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Availability of Outpatient Rehabilitation Services and Barriers to Care for Vulnerable Populations after Pediatric Traumatic Brain Injury

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Abstract

Objective—To explore associations between English proficiency, insurance status, outpatient rehabilitation service availability and travel time for children with traumatic brain injury (TBI).

Design—We used an ecologic cross-sectional design. Data were analyzed from a cohort of 82 children with moderate to severe TBI and rehabilitation providers in Washington State. Main measures included availability and travel time to services.

Results—Fewer than 20% of providers accepted children with Medicaid and provided language interpretation. Mental health services were most limited. Adjusted for median household income, multilingual service availability was lowest in counties with greater language diversity; for every 10% increase in persons >5 years old speaking a language other than English at home, there was a 34% decrease in availability of multilingual services (PR=0.66; 95%; CI:0.48-0.90). Adjusted for education and Medicaid status, children from Spanish-speaking families had significantly longer travel times to services (mean=16 additional minutes to mental health; 9 to other therapies).

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Conclusions—Children in households with limited English proficiency and Medicaid faced significant barriers in availability and proximity of outpatient rehabilitation services. Innovative service strategies are needed to equitably improve availability of rehabilitation for children with TBI. Similar studies in other regions will inform our understanding of the scope of these disparities.

Keywords

Brain injuries; Rehabilitation; Healthcare Disparities; Healthcare Accessibility; Hispanic children; disability

INTRODUCTION

Rehabilitation services can significantly improve functional outcomes after traumatic brain injury (TBI) and constitute the standard of care for treatment of physical, cognitive and behavioral impairments resulting in disability.¹ Most short- and long-term rehabilitation care is provided by community-based outpatient providers. Prior studies, mainly in adult populations, have described important racial and ethnic disparities in access to acute and inpatient rehabilitation services.^{2,3,4,5} One pediatric study described higher unmet health care needs after TBI for non-white children and those with Medicaid insurance.⁶ In addition, studies documenting outcomes after TBI have found that Hispanic and Spanish-speaking adults with TBI have poorer functional outcomes compared to non-Hispanic Whites (NHW).^{7,8} Among Hispanic children with TBI, disparities in long-term disability have also been identified.⁹ Relative to NHW children, Hispanic children experience lower levels of functioning 3 years after injury and significantly less improvement in health related quality of life, participation in activities, and ability to communicate and care for themselves.⁹

To date, the differential availability and proximity of recommended pediatric outpatient rehabilitation services by insurance status and English proficiency remain unknown. We explored potential disparities and barriers in the availability and geographic proximity of rehabilitation services for vulnerable children. We assessed the availability of outpatient rehabilitation providers and services for children with TBI, stratified by type of insurance accepted and whether multilingual services were offered. We also examined associations between county-level demographic characteristics and number of multilingual services, and we compared average travel time to rehabilitation services for families with English proficiency and Spanish-speaking families with limited English proficiency (LEP), adjusting for insurance type and parental education for an historical cohort of children with TBI. We hypothesized that fewer services would be available to children with Medicaid insurance and those requiring services in a language other than English, and that families with LEP will have longer travel times to community rehabilitation services.

METHODS

Setting and Study Population

Pediatric Outpatient Rehabilitation Providers and Services—Using a pre-existing administrative database from the Brain Injury Alliance of Washington (BIAWA) enriched

with information from hospital rehabilitation services, we created a comprehensive statewide database of pediatric providers and services in Washington State. The database is accessible via BIAWA staff to those who utilize their Resource Management services or call the Washington TBI Resource Line. An abbreviated version of the database is also freely accessible to the public via the BIAWA website at <http://biawa.org/resources.php>. The database is funded through a combination of state funds and private donations to BIAWA. It was created in 2011 and is maintained and updated by staff on an ongoing basis. Each resource in the database has been investigated by BIAWA staff for applicability and appropriateness to TBI patients; before any new resource is added, staff contact the resource directly in order to understand services offered. For this study, a service provider was defined as any health provider who offered direct rehabilitation services to children. Additionally, we classified each service provider under five major rehabilitation service categories: mental health services, physical therapy, occupational therapy, speech/language therapy and cognitive therapy.

To compile the comprehensive database we cross-referenced and incorporated the rehabilitation lists from the University of Washington and Seattle Children's Hospital with the BIAWA database. The rehabilitation resource lists from the University of Washington and Seattle Children's Hospital were obtained from the rehabilitation departments at each hospital. These lists are internally maintained by the rehabilitation departments. To further ensure accuracy and comprehensiveness of the final provider and service database, each health care facility participating in the statewide regional trauma network was contacted by telephone and asked about rehabilitation services in their catchment area. These service providers were contacted by a research assistant from June-August 2013. She called the health care providers and utilized an interview script to inquire about availability of the services of interest in the study. Typically, if it was a facility, the research assistant spoke with a representative of the rehabilitation department. A master list of providers was created using all of these sources.

Every rehabilitation provider on the master list was contacted by telephone, using a script with specific questions about types of services offered, acceptance of Medicaid insurance, availability of interpretation for non-English speaking families and families with LEP, and other facilities in the area that provide similar services.

Pediatric Patient Population—To explore potential geographic disparities in the availability of rehabilitation services by insurance and language status, we compared travel time to available rehabilitation services for children with moderate to severe TBI who were participants in the Child Health After Injury (CHAI) study. Details of the cohort and study procedures have been described in prior reports.¹⁰⁻¹³ Briefly, the CHAI study consisted of a prospective cohort of children aged 0-17 years with TBI recruited between March 1, 2007, and September 30, 2008 treated at hospitals in King County Washington and Philadelphia County, PA. TBI was defined using the Centers for Disease Control and Prevention (CDC) definition¹⁴ and injuries were classified as mild, moderate and severe based on CDC¹⁵ and World Health Organization definitions.¹⁶ Unique to this cohort was that additional efforts were made to recruit Spanish-speaking families. Participants' parents were asked about English proficiency and when needed a bilingual research coordinator conducted interviews

in Spanish. For the present study, we restricted the cohort to residents of Washington State treated at Harborview Medical Center, a level 1 hospital and excluded patients with mild TBI (defined as normal GCS by 24 hours after injury) because those patients rarely needed long-term rehabilitation services. As the only level I pediatric and adult trauma center in Washington, Harborview Medical Center treats patients with moderate and severe TBI referred from across the state.

Statistical Analysis

Provider and Service Availability—Rehabilitation services were grouped into three categories for analysis: 1) physical and occupational therapy, 2) speech, language and cognitive therapy, and 3) mental health. Statewide service availability was described. Provider addresses were then used to map the distribution of pediatric service providers across the state. For each service type, we generated maps to indicate the locations of the following: 1) pediatric providers, 2) pediatric providers accepting Medicaid, 3) pediatric providers offering language interpretation and 4) pediatric providers accepting Medicaid and offering interpretation. Maps were generated using ArcGIS Explorer Online, Redlands, CA.

Availability of Multilingual Services by County Characteristics—We examined the association between language need and availability of rehabilitation services in each county. Negative binomial regressions models with robust standard errors were used to calculate prevalence ratios (PR) and confidence intervals (CI) for the association between the number of multilingual pediatric services offered (main outcome) and the percentage of LEP persons (main exposure) at the county level. For this analysis, LEP persons were defined as the percentage of persons >5 years old speaking a language other than English in the home; these data are compiled by the US Census Bureau, American Community Survey and attempt to capture those who are fluent in another language and regularly use it at home and excludes persons who are not fluent or do not routinely use another language.¹⁷ Because it was the best measure currently available by county, we used it to define LEP for this analysis. We also examined univariate associations between the number of multilingual pediatric services offered and selected county-level covariates of interest including median household income, percentage of persons living below poverty level, percentage of persons with educational attainment of high school or higher and region of state broken down into four major regions. A multivariate model was constructed to control for covariates associated with the number of multilingual pediatric services. Negative binomial regression was employed due to overdispersion in the distribution of data. The total population of individuals younger than 18 years of age in each county was used as an offset term in the analyses. Data for Washington State counties was compiled from the United States Census Bureau, State and County Quick Facts.¹⁷ Analysis was conducted using STATA (College Station, TX).

Pediatric Patients and Travel Time to Nearest Rehabilitation Service—For the cohort of children with moderate to severe TBI, we estimated average travel times for each patient to the nearest provider using the Google Distance Matrix API.¹⁸ For a matrix of origin and destination addresses, the Google Distance Matrix application program interface (API) allows users to estimate travel distance and travel time. We identified the closest

provider for each service type who met each patient's specific insurance and language needs. For each type of service we tested a linear regression model of travel time on parental language. We adjusted for child's age, child's sex, education of parent, household income and Medicaid status. Household income and Medicaid status were significantly correlated ($r=.42$, $p<0.001$). Because our main variable of interest was insurance status, we removed household income from the model and presented those results in Table 4 (R-squared mental health=0.075; PT/OT=0.114; Speech/Language/Cognitive Therapy=0.100). When we included household income in place of insurance status in a sensitivity analysis, results were unchanged (R-squared mental health=0.065; PT/OT=0.127; Speech/Language/Cognitive Therapy=0.119). We also assessed the interaction between Spanish speaking parent and Medicaid status, but the interaction was not statistically significant.

Human subjects review: This study was approved by the Human Subjects Division at the University of Washington.

RESULTS

Provider and Service Availability

We initially identified 257 direct pediatric TBI service providers with a physical address who offered services in the three major categories. After cross referencing with the rehabilitation service lists from large regional hospitals and conducting targeted calling to rehabilitation providers across the state, a small number of additional pediatric providers (N=36) were identified. The final database contained 293 service providers offering 385 pediatric services in the three major service categories.

Overall, only 46% of providers reported they accepted children with Medicaid insurance. Children with Medicaid insurance had fewer number of rehabilitation services available, relative to children with private insurance (207 vs 385) (Table 1). In each rehabilitation category, there were fewer services for children whose families needed language interpretation. Mental health services for children represented more than half of all of the services available to children in the rehabilitation database. However, only 8% of mental health rehabilitation services were available to children with Medicaid who also needed language services. Less than half of the physical and occupational services in the database accepted children with Medicaid insurance and were able to provide language services. A similar trend was noted for speech, language and cognitive therapy. In total, less than 20% of all service providers accepted children with Medicaid insurance and were able to provide language services.

There was regional imbalance in provider availability. Most service providers were located in urban areas in the northwest region of the state (Figure 2) and there were relatively few providers in central, southern and eastern Washington.

Availability of Multilingual Services by County Characteristics

The percentage of persons >5 years old speaking a language other than English at home, or those with LEP, living in each county ranged from 3% to 50%. In univariate analysis at the county level, for every 10% increase in percentage of persons speaking a language other

than English at home, there was a 40% decrease in the number of multilingual services in the county (Table 2). The only covariate of interest significantly associated with the number of multilingual services was median household income. After adjusting for median household income, the proportion of persons with LEP in each county remained significantly associated with the number of multilingual pediatric services (PR = 0.66; 95% CI: 0.48, 0.90; per 10% difference in percentage of persons with LEP).

Pediatric Patients and Travel Time to Nearest Rehabilitation Service

The initial cohort of children with TBI from the CHAI study had a total of 690 patients who were residents of Washington State. We excluded 604 patients with mild TBI, 3 patients with out-of-state addresses and 1 patient seen at a level 3 or 4 hospital because these centers typically see lower acuity patients. A total of 82 children with moderate or severe TBI remained in the sample (Table 3). Most children were male. There was a broad age range and 20% of the sample was Hispanic. A large percentage had Medicaid insurance (40%), and 16% of the children had a documented Spanish-speaking parent with LEP.

Average travel time to the closest rehabilitation provider was significantly longer across all service types for children in the cohort with Spanish-speaking parents relative to the children with English speaking parents (Table 4). Adjusting for age, sex, parental education and Medicaid insurance status, Spanish speaking parents needed to drive an average of 16.4 (CI: 2.0, 30.9) additional minutes to reach the nearest mental health service provider, and had to drive 9.2 (CI: 3.2, 15.2) additional minutes to reach physical, occupational therapy and 9.4 (CI: 3.3, 15.5) additional minutes to speech/language or cognitive therapy.

DISCUSSION

This study was the first to examine the availability and proximity of outpatient rehabilitation services after TBI for children with different language needs and insurance types. We found that less than a 20% of all the rehabilitation providers in the statewide database accepted children with Medicaid and provided language services. Service availability was extremely limited in the mental health service category. Even after adjusting for parental education and Medicaid status, Spanish-speaking families consistently had longer travel times to reach the nearest rehabilitation service compared to English speaking families. Further, those counties with the highest proportion of children in households with LEP had the lowest availability of multilingual rehabilitation services. These findings highlight limitation in the availability of TBI rehabilitation services for families with LEP. These findings are particularly concerning in the context of the increasing diversity of children and families: individuals > 5years old speaking a language other than English at home represented 18.2% of the state population in 2012¹⁷ and 48% of children under 18 had Medicaid insurance in Washington State in 2011.¹⁹

Our study of barriers to pediatric rehabilitation access is consistent with findings from adult studies that demonstrated lower access to post-acute inpatient rehabilitation for uninsured patients⁶ and for racial and ethnic minority patients.^{2,4} Patterns in availability of pediatric outpatient rehabilitation for Spanish speakers and others with LEP are particularly challenging. Other studies have documented that non-English speaking status adversely

affects access to care for Latinos in the United States²⁰ and that, for children, parental LEP results in greater odds of children not receiving needed medical care.²¹ Studies have documented the negative impact of language barriers on not only access to care but quality of care.²² Access to rehabilitation for children with TBI is important because an association between access and better outcomes has been noted in adult patients²³ and rehabilitation services are recommended for patients to achieve maximum improvements in physical, cognitive and behavioral functioning after TBI.¹

While this study explored differences in the availability of services, disparities in functional outcomes following TBI have been documented for children from Spanish-speaking families.⁸ It is likely that limited availability of services is at least a partial explanation for the disparities noted in long-term functional outcomes for Hispanic children with TBI. Our findings also suggest that children from poor families with LEP, the majority of whom receive Medicaid insurance have fewer options for rehabilitation care. These inequities may be greater than our study indicates, as even providers who nominally accept Medicaid reimbursement may routinely limit the number of children with Medicaid insurance they will accept, citing lower Medicaid reimbursement rates.²⁴ Future research and intervention studies are needed to eliminate health disparities reflected in low outpatient rehabilitation utilization rates and outcomes among poor children with LEP and TBI. Research in other states using similar methodology as in the present study will also further define the scope of disparities noted here. In addition, the intersectionality of race, language, insurance status, location and other factors has important public health and policy implications. Understanding the influence of these intersecting identities on availability and access to care at both the individual and population levels is complex. The impact of discrimination on health is difficult to measure and likely underestimated in public health research.²⁵ Using the social justice frame embedded in intersectionality theory allows for a method to begin to unpack the complexity of the human and societal factors that impact health outcomes after TBI,²⁶ and incorporating the theory into ongoing research has the potential to increase health equity.²⁷ This study identified disparities by insurance status and language; future studies should focus on other important and multiplicative identities and processes that impact health outcomes for these patients. Of particular interest for future study is the impact of the legal status of patients and family members on access to care given the exclusion of undocumented immigrants from medical coverage under the Affordable Care Act.²⁸

Other important areas for further study include methods to assist providers to recognize rehabilitation needs and make referrals and linkages to services. Studies have found that adult trauma patients are less likely to be referred to rehabilitation services compared to stroke patients.²⁹ Focusing on successful communication and health education strategies at discharge, especially for families with LEP who require interpretation services, is particularly important. Despite regulatory requirements that health care settings provide access to language services at no cost,^{30,31} recent studies of pediatricians demonstrate that many report routinely using non-professional interpreters such as family members.^{9, 32-35} Evidence-based standardization of care transitions from acute care to outpatient rehabilitation for moderate to severely injured children with TBI will be important to address service inequalities. Understanding cultural needs and potential barriers to service

access are also important next steps. Providers and health care settings need a strong commitment to providing no-cost professional interpretation services for all encounters. Telephonic interpretation is widely available, especially for scheduled visits such as rehabilitation. Expanding the use of these services as well as using creative telemedicine models to reach families in remote locations will assist disadvantaged families to benefit from services. Such efforts have begun and shown promising results, including an online problem solving intervention to address executive dysfunction in adolescents with TBI,^{36,37} and an online positive parenting skills intervention for families of children with TBI.³⁸ Such programs lay the foundation for a healthcare system that addresses some of the multiple barriers to care access for vulnerable groups; expansion of these to include language and culturally adapted programs for families is a next step. Sustainable strategies to address the financial and practical barriers to access and utilization are needed. Finally, while TBI has been recognized since 1990 as an educational disability, previous reports indicated that the vast majority of students with TBI-related disability were not enrolled in special education and thus not receiving needed services in school.^{39,40} Future studies should examine strategies to enhance access to outpatient as well as access to school-based rehabilitation services. Within all of these efforts, reporting TBI outcomes by race/ethnicity and socioeconomic data can identify disparities that can and should be mitigated.

Study Limitations

The study had a number of limitations. While we took steps to ensure the comprehensiveness of our database of outpatient rehabilitation services, it is possible that some providers were not included if they were not listed in publicly available sources or were not referral sources for other regional hospitals and rehabilitation providers in the state. In addition, we did not include school-based services in our analysis as these services are complimentary to the community-based rehabilitation services that were the focus of this study. The information on language services and acceptance of Medicaid was self-reported by providers. In addition, the patient sample used to determine distance to services was small, impacting the analytic power to identify potential disparities in availability of care and assess potential impact of interaction between language and Medicaid status. Nonetheless, our analysis by county supports the findings of disparities for poor and LEP patients. We only included patients with moderate and severe TBI, who are typically more likely to require outpatient rehabilitation therapy. We examined availability of services for these children, but were not able to prospectively measure utilization and link these to functional outcomes. For the county-level analysis, there are likely residual confounders not accounted for in the model such as race and types of employment available. This study was conducted in Washington State; generalizability to other states is unclear. Further research is needed to confirm and expand upon our results.

Conclusions

Children with TBI and ongoing rehabilitation needs faced significant inequalities in the availability and geographic proximity of rehabilitation services. These barriers were highest for poor children with Medicaid insurance whose families had LEP. The existence of significant structural and financial barriers to outpatient rehabilitation services, including providers who refuse to provide care for children with Medicaid insurance or do not offer

language services to families with LEP, requires attention from policy makers and practitioners. Further research utilizing similar methodology in other regions of the country are needed in order to understand the scope of the disparities noted here; research is also needed to examine the direct relationship between outpatient rehabilitation availability and utilization rates and outcomes among children with TBI.

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Figure 1.
Pediatric Rehabilitation Providers, Medicaid Acceptance and Language Interpretation Services

Figure 2.
Provider location in WA State by insurance status and language service

Table 1

Availability of statewide rehabilitation services for children, by insurance status and language service

	All services accepting children	Accept Children & Medicaid	Accept Children, with Language Services	Accept Children & Medicaid, with Language Services
Mental Health, n (%)	210 (100)	77 (37)	19 (9)	16 (8)
Physical and occupational therapy, n (%)	92 (100)	64 (70)	38 (41)	38 (41)
Speech / language / cognitive therapy, n (%)	83 (100)	66 (80)	43 (52)	40 (48)
Total pediatric rehabilitation Services, n (%)	385 (100)	207 (54)	100 (26)	94 (24)
Total providers *	293 (100)	135 (46)	61 (21)	55 (19)

*
Providers could offer more than one service.

Table 2

Univariate associations between measured county-level characteristics and number of multilingual pediatric services

Characteristic	PR	95% CI
Percentage of persons using a language other than English in the home (per 10% difference)	0.60	0.43, 0.90
Median household income (per \$1,000 difference)	0.95	0.93, 0.97
Percentage of persons living below the poverty level (per 1% difference)	1.00	0.90, 1.11
Percentage of persons with educational attainment of high school or higher (per 1% difference)	1.05	0.99, 1.12
Region of state		
East	0.86	0.17, 4.24
Northwest	0.42	0.11, 1.54
Central	1.00	Referent
South	0.46	0.12, 1.72

PR: prevalence ratio; CI: confidence interval

Significant results ($p < .05$) are in **bold**.

Table 3**Characteristics of Study Sample**

<i>N</i>	82
Male, n (%)	58 (71)
Age at time of injury	
Range, years	0 to 17
Mean, years (S.D.)	10 (6)
Family-reported race/ethnicity, n (%)	
Asian	3 (4)
Black	4 (5)
Hispanic	16 (20)
White	21 (26)
Other	38 (46)
Medicaid insured, n (%)	33 (40)
Spanish Speaking Parent, n (%)	13 (16)
Household income, n (%)	
< \$30k	29 (35)
\$30k to \$60k	25 (30)
Over \$60k	26 (32)
No response	2 (2)
Education of Parent, n (%)	
High school or less	39 (48)
Some college or associates degree	29 (35)
Bachelors degree or higher	14 (17)

Association between parental language and estimated travel time in minutes to the closest service provider

Table 4

	Mental Health				Physical/occupational therapy				Speech / language/cognitive therapy			
	Coefficient	95% CI	F	p	Coefficient	95% CI	F	p	Coefficient	95% CI	F	p
Constant	16.3	1.6-31.1			17.6	11.5, 23.7			17.6	11.4, 23.8		
Age	<-.1	-.1, .1	<.01	.99	<-.1	-.03-.02	.27	.60	<-.1	-.04, .02	.42	.52
Male	1.5	-9.6, 12.6	.08	.78	1.2	-3.4, 5.8	.27	.60	1.5	-3.1, 6.2	.42	.52
Education of parent			.23	.80			.92	.40			.58	.56
High school or less (Ref) [*]	-	-			-	-			-	-		
Some college, associates	-3.4	-15.1, 8.3			-1.2	-6.0, 3.7			-1.1	-6.1, 3.8		
Bachelors degree or higher	-4.1	-18.7, 10.4			-4.1	-10.2, 1.9			-3.3	-9.5, 2.8		
Medicaid	2.7	-7.8, 13.2	.26	.61	-3.1	-7.5, 1.3	2.0	.16	-3.4	-7.8, 1.0	2.4	.13
Spanish speaking parent	16.4	2.0, 30.9	5.2	.03	9.2	3.2, 15.2	9.3	<.01	9.4	3.3, 15.5	9.5	<.01
F (p-value) for overall model	1.6 (.16)				2.7 (.02)				2.6 (.02)			
R-squared	.11				.18				.17			

N=80 (2 excluded due to missing income data)

Significant results (p<.05) are in **bold**.^{*} Reference group