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Models of palliative care delivery in the United States

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Abstract

Purpose of review—To summarize the current United States healthcare system and describe current models of palliative care delivery.

Recent findings—Palliative care services in the USA have been heavily influenced by the public–private fee-for-service reimbursement system. Hospice provides care for 46% of adults at the end-of-life under the Medicare hospice benefit. Palliative care teams in hospitals have rapidly expanded to provide care for seriously ill patients irrespective of prognosis. To date, over two-thirds of all hospitals and over 85% of mid to large size hospitals report a palliative care team. With the passage of the Patient Protection and Affordable Care Act of 2010, healthcare reform provides an opportunity for new models of care.

Summary—Palliative care services are well established within hospitals and hospice. Future work is needed to develop quality metrics, create care models that provide services in the community, and increase the palliative care workforce.

Keywords

healthcare delivery; hospice; palliative care; palliative medicine

INTRODUCTION

Palliative care in the USA has evolved from a singular focus on persons at the end-of-life, for which care was solely directed on comfort, to a more broad-based interdisciplinary specialty that addresses the needs of all seriously ill persons and their families. US palliative care is now conceptualized as patient-centered and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient/family needs, preferences, values, beliefs, and culture. Palliative care is provided concurrently with all other appropriate treatments including those directed at cure and life prolongation by a

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Conflicts of interest

There are no conflicts of interest.

team of physicians, nurses, social workers, chaplains, and other relevant healthcare professionals as needed [1].

OVERVIEW OF HEALTHCARE REIMBURSEMENT AND DELIVERY IN THE USA

Delivery of healthcare in the USA is influenced by a complex public–private payment structure. Whereas healthcare reimbursement in many countries is a mix of public and private insurers, the USA is singularly unique in the extent to which the private sector dominates public reimbursement mechanisms. In 2011, 55% of Americans under the age of 65 received private employer-sponsored insurance, 10% purchased insurance on the private market, 12% received insurance through Medicaid – a State and federal program for the indigent, and 16% were uninsured [2]. Persons over the age of 65 are almost universally covered by the federal government’s Medicare program. Even under Medicare, however, private insurers have an influential role owing to their administration of Medicare Advantage Plans (described below).

The 2010 Patient Protection and Affordable Care Act

The 2010 Patient Protection and Affordable Care Act (PPACA) resulted in the most significant changes in US healthcare since the passage of Medicare and Medicaid in 1965 [3]. The overall goals of the PPACA are to decrease the number of Americans without health insurance, improve healthcare outcomes and delivery, and lower costs [3]. Key components of the PPACA include: the ‘individual mandate’ that requires that all individuals not covered by an employer-sponsored health plan, Medicaid, Medicare, or other public insurance programs to secure an approved private insurance policy or pay a penalty; establishment of minimum standards for health insurance policies and elimination of annual and lifetime coverage caps; elimination of copayments, coinsurance, and deductibles for selected healthcare insurance benefits considered to be part of an ‘essential benefits package’; prohibitions on excluding individuals with preexisting conditions from insurance coverage; the restructuring of Medicare reimbursement from ‘fee-for-service’ to ‘bundled payments’ in which a single payment is paid to a hospital or physician group for a defined episode of care rather than individual payments to individual service providers; and the creation of the Center for Medicare and Medicaid Innovation to oversee the testing of innovative payment and delivery models. Changes mandated by the PPACA are to be phased in through 2020 [3].

Employer-sponsored insurance

Employer-sponsored insurance covers most Americans [2]. Employers provide insurance as part of their employees benefit package with the price of the premium born by both the employer (the majority) and employee. Insurance plans are administered by private companies, both for-profit and not-for-profit. Prior to the PPACA, benefits and the degree of cost sharing (co-pays and deductibles) varied widely across insurance companies and within individual plans. Under the PPACA, however, plans are required to provide more uniform benefits. Coverage of prescription drugs is not addressed by the PPACA and remains under

the purview of individual plans with some plans covering prescription drugs and some not with substantial variability in cost-sharing arrangements.

Individual market

The individual market covers the part of the population who are under age 65 and self-employed or retired. A key component of the PPACA is the requirement for individuals without employersponsored health insurance to purchase coverage or face fines beginning in 2014 [3]. The PPACA has established health insurance exchanges in each State that offer a marketplace where individuals and small businesses can compare policies and premiums, and buy insurance [3].

Medicare

Medicare is a federal program that covers individuals ages 65 and over, some persons with disabilities, and persons with end-stage renal disease on dialysis. Federal income taxes, a payroll, and individual enrollee premiums finance Medicare. Medicare has three components: Medicare Part A covers hospital services and hospice; Medicare Part B covers physician services, and Medicare Part D offers a prescription drug benefit. Medicare Part C refers to Medicare advantage – for-profit and not-forprofit insurers that administer Medicare benefits under a capitated system [4]. Gaps in Medicare coverage are considerable and include incomplete coverage for skilled nursing facilities, incomplete prescription coverage, incomplete coverage for home care and long-term care, and no coverage for dental, hearing, vision, or long-term care [4]. Thus, the majority of enrollees obtain supplemental insurance. Overall, seniors pay about 16% of their income for healthcare costs despite Medicare coverage and this percentage increases considerably in the last 5 years of life. Medicare beneficiaries spend on average US\$38 688 in the last 5 years of life (US\$101 791 for the top quarter) and more than 75% of households spend at least US\$10 000 [5,6].

Medicaid

Medicaid is a program designed for those with low income and the disabled that is jointly funded by the States and federal government. By federal law, States must cover very poor pregnant women, children, elderly, disabled, and parents. Childless adults are not covered, and many poor individuals make too much to qualify for Medicaid. The States and the District of Columbia are responsible for administering the Medicaid program; as such, there are effectively 51 different Medicaid programs in the country. Medicaid offers a fairly comprehensive set of benefits, including prescription drugs and longterm care. Despite this, many enrollees have difficulty in finding providers that accept Medicaid because of its low reimbursement rate.

OVERVIEW OF HOSPICE AND PALLIATIVE CARE

Hospice in the USA began when Florence Wald, former Dean of Yale University's School of Nursing, returned from a sabbatical at St Christopher's Hospice in London, England, and established the Connecticut Hospice in 1974 [7]. Subsequently, a Department of Health, Education, and Welfare task force in 1978 reported that 'the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds

out a means of providing a more humane care for Americans dying of terminal illness while possibly reducing costs' [7]. A hospice demonstration program was initiated in 1979 followed by the creation of the Medicare hospice benefit in 1982 [7]. Eligibility for hospice under Medicare requires that two physicians certify that the patient will die within 6 months 'if the disease runs its normal course' and that the patient agrees to forego regular insurance coverage for life-prolonging and curative treatments [8]. In 2011, there were approximately 2513 000 deaths in the USA with 1059 000 (46%) of those deaths occurring under the care of one of over 5000 hospices [9].

Modern US palliative care was developed within academic medical centers in the early 1990s based upon the recognition that the core principles of hospice care should be applied to all with serious illness, irrespective of prognosis [10]. Spurred by studies [11] that documented major inadequacies in care for the seriously ill, legalization of assisted suicide in Oregon in 1994 [7], and infusion of hundreds of millions of dollars by US philanthropic foundations to improve care of the seriously ill [7], palliative care teams rapidly expanded in US hospitals [12]. Notable landmarks in palliative care's development include the establishment of certification in hospice and palliative nursing in 2002 by the American Board of Nursing Specialties, publication of a National Framework and Preferred Practices for Palliative and Hospice Care Quality by the National Quality Forum in 2006 that established consensus quality guidelines for standardized palliative care [13], and a certification program for hospitals by the Joint Commission in 2011 [14]. Additionally, in 2008, palliative medicine was recognized as establishment of a formal subspecialty by 10 parent boards of the American Board of Medical Specialties in 2008 [15]. As of 2012, the only pathway to Board Certification is through an accredited American Council of Graduate Medical Education fellowship training program following board certification in a qualifying parent specialty. Today, over two-thirds of American hospitals and over 85% of mid-large size hospitals report palliative care teams and over 6000 physicians are certified by the American Board of Medical Specialties [12].

MODELS OF PALLIATIVE CARE DELIVERY

To date, models of palliative care delivery have been relatively few, delivered by specialist teams, and influenced overwhelmingly by reimbursement systems [7]. Home-based and nursing home care has been primarily limited to dying patients and their families provided under hospice. Interdisciplinary teams providing specialist-level palliative care to all patients with serious illness irrespective of prognosis have been largely confined to hospitals. Patients living in the community who are not hospice eligible have had few palliative care options available to them and very little palliative care is provided by generalists. The environment, however, is changing as the provisions of the PPACA provide fiscal and quality incentives to deliver palliative care outside of hospitals leading to the development of community palliative care models that include primary, secondary, and tertiary models of palliative care delivery [16].

Hospice

In addition to Medicare, the cost of hospice is covered by Medicaid and most private insurance plans using the Medicare eligibility criteria. Despite the 6-month benefit period,

median length of stay in hospice is slightly under 3 weeks and 35% of patients are discharged or die within 1 week of admission [17]. Forty-one percent of hospice patients receive care in their homes, 18% in nursing homes, 7% in residential facilities, 22% in inpatient hospice facilities, and 11% in an acute care hospital [17]. Thirty-seven percent of patients have a primary diagnosis of cancer [17]. Unlike traditional fee-for-service medicine, hospice services are provided under a daily capitated per-diem rate that is set by local coverage determinants [8].

Hospice structures and processes of care are regulated under the Medicare benefit [8]. Additionally, hospices must meet state licensing requirements and many volunteer to obtain accreditation through organizations such as the Joint Commission or other similar agencies. Services that must be provided include medical, nursing, social work, chaplaincy, and bereavement support to family members. On average, hospice is able to provide 20 h per week in personal care needs through a home health aide. Eighty percent of care must be provided in the patient's home residence and care must be available 24 h a day, 7 days a week. In actuality, there is a wide variation in the provision of hospice services. Whereas all hospices provide the core package of Medicare services, size, tax status, and geography appear to be associated with service delivery. Larger not-for-profit hospices providing considerably more additional services than for-profit or smaller programs [18–20]. Variability in case-mix (e.g., percentage of patients noncancer diagnoses) appears to be influenced by similar factors [18–20].

Hospice care has been associated with significant improvement in the quality of dying (symptom control), family and patient satisfaction with care, reduced aggressiveness of care at the end-of-life and reductions in the incidence of posttraumatic stress disorder and prolonged grief disorder as compared with those receiving usual care [21,22]. Additionally, recently published data suggest that hospices result in substantial cost savings to Medicare and reductions in healthcare utilization (e.g., hospitalizations, intensive care unit utilization, and emergency department visits) [23■].

Despite widespread public understanding and support of the hospice concept, less than 50% of all US deaths actually occur in hospice [9,24]. Barriers to the universal provision of hospice care include the inability to accurately prognosticate noncancer diagnoses, the requirement to relinquish expensive but often beneficial treatments (radiation therapy, palliative chemotherapy, blood transfusions) because such treatments are either forbidden under the benefit or prohibitively expensive given the hospice per diem, and the linkage in the minds of clinicians and patients of hospice with the end-of-life [25]. As a result, many patients who could benefit from the comprehensive care that hospice provides are not eligible under the current program [26]. Even those for whom disease-directed treatments are no longer beneficial may refuse to enroll in hospice because of its association with death and dying [26].

Hospital palliative care

The development of palliative care services has been largely influenced by the US fee-for-service system. Because current reimbursement mechanisms fail to provide support for the interdisciplinary team beyond physician reimbursement, to date, palliative care teams have

largely developed within hospitals where the demonstration of the enhanced quality provided by palliative care teams in combination with significant cost savings to hospitals has provided a strong business case to support their development [27,28,29]. Unlike the ambulatory care settings, hospitals receive a lump sum Diagnosis-related Group payment for an episode of patient care [28]. Thus, interventions like palliative care that reduce overall patient care costs for hospitals improve profit margins. Indeed, an average-size US hospital can save over US\$3 million per year by having a palliative care team [28].

The two primary models of palliative care that exist within hospitals are interdisciplinary consultation teams and inpatient units. The number of hospital palliative care teams has grown rapidly and as of 2011, 63% of all US hospitals reported a palliative care team and over 85% of hospitals with over 300 beds. Like much of healthcare in the United States, these overall statistics mask tremendous variability. For example, the presence of a palliative care team is significantly influenced by geography, hospital size, hospital type (e.g., academic medical center, faith-based institutions), and tax status (for-profit versus not-for-profit.) [30].

Hospital palliative care consultation teams are typically comprised of a physician, advance practice nurse, and social worker with larger teams having dedicated chaplains, psychologists, and volunteers [1]. Teams provide both consultation and also occasionally assume primary care. Inpatient consultation teams have been shown to improve patient symptoms, enhance family satisfaction and well being, while significantly reducing hospital costs by aligning medical treatments to patient goals and reducing misutilization [28].

Inpatient palliative care units are typically found in larger and more mature programs. Such units either assume primary responsibility for patients or continue in a consulting role. Admission to inpatient units are typically for patients with difficult to control symptoms, with medical needs that cannot be optimally managed in another care setting, with distressed families who are in need of a higher level of support, or who are imminently dying. High-volume inpatient palliative care units have also been shown to be highly cost-effective for hospitals. In one study, a dedicated palliative care unit reduced daily hospital costs by 74% as compared with usual care patients [31].

Newer models of palliative care

Newer models of palliative care focus on delivering services to patients living in the community with serious illness who are not eligible for hospice. New payment models under the PPACA that penalize hospitals for unwanted and unnecessary readmissions, bundled payment plans that capitate both inpatient and outpatient costs, and efforts to reduce hospital mortality have led to the development of new models of care. These early models include ambulatory consultation clinics [32,33] in which interdisciplinary teams provide palliative care consultation to treating physicians, interdisciplinary home care provided through certified home health agencies or hospices outside of the Medicare Hospice Benefit, [34] palliative care teams supported by capitated managed care plans [35,36], and hospital-based teams that provide physician home visits [37].

CONCLUSION

Palliative care services within the USA have undergone rapid growth and transition within the past decade. Care for the dying is well codified and established within the Medicare Hospice Benefit and hospice is a mature and vital industry within the USA. Hospital palliative care teams focused on caring for seriously ill patients, irrespective of prognosis, are now relatively established in most hospitals. Under healthcare reform, new efforts focused at expanding palliative care services to persons with serious illness and their families living in the community are underway. Future work is needed to develop appropriate quality metrics for palliative care services so as to align palliative care service delivery with federal efforts to promote and reward quality, create appropriate care models that provide services where patients and their families actually reside, and to enhance the palliative care workforce such that adequate knowledge and expertise exist within the healthcare profession to adequately deliver high-quality palliative care.

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- of special interest
- ■ of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 242).

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KEY POINTS

- Palliative care focused on enhancing quality of life for the seriously ill has been shown to improve clinical outcomes and reduce hospital costs.
- Palliative care teams are now available in the majority of US hospitals.
- Hospice teams now care for almost 50% of US deaths.