

COMPdata Monthly Monitor - Montana
October 2004
End-of-Life Care

Introduction

For hospital providers, end-of-life care refers to palliative care or hospice care or a combination of the two. Each is considered to be a model for quality, compassionate care for people facing a life-limiting illness or injury and involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.¹ One distinguishing feature of palliative care is that its benefits can be extended to a broader population that could benefit from receiving this type of care earlier in their illness or disease process.

While hospice care may be the ideal approach for most patients approaching the end-of-life, hospice care is not available at all hospitals and communities. More than 30% of Montana hospitals report that hospice service is not available to patients in their community.² Despite the success of the Medicare Hospice Benefit since its enactment in 1982, there are still barriers that prevent patients from accessing hospice care when needed. Among these barriers are:

- The Medicare requirements for hospice care such as certification of terminal illness and the foregoing of curative treatment for their terminal condition can result in real and perceived restrictions in access and eligibility.
- Patients younger than 65 may not have insurance coverage for hospice care. Funding for hospice and other end-of-life programs is often dependent on donations and private grants.
- Many patients who die in the hospital are emergency cases with relatively short lengths of stay where advance planning for hospice care may not have taken place.

The Need for End-of-Life Care

Despite the great potential for palliative care in the hospital setting, most hospitals do not have a formal palliative care program established.² Many of these hospitals do have an established relationship with a hospice program but there are still significant gaps in the system, especially from the perspective of patients and families. A 2002 Robert Wood Johnson funded study found the following:³

- Nationally, 25% of deaths occur at home, although more than 70% of Americans say that this is where they would prefer to die.
- About one-half of all deaths occur in hospitals.
- Between 16 and 37 percent of deaths among Medicare recipients in any given state include hospitalization in an intensive care unit during the last six months of life. ICU care is often uncomfortable and unwanted: A study of cancer patients in the ICU found that 55 to 75 percent had moderate to severe pain, discomfort, anxiety, sleep disturbance or unsatisfied hunger or thirst. Pain management has become a focal point for hospitals today as both the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) and Medicare have pain management guidelines and JCAHO has specific standards for pain management.

The fact that end-of-life care really matters to people was highlighted in a recent study that found that respondents to a survey were willing to trade an average of 8 months of good health for better care in an ICU at the end of their life.⁴ The key services that palliative care provides and that studies have found that patients want are:⁵

- Vigorous treatment of their pain and symptoms.
- Relief from worry, anxiety, and depression.
- Communication about their care over time.
- Coordinated care throughout the course of an illness.
- Support for family caregivers.
- Practical support.
- A sense of safety in the health care system.

The Aging Population

It's no secret that the U.S. population is aging, there are 40 million seniors today and that number is expected to double in the next 30 years. The emphasis on living and dying well will only increase among this group. More information for seniors is needed so that patients and families can make educated decisions about their end-of-life care. The more that hospitals can adopt the mindset that dying is a natural part of life and translate that to their patients, the better the end-of-life experience will be for everyone.

The other impact that the aging of the population will have is that there will be many more patients with complex, chronic illnesses. It is with these patients that palliative care is not necessarily used as an alternative to curative care but complements such medical treatment.

Hospital-Based End-of-Life Care

There are at least three key reasons that hospitals should have palliative care programs:⁶

- Hospitals are where the most severely ill patients are. Palliative care is necessary, whether its complementing life-prolonging care or delivering comfort, care, and aid to dying patients and their families.
- Hospitals are where the most money is being spent. Enormous resources are expended on the seriously ill, especially Medicare beneficiaries. Palliative care programs have great potential for making end-of-life care more efficient.
- Hospitals are the best place to plan for the next phase in the care continuum. A health crisis is what brings most patients to the hospital. Palliative care programs ensure that patients make a smooth transition to the next phase of care, such as hospice, home care, or a nursing home. In addition, a hospitalization is an opportunity to reassess the care-giving situation and to provide family caregivers with referrals and resources to help them in the community.⁷

The Center to Advance Palliative Care also cites seven benefits to hospitals that implement hospital-based palliative care programs:⁸

- Lower costs for hospitals and payers.

- A systematic approach to caring for outlier patients.
- Flexible programs support the primary care physician.
- Increased patient and family satisfaction.
- Meeting JCAHO accreditation standards.
- Easing of burdens on staff, increased retention.
- Meeting the needs of an aging population.

There is in fact growing interest among hospitals in the development of palliative care and other end-of-life programs. Several demonstration and development projects have received significant grant funding, particularly through the Robert Wood Johnson Foundation. The Foundation's Promoting Excellence in End-of-Life Care (<http://www.promotingexcellence.org>) has provided \$15 million in grants and technical support to innovative programs to improve end-of-life care programs in America. Hospitals have also been a major part of other RWJF initiatives to improve the provision of palliative care through Community State Partnerships, the Center for the Advancement of Palliative Care, and Last Acts (which recently combined with the Partnership for Caring to create the Last Acts Partnership – see Current and Future Activities in the Appendix). In addition the Agency for Healthcare Research and Quality has funded a three-year grant to create the Hospital-Based Palliative Care Consortium (<http://www.hbpcc.org>), a program established by the Hospital & Healthsystem Association of Pennsylvania. (See Resources for Hospitals in the Appendix for more information.)

As seen in some of these innovative projects, the best palliative care programs take full advantage of all resources available in the community. When possible this often entails developing partnerships with hospice organizations. Integrating hospice care with a hospital-based end-of-life care program can result in the most effective care for both dying patients and their families. Examples of such programs can be found in the Appendix under What Some Hospitals Are Doing Today.

Lastly, the importance of end-of-life care is highlighted by the fact that it is becoming an increasingly visible issue among the public, the media, payers, and regulators. For example,

- The U.S. News & World Report ranking of top hospitals now includes palliative care programs as one of its criteria.
- The American Hospital Association in conjunction with the American Medical Association, the American Association of Homes and Services for the Aging, and the National Hospice and Palliative Care Organization annually honors innovative programs that have improved the care people receive near the end of their lives whether in hospital, hospice, nursing home, or home with the Circle of Life Award. The award is sponsored by the Robert Wood Johnson Foundation. More information is available at http://www.aha.org/aha/awards-events/circle_of_life/index.html.
- In its June 2004 report to Congress, the Medicare Payment Advisory Commission (MedPAC) reiterated its call for the Secretary of Health and Human Services to make end-of-life care a national quality-of-care improvement priority for Medicare.

Montana Inpatients: End-of-Life Care and Mortality Statistics

(Note: All of the following statistics exclude newborns and obstetric cases – Major Diagnostic Categories 14 and 15.)

Of the 81,453 patients discharged from Montana hospitals in 2003, 1,899 patients died (2.3%). This is a slight decline in the overall mortality rate compared to 2000 when 1,981 patients died out of 76,819 patients (2.6%). Of the patients who died in 2003, the discharge record indicated that 103 (5.4%) received end-of-life care (ICD-9 secondary diagnosis code of V66.7). ICD-9 code V66.7 ("Encounter for palliative care") should be used as a secondary diagnosis when a physician documented any of the following services: palliative care, end-of-life care, hospice, comfort care, or terminal care.

This very low percentage of dying patients receiving end-of-life care is likely due to the underreporting of this service on the UB-92 discharge record. Clearly, hospitals are providing this type of care to many more patients. This finding should not be taken lightly however. As more organizations scrutinize the extent to which hospitals provide this important care to patients and families, it is imperative that hospitals document this activity and include it on the UB-92 record. Of all other patients who did not die, 63 received end-of-life care according to the discharge record.

Detailed Statistics. The following hospital statistics explore in more detail the characteristics of the 81,453 patients who died. The information for patients receiving end-of-life care will not be broken out due to the small number of records.

More than one-half (54.6%) of the patients who died were older than 75 years. Another 21.6% were between 65 and 74 years of age and 18.0% were 45 to 64 years. Only 5.8% were younger than 45 years of age. Thus, more than 75% of those who died were 65 years or older and potentially eligible for the Medicare Hospice Benefit.

Slightly more men than women died during 2003 (51.1% versus 48.9%, respectively.)

The majority of these patients (58.6%) were admitted through the emergency room of the hospital. Most of the rest were admitted through a physician's referral (30.1%) or were transferred from another hospital (6.0%). For the patients who died, a greater percentage were admitted through the ER or were transferred from another hospital than for patients who survived. For the patients who survived just under one-half (47.0%) were admitted through the ER, 44.8% were admitted through a physician's referral, and only 3.8% were transferred from another hospital.

Of all the patients who died, 68.9% had conditions among one of four Major Diagnostic Categories (MDC):

- Diseases & Disorders of the Respiratory System (26.6%),
- Diseases & Disorders of the Circulatory System (19.7%),
- Diseases & Disorders of the Nervous System (13.2%),
- Infectious & Parasitic Diseases (9.4%).

No other MDC accounted for more than 8% of the patients who died.

Of the patients who died, the average length of stay was 6.2 days compared to 4.1 days for patients who were discharged alive. This relatively long average length of stay demonstrates the opportunity for hospitals to provide valuable end-of-life care to patients. The average total charge of \$26,028 for the patients who died reflects the great amount of resources often utilized in the last days of life. The average total

charge for other patients was less than one-half that amount at \$12,612.

Montana Inpatient Statistics from COMPdata

All of the Montana inpatient statistics were derived from the Illinois Hospital Association's COMPdata. We encourage you to use COMPdata to examine your hospital community area(s) regarding patient mortality and end-of-life care so that you might better understand your changing patient population and the resources needed to treat, manage, and coordinate the care for end-of-life patients.

Additional Information

If you would like to develop the COMPdata reports that will provide similar statistics for your hospital or community, a training tool is available to guide you through the process. Click here to obtain the tool: <http://www.ihatoday.org/compdata/mtcaretool.pdf>. For additional assistance on using the COMPdata system, contact the COMPdata Hotline at compdata@ihastaff.org or by telephone in Illinois at (630) 276-5851. If you are calling from outside of Illinois use our toll-free number of (866) 262-6222.

For questions and suggestions regarding the COMPdata Monthly Monitor, contact: David Rivers, Senior Director, Health Information at drivers@ihastaff.org or Tanya Ternes, Health Information Analyst at tternes@ihastaff.org.

COMPdata Monthly Monitor - Montana October 2004 End-of-Life Care

APPENDIX

National Statistics and Trends

The U.S. death rate per 1,000 population decreased to 8.3 in 2003 compared to 8.5 in both 2001 and 2002. (CDC-15) In 2001, of the 2,419,960 deaths in the U.S., 1,191,276 or 49.2% died in a hospital or medical center, 22.3% in a nursing home, 22.8% at a residence, and 5.6% in another location. Of the people who died in a hospital or medical center, 80.9% died in an inpatient unit, 15.4% in an outpatient unit or emergency room, 2.7% where dead on arrival, and 1.0% died in an unknown location.⁹

Montana Statistics and Trends

In Montana, the total number of deaths increased from 8,286 in 2001 to 8,402 in 2002 then decreased in 2003 to 8,280.¹⁰

Based on the 2002 American Hospital Association/Health Forum Annual Survey of Hospitals, with 94.6% of Montana hospitals responding to the survey, 24.5% reported having a Palliative Care Program owned or provided by the hospital itself or its subsidiary. Considering all sources of care together, 26.4% of the hospitals reported having a Palliative Care Program that was owned or provided by the hospital, their health system, their health network, or through a formal contract with another provider.

A total of 41.5% of hospitals reported having a Hospice Program owned by the hospital or its subsidiary, while 49.1% reported having a Hospice Program that was owned or provided by the

hospital, their health system, their health network, or through a formal contract with another provider.

A total of 30.2% of hospitals reported having a Pain Management Program owned by the hospital or its subsidiary, while 33.4% reported having a Pain Management Program that was owned or provided by the hospital, their health system, their health network, or through a formal contract with another provider.

Considering Palliative Care and Hospice programs together, 52.8% of Montana hospitals reported having either one or both of those services available at their hospital (as provided by any source-the hospital, system, network, or contract).

Current and Future Activities

In 2001 a national leadership conference led to the development of the National Consensus Project for Quality Palliative Care. The purpose of the project was to arrive at voluntary consensus clinical practice guidelines describing the scope and characteristics of palliative care services in the U.S. In April 2004 the Clinical Practice Guidelines for Quality Palliative Care were released. The guidelines were based on the expertise and input of more than 50,000 health care professionals and consumers in all 50 states. The guidelines can be purchased for \$25 or downloaded for free by going to <http://www.nationalconsensusproject.org>.

In early 2004, in an effort to strengthen the national end-of-life care movement, two well-known national organizations that focus on improving end-of-life care in the U.S. merged. Partnership for Caring, a 66-year old organization known for its state-specific advance directives, consumer education and services to people who are dying and their families and Last Acts, a Robert Wood Johnson Foundation-funded communications campaign aimed at elevating awareness and inspiring action about improvements in end-of-life care, combined their resources and services and are now known as the Last Acts Partnership. More information is available at <http://www.lastactspartnership.org>.

Rallying Points, an initiative of Last Acts Partnership, assists community-based coalitions in increasing community awareness of end-of-life issues. There are coalitions in more than 350 communities throughout the U.S., including Montana. To find these coalitions, go to <http://rallyingpoints.org> and click on "Where Coalitions Are Located" on the home page.

Any hospital or other provider that has developed a unique or innovative program in palliative and end-of-life care is strongly encouraged to apply for the American Hospital Association Circle of Life Award. Background information and the award application can be found at http://www.aha.org/aha/awards-events/circle_of_life/index.html.

References

- 1 National Hospice and Palliative Care Organization. What is Hospice & Palliative Care? June 2003. (<http://www.nhpco.org>) Date last accessed: 10/16/2004.
- 2 American Hospital Association/Health Forum. 2002 Annual Survey of Hospitals.
- 3 The Robert Wood Johnson Foundation. Means to a Better End: Key Findings. 2003. (<http://www.rwjf.org/news/special/means.jhtml>) Date last accessed: 10/26/2004.

- 4 Bryce, CL, Loewenstein, G, Arnold, RM, et al. "Quality of death: Assessing the importance placed on end-of-life treatment in the intensive-care unit." *Medical Care* 42(5), May 2004, pp. 423-431.
- 5 Center to Advance Palliative Care. Hospital-Based Palliative Care – The Care Patients Want. 2004. (<http://www.capc.org>) Date last accessed: 10/4/2004.
- 6 Center to Advance Palliative Care. Hospital-Based Palliative Care – Why Have Palliative Care Programs in Hospitals? 2004. (<http://www.capc.org>) Date last accessed: 10/4/2004.
- 7 Levine, C. Hospital-based family caregiver programs: Building institutional resources and community ties. *Innovations in End-of-Life Care*, 2001; 3(2), <http://www.edc.org/lastacts>. Date last accessed: 10/4/2004.
- 8 Center to Advance Palliative Care. Hospital-Based Palliative Care – Making the Case – Benefits to Hospitals. 2004. (<http://www.capc.org>) Date last accessed: 10/4/2004.
- 9 Munson ML, Sutton PD. "Births, marriages, divorces, and deaths: Provisional data for 2003." *National Vital Statistics Reports*; Vol 52(22). Hyattsville, MD: National Center for Health Statistics. 2004.
- 10 Centers for Disease Control and Prevention. Deaths by Place of Death, Age, Race, and Sex: United States, 1999-2001. (http://www.cdc.gov/nchs/datawh/statab/unpubd/mortabs/gmwk309_10.htm) Date last accessed: 10/16/2004.

What Some Hospitals Are Doing Today

An excellent report published in 2001 entitled *Hospital-Hospice Partnerships in Palliative Care: Creating a Continuum of Service* contains nine case studies that illustrates the many challenges and successes of these efforts and includes helpful details regarding the regulatory and legal implications of these partnerships. The report was a joint project of the National Hospice and Palliative Care Organization and the Center to Advance Palliative Care. The report can be downloaded from the CAPC web site at <http://www.capc.org>. Click on "Publications" then look for "Hospital-Hospice Partnerships in Palliative Care" under the list of CAPC publications.

One particular program of note that is contained in the above report developed a unique hospice inpatient program by taking advantage of unused psychiatric beds in a separate building that also included medical offices. The physical space was refurbished to create a home-like atmosphere as well as clinic space for palliative care consults, community bereavement and patient support groups. This hospital had previously explored the development of its own palliative care service but found that working with an established hospice/palliative care partner would be easier, less costly and more "professional."

A small, rural hospital utilizes a dedicated palliative care coordinator to train and work with other staff to create a palliative care team that brings the care to the patient, rather than moving the patient to the care. It's an ongoing process with future areas for further assessment that include more in-depth pain and symptom monitoring, examination of health care costs of palliative care, and evaluation of the impact on delivery of care by adding psychosocial support

to the program. In addition, a community-based task force has been developed to look at the unmet needs of the palliative care clients in the community.

A recent winner of the AHA Circle of Life Award focused their effort on creating a continuum of care for patients who might not fit into current reimbursement schemes or traditional care programs. A palliative care program was created as a bridge for people whose needs do not match current hospice and home care regulatory requirements. This health system attempts to identify as early as possible those patients who may be approaching the end of life. These patients can then receive information to make more informed choices, have concerns addressed, and access the appropriate level of care. One key aspect of this system's efforts is their continuing discussions with payers to educate them on the benefits of palliative care programs such as improved care, cost savings, and improved member and physician satisfaction.

A large teaching hospital's palliative care program includes three linked programs to provide a full range of services: a symptom management consultation, a palliative care inpatient unit, and a palliative care clinic. The team members from each area form partnerships with patients, their primary care provider and family members to coordinate care and to ensure that all healthcare options are understood and dignity is maintained.

Resources for Additional Information

FOR HOSPITALS

The Center to Advance Palliative Care is a national initiative supported by The Robert Wood Johnson Foundation, with direction and technical assistance provided by the Mount Sinai School of Medicine in New York. A host of valuable resources are found at their web site (<http://www.capc.org>) including:

- Dates for upcoming seminars on building a palliative care program in a hospital.
- Customizable Excel spreadsheets to help you plan your palliative care program.
- A 2004 crosswalk of JCAHO Standards and Palliative Care.
- A Guide to Building a Hospital-Based Palliative Care Program (available for \$100).
- Information and application materials to make a 2-day site visit to and receive one year of mentoring from one of the six Palliative Care Leadership Centers located across the country.

The American Academy of Hospice and Palliative Medicine is a membership organization comprised of physicians and other health care professionals whose goal it is to advance hospice and palliative medicine in the U.S. The AAHPM web site (<http://www.aahpm.org>) has many resources available to all health care professionals. Of particular value are the end-of-life/palliative care educational resources that include the ability to search for peer-reviewed educational materials for a variety of topics and audiences. Physicians can earn CME credits by obtaining and completing the eight-volume UNIPAC Series on Hospice/Palliative Care Training for Physicians: A Self-study Program.

The Hospital-Based Palliative Care Consortium is a program that provides hospitals and health systems across the country with the opportunity to visit a palliative care learning center in order to improve and advance new, hospital-based palliative care services. HBPC provides, at no charge, interested groups with a curriculum, surveys and assessments, a daylong visit to a host

hospital's palliative care program, and ongoing technical assistance and support. Obtain more information by visiting <http://www.hbpcc.org>.

The web site for the American Association of Homes and Services for the Aging (<http://www2.aahsa.org>) features three main sections, one each for: providers, businesses and professionals, and consumers. The provider section is designed as a knowledge center on issues and trends affecting each aspect of the aging services continuum.

FOR PATIENTS AND THE COMMUNITY

The web site for the Family Caregiver Alliance (<http://www.caregiver.org>) contains tremendous resources for families and other caregivers of end-of-life patients. Topics include public policy & research, caregiving information and advice, fact sheets and publications, newsletters, groups, and much more.

The "consumers" section of the American Association of Homes and Services for the Aging web site (<http://www2.aahsa.org>) has many resources including information on how planning early works in your favor, how to navigate through the aging services spectrum, and dealing with emotional stress of caregiving.

The National Hospice and Palliative Care Organization (<http://www.nhpco.org>) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. For patients and the community there are links to more than a dozen valuable sections of information. In addition there are downloadable PDF versions of consumers' guides on these topics: Selecting a Hospice, the Medicare Hospice Benefit, and Communicating End-Of-Life Wishes.

The Center to Advance Palliative Care web site (<http://www.capc.org>) has a dedicated section on resources for patients and families. There are links to patient/family frequently asked questions and a palliative care directory.

The Caregivers Marketplace (<http://www.caregiversmarketplace.com>) not only gives cash back and discounts on a wide variety of health care products for the home, it includes other resources for caregivers such as education and skills training, resources and links, and the latest news and information on caregiving issues.

COMPdata is a product of the Illinois Hospital Association (IHA) and its affiliate AMR