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Primary Language and Participation Outcomes in Hispanics With Traumatic Brain Injury: A Traumatic Brain Injury Model Systems Study

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Abstract

Objective: To examine the relationship between primary language and participation outcomes in English- and Spanish-speaking persons with complicated mild to severe traumatic brain injury (TBI) at 1 year post-injury.

Setting: Community following discharge from inpatient rehabilitation.

Participants: A total of 998 Hispanic participants with outcomes available at year 1 follow-up; 492 (49%) indicated English as their primary language and 506 (51%) indicated Spanish as their primary language.

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Design: Prospective, multicenter, cross-sectional, observational cohort study.

Main Measures: Community participation at 1 year post-injury was assessed by 3 domains of the Participation Assessment with Recombined Tools-Objective (PART-O): Out and About, Productivity, and Social Relations.

Results: Unadjusted group comparisons showed better participation outcomes for English versus Spanish speakers for all PART-O domains and for the Balanced Total score. After controlling for relevant covariates, English-speaking participants had significantly better PART-O Balanced Total scores and better scores on the Social Relations domain, although effect sizes were small.

Conclusions: Hispanic persons with TBI whose primary language is Spanish may require greater assistance integrating socially back into their communities after TBI. However, potential cultural differences in value placed on various social activities must be considered. Potential cultural bias inherent in existing measures of participation should be investigated in future studies.

Keywords

community participation; disparities; primary language; traumatic brain injuries

HISPANICS are the largest ethnic minority group in the United States,[1] and they comprise a substantial proportion of persons with traumatic brain injury (TBI) in both civilian[2,3] and military samples.[4] Prior research has shown that Hispanics with TBI report a greater number of neurobehavioral symptoms at 1 year after injury compared with non-Hispanic Whites and Blacks.[5] Furthermore, they are less likely to be functionally independent and less likely to have good community integration or participation outcomes.[6] Compared with Whites, Hispanics, who were mostly males, have been shown to be less independent in home activities, such as cooking and managing house-hold finances.[7] Hispanics also have a significantly lower chance of employment at 1 and 2 years after injury compared with non-Hispanic Whites.[8] Disparities in outcome may be partly due to limited access to medical and rehabilitation care. Studies have documented that Hispanics with TBI are less likely than non-Hispanics to be discharged from acute care to rehabilitation, after controlling for insurance status.[9–11]

Acculturation, or the extent to which a person shares the values, language, customs, and cognitive perspective of their own culture versus that of the dominant culture, can impact health outcomes.[12] The role of acculturation in determining outcomes following TBI has not been investigated, with the exception of cognitive test performance.[13,14] While acculturation can be operationalized in various ways, primary language is considered to be one of the best proxies for acculturation.[15] According to the United States Census Bureau, based on data collected from 2009 to 2013, approximately 38 million persons speak Spanish at home, and approximately 16 000 of these speak English less than very well.[16] Few studies have focused on outcomes for Spanish-speaking Hispanics with TBI. In a sample of 57 Spanish-speaking Hispanics with TBI at a single Traumatic Brain Injury Model Systems (TBIMS) center, Jamison and colleagues[17] showed that 63% of participants were unemployed at 1 year after injury, while 41.5% required the assistance of another person for daily activities. These problems with functioning and employment persisted at 10 years after injury, when 48% of participants remained unemployed and 43.5% required assistance in daily activities.

Cultural environmental factors may impact the outcomes of Spanish speakers following TBI. Lequerica and colleagues[18] showed that Hispanics with TBI who were born outside the United States were more likely to have good productivity outcomes if they were living in a neighborhood with a higher proportion of foreign language speakers. In areas with a lower proportion of foreign language speakers, Hispanics who were born in the United States had better productivity outcomes. While these studies provide preliminary evidence of the association of primary language to outcomes following TBI in Hispanics, they are limited by small sample size and by focusing on a single participation outcome.

The purpose of this study is to assess the relationship between primary language (English vs Spanish) and community participation 1 year post-injury among Hispanic individuals with complicated mild to severe TBI. This relationship was assessed with regard to 3 domains of participation, including productivity, social relationships, and community activities, controlling for relevant covariates.

METHODS

Participants

The sample for the current study was comprised of a subset of participants in the TBIMS national database, which is a longitudinal database of persons with medically documented TBI.[19] Criteria for inclusion in the national database are: at least 16 years at the time of injury; admitted to a TBIMS trauma center within 72 hours of injury; admitted to comprehensive inpatient rehabilitation within the TBIMS within 72 hours of discharge from the trauma center; complicated mild, moderate, or severe injury severity, as defined by a Glasgow Coma Scale score of less than 13 at the time of admission to the emergency center (not due to intubation, sedation, or intoxication), loss of consciousness more than 30 minutes (not due to sedation or intoxication), posttraumatic amnesia (PTA) more than 24 hours, and/or evidence of intracranial abnormalities on neuroimaging; and informed consent of the person with injury or an authorized proxy. Collection and coding of medical record data on demographics, injury characteristics, and acute trauma care variables is part of the TBIMS protocol. In addition, participants are contacted for follow-up interviews at years 1, 2, and 5 years after injury, as well as at every 5-year interval following that.

For the current article, persons in the TBIMS national database who self-identified as Hispanic ethnicity and were due for 1-year follow-up between October 1, 2007, and June 30, 2018, were selected for analyses. The start date was chosen based on when the primary outcome measure was added to the national database. The final analytic sample included 998 Hispanic participants with outcomes available at year 1 follow-up; 492 (49%) indicated English as their primary language and 506 (51%) indicated Spanish as their primary language. See sample flowchart in Figure 1.

Outcome measures

The primary outcome measure was the Participation Assessment with Recombined Tools-Objective (PART-O).[20,21] The PART-O is a self-report measure of participation in life roles, representing functioning at the societal level. The PART-O consists of 17 items that yield 3

domain scores (Productivity, Social Relations, and Out and About). Each domain score ranges from 0 to 5 (highest level of participation). In addition, there have been 2 scoring algorithms proposed for calculating a total score, the Averaged Total and the Balanced Total, both described in more detail in Bogner et al.[21] The Averaged Total score is computed by averaging the 3 domain scores and ranges from 0 to 5. The Balanced Total score subtracts the standard deviation of the participant's 3 domain scores from the participant's Average Total score. The Balanced Total score will usually be lower than the Averaged Total score except when there is no variability in the domain scores; the greater the variability across domains, the greater will be the difference between the Averaged Total score and the Balanced Total score. The Balanced Total score ranges from less than zero (for persons with low levels of participation) to 5 (for those participating at the highest level across all 3 domains). Both Average and Balanced Total scores as well as the 3 domain scores were examined in this study.

A Spanish language version of the PART-O is used for Spanish speakers in the TBIMS national database study. The initial translation of the PART-O was conducted by a translation service under contract by the TBIMS National Database and Statistical Center. This company also completed the back translation and certification of the Spanish language version. Subsequently, 2 bilingual TBIMS investigators reviewed the Spanish version to determine any needed tweaks in language for the TBI population. Any tweaks were conducted to preserve the intended meaning of the PART-O questions for the TBI population.

Independent variables

The primary independent variable for this study was the participant's primary language spoken at home (English or Spanish). The primary language variable is coded based on a participant's response to the question, "What is the primary language spoken in your home?" This question is asked during the participant's inpatient rehabilitation stay or at the first follow-up interview if the information was not obtained during the inpatient stay. Primary language is coded as English, Spanish, other language, refused, or unknown.

Demographic variables included age at injury, biological sex (or current sex if the person is transsexual), marital status at 1 year post-injury, highest level of education at 1 year post-injury, and productivity level at injury. Marital status was categorized as never married, married, or previously married [including separated (n = 63), divorced (n = 105), widowed (n = 37), and other (n = 3)]. Level of education was categorized as 8th grade or less, 9th to 11th grade, high school diploma or GED, and more than high school [including some college (n = 197), associate's degree (n = 55), bachelor's degree (n = 49), and doctoral degree (n = 7)]. Productivity level was dichotomized as productive [including competitively employed (n = 679), full-time (n = 65) and part-time (n = 7) students, and homemaker (n = 21)] and not productive [including retired (n = 110), unemployed (n = 100), volunteer (n = 5), and other (n = 8)].

Injury characteristics included number of days until emergence from PTA and the Functional Independence Measure (FIM) at 1 year post-injury. The number of days until emergence from PTA was only available for participants who emerged during inpatient rehabilitation.

For those participants who had not emerged by rehabilitation discharge, the total number of days in acute and rehabilitation care (+1) was used to impute missing data, as this is the minimum possible PTA they could have. The FIM is an 18-item scale assessing functional independence.[22] Scores for each item range from 1 (total assistance required) to 7 (complete independence), with higher scores denoting greater independence. Rasch analysis has yielded a cognitive factor (score range 5–35) and a motor factor (score range 13–91).[23,24] The FIM has high internal consistency, with the Cronbach α ranging from 0.86 to 0.97, and it is sensitive to change over time during recovery from TBI.[25,26]

Statistical analysis

All statistical analyses were conducted using SAS v.9.4 assuming a significance level of 5% unless otherwise noted. Demographic and injury characteristics were summarized by language group (Spanish-speaking vs English-speaking) using frequency counts and percentages for categorical variables and means and standard deviations for continuous variables. These characteristics were compared between the language groups using χ^2 tests and 2-sample t tests. As the distribution of PTA is known to be markedly skewed in the TBIMS national database, the median and interquartile range were used to describe central tendency and spread, and a Wilcoxon rank-sum test was used to compare the distributions of PTA between the language groups.

First, unadjusted comparisons in PART-O outcomes among the language groups were assessed using general linear models (GLMs). All demographic and injury characteristics were considered as relevant covariates and were selected a priori. Fully adjusted GLMs were then considered for each outcome and controlled for all participant characteristics (sex, marital status, education level at 1-year follow-up, productivity level at injury, age at injury, PTA, and FIM motor and cognitive scores at 1-year follow-up). Linear and quadratic effects were included for age, PTA, FIM motor, and FIM cognitive scores to allow for a nonlinear relationship between these covariates and outcome. Comparison in PART-O outcomes among the language groups was estimated as the mean difference in outcomes along with 95% CIs. Effect sizes (ESs) were calculated as the estimated differences divided by the model root mean square error. ESs of 0.2, 0.5, and 0.8 are typically interpreted to represent small, medium, and large differences between groups, respectively.

RESULTS

Sample characteristics

The total sample consisted of 998 Hispanic participants, with 51% indicating Spanish as their primary language and 49% indicating English as their primary language. The sample characteristics are summarized in Table 1 by language group. Participants were primarily male, never married, had at least a high school level of education, and were productive at injury. English- and Spanish-speaking participants were significantly different in terms of age, sex, marital status, and education level. Spanish-speaking participants were older, more likely to be male, married, and have lower levels of education as compared with English-speaking participants.

Comparison between the analytic sample (n = 998) and the sample excluded due to missing PART-O outcome data (n = 198) did not reveal any statistically significant differences in regard to age at injury (P = .32), sex (P = .92), preinjury productivity level (P = .37), or PTA days (P = .43). Follow-up characteristics (eg, marital status, education level, and FIM scores) were not compared between these groups, as most participants in the excluded sample (81%) did not complete a 1-year follow-up interview. There was a significant difference in primary language between the groups, with the included sample having higher rates of English-speaking participants than the excluded sample (49.3% vs 37.4%, P = .0021).

Unadjusted relationships between primary language and PART-O outcomes

The estimated unadjusted means and differences in PART-O outcomes between English- and Spanish-speaking participants are summarized in Table 2. Without controlling for any other variables, all PART-O outcomes were significantly higher for English-speaking participants than for Spanish-speaking participants (all P values $<$ .01). Unadjusted ESs were small for the Social (ES = 0.17) and Out and About (ES = 0.22) domains, and moderately small for the Productivity domain (ES = 0.29) and both the Average Total (ES = 0.29) and Balanced Total (ES range = 0.33) scores.

Adjusted relationships between primary language and PART-O outcomes

Supplemental Table S1 (available at: http://links.lww.com/JHTR/A419) summarizes the fully adjusted model details for each PART-O outcome, and Table 3 summarizes the adjusted comparisons in outcomes between the language groups. After controlling for the set of demographic and injury characteristics, significant differences were found between the language groups for the Social domain (ES = 0.14, P = .0461) and the Balanced Total score (ES = 0.15, P = .0361), with English-speaking participants having significantly higher scores than Spanish-speaking participants; however, the estimated ESs were small for both outcomes.

DISCUSSION

Hispanic individuals with TBI who identified English as their primary language had significantly higher levels of community participation compared with those who identified Spanish as their primary language. However, after controlling for demographic and injury characteristics, significant differences only remained for the Social Relations domain and the Balanced Total score of the PART-O. This highlights the effects of demographic and injury characteristics on aspects of community participation, particularly in the Out and About and Productivity domains of the PART-O. While the finding of significant difference in the summary score of the PART-O was mainly driven by differences in the Social Relations domain, the effect was only found for the Balanced Total score. This score corrects for variability across domains, indicating that there are differences between English and Spanish speakers in how they perform across participation domains. This variability may be masked by using the PART-O total score, which is the average score across 3 domains, but does not subtract out variability between domains.

The Social Relations domain of the PART-O includes frequency of engaging in activities with family and friends in person, over the phone, and via social media. It also includes information about close personal relationships in the life of the respondent. All of these may be influenced by cultural factors. Cultural factors may influence how Hispanics define, perceive, place meaning in, or experience social participation following TBI. For example, certain cultures may value in-person interactions over telephone or social media interactions. They may visit more with family members and friends in person, while spending less time on the phone or on social media. This may result in a lower score on the Social Integration domain of the PART-O, but this cannot necessarily be interpreted as meaning that participation, based on their own culture's values, is a problem that needs to be treated. Primary language may be acting as a proxy for the larger construct of acculturation. If this is the case, it might be postulated that higher levels of acculturation may be associated with more social participation after TBI. Interpretation of our results must consider not only the heterogeneity among Hispanics concerning race and nationality, but also shared cultural beliefs, such as adhering to traditional gender roles, collectivistic values, familial importance, and the role of religion.

Cultural environmental factors, not assessed in the current study, may also impact social integration of Spanish-speaking persons with TBI. Recent immigrants who have a majority of their friends and family residing in their country of origin experience greater challenges resulting from the effects of limited English proficiency on social participation with the majority culture. This effect can extend to the use of social media, which can be difficult for individuals with limited access to Spanish-language internet-based resources. Previous research showed lower social participation scores among individuals with TBI who were classified as non-internet users.[27] An important consideration is whether the Spanish-speaking Hispanics are separated from their family, which may be driving the differences found in the Social Relations domain. Someone could score 5 points less on the PART-O, if they are married but living separate from their spouse following immigration to the United States. Other cultural factors potentially influencing our results might include whether they live in ethnic enclaves,[18] their ability to communicate by phone or internet with family or friends, and length of time in the United States, which were not explored in this study.

The differences identified in the Social Relations domain may be due to measurement bias, due to PART-O items being developed based on the values of the dominant culture in the United States. Methodological and conceptual factors in measurement and cross-cultural validity should be considered when researching ethnic minority outcomes.[28] The Spanish version of the PART-O is a translation of the English language version rather than a cultural adaptation. The language differences identified could be due to differential item functioning, where there is not equivalence between the English and Spanish versions of the measure, instead of true language differences.[29,30] Spanish-speaking participants may be less likely to endorse participating in certain social activities as measured by the PART-O. In addition, the underlying construct may be different for Spanish-speaking Hispanics in comparison to English-speaking Hispanics. In a previous study, Hispanics placed different importance levels on certain community integration activities.[31] Another study showed that a well-known community integration measure, with items similar to the PART-O, lacked structural validity and cross-cultural validity among Hispanics,[32] suggesting that aspects of

community integration, such as social participation, were conceptualized differently. Future research should consider the role that cultural factors play in the conceptualization of participation following TBI. Use of patient-centered outcome approaches conducted with differentially acculturated groups would be one way to approach development of more culturally valid measures of participation. Use of Rasch analysis to investigate differential item functioning of PART-O items for English- and Spanish-speaking Hispanics could be beneficial.

This is a study of people who received inpatient rehabilitation. It is not known whether these results generalize for individuals with TBI who do not receive inpatient rehabilitation, such as those with mild TBI only treated in the emergency department, or those who were deemed to be too impaired to benefit from inpatient rehabilitation. Analyses were limited to those variables collected for the TBI Model Systems dataset, and thus, other variables that may be related to primary language and also impact participation, such as family structure, rural versus urban environment, and quality of education, were unavailable to be studied. Persons from the TBIMS database who were excluded from analysis due to missing participation data were more likely to be Spanish-speaking; therefore, the Spanish speakers included in the analysis may not be representative of the larger population of Spanish-speaking Hispanics with TBI. The PART-O is an objective measure of participation; a way to assess satisfaction with the level of participation (whether high or low on the PART-O) is needed. This entire body of research should also be extended to other cultural/racial groups.

CONCLUSION

While there are many unanswered questions, rehabilitation in the inpatient and outpatient settings can take these results into consideration when designing discharge plans and providing follow-up services. Ensuring that support and educational materials are in Spanish is a first step, as is providing staff members that speak Spanish to serve as primary point people for contact. In addition, involving the family and extended community of the Hispanic individual who primarily speaks Spanish in the home in the rehabilitation and community integration process may mitigate the low objective levels of social support and maximize participation.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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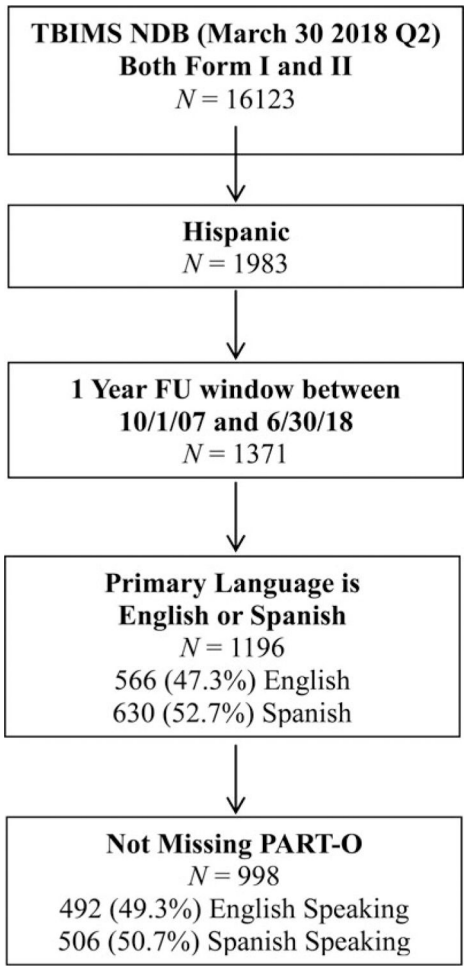

Figure 1.
Sample flowchart.

Table 1

Sample characteristics by primary language group

	English (*n* = 492) *n* (%)	Spanish (*n* = 506) *n* (%)	*P* value
Sex			.0032
Female	133 (27.0)	97 (19.2)	
Male	359 (73.0)	409 (80.8)	
Marital status at 1-y FU			<.0001
Never married	298 (60.6)	233 (46.1)	
Married	101 (20.5)	157 (31.1)	
Previously married	93 (18.9)	115 (22.8)	
[Missing]	[0] (…)	[1] (…)	
Education level at 1-y FU			<.0001
≤8th grade	21 (4.3)	136 (27.0)	
9th to 11th grade	98 (19.9)	110 (21.8)	
HS/GED	152 (30.9)	158 (31.4)	
More than HS/GED	221 (44.9)	100 (19.8)	
[Missing]	[0] (…)	[2] (…)	
Productivity level at injury			.2213
Productive	389 (79.2)	383 (76.0)	
Not productive	102 (20.8)	121 (24.0)	
[Missing]	[1]	[2]	
	Mean (SD)	**Mean (SD)**	
Age at injury	33.7 (15.9)	40.8 (19.0)	<.0001
PTA[a]	24.0 (10, 45)	28.0 (12, 46)	.2566
FIM cognitive at 1-y FU	29.8 (5.8)	29.5 (6.4)	.3661
FIM motor at 1-y FU	81.8 (16.6)	79.7 (17.3)	.0533

Abbreviations: FIM, Functional Independence Measure; FU, follow-up; GED, General Educational Development; HS, high school; PTA, posttraumatic amnesia.

[a]Median, interquartile rage (IQR), and *P* value from the Wilcoxon rank-sum test reported.

Table 2

Unadjusted relationship between primary language and PART-O outcomes

			Comparison (English/Spanish)			
	English Mean (SD)	**Spanish Mean (SD)**	**Difference**	**SE (95% CI)**	***P* value**	**ES[a]**
Productivity	1.19 (1.02)	0.90 (0.92)	0.28	0.061 (0.16, 0.41)	<.0001	0.294
Social Relations	2.12 (1.00)	1.90 (1.01)	0.22	0.064 (0.09, 0.34)	.0007	0.216
Out and About	1.52 (0.84)	1.38 (0.77)	0.14	0.051 (0.04, 0.24)	.0065	0.173
Averaged Total	1.61 (0.77)	1.40 (0.68)	0.21	0.046 (0.12, 0.30)	<.0001	0.294
Balanced Total	0.87 (0.79)	0.62 (0.70)	0.25	0.047 (0.15, 0.34)	<.0001	0.332

Abbreviations: ES, effect size; PART-O, Participation Assessment with Recombined Tools-Objective.

[a]Effect size computed as the mean difference divided by the model root mean square error.

Table 3

adjusted relationship between language group and PART-O outcomes

	Comparison (English/Spanish)			
PART-O outcome	**Difference**	**SE (95% CI)**	***P* value**	**ES[a]**
Productivity	0.074	0.054 (−0.032, 0.180)	.1691	0.099
Social Relations	0.117	0.058 (0.002, 0.231)	.0461	0.144
Out and About	0.006	0.050 (−0.092, 0.103)	.9115	0.008
Averaged Total	0.065	0.039 (−0.011, 0.142)	.0918	0.122
Balanced Total	0.088	0.042 (0.006, 0.170)	.0361	0.152

Abbreviations: ES, effect size; PART-O, Participation Assessment with Recombined Tools-Objective.

[a]Effect size computed as the mean difference divided by the model root mean square error; models adjusted for sex, marital status, education level at 1-year follow-up, productivity level at injury, age at injury, posttraumatic amnesia, and FIM motor and cognitive scores at 1-year follow-up.