and palliative care in nursing homes.[7]
- The National Center for Health Statistics included a special feature on Death and Dying in their 2011 data publication. The report states that controlling pain and other distressing symptoms near the end-of-life is a major concern identified by hospice care patients and their family members and by hospice care personnel. Nearly 90% of hospice care patients in 2007 had their level of pain assessed at the time of their admission to hospice care services. Despite this, one-third of hospice care patients had pain near the time of their death.[10]
- Although managing pain is a priority in hospice,

A landmark study published in 1995 called the SUPPORT trial found that half of all hospitalized patients experienced pain in the last days of their lives.[8]

With these findings in mind, researchers more recently looked at pain and end-of-life (EOL) care in 2012, and found that, sadly, little has changed in the nearly two decades since data from the SUPPORT trial were published. Findings include:[9]

- 41.3% hospitalized people receiving EOL care had a pain diagnosis
- the percentage of EOL patients with pain was lower (27.7%) for those with ''acute confusion''
- additionally, 30% of EOL patients had severe or significant pain at death or discharge to hospice and only 42.7% actually met the expected pain-related outcome ratings
- pain often improved within 48 hours of admission; the improvement, however, stagnated following this initial time period

The 2012 study concluded that a sizable gap between pain science and clinical practice continues today.

findings from one study suggest that recommended evidence-based practices for assessment and management of pain in older persons with cancer are not being fully implemented, or if they are, they are not being documented. While data suggest more than 70% of patients had their pain controlled throughout their first two weeks after hospice admission, the lack of documentation of pain intensity ratings bring into question the degree of pain that may have been overlooked.[11]

Hospice and Caregiver Pain Management Concerns

- One study of caregivers in a hospice setting found that while only a small percentage expressed concern about communicating information about the patient's pain, more than a quarter were concerned about addiction, tolerance, and side effects from medications.[13]
- One-fourth of the caregivers had difficulty administering medications because of fear of doing something wrong and difficulty deciding which or what amount of medications to give. Male caregivers and hired caregivers had greater concerns, both about reporting information about the patient's pain and administering medications.[13]
- Caregivers in the home were significantly more concerned about addiction and the belief that pain could not be controlled than were staff nurse caregivers in skilled care facilities. Caregivers who had greater concern about addiction and tolerance, and more difficulty administering medications, rated the patient's pain as less completely controlled.[13]
- One study of social workers who work in a hospice setting found that respondents reported devoting approximately 21% of their time to pain management issues. In contrast, they reported wishing they could spend 28% of time handling pain management concerns. On a scale of 1 (never discuss) to 10 (always discuss), social workers reported a mean of 7.58 relative to the frequency of discussion with the caregiver about physical pain. Similarly, they reported:[14]

  – 8.2 for discussions of psychological pain

  – 7.5 for social pain, and

  – 6.2 for spiritual pain

NHPCO Facts and Figures: Hospice Care in America[6]

Location of Death	2012	2011
Patient's Place of Residence	66.0%	66.4%
Private Residence	41.5%	41.6%
Nursing Home	17.2%	18.3%
Residential Facility	7.3%	6.6%
Hospice Inpatient Facility	27.4%	26.1%
Acute Care Hospital	6.6%	7.4%

"The American Society for Pain Management Nursing (ASPMN) holds the position that nurses and other health care providers must advocate for optimal pain and symptom management to alleviate suffering for every patient receiving end-of-life care."[12]

Additional Resources

AARP
601 E Street, NW
Washington, DC 20049
Phone: (888) 687-2277
E-mail: member@aarp.org
Twitter: @AARP
www.aarp.org

Administration for Community Living
Washington, DC 20201
Phone: (202) 619-0724
Fax: (202) 357-3555
E-mail: aclinfo@acl.hhs.gov
Twitter: @ACLgov
www.acl.gov

American Academy of Hospice and Palliative Medicine
8735 West Higgins Road
Suite 300
Chicago, IL 60631
Phone: (847) 375-4712
Fax: (847) 375-6475
E-mail: info@aahpm.org
Twitter: @AAHPM
www.aahpm.org

American Cancer Society
250 Williams Street, NW
Atlanta, GA 30303
Phone: (800) 227-2345
E-mail: Via website
Twitter: @AmericanCancer
www.cancer.org

American Cancer Society Cancer Action Network
E-mail: Via website
Twitter: @ACSCAN
www.acscan.org

American Society of Clinical Oncology
2318 Mill Road
Suite 800
Alexandria, VA 22314
Phone: (571) 482-1300
E-mail: Via website
Twitter: @ASCO
www.asco.org

Capital Caring
2900 Telestar Court
Falls Church, VA 22042
Phone: (703) 538-2065
E-mail: Via website
Twitter: @CapitalCaring
www.capitalcaring.org

Caregiver Action Network
2000 M Street
Suite 400
Washington, DC 20036
Phone: (202) 772-5050
E-mail: info@caregiveraction.org
Twitter: @CaregiverAction
www.caregiveraction.org

C-Change
1634 Eye Street, NW
Suite 800
Washington, DC 20006
Phone: (202) 349-0902
Fax: (202) 347-5266
E-mail: Via website
Twitter: @CChangetogether
www.c-changetogether.org

Center for Practical Bioethics
Harzfeld Building
1111 Main Street
Suite 500
Kansas City, MO 64105-2116
Phone: (800) 344-3829
Phone: (816) 221-1100
Fax: (816) 221-2002
E-mail: Via website
Twitter: @PracBioethics
www.practicalbioethics.org

Center to Advance Palliative Care
55 West 125th Street
13th Floor
Suite 1302
New York, NY 10027
Phone: (212) 201-2670
E-mail: capc@mssm.edu
Twitter: @CAPCpalliative
www.capc.org

Additional Resources

Hospice and Palliative Nurses Association
1 Penn Center West
Suite 229
Pittsburgh, PA 15276
Phone: (412) 787-9301
E-mail: Via website
Twitter: @HPNAinfo
www.hpna.org

The Hospice Association of America
228 Seventh Street, SE
Washington, DC 20003
Phone: (202) 547-7424
Fax: (202) 547-3540
E-mail: Via website
Twitter: @OfficialNAHC
www.nahc.org

The Hospice Education Institute
3 Unity Square
P.O. Box 98
Machiasport, ME 04655–0098
Phone: (800) 331–1620
Phone: (207) 255–8800
Fax: (207) 255-8008
E-mail: info@hospiceworld.org
www.hospiceworld.org

Hospice Net
401 Bowling Avenue
Suite 51
Nashville, TN 37205–5124
E-mail: info@hospicenet.org
www.hospicenet.org

Resources verified April 2014.

Institute on Care at the End-of-Life
Duke Divinity School
407 Chapel Drive
Duke Box 90968
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Phone: (919) 660-3400
Fax: (919) 660-3473
E-mail: iceol@div.duke.edu
Twitter: @DukeDivinity
www.divinity.duke.edu

International Association for the Study of Pain
1510 H Street, NW
Suite 600
Washington, DC 20005
Phone: (202) 524-5300
Fax: (202) 524-5301
E-mail: IASPdesk@iasppain.org
Twitter: @IASPPAIN
www.iasp-pain.org

International Association of Hospice and Palliative Care
5535 Memorial Drive
Suite F-PMB 509
Houston, TX 77007
Phone: (866) 374 2472
Phone: (936) 321-9846
Fax: (713) 880-2948
E-mail: Via website
Twitter: @IAHPC
www.hospicecare.com

LIVESTRONG Foundation
2201 East Sixth Street
Austin, TX 78702
Phone: (877) 236-8820
E-mail: Via website
Twitter: @LIVESTRONG
www.livestrong.org

National Hospice and Palliative Care Organization
1731 King Street
Alexandria, VA 22314
Phone: (703) 837–1500
Fax: (703) 837-1233
E-mail: nhpco_info@nhpco.org
Twitter: @NHPCO_news
www.nhpco.org

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