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Data Article

Racial disparities in palliative care utilization among metastatic gynecological cancer patients living at last follow-up: An analysis of the National Cancer Data Base



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ABSTRACT

The National Comprehensive Cancer Network recommends palliative care should be integrated in to cancer care starting from cancer diagnosis. However, traditionally palliative care is prioritized for cancer patients at the end-of-life. In our main article titled “Racial and Ethnic Disparities in Palliative Care Utilization Among Gynecological Cancer Patients” we present data describing racial/ethnic disparities among metastatic gynecological cancer patients who were deceased at last follow-up. Here, we expand our population to evaluate racial disparities in palliative care utilization among (1) all metastatic gynecologic cancer patients, regardless of vital status (alive or deceased) ($n=176,899$) and (2) among only patients who were alive at last follow-up ($n=66,781$). We used data from the 2016 National Cancer Database (NCDB) and included patients between ages 18–90 years with metastatic (stage III–IV) gynecologic cancers including, ovarian, cervical and uterine cancer. Palliative care was defined by NCDB as non-curative treatment, and could include surgery, radiation, chemotherapy, and pain

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management or any combination. We used multivariable logistic regression to evaluate racial disparities in palliative care use among our two populations of interest. Overall, the mean age of gynecologic cancer patients utilizing palliative care was 66 years. Five percent of all metastatic gynecologic oncology patients utilized palliative care overall; and by cancer site palliative care use was as follows: 4% among ovarian, 9% among cervical, and 11% among uterine cancer patients. Among patients who utilized palliative care, 62% utilized surgery, radiation or chemotherapy only and 12% utilized pain management as a form of palliative care. Among ovarian cancer patients, Hispanic ovarian cancer patients were less likely to utilize palliative care compared to their NH-White counterparts (aOR: 0.79, 95% CI: 0.68–0.91). Among cervical cancer patients, we observed that Hispanic (aOR: 0.65, 95% CI: 0.56–0.75) and Asian (aOR: 0.74, 95% CI: 0.59–0.93) were less likely to utilize palliative care than NH-White cervical cancer patients. We observed no racial disparities in palliative care utilization among uterine cancer patients. When we focused on patients who were alive at last follow-up we found that only 3% of patients utilized palliative care. We also conducted multivariable analyses of racial/ethnic disparities among ovarian and cervical cancer patients who were alive at last follow-up. We were unable to conduct multivariable analyses of uterine cancer patients who were alive at last follow-up due to limited sample size of those who utilized palliative care. We observed no racial/ethnic disparities among this patient population of metastatic gynecologic patients.

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Specifications Table

Subject	Health and Medical Sciences: Oncology
Specific subject area	Racial disparities in palliative care use among patients living with gynecological cancers
Type of data	Table Figure
How data were acquired	For this analysis, we used the 2016 Participant Use Files (PUF) of the National Cancer Data Base (NCDB), a United States (U.S.) cancer database hospital-based oncology database. The NCDB is a joint project of the American Cancer Society and the Commission on Cancer of the American College of Surgeons. The database comprises of more than 29 million unique cases or 70% of all U.S. patients with newly diagnosed cancer. NCDB data are collected from patients seen at any of the 1500 Commission on Cancer (CoC)-accredited institutions in the U.S. Annually, CoC hospitals report over one million cancer cases to the NCDB. To collect data from CoC-accredited hospitals, data are abstracted from electronic medical records by Certified Tumor Registrars who undergo specific training in cancer registry operations. During data abstraction, data are highly standardized to harmonize data cross CoC sites and extensive internal quality monitoring and validity reviews takes place. The NCDB are available to be acquired from the American College of Surgeons. Analyzed (using secondary existing data)
Data format	
Parameters for data collection	Data included in the NCDB are from patient charts abstracted by Certified Tumor Registrars (CTR) who undergo training specific to cancer registry operations. Trained data abstractors use standardized methods to collect sociodemographic, including race/ethnicity, and clinical data, including tumor type, stage, grade, and treatments.

(continued on next page)

Description of data collection	The NCDB includes information on any palliative care utilization from patients' clinical medical records. The NCDB codes treatments as palliative only if the patient's medical records explicitly mentioned that the goal of treatment is palliation and not cure. Specifically, any procedure was categorized as palliative care if treatment was provided to "prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable." Palliative care includes pain management therapy, surgery, radiation therapy, or systemic chemotherapy administered to alleviate symptoms. Palliative care utilization was compared to those who did not utilize palliative care.
Data source location	The National Cancer Database Website: https://www.facs.org/quality-programs/cancer/ncdb/puf
Data accessibility	The National Cancer Data Base data can be requested from the American College of Surgeons using the following link: https://ncdbapp.facs.org/puf/ NCDB Participant User Files (PUFs) are only available through an application process to investigators associated with CoC-accredited cancer programs. The Request for Applications is open year round, and PUFs are referred to by their most recent year of diagnosis included in the data file. PUFs are made available in flat text files and are accompanied by SAS and SPSS file scripts to assign value and variable labels. The aggregated data used for this analysis can be found here: https://data.mendeley.com/datasets/p28bwxgqxh/draft?a=dc6ee472-3367-4108-b4de-ad0cb254368b
Related research article	Islam JY, Deveaux A, Previs RA, Akinjemiju T. Racial and ethnic disparities in palliative care utilization among gynecological cancer patients. <i>Gynecol Oncol</i> . 2020 Dec 1:S0090-8258(20)34159-7. doi: 10.1016/j.ygyno.2020.11.031 . Epub ahead of print. PMID: 33276985 [1]

Value of the Data

- This analysis of the U.S. National Cancer Database illustrates disparities in palliative care use among metastatic gynecological cancer patients exist, indicating unequal treatment among cancer patients by race/ethnicity.
- Findings from this analysis can inform the practice of health care providers overseeing the recommended cancer treatment course of gynaecologic cancer patients. Demonstrating that racial disparities in palliative care utilization among gynaecologic cancer patients exist may encourage health care providers to re-examine their treatment recommendations and improve equitable receipt of high-quality cancer care in the United States.
- Our results can be used as rationale to develop and implement interventions to improve equitable provision of palliative care among gynaecologic cancer patients in the United States.

1. Data Description

1.1. Data source

Data for this study were obtained from the 2016 Participant Use Files (PUF) of the National Cancer Data Base (NCDB), a United States hospital-based oncology database combining data on patients seen at any of the 1500 Commission on Cancer (CoC) accredited institutions in the United States [2,3]. The NCDB registry is a joint project of the American Cancer Society and the Commission on Cancer of the American College of Surgeons, comprising more than 29 million unique cases or 70% of all patients with newly diagnosed cancer in the United States [4]. Data reported to the NCDB are highly standardized and like other state health departments and federal cancer registry data systems including the Surveillance, Epidemiology, and End Results (SEER). Data included in the NCDB are from patient charts abstracted by Certified Tumor Registrars (CTR) who undergo training specific to cancer registry operations [5]. The data abstractors use standardized methods to collect sociodemographic, including race/ethnicity, and clinical

data, including tumor type, stage, grade, and treatments. Additionally, to ensure high-quality and accurate data, CoC-accredited sites are required to undergo an external review of hospital charts and registry abstracts to verify that the NCDB registry data correctly reflect the information documented in individual patient records using a sample of at least 10% of records [6]. Data for this analysis were accessed in January 2020, and the analysis was performed in April-May 2020. The aggregated data for the study can be accessed in the Mendeley dataset.

1.2. Data

In our main analysis we focused on all metastatic gynecologic cancer patients, both alive and deceased at last follow-up per their vital status ($n = 176,899$). Table 1 descriptively summarizes distribution of sociodemographic characteristics by palliative care use among these gynecologic cancer patients. Overall, the mean age of gynecologic cancer patients utilizing palliative care was 66 years. Five percent of all metastatic gynecologic oncology patients utilized palliative care overall; and by cancer site palliative care use was as follows: 4% among ovarian, 9% among cervical, and 11% among uterine cancer patients. Among patients who utilized palliative care, 62% utilized surgery, radiation or chemotherapy only and 12% utilized pain management as a form of palliative care. When we descriptively evaluated palliative care use by race/ethnicity, we observed that 6% of non-Hispanic (NH) White, 7% of NH-Black, 4% of Hispanic, 5% of Asian, 5% of American Indian/Alaskan Native, and 10% of Native Hawaiian/Pacific Islander utilized palliative care. The highest proportions of palliative care utilization were among patients treated at a Community Cancer Program (8%) and at a hospital in the Northeast (8%). The proportion of gynecologic cancer patients utilizing palliative care increased from 3% in 2004 to 7% in 2016. Patients with stage IV gynecologic cancers received a higher proportion of palliative care (11%) compared to patients with stage III (2%).

We conducted a secondary analysis to evaluate palliative care use among only gynecologic cancer patients who were alive at last follow-up ($n = 66,781$). When we focused on this patient population, we found that only 3% of patients utilized palliative care. Fig. 1 summarizes palliative care use by cancer site among all metastatic gynecologic cancer patients (Panel A) and only those who were alive at last follow-up (Panel B). Among all ovarian cancer patients were observed that 4% of NH-White, 5% NH-Black, 3% of Hispanic, and 3% of Asian patients utilized palliative care ($\chi^2 p < 0.001$) (Fig. 1, Panel A). Additionally, among cervical cancer patients, 9% of NH-White, 10% of NH-Black, and 6% of Hispanic and Asian patients utilized palliative care ($\chi^2 p < 0.001$). Finally, the highest proportions of palliative care use were observed uterine cancer patients at 11% among NH-White, 11% among NH-Black, 9% Hispanic, and 12% Asian patients ($\chi^2 p = 0.62$). When we focused on metastatic gynecologic cancer patients who were alive at last follow-up (Panel B), we saw similar trends in use of palliative care across cancer site. Among ovarian cancer patients, 3% of NH-White, 4% of NH-Black, and 2% of Hispanic and Asian patients utilized palliative care ($\chi^2 p = 0.05$). Next, among cervical cancer patients, 4% of NH-White, 5% NH-Black, 3% of Hispanic, and 4% of Asian patients utilized palliative care ($\chi^2 p < 0.001$). Finally, again, we observed largest proportions of palliative care use among uterine cancer patients: 8% of NH-White, 7% of NH-Black, 5% of Hispanic, and 9% of Asian uterine patients alive at last follow-up utilized palliative care (Fig. 1, Panel B).

Fig. 2 summarizes the multivariable analysis of racial/ethnic disparities by cancer site among all metastatic gynecologic cancer patients. In the multivariable analysis we adjusted for age, follow-up time from cancer diagnosis to last contact or death, insurance type, median income, comorbidity score, cancer care facility type, census region, year of cancer diagnosis, and cancer grade. Among ovarian cancer patients, we observed no racial disparities among NH-Black (aOR: 0.97, 95% CI: 0.88–1.08) and Asian (aOR: 0.90, 95% CI: 0.74–1.11) when compared to NH-White patients. Hispanic ovarian cancer patients were less likely to utilize palliative care compared to their NH-White counterparts (aOR: 0.79, 95% CI: 0.68–0.91). Among cervical cancer patients, we observed that Hispanic (aOR: 0.65, 95% CI: 0.56–0.75) and Asian (aOR: 0.74, 95% CI: 0.59–0.93)

Table 1

Characteristics of all metastatic ovarian, uterine, and cervical cancer patients with known palliative care utilization status, United States, 2016 National Cancer Data Base (n = 176,899).

	No Palliative Care (n = 167,181)		Utilized Palliative Care (n = 9839)	
	N	Row%	N	Row%
Age (Mean, SD)	61.8, 14.3		65.6, 14.7	
Cancer Type				
Ovarian cancer	121,767	95.7	5470	4.3
Cervical cancer	39,298	91.5	3646	8.5
Uterine cancer	6006	89.4	712	10.6
Palliative Care Provided				
No palliative care	167,071	100	0	0
Surgery/radiation/chemo only	0	0	6101	62.1
Pain management only	0	0	1198	12.2
Combination of surgery/radiation/chemo or pain management	0	0	1027	10.4
Palliative care type unknown	0	0	1502	15.3
Race and Ethnicity				
Non-Hispanic White	120,970	94.4	7126	5.6
Non-Hispanic Black	17,905	93.0	1354	7.0
Hispanic	12,231	95.6	559	4.4
Asian	4839	95.5	227	4.5
American Indian/Alaskan Native	650	95.2	33	4.8
Native Hawaiian/Pacific Islander	332	90.5	35	9.5
Other Race	9107	95.3	454	4.7
Missing	1037	96.3	40	3.7
Primary Payer				
Not Insured	9055	93.5	634	6.5
Private Insurance/Managed Care	67,846	96.2	2676	3.8
Medicaid	17,463	93.0	1321	7.0
Medicare	68,174	93.2	4977	6.8
Other Government	1595	95.0	84	5.0
Insurance Status Unknown	2938	95.6	136	4.4
Median Household Income of Patient's Residential Zip Code*				
< \$40,227	32,983	93.6	2242	6.4
\$40,227–50,353	37,229	94.0	2376	6.0
\$50,354–63,332	38,378	94.5	2241	5.5
≥\$63,333	55,767	95.2	2820	4.8
Missing	2714	94.8	149	5.2
Charlson-Deyo Score (Comorbidities)				
0	133,103	94.9	7128	5.1
1	25,715	93.3	1842	6.7
2	5823	91.1	570	8.9
≥3	2430	89.4	288	10.6
Treatment Facility Type				
Community Cancer Program	9660	92.2	815	7.8
Comprehensive Community Cancer Program	59,851	94.0	3812	6.0
Academic/Research Program	64,939	95.1	3378	4.9
Integrated Network Cancer Program	21,403	93.9	1390	6.1
Missing	11,218	96.3	433	3.7
Census Region of Patient				
Northeast	31,674	92.5	2563	7.5
South	59,039	94.5	3408	5.5
Midwest	37,689	94.1	2358	5.9
West	27,451	96.3	1066	3.7
Missing	11,218	96.3	433	3.7
Year of Cancer Diagnosis				
2004	11,158	96.7	376	3.3
2005	11,621	96.6	415	3.4
2006	11,611	95.9	497	4.1
2007	11,853	95.6	551	4.4

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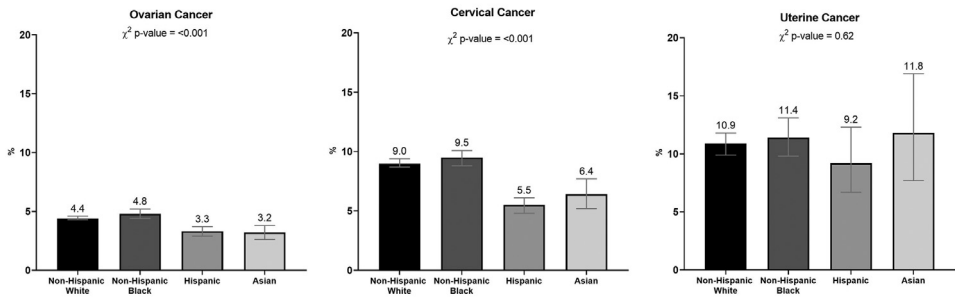
Table 1 (continued)

	No Palliative Care (n = 167,181)		Utilized Palliative Care (n = 9839)	
	N	Row%	N	Row%
2008	12,405	95.1	641	4.9
2009	12,670	95.0	662	5.0
2010	13,071	94.7	731	5.3
2011	13,234	94.1	835	5.9
2012	13,342	93.7	898	6.3
2013	13,945	93.6	955	6.4
2014	14,089	92.6	1120	7.4
2015	14,519	93.0	1089	7.0
2016	13,553	92.8	1058	7.2
Cancer Grade				
Well differentiated, differentiated, NOS	4975	97.2	141	2.8
Moderately differentiated, moderately well differentiated, intermediate differentiation	21,557	95.5	1004	4.5
Poorly differentiated	69,652	95.9	3003	4.1
Undifferentiated, anaplastic	17,310	95.9	731	4.1
Cell type not determined, not stated or not applicable, unknown primaries, high grade dysplasia	53,577	91.5	4949	8.5
NCDB Analytic Stage Group				
Stage III	105,659	97.6	2588	2.4
Stage IV	61,412	89.5	7240	10.5

Abbreviations: NOS, Not otherwise specific; NCDB: National Cancer Database.

* Measured in Quartiles and based on data from the 2016 American Community Survey data, spanning years 2012–2016 and adjusted for 2016 inflation.

Panel A: All Metastatic Gynecological Patients (n = 176,899)



Panel B: Metastatic Gynecological Patients Alive at Last Follow-Up (n = 66,781)

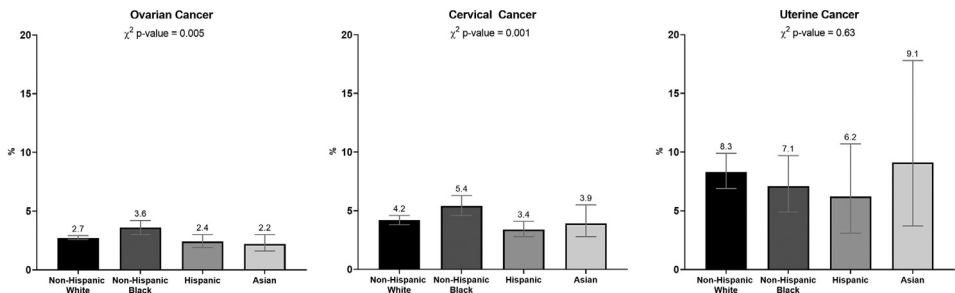
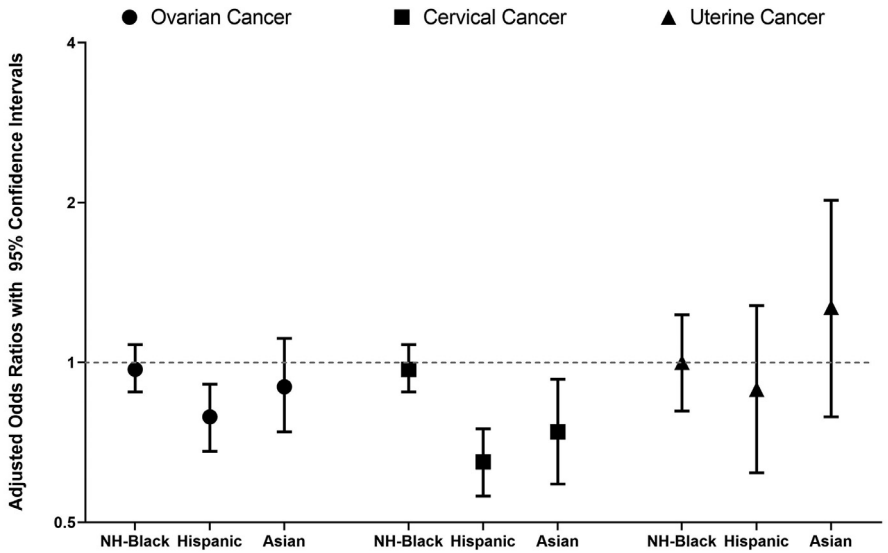


Fig. 1. Racial/Ethnicity Differences of Palliative Care Utilization by Gynecological Cancer Site among Patients in the United States, National Cancer Data Base (2004 - 2016).



(Ref: Non-Hispanic White)

Adjusted Odds Ratios Summarized on the Logarithmic Scale.

Adjusted for: Age, Follow-Up Time from Cancer Diagnosis to Last Contact or Death (Months), Insurance Type, Median Income, Comorbidity Score, Cancer Care Facility Type, Census Region, Year of Cancer Diagnosis, Cancer Grade

Fig. 2. Associations of Race/Ethnicity to Palliative Care Utilization Among All Patients with Metastatic Gynecological Cancers (2004–2016).

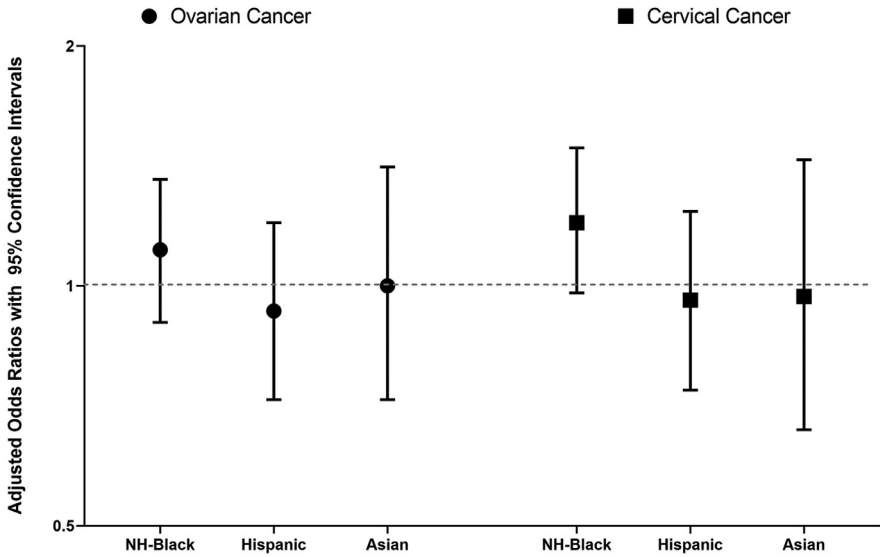
were less likely to utilize palliative care than NH-White cervical cancer patients. We observed no racial disparities in palliative care utilization among uterine cancer patients.

Fig. 3 summarizes multivariable analyses of racial/ethnic disparities among ovarian and cervical cancer patients who were alive at last follow-up. We were unable to conduct multivariable analyses of uterine cancer patients who were alive at last follow-up due to limited sample size of those who utilized palliative care. We observed no racial/ethnic disparities among this patient population of metastatic gynecologic patients.

2. Experimental Design, Materials and Methods

2.1. Study cohort

Study participants included patients with Stage III and IV ovarian, cervical and uterine cancers at diagnosis. Patients with missing or unknown cancer stage were excluded from this analysis ($n = 35,346$, 9.9%). We included patients diagnosed between January 1, 2004, to December 31st, 2016 using the following International Classification of Diseases for Oncology, Third Edition topography codes: ovarian C569, cervical C530, C531, C538, C539, and uterine C559. We excluded patients with missing data on palliative care utilization ($n = 1018$, 0.6%). We estimated palliative care utilization among (1) all metastatic gynecologic cancer patients regardless of vital status ($n = 176,899$) and (2) metastatic gynecologic cancer patients who were alive at last follow-up or contact ($n = 66,7891$).



(Ref: Non-Hispanic White)

Adjusted Odds Ratios Summarized on the Logarithmic Scale. Adjusted for: Age, Follow-Up Time from Cancer Diagnosis to Last Contact or Death (Months), Insurance Type, Median Income, Comorbidity Score, Cancer Care Facility Type, Census Region, Year of Cancer Diagnosis, Cancer Grade

Fig. 3. Associations of Race/Ethnicity to Palliative Care Utilization Among Metastatic Ovarian and Cervical Cancer Patients Alive at Last Follow-Up (2004–2016).

2.2. Palliative care utilization

The main outcome of this analysis was palliative care service utilization as defined by the NCDB, as in previously published studies [3,7–9]. The NCDB includes information on any palliative care utilization from patients’ clinical medical records. The NCDB codes treatments as palliative only if the patient’s medical records explicitly mentioned that the goal of treatment is palliation and not cure. Specifically, any procedure was categorized as palliative care if treatment was provided to “prolong a patient’s life by controlling symptoms, to alleviate pain, or to make the patient more comfortable [10].” Palliative care includes pain management therapy, surgery, radiation therapy, or systemic chemotherapy administered to alleviate symptoms. Patients utilizing palliative care in the NCDB may also concurrently be undergoing curative treatment. Palliative care utilization was compared to those who did not utilize palliative care.

2.3. Study variables

The main exposure of this analysis was race/ethnicity. We combined reported race/ethnicity as follows: Non-Hispanic White (NH-White), NH-Black, Hispanic, Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, and other Race. The NCDB categorizes the following identities as Hispanic: Mexican, Puerto Rican, Dominican Republic, Cuban, South or Central American (excluding Brazil), and Other specified Spanish/Hispanic origin. For the main analysis, we focused on comparisons of NH-White, NH-Black, Hispanic, and Asian patients. Patient demographics included age, sex (male/female), comorbidity score (Charlson-Deyo Score, 0–≥3), median annual income (in zip code of residence based on 2016 American Community Sur-

vey (ACS) <\$42,227, \$40,227–50,353, \$50,354–63,332, \geq \$63,333), and census region of patient (Northeast, South, Midwest, West). Clinical and tumor characteristics included histology grade (well, moderately, poorly differentiated or undifferentiated), NCDDB analytic stage group (Stage III or Stage IV), follow-up time from cancer diagnosis to last contact or death (<6 months, 6–24 months, >24 months), type of treating institution (community cancer program, comprehensive community cancer program, academic/research cancer program, or other/unknown), and treatment year (2004–2016). Patients were categorized on the basis of follow-up time (<6, 6–24, and >24 months) to provide insights into survival length and severity of disease independent of the stage of cancer. Our rationale was that patients with relatively shorter survival periods from diagnosis were more likely to have a more aggressive cancer in comparison with those who survived longer.

2.4. Statistical analysis

We descriptively summarized patient characteristics as percentages by palliative care utilization. We evaluated racial and ethnic differences in utilization of palliative care by cancer type using bivariate statistical analyses (χ^2 tests of significance) and multivariable logistic regression. For the multivariable analysis, we used logistic regression and report adjusted odds ratios (aOR) and 95% confidence intervals (95% CI). We identified covariates of interest based on prior literature and known factors that may impact palliative care utilization: age, follow-up time in months from cancer diagnosis to last contact or death, insurance type, median income, comorbidity score, cancer care facility type, census region, year of cancer diagnosis, and cancer grade. We assessed for collinearity using the variance inflation factor to ensure a strong linear relationship among independent variables included in the model was not present, and used a complete case approach. All analyses were performed with Stata, version 15.0 (StataCorp).

Ethics Statement

The study was approved by Duke University Institutional Review Board under a general study protocol (IRB#: Pro00102834) for analyses using NCDDB data.

CRedit Author Statement

JYI and TA conceptualized the project. JYI carried out statistical analyses and led manuscript development. AD, RAP, TA provided critical and expert interpretation of results. All authors contributed to writing and finalizing the manuscript.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships which have or could be perceived to have influenced the work reported in this article.

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