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A Review of Barriers to Utilization of the Medicare Hospice Benefits in Urban Populations and Strategies for Enhanced Access

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ABSTRACT *Disparities in access to health care extend to end-of-life care. Lack of access to hospice mirrors lack of access to health maintenance and primary care. Patients who are served by hospice nationally are disproportionately white and likely to reside in economically stable communities. In many urban low-income communities, less than 5% of decedents receive hospice care in the last 6 months of life. This review focuses on barriers to palliative care and hospice in urban, predominantly low-income communities, including cultural and reimbursement factors and the paucity of hospice providers, outreach projects, and in-patient hospice beds in urban communities. This review will also address some strategies that are being implemented by hospices locally and nationally to overcome demographic barriers to hospice care.*

KEYWORDS *End-of-life, Health disparities, Hospice, Urban.*

INTRODUCTION

There has been relatively little focus from public health communities on the increased needs, dependency, and greater vulnerability of patients nearing the end of life. The care of such patients is fragmented across multiple settings and with little communication by multiple providers across the trajectory of care settings. Health-care expenditures in the USA are consuming increasingly larger proportions of the Gross National Product each year. However, there is little evidence to suggest that the amount that is spent on health care correlates with better outcomes for individual patients. This is nowhere more apparent than in end-of-life care and in regard to the utilization of the hospice Medicare benefit in particular with significant socioeconomic and racial disparities existing in the uptake of this benefit.

In this article, we will focus on hospice as it is the most widely institutionalized system of care for patients at the end of life. We will describe some of the barriers that account for the lack of utilization of hospice by minority and low-income patients in urban settings and the accompanying disparities in health-service utilization and clinical outcomes. We will describe novel programs and initiatives that can offset barriers to effective end-of-life care in urban settings. We will also

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describe initiatives by hospice organizations to foster the growth of palliative-care programs in urban community medical centers and partnerships between hospice, acute care, and long-term-care institutions that enhance end-of-life care.

Over one third of terminally ill patients have substantial care needs. Evidence suggests that the last phase of life is often characterized by prolonged dying, accompanied by significant emotional distress and financial expense and inadequate support for patients and families. An exhaustive examination of care at the end of life by the Hastings Center, in collaboration with the National Hospice Work Group, revealed that for most Americans, the health-care experience in the last months of life is "deplorable and in need of full reconstitution."[1–3] The 1995 Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment study characterized dying as "painful, lonely and invasive." Families of patients who died in hospitals reported ineffective pain control, depletion of financial resources, illnesses in caregivers as a result of the burden of the illness, and insufficient information about existing community resources such as home hospice.[4]

Acute-care hospitals have responded to this in the last two decades with the development of multidisciplinary palliative-care teams. Unlike hospice, palliative-care services do not confine their activities to patients who are within 6 months of death or focus on patients who have transitioned to supportive as opposed to curative treatments. They currently have limited scope of service due to limited funding mechanisms. Low-income patients who receive their care in urban community medical centers are likely to receive less support. The activities of palliative-care services are typically confined to single institutions or organizations and typically reach relatively small numbers of patients, often only on an episodic basis. A recent study of 1,596 patients in 35 university medical centers identified that, on average, only 13% of patients who met the authors' criteria for end of life received a palliative-care consultation.[5]

THE MEDICARE HOSPICE BENEFIT

Hospice is a program of care for persons in the last phases of an incurable disease and their families or caregivers. Eligibility for this benefit is predicated on a physician's estimate of prognosis of 6 months or less and the presence of one or more progressive illnesses. The goal of hospice is to manage the physical, psychological, spiritual, social, and practical issues that present as a result of the dying process and continue for the family in the yearlong bereavement period that follows death. Hospice is provided in both home and facility-based settings by an interdisciplinary team of professionals—physicians, nurses, medical social workers, therapists, counselors, and volunteers—who coordinate an individualized plan of care for each patient and family.

The modern concept of hospice emerged in France in 1842 when Madame Jeanne Garnier used the word 'hospice' to describe the care of dying. She established several hospices or 'calvaires' in Lyons. The first use of the term in this country was by Calvary Hospital in the Bronx in 1899 which cared for impoverished people with incurable illnesses. Hospice began to be widely available in the USA as a result of the volunteerism of many health professionals in response to the increasingly technical nature of death in the second half of the twentieth century. Hospice became institutionalized in 1982 when Congress added hospice care as a Medicare Benefit when it enacted the Tax Equity and Fiscal Responsibility Act (TEFRA).[6] The Act defined how hospice would be paid for under the Medicare benefit. By 2003, there

TABLE 1 Demographics of hospice in the USA

	1993–1994	1999–2000
Number of hospice beneficiaries	275,000	700,000
Number of certified hospice providers	2,059	3,100
Primary payment source		
Medicare (%)	65.4	79
Private (%)	15.3	11.6
Medicaid (%)	4.3	4.4
Other (%)	15.0	4.9
Setting		
Urban (%)	N/A	13
Urban/rural (%)	N/A	38
Rural (%)	N/A	49
Race[a]		
Non-Hispanic white (%)	77.5	74.1
Non-Hispanic black (%)	11.5	14.6
Other (%)	11.4	11.4
Median length of stay (days)	29	20.5
Residence		
House/apartment (%)	81.44	60.7
Inpatient facility (%)	11.67	35.17
Other (%)	6.89	4.13

[a] Weighted percentages for enrollment on hospice.

were approximately 3,300 operational hospice programs in the USA serving 850,000 patients and families annually. However, the goals of TEFRA have not been fully realized.

Hospice continues to serve a relatively small proportion of dying Americans and their families. This is more pronounced in urban communities and for low-income persons and minorities in particular (Table 1). The Urban Institute analysis of 1995–1998 Medicare Current Beneficiary Survey Cost and Use Files demonstrated that 11% of nonwhite decedents used hospice in comparison with 17% of white decedents. Fourteen percent of decedents who had incomes less than 100% of the Federal Poverty level had hospice use in comparison with 20% of decedents with reported incomes 300% or greater than the federal poverty level.[1,7–9]

DISPARITIES IN MEDICAL CARE AT THE END OF LIFE

Profound racial, socioeconomic, and ethnic disparities persist in the care of patients in this country with life-threatening illnesses. These disparities occur in the use of diagnostic, curative, life-sustaining, and palliative interventions. A recent analysis of Medicare administrative data indicates that costs for end-of-life care for minorities were 18% higher in the last year of life but 25% less in the 3 years prior to death than for others; however, within minorities, costs were only higher for African-Americans. Costs for others including those for Hispanics were not significantly different than for the rest of the population. Minorities were more likely to die in hospitals and also had higher out-of-pocket expenditures than whites. Medicare expenditures were significantly higher in urban areas. Beneficiaries who resided in areas with zip codes with lower average incomes and higher rates of poverty had higher end-of-life expenditures and likelihood of dying in the hospital and lower rates of utilization of hospice.[10]

Factors that may render low-income patients at the end of life at increased risk of hospitalization include a lack of supplemental insurance, inability to sustain co-payments for medications and formal caregivers, and strained social-support systems.[11,12]

Predictable complications of advanced illness such as pain are often poorly controlled in minority and low-income persons in urban settings. Pain and its control are used by epidemiologists and researchers involved in end-of-life care nationally and internationally as a benchmark for the quality of palliative care.[13,14] Studies have revealed that in the emergency-room setting,[15] the post-operative,[16] and the outpatient setting[17,18] minority patients were more likely to receive inadequate analgesia than nonminority patients. A 2000 study of pharmacies in all five New York City boroughs revealed that, while 72% of pharmacies in predominantly white neighborhoods stocked opioids sufficient to treat severe pain, only 25% of pharmacies in predominantly nonwhite neighborhoods had these drugs available.[19] The lack of access to medications that can afford relief to 90% of patients could account in part for higher rates of hospitalization of minority patients at the end of life.[20] Such deficits in access to effective symptom control could be offset in part by use of the hospice benefit.

HOSPICE AND MINORITY PATIENTS

Table 1 illustrates the underutilization of the Medicare hospice benefit by minorities. While there has been a trend to increased enrollment on hospice by African Americans, Hispanic/Latino, and Asian Americans between 2000 and 2003, hospice continues to serve predominantly white and more economically stable patients.[7]

Barriers to Hospice and Palliative Care in Urban Minority Communities

Racial disparities in medical services for patients represent a significant barrier to hospice. Unsurprisingly, minority patients who have less access to preventive measures are more reluctant to choose "nonaggressive" measures at the end of life. African-American patients living with HIV are more likely to want to have aggressive interventions, and African Americans living in skilled nursing facilities are more likely to want cardiopulmonary resuscitation.[21,22] Elderly minority patients with low income and lower educational levels also accustomed to having fewer choices in health care are more likely to want life-sustaining treatments.[11,23]

Distrust of the health-care system on the part of minorities may represent an additional barrier to hospice care. Fifteen percent of minorities believed that they would receive better health care if they were of a different race. One recent qualitative study of patients with advanced illness, who were receiving home care from the Visiting Nurse Services in New York but who were not currently enrolled on hospice, identified that 32% of African-American patients believed that they would receive better care were their race or ethnicity different.[24] Minority patients may be more likely to fear that hospice will provide them with lower quality care than the care that they can receive in an acute-care hospital.[25,26]

Lack of diversity in hospice teams and sensitivity to the cultural values of diverse communities has historically been a barrier to hospice care. Hospice providers who come from different cultural and ethnic backgrounds to the patients that they serve may be less likely to recognize the religious traditions of their patients or inadvertently to impede care from the patients' religious community. Even the language that is used by health-care professionals who focus on end-of-life care may alienate African Americans with strong beliefs in immortality in contrast to the palliative-care community's notion of "end-of-life" care. Many Hispanics may believe that death is determined by "God's Will" and suffering is an integral part of this. Hospice philosophy which encourages aggressive pain control and the formalization of advance directives may be antithetical in such communities that emphasize the protection of the dying person against the knowledge of impending death for fear of precipitating death due to the removal of hope.[25,26]

Other reported barriers to hospice for African Americans in particular include hospice-admission criteria such as the requirement for a primary care provider to agree with an estimate of prognosis of 6 months or less. Hospice organizations have identified problems in serving Hispanics including reimbursement barriers (higher proportions of dying Hispanics than African Americans are covered by Medicaid), language barriers, and severity of illness. The percentage of hospice patients with Medicare as their primary payment source increased from 63% to 79% between 1991–1992 and 1999–2000, and the weighted percentage of patients with Medicaid as a primary payment source decreased from 5.81% to 4.46%.[7,27]

Practical barriers to the uptake of the hospice benefit in urban settings include the length of time it can take to qualify patients for Medicaid, the rise in the number of undocumented immigrants who do not qualify for Medicaid, and the lack of access to inpatient hospice beds in economically disenfranchised urban communities. Health-care providers caring for minority patients may be unaware of existing services or the process for referral. Many minority patients may be less likely to be informed of hospice by their medical providers. In a recent study, minority patients were less likely to have heard of hospice from their medical providers. Other factors that were negatively correlated with knowledge of hospice were lower educational level and primary place of medical care other than a private physician's office.[24]

Certain vulnerable populations may have additional barriers. Some hospices have declined to care for patients without permanent residences. Many homeless shelters are not equipped to care for medically ill homeless patients, and the historic requirement that hospice patients should have a primary care provider may limit access to hospice for the homeless. The homeless may often be forced to access end-of-life care in the emergency room.

DISPARITIES IN UTILIZATION OF THE HOSPICE BENEFIT BY URBAN POPULATIONS

Such disparities are reflected in regional and local patterns of hospice and Medicare expenditures at the end of life. Across New York, the home state of the authors, for example, there are wide disparities in access to hospice. Between 2000 and 2003, New York had the fifth lowest percentage of patients dying with the Medicare Hospice benefit in place (18.7%) compared with the national average of (27.2%). While some up-state communities reported up to 42.6% enrollment on hospice, no medical center in New York City reported more than 25% enrollment in hospice. Hospice enrollment in medical centers serving the poorest sections of the community with the highest proportion of minorities was typically less than 5%. The lowest rate reported for one medical center in the Bronx was less than one fifteenth the averages for the state.[28]

This underutilization of hospice was accompanied by greater use of acute care at the end of life. In 2003, New York Medicare beneficiaries spent an average of 4 days more in acute-care hospitals than the national average and had the highest percentage of patients dying in acute-care hospitals in the country, 38.3% compared with the national average of 30.4%. During the last 6 months of life, 72.6% of New York Medicare beneficiaries were hospitalized for an average of 15 days.[15]

HOSPICE INITIATIVES THAT HAVE FOCUSED ON PALLIATIVE-CARE NEEDS OF URBAN COMMUNITIES

Hospices can enhance access for urban populations by creating teams that are more inclusive and reflective of the communities that they serve. Useful strategies include outreach programs, linkages with other programs in community facilities, and trained volunteers and staff who can work with patients in nontraditional settings.[29,30]

The Hospice of Florida Sun coast, for example, is a nonprofit group that was established by volunteers and serves more than 1,200 patients per day in Pinellas County in Florida. About three quarters of its AIDS patients and about half of its nursing-home residents are Medicaid beneficiaries. It is able to offer $8 million a year in uncompensated care through the fund-raising efforts of a dedicated foundation and well-developed volunteer programs. Its intergenerational teen volunteer programs includes a 'Life Time Legacies' life-review program by trained teens with terminally ill patients. It has also created a coalition of 22 faith-based communities with more than 130 volunteers who provide care for terminally ill or older members. Its 67-bed residential program has offered more than 1,300 patients the ability to live in a 24-h home-like setting who would not be able to live in other living arrangements. It also offers service to 88 of the 91 skilled nursing facilities in Pinellas County. It has also pioneered a patient-information system 'Sun coast solutions' that is currently used in the care of over 20,000 patients each day across the country. This allows teams to exchange information electronically, access clinical data 24 h/day, and to access optimal symptom-management protocols and increases the proportion of clinicians' time spent with patients each week by 20%.

African Americans and Latinos have been highly receptive to end-of-life care services that emphasize family consensus and spirituality and provide relief for patients and families. Surveys indicate a need for improving awareness of hospice in these communities.[24]

One New York hospice, Continuum Jacob Perlow, has enhanced access to palliative care for economically disenfranchised patients through initiatives such as a hospice residence in the Bronx which was established in 2005. Of 136 sequential admissions, 38 have been for patients who were homeless and would not otherwise have had access to hospice services. Its staff's diversity reflects that of the borough. Thirty eight percent are white, 34% African American and Afro-Caribbean, 25% Hispanic, and 3% are Asian. The staff provides care to an average daily census of 135–150 Bronx residents and their families. In 2005, they cared for 730 patients and their families. Ninety percent of this care is provided in the patients' homes. The diversity of its staff coupled with outreach programs are allowing inroads to be made in access to hospice care for a predominantly low-income and minority population. A hospice-supported palliative care and case-management team in collaboration with the palliative-care service in the Emergency Department at Montefiore Medical Center (MMC) allowed close to one third of patients who died over the course of the pilot project's activities access to hospice services; this compares favorably with an estimate of 7.7% of patients who were admitted to acute care at the medical center between 2000 and 2003 who died with the hospice benefit in place. Of patients served, 65% were African American or Hispanic. Of significance, approximately 78% of patients who died who were served by this project died outside of the medical center. The enhanced availability of home hospice and palliative homecare services may account for these patients ability to die in their place of residence.[28,31] The development of hospice contracts with many local long-term-care facilities has permitted terminally ill older adults who require more care than can be provided in the home-care setting with access to an additional tier of services in nursing homes that may also account for some reduced utilization of the acute-care setting by such patients.

Community hospitals nationally and in the Bronx have increased access to hospice by the development of contracts with multiple hospice providers and designation of hospital beds as being available for hospice ensuring access to acute care for patients who have acute worsening of progressive illnesses warranting hospitalizations. Hospices provide services on available community resources and participate in interdisciplinary rounds for patients who are hospitalized to identify patients who would benefit from hospice.

This integration of hospice into the operations of acute-care hospitals has occurred in parallel with the development of full-time multidisciplinary palliative-care consultation services in most of the acute-care hospitals in the Bronx. The palliative-care service at MMC, for example, is now able to provide consultative and primary in-patient care to approximately 40% of the adult patients who die at the Medical Center each year. In one advance-practice-nurse-staffed intensive-care-unit-based project, 75 critically ill patients were able to be placed on hospice between 2005 and 2007. Formalized training on hospice and palliative medicine has been incorporated into the curricula of family-medicine and internal-medicine residencies, medical students, geriatric, psychiatry, and oncology fellowships at MMC. Hospice is supporting the development of hospice and palliative-care physicians and social-work fellowships at MMC and in other community medical centers for health-care professionals who will subsequently develop similar programs for low-income patients and families in other community urban settings.

Other recent developments in hospice care include a shift from the traditional dichotomous cure or palliation paradigms with the advent of *Open Access* policies for hospice eligibility which remove the stipulation that patients discontinue disease-modifying therapy to enroll on hospice. For urban economically disenfranchised patients, the ability to continue certain therapies, such as palliative chemotherapy or radiation at the same time as which they can receive multidisciplinary home hospice care, may facilitate the transition to end-of-life care that is more supportive in its focus and less likely to be associated with death associated with the use of life-prolonging treatments.

Financial Implications of Greater Access to Hospice

While many acute-care hospitals can support home-care agencies, most hospices are not divisions of acute-care hospitals. To maintain a census sufficiently high to support the cost of a multidisciplinary team, most hospices partner with multiple acute-care and long-term facilities. The provision of palliative home care is time-intensive and requires specific expertise and training. Hospices can partner with home-care agencies through the provision of one-time consultations by advance-practice nurses or physicians which can be reimbursed through Medicare part B without an increment in cost to the home-care organization.[32]

In long-term-care settings, the hospice can add another tier of services for patients that are also reimbursed through Medicare. Such services can enhance quality of care such as additional nurses' aide hours for patients with advanced dementia, increased focus on pain as a result of weekly visits by nurses and focus on psychosocial and spiritual well-being by hospice social workers and chaplains. However, for many older long-term residents at the end of life who are not yet dual eligible for Medicare and Medicaid, hospice may not be an option as the room and board charges for the nursing home would be out of pocket.

Hospice may enhance the impact of hospital palliative-care teams on rates of use of acute care. Home visits by hospital-based teams are sporadic, time-intensive, and not sustained by the reimbursement for such services by payers. Enrollment on hospice can permit a moderate revenue stream for acute-care hospitals for patients who are critically ill at the end of life who require on-going hospitalization and for whom discharge is not practical due to the level of medical support that they require. Such patients are likely to have protracted hospitalizations which exceed the Diagnosis-Related Group limits of payment by many payers. Hospice can also subsidize the cost of implementation of hospital palliative-care programs which cannot sustain themselves financially through reimbursement by payers. For many financially strained urban community hospitals, this could permit the implementation of palliative-care programs.

CONCLUSION

Profound ethnographic disparities exist in the care of patients at the end of life. Much of this imbalance is associated with general distrust of the medical system by low-income and minority patients accustomed to disparities in access to preventative and health-maintenance services. Limited ability to bridge the cost of care at the end of life for low-income patients coupled with reimbursement barriers further limit access to the hospice benefit for minority patients. These barriers were, until recently, compounded by limited numbers of hospice personnel in predominantly low-income and minority communities and a scarcity of in-patient hospice beds.

The striking imbalance in the uptake of the hospice benefit, health-service utilization, and place of death by urban low-income patients emphasizes the need for interventions that are sensitive to the values and needs of certain minority populations. Greater uptake of hospice may be achieved in urban settings by the development of outreach programs in settings where patients access care and through the development of hospice teams whose diversity reflects that of the communities that they serve and through the development of partnerships with acute and long-term organizations to improve direct patient care and enhance educational opportunities in end-of-life care.

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