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Ethnic Disparities in Hospice Use Among Asian-American and Pacific Islander Patients Dying with Cancer

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Abstract

Asian Americans and Pacific Islanders (AAPIs) are a rapidly growing population in the United States, yet little is known about hospice use and length of stay in hospice of older AAPIs dying with cancer. A retrospective study was conducted of the last year of life of AAPI and white Medicare beneficiaries registered in the Surveillance, Epidemiology, and End Results Program. White (n = 175,467) and AAPI (n = 8,614) patients aged 65 and older who were dying with lung, colorectal, breast, prostate, gastric, or liver cancer were studied. Cox proportional hazards models were used to examine hospice use and length of stay in hospice. All AAPI subgroups studied had lower rates of hospice use (Chinese (adjusted hazard ratio (HR) = 0.62, 95% confidence interval (CI) = 0.55–0.69), Japanese (adjusted HR = 0.67, 95% CI = 0.60–0.73), Filipino (adjusted HR = 0.61, 95% CI = 0.54–0.70), Hawaiian/Pacific Islanders (adjusted HR = 0.78, 95% CI = 0.67–0.91), and other Asians (adjusted HR = 0.70), 95% CI = 0.55–0.90) than white patients, adjusting for patient demographic and clinical characteristics. Of those who enrolled in hospice (approximately 20% of the total sample), Japanese Americans had a shorter median length of stay (21 days), and Filipino Americans had a longer median length of stay (32 days) than white patients (26 days). Overall, approximately 20% of patients enrolled within 7 days of death, and only 6% had hospice stays that were longer than 2 months, with no significant differences across racial or ethnic groups. In conclusion, in every ethnic subgroup studied, AAPIs were less likely than whites to enroll in hospice. Further research is needed to understand these differences and eliminate potential barriers to hospice care.

Keywords

hospice; end of life; Asians; Pacific Islanders; palliative care

Of the 2.4 million Americans who die each year,¹ more than 70% are aged 65 and older.² As the population of “baby boomers” ages in the coming decades, it is more important than ever

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to make sure that the dying process is as humane as possible. A recent Institute of Medicine report urged improvement in end-of-life care.² The Medicare Hospice Benefit was established more than 20 years ago to support hospice use at the end of life.³ Hospice care has been shown to improve symptom management and quality of life at the end of life,^{4,5} yet hospice is underused, especially by minority Americans.^{6–9}

Asian Americans and Pacific Islanders (AAPIs) are one of the fastest-growing ethnic groups in the United States, with an increase of 72% (5.0 million people) between the 1990 and 2000 census.¹⁰ The Census Bureau projects that, by 2050, the Asian-American population will grow to 37.6 million and constitute 9.3% of the population.¹¹ Cancer is the leading cause of death for AAPIs in the United States,¹¹ yet they have one of the lowest rates of hospice use.⁹ Fewer than 2% of hospice patients are AAPIs,⁹ although they represent approximately 5% of the U.S. population.¹² Previously, it was found that AAPIs, especially those who were foreign born, used hospice substantially less than non-Hispanic whites,¹³ although AAPIs comprised more than 30 distinct ethnic groups that are culturally and linguistically heterogeneous.¹⁴ Asian Americans include Japanese Americans (1.1 million), many of whom are second- or third-generation Americans whose families immigrated to the United States in the 19th century.¹⁰ Asian Americans also include Chinese (2.7 million) and Filipino Americans (2.4 million), the two largest subgroups, who are more likely to be recent immigrants and foreign born.¹⁰ Pacific Islanders comprise Native Hawaiians, Samoans, Tongans, and others from the Pacific Basin and include 874,000 individuals.¹⁵ Little is known about the rates of hospice use in subgroups of older AAPI patients dying with cancer compared with those of white patients. Therefore, hospice enrollment of AAPI subgroups was examined. Furthermore, in those who enrolled in hospice, length of stay in hospice across subgroups was studied.

METHODS

Data Source

A retrospective analysis of the last year of life of patients diagnosed with cancer using the Linked Medicare–Tumor Registry Database was conducted. The linked database contains cancer information on patients aged 65 and older from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program and Medicare enrollment and utilization information from the Centers for Medicare and Medicaid Services. Specific information describing the linkage between SEER and Medicare has been published elsewhere.¹⁶

SEER Program

The SEER Program is an epidemiological surveillance system developed in 1973 to track cancer incidence and mortality for designated population-based cancer registries in diverse regions of the United States. These regions include five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and six metropolitan areas (Atlanta, Detroit, Seattle-Puget Sound, San Francisco-Oakland, San Jose-Monterey, and Los Angeles). SEER captures approximately 13% of U.S. whites, 12% of African Americans, 27% of Native Americans, and 25% of Hispanics of all races.¹⁷ Currently, 41% of AAPIs reside in SEER areas, including 43% of Chinese, 49% of Filipino, 60% of Japanese Americans, and 46% of Hawaiian/Pacific Islanders.¹⁷ SEER tumor registries collect information on all newly diagnosed cancer cases that occur in patients residing in geographically defined SEER areas. Abstractors extract selected clinical and demographic data from the records of hospitals, clinics, and nursing homes and obtain mortality data from state death certificates and the Social Security Administration.^{16,18} SEER data are considered to be highly valid, with a 98% program standard for the completeness of case ascertainment.¹⁹

Medicare Program

The Medicare Program covers medical services for more than 97% of persons aged 65 and older.¹⁶ The Medicare enrollment and hospice files were used in this study. The enrollment file is updated annually and contains specific demographic and enrollment information for every Medicare beneficiary. The hospice file contains one or more claims for every beneficiary who received hospice services under the Medicare Hospice Benefit, including inpatient and outpatient hospice services provided to beneficiaries enrolled in managed care.

Study Sample

Hospice use in the last year of life was examined for patients who were diagnosed with a first primary lung, colorectal, gastric, liver, breast, or prostate cancer between January 1, 1973, and December 31, 1996, in one of nine SEER areas and who died between January 1, 1988, and December 31, 1998. These cancers were selected, because they are the most commonly diagnosed cancers in older adults (lung, colorectal, prostate, breast) and in AAPIs (gastric, liver). Only patients diagnosed with cancer at age 66 or older were included to ensure that all had Medicare coverage for at least 1 full year before their death ($n = 235,849$). A total of 6,735 patients diagnosed with in situ disease or with cancer after entering hospice care and 22,117 patients with unknown birthplace were excluded. Of the remaining 206,997 eligible patients, 85% were non-Hispanic whites ($n = 175,467$), 4% were AAPIs ($n = 8,614$), and 11% were of other race or ethnicity ($n = 22,916$), which were excluded from the study. The final study sample consisted of 184,081 patients with cancer who were non-Hispanic whites or AAPIs who died between 1988 and 1998.

Measures

The following sociodemographic information was obtained from the SEER file: age and marital status at diagnosis, sex, race or ethnicity, place of birth, year of diagnosis, and SEER area of residence. Race or ethnicity was categorized as non-Hispanic white, Chinese American, Japanese American, Filipino American, other Asian, or Hawaiian/Pacific Islander. Place of birth was categorized as foreign or U.S. born. There were 121 patients born in one of the U.S. territories in the Pacific (Guam, American Samoa, etc.) who were classified as U.S. born. Age at diagnosis was categorized as 66 to 69, 70 to 74, 75 to 79, 80 to 84, and 85 and older. Marital status was classified as married or not. SEER area was defined according to the tumor registry. Year of diagnosis was categorized in five groups: 1973 to 1981, 1982 to 1985, 1986 to 1989, 1990 to 1993, and 1994 to 1996. Individual socioeconomic information such as income and education are not available in SEER or Medicare data. Therefore, 1990 U.S. Census data were used to classify patients according to the median household income of their ZIP code of residence and grouped into quintiles. Medicare enrollment information was used to identify patients enrolled in managed care during the last 6 months of life.

SEER collects information regarding tumor stage at diagnosis using two systems. The historical staging system, collected by SEER since its inception, classifies tumors as local, regional, distant, and unstaged. In this study, the historical staging system was used for two reasons. First, SEER has collected the historical staging system since its inception, and it is available for all patients. Although SEER began collecting data according to the American Joint Committee on Cancer (AJCC) staging system for some cancers in 1988, it is available for few patients diagnosed before 1988. Second, the AJCC system is not available for patients with gastric or liver cancer (2 of the 6 cancers studied).

The two primary outcomes were time to hospice enrollment and length of stay in hospice care. Time to hospice enrollment was measured from patients' date of cancer diagnosis to hospice entry or death, whichever came first. Length of stay in hospice care was measured from the date of hospice enrollment until discharge or death.

Statistical Analyses

All statistical analyses were performed using SAS 9.1 (SAS Institute, Inc., Cary, NC). Bivariable analyses were conducted to characterize the study sample and examine variations in hospice use across ethnic groups. Because of the large sample size, *P*-values for bivariable comparisons were not presented; instead, the focus was on differences with meaningful magnitudes.

Multivariable Cox proportional hazards models were fitted for each outcome to determine whether ethnic differences in hospice utilization persisted after adjusting for demographic (sex, race or ethnicity, birthplace, marital status, residence in urban or rural area, median household income of ZIP code of residence, and type of insurance) and clinical (stage at diagnosis and type of primary cancer, e.g., lung, colorectal) factors. Additionally, adjustment for the effects of the different locations of the SEER tumor registries was done using a proportional hazards model that allowed a different underlying hazard for each tumor registry. The hospice enrollment model also adjusted for age and year of diagnosis, whereas the model incorporating length of stay in hospice adjusted for age and year at hospice entry and illness duration (measured as time from diagnosis until hospice entry). Adjusted hazard ratios (HRs) and corresponding 95% confidence intervals (CIs) were estimated from beta-coefficients and standard errors of the Cox models. For models predicting time to hospice enrollment, adjusted HRs less than 1.0 signify lower rates of hospice enrollment. For models predicting length-of-stay in hospice, adjusted HRs less than 1.0 indicate longer hospice stays.

For patients who enrolled in hospice, Kaplan–Meier estimates of median length of stay were computed, and log-rank tests were used to identify significant differences in hospice length of stay. The distribution of length of stay according to race or ethnicity was examined. First, proportions of patients who had enrolled in hospice within 7 days of death were examined as a potential indicator of late hospice enrollment.^{20,21} Because there is no set standard of care and no consensus on what is considered the “optimal amount of time in hospice,” hospice enrollment for 2 months or longer was examined, because it has been used in previous research.^{20,22}

RESULTS

Table 1 shows the demographic and clinical characteristics of non-Hispanic whites and AAPIs. Chinese (67.2%) and Filipino (90.6%) Americans were more likely to be foreign born than Japanese Americans (15.3%). In general, all AAPI subgroups were more likely than whites to have gastric and liver cancer. They were also more likely to have been diagnosed with distant metastases and were more likely than whites to die within 6 months of diagnosis.

Table 2 shows the percentage of hospice enrollment according to ethnic group and time to hospice enrollment after adjustment for demographic and clinical factors. For all ethnic groups, AAPIs had lower rates of hospice enrollment than white patients after adjustment for demographic and clinical factors.

Of those who enrolled in hospice (Table 3), Japanese Americans had a shorter median length of stay (21 days) and Filipino Americans had a longer median length of stay (32 days) than whites (26 days). These differences persisted after adjustment for demographic and clinical factors. Overall, approximately 20% of patients enrolled within 7 days of death, and only 6% had hospice stays that were longer than 2 months; there were no important differences across ethnic groups in the proportion who enrolled within 7 days of death and those who enrolled for more than 2 months (results not shown, available upon request).

DISCUSSION

To the authors' knowledge, this is the first study to examine hospice use in subgroups of older AAPIs with cancer. In every subgroup examined, AAPIs had lower rates of hospice enrollment than whites after adjustment for demographic and clinical characteristics. These findings are similar to those found in other racial or ethnic minority groups. Previous research has shown that African Americans and Latinos are also less likely to enroll in hospice than non-Hispanic whites.^{6,8,9} Although ethnic minorities constitute more than 25% of the U.S. population, they represent only 18% of patients enrolled in hospice.⁹

Systemic barriers related to the Medicare Hospice Benefit legislation may result in lower enrollments among minorities. For example, Medicare requires that a full-time caregiver be present to care for the patient.²³ This requirement was a deterrent to hospice enrollment for minority patients who did not have family members nearby or whose family members were working.^{23,24} Furthermore, to be eligible for the Medicare Hospice Benefit, patients must provide informed consent, which involves knowledge and acceptance of a terminal diagnosis and prognosis.³ Inherent in this requirement are Western values of individual patient autonomy and informed consent. Many AAPIs prefer a family-centered model of decision-making.^{25–27} This family-centered model of decision-making, along with the principle of “filial piety,” may result in families not wanting patients to know about their terminal prognosis. Filial piety (the moral obligation of children to care for elderly parents) is prominent in many Asian cultures.^{27,28} Filial piety may lead family members to want to “protect” the patient from the knowledge of a terminal prognosis in order to prevent despair and maintain hope. Thus, family members may not want to have the patient sign the statement choosing hospice care instead of curative therapies, as required by the Medicare Hospice Benefit.

The current study found that, of AAPIs who enrolled in hospice, Japanese Americans were more likely to enroll later than whites. Studies have shown that many Japanese and Japanese Americans prefer nondisclosure of a terminal diagnosis and prognosis to the patient.^{26,29,30} In Japan, terminally ill patients often rely more on the family and the physician to make end-of-life decisions, and there is less emphasis on patient autonomy. Hospice care may be interpreted as “giving up” on the patient, because disease-modifying treatments are commonly unavailable in hospice. This can result in high levels of emotional distress for family members who must make that decision.³¹ In addition, non-verbal communication (*ishin-denshin*) is especially important in Japanese culture.²⁶ Thus, even in Japanese who favor the disclosure of a terminal prognosis, many desire that physicians use nonverbal cues and implicit communication rather than explicit statements. Thus, the requirements of Medicare Hospice Benefit for full patient disclosure may act as barriers to hospice enrollment. In Japan, in contrast to the United States, patients can be enrolled in hospice without signing “informed consent.”³²

The study also showed that Filipino Americans were more likely to enroll earlier and have longer hospice stays than white patients. The reasons for these findings are unclear. In contrast to other AAPI subgroups, many Filipino Americans tend to be more “Westernized” because of Spanish colonial influences; speak English, thus possibly having less of a language barrier when discussing sensitive end-of-life decisions with their providers; and are predominantly Roman Catholic.³³ Catholics believe in eternal life and see death as the ultimate union with God. Catholic institutions (such as Catholic-affiliated hospitals and healthcare systems) also have had long-standing involvement in the hospice movement.^{34,35} Thus, as Catholics, Filipino Americans may regard hospice as an acceptable option at the end of life. Although patients' religious affiliations were not obtainable in this study, it is possible that patients' religions influenced their views of hospice.³⁶ The findings of the current study differ from those of another study that found that Filipinos in Hawaii were less accepting of hospice than other ethnic groups,³⁷ although those results were obtained from a random-digit survey of the general

population and may not reflect the views of older Filipino patients with terminal cancer like those in this sample.

This study has several limitations. First, SEER ascertains information on patients' race or ethnicity from medical records. Nevertheless, misclassification of race or ethnicity is unlikely to be related to hospice use and would bias the results toward the null. Second, the completeness and reliability of cancer registry data for place of birth vary between patient subgroups, although deceased patients are more likely to have complete data than living patients, possibly because of additional information obtained from patients' death certificates.³⁸ Third, data on patients' acculturation levels (degree of assimilation to the dominant culture) were not available in this dataset. More-acculturated patients may be more accepting of hospice. Fourth, information was not available on patient's preferences for care and on physician specialty or practice patterns that may lead to differences in hospice referral. Finally, these data reflect hospice use only until 1998, although it is unlikely that the patterns of hospice use of AAPIs have changed substantially since then.

A culturally sensitive model of hospice for AAPIs may involve simultaneous curative and hospice services, less emphasis on patient autonomy and "truth telling" and more emphasis on family-centered decision-making, and a home-based hospice model. In the last few years, new models of hospice have emerged that allow physicians to bridge the gaps between traditional "curative" and "hospice" care.^{39,40} Physicians assess palliative needs continuously throughout treatment. As the disease progresses, physicians shift focus from more disease-directed to more palliation-directed therapy.³⁹ This gradual transition does not require the dichotomization of "curative" versus "hospice" care and may be more acceptable to AAPI patients. In addition, a hospice model that allows the patient to delegate decision-making to family members may be more culturally appropriate. In many AAPI cultures, medical decision-making is regarded as a duty of the family, whose responsibility is to protect the dying patient from the burden of making difficult decisions.²⁷ Clinicians establish with the patient who should receive all medical information and make medical decisions. If the patient designates someone other than himself to have this responsibility, this preference for a proxy can be documented in the medical chart and honored as the patient's wish.²⁷ Finally, home-based hospice models that allow patients to receive intense skilled palliative care while at home, often with family members as paid caregivers, may be more acceptable to AAPI patients.⁴⁰ Home-based hospice models allow the family to be the primary caretaker, thus fulfilling the cultural "filial piety" duty that is required. Fulfilling family obligations is especially important in Asian cultures, because how well families fulfill their duties is often open to community scrutiny and judgment. Thus, the family saves "face" if its members take care of their own at the end of life.

Decisions to use hospice services near the end of life exist in a cultural context.^{27,41} For AAPIs, cultural values and norms that conflict with the Medicare Hospice Benefit requirements may result in low hospice enrollment. More research is needed on patients' values and preferences and physicians' hospice referral patterns for ethnically diverse patients. Physicians can be educated and trained to be sensitive to cultural barriers to hospice use.⁴¹ These efforts may lead to better understanding and decreasing potential barriers to hospice care for older minority patients with cancer.

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Table 1

Demographic and Clinical Characteristics of Non-Hispanic White and Asian-American and Pacific Islander Patients (AAPIs)

Characteristic	Whites (n = 175,467)	Chinese (n = 2,145)	AAPIs		Hawaiian/Pacific Islanders (n = 856)		Other Asians (n = 322)
			Japanese (n = 3,510)	Filipino (n = 1,781)			
Demographic factors							
Mean age at diagnosis	75.9	76.2	75.9	76.4	73.6		74.9
Male, %	60.0	61.3	65.8	79.5	56.8		64.9
Married, %	55.1	62.8	65.0	68.6	50.7		63.4
Enrolled in managed care, %	8.7	30.8	41.9	20.2	12.1		12.1
Lived in urban ZIP code, %	79.5	98.2	77.5	81.5	72.3		97.2
Lived in ZIP code with income < \$25,000, %	14.0	14.6	6.4	9.9	9.3		12.4
Foreign born, %	9.1	67.2	15.3	90.6	3.0		71.4
Cancer characteristics							
Primary cancer type, %							
Lung	27.6	34.6	22.2	26.8	34.2		35.4
Colorectal	25.6	29.1	28.3	22.6	17.2		16.5
Breast	17.2	7.8	8.2	5.3	16.9		5.0
Prostate	25.1	15.0	20.7	35.3	18.7		14.3
Gastric	3.6	7.1	17.9	5.8	10.6		17.7
Liver	0.9	6.3	2.8	4.2	2.3		11.2
Diagnosed with distant metastases	24.6	32.3	26.2	30.5	30.5		31.7
Died within 6 months of diagnosis	20.9	27.2	21.6	22.3	23.3		37.6

Table 2

Hospice Enrollment According to Race or Ethnicity and Place of Birth

Race or Ethnicity and Place of Birth	n	Enrolled in Hospice, n (%)	Hospice Enrollment, Adjusted HRs (95% Confidence Interval) [*]
Race or ethnicity			
Non-Hispanic white	175,467	35,569 (20.3)	1.00
Chinese	2,145	384 (17.9)	0.62 (0.55–0.69)
Japanese	3,510	702 (20.0)	0.67 (0.60–0.73)
Filipino	1,781	270 (15.2)	0.61 (0.54–0.70)
Hawaiian or Pacific Islander	856	209 (24.4)	0.78 (0.67–0.91)
Other Asians	322	67 (20.8)	0.70 (0.55–0.90)
Place of birth			
United States	164,331	34,002 (20.7)	1.00
Foreign born	19,750	3,199 (16.2)	0.97 (0.93–1.01)

* Adjusted hazard ratios (HRs) < 1.0 signify lower rates of hospice enrollment. Adjusted for age at diagnosis; sex; marital status; managed care enrollment; residence in rural area; median household income of ZIP code of residence; Surveillance, Epidemiology, and End Results registry; year of diagnosis; primary cancer type; and stage at diagnosis.

Table 3

Length of Stay in Hospice According to Race or Ethnicity and Place of Birth

Race or Ethnicity and Place of Birth	n	Median Length of Stay in Hospice, Days (Q1, Q3) [*]	Length of Stay in Hospice, Adjusted HR (95% Confidence Interval) [†]
Race or ethnicity			
Non-Hispanic white	35,335	26 (9, 68)	1.00
Chinese	382	26 (9, 72)	1.00 (0.89–1.13)
Japanese	697	21 (9, 53)	1.20 (1.08–1.32)
Filipino	270	32 (12, 98)	0.83 (0.72–0.95)
Hawaiian or Pacific Islander	209	25 (9, 68)	0.97 (0.82–1.14)
Other Asian	67	31 (8, 88)	0.93 (0.73–1.29)
Place of birth			
United States	34,002	26 (9, 68)	1.00
Foreign born	3,199	26 (10, 70)	1.00 (0.96–1.04)

^{*} Interquartile range: 25th and 75th percentiles.

[†] Adjusted hazard ratios (HRs) >1.00 indicate shorter length of stay and <1.00 indicate longer length of stay. Adjusted for age at hospice entry; sex; marital status; managed care enrollment; residence in rural area; median household income of ZIP code of residence; Surveillance, Epidemiology, and End Results registry; year of hospice entry; primary cancer type; stage at diagnosis; and illness duration.