Neighborhood Deprivation and Ambulatory Function Among Children in the Cerebral Palsy Research Network Registry in Washington State

Deborah Grenard

A thesis
submitted in partial fulfillment of the
requirements for the degree of

Master of Public Health

University of Washington

2024

Committee:

Daniel Enquobahrie

Stephen Mooney

Program Authorized to Offer Degree:

Epidemiology

University of Washington

Abstract

Neighborhood Deprivation and Ambulatory Function Among Children in the Cerebral Palsy Research Network Registry in Washington State

Deborah Grenard

Chair of Supervisory Committee:

Daniel Enquobahrie

Department of Epidemiology

Objective This study investigated the association between neighborhood-level resources and ambulatory function among children enrolled in the Cerebral Palsy Research Network Registry at Seattle Children's Hospital.

Methods: A total of 1,242 children enrolled in the Cerebral Palsy Research Network (CPRN) clinical registry at Seattle Children's Hospital were included in the analysis. The exposure of interest was the Area Deprivation Index (ADI) associated with the patient's home address. The outcome was ambulatory function as determined by Gross Motor Functional System Classification (GMFCS): I-III ambulatory and IV-V non-ambulatory. Robust Poisson regression was used to calculate Relative Risks (RR) and corresponding 95% confidence intervals.

Results: Of the study population, 47% were female and 53% were identified as white. The regression analysis found that for each increase in ADI decile, the RR of not being ambulatory was 1.04 [1.01,

1.07], indicating a 40% increased risk between the most and least disadvantaged neighborhoods. The RR remained unchanged after adjusting for travel to care and preterm birth. In a sensitivity analysis limited to enrollees living in King County, WA, the RR was 1.07 [1.02, 1.12], indicating that this association is not likely related to distance to care or urbanicity.

Conclusion: Our findings demonstrate that ADI is associated with functional outcomes for persons with cerebral palsy. It highlights the need for further research on the influence of home community resources on functional outcomes in persons with cerebral palsy.

INTRODUCTION

Cerebral Palsy (CP) is the most common motor disability in childhood across the United States, with a reported prevalence ranging between 1.5 and 4 per 1,000 live births in the United States[1–3]. This disability is characterized by non-progressing brain injury that affects motor function, occurring early enough in childhood that it impacts typical development of motor skills (e.g., walking and sitting). The spectrum of physical independence experienced by persons with CP varies widely, from independently engaging in most activities to completely relying on others for their activities of daily living (ADL). Although the extent of physical independence often correlates with the severity and location of the initial brain injury in early life, there is variation in functional outcomes presumably due to brain neuroplasticity throughout childhood development [4].

Previous studies in populations outside of the United States (US) have identified associations of socio-economic factors with prevalence and functional outcomes for persons with CP. Studies conducted by Sung-Hui et al[5], Woolfenden et al[6], and Dolk et al[7] found associations between measures of socio-economic status (SES) and CP incidence as well as degree of motor impairment among children in Taiwan, Australia, and the United Kingdom, respectively. Notably, a meta-analysis by Solaski et al[8] found that associations between measures of SES and CP remained after adjusting for pre-term birth, low birth weight and postnatal trauma. Moreover, Solaski's analysis highlighted that community SES measures exhibited stronger associations with CP than individual SES measures. These findings suggest that the resources available within a person's home community can significantly shape a child's risk of developing CP, and their functional outcomes, beyond other risk factors. However, these observed associations remain unconfirmed for populations of children with CP in the US.

Area Deprivation Index (ADI) is a well-validated composite measure of socioeconomic disadvantage in the United States at the census block level. It is determined from 17 variables derived from census and American Community Survey (ACS) 5-year data. These variables address income, education, employment, and housing quality [9]. This measure has been used to identify associations between neighborhood disadvantage and several health outcomes and as a result, is now used for research to support policy and health intervention planning [10].

The Gross Motor Function Classification System (GMFCS) score is a 5-scale metric related to how independently a child moves within home and community settings adjusted for each developmental stage[11]. This scale is frequently referenced for clinical decisions and corresponds closely with the specific needs of caregivers and persons with CP.

In this study, we sought to investigate the association between neighborhood-level resources, as assessed by ADI, and ambulatory function among a cohort of children with CP who received care at a specialty care hospital in Washington state. Additionally, we sought to explore whether any such association remains statistically significant after considering gestational age at birth and known barriers (e.g., distance) to reaching healthcare services.

METHODS

Study Setting, Data Source, and Study Population

We utilized a local subset of the Seattle Children's Hospital (SCH) portion of the Cerebral Palsy Research Network's (CPRN) clinical registry [12]. SCH provides comprehensive specialty care across various medical sub-specialties to children throughout Washington State. CPRN is the largest CP-specific registry in the United States, capturing information about persons with CP as a part of their regular care across 32 medical centers. The inclusion of clinical data, such as the GMFCS score, makes this registry particularly helpful for addressing questions related to daily life impacts for persons with CP. SCH is the second largest enrolling site of the medical centers and data from the entire population of CP patients at SCH is included in the CPRN's registry.

The focus on a local subset was necessary because the CPRN did not include measures of location or SES at the time of data abstraction, making a whole registry analysis unfeasible. Enrollment in the registry is open to patients receiving any CP-related care, not limited to specific specialists, ensuring a more representative cohort of the CP population in Washington State. Additionally, SCH was able to calculate ADI for registry participants and facilitate data linkage.

At the time of data abstraction, 1,492 patients were enrolled in the Seattle CPRN clinical registry. Thirty were missing GMFCS levels, 221 were missing location information or lived outside of Washington State. Thus, our analytic population included 1,242 persons (83% of registry enrollees).

This project received approval from the University of Washington IRB with a waiver of consent.

Exposure

ADI was determined using the home mailing address on file in the medical record and ranked by the 2022 state deciles provided by Neighborhood Atlas.

Outcome

Ambulatory status was a dichotomous variable determined using the GMFCS level (range from I-V)[11]. Those with scores I – III, coded as ambulatory, can navigate much of their community without their wheelchair, though possibly with assistive devices such as walkers or crutches. On the other hand, those assigned IV or V were coded as non-ambulatory as they navigated their home and community in a wheelchair.

Other Covariates

Distance-to-care variables were created to categorize the travel-for-care challenges families experience when accessing CP specific care at SCH. This variable was defined based on the patient's home address and identified as one of three categories: within of the same county as the medical center (King County), outside of King County on the same side of the Cascade Mountains (Travel) or outside of King County and across the Cascade Mountains (Mountain Travel).

Preterm birth categories were calculated from gestational age at birth in weeks; term (37+ weeks), near term (35-36 weeks), moderately preterm (32-34 weeks), very preterm (28-32 weeks) and extremely preterm (<28 weeks).

Statistical Analyses

We described selected characteristics of study participants, stratified by ambulatory status, using numbers (and percentages) for categorical variables and means (and standard deviations) for continuous variables. To measure association between ADI and ambulatory function in this population, we employed Poisson linear regression models to estimate the Relative Risk (RR) (and corresponding 95% confidence intervals, CIs) relating ADI to ambulatory status. We chose Poisson models over logistic regression due to the outcome not being rare in this population, making odds ratios an unreliable approximation of the association. We fitted both unadjusted and adjusted (adjusted for distance traveled to care and preterm birth) models. In addition, in sensitivity analyses to assess the impact of urbanicity on the relationships, we repeated the analyses only among participants residing in King County.

All models were fit using R version 3.11.0 [13] and p-values less than .05 were considered significant.

RESULTS

The analytic cohort had a mean enrolment age of 8.45 years (SD 5.34). About 47% were not ambulatory, 53% were white, 20% were Hispanic and 42% were female (**Table 1**). These demographic distributions aligned closely with the characteristics of all patients seen at SCH: 47% female, 18% Hispanic, 51% white. Children in strata of functional status (ambulatory vs. non-ambulatory) differed significantly in ethnicity and current age.

The number (%) of participants in ADI decile groups stratified by ambulatory function are shown in **Table 2**. Overall, percentages of ambulatory participants in the lower ADI deciles were higher compared with similar percentages for participants who were non-ambulatory (e.g., 16.1% vs 11.6% of ambulatory and non-ambulatory participants, respectively, were in the first ADI decile group).

The unadjusted RR of being non-ambulatory per decile increase of ADI was 1.04 (95%CI: 1.01 - 1.07) (**Table 3**). The RR did not change when adjusting for distance or mountain travel for care (RR: 1.04; 95%CI: 1.01 - 1.07) or preterm birth (RR:1.04; 95%CI: 1.01 -1.07). In sensitivity analyses, a model fit to the subset of data from King County, where SCH is located, identified a RR of 1.07 (95%CI: 1.02 - 1.12; p-value=0.009). There was no change in RR when adjusting for preterm birth (RR: 1.07; 95%CI: 1.01 - 1.13). Since all participants of this subset were in the same county as the medical center, the travel to care adjustment was not applicable.

DISCUSSION

Our results suggest that children with CP residing in the most disadvantaged neighborhoods (highest ADI decile) in Washington have a significantly (40%) increased risk of being non-ambulatory compared to those in the least disadvantaged areas (lowest ADI decile). This association remained after adjustment for prematurity or distance traveled to care. A sensitivity analysis, looking only at those living within King County, found a RR consistent with the main analysis, suggesting that this association between neighborhood disadvantage and non-ambulatory status is not different between living in urban and rural areas.

Our findings are similar to previous studies in populations outside of the US that have demonstrated associations between socio-economic factors and functional outcomes for persons with CP. Particularly Woolfenden et al[6] who conducted a very similar analysis in Australia finding that children with CP in the lowest quintile of neighborhood SES were at a higher risk of being GMFCS level IV or V (RR: 1.2; 95%CI: 1.1 - 1.4) when compared to those living in neighborhoods in the highest quintile of SES.

These findings highlight the importance of understanding the patient's neighborhood context when making recommendations and identifying intervention and/or support needs for CP patients. Understanding this disproportionate risk is essential for public health and policy decisions, as well as informing health services planning. Our study underscores the need for further analysis of nationwide cohorts and the value of including non-identifying measures of SES in registry data to explore contextual associations of neighborhood or SES factors with health outcomes.

Future research should investigate whether the higher risk of being non-ambulatory in lower resource neighborhoods persists in other populations and identify which elements of area deprivation might be most impactful on ambulation for children with CP. For instance, exploring the influence of specific neighborhood factors on walking function could lead to targeted environmental and contextual interventions and potentially drive beneficial structural improvements.

Sampling from the largest regional specialty care pediatric hospital increased the likelihood that our study sample is representative of the Washington state population of children with CP. The use of a validated functional mobility metric (GMFCS) and updated census-based SES variable are additional strengths of the current study.

Although there are no indicators suggesting that this sample is not representative of children with CP in Washington State, it did not include all children with CP in the state. Additionally, the individual elements of ADI are not standardized in relation to each other, with scores potentially more influenced by median home values and income. The ADI may therefore be less multi-dimensional than previously understood, potentially leading to poor differentiation of area resource levels, particularly in metropolitan areas. Despite this, the relationship remained consistent throughout the population, especially in metropolitan areas around the medical center.

CP affects nearly one million people in the United States, with an incidence of ranging between 1.5 and 4 per 1,000 children. Identifying communities at higher risk of significant functional difficulties can inform public policy on social safety nets and public services and improve the implementation of public health programs and interventions. These findings can also aid clinical institutions in resource

allocation, particularly for early childhood support. These findings highlight the notable effect that community resource has on the functional levels of children with CP. It is imperative that this information be considered in both clinical and public health practice as well as in future research.

Table 1 Characteristics of Participants Stratified by ambulatory Status

Characteristic	**Ambulatory** n = 658 **n (%)**	**Non - Ambulatory** n = 584 **n (%)**
Female	270 (41.0%)	250 (42.8%)
Race		
Hispanic *	121 (18.4%)	131 (22.4%)
Race		
American Indian or Alaska Native	8 (1.2%)	7 (1.2%)
Asian	48 (7.3%)	41 (7.0%)
Black or African American	40 (6.1%)	43 (7.4%)
Native Hawaiian or Other Pacific Islander	6 (0.9%)	20 (3.4%)
White	380(57.8%)	283 (48.5%)
Multi-Racial	32 (4.9%)	36 (6.2%)
Unknown	144 (21.9%)	154 (26.4%)
Preterm Status		
Term (37+= weeks)	327 (49.7%)	304 (52.1%)
Near term (35-36 weeks)	59 (9.0%)	45 (7.7%)
Moderately Preterm (28-32 week)	68 (10.3%)	54 (9.2%)
Very Preterm (28-32 weeks)	77 (11.7%)	55 (9.4%)
Extremely preterm (<28 weeks)	90 (13.7%)	90 (15.4%)
Missing	37 (5.6%)	36 (6.2%)
Travel Barrier to Care		
King County	271 (41.2%)	229 (39.2%)
Distance only	214 (32.5%)	180 (30.8%)
Mountains and Distance	173 (26.3%	175 (30.0%)
Age* (Mean(SD))	7.86 (4.95)	9.35 (5.56)

* indicates significant difference between groups (p-value<0.05)

Table 2: ADI deciles stratified by ambulatory Function

State ADI Decile *P test = 0.007*	**Ambulatory** (n = 658)	**Non Ambulatory** (n = 584)
1	106 (16.1%)	75 (11.6%)
2	69 (10.6%)	58 (9.9%)
3	93 (12.5%)	68 (11.6%)
4	80 (11.1%)	59 (10.1%)
5	64 (8.8%)	65 (11.1%)
6	57 (7.9%)	66 (11.3%)
7	59 (8.4%)	57 (9.8%)
8	47 (7.1%)	53 (9.1%)
9	51 (7.8%)	35 (6.0%)
10	31 (4.7%)	54 (9.2%)
NA	1(0.2%)	1(0.2%)

Table 3: Relative Risk Estimates from Regression Models for Non-Ambulation per ADI decile

Poisson Regression Model ADI ~ Ambulatory Status	Relative Risk Estimate	95% Confidence Interval
Unadjusted	1.036	1.008 - 1.065
Adjusted for Travel for Care	1.040	1.005 - 1.077
Adjusted for Preterm Status	1.038	1.009 - 1.068
King County Unadjusted	1.070	1.015 - 1.123
King County adjusted for preterm status	1.066	1.008 - 1.125

References

1. Zablotsky B, Black LI, Maenner MJ, et al. Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*. 2019;144(4). doi:10.1542/peds.2019-0811

2. Boyle CA, Boulet S, Schieve LA, et al. Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics*. 2011;127(6):1034-1042. doi:10.1542/peds.2010-2989

3. Kirby RS, Wingate MS, Van Naarden Braun K, et al. Prevalence and functioning of children with cerebral palsy in four areas of the United States in 2006: A report from the Autism and Developmental Disabilities Monitoring Network. *Res Dev Disabil*. 2011;32(2):462-469. doi:10.1016/j.ridd.2010.12.042

4. Hilderley, A. J., Wright, F. V., Taylor, M. J., Chen, J. L., & Fehlings, D. (2023). Functional Neuroplasticity and Motor Skill Change Following Gross Motor Interventions for Children With Diplegic Cerebral Palsy. *Neurorehabilitation and Neural Repair*, *37*(1), 16–26. https://doi.org/10.1177/15459683221143503

5. Tseng SH, Lee JY, Chou YL, Sheu ML, Lee YW. Association between socioeconomic status and cerebral palsy. *PLoS One*. 2018;13(1). doi:10.1371/journal.pone.0191724

6. Woolfenden S, Galea C, Smithers-Sheedy H, et al. Impact of social disadvantage on cerebral palsy severity. *Dev Med Child Neurol*. 2019;61(5):586-592. doi:10.1111/dmcn.14026

7. Dolk H, Pattenden S, Bonellie S, et al. Socio-economic inequalities in cerebral palsy prevalence in the United Kingdom: A register-based study. *Paediatr Perinat Epidemiol*. 2010;24(2):149-155. doi:10.1111/j.1365-3016.2009.01083.x

8. Solaski M, Majnemer A, Oskoui M. Contribution of socio-economic status on the prevalence of cerebral palsy: A systematic search and review. *Dev Med Child Neurol*. 2014;56(11):1043-1051. doi:10.1111/dmcn.12456

9. Kind AJH, Buckingham WR. Making Neighborhood-Disadvantage Metrics Accessible — The Neighborhood Atlas. *N Engl J Med*. 2018;378(26):2456-2458. doi:10.1056/NEJMP1802313

10. Powell, W. R., Sheehy, A. M., & Kind, A. J. H. (2023). The Area Deprivation Index Is The Most Scientifically Validated Social Exposome Tool Available For Policies Advancing Health Equity. In *Health Affairs Forefront*. https://www.healthaffairs.org/do/10.1377/forefront.20230714.676093/full/

11. Silva, D. B. R., Pfeifer, L. I., & Funayama, C. A. R. (2013). Gross motor function classification system expanded & revised (GMFCS E & R): Reliability between therapists and parents in

Brazil. *Brazilian Journal of Physical Therapy*, *17*(5). https://doi.org/10.1590/S1413-35552012005000113

12. Gross P, Gannotti M, Bailes A, et al. Cerebral Palsy Research Network Clinical Registry: Methodology and Baseline Report. *Arch Rehabil Res Clin Transl*. 2020;2(3):100054. doi:10.1016/j.arrct.2020.100054

13. R Core Team (2023). _R: A Language and Environment for Statistical Computing_. R Foundation for Statistical Computing, Vienna, Austria. <https://www.R-project.org/>.