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Racial/Ethnic and Insurance Status Disparities in Distance Travelled to Access Children's Hospital Care for Severe Illness: The Case of Children with Leukodystrophies

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Abstract

Families of children with special health care needs may travel substantial distances to access specialized healthcare. However, it is not known how race/ethnicity, insurance status, and access to disease-specific specialty care affect travel distances. This analysis examines patients aged 18 years or younger who were discharged from a Pediatric Health Information System (PHIS) children's hospital (n=52) with a diagnosis of an inherited leukodystrophy between October 1, 2015 through September 30, 2018 (n=950 patients). Leukodystrophies are rare but very serious neurological illnesses, with elevated mortality and morbidity rates. Bivariate and hierarchical generalized linear models reveal that white children, privately-insured children, and children visiting leukodystrophy specialist centers travel farther for children's hospital care. These findings indicate that socially privileged families travel greater distances to obtain specialized health care, which could affect clinical outcomes.

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Compliance with Ethical Standards

Disclosure of potential conflicts of interest

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Ethical approval

This article does not contain any studies with human participants or animals performed by any of the authors.

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Keywords

Geographic disparities; children with special health care needs; leukodystrophies; racial/ethnic disparities

INTRODUCTION

Families of children with special health care needs confront myriad challenges e.g., daily caregiving, financial difficulties, and frequent interactions with the health care system. Children with special health care needs (CSHCN) are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally [1]. In addition, families sometimes must travel substantial distances to access specialized health care [2]. Distance, and the corresponding time requirements, are linked challenges for the families of CSHCN [2]. In addition to challenges facing any traveler, like motion sickness [3], exposure to respiratory or gastrointestinal infections [4], and with air travel, hypoxia, which can exacerbate some health conditions [5], travel itself poses particular challenges for CSHCN. Feedings, medical treatments, and medications must be administered in unfamiliar settings on a potentially irregular basis.

While long distances between homes and health care can pose barriers to accessing care [6, 7], the ability to travel long distances to access health care represents greater familial capacity to meet a child's health care needs. This may be of particular importance for CSHCN, as patients with more complex illnesses tend to travel farther for hospital care [8, 9]. Apart from severity of illness and other factors that influence travel decisions (e.g., extent of in-network arrangements, and non-restrictive insurance coverage [10]), a small body of research suggests that more socially privileged patients travel farther to access higher-quality health care [11]. In Pennsylvania, for example, more affluent and white children traveled longer distances for hospital care than poorer and minority children, when holding constant the type and severity of the illness (e.g., burns vs. asthma; emergency room admission vs. not; presence of comorbidities) [12]. In Florida, white mothers were more likely to travel longer for spina bifida care for their infants than were minority mothers [13].

Another reason why families might travel greater distances is to access specialty care for their children that is not available nearby [10]. Families have been shown to travel farther for children's hospital care than for other types of hospital care [12]. Specialty hospitals often benefit patients in terms of quality, efficiency, and cost of care [14]. However, social disparities can impact which families obtain access to specialty care [15, 16]. A literature review found that children with public insurance have poorer access to specialty care than children with private insurance [17]. A study in Cook County (IL, USA) found that children with public insurance had to wait 22 days longer for appointments than privately insured children at outpatient specialty clinics that accepted both types of insurances [18]. Nationwide in the U.S., African Americans and Hispanics have disproportionately worse access to high-quality specialist neuro-oncology care over time compared with whites. Higher countywide median household income and decreased countywide poverty rate were

associated with access to higher quality neuro-oncology centers [19]. Which hospital a person uses can have a measurable impact on his/her health outcomes [20, 21] and obtaining health care at a specialized hospital can be advantageous [14].

Parents' decision-making about children's health care needs, such as if the child should be taken out of state to a specialty health care center, can be understood through a 'forms of capital' perspective, which includes economic, cultural and social capital [22]. Each capital can be thought of as an influence on the power to achieve desired ends. Economic capital is the root of other types of capital [22]; it is an indicator of economic status and is often measured as income [23]. Cultural capital is defined as the mastery of the cultural practices that a given society recognizes as legitimate and it is reflected in the long-lasting dispositions instilled through investments of time by others [22]. Cultural capital includes social and technical knowledge, perceptions and values [24]. While cultural capital can be used by socially marginalized people to gain access to exclusionary spaces [25], it more often reinforces power and privilege. Social capital involves "contacts and group memberships which, through the accumulation of exchanges, obligations and shared identities, provide actual or potential support and access to valued resources" [26, p. 143]. Although the quantity of people in a network is important, the power of the people in one's network is perhaps more important, since it is critical to achieving desired ends [27].

As applied to health care, economic capital includes the financial resources available for health care, which includes money for co-payments as well as the funds for long distance trips to specialty centers. Cultural capital during health care encounters can be thought of as a 'tool kit of resources', which can be used to create 'strategies of action' in sometimes unconscious ways [28]. Among parents of asthmatic children, parents with more cultural capital were better able to solve health care-related problems and make informed decisions about health care; those parents spoke English, had a college degree, and were born in the United States [27]. Important social capital for parents of children with asthma was the power that comes from knowing health care professionals personally (which influenced treatment decisions and the selection of additional providers) and having a network of friends to call for assistance and advice. Social capital helps parents solve problems and 'work the system' more effectively by gaining insider knowledge from others [27].

While disparities in distance travelled have been examined in pediatric patients, no prior studies have examined how race/ethnicity, insurance status, and accessing care at disease-specific specialty centers affect travel distance differences. This study uses the case of inherited leukodystrophies to investigate this previously unaddressed question. Detailed information on diagnosis, clinical burden, and racial/ethnic differences in diagnosis rates for leukodystrophies can be found elsewhere [29–32]. Leukodystrophies are a useful model for investigating these questions. First, leukodystrophies are complex conditions affecting brain white matter (myelin) and patients require access to sub-specialists and hospital care. Leukodystrophies cause significant morbidities and lead to death in one-third of patients by the age of 8 years [29]. Second, given the relative rarity of leukodystrophies, specialized care is particularly important and is limited to certain hospitals/centers [33]. Third, children with serious neurological conditions have not been investigated when examining social disparities, specialty care, and distance travelled. It is important to examine travel distance in

this population because neurological impairments, including leukodystrophies, account for one-third of all U.S. children's hospital charges [34], making examination of this population quite timely.

The paper addresses two specific questions: (1) Among children with leukodystrophies admitted to children's hospitals, how are race/ethnicity, insurance status, and access to care at disease-specific specialty centers associated with travel distance? And, (2) what is the combined effect of access to disease-specific specialty center care and race/ethnicity or insurance status on travel distance? We address these questions through use of bivariate and multivariate models, i.e., comparisons of mean and median distances, and then analysis with three two-level hierarchical generalized linear models. Question 1 analyses examine the independent effects of race/ethnicity, insurance status, and access to specialty center care on distance traveled. Question 2 analyses includes a series of categorical terms representing the intersection of race/ethnicity and insurance status with access to specialty center care. Our hypothesis is that children who are white, children who are privately insured, and children accessing disease-specific specialty care will travel farther than other groups.

MATERIALS & METHODS

Data Source

The Pediatric Health Information System (PHIS) database has information from 52 children's hospitals in the U.S. [35], which are affiliated with the Children's Hospital Association. PHIS retains a patient specific identifier but the patient is de-identified, permitting tracking of patient medical care and use. Data are pulled from medical records, and include patient and visit demographics such as, age, sex, race/ethnicity, insurance type, type of visit, length of stay, and International Classification of Diseases (ICD) coding. Other family, parental and household characteristics of the patient are not included.

Study Population

Inclusion criteria for this study are being an inpatient aged 18 years or younger and being discharged from a PHIS children's hospital with a diagnosis of leukodystrophy during the data capture window of October 1, 2015 through September 30, 2018 (n=950). Patients with leukodystrophy were identified based on ICD-10 codes. We included all patients with metachromatic leukodystrophy [E75.25], X-linked adrenoleukodystrophy [E71.520, E71.521, E71.528, and E71.529], adrenomyeloneuropathy [E71.522], Krabbe disease [E75.23], Hurler disease [E76.01], or sphingolipidosis NEC [E75.29]. The study was not considered human subjects research and was exempted by the Institutional Review Boards at the authors' university and health care employers.

Dependent Variable

The dependent variable is patient-level and it approximates the distance that the child travelled from his/her home to the children's hospital. Specifically, the variable represents the distance in miles from the centroid of the ZIP Code hosting the children's hospital to the centroid of each patient's home ZIP Code. These sorts of measures provide reasonable estimates of driving distance for epidemiologic research [36] and are commonly used [37].

Key Independent Variables

We have three key independent variables at the patient-level. The first is whether the child accessed disease-specific specialty care, operationalized as the child being admitted at a regarded leukodystrophy specialist center (LSC). To identify LSCs, we used published lists from the Global Leukodystrophy Initiative (GLIA, <http://theglia.org/our-clinical-centers>) and from the Leukodystrophy Care Network (LCN, <https://www.huntershope.org/family-care/leukodystrophy-care-network/lcn-care-centers/>). GLIA identifies nine LSCs that are children's hospitals and the LCN identifies three additional children's hospital LSCs not listed in GLIA. Of these 12 hospitals, eight are in PHIS. Those eight hospitals, shown in Figure 1, are: Ann & Robert H. Lurie Children's Hospital of Chicago; Children's Healthcare of Atlanta; University of Utah/Primary Children's Hospital (Salt Lake City); Children's Hospital of Colorado (Aurora); Children's National (Washington D.C.); Children's Hospital of Pittsburgh of UPMC; Children's Hospital of Philadelphia (CHOP); and Lucile Packard Children's Hospital Stanford (Palo Alto, CA).

The second key independent variable was patient race/ethnicity, coded as Hispanic of any race, non-Hispanic black, non-Hispanic Asian, non-Hispanic Other/multiple races and non-Hispanic white. These data were self-reported by the child's parent/guardian at admission, which is the most common approach for gathering this information [38]. While the meaning, significance and use of the concept of race/ethnicity is historically variable and contingent upon social practices, social scientists see race/ethnicity as a social construction. This means that they deny the existence of "natural" ordering of people by visible physical characteristics or ancestral origins [38]. Instead, they view race/ethnicity as a classification system borne out of socio-political processes. This is not to say that race is not real or consequential; the lived experience of a racialized identity is potentially devastating [38], as revealed in the literature on racial inequalities in health [39].

The third key independent variable is patient insurance status. This is reflected in the payer for the child's hospital admission and it is coded as government (e.g., Medicaid), commercial/private (e.g., HMO, PPO) and other payer (e.g., self-pay). Since the U.S. does not have a single payer system, some insurance statuses are loosely related to socioeconomic status (SES) at the child-level. Public insurance is provided through the government as entitlement programs for qualifying children. Medicaid and the Children's Health Insurance Program (CHIP) are generally available to poor and near-poor children respectively, while Medicare benefits, usually reserved for those over age 65, are extended to children with disabilities. Private or commercial insurance is not provided by the government and it is usually accessed through the parent's employer. This payer category generally maps to higher SES than government payer. The other payer category is a catch-all group for payers that do not clearly align with SES. This group includes health insurance provided to the families of military members, those who pay for their bill without insurance, and those receiving free care due to participation in research trials.

We combined the race and payer data with the LSC information to create two additional groups of binary independent variables. The first consists of 10 variables representing race/ethnicity by LSC care, e.g., Hispanic child that received care at a LSC. The second consists of six variables representing payer by LSC, e.g., child with government insurance that does

not receive care at a LSC. These two categorical variables are used to answer research question 2.

Control Variables

We also controlled for patient sex and age, if the patient had the unspecified sphingolipidosis [E75.29] form of the disease or a specific type of leukodystrophy, and the number of inpatient days over the study period (as per the patient's total number of days in PHIS during capture window). While we already partially account for illness severity by restricting our analysis to only leukodystrophy patients, controlling for leukodystrophy type and number of inpatient days allows us to better account for the dynamic of patients with more severe and complex conditions travelling longer distances [8, 9, 40].

Given that contextual characteristics influence how far a patient travels for hospital care and PHIS does not collect patient-level income or access to primary care data, we incorporated ZIP Code-level predictors into the model. ZIP Code captures the community context. We adjust for median household income (2015), percentage of residents who were non-white (2015), and whether the ZIP Code was designated as a Health Professional Shortage Area (HPSA). HPSA status is a general access to primary care variable as areas may receive HPSA designation when the population to primary care physician ratio is >3500-to-1 or the primary care physicians in surrounding areas are unavailable to serve the designated population [41]

We also controlled for ZIP Code-level urban/rural context using a construct with five categories, based on Rural-Urban Commuting Area (RUCA) codes. RUCA codes are based on population density, urbanization, and commuting patterns. While four categories are standard, we incorporated "urban core" and "other urban" apart (as opposed to considering them together), borrowing from the seven category classification [42]. These categorical are: large Rural (includes RUCA codes: 4.0, 4.2; 5.0, 5.2, 6.0, 6.1), small rural (7.0, 7.2, 7.3, 7.4; 8.0, 8.2, 8.3, 8.4, 9.0, 9.1, 9.2); isolated (10.0, 10.2, 10.3, 10.4, 10.5, 10.6.); urban core (1.0, 1.1) and other urban (2.0, 2.1, 3.0, 4.1, 5.1, 7.1, 8.1, 10.1) [42]. In addition to being important for examining urban/rural differences, inclusion of the urban/rural categorization in the model has the added benefit of improving the accuracy of predicted travel distance [36].

Statistical Approach

We first calculated descriptive statistics for all variables using SPSS 25 and mapped the rate of leukodystrophies in U.S. counties using ArcGIS 10.5.1. Second, we used bivariate methods to answer both research questions. We compared mean and median distance travelled to hospital by racial/ethnic group, payer group, and access to LSC care group (to address the first question), and LSC by race/payer (to answer the second research question). We did this using one-way ANOVA for difference of means and the nonparametric independent samples test for difference in medians using SPSS 25. We chose to conduct bivariate analyses for mean and median distance. While mean represents the average distance travelled, the median refers to the mid-point value of the distribution. Together, they

give a more complete picture of associations between the independent variables and travel distance than either would alone.

Third, we estimated three two-level hierarchical generalized linear models (HGLM) using HLM software to predict how far the patients travelled for children's hospital care. HGLM is appropriate for these analyses because our data have a two-level structure: children at level 1, nested within ZIP Codes at level 2. Children missing ZIP Code identifiers or values for ZIP Code-level variables ($n=50$) and those missing data from any level-1 variable ($n=86$) were excluded from the HGLM models (leaving $n=816$). HGLM was needed since traditional regression techniques may result in inaccurate parameter estimates when examining effects at multiple levels [43].

Independent variables at the patient- and ZIP Code-level were included in the models. The first model included the main effects for the key independent variables and the control variables and it addresses the first research question. The second and third models included the interaction terms and address the second research question. The second model used the race/ethnicity by LSC variables and the third included the payer by LSC variables. We consider results to be statistically significant and we interpret them if the p -value is under 0.05.

We have adequate statistical power in our models to detect small effects. To determine this, we conducted power analyses that are appropriate for HGLMs [43, 44] using G*Power 3.1.9.2. For the main effects model (Model 1), we had 7 ZIP Code-level variables and 11 patient-level variables. This means that at least 74 children would be required to have an appropriate statistical power of 0.80 [45] (Cohen 1988). If we increased the statistical power to 0.95, then 99 children would be needed. Similarly, for Model 2, which included the race/ethnicity by LSC terms, we had 7 ZIP Code-level variables and 15 patient-level variables and the power analysis showed that at least 108 children would be needed to achieve statistical power of 0.95. For Model 3, which included the payer by LSC terms, we had 7 ZIP Code level-variables and 13 patient-level variables, and 103 children would be required for statistical power of 0.95. Since we included 816 children in our HGLMs, our statistical analyses are adequately powered.

RESULTS

During the period under study, we identified 950 leukodystrophy patients, who were seen at the 52 PHIS hospitals. Figure 1 provides a county-level map rate of the rate of leukodystrophy among all children discharged from PHIS hospitals in the U.S. during the study period. This map shows some general geographic trends in leukodystrophy rates. It shows higher rates of leukodystrophy near the specialty centers. This pattern has been quantified statistically; PHIS patients seen at a leukodystrophy specialty center were 1.73 times more likely to be diagnosed with leukodystrophy than patients at non-leukodystrophy specialty center [46]. Table 1 presents patient-level and ZIP Code-level descriptive statistics for all analysis variables. Among the children with leukodystrophy, 30.6% had accessed care at a LSC. In terms of demographics, the average age was 6.5 years old and 39% were

female,. Over half (56.7%) had government payer. Over half were also White, non-Hispanic (54%) and 20% were Hispanic, 11% were Black and 3% were Asian.

Table 2 presents results of the difference of means and medians tests. Results for race/ethnicity show that the differences are statistically significant ($p<.05$) and that white children travelled the farthest (mean=116 miles; median=35 miles) and black children travelled the shortest (mean=33 miles; median=11 miles). Payer findings were also statistically significant ($p<.001$). Children with commercial/private and other payer travel farther (mean=133 and 193 miles; median=27 and 62 miles, respectively) than children with government insurance (mean=62 miles; median=20 miles). Children accessing LSC care travelled on average 162 miles (median=28 miles), whereas children receiving care from another children's hospital travelled 64 miles for care (median=22 miles) ($p<0.05$).

Table 2 also shows results comparing mean and median distance traveled for 10 groups based on race/ethnicity by LSC categories and the six groups of payer by LSC categories. In the race/ethnicity by LSC analysis, the differences were statistically significant ($p<.001$). Patients accessing LSC care who were also white (mean=191 miles; median=43 miles) or Hispanic (mean=122 miles; median=23 miles) travelled the farthest. In terms of which group travelled the shortest, the results differed depending on mean vs median. For mean distance, Asian children not accessing LSC care travelled the shortest (23 miles on average). For median distance, black children not accessing LSC care travelled the shortest (10 miles). In the payer by LSC analysis, patients accessing LSC care who had other payer (mean=403 miles; median=141 miles) or were privately insured (202 miles; 34 miles) travelled the farthest. Those receiving care at other children's hospitals who had government insurance travelled the shortest (mean=47 miles; median=20 miles).

Table 3 presents results from the main effects model (Model 1) predicting travel distance among leukodystrophy patients. Children accessing care at a LSC travelled 58 miles further ($p=0.027$) than children receiving care at other children's hospitals. Asian children travelled 67 miles shorter ($p=0.045$) than white children to obtain children's hospital care. Black, Hispanic and Other race children also travelled shorter than white children, but those differences were not statistically significant. Children with government insurance travelled 63 miles shorter ($p=.020$) to receive children's hospital care than children with private insurance. Children from "large rural" ($p<.001$) and "small rural" ($p<.001$) ZIP Codes traveled 95 and 100 miles further respectively to receive children's hospital care than "urban core" children.

Table 4 presents results of Model 2 and Model 3. The first set of results (A) shows the differences in adjusted distance traveled based on race/ethnicity by access to LSC. All groups travelled shorter distances than the reference group, which is white patients who accessed care at a LSC. As compared to white patients accessing care at a LSC, white patients who did not access children's hospital care at a LSC travelled 90 miles shorter ($p=.033$); Hispanic patients not accessing a LSC travelled 116 miles shorter ($p=.037$); black patients not accessing a LSC travelled 118 miles shorter ($p=.047$); black patients accessing a LSC travelled 126 miles shorter ($p=.050$); Asian patients not accessing care at a LSC travelled 122 miles shorter ($p=.014$); and Asian patients accessing a LSC travelled 112 miles

shorter ($p=.049$) The groups not travelling significantly ($p>.05$) shorter than whites/LSC were Hispanics/LSC and both groups of Other race children.

The second set of results in Table 4 (B) show the differences in distance travelled based on payer by access to LSC. As compared to patients accessing care from a LSC and being privately insured, those not accessing a LSC that had government ($p=.016$) or other payer ($p=.043$) travelled 126 and 93 miles shorter, respectively. Those with private insurance who did not access care at a LSC travelled shorter, but not significantly, than privately insured patients accessing a LSC.

DISCUSSION

Our findings show that children with leukodystrophies travelled significant distances for care at a children's hospital, and children receiving care from specialty leukodystrophy centers travelled even farther. Previous research has shown that living more than 80 km (50 miles) from a hospital for a child with a chronic condition leads to disruptions in family life and difficulties with the quality and cohesion of family relationships [2]. In our sample, 32% of patients travelled more than 50 miles for children's hospital care. The pattern of leukodystrophy patients travelling for care that we documented is part of a broader trend whereby children venture long distances for neurological health care. The average distance that a US child needed to travel to a certified physician specializing in a "neurodevelopmental disabilities" subspecialty was 73 miles in 2003. This was the second longest distance of any of the 16 pediatric subspecialty included in the study (sports medicine was #1 at 78 miles) [47].

We also found that white children with leukodystrophy travel farther for children's hospital care than racial/ethnic minority children. Even among those going to a leukodystrophy specialty center, black, Asian and Hispanic children travelled shorter distances than white children (although the Hispanic finding was not significant in the multivariate model). Black children receiving care from a leukodystrophy specialty center travelled the shortest adjusted distance vis-à-vis the reference group. We think that the presence of specialty leukodystrophy centers in major metropolitan areas with significant African-American populations, such as Atlanta and Philadelphia, may account at least in part for this finding.

While financial resources are necessary to travel long distances for health care, to some extent, our models control for the effect of socioeconomic status (through ZIP Code median income and patient insurance status). The 'forms of capital' framework [23, 24, 27] is useful for conceptualizing other unmeasured factors that could be potentially be responsible for these racial/ethnic differences in travel distance, apart from economic capital. We assume that parents who travel farther to access children's hospital care for their child with leukodystrophy are seeking to obtain better quality health care than what is available close to home. In order to do this, social and cultural resources are likely necessary. It may be that racial/ethnic disparities in parental cultural and social capital [23, 24, 27] could explain why white children travel farther than minority children.

In the case of leukodystrophies, parents with cultural capital would be able to determine the existence of specialty centers, request referral to them, and arrange travel. They would deploy social capital to find the best doctors and gain useful information from other parents of CSHCN. While any parent can have cultural and social capital to aid in the managing of a child's chronic illness, these characteristics are likely more common in white and more affluent Americans. Cultural and social capital were unmeasured in this study, but future research on distance travelled could incorporate their measurement since social and cultural resources may be at play when explaining these findings.

In addition to having fewer cultural, social, and financial resources as compared to white parents, minority parents are more likely to face discrimination in the referral processes and have less mobility. Previous research has documented serious race-based differentials in quality of health care. There is a high degree of segregation in the receipt of primary health care in the U.S., with a majority of African-Americans seeing a relatively small number of lower-quality doctors [48]. Those doctors are more likely to report that they were unable to provide high-quality care to all their patients and more likely to report that they faced difficulties in obtaining access to high-quality subspecialist care for their patients than physicians serving white patients [48]. While focused on surgery, a national U.S. study found that black patients disproportionately received surgical care in low-quality hospitals, even though they lived closer to high quality hospitals than white patients, suggesting that biased physician referral patterns may play a role [49].

It is also the case that minority parents may be uncomfortable travelling due to fears and concerns about discrimination and exclusion as people of color in the U.S. While not focused on health care-related travel, a body of research explores how racism affects travel decisions among racial/ethnic minority Americans. Ethnographic research has demonstrated that African Americans' travel patterns (e.g., taking fewer and shorter trips, avoiding unplanned stops) should be conceived as defensive mechanisms against potential racial discrimination [50]. When traveling within cities, persons with black-sounding names faced discrimination in their use of ride-share services (e.g. Uber, Lyft), in terms of significantly longer waits and more frequent cancelations [51]. Discrimination also affects the mobility of other ethnic minority and immigrant populations in the U.S. A study of Chinese immigrants in Flushing (New York City) found that they rarely travelled outside of Flushing, due to language barriers, time, poverty, and concerns about racism [52]. These potential explanations for our findings derive from published literature and our theoretical framework, but they are still speculative and should be tested directly in future studies. Interviews with parents from different racial/ethnic backgrounds would be useful to ascertain how they make decisions about travelling for children's health care.

Results for insurance status reveal that children with leukodystrophy who had private payer travelled farther than those with government insurance. While children with other payer travelled farther in the bivariate analysis, the association became insignificant in the adjusted model. For epilepsy, the availability of a specialized centers near where patients lived did not influence access to specialized epilepsy care in people who had private insurance, but it did for patients with government or no insurance [53]. This finding suggests that privately insured epilepsy patients were overcoming the friction of distance to access specialty care,

while others were not. In this analysis of leukodystrophy patients, we found that private patients visiting a leukodystrophy specialty center traveled significantly farther than private patients using another children's hospital and there was no significant difference in adjusted distance between government insured patients using a leukodystrophy specialty center vs not. While some privately insured leukodystrophy patients travelled long distances for specialty care, this was not the case for children with government insurance. It maybe that children with government insurance are less likely to be referred, or, if they are referred, their referrals are more likely to be denied [18]. Resources could also come into play with parents of children on government insurance possibly lacking cultural and social capital to navigate the referral and travel process, as discussed above, or the economic capital to cover travel expenses to a leukodystrophy specialty center. These potential explanations should be explored in future studies using in-depth interviews with parents to elucidate the mechanisms behind which private insurance is linked to longer travel distances.

Limitations for this study are its use of retrospective PHIS data, the three-year duration of data collection, the use of ZIP Code-level measures, omitted variable bias, and generalizability. Comparisons with the 2016 Kids Inpatient Database (KID) from Agency for Healthcare Research and Quality's Healthcare Cost and Utilization Project (CHUP) allow us to estimate what percentage of leukodystrophy care in the U.S. is happening at PHIS hospitals. Based on our analysis of the data, we have determined that PHIS is capturing 46% of all pediatric inpatient admissions for leukodystrophy in the U.S. and 89% of all leukodystrophy visits to children's hospitals [54]. This means that our study captures the majority of the children with leukodystrophies that attend children's hospitals, but we are missing some children who seek care at non-children's hospitals. This suggests that our analyses might be understating the disparities, since families travel farther for children's hospital care than for other types of hospital care [12]. The time limitation was necessary because ICD-10 coding has only been in use since 2015, and ICD-10 code use was necessary to have sufficient specificity in extracting the cases with leukodystrophy.

Although the use of ZIP Codes to approximate travel distance does not take into account traffic patterns, speed limits, and other factors that could affect the travel time, distance-based assessments have been reported to correlate well in children [12, 40]. The analysis also did not consider mode of travel, which is important since shorter distances can be more substantial barriers than longer distances, if families are reliant on public transportation [55]. We used patient ZIP Codes to approximate travel distance, urban/rural context, access to primary health services, household income, and community racial makeup. Although previous studies have reported a strong relationship between neighbourhood-level characteristics and health outcomes [56], alternative sources of patient-level data (e.g., asking income directly) would be preferable, but is impossible with PHIS [40]. It is also possible that some of the racial/ethnic effects reported in this study are due to unmeasured elements of SES. We included ZIP-code level median household income and patient insurance status, which are the best available measures in PHIS, but those do completely gauge SES. In addition to unmeasured elements of SES, other omitted variable bias is possible. Lastly, results may not be generalizable to children with other special health care needs. Future research should examine similar questions in other patient populations.

CONCLUSION

While families and children with leukodystrophies often travel significant distances to receive children's hospital care, there are distinct disparities in the distance travelled for this care. We found that white patients travelled the farthest of all racial/ethnic groups, especially when seeking care from a specialty leukodystrophy center. Privately insured children travelled longer distances than children with government insurance. This suggests that the opportunity and ability to travel farther to seek specialized leukodystrophy care could positively affect outcomes in more socially privileged children. This is especially the case as cutting -edge therapies for specific leukodystrophies (such as ALD or MLD) are developed [57, 58] and are only available at a few select centers.

Our findings raise several important directions for future research. First, other groups of children with special health care needs should be examined to determine whether these findings for leukodystrophies are true for other pediatric diseases. Second, interviews with parents would help explain the reasons behind the patterns we uncovered. Third, future research should determine whether the distance traveled is associated with differences in diagnosis and/or outcomes. While travelling is challenging for families, travelling for specialty care could result in better outcomes. In future studies, research should evaluate whether the pursuit of specialty care at a leukodystrophy specialty center leads to improved diagnosis rates and better outcomes. Results also suggest consideration of potential interventions. For example, given that the referral process is critical to accessing high-quality care [49], the use of care navigators—people with expertise in referral processes and sensitivity to cultural barriers—could improve processes for patients, families, and referring physicians to obtain specialty care [49, 59].

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Figure 1.

Leukodystrophy specialty centers and county-level leukodystrophy rates, calculated based on number of PHIS patients, 2015–2018.

Note: The leukodystrophy specialty centers in the map are only those included in PHIS and therefore this analysis.

Table 1.

Descriptive Statistics for leukodystrophy inpatients in PHIS, age 18 and under, 10/1/2015–09/30/2018 (n=950 children)

Variables	N	Min.	Max.	Mean.	Std. Dev	Yes N (%)	No N (%)
PATIENT LEVEL							
Distance to Hospital in miles	939	<.01	4918.3	94.8	304.1		
Inpatient days per days in PHIS	950	<.01	1.0	.04	.1		
Age in years at first admit	950	0	18	6.47	5.5		
ZIP CODE LEVEL							
Proportion not white	784	0	1.8	.7	.4		
Median HH income	784	14,008	143,384	46,897	18,997		
HPSA	784					321 (40.9)	463 (51.9)
Urban core [reference]	784					564 (71.9)	220 (28.1)
Other urban	784					86 (11.0)	698 (89.0)
Isolated	784					24 (93.1)	760 (96.9)
Small Rural	784					39 (5.0)	745 (95.0)
Large Rural	784					63 (8.0)	721 (92.0)
PATIENT LEVEL							
Accessed care at LSC	950					291 (30.6)	659 (69.4)
Female	950					373 (39.3)	577 (60.7)
Has a unspecified leukodystrophy	950					449 (47.3)	501 (52.7)
Government Payer	942					534 (56.7)	408 (43.3)
Private Payer [reference]	942					355 (37.7)	587 (62.3)
Other Payer	942					53 (5.6)	889 (94.4)
White (non-Hispanic) [reference]	860					464 (54.0)	396 (46.0)
Hispanic (any race)	878					191 (20.1)	687 (78.2)
Black (non-Hispanic)	860					95 (11.0)	765 (89.0)
Asian (non-Hispanic)	860					25 (2.9)	835 (97.1)
Other races (non-Hispanic)	860					85 (9.9)	775 (90.1)
<u>Race/Ethnicity by LSC</u>							

Variables	N	Min.	Max.	Mean.	Std. Dev	Yes N (%)	No N (%)
White & LSC [reference]	937					152 (16.2)	785 (83.5)
White & not LSC	873					312 (35.7)	561 (64.3)
Hispanic & LSC	938					42 (4.5)	896 (95.5)
Hispanic & not LSC	890					149 (16.3)	741 (83.7)
Black & LSC	937					36 (3.8)	901 (96.2)
Black & not LSC	873					59 (6.8)	814 (93.2)
Asian & LSC	937					13 (1.4)	924 (98.6)
Asian & not LSC	873					12 (1.4)	861 (98.6)
Other race & LSC	937					36 (3.8)	902 (96.2)
Other race & not LSC	873					50 (5.7)	823 (94.3)
<u>Race/Ethnicity by LSC</u>							
Government payer & LSC [reference]	950					147 (15.5)	803 (84.5)
Government payer & not LSC	942					387 (41.0)	555 (59.0)
Private payer & LSC	950					125 (13.3)	825 (86.7)
Private payer, & not LSC	942					230 (24.4)	712 (75.6)
Other payer & LSC	950					19 (2.0)	931 (98.0)
Other payer & not LSC	942					34 (3.6)	908 (96.6)

Note: PHIS, Pediatric Health Information System; LSC, leukodystrophy specialty center

Table 2.

Bivariate tests comparing mean and median distance travelled for children's hospital care among leukodystrophy patients based on race/ethnicity, payer and access to leukodystrophy specialist center (LSC) care (n=950 children)

Grouping	N	Mean Distance (in miles)	P ^a	Median Distance (in miles)	P ^b
RACE/ETHNICITY					
Hispanic	189	56.12		17.7	
Black (NH)	95	32.76		11.4	
Asian (NH)	24	32.06	.032	16.3	<.0001
Other (NH)	81	97.67		15.2	
White (NH)	463	116.12		35.2	
PAYER					
Government	532	62.06		20.4	
Private	354	132.74	<.001	27.2	<.0001
Other	44	193.24		62.1	
LSC					
Receipt of care at LSC	288	162.13		28.0	
No receipt of care at LSC	650	65.00	<.001	22.0	0.007
RACE/ETHNICITY BY LSC					
White & LSC	152	191.46		43.15	
White & not LSC	311	79.30		33.5	
Hispanic & LSC	42	122.37		22.95	
Hispanic & not LSC	147	37.19		17.2	
Black & LSC	36	31.45	.001	11.9	<.0001
Black & not LSC	59	33.57		10.3	
Asian & LSC	13	39.99		15.3	
Asian & not LSC	11	22.70		17.3	
Other race & LSC	32	70.62		12.2	
Other race & not LSC	49	115.34		19.8	
PAYER BY LSC					
Government payer & LSC	147	102.24		21.8	
Government payer & not LSC	385	46.72		19.8	
Private payer & LSC	125	201.56		33.5	
Private payer, & not LSC	229	95.18	<.0001	23.8	<.0001
Other payer & LSC	16	404.33		141.1	
Other payer & not LSC	28	72.61		55.15	

^a *p* applies to one-way ANOVA test

^b *p* applies to nonparametric independent samples median test

Note: NH, non-Hispanic; LSC, leukodystrophy specialty center

Table 3.

Two-level hierarchical linear model predicting distance travelled to hospital among leukodystrophy patients (n=816 children)

Patient-level	parameter	SE	95% Confidence Interval	p
LSC	58.214	25.811	(6.848, 109.579)	*
White, NH	Ref	Ref	Ref	
Hispanic	-29.779	37.082	(-103.572, 44.013)	
Black, NH	-62.240	39.819	(-141.480, 17.000)	
Asian, NH	-66.673	32.702	(-131.751, -1.595)	*
Other Race, NH	-8.6236	50.785	(-109.685, 92.438)	
Commercial/Private payer	Ref	Ref	Ref	
Government payer	-62.754	26.336	(-115.162, -10.346)	*
Other payer	40.177	65.112	(-89.398, 169.752)	
Female	18.600	18.659	(-18.531, 55.731)	
Inpatient days	83.062	145.563	(-206.607, 372.732)	
Unspecified leuko.	4.552	18.966	(-33.189, 42.293)	
Age in years at first admit	0.395	1.205	(-2.002, 2.792)	
ZIP Code level				
Intercept	92.705	38.798	(16.546, 168.865)	*
Proportion not white	86.900	70.716	(-51.915, 225.715)	
HPSA	-14.116	26.111	(-65.372, 37.141)	
Median HH income	0.0007	0.001	(-0.001, 0.003)	
Urban	Ref	Ref	Ref	
Other urban	60.430	36.999	(-12.199, 133.059)	
Isolated	108.535	56.373	(-2.125, 219.195)	
Small Rural	100.478	30.258	(41.082, 159.875)	***
Large Rural	94.8239	26.485	(42.834, 146.814)	***

Note: LSC, leukodystrophy specialty center; NH, non-Hispanic; HPSA, health professional shortage area; Ref=reference category* $p < .05$

100>*d*

10>*d*
**

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Table 4.

Results of two-level hierarchical linear models predicting distance travelled for children's hospital care for leukodystrophy patients (n=816 children), exploring (A) race/ethnicity and (B) payer by specialty center interactions

Patient-level Variables	parameter	SE	95% Confidence Interval	p
(A) RACE/ETHNICITY BY LSC				
White, NH & LSC	Ref	Ref	Ref	
White, NH & not LSC	-89.687	41.325	(-172.006, -7.368)	*
Hispanic & LSC	-36.217	82.771	(-201.097, 128.662)	
Hispanic & not LSC	-116.045	54.762	(-225.128, -6.962)	*
Black, NH & LSC	-125.642	63.121	(-251.379, 0.094)	*
Black, NH & not LSC	-118.264	58.642	(-235.078, -1.450)	*
Asian, NH & LSC	-111.879	55.899	(-223.229, -0.529)	*
Asian, NH & not LSC	-122.335	48.58649	(-219.119, -25.551)	*
Other race, NH & LSC	-96.679	74.702	(-245.486, 52.127)	
Other race, NH & not LSC	-46.078	72.045	(-189.591, 97.435)	
(B) PAYER BY LSC				
Government payer & LSC	Ref	Ref	Ref	
Government payer & not LSC	-81.1649	53.161	(-187.009, 24.679)	
Private payer & LSC	-100.157	54.560	(-208.785, 8.471)	
Private payer, & not LSC	-125.728	51.06	(-227.388, -24.067)	*
Other payer & LSC	145.8399	180.081	(-212.701, 504.380)	
Other payer & not LSC	-93.3538	45.317	(-183.581, -3.127)	*

NOTE: Models control for patient-level covariates: patient sex, if the patient had spina/gliosis [E75.29] or one of the more specific types of leukodystrophy, the number of inpatient days over the study period, and the patient age. For model (A), patient payer status is included, and in model (B), patient race/ethnicity included. At the ZIP Code level, covariates included are: median household income, percentage of residents who were non-white and non-Hispanic, whether the ZIP Code was a Health Professional Shortage Area, and urban/rural context using a five categories.

Note: NH, non-Hispanic; LSC, leukodystrophy specialty center; Ref=reference category

* $p < .05$

** $p < .01$

*** $p < .001$