Racial disparities in the diagnosis and management of trigeminal neuralgia

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OBJECTIVE A number of studies have documented inequalities in care and outcomes for a variety of clinical conditions. The authors sought to identify racial and socioeconomic disparities in the diagnosis and treatment of trigeminal neuralgia (TN), as well as the potential underlying reasons for those disparities, which could serve as areas of focus for future quality improvement initiatives.

METHODS The medical records of patients with an ICD-9 code of 350.1, signifying a diagnosis of TN, at the Henry Ford Medical Group (HFMG) in the period from 2006 to 2012 were searched, and clinical and socioeconomic data were retrospectively reviewed. Analyses were conducted to assess potential racial differences in subspecialty referral patterns and the specific type of treatment modality undertaken for patients with TN.

RESULTS The authors identified 652 patients eligible for analysis. Compared with white patients, black patients were less likely to undergo percutaneous ablative procedures, stereotactic radiosurgery, or microvascular decompression ($p < 0.001$). However, there was no difference in the likelihood of blacks and whites undergoing a procedure once they had seen a neurosurgeon (67% vs 70%, respectively; $p = 0.712$). Blacks and whites were equally likely to be seen by a neurologist or neurosurgeon if they were initially seen in either the emergency room (38% vs 37%, $p = 0.879$) or internal medicine (48% vs 50%, $p = 0.806$). Among patients diagnosed (268 patients) after the 2008 publication of the European Federation of Neurological Societies and the American Academy of Neurology guidelines for medical therapy for TN, fewer than 50% were on medications sanctioned by the guidelines, and there were no statistically significant racial disparities between white and black patients ($p = 0.060$).

CONCLUSIONS According to data from a large database from one of the nation's largest comprehensive health care systems, there were significant racial disparities in the likelihood of a patient undergoing a procedure for TN. This appeared to stem from outside HFMG from a difference in referral patterns to the neurologists and neurosurgeons.

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KEY WORDS trigeminal neuralgia; racial disparity; socioeconomic status; chronic pain management; functional neurosurgery; pain

EPIDEMIOLOGICAL studies have estimated the incidence rate of trigeminal neuralgia (TN) in a range from 11.0 to 42.0 cases per 100,000 people per year with a female preponderance.¹⁷ While TN can afflict people of any age, the majority of patients are between the ages of 50 and 60 years.¹⁰ A paucity of literature is dedicated to the racial epidemiology of TN, although some epidemiological studies have been performed at the Mayo Clinic in

Rochester, Minnesota,^{13,14} and the University of São Paulo in Brazil.¹⁵ While the Mayo study found no difference in the incidence of TN among different races, the Brazilian study revealed a higher incidence of TN in whites than in other races.

The European Federation of Neurological Societies (EFNS) and the American Academy of Neurology (AAN) have promulgated guidelines for the medical and surgi-

ABBREVIATIONS AAN = American Academy of Neurology; EFNS = European Federation of Neurological Societies; ER = emergency room; HFMG = Henry Ford Medical Group; MS = multiple sclerosis; MVD = microvascular decompression; PCTR = percutaneous rhizotomy; SRS = stereotactic radiosurgery; TN = trigeminal neuralgia.

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cal treatment of TN since 2008.^{1,2,4} Radiation therapy in the form of Gamma Knife surgery or other stereotactic radiosurgery (SRS); ablative procedures such as percutaneous rhizotomy (PCTR), balloon compression, glycerol rhizotomy, or radiofrequency ablation; and microvascular decompression (MVD) are accepted treatment options for patients with medically refractory TN.⁹

The current study was launched after we noted that a seemingly smaller number of black patients compared with the number of white patients were being referred for the surgical management of TN despite a large black population in Southeast Michigan. According to the 2010 US Census, of the 4,704,743 citizens in Southeast Michigan, 68.5% were white, 21.6% black, 3.9% Hispanic, and 3.6% Asian (Census.gov). Although prior studies have noted racial disparities in the performance of inpatient TN procedures,^{12,18} we elected to examine racial disparities in the diagnosis, medical management, and both inpatient and outpatient procedures for the treatment of TN in a large, urban health system with a diverse patient population and large referral base. Our primary analytical goal was to examine steps in the diagnosis, referral, and treatment sequence to identify the points at which racial disparities appeared in that sequence. We hypothesized that black patients are more frequently diagnosed in the emergency room (ER) rather than in the outpatient clinic setting and, perhaps because of lower rates of health insurance coverage and reduced access to health care, would not get referrals to outpatient subspecialty clinics or would be lost to follow-up more often than their white counterparts.

Methods

After receiving approval from our institutional review board, we queried an administrative database to identify patients with a diagnostic code of 350.1 (TN) who had been evaluated and treated for facial pain at the Henry Ford Medical Group (HFMG) between 2006 and 2012. The database covered care provided by HFMG physicians in 2 inpatient facilities, approximately 36 outpatient facilities, and emergency departments located in both inpatient and 3 of the outpatient facilities. We performed a retrospective chart review and developed a database of the identified patients, abstracting information about patient age; sex; race (white, black, or other); imputed household income based on geocoded census tract (when available) or residential zip code (in US dollars); type of health care coverage at TN diagnosis (Medicare, Medicaid, private insurance, or self-pay [that is, uninsured]); laterality of symptoms; presence of atypical features such as constant, dull facial pain or numbness resulting from facial trauma or oral surgery; history of multiple sclerosis (MS); health care setting of initial diagnosis (ER, specific HFMG outpatient clinic, or sites other than HFMG); any referrals to subspecialty clinics; medications prescribed; and procedure performed (SRS, PCTR, or MVD); as well as the time between diagnosis and any procedure performed. Data on age at TN diagnosis; atypical features such as constant, dull facial pain, numbness resulting from facial trauma or oral surgery; and history of MS were obtained from notes made by neurologists or neurosurgeons. The

site of TN diagnosis was abstracted from notes made by neurologists and neurosurgeons as well. If a neurologist or neurosurgeon did not see the patient, the records were still abstracted for the site of initial diagnosis. Data regarding TN medications were abstracted from listings of medications or from the sections labeled “history of present illness” in the clinical notes.

Statistical Analysis

Pairwise comparisons of the racial groups (white vs black, white vs other, and black vs other) were performed. Chi-square tests were used for categorical and binary characteristics, whereas 2-sample t-tests and Wilcoxon tests were used for age, number of medications, and median household income. Logistic regression methods were used to adjust for socio-demographic information when assessing racial differences. Significance was set at a *p* value of 0.05 with no adjustments for multiple comparisons. Statistical analyses were performed using SAS version 9.2 (SAS Institute Inc.).

Results

Twenty-one of 673 patients were of unknown race; thus, 652 patients were included in our analyses. Missing data regarding year of and patient age at diagnosis (57 patients) and duration between diagnosis and treatment (28 patients) were coded as missing and thus not included in the final analysis. For patients in whom the place of diagnosis was not documented in our electronic medical records (120 patients), we assumed that the diagnosis had been rendered outside of our institution.

Six hundred fifty-two patients were included in the final analysis, 484 (74%) of whom were female. Among the 652 patients, 409 (63%) were white, 196 (30%) were black, and 47 (7%) were another race (Fig. 1). Mean age at the time of diagnosis was 60.3 years (SD $\pm$ 15.2), with a range of 17 to 94 years. White patients were an average of 7 years older than black patients ($p < 0.001$) and 4 years older than other-race patients ($p = 0.107$) at the time of diagnosis. The male/female ratio was similar across the 3 racial groups. White patients had a higher rate of MS than black patients (6% vs 2%, $p = 0.028$). The distribution of the type of insurance coverage differed between the white and black patients: white patients were more likely to have Medicare coverage ($p = 0.019$), whereas black patients were more likely to have Medicaid coverage ($p < 0.001$). The uninsured rate was not different among the 3 racial groups. Table 1 summarizes the key characteristics of patients included in the study.

The overall rate of undergoing at least 1 procedure was 29% of all patients (190 of 652), with 20% having at least 1 MVD, 5% having at least 1 SRS, and 10% having at least 1 PCTR. As expected from our initial impression, black patients were less likely than white patients to undergo any procedures (21% vs 34%, respectively, $p < 0.001$). White patients were more likely than black patients to undergo one of the ablative procedures (12% vs 7%, $p = 0.035$), SRS (6% vs 3%, $p = 0.047$), or MVD (24% vs 15%, $p = 0.012$). White patients were more likely than other-race patients to undergo any procedures (34% vs 17%, $p = 0.016$), including

FIG. 1. Racial distribution of 652 patients with TN.

MVD (24% vs 6%, $p = 0.005$). No statistically significant differences in undergoing any procedure were detected between the black and other-race patients. These differences in undergoing any procedure between whites and other racial groups remained after adjusting for age, type of insurance, and median household income (Table 2).

Possible Mechanisms for Treatment Disparities

Time Since Initial Diagnosis

Of those patients who underwent any procedure, no differences were detected among the racial groups for the time from initial TN diagnosis to the time of the procedure, with a median of 2 years for whites and blacks and 1.5 years for other races (Table 3).

Choice of Treatment by Neurosurgeons

Of the 190 patients undergoing at least 1 procedure, 180 (95%) were seen by an HFMG neurosurgeon. Among the 266 TN patients seen by HFMG neurosurgeons, there was no difference between white (70%) and black (67%) patients ($p = 0.712$) in the rate of undergoing at least 1 procedure. Other-race patients had a significantly lower rate of undergoing a procedure (44%) than white patients ($p = 0.032$) and showed a trend toward a lower rate of procedures than black patients ($p = 0.086$). These patterns by race were specifically observed for MVD; that is, there were no differences between white and black patients (50% vs 48%, $p = 0.81$), and there were significant differences between other-race patients (19%) and the 2 other racial groups ($p = 0.016$ for white and $p = 0.034$ for black). No racial differences were detected in the rates of PCTR (white 25%, black 22%, and other 13%, overall $p = 0.51$) or SRS (white 12%, black 9%, and other 13%, overall $p = 0.768$).

There were no statistical differences based on age and

type or lack of insurance in the likelihood of a patient seen by a neurosurgeon to undergo a procedure (Table 2). For the subset of patients seen by HFMG neurosurgery, patients with higher incomes were slightly less likely to undergo a procedure (OR for every increase of \$10,000 was 0.89, 95% CI 0.79–0.99, $p = 0.028$).

Patterns of Referral to Neurosurgery

The HFMG comprises more than 1100 physicians and researchers from over 40 different specialties. With 2 main hospital branches and 26 medical centers, including 8 emergency medicine centers, the HFMG serves all of Southeastern Michigan. In 2009, a new 191-bed hospital was constructed in the northeastern suburbs of Detroit. These centers combined reported nearly 3.4 million outpatient visits and more than 73,000 surgical procedures in 2014.

A significant racial difference was detected in the initial setting of TN diagnosis in comparing white and black patients ($p < 0.001$), as well as in comparing white patients to other-race patients ($p = 0.008$): White patients had a higher rate of initial diagnosis outside of HFMG as compared with blacks (36% vs 16%, $p < 0.001$) and corresponding lower rates of diagnosis in our institution's ER and internal medicine department (8% vs 31%, $p < 0.001$; 15% vs 23%, $p = 0.015$, respectively). Compared with other-race patients, whites also had lower rates of diagnosis in our ER (8% vs 26%, $p < 0.001$). Besides the departments of internal medicine, neurology, and neurosurgery, patients with TN can be seen within the HFMG at 1 of the 8 ERs. To our knowledge, no algorithm exists within the emergency department for the management and evaluation of patients with TN. No differences were seen between black and other-race patients for the initial setting of diagnosis (Table 1).

TABLE 1. Demographic and diagnosis information for 652 patients with TN overall and by race*

Variable	All Patients	White	Black	Other	p Value		
					White vs Black	White vs Other	Black vs Other
No. of patients	652	409	196	47			
Mean age ($\pm$ SD) at diagnosis in yrs [†]	60.3 $\pm$ 15.2	62.8 $\pm$ 14.6	55.7 $\pm$ 15.4	59.1 $\pm$ 14.7	<0.001	0.107	0.172
Sex					0.299	0.911	0.497
Male	168 (26)	110 (27)	45 (23)	13 (28)			
Female	484 (74)	299 (73)	151 (77)	34 (72)			
Median household income (IQR)	\$51,673 (\$37,690–\$68,036)	\$60,357 (\$46,607–\$76,414)	\$37,143 (\$26,862–\$47,708)	\$44,792 (\$28,658–\$65,086)	<0.001	<0.001	0.027
Insurance					<0.001	0.232	0.227
None	77 (12)	56 (14)	18 (9)	3 (6)			
Private/self pay	391 (60)	232 (57)	125 (64)	34 (72)			
Medicare	150 (23)	106 (26)	34 (17)	10 (21)			
Medicaid	19 (3)	6 (1)	13 (7)	0 (0)			
Other	15 (2)	9 (2)	6 (3)	0 (0)			
Symptom/side					0.382	0.267	0.148
No side	145 (22)	88 (22)	52 (26)	5 (11)			
Unilat	472 (72)	299 (73)	134 (68)	39 (83)			
Atypical	28 (4)	19 (5)	7 (4)	2 (4)			
Bilat	7 (1)	3 (1)	3 (2)	1 (2)			
Yr of diagnosis [†]					0.065	0.296	0.945
<2000	66 (11)	47 (13)	15 (8)	4 (9)			
2000–2009	363 (61)	228 (62)	109 (59)	26 (56)			
2010–2012	166 (28)	90 (25)	60 (33)	16 (35)			
Initial setting of TN diagnosis							
ER	106 (16)	34 (8)	60 (31)	12 (26)	<0.001	<0.001	0.493
Internal medicine	115 (18)	63 (15)	46 (23)	6 (13)	0.015	0.632	0.108
Neurology	166 (25)	112 (27)	42 (21)	12 (26)	0.115	0.787	0.543
Neurosurgery	54 (8)	38 (9)	10 (5)	6 (13)	0.074	0.444	0.057
Other HFMG	20 (3)	13 (3)	7 (4)	0 (0)	0.80	0.215	0.188
Outside HFMG	191 (29)	149 (36)	31 (16)	11 (23)	<0.001	0.076	0.216

* Data are number of patients (%) unless otherwise indicated.

† Data were missing in 57 patients.

For patients with an initial diagnosis performed in our institution's ER, internal medicine, or other HFMG department (such as the pain clinic, ophthalmology, otolaryngology, and psychiatry), there were no differences among the races in the likelihood of going on to see an HFMG neurologist or neurosurgeon (Table 4). Similarly, among the patients with an initial diagnosis in our institution's neurology department (166 patients), the overall percentage of patients subsequently seen by neurosurgery was 30%, with no significant differences found among the racial groups (white 29%, black 38%, and other 17%, overall $p = 0.296$). Taken together, these findings reveal a racial difference in the site of initial diagnosis but not in the likelihood of subsequently being seen in neurology or neurosurgery if one is first seen in other HFMG departments.

Pharmacological Treatment of TN

White patients were more likely to have used multiple medications for their TN as compared with black patients (29% vs 19%, $p = 0.005$). Fewer than 50% of patients diagnosed after the 2008 publication of the EFNS-AAN guidelines for medical therapy for TN, across all races, were on medications sanctioned by the guidelines (Table 5). There was a trend toward black patients having a higher rate of EFNS-AAN-sanctioned medications as compared with white patients; however, this difference did not reach statistical significance (56% vs 44%, $p = 0.060$).

Discussion

The 2002 Institute of Medicine report "Unequal Treatment" summarized a large body of published literature

TABLE 2. Multivariate logistic regression results for the outcome of undergoing at least 1 procedure to treat TN*

Variable	All TN Patients (n = 652)		TN Patients Referred or Seen in HFMG Neurosurgery (n = 266)	
	OR (95% CI)	p Value	OR (95% CI)	p Value
Race				
White vs black	2.29 (1.42–3.71)	<0.001	1.68 (0.78–3.59)	0.184
White vs other	2.48 (1.11–5.55)	0.027	2.93 (0.98–8.77)	0.054
Black vs other	1.08 (0.46–2.54)	0.862	1.75 (0.52–5.84)	0.364
Increase of 10 yrs in age	0.99 (0.88–1.13)	0.903	0.94 (0.77–1.15)	0.564
Increase of \$10,000 in median household income	0.97 (0.90–1.05)	0.407	0.89 (0.79–0.99)	0.028
Type of insurance		0.472		0.567
Private vs none	0.80 (0.46–1.39)		1.57 (0.72–3.44)	
Medicare vs none	0.56 (0.30–1.07)		0.95 (0.39–2.31)	
Medicaid vs none	0.72 (0.21–2.51)		2.31 (0.23–22.6)	
Other vs none	0.73 (0.21–2.58)		1.85 (0.16–20.9)	

* Although whites were more likely to undergo a procedure in general, there was no statistically significant racial bias between blacks and whites among those seen by HFMG neurosurgery. Of those patients seen by HFMG neurosurgery, the wealthier patients were slightly less likely to undergo a procedure.

on racial/ethnic inequalities in the delivery and quality of health care.¹⁶ A large number of studies since then have continued to document disparities in various dimensions of medical care, including cancer care, myocardial infarction care, diabetes management, and asthma care.^{5,6,8,11} The studies by Kalkanis et al. and Wang et al. demonstrated a significant racial bias in the use of inpatient surgical procedures for TN in the US.^{12,18} Our findings on disparities in treatment among patients seen in a single organization are consistent with the results of those studies.

There is no evidence that different racial groups are more or less likely to suffer from TN, so a difference in the rates of disease incidence does not seem to be a likely explanation for observed differences in procedural treatment rates.

Our primary objective was to identify how race could influence the ways in which patients with TN were diagnosed, triaged to specialty clinics, and, ultimately, medically and surgically treated. While it is clear that white patients underwent procedures for TN more frequently than other races at our institution, these differences do not appear to stem from differences in referral patterns from

within our institution. Blacks and whites were equally likely to undergo surgery once they were seen by an HFMG neurosurgeon. Neither was there a difference in the type of procedure that blacks and whites were likely to undergo among MVD, PCTR, and SRS. Blacks and whites were equally likely to be seen by a neurosurgeon after being seen by an HFMG ER physician, internal medicine practitioner, or neurologist. However, the majority of patients who received outside referrals to HFMG neurologists and neurosurgeons were white. This finding may be attributable to racial disparities outside HFMG or differences in patterns of referral by outside clinicians to HFMG versus other neurosurgeons in the region who treat TN.

A possible explanation for the racial disparity in the referral pattern may stem from cultural beliefs and perceptions about surgical and nonsurgical treatments. Goldstein et al. found that inner-city African Americans were more likely to express interest in complementary and alternative medicine.⁷ Such opinions expressed to a patient's primary care physician or outside referring physician may account for a decrease in neurosurgical referrals. In addition, culture-specific values influence patient roles and expectations, how much information about illness and treatment is desired, sex and family roles, and processes of decision making. In the African American culture, illness is sometimes seen as a natural event, occurring according to "God's plan." Furthermore, huge emphasis is placed on the importance of family and church. In addition, if surgery is decided on, the logistics of the peri- and postoperative period can pose a huge strain on a family.

Chan et al. found that similar racial disparities regarding surgical treatment exist within the neurosurgical realm.³ African Americans were less likely to undergo electrode placement for deep brain stimulation for Parkinson's disease despite the fact that they, compared with other races, are more often discharged from larger urban teaching hospitals with both deep brain stimulation capabilities and well-trained neurologists and neurosurgeons

TABLE 3. Time between diagnosis and procedure for each race group among 160 patients who underwent at least 1 procedure*

Racial Group	No. of Patients	Median	Range	IQR
White	118	2	0–37	0–5
Black	34	2	0–11	0–4
Other	8	1.5	0–22	0.5–6

* Thirty patients (23 white and 7 black) of the 190 who had undergone at least 1 procedure had a missing year of diagnosis or of first procedure and thus were excluded from analysis. Median, range, and interquartile range expressed in years. Medians and ranges are provided because the extreme outliers influenced the means and standard deviations. None of the differences between the race groups were significant (white vs black $p = 0.733$, white vs other $p = 0.874$, and black vs other $p = 0.821$).

TABLE 4. Referral rates to neurology or neurosurgery from other HFMG clinical settings as stratified by race*

Initial Setting of Diagnosis	All (n = 241)		White (n = 110)		Black (n = 113)		Other (n = 18)		p Value		
	No.	No. w/ Ref (%)	No.	No. w/ Ref (%)	No.	No. w/ Ref (%)	No.	No. w/ Ref (%)	White vs Black	White vs Other	Black vs Other
ER	106	41 (39)	34	13 (38)	60	22 (37)	12	6 (50)	0.879	0.476	0.387
Internal medicine	115	55 (48)	63	30 (48)	46	23 (50)	6	3 (50)	0.806	0.502	0.442
Other HFMG location	20	10 (50)	13	6 (46)	7	4 (57)	0	0	0.639	NA	NA

NA = not applicable; Ref = referral.

* There were no statistically different rates of referral to neurology or neurosurgery based on race within the different clinical settings. There were significant differences in referral rates to neurology or neurosurgery based on the initial setting of diagnosis, and this difference was consistent across racial groups.

to perform such procedures. This finding suggests that members of different races may hold differing views and levels of comfort with surgical procedures.

Our study showed that a large percentage of patients were not treated with appropriate medications after the dissemination of the EFNS-AAN guidelines. Although not statistically significant, there was a trend for poorer adherence to the guidelines in white patients. This may reflect the fact that the majority of white patients were referred from outside of HFMG. Our study also demonstrated that only a minority of patients seen by ER, internal medicine, and other practitioners at the HFMG subsequently go on to see a neurologist or neurosurgeon. It is unclear if this is attributable to spontaneous or pharmacological improvement in patient pain or whether the patients chose to see neurologists and neurosurgeons outside of HFMG.

Other minor determinants include health literacy, support structure, psychosocial factors, and social values.¹ It is widely known that different cultures have different views on what causes illness, how it should be addressed, and who should be involved in the process. Cultural differences affect patient attitudes about medical care and their ability to understand, manage, and cope with the course of an illness, the meaning of a diagnosis, and the consequences of medical treatment. Additionally, The Commonwealth Fund reports that blacks commonly experience disrespect in the health care setting. Assumptions based on negative societal images of blacks contribute to the negative experiences many encounter when they present for health care, thus creating a lack of trust among black patients when the treating physician is a different race. With all these factors in play, primary care physicians outside the HFMG who encounter black patients with TN may decide against neurological referrals in response to the patients' wishes.

This retrospective institutional study suffers from a number of limitations. Because we could not control outcome assessment and we had to rely on the accurate record keeping of other individuals, our study may suffer from

sampling or information bias. We attempted to minimize this bias by individually reviewing each patient's medical records from the time of his or her first encounter at our institution and by excluding patients who were subsequently diagnosed as having facial pain that was not consistent with TN. By doing this, we were able to eliminate patients whose description of their facial pain characteristics did not fit the recorded diagnostic code. Data regarding the reported severity of symptoms or visual analog scale scores are not available in our database. While this information may be available in patient records, it is not routinely documented in every facial pain encounter; therefore, we were unable to ascertain whether the severity of a patient's symptoms had an impact on their choice of treatment. We were unable to determine patient preferences regarding treatment options for TN. Established differences in pain thresholds and response to painful stimuli across ethnic backgrounds reported in the literature⁵ and cultural views toward surgery may have influenced our patients' decisions regarding specific treatment options. Future studies will address patient preferences and satisfaction with their care. Given the aforementioned limitations, it may be difficult to generalize our findings to other health care systems or to the general populace. However, our investigation is unique in that we are the first to examine disparities in the medical and surgical management of TN.

Conclusions

Racial inequalities in the diagnosis and management of chronic pain disorders are well reported in the literature. Our analysis revealed that race, rather than median household income or insurance coverage, was associated with the likelihood of undergoing a procedure for TN. However, once a patient was evaluated by an ER, internal medicine, neurology, or neurosurgery practitioner within the HFMG, both white and black patients underwent similar rates of procedures. There were no racial differences in the preferences for particular procedures, be it MVD,

TABLE 5. Use of AAN-EFNS-sanctioned medications in patients diagnosed after 2008

Variable	All Patients	White	Black	Other	p Value		
					White vs Black	White vs Other	Black vs Other
Total no. of patients	268	150	94	24			
Guideline medication (no. [%])	130 (49)	66 (44)	53 (56)	11 (46)	0.059	0.866	0.354

PCTR, or SRS. Therefore, addressing referral or treatment decision processes within the HFMG will not decrease racial disparities. Future efforts will be needed to examine regional or national databases that contain outpatient information and potentially target practitioners outside the HFMG. Adherence to EFNS-AAN guidelines for the pharmacological management of TN was equally poor for both whites and blacks.

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Disclosures

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Author Contributions

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