

# The Growth of Palliative Care in the United States

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Annu. Rev. Public Health 2014. 35:459–75

The *Annual Review of Public Health* is online at [publhealth.annualreviews.org](http://publhealth.annualreviews.org)

This article's doi:  
10.1146/annurev-publhealth-032013-182406

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## Keywords

palliative care, supportive care, hospice care, cost avoidance, medical economics

## Abstract

Palliative care has been one of the most rapidly growing fields of health care in the United States in the past decade. The benefits of palliative care have now been shown in multiple clinical trials, with increased patient and provider satisfaction, equal or better symptom control, more discernment of and honoring choices about place of death, fewer and less intensive hospital admissions in the last month of life, less anxiety and depression, less caregiver distress, and cost savings. The cost savings come from cost avoidance, or movement of a patient from a high cost setting to a lower cost setting. Barriers to expanded use include physician resistance, unrealistic expectations of patients and families, and lack of workforce. The future of palliative care includes more penetration into other fields such as nephrology, neurology, and surgery; further discernment of the most effective and cost-effective models; and establishment of more outpatient services.

## INTRODUCTION

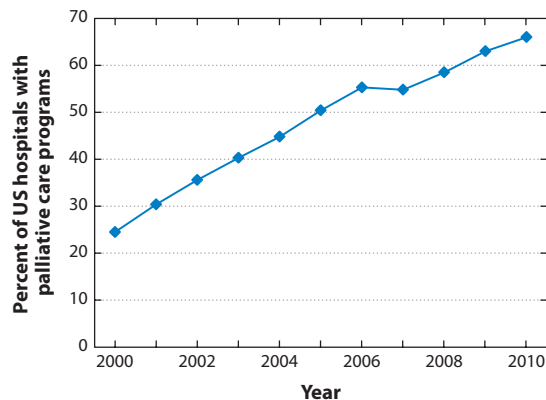
Palliative care is growing. Palliative care provides an extra layer of support that can be provided alongside disease-oriented treatments (see sidebar, WHO Definition of Palliative Care).

The United States has seen an increased demand for and supply of palliative care, and this trend is likely to continue in the future. Over the past 10 years, more than 1,000 new hospital-based palliative care programs have been created. In 2000, only 25% of US hospitals with more than 50 beds had a palliative care team, whereas in 2010, two-thirds of hospitals offered palliative care (**Figure 1**). Access to palliative care services within different states ranges from 20% to 100% of hospitals, with more than 50% of states having palliative care programs in greater than 60% of hospitals (20, 68). Larger, academic, or religious-based hospitals are more likely to have a palliative care team (21). Of National Cancer Institute cancer centers, 98% report having a palliative care program, 92% of which have an inpatient palliative care consultation team and 59% have an outpatient palliative care clinic (47). In pediatrics, 58% of institutions participating in the Children's Oncology Group have a palliative care team (50).

We see the need for palliative care growing substantially in the next decades. Over the 30 years that the field of palliative care has developed in the United States, the US population has grown from 228 million to 309 million people, with a 10% increase in the past decade (100). America's population is getting older, as well; in 1980, 11% of the population was 65 years old or older, whereas in 2010, this figure rose to 13%. With the aging of baby boomers and the increased longevity of earlier generations, 5 million more people were 65 years and over in 2010 (40.3 million) compared with a decade earlier (35.0 million), representing a 15% increase. The fastest rate of growth among older Americans occurred in the age group between 85 and 94 years old, which grew by 30% between 2000 and 2010 (104).

## WHO DEFINITION OF PALLIATIVE CARE

According to the World Health Organization, "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (106).



**Figure 1**

Growth of palliative care programs in the United States. Modified from CAPC website (<http://www.capc.org>).

Coupled with the aging of America's population is the fact that more people are living with chronic disease. In 2005, 133 million Americans had at least one chronic disease, and nearly 25% of people with a chronic disease had limitations in their activities of daily living (17). According to the Centers for Disease Control and Prevention (CDC) Surveillance System, 17% of Americans rated their health status as fair or poor in 2012 (18). In 2005, 70% of deaths each year were from chronic diseases. Ten of the top 15 causes of death were chronic disease; heart disease, cancer, and stroke accounted for the majority of deaths (56).

Health care systems are facing additional stresses. Patients are incurring more out-of-pocket expenditures in their last five years of life (52). Family members are being called on to provide more informal caregiving to both young and elderly loved ones with chronic illness or debility (11, 12). With changing family dynamics, baby boomers have become a sandwich generation who take responsibility for both the older and the younger generations (32). Changes in attitudes toward kinship obligations entail potentially less availability of family caregivers (36). The need for many family caregivers to remain in the workforce leads to the outsourcing of caregiving to individuals outside the family (12). Parents of children with cancer are likely to experience disruption in their work schedules and loss of income (27). Policies need to address the growing network of informal caregivers (58). This need is particularly important for conditions such as Alzheimer's disease and cancer (4, 108). In oncology, which has noted an increase in cancer prevalence and survival, these demographic changes come at a time of a projected 40% shortfall in the oncology workforce (53) and a similar shortfall in the palliative care workforce (59). All branches of medicine anticipate escalating costs, especially oncology, which is expected to cost 2% or more every year (108). These data point to a greater need for palliative care, and palliative care was recently highlighted in an Institute of Medicine report to help sustain Medicare (37).

The clinical benefits of palliative care include improvement in quality of life, better quality of care with less aggressive end-of-life care, and less emotional distress (7). Some studies have also demonstrated possible prolongation of life with use of a palliative care approach or hospice (7, 86, 97). The economic and financial benefits include more equitable resource utilization, reversing the trend for increasing hospitalization and use of the intensive care unit (ICU) at the end of life (98), and dollars produced by both cost savings and revenue generation, as shown in **Table 1** (13, 34, 69, 72, 91, 92).

Palliative care can be delivered in a variety of ways. Palliative care was first implemented after the birth of the hospice movement in the 1980s (67). Today, hospice services are provided to ~1.65 million patients per year, 66% of which are delivered in a patient's residence and 26% in an inpatient hospice facility. Roughly 45% of all deaths in the United States in 2011 occurred within a hospice program (76).

The Medicare hospice benefit can be offered only to individuals diagnosed with a terminal illness, but palliative care can be delivered to the larger population of individuals living with chronic or advanced illnesses (70). Interdisciplinary, hospital-based palliative care consultation services have been the main form of delivering palliative care over the past 20 years, but recent trends have included creation of palliative care units and outpatient consultation clinics. Calls have been made to increase the availability of and access to palliative care services in the US health care system (62).

## THE FUTURE OF PALLIATIVE CARE

### The Types of Palliative Care

Similar to oncology or cardiology care, palliative care comes in three types (103). Primary palliative care is delivered every day in the medical office and should be part of the standard skill set of

**Table 1 Outcomes from randomized trials of palliative care performed in the past 10 years<sup>a</sup>**

Citations	Outcomes							
	Symptoms	Quality of life	Mood	Satisfaction	Resource use	Advance care planning	Survival	Costs
Bakitas et al. 2009 (8) Nurse-led intervention	Improved $p = 0.06$	Improved $p = 0.02$	Improved $p = 0.02$	Not measured	No difference	No difference	No difference	No difference
Brumley et al. 2007 (13) PC team intervention	Not measured	Not measured	Not measured	Improved $p < 0.05$	Cost \$7,500 less, $p = 0.03$ Hospital days reduced by 4.36 ( $p < 0.001$ ) ED visits reduced by 0.35 ( $p = 0.02$ )	Not measured	No difference	Lower
Gade et al. 2008 (34) PC team intervention	No difference	No difference	No difference	IPCS, greater satisfaction with care ( $p = 0.04$ ) and communication ( $p = 0.0004$ )	Costs \$6,766 less ( $p < 0.001$ ). Net cost savings of \$4,855 ( $p < 0.001$ ). Longer median hospice stays (24 versus 12 days, $p = 0.04$ )	IPCS patients had more ADs at discharge than UC patients (91.1% versus 77.8%; $p < 0.001$ )	No difference	Lower
Higginson et al. 2011 (45) PC team intervention in OP setting	Improved	Improved	NR	NR	Lower with PC	NR	NR	Lower
Temel et al. 2010 (97) PC team intervention	Improved $p = 0.04$	Improved $p = 0.03$	Less depression $p = 0.01$	Not measured	Less aggressive care $p = 0.05$ , \$2,200 per-person savings	More ADs documented in PC group $p = 0.05$	11.6 versus 8.9 months $p = 0.02$	Lower
Zimmermann et al. 2012 (110) PC team intervention in OP clinics	Improved ( $p = 0.05$ )	Improved ( $p = 0.007$ )	NR	Improved ( $p < 0.001$ )	NR	NR	NR	NR

<sup>a</sup>Abbreviations: AD, advance directive; ED, emergency department; IPCS, interdisciplinary palliative care service; NR, not reported; OP, outpatient; OR, odds ratio; PC, palliative care; UC, usual care.

all practitioners. It includes symptom assessment, spiritual assessment, effective communication with “ask, tell, ask,” and discussion of advance care planning with transition prompts to end-of-life care. Secondary palliative care is delivered by specialized teams at specialized programs or inpatient units. Such teams are interdisciplinary and either provide direct responsibility for a patient’s care or serve as consultants to a primary team. One example is the palliative care clinic, which can help primary physicians across a wide spectrum of diseases with such things as pain management and determining goals of care (90). Tertiary palliative care is delivered by specialized teams with expertise in advanced pain and symptom management, such as implantable intraspinal drug-delivery systems for pain, palliative sedation, or advanced delirium management.

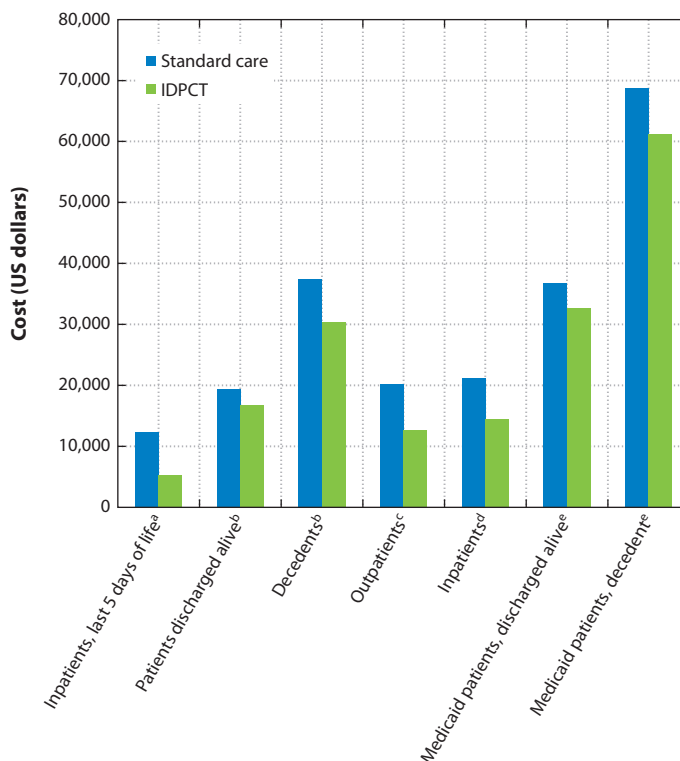
Several specialty groups are attempting to work with other practitioners to promote education about primary palliative care; for instance, the American Society of Clinical Oncology has partnered with the American Academy of Hospice and Palliative Medicine to develop the necessary competencies, curriculum, and assessment tools for oncologists to provide proficient primary palliative care. The current oncology self-assessment program, Quality Oncology Project Initiative (QOPI), has a number of palliative and hospice care metrics such as number of patients referred to hospice and the length of stay in hospice (79). QOPI has successfully reduced the number of patients receiving chemotherapy within the last two weeks of life and has improved pain management when its metrics are applied in practice (10).

## Models that Work

Multiple models of palliative care show promise in fulfilling the “triple aim” of better quality, improved access, and lower costs (82). We illustrate some of the range of programs here.

The most convincing data that led to complete adoption by a health care system have come from randomized trials performed by the Kaiser Permanente health maintenance organization (HMO), a vertically integrated health care system. Kaiser Permanente is both an insurer and a provider of medical care for a defined population. As shown in **Table 1**, the clinical advantages were clear-cut, survival rates were the same in the intervention and control arms, and Kaiser Permanente saved \$5,000–7,000 per person. Cost savings occurred even when accounting for the cost of the interdisciplinary palliative care team, as shown in **Figure 2**. In the Kaiser model, the interdisciplinary care team consists of a physician, an advanced practice nurse, a social worker, and a chaplain. Subsequent to the published study, this model of care was made standard in all areas for which Kaiser Permanente has a significant market share (93).

Other integrated health care systems have adopted similar models. Like Kaiser Permanente, Sutter Health is a vertically integrated HMO that provides medical services to an insured population. The Sutter Health Program of Advanced Illness Management (AIM) started with a needs analysis that showed lack of home care and home assistance, leading to emergency room (ER) visits and admissions, with lack of system-wide communication (23). Sutter Health redesigned their medical care services to include more home care and visits, with an emphasis on choices (advance directives) in seriously ill patients (63). Their data showed “. . .significant improvements in patient, family, and physician satisfaction when late-stage patients were served through AIM rather than through home care by itself” (57, p. e-S34). The hospital experienced a 54% reduction in admissions, 80% reduction in ICU days, and 26% (2 days) reduction in inpatient length of stay. Physicians noted a 52% reduction in visits, whereas home care had a 60% increase in hospice enrollment and a 49% increase in home health enrollment. The Sutter Health AIM program was recently awarded a Center for Medicare Innovations grant to expand the model system-wide, and the projected savings will be more than \$700 per member per month. Of note, the revenue to Sutter Health Systems will actually decrease as the savings to Medicare increase, owing to a shift



**Figure 2**

The financial effect of palliative care plus standard care versus standard care alone. <sup>a</sup>Reference 74, <sup>b</sup>Reference 72, <sup>c</sup>Reference 13, <sup>d</sup>Reference 34, <sup>e</sup>Reference 69. Abbreviation: IDPCT, interdisciplinary palliative care team.

from more profitable hospital and ER services to less profitable home care services (B.M. Stuart, personal communication). These dramatic shifts in health care utilization will be welcomed by vertically integrated systems that are both insurer and provider but could be devastating to individual practitioners and hospitals with low occupancy rates that need the revenue from hospitalizations, and the increased utilization could be overwhelming to home health/hospice providers.

Other community-wide innovations have dramatically increased the use of palliative care and hospice programs. Gundersen Health System in Wisconsin has promoted community-wide advance care planning with high penetration into the community ([http://respectingchoices.org/about\\_us](http://respectingchoices.org/about_us)). This program has led to a regional prevalence of 90% of patients having advance directives and 99% of those advance directives being available on admission to the hospital (42). More than two-thirds of patients have physician orders for life-sustaining treatment (POLST) on admission to the hospital to guide the admitting health care team about limitations to care (43). Whether these results can be accomplished in a more heterogeneous and/or disadvantaged population with less trust in the health care system has not been tested.

Whether “integrated” (the same practitioners doing palliative and longitudinal care) or “consultative” (referral to specialists in or out of the practice) models are better cannot be answered at the present time. Not all studies have shown significant improvements. The palliative care group at the University of San Francisco did two early trials of outpatient (85) and inpatient palliative care (81) consultation and showed no major differences in symptom management between the

two groups (usual care versus usual care and palliative care). Both of these studies were done early in the development of palliative care (1998–2001 and 2002–2003, respectively) and did not fully utilize members of the interdisciplinary team. Recommendations made by the comprehensive care team in the outpatient study received low uptake by primary care physicians. Neither study documented any harm to patients, and the team at San Francisco has continued to expand and refine their palliative care inpatient, consultation, and outpatient services (S. Pantilat, personal communication).

Other studies have shown benefits of integrating palliative care into practice settings. Alesi (2) documented several examples of practices that have fully integrated palliative care into oncology outpatient practice. Palliative care in the clinic improved symptom management, mostly paid for itself, and was feasible in typical oncology offices. The collaboration between Capital Caring and Hospice and US Oncology added a nurse practitioner and physician to the standard oncology office (73). By the end of the two-year study, referrals from the oncologists increased 87%, patient symptom burden decreased more than 20%, and the oncologists' overall satisfaction with the palliative care consult practice was rated 9/10. Most importantly, from a business perspective, Muir et al. (73) estimated that each oncology referral saved ~170 minutes of the referring oncologist's time. This model was based on US reimbursement patterns and included only physician and advanced practice nurse time; it did not include chaplains, psychologists, or social workers unless they could perform billable services. The ongoing program generates enough revenue to cover salaries and space, but it does not fulfill the true sense of an interdisciplinary team as seen in the Kaiser model. The US Oncology model also requires a level of work intensity that some palliative care professionals may not endorse, with 4 new and 10–14 follow-up patients for each half-day session for the nurse–doctor team. Recent publications have stressed that the main problems are staffing and being overwhelmed by referrals, regardless of the type of palliative care clinic (90).

The setting in which studies take place affects the outcomes, too. Hanks et al. (44) did a randomized controlled trial (RCT) in a 400-bed acute care teaching hospital assessing a hospital palliative care team (PCT) versus limited telephone advice (telephone-PCT, the control group). Highly significant improvements were observed in symptoms, health-related quality of life, mood and “emotional bother” in full PCT at 1 and 4 weeks; a smaller effect was seen in telephone-PCT, but there were no significant differences between the groups when the baseline levels of symptoms were considered. No differences between the groups were seen in length of stay, readmission rates, resource utilization, or costs. The authors noted that the study hospital already had excellent long-standing palliative care practices, and the intervention was limited to nonacute patients not needing an immediate consult; therefore, the chance of detecting differences was small (44).

The US move to accountable care organizations (ACOs)—vertically integrated health care systems of comprehensive outpatient and inpatient care with bundled or episodic payments rather than fee-for-service—will allow further evolution of integrated palliative care. Because of the need to best utilize limited resources, palliative care has been widely adopted by the largest “ACO” in the United States: the Veterans Administration Medical Centers. The VAMC offers expanded-access hospice up to two years prior to expected death. People with cancer or congestive heart failure, for instance, can receive additional hospice and home care benefits while receiving conventional treatment without needing to forego curative treatment. The VAMC has embarked on an ambitious training program to have palliative care available in all regions and settings ([http://www.va.gov/GERIATRICS/guide/longtermcare/Hospice\\_and\\_Palliative\\_Care.asp](http://www.va.gov/GERIATRICS/guide/longtermcare/Hospice_and_Palliative_Care.asp)). Long-term data on outcomes from the VAMC expansion are not yet available, but preliminary data suggest that palliative care consultations can reduce the growing aggressiveness of care and use of critical care services, but only if given early in the disease trajectory and not during the terminal admission (40).

Insurers are also adopting palliative care and expanded-access options as services covered by conventional insurance. Aetna's Compassionate Care Program started this move. Using medical administrative records (billing claims), Aetna's program identified patients receiving treatment for advanced cancer. These patients were offered additional case-management services, expanded-access and concurrent hospice up to one year instead of Medicare's six months, telephone help with symptoms, and assistance with advance directives and durable powers of medical attorney. In a pre- and postseries analysis, survival appeared to be the same, patient satisfaction with the expanded services was high, and hospitalizations to regular beds and the ICU were cut dramatically (94). Further analysis showed that costs were reduced by 22% in the last 40 days of life as a result of reduced hospitalizations (54, 55).

Not all palliative care programs have shown economic savings. In Germany, the widespread use of palliative care inpatient units has resulted in the delivery of excellent care, but the inpatient units are more expensive than home-based care. In one recent study, the costs of expanded palliative care actually increased per-person health system costs by 3,994 Euros, 21,879€ ( $\pm 14,351\text{€}$ ) versus 17,885€ ( $\pm 14,326\text{€}$ ), because 70% of the inpatient cases died in the hospital versus 53% of home care cases, the patients who used inpatient services were significantly sicker, and there is little available home hospice care (35).

### Medical Specialties Where Palliative Care Is and Needs to be

We have seen dramatic increases in the use of palliative care in some fields such as oncology and geriatrics, usually following randomized trials showing benefits from the use of palliative care. Nearly all these studies have involved either inpatient (34) or outpatient consultative models (14, 97, 110). Other fields of medicine have substantial opportunities to investigate the benefits and costs of palliative care. As can be seen in **Table 2**, there is a paucity of articles describing specialty-specific RCTs assessing palliative care. In surgery, the study by Wallen et al. (101) of surgical oncology patients with advanced malignancies was hampered by high attrition rates owing to progression of disease or death, as well as crossover of usual care patients when they required more palliative care. The most palliative care RCT articles over the past decade were specific to oncology, but this is somewhat misleading because five of the seven articles were related to the landmark study on non-small-cell lung cancer (16). The two other oncology studies involved nursing interventions. de Raaf et al. (25) showed that nursing appointments involving systematic assessment of nine symptoms improved cancer-related fatigue and symptom burden. Psychoeducational sessions conducted by advanced practice nurses for patients with advanced cancer in the Project ENABLE study improved patients' quality of life and mood, although the sessions did not have an impact on symptom intensity or visits to the hospital, ICU, or emergency department. Studies of the use of palliative care in family medicine and pulmonology include the previously described outpatient and inpatient consultative approaches in San Francisco (41–43), as well as a study from Australia showing that case conferences bringing together general practitioners and specialist palliative care teams may improve some aspects of patient quality of life (65). Gade et al. (34) found improvement in care for hospitalized patients with life-limiting illnesses using an interdisciplinary palliative care service and internal medicine (19, 34). In pediatrics, Dallas et al. developed an RCT on family-centered advance care planning for adolescents with AIDS and their family decision maker (24), similar to colleagues' work on adolescents with cancer (60). The latter study showed improvement in congruence between adolescent patients and their family member when they participated together in advance care planning discussions. Trials of palliative care in critical care and emergency medicine are under way. In general, most medical specialty organizations advocate for enhanced study of palliative care in their discipline, but the number of well-designed, high-powered randomized trials remains low.



**Table 2 PubMed search for penetration of palliative care in the medical literature**

Discipline	Number of PubMed citations	Number of clinical trials	Number of RCTs (adults)	Number of RCT palliative care treatments or interventions <sup>a</sup>	Number of RCT palliative care programs <sup>b</sup>	Number of RCT specialty-specific palliative care programs
Surgery	4,249	305	305 (260)	74	1	1
Oncology	2,933	301	301 (265)	44	7	7 <sup>c</sup>
Family medicine	1,578	91	91 (65)	5	5	3 <sup>d</sup>
Critical care	1,117	49	49 (35)	7	2	1
Internal medicine	1,023	82	82 (66)	10	2	1 <sup>e</sup>
Radiation oncology	624	71	71 (64)	12	0	0
Pediatrics	494	32	32 (11)	1	1	1
Geriatrics	380	23	23 (21)	6	1	0
Pulmonology	346	29	29 (22)	6	3	1
Hepatology	332	47	47 (46)	15	0	0
Gastroenterology	320	46	46 (45)	15	0	0
Cardiology	263	21	21 (3)	2	0	0
Neurology	182	13	13 (10)	3	1	0
Emergency medicine	164	8	8 (6)	0	2	0
Nephrology	67	3	3 (1)	0	0	0

<sup>a</sup>Palliative care treatment or intervention: Specific intervention for a particular symptom (e.g., pain or dysphagia) or for style of communication (or skills teaching) if it involved patient outcomes.

<sup>b</sup>Palliative care program: Palliative care as an entire intervention (e.g., interdisciplinary team, consult service, palliative care unit, or global approach to decision-making).

<sup>c</sup>5 of the 7 manuscripts referred to the same study.

<sup>d</sup>2 of the 3 manuscripts were in internal medicine and referred to the same study.

<sup>e</sup>Same study as for critical care.

Search strategy: specialty AND palliative care (limits: English, past 10 years).

Limits: clinical trial.

Limits: randomized controlled trial (RCT).

Limits: Adults (19+ years of age).

Abstracts from RCT tally hand-searched for randomizing palliative care clinically, either as intervention for symptom(s) or as entire program.

We are beginning to see the connection of randomized trials with some particular diseases and conditions. As an example of a well-designed strategy, Higginson and colleagues (45) noted a high symptom burden in patients and families dealing with multiple sclerosis (MS). They collaborated with MS groups to design and pilot test an MS-specific intervention with more home care and concurrent palliative care. After successful pilot testing, they did a randomized phase III trial of early versus delayed palliative care and showed better symptom management, less distress, fewer hospitalizations, and less cost (£1789, US\$2741 for the 12 weeks) to the National Health Service with concurrent palliative care (45).

No randomized trials of concurrent palliative care have been conducted in some obvious study targets such as patients with bone marrow/stem cell transplantation, hematologic malignancies (28), acute leukemia (111), or any solid organ transplant group. There are promising pilot data

in such diverse fields as severe pulmonary hypertension (41, 96), left ventricular assist devices (95), advanced cardiovascular disease (39), and a number of other fields. Conditions or diseases in need of studies with randomized trials of palliative care include cardiology (congestive heart failure), nephrology (hemodialysis), pulmonology (pulmonary fibrosis), neurology (acute stroke), and hepatology (cirrhosis and liver transplantation), among others.

## Effects of Palliative Care on Costs

We strongly suggest that palliative care programs “cobrand” their services as being beneficial in their own right, but also as helpful in reducing readmissions and lowering health care costs as part of the health system strategic goal. Data from pilot trials, administrative databases, and randomized trials all show the benefits of palliative care with transition to hospice when appropriate.

The current state of knowledge supports the following suppositions. Palliative care reduces the cost of inpatient stays (69, 72, 92) and allows each hospital to calculate the financial savings from adding or expanding their palliative care team (16, 19). The savings estimate is partly based on reductions in inpatient length of stay, but it also includes savings from moving a patient from a high-cost venue such as the ICU to a lower-cost setting such as usual or palliative care—so called “cost avoidance” (91). One study has estimated that if the state of New York had palliative care programs in all its hospitals, with subsequent reductions in length of stay and greatly increased referrals to hospice when appropriate, the cost to Medicaid would be decreased by \$84 million to \$252 million annually (69).

Reducing readmissions is currently part of a national strategy to reduce health care costs, the main target being 30-day readmission rates. Palliative care programs help to reduce readmissions by 50% (77), increase referrals to hospice (63), decrease stress to caregivers (77), and lower overall health care costs (69). Palliative care programs do not increase hospital mortality rates because mature programs are better than the standard of care at getting people home and preventing those admissions that are intended solely to allow the patient to die in the hospital (16).

Linking palliative care to more appropriate hospice use is important. Hospice is underutilized; in one study at a large hospital, only 14% of hospital decedents who were hospice eligible were offered hospice on their penultimate admission because doctors failed to recognize patients’ eligibility (33). When hospice was offered and accepted, the patients in hospice were readmitted less frequently, and their terminal hospitalization cost was one-tenth as much as those who did not utilize hospice (102). Preliminary data from nonrandomized trials show that patients discharged home with hospice have a 5% 30-day readmission rate, those with palliative care showed an 8% rate, and those with no services showed a 25% rate (29). In the definitive trial of palliative care at diagnosis for lung cancer patients, hospice use and length of stay in hospice were both increased in the group that had concurrent palliative care (97).

The field still needs mechanisms to better identify triggers to start the palliative consultation process, to discuss hospice, and to set up advance directives at earlier stages of a patient’s disease or condition. An earlier study of concurrent care with “before you need it” referrals and introductions to the palliative care team showed hospice length of stay increased from 14 to 48 days (83). Hoverman and colleagues (46, 78) at US Oncology have been engaged in a redesign of services from fee-for-service chemotherapy to evidence-based clinical pathways that emphasize clinical recognition that an illness may be terminal. Preliminary data from colon and lung cancer patients show equal or better survival, double the use of hospice and length of stay in hospice of 30+ days, and one-third less cost of care for the illness.

## BARRIERS TO FURTHER INTEGRATION OF PALLIATIVE CARE

Despite the advances made in our understanding of palliative care treatments over the past 30 years, deficiencies in clinical knowledge about palliative care remain. Multiple symptoms are still not currently relieved, and the data are often not sufficient to guide clinical practice definitively. For instance, fatigue affects more than half of all palliative care patients, but there are no proven drugs that can be recommended to all patients. American ginseng helps cancer survivors with fatigue (9), and modafinil helps multiple sclerosis fatigue (48) but does not help cancer survivors (49). Definitive interpretation of clinical trials has been hampered by conflicting results, small numbers, or inadequate long-term follow-up (49, 66, 69, 109). Similarly, the evidence base to suggest the best treatment is lacking for dyspnea, delirium, ascites, pain control without opiates, and cognitive impairment. **Table 2** indicates that palliative care interventions have been studied with RCTs for some symptoms (e.g., dysphagia or bone pain or pruritus from biliary obstruction), but these are often modalities used in interventional specialties (comparison of stents, surgical procedures, or types of radiation therapy protocols).

One of the largest issues facing palliative care in the coming years is the workforce. Currently, 4,400 physicians work in hospice and palliative programs, which translates to 1 hospice and palliative medicine (HPM) physician for every 20,000 older adults with a life-limiting illness and 1 HPM physician for every 11,000 Medicare deaths (29). As noted above, Lupu (59) estimated a shortfall of 6,000–10,000 palliative care physicians and an equal number of advanced practice nurses. Board certification in HPM is now only available through fellowship training. The number of fellowship positions in the United States is currently fewer than 200 per year, with little chance of more government funding, so the problem will continue for the foreseeable future. A related problem is increased compensation for a cognitive specialty, HPM. Current websites list incomes near \$200,000 per year (87) and blogs note \$120,000–240,000 (22). Whether this income range will be sufficient to grow the field is unclear. It is not known whether enough clinicians in other cognitively based specialties such as internal medicine and family practice will be incentivized by the current compensation structure to pursue additional training and certification in HPM. Burnout may also play a role in the profession's slow growth. Although rates of burnout may not be different in palliative care as compared with those in other disciplines (26, 61) and even though guidelines exist to help HPM clinicians manage stress (51, 105), attrition of current practitioners due to work-related stress could contribute to the shortage. This shortage will reinforce the continued need for all practitioners to learn primary palliative care strategies and for specialized resources to be available by consultation (84).

Attitudinal barriers exist for both primary and secondary palliative care. Although primary care physicians may perform palliative care *de facto* for some of their patients, many have not received training in palliative care and may not adequately address certain issues such as symptom management, spiritual needs, and economic issues (30, 64). A recent study shows that if the primary care physician remains involved, patient and family have less distress (5). Educational programs have been successful in teaching physicians, in training and in practice, important knowledge and communication skills used in palliative care (3, 6, 30, 31, 80, 89), but much more needs to be done to deliver primary palliative care across the health care system. Variation exists with regard to physician willingness to refer patients to a secondary palliative care specialist or team (1, 99).

Research support for hospice and palliative medicine is also lacking. At present, less than 1% of the National Institutes of Health's (NIH) budget is dedicated to palliative care, although there have been substantial increases (240%) in NIH-funded investigators (now 294) and grants (now 391) since 2006 (38). Some foundations have funded innovative research and demonstration projects

(15), and institutional programs have been created to try to build the research base (71). But more funding support is needed to further the research agenda.

We continue to need administrative support for programs that are not flashy, billboard generating, or highly profitable. The growth of ACOs and the adoption of palliative care by HMOs such as Kaiser Permanente, Geisinger Health System (<http://www.geisinger.org/services/palliative>), the Mayo Clinic (<http://www.mayoclinic.org/palliative-care/>), and the VAMC ([http://www.va.gov/GERIATRICS/guide/longtermcare/Hospice\\_and\\_Palliative\\_Care.asp](http://www.va.gov/GERIATRICS/guide/longtermcare/Hospice_and_Palliative_Care.asp)) should lend strong administrative credence to the benefits of palliative care.

The palliative care leadership has been careful to evolve credible standards for programs that are both aspirational and practical. The National Consensus Standards for Palliative Care (75) were intentionally created as the framework for the Joint Commission Accreditation Program in Palliative Care ([http://www.jointcommission.org/certification/palliative\\_care.aspx](http://www.jointcommission.org/certification/palliative_care.aspx)). As noted above, at least one professional society, the American Society of Clinical Oncology, incorporates many of the current standards into its own practice improvement initiatives, such as pain assessment, pain management, and hospice referrals and hospice length of stay, and stresses palliative care in the “Choosing Wisely” campaign (88). The nephrology Choosing Wisely campaign also stresses realistic communication about prognosis and shared decision making (107).

## CONCLUSIONS

Palliative care programs have grown rapidly in the United States and the world owing to the combination of better quality of life, better quality of care, and the provision of care at an affordable cost. The clinical and financial arguments are compelling to expand palliative care, particularly with an older sicker population, and to perform more research into both symptom control and development of model systems. The major barriers will continue to be the lack of workforce and training programs and the inadequate funding for research.

## DISCLOSURE STATEMENT

The authors are not aware of any affiliations, memberships, funding, or financial holdings that might be perceived as affecting the objectivity of this review.

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