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Racial differences in patient expectations prior to resective epilepsy surgery

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Abstract

We assessed the nature and frequency of preoperative expectations among patients with refractory epilepsy who were enrolled in a seven-center observational study of epilepsy surgery outcomes. At enrollment, patients responded to open-ended questions about expectations for surgical outcome. Using an iterative cutting and sorting technique, expectation themes were identified and rank-ordered. Associations of expectations with race/ethnicity were evaluated. Among 391 respondents, the two most frequently endorsed expectations (any rank order) were driving (62%) and job/school (43%). When only the most important (first-ranked order) expectation was analyzed, driving (53%) and cognition (17%) were most frequently offered. Non-whites endorsed job/school and cognition more frequently and driving less frequently than whites (all $p \leq 0.05$), whether we included expectations of any order or only the first ranked ones. Elucidating the reason for these differences can aid in the clinical decision-making process for resective surgery and potentially address disparities in its utilization.

Keywords

Epilepsy surgery; expectations; race/ethnicity

Introduction

Epilepsy surgery is an established treatment for medically refractory epilepsy, with the potential to eliminate seizures and improve health-related quality of life [1]. However, resective epilepsy surgery appears to be underutilized, particularly among African Americans [2]. For example, African Americans were less likely to undergo resective epilepsy surgery compared to non-Hispanic whites in a study of 130 patients with refractory temporal lobe epilepsy, even after controlling for demographic and socioeconomic characteristics, medical insurance

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coverage, and clinical factors [2]. Differences in patient expectations of both the benefit and potential side effects of the surgery may underlie such disparities of utilization.

Previous studies of preoperative expectations for resective epilepsy surgery have identified themes beyond seizure freedom [3-5]. These expectations include the desire for employment, driving, greater independence, socializing and friendship, and medication change, among others. However, these studies did not assess how expectations may vary by race/ethnicity.

This study's goals were to assess the nature, range, and frequency of preoperative expectations for resective epilepsy surgery, and to explore whether expectations vary across patient sociodemographic and clinical characteristics, with a particular focus on racial-ethnic differences, among a large cohort of surgical candidates across multiple US epilepsy centers.

Methods

Sample

396 adults and adolescents with refractory epilepsy were enrolled during a presurgical evaluation period in an observational cohort study at one of seven participating centers and subsequently underwent resective epilepsy surgery. Inclusion criteria are delineated in previous reports [6,7]: 1) age ≥ 12 years at initial presentation for surgical evaluation; 2) ≥ 20 partial or secondarily generalized seizures during the previous 2 years; 3) failure of at least two first-line antiepileptic drugs to control seizures; 4) no prior epilepsy surgery. Institutional Review Board approval was obtained at all sites. Written informed consent was obtained from all participants.

Data collection

Data regarding seizure history, clinical and demographic characteristics including race and ethnicity, employment, education level, marital status, and expectations of what will change with surgery were obtained at the time of enrollment by a structured face-to-face interview administered by trained research associates at each center. The wording of the question study participants were asked about race/ethnicity was "How do you prefer to describe your racial/ethnic background?" with response choices as listed in Table 1; up to two responses could be recorded but we classified participants on race/ethnicity according to their first indicated preference. The median interval from the time of this enrollment interview to date of surgery was 4.5 months (IQR = 2.5-8.2 months).

To qualitatively assess the nature and range of preoperative expectations for resective epilepsy surgery, patients were asked: "In what ways do you feel limited by your epilepsy? What do you most hope to change as a result of this surgery?" Interviewers were given the following instructions written below the above question: "After they list one thing, prompt 'Anything else?' After they list a second thing (if they do), prompt, 'Anything else?'". As such, more than one response could be recorded. All participants (n=565) were asked these questions at the time of enrollment, but the analyses focused on those subjects that subsequently did undergo resective epilepsy surgery (n=396).

Analysis

Investigators reviewed text responses and identified a preliminary set of expectation themes. Themes and subthemes were further identified using a cutting-and-sorting technique [8]. Using this technique, quotes pertaining to one of the preliminary identified themes were cut out and placed on a note card, while maintaining some of the context in which it occurred. The backs of the cards were labeled with a study ID number and the rank ordering of the expectation for a given individual. Cards were then sorted into piles of similar quotes and categorized by consensus of three study investigators (C.B., E.C., B.V.). These categories, or subthemes, were

recorded and then collapsed into overarching themes. Codes were applied to each theme and then entered into a spreadsheet, along with exemplars for each theme [9].

Frequencies of each theme, or expectation category, were calculated. Differences in the proportions of participants who reported one of the nine most frequently reported expectations were compared across race/ethnicity, gender, education, employment status, age, marital status, whether temporal or extratemporal lobe epilepsy, side of surgery, and study site, using chi-square analysis (two-tailed) including Fisher's exact test where cell sizes were fewer than 10. Additionally, we explored unique associations of these nine expectations with sociodemographic and clinical factors, using forward step-wise logistic regression ($p \leq 0.15$). A sensitivity analysis was performed in order to account for the rank-order response of expectations by subjects, or the relative importance of each response. More specifically, the analysis was re-run evaluating only the first expectation given by each subject. Because our non-white subgroup was heterogeneous, we re-ran our analyses comparing non-Hispanic whites with a minority subgroup of Black/African American and Hispanic combined ($n=55$), as these represented the two largest minority groups and are both considered underserved minority groups in the US. Analyses were performed using Stata (9.2) and SAS (9.1) software.

Results

Sociodemographic and clinical characteristics of cohort

Table 1 shows sociodemographic and clinical characteristics of the 391 adults and adolescents (out of 396) that completed this portion of the interview.

Identification of expectation themes

Card-sort analysis resulted in 61 subthemes, from which 15 overarching expectation themes were identified. Nine of these 15 unique themes were identified by $\geq 15\%$ of the sample (Table 2): driving (62%), job/school (43%), independence (29%), seizure cessation (26%), social functioning (23%), quality of life (20%), medication discontinuance (20%), physical activities (18%), and cognition (17%). Expectations endorsed by less than 15% of the sample included embarrassment/stigma, emotional, fatigue, general health, family planning, and no limitation/no expectation. Each expectation theme was composed of subthemes; exemplars are in Table 2. For example, the exemplars of the independence theme included: "be self-sufficient and independent", "not having to depend on others", and "doesn't want to be a burden".

Sensitivity analysis for the first ranked expectation given by each subject showed that driving was the most frequent (53%) followed by cognition (17%). All other first ranked expectations were endorsed by less than 5% of the sample.

Associations of expectations with sociodemographic and clinical characteristics

Race/ethnicity was the only sociodemographic or clinical characteristic that was significantly associated with more than two expectations. More specifically, in bivariate and multivariate models, race was uniquely associated with 3 of 9 expectations, with non-whites (19% of sample) endorsing job/school and cognition more frequently and driving less frequently than whites (all $p \leq 0.05$) (Figure 1). Moreover, these three differences between whites and non-whites persisted in the sensitivity analysis in which only the number one ranked expectation was analyzed by race. Furthermore, a sensitivity analysis restricting the non-white group to only Black/African American and Hispanic was performed for all expectations (regardless of ranking) and of first-ranked expectation. This analysis again showed statistically significant differences in driving and cognitive expectations (either any ranking or as first-ranked expectation). Additionally, there was a trend for a difference across the groups on the job/

school expectation regardless of ranking (white 39.9% vs. non-white 50.9%; $p = 0.1$); a similar result was found for the first-ranked expectation as well.

While driving was the most frequently endorsed expectation among the entire study sample, we noted that subjects at Columbia University (whose catchment area is predominantly Manhattan with subjects potentially less reliant on driving compared to other urban sites, whose catchment areas extend into suburban/rural locations) endorsed driving significantly less frequently than subjects at the other 6 sites (35% versus 65%, $p < 0.001$). Moreover, subjects at Columbia were also more likely to be non-white than at the other six sites (42% versus 15%, $p < 0.001$). To determine if the results at Columbia were responsible for the association between driving expectations and race for the entire study sample, we re-analyzed the data after excluding data from subjects at the Columbia site. However, the subsequent multivariate models still showed that whites endorsed driving more frequently than non-whites ($p = 0.04$).

Discussion

Patients awaiting resective epilepsy surgery have definable expectations for surgery, the most frequent of which is driving, followed by employment/educational attainment. However, the frequency of expectations differs by race with non-whites endorsing job/school and cognition more frequently and driving less frequently than whites.

While seizure cessation was only the fourth most frequent overall expectation in our study, some subjects may have thought that it was implied when they were asked about their expectations for resective epilepsy surgery. The question posed to our subjects, "What do you most hope to change as a result of this surgery?" could suggest actions that individuals undertake themselves, and not results external to an individual's control, like seizure control. In this regard, some subjects may have felt that seizure cessation was already implied and therefore, they did not formerly endorse it as a discrete expectation. The fact, however, that seizure cessation was endorsed by 26% of subjects, however, suggests that not all subjects felt that such an expectation was implicit. There is no standardized instrument to evaluate preoperative expectations for resective epilepsy surgery. Such a lack of a standardized instrument evaluating expectations may therefore, account for the fact that seizure cessation is not always delineated as a preoperative expectation. More specifically, Wilson et al. found that seizure cessation was the most frequently endorsed expectation [5] while in the studies by Taylor et al. and Wheelock, the questions posed to subjects assumed that seizure freedom prior to analysis, and therefore, this expectation theme is not reflected in their results [3,4]. For expectations other than seizure cessation, the expectations most frequently endorsed were similar to those of other studies [3-5].

This sensitivity analysis showed that the majority of subjects reported driving to be their most important expectation, the same as for the analysis including all expectations regardless of ranking. We also found, somewhat surprisingly, that cognition was the next most frequent first ranked expectation. Indeed, for those patients that endorsed cognition as a preoperative expectation, it was always ranked first. Such a finding suggests that patients hoping to attain improved cognition from resective epilepsy surgery may differ from other subjects in some regard. Additionally, we found that job/school, a frequently endorsed expectation when counting them in all ranked positions, was rarely endorsed as the first ranked expectation. A possible explanation is that subjects may need to improve another domain of health (driving status, cognition) before they can address job/school issues.

To our knowledge, this is the first study to report racial differences in preoperative expectations for resective epilepsy surgery. We found racial differences among one-third of the most frequently endorsed expectations. Non-whites endorsed driving less frequently than whites.

Swartztrauber et al., reported that African-Americans underestimated the benefits of epilepsy surgery compared to whites [10]. On the other hand, non-whites endorsed expectations of employment/educational and cognitive improvement more frequently than whites. It is possible that these results reflect general differences in socioeconomic status by race. For example, the greater expectation for employment among non-whites compared to whites might be due to the higher unemployment status among non-whites in this cohort (64% of non-whites unemployed compared to 45% of whites unemployed). We did adjust for available sociodemographic characteristics in our multivariate models, but we did not have information on income and rural/urban status. Furthermore, the number of subjects in each non-white subgroup (African American, Hispanic, Native American or Alaskan Native, Asian or Pacific Islander, and other) was insufficient to make definitive conclusions as to whether all non-whites are homogeneous in their endorsement of specific preoperative expectations. Future studies are needed to explore these racial differences in expectations in order to understand how such differences may be a potential factor in the differential utilization of resective epilepsy surgery. Racial/ethnic differences in presurgical expectations may be an important factor in explaining disparities in the utilization of resective epilepsy surgery. For example, racial differences in attitudes toward surgery partly account for the disparities of utilization of carotid endarterectomy [11].

More research is needed determine how presurgical expectations may aid in the clinical decision-making process for surgery, and how perceptions of outcome are influenced by presurgical expectations versus actual amount of benefit. In addition, how these expectations potentially influence patients' preferences toward choosing to undergo resective epilepsy surgery may provide insight into how to improve communication around risks and benefits of surgery. Studies of how well surgery produces desired outcomes are needed and should be used in conjunction with other outcome measures assessing quality of life and seizure frequency in order to provide more relevant and specific counseling for patients considering resective surgery for medically refractory epilepsy.

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Figure 1. Racial Differences in Preoperative Expectations

*Non-Hispanic white and non-white differ at $p \leq 0.03$ significance level (any rank order and first-ranked expectation themes).

Table 1

Sample characteristics (N = 391)

	Mean (SD) or N(%)
Age at onset, years, mean (SD)	14.4 (11.5)
Age at study entry, years, mean (SD)	37.1 (11.2)
Duration of epilepsy, years, mean (SD)	22.2 (12.6)
Male	187 (47.8)
Racial/Ethnic Background ^{a,b}	
White, not of Hispanic origin	318 (81.5)
Non-white:	72 (18.5)
Black or African American, not of Hispanic origin	35 (9.0)
Hispanic	20 (5.1)
Native American or Alaskan Native	4 (1.0)
Asian or Pacific Islander	8 (2.1)
Other	5 (1.3)
High school graduate or greater ^a	333 (85.4)
Married ^a	169 (43.3)
Employed full or part-time (versus unemployed, homemaker, retired, other, unpaid volunteer, seasonal/irregular) ^c	200 (51.4)
Temporal (versus extratemporal) site resection	344 (88.0)
Right side of surgery (versus left side)	190 (48.6)

^aMissing information on race/ethnicity, highest level of education, and marital status (n=1 each)

^b12 of 318 (3.8%) white not of Hispanic origin and 3 of 72 (4.2%) of all non-white categories study participants indicated a second response regarding their race/ethnicity; the first response for preferred description of racial/ethnic background for these study participants is reported here

^cMissing information on employment (n=2)

Table 2

Expectation Themes

Themes	Frequency of Expectation N (%)	Subthemes	Exemplars
1. Driving	241 (61.6)	<ul style="list-style-type: none"> • General driving 	“to be able to drive”; “get driving license back”
2. Job/School	166 (42.5)	<ul style="list-style-type: none"> • Job/Work • School • Economic 	“to be able to work”; “would like to be able to get a job” “go to college”; “go back to school again” “make more money”; “economic”; “earn money to support self”
3. Independence	115 (29.4)	<ul style="list-style-type: none"> • General independence • General mobility • Being dependent on others • Family worry/burden on others • Travel • Freedom • Live on own • Reduce limitations • Public transportation 	“more independence”; “be self-sufficient and independent” “increased mobility”; “feel less confined” “not having to depend on others”; “not having to rely on others” “normal life for husband and kids”; “doesn't want to be a burden” “want to travel” “freedom to do things”; “would like to be free to do more” “get own place to live”; “moving back out on my own” “to not have limitations”; “want to do what I want, a lot of restrictions” “go on public transportation”
4. Seizure cessation	100 (25.6)	<ul style="list-style-type: none"> • Stop seizures • Seizure worry • Disease control/unpredictability • Seizure manifestations 	“stop seizures”; “hope to eliminate seizures entirely”; “become seizure free” “no worry about seizures” “increase degree to which sees a seizure coming”; “get epilepsy under control” “stop urinating during seizures”; wants to stop biting tongue”
5. Social functioning	90 (23.0)	<ul style="list-style-type: none"> • Social (general) • Social interactions with children • Marriage/dating/relationships • Social isolation • Friends • Family 	“social life”; “go to parties, concerts, clubs” “do more things with kids” “get married”; “be in a relationship” “would like to be around more people (socially)” “hang out more with friends” “do more for family”; “decrease conflict between me and family”
6. Quality of life	82 (20.1)	<ul style="list-style-type: none"> • Normal • Get life back • Self-esteem • Quality of life (general) • My whole life 	“want to live a more ‘normal’ life” “have life back”; “become my old self” “more self-confidence” “increase quality of life”; “quality of life-open more doors” “have a life”

Themes	Frequency of Expectation N (%)	Subthemes	Exemplars
		<ul style="list-style-type: none"> • Life on hold • To be cured • Achievements 	<p>“go on with life”</p> <p>“hope to be cured of epilepsy”</p> <p>“wants to be able to accomplish something with her life”</p>
7. Medication discontinuance	78 (19.9)	<ul style="list-style-type: none"> • Stop medications • Specific medication side effects • Nonspecific medication side effects • Food/alcohol • Cosmetic side effects • Going to the doctor 	<p>“stop taking medications”</p> <p>“get appetite back”</p> <p>“decrease side effects of meds”</p> <p>“foods”; “drink alcohol”</p> <p>“cosmetic”; “my weight gain”</p> <p>“going to the doctors”</p>
8. Physical	71 (18.2)	<ul style="list-style-type: none"> • Sports related activity • General physical activity • Home related activities • Safety/avoid injury (general) • Swimming/water safety • Sports safety • Machinery safety • Children safety • Heights safety 	<p>“play sports and be more active</p> <p>“do physical activities”</p> <p>“renovate house”; “take care of house”</p> <p>“no more injuries secondary to seizures”</p> <p>“start swimming again”</p> <p>“would like to be able to hunt, fish, and play sports”; “lifting weights”</p> <p>“like operate machinery”</p> <p>“to be able to hold a baby again”</p> <p>“wants to climb ladders”</p>
9. Cognition	67 (17.1)	<ul style="list-style-type: none"> • Memory • Concentration/attention • Higher function/decision-making • Language communication 	<p>“would like memory to improve”</p> <p>“be able to concentrate more easily”; “to be able to concentrate while reading”</p> <p>“make better decisions”; “to become smarter”</p> <p>“language-speak better”</p>