

Access to specialized treatment by adult Hispanic brain tumor patients: findings from a single-institution retrospective study

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Background: The Hispanic population accounts for 15% of the population of the United States, and for as much as 75% in cities throughout California. Racial disparities that are reflected by limited access to health care and worse disease outcomes are well documented for adult Hispanic cancer patients.

Objective: To determine whether there are similar disparities—including delays in accessing surgery, radiation, and oncologic care—for adult Hispanic non-English-speaking (HNES) neuro-oncology patients and white English-only-speaking (WES) patients in an academic, tertiary care center with a multidisciplinary neuro-oncology team.

Methods: This retrospective study was conducted at the Chao Family Comprehensive Cancer Center of the University of California, Irvine. All patients who were diagnosed with a primary brain tumor during January 1, 2003, to December 31, 2008, were identified and data were collected on their age, sex, ethnicity, languages spoken, diagnosis, and insurance status. The times from the date of diagnosis to the date of surgery, from the date of surgery to the date of starting radiation (if indicated), and from the date of finishing radiation to the date of starting chemotherapy (if indicated) were also recorded.

Results: Most of the HNES patients (56.4%) had state insurance for the indigent, whereas most of the WES patients (41.8%) had private insurance from a health maintenance organization. Moreover, 12.8% of HNES patients were uninsured, compared with 4.5% of WES patients. There were no significant delays in the time from diagnosis to surgery, but there was a significant delay in access to radiation treatment ($P = .023$). There were no differences on overall survival between the 2 groups of patients.

Limitations: This is a retrospective study of a relatively small number of patients. Larger studies are needed to corroborate these findings.

Conclusions: The findings demonstrate that there are disparities in insurance status and access to radiation therapy between HNES and WES neuro-oncology patients.

According to the United States Census Bureau, there were 45.5 million Hispanics residing in the United States as of July 1, 2007, which accounts for 15.1% of the US population. Hispanics constitute the largest and fastest-growing minority group in the United States, and California has the largest number of Hispanic residents. A recent study that identified health care disparities between whites and Hispanics revealed that the language barrier could be a factor in Hispanics not receiving recommended health

care services, compared with individuals who are fluent in English.¹

Not only is there often a language barrier between Spanish-speaking Hispanics and their health care providers, but two-thirds of the Spanish-speaking Hispanic patients seen in an academic oncology center in the United States were identified as having inadequate or marginal English literacy, which can limit patients' understanding of diagnosis, discharge instructions, and treatment options.² In addition, members of minority groups in general are more likely to be uninsured or to have Medicaid insurance than are non-Hispanic whites.^{3,4} In turn, uninsured and Medicaid patients are at a greater risk of being

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diagnosed with cancer at a later stage than are patients who are privately insured.⁵

Primary brain tumors, such as high-grade (World Health Organization grades III and IV) gliomas are highly aggressive and can progress rapidly.⁶ Mathematical modeling of the survival data for glioblastoma patients suggests that these tumors can double every 24 days in the absence of treatment.⁷ Thus, early treatment of malignant gliomas—including tumor resection, radiation, and chemotherapy—can have a substantial effect on a patient's overall prognosis and survival.

Early radiation treatment has been shown to be effective in a number of different malignancies, whereas the risk of recurrence has been shown to increase with an increase in waiting time to receive radiotherapy.⁸ Similarly, the time from a patient's presenting with malignant glioma to receiving radiation therapy has a significant impact on patient survival, whereas each week the radiotherapy is delayed could increase the risk of death.⁹ The delay in starting radiotherapy is often a result of advanced age, poor performance status, or operative complications, but access to appropriate care also depends on the patient's financial status.

For example, racial, ethnic, and socioeconomic disparities may be associated with outcomes from craniotomy in adult brain tumor patients,^{10,11} with black patients dying more often or having more adverse outcomes than do white patients, and Medicaid patients having higher mortality than do private-pay patients. Of note, black and Hispanic patients, as well as patients with Medicaid, tended to be seen in hospitals that had a lower volume of brain tumor cases and that lacked multidisciplinary, specialized neuro-oncological care.^{10,11} Consistent with those data is the observation that white patients with gliomas more frequently participate in clinical trials, which are generally offered only by high-volume, large academic centers, compared with racial and ethnic minority patients.¹² These differences can be explained in large part by health care economics (insurance status), as demonstrated in a study in which there were no differences in survival between white and black elderly glioblastoma multiforme patients who had Medicare Parts A and B.¹³

The current study was designed to explore the possibility that HNES patients experience a delay in receiving life-prolonging treatment, compared with WES patients, even in an academic, specialized cancer center; to define the anatomy of that delay; and to investigate its potential consequences.

Methods

To be eligible for inclusion on our study, patients needed to meet the following criteria: newly diagnosed supratentorial, intra-axial primary brain tumor, and established, outpatient follow-up in the Chao Family Comprehensive

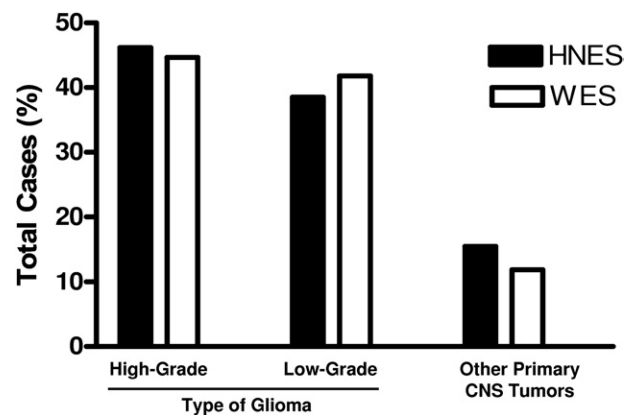


FIGURE 1 Distribution of patient pathology by language group. Nonglial tumors include medulloblastoma, ependymoma, and primary CNS lymphoma. HNES indicates Hispanic non-English-speaking; WES, white English-only-speaking.

Cancer Center oncology clinics from January 1, 2003 to December 31, 2008. The data for each patient consisted of self-identified ethnicity and language(s) spoken, as well as age, sex, insurance status, pathology (tumor type and grade; Figure 1), type of treatment received, date of diagnosis, date of surgery, date of first radiation session (if applicable), date of first chemotherapy administered (if applicable), and date of death (or last appointment if the patient is still alive).

We examined 3 waiting time variables—time from diagnosis to surgery, time from surgery to the start of radiation treatment, and time from radiation completion to the first postradiation adjuvant chemotherapy dose—and recorded them in days. (Patients receiving concomitant radiation and chemotherapy were excluded from this analysis.) We also determined overall survival (OS) from date of initial diagnostic surgery to date of death. Time-to-event data for HNES patients and WES patients were displayed as Kaplan-Meier curves, and were compared by using the log rank test. A *P* value of $\leq .05$ was considered statistically significant.

Results

Patients

Between 2003 and 2008, 135 patients with newly diagnosed, primary neoplasms of the brain were seen in the center. Of those patients, 67 self-identified as WES, and 45 as HNES. This distribution is representative of patient demographics in Southern California, where 49% of patients are US-born whites and 33% are non-English-speaking immigrants from Central and South America. We excluded patients who were bilingual or spoke languages other than Spanish (17% of patients).

TABLE 1 Patient characteristics and insurance status by ethnicity

Characteristic	Study group	
	WES	HNES
No. of patients	67	45
Age, y	50.9 (20-87)	51.8 (21-75)
Sex, %		
Women	50.7	48.7
Men	49.3	51.3
KPS, %	90 (70-100)	90 (70-100)
Insurance, %		
HMO	41.8	28.2
PPO	29.9	2.6
State-sponsored program	22.3	56.4
Uninsured	4.5	12.8

Abbreviations: HNES, Hispanic non-English-speaking; HMO, health maintenance organization; KPS, Karnofsky Performance Status (100% = normal, no evidence of disease; 0% = dead); no., number; PPO, preferred provider organization; WES, white English-only-speaking; y, year.

The two groups (WES and HNES) were similar with respect to demographic characteristics (Table 1). The median age was 51 years (range, 20-87 years) for WES patients and 52 years (range, 21-75 years) for HNES patients. In all, 50.5% of WES patients were women and 48.7% of HNES patients were women. The Karnofsky Performance Status (KPS) scores were also similar between the 2 groups, with most of the patients' scoring 80% or higher. Low-grade glioma histology was somewhat more frequent in HNES patients (53.8% of diagnoses), compared with WES patients (41.8% of diagnoses).

Insurance status

At the time of initial brain tumor diagnosis, most of the patients in the HNES group (56.4%) were covered by the state-funded Medicaid program (Medi-Cal), whereas most of those in the WES group (41.8%) had private health maintenance organization (HMO) coverage (Table 1). Moreover, 12.8% of the HNES patients were uninsured, compared with 4.5% of WES patients.

Time between diagnosis and surgery

The median time from diagnosis to surgery for WES patients was 12 days (11 days for those with high-grade [III or IV] gliomas, and 33 days for those with low-grade gliomas and other tumors; Figure 2). For HNES patients, the median time from diagnosis to surgery was 18 days (17 days for those with high-grade gliomas, and 44 days for those with low-grade gliomas). The difference in time

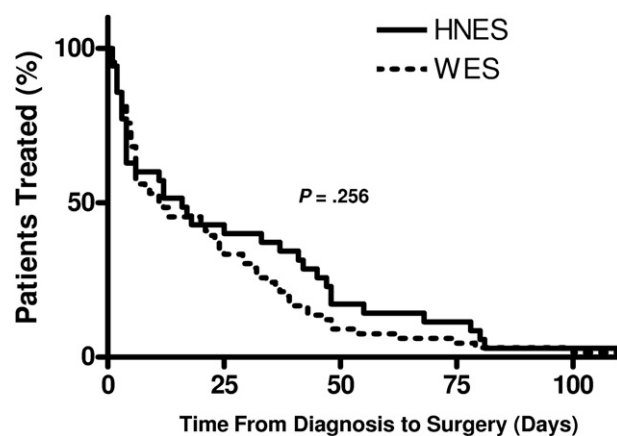


FIGURE 2 Patients' access to brain tumor surgery by language group. The difference in time from diagnosis to surgery between all WES patients and all HNES patients was not statistically significant. HNES indicates Hispanic non-English-speaking; WES, white English-only-speaking.

from diagnosis to surgery between all WES and all HNES patients was not statistically significant ($P = .26$).

Time between surgery and the start of radiation treatment

The median times from diagnosis to the start of radiation treatment for WES patients with either a high-grade glioma or a high-risk (defined as patient age older than 45 years, subtotal resection, and/or tumor crossing the midline), low-grade glioma were 41 days and 44 days, respectively. For HNES patients, the median time was 60 days for both pathologies. The difference in the time from diagnosis to the start of radiation for all WES patients, compared with all HNES patients, was statistically significant ($P = .02$; Figure 3). All patients for whom radiation was indicated were seen in consultation by radiation oncology-department faculty in the first week after the determination was made. The delay in starting radiation was due entirely to the time required to obtain insurance approval for treatment.

Time from last radiation day to first chemotherapy dose

Most of the patients (WES and HNES) included in this report began radiation after March 2005 and received daily temozolomide during radiation (75 mg/m² per day) concurrent with radiation (2 Gy/day to a total of 60 Gy), as shown to be beneficial by the EORTC trial¹⁴ published in the same year. Only 3 of 10 (30%) HNES and 8 of 15 (53%) WES malignant glioma patients who had been treated before December 2004 received chemotherapy after completing their radiation. For this very small number of patients, the average waiting time to start chemo-

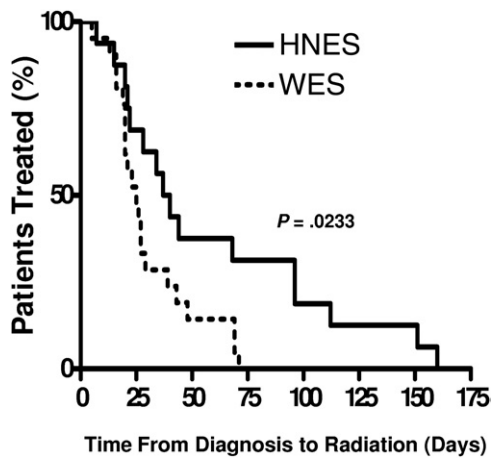


FIGURE 3 Patients' access to brain tumor radiation treatment by language group, measured as time in days between diagnosis of high-grade glioma and the first day of radiation treatment. The delay to receiving radiation for HNES patients was significant, compared with that for WES patients. HNES indicates Hispanic non-English-speaking; WES, white English-only-speaking.

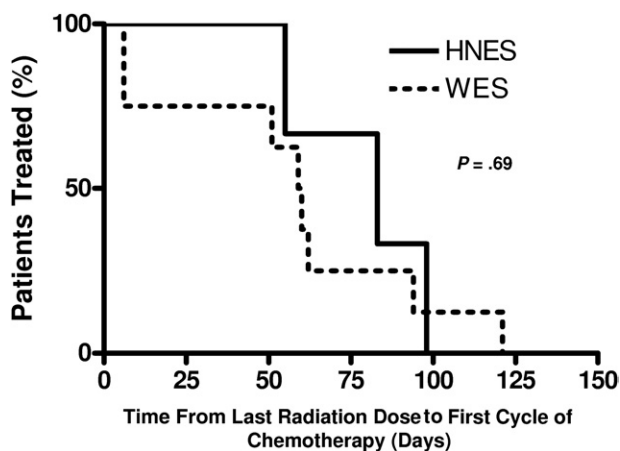


FIGURE 4 Patients' access to brain tumor chemotherapy by language group, measured as time in days between the last day of radiation treatment and the beginning of the first cycle of chemotherapy. There was no difference in access to brain tumor chemotherapy between all WES and all HNES patients. HNES indicates Hispanic non-English speaking; WES, white English-only-speaking.

therapy was 57 days for WES patients and 79 days for HNES patients ($P = .69$; Figure 4).

Overall survival

For the patients included in our retrospective study, no survival difference was seen between HNES and WES, with a median OS of 3.3 years for both groups ($P = .4$; Figure 5). Similar results were obtained when patients with high-grade and low-grade tumors were analyzed separately.

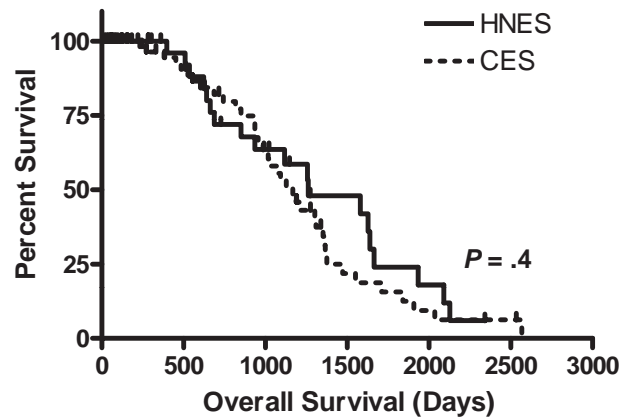


FIGURE 5 Overall survival by language group, measured as time in days from brain tumor diagnosis. There are no differences in overall survival between the 2 patient groups. HNES indicates Hispanic non-English-speaking; WES, white English-only-speaking.

Discussion

Several limitations are pertinent to a retrospective study such as ours. Our study population was relatively small. The treatments that were used (in particular, the preferred chemotherapy) changed during the 5-year period of the study; numerous physicians from neurosurgery, radiation oncology, oncology, and neuro-oncology were involved in determining the treatment of the study patients and possibly imposed their own treatment biases. However, a consistent trend emerged from all our results: At all steps of treatment, there is a delay in access to care for adult Hispanic brain tumor patients who do not speak English, and this delay achieves statistical significance with respect to radiation therapy.

Compared with surgery, which is often done on an emergency basis in the hospital setting, external beam radiation therapy is an outpatient procedure that is done at significant cost to patients and their insurers. Under our current health care system, it is impossible to administer radiation therapy in the absence of insurance, and just under 13% of the HNES patients in our study were initially uninsured, although all our patients were finally able to be enrolled in the state-run Medi-Cal system.

Much research has been done on the effects of delaying radiotherapy initiation for patients with malignant gliomas, although the results of different studies from numerous geographical areas are contradictory (Table 2).¹⁵ In some of the studies, longer waiting times were associated with worse outcomes,^{9,16-18} in others, investigators failed to replicate the results;¹⁹⁻²² and in one study, investigators even suggested that early treatment might have more side effects and lead to decreased survival.²³ In the present study, it is important to note that the treatment delay seemed to play a more important role in

TABLE 2 Studies linking delay in radiotherapy with survival in patients with malignant gliomas

Source (country of study)	No. of patients	Postoperative time to radiation, d	Effect on survival
Do, ⁹ 2000 (Australia)	182	26	Risk of death increased by 2% for each day of waiting.
Fazeny-Dörner, ¹⁸ 2003 (Austria)	98	42	Risk of death increased after 14 days.
Irwin, ¹⁶ 2007 (New Zealand)	172	35	Risk of death increased by 8.9% for each week of waiting.
Noël, ²⁰ 2009 (France)	94	46	No effect on survival.
Lopez, ²¹ 2008 (France)	60	44	No effect on survival.
Blumenthal, ²³ 2009 (RTOG, international)	2,855	21	Short delay improved outcomes.
Caloglu, ¹⁷ 2009 (Turkey)	78	NA	Increased risk of death after 20 days.
Lai, ¹⁹ 2010 (US, Medicare database)	1,375	15	No effect on survival.
Erridge, ²² 2011 (Scotland)	1,175	36	No effect on survival.

patients who were treated before 2007, for whom 3 of 3 studies found that radiotherapy delay correlates with poor prognosis, compared with those treated after 2007, for whom only 1 of 6 studies found that radiotherapy delay correlates with poor prognosis (Table 2). In our opinion, this difference is probably related to the generalization of more-effective treatment paradigms for malignant gliomas after 2005,¹⁴ which might mitigate for the tumor growth in the waiting period between diagnosis and treatment initiation. In our study, there was no survival difference between HNES and WES, a finding similar to those in other studies published after 2007. However, we cannot exclude the fact that the lack of significant survival difference might be a consequence of our limited number of patients.

Outcome disparities are often subtle and may not become apparent until very large patient populations are studied. A comprehensive, retrospective analysis of the Nationwide Inpatient Sample database from 1988 to 2005 assessed whether there were disparities in access to pediatric neuro-oncologic care in the US population.²⁴ The study included a total of 4,421 patients. Significantly, Hispanic ethnicity was associated with worse access to high-volume centers. This was a particularly worrisome finding, because previous studies have shown that high-volume academic hospitals have lower morbidity and mortality for pediatric brain tumor–craniotomy patients.²⁵ A similar analysis was also recently published for adult neuro-oncology patients.²⁶ Of the total 76,436 patients included in the analysis, only 33% were admitted to the high-volume hospitals. Although access to high-volume, high-quality care improved overall between 1988 and 2005, the ethnic disparities for Hispanic patients have worsened in recent years.²⁶ Although patient outcomes were not included in the studies, this finding is particularly worrisome because

it suggests that minority patients receive less optimal care than do their majority counterparts.

In previous studies that included HNES patients, the most common barrier to treatment has been identified as the communication between the patient and the medical provider and support staff.²⁷⁻³⁴ For that reason, we did not include Hispanic patients who were able to communicate in English, nor patients who came from other non-English-speaking cultures. A translator was used for every medical visit, but none of the physicians spoke fluent Spanish, and we did not use a patient navigator to help the patient address any barriers to care. On the basis of our study findings, we are now considering employing a patient navigator, but the position is not covered by insurance and might be an additional strain on our already overtaxed system.³⁵ Another possible option to address the disparities in access to care would be early referral through the state insurance system to a comprehensive neuro-oncology program. Although that method has not been tried in the United States, very positive results were seen in a study conducted in Singapore, in which patients who had malignant glioma and were preferentially guided to a multidisciplinary program had more aggressive surgery, improved access to radiotherapy, and 50% longer overall survival, compared with patients who were not part of the multidisciplinary program (18.7 months vs. 11.9 months, respectively).³⁶

The 2001 Cancer Panel Report to the President titled “Voices of a Broken System” concluded that “[no] person with cancer should go untreated. No person with cancer should be bankrupted by a diagnosis of cancer. No person with cancer should be forced to spend more time fighting their way through the healthcare system than fighting their disease.” However, there are disparities in access to specialized care among both underprivileged Hispanic

pediatric brain tumor patients³⁷ and Hispanic adult brain tumor patients, as shown in our study. Greater health care policy efforts need to be marshaled to reduce the inequalities in access to care among brain tumor patients for whom days or weeks of delay could cause them to prematurely lose their fight with cancer.

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