Published in final edited form as:

J Pediatr Hematol Oncol. 2014 January ; 36(1): 51–56. doi:10.1097/MPH.0000000000000013.

Insurance Status as a Sociodemographic Risk Factor for Functional Outcomes and Health-related Quality of Life Among Youth With Sickle Cell Disease

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Summary

Youth with sickle cell disease (SCD) are at risk for functional limitations and poor health-related quality of life (QoL). This study examined sociodemographic factors that may interact with medical complications to reduce functional ability and QoL among youth with SCD. Fifty-three patient/caregiver pairs (children 8 to 18 years; $M = 12.3$ y) with SCD completed the Functional Disability Inventory and Pediatric Quality of Life Inventory questionnaires. Medical database reviews were conducted to collect health care utilization, disease complications, and sociodemographic information; insurance type (public vs. private insurance) and family zip code to access Census tract data reflecting neighborhood distress. Insurance type, but not neighborhood sociodemographic risk indicators, was significantly associated with disease-related complications and QoL. There were significant differences in both health care utilization and QoL by insurance type. Complications were higher in the group with public insurance. Insurance type seems to be more strongly related to disease outcomes and QoL than neighborhood sociodemographic distress. Closer attention to the contribution of insurance type to health outcomes may provide important insight to potential barriers for disease management. These issues are critically important for health care efficiency and equity for poor and underserved children with chronic health conditions.

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The authors declare no conflict of interest.

Keywords

sickle cell disease; insurance coverage; sociodemographic factors; health disparities; chronic health conditions

Racial and ethnic minority children access medical care significantly less than do white children, and¹ African American children have higher rates of disability, primarily due to issues related to poverty as compared with white children.² The impact of sociodemographic factors on health outcomes has been well documented in adults with chronic health conditions.³ The effect of these disparities on health outcomes is less clear for children with chronic health conditions, such as sickle cell disease (SCD), who rely on caregivers to access appropriate health care services. Social ecological factors, such as poverty level, neighborhood violence, and household structure, have been associated with poorer health outcomes in a national sample of children with SCD.⁴

SCD is a group of inherited red blood cell/hematological disorders in which the sickle hemoglobin predominates. The incidence of SCD in the United States is 1 in every 400 to 500 live births for the African American population in which SCD is most prevalent. The vast majority of SCD symptoms are managed at home; however, the condition is chronic and treatments involve routine administration of analgesic medication during outpatient visits or hospitalizations, prophylactic antibiotics to reduce susceptibility to infections, and folic acid supplementation to support red cell production.⁵ Symptom complications are unpredictable and recurrent, including episodes of severe pain, pneumococcal infections, anemia, nocturnal enuresis, stunted growth, and strokes.^{6,7} Although symptom severity varies across SCD genotypes, the chronic nature of SCD presents major challenges throughout development, which present significant disruptions in the child's daily routine (eg, activity limitations, sleep disruptions, and reduced functional ability).^{6,8} Research has indicated that children with SCD have poor quality of life (QoL)⁹ and functional impairment among youth with SCD is rated in the moderate to high level.¹⁰ The presence and intensity of SCD pain was significantly correlated with functional impairment.^{11,12} The added burden of neighborhood distress (poverty, crime, insufficient community resources) and/or insurance access for health care utilization in this vulnerable group has not been fully explored.

Although significant contributions from neighborhood influences (crime/violence, access to critical resources) and contextual factors (female-headed household, unemployment/underemployment) have been reported to negatively impact health outcomes,¹³ the lack of health insurance coverage is the single most important factor in the ability of minorities to access medical care.^{14,15} For example, before enrollment in a state-funded children's health insurance program (SCHIP, New York), African American children had significantly greater levels of unmet needs (delayed and foregone preventive, acute, specialty, emergency care, and prescriptions) relative to white children (38% vs. 27% respectively). These differential effects were eliminated when children were enrolled in the SCHIP, with unmet needs at 19% for both groups postenrollment.¹⁶ Thus, insurance coverage may significantly impact access

to health care, and access to appropriate health care management, among African American children.

Notably within some chronic health conditions (ie, asthma, diabetes, traumatic brain injury), African American children tend to experience greater health difficulties than white children.¹⁷ Larson et al¹⁸ reported that the percentage of children in poorer health increased with the number of social risk factors they were exposed to across the course of the illness; specifically, maternal mental health difficulties, race/ethnicity disparities, and lack of medical insurance. Earlier research with SCD patients advocated for inclusion of both the social and cultural context of SCD to better understand sociodemographic factors that shape the disease experience and impact the patient's response to the disease process.^{8,11,12,19} For example, low-income children with SCD were 4 times more likely than other African American children to be in fair or poor health.²⁰

However, questions remain about how to best capture sociodemographic risks while measuring health disparity rates among minority children. Estimates of neighborhood social risk factors using Census tract data for the family's zip code have been shown to be a reliable source for sociodemographic information relative to the associations between neighborhood distress (eg, high male unemployment rate, caregiver underemployment and/or low education, single parent homes, and poverty rate for neighborhoods defined by zip code) and health outcomes.^{10,21,22} Palermo et al¹⁰ examined the relationship between sociodemographic factors, functional disability, and QoL for children and adolescents with SCD and their caregivers. Lower parent education and income were significant predictors of child functional disability and QoL (both physical and psychosocial), whereas neighborhood distress indicated by Census tract data only predicted physical health-related QoL. These results suggest that individual and family factors may be more relevant to functional outcomes and QoL in children with SCD, with neighborhood distress contributing to these outcomes in a smaller independent manner.

With insurance type as a gateway to access medical care, health care utilization costs have the potential to negatively impact health promotion activities for patients who have restricted/limited medical coverage.^{18,23} In 1 report of statewide insurance coverage, children with SCD incurred medical expenditures that were 6 to 11 times higher than those of children without SCD.²⁴ Examination of the effects of insurance type on health care utilization activities for children with SCD will help to evaluate equity in health care delivery for this population.

Using a social ecological framework²⁵ to describe potential risk factors for health outcomes, the current study examined sociodemographic factors for poor functional outcomes and QoL for children with SCD. After the findings of Palermo and colleagues that described the role of neighborhood distress on psychosocial outcomes among patients with SCD, we expected significant associations between both individual socioeconomic distress and neighborhood distress with functional disability and QoL.¹⁰ Namely, the current study examined the contributions of both individual (parent education, family income) and neighborhood (household structure, male unemployment) sociodemographic indicators, based on family zip code to access Census tract data, on several health outcomes (functional disability,

QoL).²⁵ Using insurance type (public vs. private insurance) and neighborhood indicators of sociodemographic distress (based on family zip codes to access Census tract data), associations among SCD complications, health care utilization (from medical chart reviews), parent reports of child QoL, and functional outcomes were examined. It was hypothesized that children with SCD with public insurance and children from more distressed neighborhoods would have higher functional disability and poorer QoL. The relative contribution of insurance status and neighborhood risk to QoL was also investigated.

MATERIALS AND METHODS

Participants

The current study utilized baseline data from a prospective study examining associations among pain, sleep, QoL, and functional ability for children and adolescents with SCD. Children and their primary caregivers were approached during their hematology visit for SCD follow-up care. The inclusion criteria for participants were patients of the sickle cell center between the ages of 8 and 18 years of age with any sickle cell hemoglobinopathy. Patients who did not speak English or who had significant cognitive limitations were excluded from the study. The final sample comprised of 53 children and adolescents and their primary caregiver (sample demographics are described in Table 1). The children were on average 12.19 years of age ($SD = 2.91$) when they enrolled in the study.

A total of 80 families were approached to participate: 55 enrolled, 5 reported they were not interested, 1 child was excluded because of cognitive limitations, and 19 families indicated they were interested in participating at a later date but were not enrolled before the study was closed. Of the 55 children enrolled, 1 family completed consent but had to leave the appointment before completing baseline measures and 1 child was not included in analyses due to not being seen at our center for several years before study participation, thus not having data on disease status variables or health care utilization available by medical chart review.

Measures

Medical Chart Review—Participants' medical charts were reviewed to confirm exclusion criteria and to assess disease characteristics and the occurrence of health care visits (routine and acute care). Disease complications were also calculated based on medical chart review using total number of pain episodes over the past year, lifetime occurrence of cerebral vascular accident, a diagnosis of acute chest syndrome in the past year, surgery in the past year, lifetime asthma/reactive airway diagnosis, currently receiving transfusion, and other SCD-related complications (eg, avascular necrosis, splenic sequestration, obstructive sleep apnea). Summary of disease-related complications scores have been used previously to estimate disease severity in patients with SCD.^{26,27} Higher complication scores indicate more disease-related complications.

The Total Healthcare Utilization Score was calculated based on the following information from medical chart reviews: acute care/emergency room visits, routine care/clinic visits, transfusion appointments, calls to clinic, and total days admitted to the hospital for the year

before the study was started. To further understand specific types of health care utilization, a summary of Urgent Healthcare Utilization was also calculated based on number of acute care/emergency room visits and the total days admitted to the hospital over the year before study participation. Health care utilization^{26–28} and urgent health care utilization²⁹ have been used previously to measure health status with other SCD samples.

The child's primary insurance type was collected during medical chart review, verified through the hospital medical record database, and classified as either public insurance (n = 40) or private insurance (n = 13) as a proxy of the family's socioeconomic status (SES). Five patients had both public and private insurance and they were classified as having private insurance for dichotomous group analyses.

Neighborhood SES—Families were classified as living in distressed neighborhoods based on criteria outlined by O'Hare and Mather¹³ previously. Distressed neighborhoods are those that are greater than 1 SD above the national average in 3 of 4 variables (individuals living in poverty, high school dropout rate, female head of household, and male unemployment). Family zip codes were collected from the hospital medical record database and used as a proxy for neighborhood distress. Neighborhood distress was estimated using an index score from the 2000 Census tract data from the US Bureau of Census. Census tract data (based on zip codes) have been used in other studies of health outcomes in pediatrics²² and SCD¹⁰ and this data represents many characteristics of a neighborhood that can indicate socioeconomic distress. Dichotomous variables indicating that a zip code met the following criteria were created: (1) >25.1% individuals in poverty; (2) >20.7% high school dropout rate; (3) >34.3% female head of household; and (4) >37.1% male unemployment rate. Zip codes meeting 3 of 4 of these criteria were categorized as distressed. Zip code data to describe the neighborhood distress factors are shown in Table 1. Using this criterion, 16 (29.6%) of 53 families were classified as living in distressed neighborhoods.

Functional Disability Inventory (FDI)—The FDI is a 15-item parent-report questionnaire used to evaluate the impact of age-appropriate physical activities on the child's daily functioning for the last week (FDI).³⁰ Participants rated the difficulty of each item on a 0 to 4 Likert-type scale with higher scores indicating more difficulty. The FDI demonstrated good internal consistency at baseline ($\alpha = 0.88$). The FDI total score was used for analyses.

Pediatric Quality of Life Inventory (PedsQL)—The PedsQL is a 23-item parent-report measure used to assess health-related QoL, with subscale scores indicating physical health QoL and psychosocial health QoL (PedsQL).^{31,32} Caregivers were asked to report how much of a problem each of the items have been for their child during the last month on a Likert-type scale indicating frequency. Higher scores on the PedsQL indicate better health-related QoL. Cronbach α for the PedsQL total score, physical health subscale, and psychosocial health subscale at baseline ($\alpha = 0.89$ to 0.94) were acceptable. Physical health QoL and psychosocial health QoL were used for analyses.

Procedure

A research assistant approached families who met the inclusion criteria about participating in the study. Interested families completed written informed consent and assent forms with the research assistant. The research assistant then reviewed the instructions for the measures and helped the families complete the baseline questionnaires. The current study was approved by the Institutional Review Board.

Data Analysis

Data were examined for skew and kurtosis. All variables were normally distributed with the exception of the FDI, which exhibited significant positive skew and kurtosis, and the urgent health care utilization score, which also exhibited significant positive skew. The FDI total score was transformed using a log transformation,³³ which yielded a more normally distributed variable (skewness = -0.21, SE = 0.33; kurtosis = -1.461, SE = 0.64). Urgent health care utilization was also transformed using a log transformation,³³ and the transformation yielded a more normally distributed variable (skewness = 0.18, SE = 0.33; kurtosis = -1.53, SE = 0.64). Power analysis³⁴ indicated that with a medium effect size and α set at 0.05, power for the ANOVA was 0.43 and power for the hierarchical regression was 0.62.

Demographic factors (age, sex, neighborhood distress) were examined as potential covariates using Pearson correlations and *t* tests. The associations among neighborhood distress, disease status variables (disease complications, total and urgent health care utilization), and health outcome variables (FDI, PedsQL scores) were examined using Pearson correlations. To understand differences in health outcomes by insurance status, the sample was split into primary insurance = public (*n* = 40) and primary insurance = private (*n* = 13). ANOVAs were conducted to compare insurance groups on measures of disease complications, health care utilization (total and urgent), functional disability (FDI), and QoL (PedsQL). A hierarchical regression was conducted to predict total and urgent health care utilization based on a socioecological model using disease complications as an indicator of individual contributions entered on step 1, primary insurance as an indicator of family SES on step 2, and living in a distressed neighborhood on step 3.

RESULTS

Demographic Factors, Neighborhood Distress, and Health Outcomes

Using Pearson correlations, child age was not related to disease complications, health care utilization (total and urgent), functional disability, or parent-reported QoL (physical or psychosocial). Disease factors, health care utilization, functional disability, and QoL also did not differ by sex. Indicators of neighborhood distress were not associated with disease complications, health care utilization (total and urgent), functional disability, or QoL.

Insurance Type and Health Outcomes

There were no differences between insurance groups for indicators of neighborhood distress (zip code percent below poverty line $F_{1, 51} = 0.17$, $P = 0.679$; zip code high school dropout $F_{1, 51} = 0.36$, $P = 0.552$; zip code percent female head of house $F_{1, 51} = 0.06$, $P = 0.804$; zip

code male unemployment $F_{1,51} = 0.01$, $P = 0.909$). Genotypes were evenly distributed between insurance types ($\chi^2_3 = 2.99$, $P = 0.393$). Sex also did not differ between insurance types ($\chi^2_1 = 0.58$, $P = 0.540$).

Table 2 presents group comparisons between public and private insurance, disease complications, health care utilization (total and urgent), functional disability, and QoL. Chart reviews indicated that children with public insurance experienced significantly more disease complications ($F_{1,51} = 6.96$, $P = 0.011$), more total health care utilization ($F_{1,51} = 24.06$, $P < 0.001$), and more urgent health care utilization ($F_{1,51} = 7.83$, $P = 0.007$) than children with private insurance. The groups did not differ in reports of functional disability. Parents of children with public insurance reported poorer physical ($F_{1,51} = 9.91$, $P = 0.003$) and psychosocial ($F_{1,51} = 14.84$, $P < 0.001$) QoL compared with parents of children with private insurance.

Models Predicting Health Care Utilization

The hierarchical regression model predicting total health care utilization from disease complications, insurance, and neighborhood distress was significant ($F_{3,49} = 16.40$, $P < 0.001$), explaining 50.1% of the variance (Table 3). Complications and insurance were significant predictors and explained a separate portion of the variance, suggesting that individual and family factors contribute independently to total health care usage in children with SCD. As disease complications increased, total health care utilization increased; total health care utilization also increased in families with public insurance. The model predicting only urgent health care use (emergency visits and total days admitted to the hospital) with complications, insurance type, and distressed neighborhood as predictors was also significant ($F_{3,49} = 20.72$, $P < 0.001$). Disease complications and insurance were significant predictors, explaining 56.0% of the variance (Table 3). Again, there was a positive relationship between disease complications and urgent health care utilization, and children with public insurance had higher urgent health care usage.

DISCUSSION

This study was limited by a small sample size; however, despite low power, significant relationships were found between disease status variables and sociodemographic factors. Our findings confirm prior research suggesting that family factors have significant associations with disease complications and QoL.^{10,26} Although similar distributions of more severe genotypes (eg, HBSS and HB β^0 thalassemia) between insurance type groups were observed, disease complications were higher in the group with public insurance independent of disease severity classification. Our findings further suggest that insurance type and health care utilization are closely linked for children with chronic health conditions. Significant differences in health status variables by insurance type (public vs. private) were evident; based on medical chart reviews, in general, pediatric patients with public insurance evidenced more SCD complications and greater health care utilization (urgent and total utilization) than patients with private insurance. As our sample was enrolled in a sickle cell center program, we expected total health care usage to be normally distributed across diagnosis, due, in part, to comprehensive care protocols that are in place

from the time of diagnosis. Although higher health care utilization among patients with public insurance coverage may provide more evidence for impact of sociodemographics on health outcomes based on regression results, individual and family characteristics seem to be more salient for both total health care usage and urgent health care utilization. Further, the functional status measure (FDI score) (eg, combing hair, participate in family activities) and neighborhood distress markers (zip code indicators of distress) were not significantly different by insurance type suggesting differences observed are more closely tied to individual and family factors than neighborhood distress. Although SCD complications varied by insurance coverage type, where public insurance coverage was associated with more SCD complications, the data revealed functional status was not significantly different between public and private insurance patients. Questions remain about the relationships between disease complications, health care utilization, and functional status.

FDI scores may not adequately reflect disease impact on ability to perform age-appropriate activities of daily living. For families in our study, disease complications and health care utilization seem to provide a consistent picture of functional status related to SCD diagnoses. Functional limitations in children with chronic conditions may be more sensitively evaluated when the combined effects of social, ecological, and disease factors are considered. The PedsQL scores in the current study are similar to previous published results in other samples with SCD.^{31,35} Of note, our private insurance group reported levels of QoL similar to Panepinto et al's³¹ non-SCD group. In contrast, the public insurance group reported poorer QoL, in both physical and psychosocial domains. QoL takes into account estimates of physical (health status/SCD complications) and psychosocial (community/neighborhood/family barriers and resources) factors. Thus, QoL measures may provide a more coherent assessment of health status and their effects on disease outcomes among minority youth with chronic illness.

Disparities in quality of health care remain despite improvement in health care access, in part due to health insurance inequity.³⁶ Insurance coverage is the single most important element in the ability of minorities to access quality medical care.^{14,15} It has been established that families of children with complex health conditions who received public insurance for their medical care reported a high level of stress associated with fragmentation of care and dealing with multiple agencies and providers to receive necessary medical services.³⁷ Medical insurance inequities may inflate health care utilization where multiple medical contacts/services are needed to achieve the desired effect particularly for those who have limitations in services imposed by insurance coverage type. Closer attention to the role of insurance type on measures of disease outcomes is critical to the public health agenda for poor and underserved families as they navigate the health care system.

What is less clear for service providers is how to develop integrated systems of care that are both time and cost efficient and serve to promote interdependence between patient and provider, thus improving health literacy and efficiency among consumers of care. Universal health insurance may be the next safety net in the absence of regional comprehensive care centers to establish a medical home model for care of children with chronic genetic conditions. This model aims to improve coordination of care and utilization costs of health care service for both individuals and third-party payers.³⁸ Health care utilization costs and

insurance benefit limitations are important factors for consumer, provider, and health care practitioners under the new service delivery system in the Affordable Care Act.

Acknowledgments

Grant support to the M.R.R. through PHEC Reunification Endowments Franklin Trust, Drexel University College of Medicine, Department of Pediatrics, Division of Hematology, St Christopher's Hospital for Children, Philadelphia, PA.

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TABLE 1

Sample Description

	N = 53 (n [%])
Sex (female)	24 (44.4)
Ethnicity	
African American	51 (94.4)
Hispanic	1 (1.9)
Other	1 (1.9)
Hemoglobinopathies	
HBSS	31 (57.4)
HBSC	19 (35.2)
HBS β^0 thalassemia	2 (3.7)
SJ Baltimore	1 (1.9)
Caregiver relationship	
Mother	46 (85.2)
Father	4 (7.4)
Grandmother	3 (5.6)
Insurance type	
Public	40 (74.1)
Private	13 (24.1)
Neighborhood census data	
Percent below poverty >25.1%	19 (35.2)
High school dropout >20.7%	4 (7.4)
Female head of household >34.3%	16 (29.6)
Male unemployment >37.1%	19 (35.2)

TABLE 2

Comparison of Psychosocial and Health Variables by Insurance Type

Measures	Full Sample (M [SD]) N = 53	Public Insurance (M [SD]) n = 40	Private Insurance (M [SD]) n = 13	Group Difference (F)	Cohen d
Disease complications	3.21 (2.13)	3.62 (2.08)	1.92 (1.80)	6.96*	0.87
Total health care utilization	10.40 (8.72)	12.57 (8.86)	3.69 (3.22)	12.40**	1.33
Urgent health care utilization [†]	0.57 (0.51)	0.74 (0.46)	0.07 (0.25)	24.06**	1.67
FDI [†]	1.61 (1.18)	1.75 (1.11)	1.16 (1.36)	2.37	0.48
PedsQL physical health	69.75 (21.55)	64.84 (20.51)	84.85 (17.85)	9.91**	1.04
PedsQL psychosocial health	67.88 (18.11)	63.03 (17.22)	82.82 (11.69)	14.82**	1.34

* $P < 0.05$.** $P < 0.01$.[†] Variable log transformed.

FDI indicates Functional Disability Inventory; PedsQL, Pediatric Quality of Life Inventory.

TABLE 3**Hierarchical Regression Predicting Health Care Utilization**

Variables	Cumulative R^2	F	β	Change in R^2
Total health care utilization				
Step 1	0.42	36.79**		0.42
Disease complications			0.59**	
Step 2	0.47	22.44**		0.05
Insurance type			-0.24*	
Step 3	0.50	16.40**		0.03
Distressed neighborhood			0.17	
Urgent health care utilization				
Step 1	0.43	37.94**		0.43
Disease complications			0.52**	
Step 2	0.56	31.54**		0.13
Insurance type			-0.38**	
Step 3	0.56	20.71**		0.01
Distressed neighborhood			-0.04	

* $P < 0.05$.** $P < 0.01$.