

Racial and ethnic disparities in end-of-life care for patients with oesophageal cancer: death trends over time



Simar S. Bajaj,^a Bhav Jain,^a Alexandra L. Potter,^a Edward Christopher Dee,^b and Chi-Fu Jeffrey Yang^{a,*}

^aDivision of Thoracic Surgery, Department of Surgery, Massachusetts General Hospital, Boston, MA, USA

^bDepartment of Radiation Oncology, Memorial Sloan Kettering Cancer Center, New York, NY, USA



Summary

Background Given significant morbidity and mortality associated with oesophageal cancer, supportive, high-quality end-of-life care is critical. Most patients with advanced cancer prefer to die at home, but incongruence between preferred and actual place of death is common. Here, we examined trends and disparities in location of death among patients with oesophageal cancer.

Methods Using the Centers for Disease Control and Prevention Wide-Range Online Data for Epidemiologic Research database, we utilized multinomial logistic regression to assess associations between sociodemographic characteristics and location of death for patients with oesophageal cancer ($n = 237,063$). Additionally, we utilized linear regression models to evaluate the significance of changes in location of death trends over time and disparities in the relative change in location of death trends across sociodemographic groups.

Findings From 2003 to 2019, there was a decrease of deaths in hospitals, nursing homes, and outpatient medical facilities/emergency departments and an increase of deaths at home and in hospice. Relative to White decedents, Black and Asian decedents were less likely to die at home (relative risk ratio (RRR): 0.58 [95% confidence interval (CI): 0.56–0.60], RRR: 0.57 [95% CI: 0.53–0.61]) and in hospice (RRR: 0.67 [95% CI: 0.64–0.71], RRR: 0.49 [95% CI: 0.43–0.55]) when compared to the hospital. Similar disparities were noted for American Indian and Alaska Native (AIAN) decedents. These disparities persisted even upon stratifying by the number of listed causes of death, a proxy for severity of illness. Time trend analysis indicated that increases in deaths in hospice over time occurred at a slower rate for AIAN and Asian decedents relative to White decedents.

Interpretation 2 in 5 patients with oesophageal cancer die at home, with an increasing proportion dying at home and in hospice—in line with general patient preferences. However, location of death disparities have largely persisted over time among racial and ethnic minority groups. Our findings suggest the importance of improving access to advance care planning and delivering tailored, person-centred interventions.

Funding None.

Copyright © 2022 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Keywords: End-of-life care; Location of death; Race; Ethnicity; Disparities; Health Equity

Introduction

End-of-life care is a critical consideration for patients given the inevitability of death. Terminal cancer, in particular, presents numerous challenges to delivering quality care, from intense physical pain and depression to a loss of hope and dignity. Recent efforts have sought to foster the conditions for a good death for all patients with cancer,¹ but the unique needs and considerations for socially disadvantaged individuals, especially racial and ethnic minorities, are poorly understood. While it

remains challenging to characterize end-of-life care inequities, examining disparities in location of death may offer one indicator for the quality of death.

Indeed, a robust literature has established that a majority of adult patients with advanced cancer prefer to die at home, with deaths in institutionalized settings associated with poor respect, emotional support, and symptom management.^{2–7} Death in a preferred place can reflect greater quality of death in affording patients a sense of control and increasing time with loved ones. In

The Lancet Regional Health - Americas
2023;17: 100401
Published Online 8 December 2022
<https://doi.org/10.1016/j.lana.2022.100401>

*Corresponding author. Massachusetts General Hospital, 55 Fruit St, Boston, MA, 02114, USA.

E-mail address: cjyang@mgh.harvard.edu (C.-F.J. Yang).

Research in context

Evidence before this study

We searched through PubMed the following terms: 'oesophageal cancer' AND 'end-of-life,' as well as 'oesophageal cancer' and 'disparities.' Several studies studied hospice utilization, various palliative interventions, and patient deterioration while dozens of others probed for disparities in cancer diagnosis and treatment—but rarely end-of-life care. No study to date has examined location of death disparities for patients with oesophageal cancer. Most patients with cancer prefer to die at home but often do not do so, and deaths in institutionalized settings have been associated with poor symptom amelioration, emotional support, and respect.

Added value of this study

To our knowledge, this is the largest analysis of location of death trends for patients with oesophageal cancer. While

increases in deaths at home and in hospice over time have corresponded to decreases in deaths in institutionalized settings, such increases may have been primarily driven by White decedents, even after controlling for severity of illness. Our analysis also reveals that nearly all racial and ethnic disparities in location of death have persisted over the 17-year study period.

Implications of all the available evidence

Our findings suggest the importance of improving access to advance care planning to ensure congruence between patients' preferred and actual places of death. Although patients generally prefer to die at home, further research is needed to ascertain whether there are disparities in these preferences as well.

2017, deaths at home exceeded hospital deaths for the first time in the United States since the early 20th century,⁸ but incongruence between patients' preferred and actual place of death, with most not dying in their preferred location, has nonetheless persisted. Such incongruence is cause for concern given well-documented palliative care disparities by race, ethnicity, and other sociodemographic characteristics, in terms of lower access, utilization, and quality of care.^{9,10}

These disparities may be exacerbated for diseases that exert an unequal burden over the population. One example is: oesophageal cancer, whose incidence is 2 times higher in Black individuals than White individuals and 3 times higher in men than women.^{11,12} Oesophageal cancer is also one of the deadliest, least studied cancers, with a 5-year survival rate of 20% for all stages combined and 5% for metastatic disease at presentation.¹³ With significant treatment-related morbidity meriting early input from palliative care services,¹⁴ oesophageal cancer is a particularly important case to study end-of-life care. Therefore, we assessed trends and disparities in location of death for patients with oesophageal cancer. We hypothesized that deaths in institutionalized settings would decrease over time while deaths at home and in hospice would increase but also that these trends would not be driven by racial and ethnic minorities.

Methods

Data source and study design

We analysed the Underlying Cause of Death Public Use Record from the de-identified, publicly available Centers for Disease Control and Prevention (CDC) Wide-Ranging Online Data for Epidemiologic Research (WONDER) database. CDC WONDER is a national

dataset with mortality data coded by the states and provided to the CDC's National Center for Health Statistics through the Vital Statistics Cooperative Program. Based on the death certificates of U.S. residents from all fifty states and the District of Columbia, these data include demographic variables and the underlying cause of death (COD). When more than one condition is entered by the physician, the underlying cause is ascertained per the sequence of conditions on the certificate, provisions of the International Classification of Diseases and Related Health Problems (ICD), and associated selection rules and modifications. ICD-10 codes alone are available to classify the underlying COD.

This study was a national population-based observational cohort study of patients in the U.S. with the underlying COD noted as malignant neoplasm of the oesophagus (ICD-10 codes: C15.3–15.9) between 2003 and 2019. The study was limited to this period because the hospice location of death variable was introduced to CDC WONDER in 2003. We examined changes in location of death over time and assessed whether changes in the proportion of death at each location differed by patient race and ethnicity. We also conducted sub-analyses of patients with and without multiple CODs to control for severity of illness.

Clinical and sociodemographic covariates

The primary dependent variable of interest was location of death, which included 5 categories: hospital, home, nursing facility, hospice facility, and outpatient medical facility/emergency department (ED). The hospice facility categorization did not include hospice services provided in the hospital, at home, or in the other locations of death. Independent variables included patient age (≤ 64 , 65–74, 75–84, ≥ 85 years), sex (female, male), race

(White, American Indian and Alaska Native [AIAN], Black, Asian), ethnicity (Non-Hispanic, Hispanic), marital status (unmarried, married), education (high school or less, some college or more), and the number of CODs (one, multiple). As per standard U.S. Census definitions,¹⁵ race refers to groups with similar physical traits while ethnicity refers to groups with similar cultural identities.

Statistical analysis

Multivariable multinomial logistic regression was used to evaluate associations between the aforementioned decedent characteristics, excluding the number of CODs, and each location of death for patients with oesophageal cancer. We report relative risk ratios with 95% confidence intervals, with hospital as the base outcome. Following multinomial logistic regression, we conducted predicted marginal modelling to provide national estimates of the percentage of adults in each sociodemographic group associated with each location of death. As employed in prior epidemiologic studies, marginal modelling averages over all regression covariates to express how the predicted probability of a binary outcome varies with a change in a risk factor; it is also less sensitive to the statistical model conditions that influence the reported values of relative risk.¹⁶ Subsequently, we conducted subgroup analyses with

multivariable multinomial logistic regression models, stratifying by the number of CODs and employing Pearson's chi-square test for between-group comparisons.

For the primary analysis, we also evaluated the significance of changes in location of death over the study period with linear regression models adjusting for time alone, reporting annual percentage changes (APCs). Further linear regression models examined the relative change in location of death by sociodemographic group over time by including the main effects and interaction terms for race and time, as well as ethnicity and time. We report linear regression coefficients with 95% confidence intervals. All analyses were performed using Stata v16.1 (College Station, TX).

Ethics approval

Approved by Massachusetts General Hospital IRB #2020P004110.

Role of the funding source

None.

Results

237,063 patients had oesophageal cancer as their underlying COD. Baseline characteristics of the study

Characteristic	Total Cohort	Hospital	Home	Nursing Home	Hospice	Outpatient Medical Facility/ED
Number	237,063 (100%)	70,439 (29.7%)	99,253 (41.9%)	28,425 (12.0%)	22,266 (9.4%)	16,680 (7.0%)
Age, year						
≤64	84,757 (35.8%)	28,971 (41.1%)	35,110 (35.4%)	6308 (22.2%)	8081 (36.3%)	6287 (37.7%)
65-74	69,563 (29.3%)	21,827 (40.0%)	29,417 (29.6%)	7173 (25.2%)	6689 (30.0%)	4457 (26.7%)
75-84	57,367 (24.2%)	15,140 (21.5%)	24,195 (24.4%)	8770 (30.9%)	5192 (23.3%)	4070 (24.4%)
≥85	25,376 (10.7%)	4501 (6.4%)	10,531 (10.6%)	6174 (21.7%)	2304 (10.4%)	1866 (11.2%)
Sex						
Female	49,009 (20.7%)	13,239 (18.8%)	19,282 (19.4%)	7755 (27.3%)	4794 (21.5%)	3939 (23.6%)
Male	188,054 (79.3%)	57,200 (81.2%)	79,971 (80.6%)	20,670 (72.7%)	17,472 (78.5%)	12,741 (76.4%)
Race						
White	210,132 (88.6%)	60,045 (85.2%)	90,571 (91.3%)	25,084 (88.3%)	20,055 (90.1%)	14,377 (86.2%)
American Indian/Alaska Native	1154 (0.5%)	378 (0.5%)	459 (0.5%)	159 (0.6%)	72 (0.3%)	86 (0.5%)
Black	21,713 (9.2%)	8353 (11.9%)	6745 (6.8%)	2837 (10.0%)	1865 (8.4%)	1913 (11.5%)
Asian	4064 (1.7%)	1663 (2.4%)	1478 (1.5%)	345 (1.2%)	274 (1.2%)	304 (1.8%)
Ethnicity						
Non-Hispanic	226,986 (95.7%)	66,800 (94.8%)	95,102 (95.8%)	27,636 (97.2%)	21,410 (96.2%)	16,038 (96.2%)
Hispanic	10,077 (4.3%)	3639 (5.2%)	4151 (4.2%)	789 (2.8%)	856 (3.8%)	642 (3.9%)
Marital Status						
Unmarried	103,359 (43.6%)	29,718 (42.2%)	35,568 (35.8%)	18,651 (65.6%)	10,404 (46.7%)	9018 (54.1%)
Married	133,704 (56.4%)	40,721 (57.8%)	63,685 (64.2%)	9774 (34.4%)	11,862 (53.3%)	7662 (45.9%)
Education						
High school or less	145,926 (61.6%)	43,417 (61.6%)	59,732 (60.2%)	19,377 (68.2%)	12,824 (57.6%)	10,576 (63.4%)
Some college or more	91,137 (38.4%)	27,022 (38.4%)	39,521 (39.8%)	9048 (31.8%)	9442 (42.4%)	6104 (36.6%)

ED, Emergency Department.

Table 1: Baseline characteristics for decedents with oesophageal cancer.

Location of Death	Coefficient (95% Confidence Interval)	t-Statistic	P-value	R-Squared
Hospital				
Annual Percentage Change (Slope) (%/year)	-0.67 (-0.79, -0.55)	-11.95	<0.001	0.90
Intercept (%)	35.30 (34.18, 36.42)	67.18	<0.001	
Home				
Annual Percentage Change (Slope) (%/year)	0.27 (0.19, 0.35)	7.14	<0.001	0.77
Intercept (%)	39.28 (38.53, 40.03)	112.12	<0.001	
Nursing Home				
Annual Percentage Change (Slope) (%/year)	-0.28 (-0.33, -0.23)	-11.77	<0.001	0.90
Intercept (%)	14.43 (13.95, 14.91)	64.06	<0.001	
Hospice				
Annual Percentage Change (Slope) (%/year)	0.95 (0.84, 1.06)	18.28	<0.001	0.96
Intercept (%)	1.42 (0.38, 2.47)	2.92	0.011	
Outpatient Medical Facility/ED				
Annual Percentage Change (Slope) (%/year)	-0.27 (-0.36, -0.17)	-6.14	<0.001	0.72
Intercept (%)	9.56 (8.69, 10.43)	23.45	<0.001	

Data are shown as linear regression coefficients with 95% confidence intervals. ED, Emergency Department.

Table 2: Trends in location of death for individuals with oesophageal cancer between 2003 and 2019.

cohort are detailed in Table 1. 1154 (0.5%) patients were AIAN, 21,713 (9.2%) were Black, 4064 (1.7%) were Asian, and 10,077 (4.3%) were Hispanic. During the study period, most patients died in the hospital (29.7%) or at home (41.9%).

From 2003 to 2019, the proportion of deaths in hospitals, nursing homes, and outpatient medical facilities/EDs decreased over time with APCs of -0.67%/year, -0.28%/year, and -0.27%/year, respectively (all $p < 0.001$, Table 2). Conversely, proportions of deaths at home (APC: 0.27%/year, $p < 0.001$) and in hospice (APC: 0.95%/year, $p < 0.001$) increased over the study

period. Ultimately, among the 15,982 patients who died of oesophageal cancer in 2019, the most recent year of data included, 43.0% ($n = 6866$) died at home, 26.6% ($n = 4250$) in the hospital, 10.3% ($n = 1645$) in a nursing home, 14.8% ($n = 2358$) in hospice, and 5.4% ($n = 863$) in an outpatient medical facility/ED (Fig. 1).

We subsequently examined the associations between decedent sociodemographic characteristics and location of death (Table 3). Relative to White decedents, Black and Asian decedents had decreased relative risk of death at home, in a nursing home, in hospice, and in an outpatient medical facility/ED when compared to death

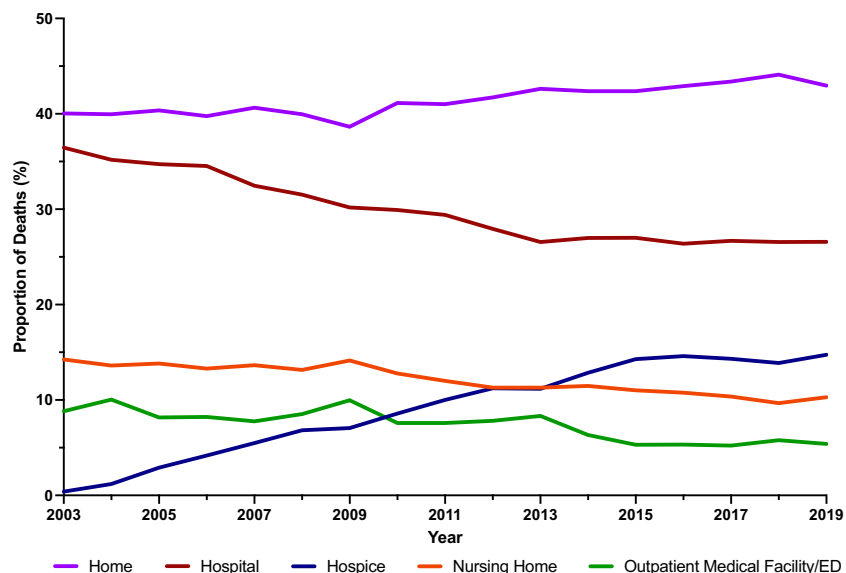


Fig. 1: Trends in location of death for decedents with oesophageal cancer between 2003 and 2019. ED, Emergency Department.

Characteristic	Home vs Hospital (Reference)	Nursing Home vs Hospital (Reference)	Hospice vs Hospital (Reference)	Outpatient Medical Facility/ED vs Hospital (Reference)
Age, year				
≤64	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
65-74	1.07 (1.04-1.09) ***	1.58 (1.52-1.65) ***	1.08 (1.04-1.12) ***	0.96 (0.92-1.00) *
75-84	1.26 (1.23-1.29) ***	2.65 (2.55-2.75) ***	1.19 (1.14-1.24) ***	1.22 (1.17-1.28) ***
≥85	1.91 (1.84-1.99) ***	5.37 (5.12-5.64) ***	1.69 (1.60-1.79) ***	1.72 (1.62-1.83) ***
Sex				
Female	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Male	0.92 (0.90-0.94) ***	0.97 (0.94-1.00) n.s.	0.91 (0.87-0.94) ***	0.89 (0.85-0.92) ***
Race				
White	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
American Indian/Alaska Native	0.88 (0.76-1.00) n.s.	1.02 (0.85-1.24) n.s.	0.58 (0.45-0.75) ***	0.91 (0.72-1.16) n.s.
Black	0.58 (0.56-0.60) ***	0.77 (0.73-0.80) ***	0.67 (0.64-0.71) ***	0.88 (0.83-0.93) ***
Asian	0.57 (0.53-0.61) ***	0.51 (0.45-0.58) ***	0.49 (0.43-0.55) ***	0.77 (0.68-0.87) ***
Ethnicity				
Non-Hispanic	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Hispanic	0.77 (0.74-0.81) ***	0.49 (0.46-0.54) ***	0.72 (0.67-0.78) ***	0.72 (0.66-0.78) ***
Marital status				
Unmarried	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Married	1.32 (1.29-1.35) ***	0.42 (0.41-0.43) ***	0.82 (0.80-0.85) ***	0.65 (0.63-0.67) ***
Education				
High school or less	1 (Reference)	1 (Reference)	1 (Reference)	1 (Reference)
Some college or more	0.99 (0.97-1.01) n.s.	0.82 (0.79-0.85) ***	1.20 (1.14-1.21) ***	0.98 (0.94-1.01) n.s.

Data are shown as relative risk ratios with 95% confidence intervals. ED, Emergency Department (***: $p < 0.001$; **: $p < 0.01$; *: $p < 0.05$, n.s.: not significant).

Table 3: Association between decedent sociodemographic characteristics and location of death for patients with oesophageal cancer with hospital location as reference group.

in the hospital. Hispanic patients were similarly less likely than non-Hispanic patients to die at home, in a nursing home, in hospice, and in an outpatient medical facility/ED instead of the hospital. When compared with White decedents, AIAN decedents had lower relative risk of death at home or hospice compared to the hospital, although the former difference did not reach the level of statistical significance.

Marginal modelling estimates provided additional insight into specific sociodemographic factors accounting for location of death disparities (Fig. 2). Age (≤64 years: 34.1% [33.8%–34.5%] vs ≥ 85 years: 19.0% [18.5%–19.5%]) and race (White: 29.0% [28.8%–29.2%] vs Asian: 41.8% [40.3%–43.4%]) predicted the widest relative disparity for deaths in the hospital while marital status (unmarried: 35.3% [35.0%–35.6%] vs married: 48.1% [47.8%–48.4%]) predicted the widest relative disparities for deaths at home, based on the largest

statistically significant differences in proportions. The widest relative disparity for deaths in hospice was predicted by race (White: 9.8% [9.7%–9.9%] vs. Asian: 6.9% [6.1%–7.6%]).

To control for the effect of severity of illness, we performed sub-analyses for decedents with one COD versus multiple CODs. Of the 237,063 patients in our study, 99,062 (41.8%) had only one COD listed, and 138,001 (58.2%) had multiple CODs listed (Supplementary Table S1). Decedents with one COD were less likely to die in the hospital (18.2% vs 38.0%) and more likely to die at home (50.8% vs 35.4%, χ^2 : $p < 0.001$ for both) when compared with decedents with multiple CODs. In both multinomial logistic regression analyses of patients with only one COD and multiple CODs, Black and Asian decedents were less likely than White decedents to die at home, in a nursing home, and in hospice when compared to the hospital

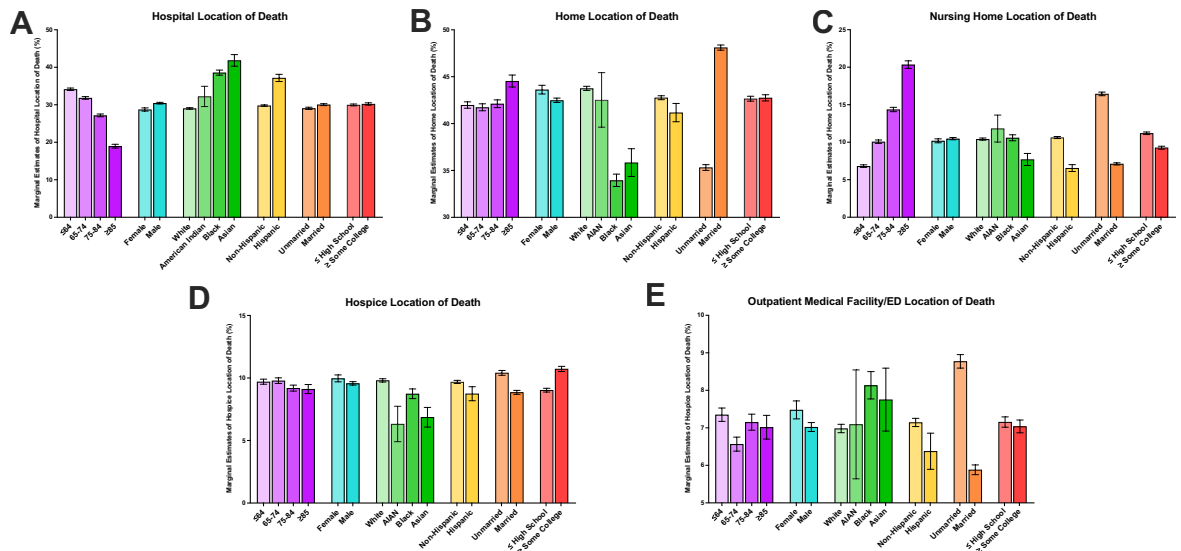


Fig. 2: National estimates of location of death for patients with oesophageal cancer in (A) hospital, (B) home, (C) nursing home, (D) hospice, and (E) outpatient medical facility/ED by age, sex, race, ethnicity, marital status and education. Data are shown as predicted marginal modelling estimates with 95% confidence intervals. ED, emergency department. AIAN, American Indian/Alaska Native.

(Supplementary Table S2, Supplementary Table S3). Moreover, relative to non-Hispanic decedents, Hispanic decedents in both analyses were less likely to die at home, in a nursing home, in hospice, and in an outpatient medical facility/ED. Marginal modelling estimates supported these findings as well (Supplementary Fig. S1).

Finally, we constructed linear regression models with interaction terms for race and ethnicity (Fig. 3, Table 4). At baseline, Black decedents were less likely than White decedents to die at home (race slope: -13.6% , $p < 0.001$), but this disparity narrowed over time (time**race* interaction slope: $0.20\%/year$, $p = 0.004$). Black decedents were also less likely to die in hospice (race slope: -0.8% , $p = 0.027$) and more likely to die in the hospital (race slope: 9.8% , $p < 0.001$) at baseline; however, neither disparity changed significantly over time (time**race* interaction slopes: $0.05\%/year$, $p = 0.25$; $-0.08\%/year$, $p = 0.22$). Similarly, Asian decedents were less likely to die at home (race slope: -8.8% , $p < 0.001$) and more likely to die in the hospital (race slope: 12.6% , $p < 0.001$) when compared with White decedents. But neither of these differences changed significantly over time (time**race* interaction slopes: $0.23\%/year$, $p = 0.15$; $-0.03\%/year$, $p = 0.86$). Contrastingly, even as baseline hospice rates were similar, increases in deaths in hospice over time occurred at a slower rate for AIAN (time**race* interaction slope: $-0.39\%/year$, $p = 0.022$) and Asian (time**race* interaction slope: $-0.43\%/year$, $p < 0.001$) decedents relative to White decedents. Compared to non-Hispanic decedents, Hispanic decedents were less likely to die at home (ethnicity slope: -3.0% , $p = 0.004$),

although this disparity narrowed over time (time**ethnicity* interaction slope: $0.24\%/year$, $p = 0.020$), and more likely at baseline to die in the hospital (ethnicity slope: 8.6% , $p < 0.001$), although this disparity did not change significantly over time (time**ethnicity* interaction slope: $-0.17\%/year$, $p = 0.066$).

Discussion

In this analysis of 237,063 patients who died from oesophageal cancer between 2003 and 2019, we characterized trends and disparities in location of death. We found that about two in five patients die at home and that there has been an increase in deaths at home and in hospice over time. Simultaneously, there have been decreases in deaths in institutionalized settings, such as hospitals, nursing homes, and outpatient medical facilities/EDs. Older age, female sex, and being married were all associated with greater likelihood of a home death, much like previous studies have shown.¹⁷ Contrastingly, AIAN, Black, and Asian decedents were less likely to die at home and in hospice than White decedents. These racial and ethnic location of death disparities persisted even upon stratifying by the number of CODs, a proxy for severity of illness. Finally, we demonstrated disparities concerning Black, Asian, and Hispanic deaths in the hospital that existed at baseline and have not improved over time. Deaths in hospice facilities have increased at a slower rate for AIAN and Asian populations such that general increases in hospice deaths may have been primarily driven by White decedents. Our findings emphasise that, despite overall

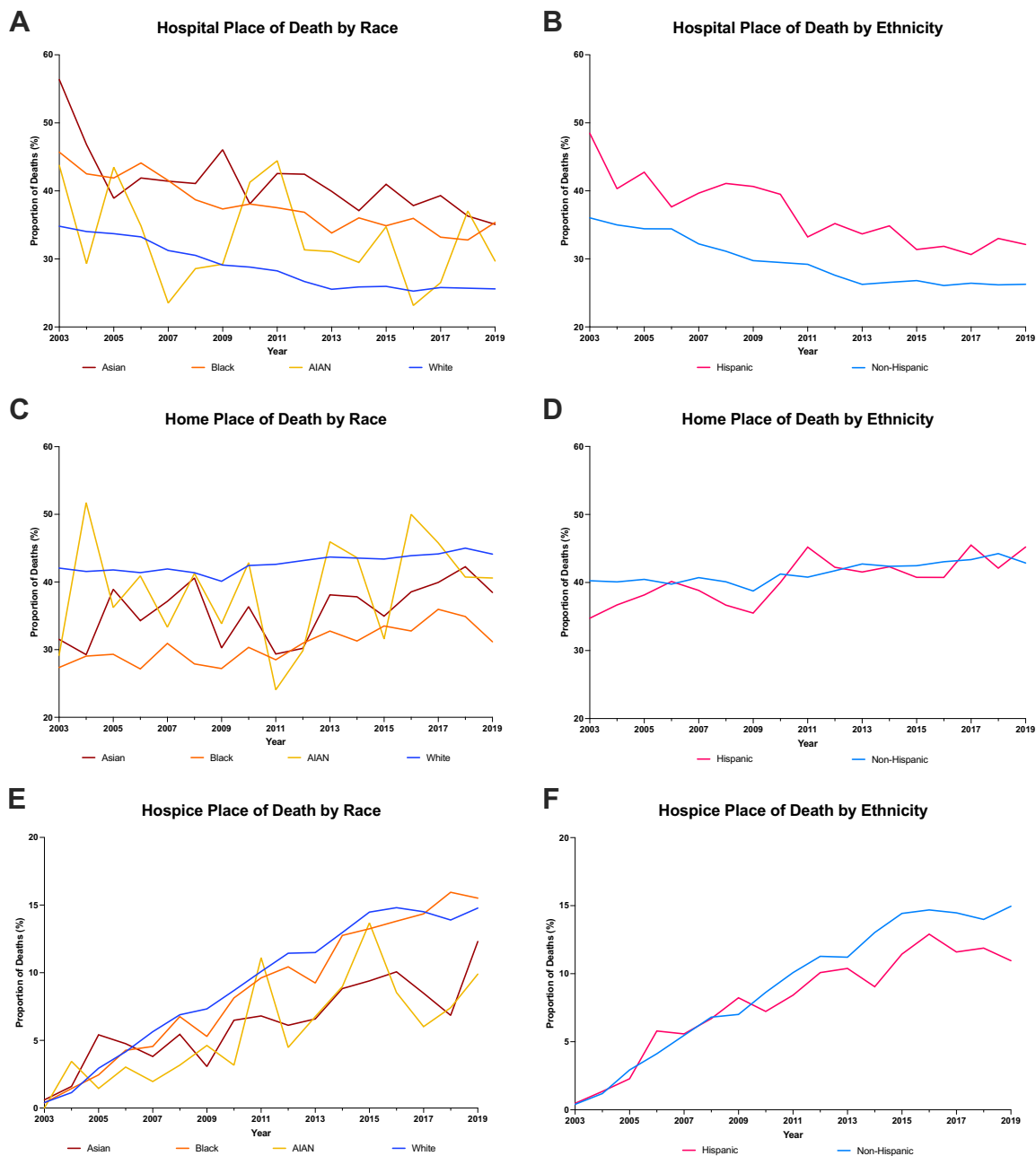


Fig. 3: Proportion of decedents with oesophageal cancer between 2003 and 2019 with (A,B) hospital, (C,D) home, and (E,F) hospice as place of death, by race and ethnicity. AIAN, American Indian and Alaska Native.

increases in deaths at home and in hospice, racial and ethnic minorities with oesophageal cancer face significant, persistent location of death disparities.

It has long been recognised that patients with advanced cancer do not prefer to die in institutionalized settings, with the most common preference being death at home, followed by death in hospice.² In a recent

cross-national survey, 70% of respondents would prefer to die in their own home if faced with advanced cancer, 20% would prefer to die in hospice or a palliative care unit, and only 7% would prefer to die in the hospital.³ Despite these preferences, most patients with cancer do not actually die at home.^{18–22} Discordance between patient's preferred and actual place of death is of

Location of Death	Hospital Death	Home Death	Hospice Death
Racial Disparities	<i>Model 1</i>	<i>Model 2</i>	<i>Model 3</i>
Year (Continuous) (%/year)	-0.63 (-0.67, -0.59) ***	0.22 (0.18, 0.26) ***	0.95 (0.92, 0.97) ***
Race			
White	Reference	Reference	Reference
American Indian/Alaska Natives (%)	2.6 (-2.7, 7.9) n.s.	-4.2 (-10, 1.5) n.s.	-0.3 (-3.6, 3.1) n.s.
Black (%)	9.8 (8.7, 11.0) ***	-13.6 (-14.9, -12.4) ***	-0.8 (-1.5, -0.1) *
Asian (%)	12.6 (9.7, 15.6) ***	-8.8 (-11.9, -5.6) ***	0.6 (-1.3, 2.4) n.s.
Race*Year Interaction			
White*Year	Reference	Reference	Reference
American Indian/Alaska Native*Year (%/year)	0.19 (-0.33, 0.72) n.s.	0.08 (-0.48, 0.65) n.s.	-0.39 (-0.72, -0.06) *
Black*Year (%/year)	-0.08 (-0.20, 0.05) n.s.	0.20 (0.06, 3.3) **	0.05 (-0.03, 0.12) n.s.
Asian*Year (%/year)	-0.03 (-0.31, 0.26) n.s.	0.23 (-0.08, 0.54) n.s.	-0.43 (-0.61, -0.25) ***
Constant (%)	33.9 (33.5, 34.3) ***	41.0 (40.6, 41.4) ***	1.6 (1.3, 1.8) ***
Ethnic Disparities	<i>Model 4</i>	<i>Model 5</i>	<i>Model 6</i>
Year (Continuous) (%/year)	-0.66 (-0.70, -0.62) ***	0.26 (0.22, 0.30) ***	0.96 (0.93, 0.98) ***
Ethnicity			
Non-Hispanic (%)	Reference	Reference	Reference
Hispanic (%)	8.6 (6.7, 10.4) ***	-3.0 (-5.0, -0.9) **	1.2 (0.0, 2.4) n.s.
Ethnicity*Year Interaction			
Non-Hispanic*Year (%/year)	Reference	Reference	Reference
Hispanic*Year (%/year)	-0.17 (-0.36, 0.01) n.s.	0.24 (0.04, 4.38) *	-0.29 (-0.41, -0.18) ***
Constant (%)	34.9 (34.6, 35.3) ***	39.4 (39.0, 39.8) ***	1.4 (1.2, 1.7) ***

Data are shown as linear regression coefficients with 95% confidence intervals. ED, Emergency Department (***: p < 0.001; **: p < 0.01; *: p < 0.05, n.s.: not significant).

Table 4: Linear regression for racial and ethnic disparities in location of death for individuals with oesophageal cancer.

practical significance because, in addition to being associated with increased economic burden to caregivers and the healthcare system,²³ deaths in institutionalized settings have been associated with poor symptom amelioration, emotional support, and respect.⁷

Indeed, patients have previously identified five key domains to quality end-of-life care—adequate pain and symptom management, sense of control, burden relief, strengthened relationships, and avoidance of inappropriate prolongation of death.²⁴ For oesophageal cancer, the symptomatic burden can be significant, with palliative care professionals reporting management of patients’ advanced dysphagia, nausea and vomiting, malnutrition, debilitating pain, and psychological distress.²³ Furthermore, the significant morbidity associated with curative therapy and high mortality rate of oesophageal cancer (5% 5-year survival rate for metastatic disease) may result in poor quality of life and

correspondingly influence patients’ end-of-life care decisions.^{13,14} Trends showing decreases in deaths in the hospital over time, as well as increases in deaths at home and in hospice, are encouraging. However, our finding that racial and ethnic minorities are less likely than White decedents to die at home and in hospice versus the hospital, as well as the continuance of key disparities over the study period, should give cause for concern.

Many factors may help to explain these location of death disparities for patients with oesophageal cancer. Hospice care has rapidly expanded over the past few decades after the U.S. Congress enacted the Medicare hospice benefit in 1972, but access to hospice services has not been equitably distributed.²⁵ Even after adjusting for clinical and sociodemographic factors, racial and ethnic minorities are less likely to use hospice services than White individuals.^{26–28} Disparities in hospice

utilization and location of death more broadly may reflect linguistic and cultural barriers: because of poor patient-clinician communication, racial and ethnic minorities are less likely to discuss end-of-life care preferences before death.²⁷

Indeed, oesophageal cancer's unique epidemiology with its primary presentation in White male individuals may undermine advance care planning among racial and ethnic minorities through limited patient health literacy and reduced clinician familiarity.^{11,12} However, cultural taboos, patient preferences for aggressive end-of-life care, and differences in available caregiver support could also drive deaths in the hospital versus at home or in hospice.²³ As one example, Black patients are more likely to use the ED for standard care and are less willing to withhold late-stage intensive therapy²⁸ because of a paucity of trust in healthcare systems and a multitude of other reasons.²⁹ Older age, female sex, lower educational attainment, and not being married may also be associated with reduced preferences for a home death, although further research is needed.³ Finally, socioeconomic factors may be driving some of the racial and ethnic disparities in this study given that low socioeconomic status has previously been associated with more aggressive end-of-life care for patients with terminal cancer.³⁰ Indeed, socioeconomic status is among the most robust determinants of variations in health outcomes throughout the world.³¹

The multifactorial roots of location of death disparities suggest that a multitude of interventions may be necessary. To combat language disfluency and poor cultural competency, increasing availability of translation services, incorporating community-based cultural leaders, and embracing racially and ethnically concordant clinical pairings may help bridge gaps in information-giving and patient understanding.^{29,32,33} Physicians should also proactively engage in advance care planning discussions with all patients to ensure awareness and respect of individual end-of-life care preferences. Treatment preferences also often change following these discussions.³⁴ Ultimately, greater awareness of the disparities racial and ethnic minorities face in accessing high quality end-of-life care is the first step to developing tailored, person-centred interventions to deracinate such disparities.

Our findings should be interpreted with several limitations in mind. For one, the small sample size of AIAN patients relative to White, Black, or Asian patients produced larger confidence intervals for relative risk ratios and marginal modelling estimates in this population, which may have limited the interpretability of AIAN disparities. Furthermore, given data constraints, we could only evaluate a limited number of decedent characteristics, and we recognize that socioeconomic variables such as income and insurance status, as well as health status variables such as disease stage and

number of decedent comorbidities, may significantly influence patient location of death. We attempted to account for potential differences in severity of illness by conducting a subgroup analysis of patients with only one COD.

Another limitation is that, with the CDC WONDER database, we are unable to evaluate location of care during the course of disease, which may be distinct from location of death and also influence patient preferences for location of death. Additionally, we recognize that a home death is not always optimal, feasible, or preferred by all patients and that quality of death in hospitals can be high, especially with the provision of palliative care.³⁵ Finally, this study relies entirely on data from death certificates to determine decedent characteristics and the underlying COD; errors in these death certificates may have subjected our analysis to unavoidable inaccuracies.

In conclusion, in this national population-based study of 237,063 patients who died from oesophageal cancer in the United States, we identified key location of death disparities, with racial and ethnic minorities being less likely to die at home and in hospice than in the hospital, even upon stratifying by severity of illness. These disparities have largely persisted over the study period between 2003 and 2019. Our findings emphasize the need for further research into the individual, interpersonal, and structural factors that contribute to location of death disparities and into the efficacy of various educational and policy interventions for achieving health equity.

Contributors

SSB, BJ, ALP, ECD, CJY conceptualized the manuscript. BJ and SSB did the formal analysis and made the visualizations. SSB wrote the original draft; BJ, ALP, ECD, CJY reviewed and edited the draft. CJY supervised the manuscript.

Data sharing statement

Data are publicly available.

Declaration of interests

None.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.lana.2022.100401>.

References

- 1 Zaman M, Espinal-Arango S, Mohapatra A, Jadad AR. What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. *Lancet Healthy Longev*. 2021;2(9):e593–e600.
- 2 Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med*. 2000;3(3):287–300.
- 3 Gomes B, Higginson IJ, Calanzani N, et al. Preferences for place of death if faced with advanced cancer: a population survey in

- England, Flanders, Germany, Italy, The Netherlands, Portugal and Spain. *Ann Oncol Off J Eur Soc Med Oncol*. 2012;23(8):2006–2015.
- 4 Fereidouni A, Rassouli M, Salehi M, Ashrafzadeh H, Vahedian-Azimi A, Barasteh S. Preferred place of death in adult cancer patients: a systematic review and meta-analysis. *Front Psychol*. 2021;12:3747.
 - 5 Rainsford S, MacLeod RD, Glasgow NJ. Place of death in rural palliative care: a systematic review. *Palliat Med*. 2016;30(8):745–763.
 - 6 Bell CL, Somogyi-Zalud E, Masaki KH. Factors associated with congruence between preferred and actual place of death. *J Pain Symptom Manage*. 2010;39(3):591–604.
 - 7 Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291(1):88–93.
 - 8 Cross SH, Warraich HJ. Changes in the place of death in the United States. *N Engl J Med*. 2019;381(24):2369–2370.
 - 9 Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med*. 2013 Nov;16(11):1329–1334.
 - 10 Wachterman MW, Sommers BD. Dying poor in the US—disparities in end-of-life care. *JAMA*. 2021;325(5):423–424.
 - 11 Baquet CR, Commiskey P, Mack K, Meltzer S, Mishra SI. Esophageal cancer epidemiology in blacks and whites: racial and gender disparities in incidence, mortality, survival rates and histology. *J Natl Med Assoc*. 2005;97(11):1471–1478.
 - 12 *Key Statistics for Esophageal Cancer [Internet]*. American Cancer Society; 2022 [cited 2022 Jan 12]. Available from: <https://www.cancer.org/cancer/esophagus-cancer/about/key-statistics.html>.
 - 13 *Survival Rates for Esophageal Cancer [Internet]*. American Cancer Society; 2022 [cited 2022 Jan 12]. Available from: <https://www.cancer.org/cancer/esophagus-cancer/detection-diagnosis-staging/survival-rates.html>.
 - 14 Graham L, Wikman A. Toward improved survivorship: supportive care needs of esophageal cancer patients, a literature review. *Dis Esophagus*. 2016;29(8):1081–1089.
 - 15 Rouan R. *New Census Numbers Paint Picture of Race and Ethnicity in U.S. But How are Those Defined? [Internet]*. USA TODAY; 2021 [cited 2022 Jul 24]. Available from: <https://www.usatoday.com/story/news/politics/2021/08/12/how-census-defines-race-and-ethnicity/5559216001/>.
 - 16 Norton EC, Dowd BE, Maciejewski ML. Marginal effects—quantifying the effect of changes in risk factors in logistic regression models. *JAMA*. 2019;321(13):1304–1305.
 - 17 Wales J, Kurahashi AM, Husain A. The interaction of socioeconomic status with place of death: a qualitative analysis of physician experiences. *BMC Palliat Care*. 2018 Jun 20;17(1):87.
 - 18 Bruera E, Russell N, Sweeney C, Fisch M, Palmer JL. Place of death and its predictors for local patients registered at a comprehensive cancer center. *J Clin Oncol*. 2002;20(8):2127–2133.
 - 19 Tang ST, McCorkle R, Tang ST, McCorkle R. Determinants of place of death for terminal cancer patients. *Cancer Invest*. 2001;19(2):165–180.
 - 20 Pritchard RS, Fisher ES, Teno JM, et al. Influence of patient preferences and local health system characteristics on the place of death. *J Am Geriatr Soc*. 1998;46(10):1242–1250.
 - 21 Burge F, Lawson B, Johnston G. Trends in the place of death of cancer patients, 1992-1997. *CMAJ Can Med Assoc J J Assoc Medicales Can*. 2003;168(3):265–270.
 - 22 Higginson IJ, Astin P, Dolan S. Where do cancer patients die? Ten-year trends in the place of death of cancer patients in England. *Palliat Med*. 1998;12(5):353–363.
 - 23 Chino F, Kamal AH, Leblanc TW, Zafar SY, Suneja G, Chino JP. Place of death for patients with cancer in the United States, 1999 through 2015: racial, age, and geographic disparities. *Cancer*. 2018;124(22):4408–4419.
 - 24 Singer PA, Martin DK, Kelner M. Quality end-of-life CarePatients' perspectives. *JAMA*. 1999;281(2):163–168.
 - 25 Carlson MDA, Bradley EH, Du Q, Morrison RS. Geographic access to hospice in the United States. *J Palliat Med*. 2010;13(11):1331–1338.
 - 26 Smith AK, Earle CC, McCarthy EP. Racial and ethnic differences in end-of-life care in fee-for-service Medicare beneficiaries with advanced cancer. *J Am Geriatr Soc*. 2009;57(1):153–158.
 - 27 Orlovic M, Smith K, Mossialos E. Racial and ethnic differences in end-of-life care in the United States: evidence from the health and retirement study (HRS). *SSM - Popul Health*. 2018;7:100331.
 - 28 Ornstein KA, Roth DL, Huang J, et al. Evaluation of racial disparities in hospice use and end-of-life treatment intensity in the REGARDS cohort. *JAMA Netw Open*. 2020;3(8):e2014639.
 - 29 Bajaj SS, Stanford FC. Beyond tuskegee — vaccine distrust and everyday racism. *N Engl J Med*. 2021;384(5):e12.
 - 30 Chang CM, Wu CC, Yin WY, Juang SY, Yu CH, Lee CC. Low socioeconomic status is associated with more aggressive end-of-life care for working-age terminal cancer patients. *Oncologist*. 2014;19(12):1241–1248.
 - 31 Williams DR, Priest N, Anderson N. Understanding associations between race, socioeconomic status and health: patterns and prospects. *Health Psychol Off J Div Health Psychol Am Psychol Assoc*. 2016;35(4):407–411.
 - 32 Dressler G, Ciccolello K, Anandarajah G. “Are they saying it how I’m saying it?” a qualitative study of language barriers and disparities in hospice enrollment. *J Pain Symptom Manage*. 2021;61(3):504–512.
 - 33 Bajaj SS, Jain B, Dee EC, Wo JY, Qadan M. ASO research letter: trends in location of death for individuals with pancreatic cancer in the United States. *Ann Surg Oncol*. 2022;29(5):2766–2768.
 - 34 Garrido MM, Harrington ST, Prigerson HG. End-of-life treatment preferences: a key to reducing ethnic/racial disparities in advance care planning? *Cancer*. 2014 Dec 15;120(24):3981–3986.
 - 35 Haugen DF, Huffhammer KO, Gerlach C, et al. Good quality care for cancer patients dying in hospitals, but information needs unmet: bereaved relatives' survey within seven countries. *Oncol*. 2021;26(7):e1273–e1284.