



**Palliative Care in U.S. Hospitals:  
Implications for Access to Quality Healthcare**

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Senator Whitehouse, Senator Smith, Chairman Kohl, and other distinguished committee members, thank you for the opportunity to speak before the Senate Special Committee on Aging. I am a geriatrician and palliative care physician at Mount Sinai School of Medicine in New York City where I have an active clinical practice, I conduct research on palliative care and I direct a palliative care consultation and teaching service. Our palliative care program cares for over one thousand patients per year and educates hundreds of medical students, residents, and other health professionals in the principals of pain and symptom management, high quality communication between doctors and patients and families, and helping patients and families negotiate the fragmented and confusing health care system in the U.S. In addition, I lead a national initiative called the *Center to Advance Palliative Care* whose mission is to improve access to quality palliative care across the U.S. I was drawn to this work because of my distress about how our sickest and most vulnerable fellow citizens are treated in the U.S. Too many of the patients I was seeing were suffering from untreated pain, had little to no understanding of what was happening to them nor why, and were spending long periods of time in impersonal and risky hospital settings. The following true story about one of our patients exemplifies the need for palliative care and, I hope, will put a human face on the data I will present in this testimony.

*Mrs. J was an 85 year old woman with multiple medical problems including dementia, coronary artery disease, kidney failure, and vascular disease who was admitted to the intensive care unit with a bloodstream infection. Her hospital course was complicated by the development of gangrene of her left foot and development of several deep pressure ulcers on her back resulting from prolonged ICU bedrest, and recurrent major infections. She underwent 5 surgical debridements of her wounds under general anesthesia. When they were asked by the primary doctor, her family consistently said that they wanted "everything done".*

*On day 63 of her hospitalization, a palliative care consultation was initiated to help clarify the goals of care and to treat Mrs. J's' evident pain and discomfort. She was persistently moaning in pain and would scream and lash out when the nurses tried to change her surgical dressings. She resisted all efforts to reposition or transfer her or to change her dressings. The palliative care team met with her son (her health care proxy) and her two grandchildren. During a 90 minute discussion, the team reviewed the hospital course*

*and clarified any confusion about her diagnosis and prognosis. The team asked the son what he was hoping to accomplish for his mother. He responded "She is in so much pain! Why can't they do anything about it? They said that pain medicines would make her more confused but she gets worse every day that she's here. When I visit all she does is moan and turn away from me." Possible sources of discomfort and pain were identified. A treatment plan was initiated which included morphine to treat the pain associated with her back and foot wounds with extra doses before dressing changes, discontinuing the antibiotics which were causing resistant infections and had no impact on her wound healing, treating fever with Tylenol, and transferring her to the palliative care unit. The pain relief led to a marked improvement in her mood, interaction, and function- she tolerated her dressing changes without complaint, participated in physical therapy, and recognized and enjoyed the visits of her family. She was discharged from the hospital 2 days later back to the nursing home she had come from, but this time with a referral for hospice care while in the nursing home. The hospice team followed the care plan developed by the hospital palliative care team and continued provision of expert pain management and wound care, and the patient slowly recovered to her previous state of health and awareness. The family expressed tremendous satisfaction with the resolution of her hospitalization and continues to visit her daily in the nursing home where she is reported to be interactive and comfortable.*

Patients like these are the basis and motivation for the development of palliative care programs in the U.S. This patient was getting the wrong care in the wrong place. She and her family suffered enormously, and the cost of her over 2 month hospitalization exceeded one hundred thousand dollars. When goals and alternatives were clarified, a process that required skilled communication and discussion with her distraught family members, an appropriate and effective plan was initiated- the patient was able to go back to her home and be among her familiar caregivers, her pain was easily controlled, and her wounds began to heal- she was restored to herself- a process that required the intervention of a palliative care team to help her get on the right path.

Palliative care programs in hospitals are a rapidly diffusing innovation (Figure 1) and have been shown to both improve quality and reduce costs of care for America's sickest and most complex patients- a group at high risk for pain, suffering, and fragmented unreliable medical care that fails to meet their most fundamental needs. The chronically and seriously ill constitute only 5-10% of our patients, but account for well over half of the nation's healthcare costs. Palliative care programs are a solution to this growing quality and cost crisis.

**Why palliative care?** Despite enormous expenditures, studies demonstrate that patients with serious illness and their families receive poor quality medical care, characterized by untreated pain and other symptoms, unmet personal care needs, high caregiver burden, and low patient and family satisfaction.<sup>1-4</sup> Of the \$432 billion spent by Medicare in 2007, 30% (\$186 billion) was spent on acute care (hospital) services and a very small proportion -- 5% -- of the sickest Medicare beneficiaries account for fully 44% of total program spending.<sup>3,46</sup> Similarly, of the \$272.6 billion spent by Medicaid in 2004, 76% (207.8 billion) was spent on acute care (hospital) services and a very small proportion -- 4% -- of the sickest Medicaid beneficiaries account for fully 48% of total program spending.<sup>3</sup> This small but disproportionately ill subset of the nation's patients are the target population for palliative care services.

***What is palliative care and how does palliative care differ from hospice?***

As defined by CMS, ***Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.***<sup>41</sup>

Non-hospice palliative care is appropriate at any point in a serious illness. It is provided at the same time as life-prolonging treatment. There is no prognostic requirement, and no need to choose between life prolonging and palliative treatment approaches.

Hospice is a form of palliative care that provides care for those in the last weeks-few months of life. Hospice-eligible patients must have a 2 MD-certified prognosis of less than 6 months and give up insurance coverage for curative treatment in order to access hospice services.

***How does palliative care improve care quality?*** Palliative care programs address pain and symptoms that cause untold human misery and are the number one concern of patients living with chronic illness.<sup>40</sup> As in my patient described above, pain and other distressing symptoms have been shown to increase hospital complications and lengths of stay, and many studies have demonstrated poor to non-existent communication between patients, families, and physicians about the disease, the treatment options and what to expect. Palliative care teams provide expert treatment of pain and other symptoms, meet with patients, families, and physicians to establish clear and feasible care goals, address care alternatives including withdrawing or not initiating treatments that don't meet those goals, and develop safe and effective discharge plans for these medically complex patients. Through these methods palliative care programs improve the quality of medical care received by our sickest patients while reducing hospital costs, readmissions, and emergency department visits. Typically delivered by an interdisciplinary consultation team working in concert with the patient's primary physician, hospital palliative care programs provide highly specialized and expert care to patients with the most serious and complex illness.

Research demonstrates that palliative care programs improve physical and psychological symptoms (Figure 2)<sup>34</sup>, caregiver well-being (Table 1), and consulting physician satisfaction (Figure 4).<sup>7-17,34</sup> Employing interdisciplinary teams of physicians, nurses, social workers, and additional personnel when needed (chaplains, physical therapists, psychologists), palliative care teams identify and rapidly treat distressing symptoms which have been independently shown to impede recovery, increase confusion and delirium, and lengthen hospitalizations (Figure 3).<sup>10,16,17</sup> Palliative care team members meet and talk extensively with patients and their families to make sure they understand their illness and what it means, support families in crisis, and plan for safe transitions out of hospitals to lower intensity community settings that are preferred by patients and families in the overwhelming majority of cases.<sup>42</sup> (Table 1). Finally, because of the assistance that they provide to already time-pressured

physicians, palliative care programs are valued and heavily utilized by referring physicians (Figure 4).

***How does palliative care promote patient-centered care while reducing healthcare costs?***

Palliative care is genuinely patient centered because it begins with the goals and preferences of the patient and family, and, as in the case of Mrs. J, supports development of a realistic care plan that meet these goals. Health care costs are reduced because seriously ill patients are able to leave the hospital and receive care in settings more appropriate to their needs- often in the place where more than 90% of patients say they want to be- at home. This is possible because palliative care teams ensure the necessary level of professional medical and nursing support for family members providing direct care to the patient after hospital discharge. Successful transition management requires expert and effective care coordination, and reliable access to sophisticated support from home care and hospice agency referrals. Had hospice not been available to Mrs. J in her nursing home, we could not have assured the pain management expertise so critical to her wound care and healing process. In addition, when a patient with advanced illness turns to an emergency department for help, they can be admitted and cared for directly by the hospital palliative care specialists best able to address their needs, instead of defaulting to a critical care setting as occurred in Mrs. J's case; hence more patients with advanced chronic illness are admitted directly to the palliative care service instead of a high cost ICU bed; patients not benefiting from an ICU setting are transferred out to more appropriate and lower intensity settings; and non-beneficial, potentially harmful, or futile imaging, laboratory, specialty consultation, drugs and procedures are avoided (Figure 5).<sup>37</sup>

Studies of a range of palliative care interventions from Europe, Canada, Australia, and the U.S. demonstrate consistent improvement in pain and other symptoms, patient and family satisfaction, and likelihood of receiving care in the place of choice.<sup>34</sup> Research from Europe in which patients were randomized to usual care or palliative care<sup>7,11,12,17</sup> (studies that would be

impossible to perform in the U.S.) and single- and multisite observational studies in the U.S. also demonstrate that the efficiency associated with palliative care can be substantial.<sup>21-26,34,37</sup> In a recently published study<sup>37</sup> of 8 U.S. hospitals serving low, medium, and high cost markets, seriously ill patients receiving hospital palliative care consultation and compared to matched patients who received usual care, had an adjusted net per admission savings of \$1,696 for patients discharged alive, and \$4,908 for patients who died (Table 2).

***Essential elements of quality palliative care.*** Palliative care is not hospice<sup>5</sup>. Until recently, palliative care services were typically available only to patients enrolled in hospice. Now, palliative care programs are found increasingly in hospitals – the main site of care for the seriously ill and site of death for 50% of adults on average nation-wide. As of 2006, 30% of U.S. hospitals and over 70% of hospitals with more than 250 beds reported the presence of a palliative care program – an increase of 96% from 2000 (Figure 1).<sup>6,33,35</sup> As outlined (Table 3) by the National Quality Forum<sup>27</sup> and the National Consensus Project for Quality Palliative Care<sup>5</sup>, the essential structural elements of hospital palliative care programs include:

- Interdisciplinary team of clinical staff (MD, RN and SW)
- Staffing ratios determined by hospital size
- Staff trained, credentialed and/or certified in palliative care
- Access and responsiveness 24 hours per day, 7 days per week

Based on the National Quality Forum's Framework and Preferred Practices for Hospice and Palliative Care released in 2006.<sup>27,38</sup> The Joint Commission has developed a new Palliative Care Certificate Program to be offered in the Autumn of 2008.<sup>43</sup> This mechanism will stimulate development of standardized and reliably high quality palliative services in America's hospitals through adherence to existing quality guidelines.

**Access to palliative care:** Recent data<sup>35</sup> demonstrate large variability in access to palliative care in U.S. hospitals. As in many other aspects of our health care system, where you live matters. An analysis of hospitals with more than 50 beds (larger hospitals are where most Americans receive care) found that 53% reported a palliative care program on the 2006 annual hospital survey administered by the American Hospital Association. Over 80% of the nation's medical schools report an association with a teaching hospital palliative care program, creating at least the potential for effective education of the next generation of physicians and other health care providers. However, considerable state by state variation was observed. Aside from location, factors increasing likelihood of a palliative care program include larger hospital size, teaching hospital status, higher educational level in the community, and the presence of a hospital-owned hospice program. Factors associated with lower likelihood of a palliative care program include smaller hospital size, for-profit ownership status, and public or sole community provider status. This study also suggests that states with higher palliative care program penetration had fewer hospital deaths, fewer patients requiring ICU admissions, and, as a result, lower overall expenditure per Medicare beneficiary.<sup>35</sup> A detailed state-by-state report card on access to palliative care may be found at [www.capc.org/reportcard](http://www.capc.org/reportcard).

**What prevents equitable access to quality palliative care?** Barriers preventing equitable access to quality palliative care for America's seriously ill citizens include: 1) Lack of an adequate evidence base to guide rigorous quality care at the bedside; 2) lack of medical and nursing school teaching faculty needed to train the next generation in the core competencies of palliative care (such as assessment and treatment of pain and other symptoms); and 3) an inadequate workforce pipeline to meet the palliative care needs of America's seriously ill patients because of lack of support for graduate medical and nursing education in palliative care.

**The research gap:** Despite the fact that each one of us will eventually get sick and die, almost no federal support for research aimed at improving the quality of life during chronic and serious illness has been available to develop the evidence base necessary to relieve suffering and reliably help patients and families in need. Mrs. J's doctors' fear of using opioid analgesics in elderly patients was based on myths that recent research has finally debunked- multiple studies have now shown that contrary to what most of us were taught, it is untreated pain that causes confusion, and treatment and prevention of pain actually reduces the risk of delirium. A recent study found that less than one half of one percent of all NIH dollars was used to support research on improving the quality of life during a serious illness.<sup>36</sup> Those NIH Institutes most qualified to invest in palliative care research because of their size, budget, and disease focus (including NCI, NHLBI, NIDDK, NIA) have for the most part, failed to do so. *NIH funding specifically designated for support of research in palliative care is necessary to correct this imbalance in NIH priorities.*

**Faculty development:** The training of future generations of front line health care providers is entrusted to the faculty in the nation's medical and nursing schools. The poor quality of care experienced by the seriously ill in this country (high symptom burden, poor doctor patient communication, widespread fragmentation and inefficiency) is directly attributable to a near total lack of medical and nursing education in palliative care. During 9 years of medical education after college- (4 years of medical school, 3 years of internal medicine, and 2 years of geriatrics training) I did not receive a single lecture on pain management, treatment of other symptoms like shortness of breath or nausea, or how to communicate bad news and discuss goals of care with patients and their families. Most regular non-medical people find this difficult to believe- how can it be true that doctors and nurses are not taught how to manage pain? But it is true, and this is major reason for the poor quality of care reported by patients and their families. This has begun, very slowly, to change as medical schools try to make room in their crowded curricula for these fundamental aspects of patient care-, but the persistent barrier to providing

such teaching is the need for expert palliative care faculty educators. Such education cannot take place without a cadre of teaching faculty at all of the nation's medical and nursing schools. A mechanism for support of medical and nursing faculty in palliative care is needed. *A model similar to that employed to improve the geriatrics faculty workforce (HRSA's Geriatric Academic Career Awards - GACA) is necessary to create the palliative care teaching faculty prerequisite to an adequately trained healthcare workforce. A proposed model for Palliative Care Academic Career Awards (PACA) has been developed.*<sup>44</sup>

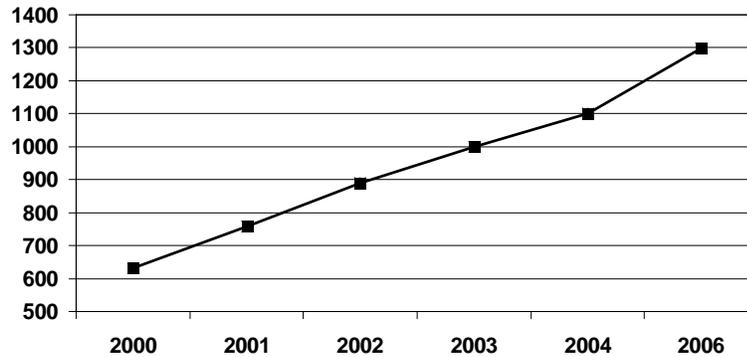
**Workforce pipeline:** The largest impediment to delivery of palliative care across our nation is the lack of professionals specifically trained to do this work. Hospitals and medical schools are all competing for the same few well trained palliative care professionals to lead and staff their programs, teach their students, and assure quality of care to the seriously ill. In 2006 the American Board of Medical Specialties did approve palliative medicine as a new medical specialty under 10 parent boards, including internal and family medicine, surgery, and pediatrics. The first American Board of Internal Medicine administered board certification examination will be given in November 2008. The Accreditation Council for Graduate Medical Education (ACGME) followed with approval of subspecialty graduate medical fellowship training programs in palliative medicine. Despite these major strides, the cap on Graduate Medical Education (GME) dollars imposed on teaching hospitals under the Balanced Budget Act of 1997<sup>45</sup> means that there is no funding to support specialty training in palliative medicine. Without support for graduate medical (and nursing) education in palliative medicine, there is no workforce to lead clinical programs in America's hospitals, no faculty to teach future generations of providers, and no clinical researchers to improve the quality of our care. It is unrealistic to expect teaching hospitals to support graduate palliative medicine trainees by eliminating other badly needed training positions, and it has not occurred. The result is that few training slots for specialty palliative medicine are available in the U.S. at this time, and most of these are insecurely funded by philanthropy. *The solution to the physician workforce deficit is an*

*exemption to the cap on GME slots for teaching hospitals offering ACGME-accredited palliative medicine training programs. Training programs targeted to masters-prepared nurses and nurse practitioners (perhaps through HRSA funding) are another key solution to the workforce deficit.*

When I broadened my career focus from geriatrics to include palliative medicine in 1995 I did not know how we would address the problems facing patients like Mrs. J- just that we had to figure out a way and do something to make things better. In large part thanks to enormous investments from charitable foundations (such as the Robert Wood Johnson Foundation, John A. Hartford Foundation, Open Society Institute and others), who contributed over 250 million dollars to building the field between the late 80's through the present, substantial progress has been made. Hospital palliative care programs are present in the majority of hospitals with more than 50 beds. Palliative medicine is a new medical subspecialty. Young people completing their training in medicine and nursing can now choose palliative care as a career path. We have come a long way in a short period of time. For palliative care to become an integral and reliable component of the U.S. healthcare system, however, will require some help from you.

Thank you for your interest in our work in palliative care.

**Figure 1: Can Patients Access Hospital Palliative Care Programs? Growth in Number between 2000-2006** (Source: AHA Annual Survey)



**Figure 2**

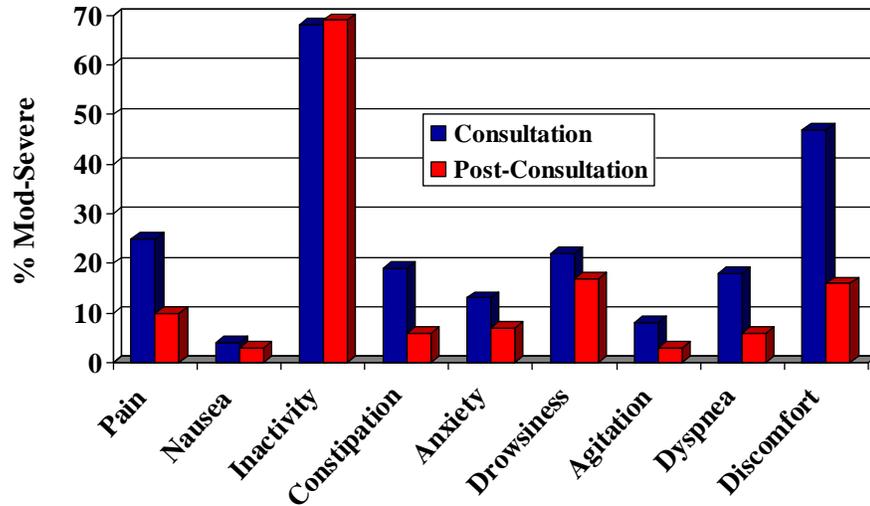
## Palliative Care Improves Patient Care

- Mortality follow back survey palliative care vs. usual care
- N=524 family survivors
- Overall **satisfaction markedly superior** in palliative care group,  $p < .001$
- Palliative care superior for:
  - emotional/spiritual support
  - information/communication
  - care at time of death
  - access to services in community
  - well-being/dignity
  - care + setting concordant with patient preference
  - pain
  - PTSD symptoms

Casarett et al. J Am Geriatr Soc 2008;56:593-99.

Figure 3: Symptom Improvement Following Palliative Care Consultation at Mount Sinai Hospital in New York, NY.

Symptoms at Time of Palliative Care Consultation (hospital Day 10 on average) and 72-96 hours later (N=3,491)



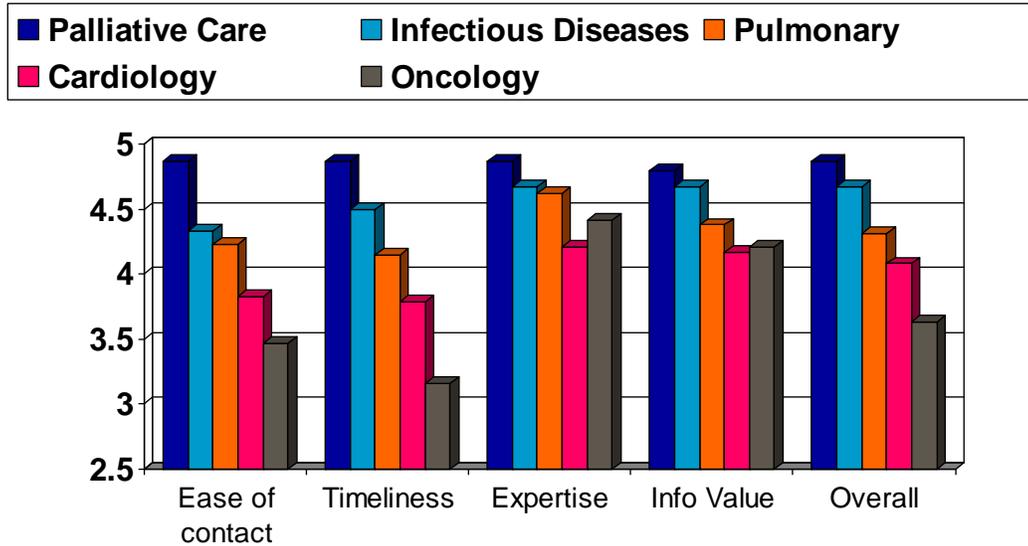
**Table 1: Effect of Palliative Care on Family Satisfaction and Family Needs\***

	<b>Palliative Care</b>	<b>Usual Care</b>	<b>P</b>
Religious and spiritual beliefs addressed	46%	24%	.004
Enough support for their own feelings	73%	55%	.04
Confident that they knew what to do when patient died	87%	71%	.03
Received referral for psychosocial support	36%	14%	.002

\*Adjusted for: Patient age, race (white versus nonwhite), diagnosis, bed-bound, insurance (Medicaid versus non-Medicaid) and if died in ICU

Gelfman LP, Meier DE, Morrison RS. Does palliative care improve quality? A survey of bereaved family members. *J Pain Sympt Manage* 2008 Apr 12;

**Figure 4: Physician Satisfaction with Internal Medicine Consultation Services (range 1-5)**

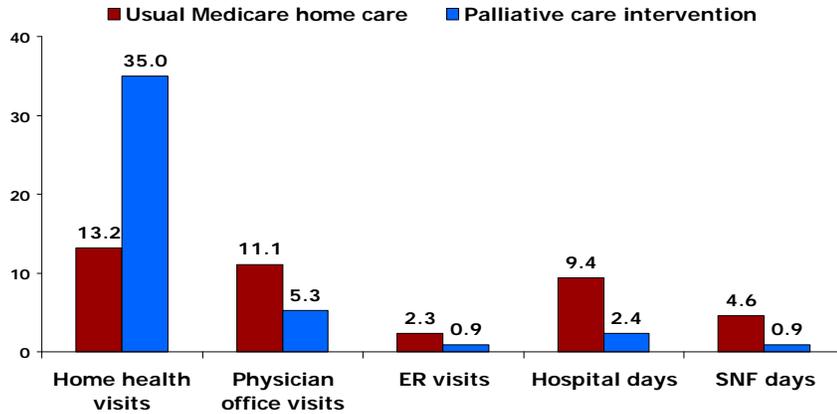


Source: MCW Froedert Hospital Medical Staff Survey, Milwaukee, WI, 2007

# Figure 5

## Palliative Care Shifts Care Out of Hospital to Home

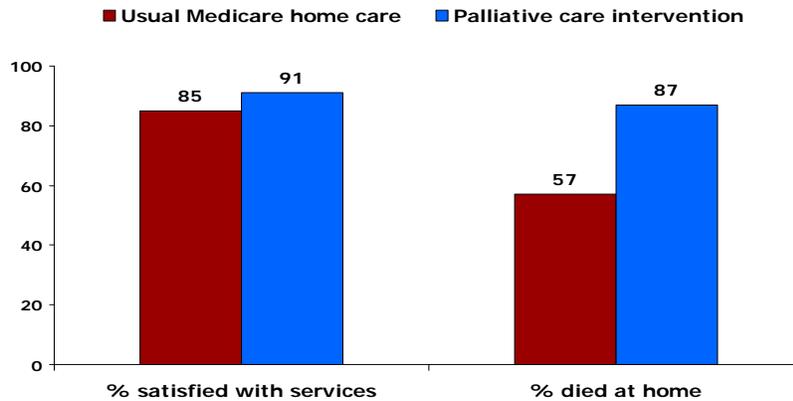
Service Use Among Patients Who Died from CHF, COPD, or Cancer Palliative Home Care versus Usual Care, 1999–2000



Brumley, R.D. et al. 2003. *The Permanente Journal* 7(2): 7–12.

## Palliative Care Allows People to Die at Home instead of Hospital

Outcomes Among Patients Who Died from CHF, COPD, Cancer Palliative Care versus Usual Care, 1999–2000



Brumley, R.D. et al. 2003. *The Permanente Journal* 7(2): 7–12.

# Table 2

## Hospital Palliative Care Reduces Costs Cost and ICU Outcomes Associated with Palliative Care Consultation in 8 U.S. Hospitals

Costs	Live Discharges			Hospital Deaths		
	Usual Care	Palliative Care	Δ	Usual Care	Palliative Care	Δ
Per Day	\$867	\$684	\$183*	\$1,515	\$1,069	\$446*
Per Admission	\$11,498	\$9,992	\$1,506*	<b>\$23,521</b>	<b>\$16,831</b>	<b>\$6,690*</b>
Laboratory	\$1,160	\$833	\$327*	\$2,805	\$1,772	\$1,033*
ICU	\$6,974	\$1,726	\$5,248*	\$15,531	\$7,755	\$7,776***
Pharmacy	\$2,223	\$2,037	\$186	\$6,063	\$3,622	\$2,441**
Imaging	\$851	\$1,060	-\$208***	\$1,656	\$1,475	\$181
Died in ICU	X	X	X	<b>18%</b>	<b>4%</b>	<b>14%*</b>

\*p<.001

\*\*p<.01

\*\*\*p<.05

Morrison, RS et al. Archives Intern Med 2008;

## Table 3: NQF Preferred Practices for Palliative Care<sup>27</sup>

### A National Framework and Preferred Practices for Palliative and Hospice Care Quality

#### A National Quality Forum (NQF) Consensus Report

The National Quality Forum has recently identified palliative care and hospice care as national priority areas for healthcare quality improvement. The highly influential NQF report provides a framework and set of NQF-endorsed™ preferred practices that focus on improving palliative care and hospice care across the Institute of Medicine's six dimensions of quality – safe, effective, timely, patient-centered, efficient, and equitable. The preferred practices mark a crucial step in the standardization of palliative care and hospice.

#### Preferred Practices...

1. Provide palliative and hospice care by an **interdisciplinary team** of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).
2. Provide access to palliative and hospice care that is responsive to the patient and family **24 hours a day, 7 days a week**.
3. Provide **continuing education** to all healthcare professionals on the domains of palliative care and hospice care.
4. Provide adequate **training and clinical support** to assure that professional staff is confident in their ability to provide palliative care for patients.
5. Hospice care and specialized palliative care professionals should be appropriately **trained, credentialed, and/or certified** in their area of expertise.
6. Formulate, utilize, and regularly review a **timely care plan** based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.
7. Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that **continuity of care and seamless follow-up** are assured.
8. Healthcare professionals should present **hospice as an option** to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare **professionals' ability to discuss hospice** as an option.
10. **Enable patients to make informed decisions** about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
11. Provide **education and support to families** and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.
12. Measure and **document pain, dyspnea, constipation, and other symptoms** using available standardized scales.
13. Assess and **manage symptoms and side effects** in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
14. Measure and **document anxiety, depression, delirium, behavioral disturbances**, and other common psychological symptoms using available standardized scales.
15. **Manage anxiety, depression, delirium, behavioral disturbances**, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.

16. Assess and **manage the psychological reactions** of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
17. Develop and offer a **grief and bereavement care plan** to provide services to patients and families prior to and for at least 13 months after the death of the patient.
18. Conduct regular **patient and family care conferences** with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
19. Develop and implement a comprehensive **social care plan** that addresses the social, practical, and legal needs of the patient and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
20. Develop and document a plan based on an assessment of **religious, spiritual, and existential concerns** using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
21. Provide information about the **availability of spiritual care services**, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
22. Specialized palliative and hospice care teams should **include spiritual care professionals** appropriately trained and certified in palliative care.
23. Specialized palliative and hospice spiritual care professionals should build **partnerships with community clergy** and provide education and counseling related to end-of-life care.
24. Incorporate **cultural assessment** as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
25. Provide professional **interpreter services** and culturally sensitive materials in the patient's and family's preferred language.
26. Recognize and **document the transition to the active dying phase**, and communicate to the patient, family, and staff the expectation of imminent death.
27. **Educate the family on a timely basis regarding the signs and symptoms of imminent death** in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
28. As part of the ongoing care planning process, routinely ascertain and **document patient and family wishes** about the care setting for the site of death, and fulfill patient and family preferences when possible.
29. Provide **adequate dosage of analgesics and sedatives** as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using narcotics and of analgesics hastening death.
30. **Treat the body after death with respect** according to the cultural and religious practices of the family and in accordance with local law.
31. Facilitate effective grieving by implementing in a timely manner a **bereavement care plan** after the patient's death, when the family remains the focus of care.
32. **Document the designated surrogate/decision maker** in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
33. **Document the patient/surrogate preferences for goals of care**, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
34. **Convert the patient treatment goals into medical orders**, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency

medical services, and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.

35. **Make advance directives and surrogacy designations available across care settings**, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.

36. Develop healthcare and community collaborations to **promote advance care planning** and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.

37. Establish or have access to **ethics committees or ethics consultation** across care settings to address ethical conflicts at the end of life.

38. **For minors with decision making capacity, document the child's views and preferences** for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

**Order a copy of the NQF Consensus Report online.**

**Go to [www.qualityforum.org/publications/reports](http://www.qualityforum.org/publications/reports)**

Distributed courtesy of the National Consensus Project.

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