Center for Financial Security
UNIVERSITY OF WISCONSIN-MADISON
Retirement & Disability Research Center

Kendall L. Moody
PhD, LCSW

Howard University

Medicaid Receipt and Health Outcomes in Youth with Sickle Cell Disease

Center for Financial Security

University of
Wisconsin-Madison

1300 Linden Drive
Madison, WI 53706

608-890-0229
cfs@mailplus.wisc.edu
cfs.wisc.edu

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1. Abstract

Youth diagnosed with sickle cell disease (SCD) are at risk for morbidity, mortality, and decreased quality of life. The receipt of Medicaid among youth diagnosed with a chronic illness is associated with favoring outcomes, such as increased well-child visits and decreased emergency room (ER) and inpatient visits; however, the relationship between Medicaid receipt and health outcomes among children and adolescents diagnosed with SCD is not well understood. While vulnerable populations relying on the receipt of Medicaid receive access to healthcare services, there is variability amongst research studies examining Medicaid receipt and health outcomes among beneficiaries. Therefore, this preliminary research study investigates whether the receipt of Medicaid is linked with disease severity (e.g., frequency of pain crises and disease-related symptoms) among youth diagnosed with SCD. A total of 150 patient-parent dyads were enrolled in this cross-sectional quantitative study. Parents of pediatric patients completed a demographic information questionnaire, which gathered Medicaid status and the frequency that the patient experienced pain along with other disease-related symptoms. A linear regression model showed Medicaid receipt was associated with both a higher frequency of pain and disease-related symptoms. Findings highlight the complexities that encompass Medicaid research involving youth with chronic illness and provide implications for future research.

Keywords: Medicaid, Supplemental Security Income, Sickle Cell Disease, Chronic Illness, Pain

JEL Codes: I12 Health Behavior; I13 Health Insurance, Public and Private

2. Introduction

Youth diagnosed with sickle cell disease (SCD) are at increased risk of adverse medical outcomes, such as pain, infection, and early death (Lee et al., 2019). The prevalence of SCD across the nation is rare, impacting approximately 100,000 individuals; however, it is the most common genetic blood disorder in the US and is associated with increased healthcare utilization (Moody, 2022; U.S. Department of Health & Human Services, 2022).

For patients with SCD, Medicaid pays a significant portion of their healthcare needs. Recent data shows there are 41,995 Medicaid beneficiaries with SCD (Centers for Medicare & Medicaid Services [CMS], 2022). On average, Medicaid pays up to five times more for the health care of those with SCD in comparison to those without this disease (Grady et al., 2021), this is significant considering patients may have a lifetime SCD-related medical expense of $1.1 billion, according to a 2009 analysis of Medicaid data (Kauf et al., 2009).

Although Medicaid provides insurance coverage and healthcare access to children, pregnant women, adults, the disabled, and elderly persons with low-income or living in poverty, literature investigating Medicaid recipients' health outcomes have variable outcomes (Dennett & Baicker, 2022). For example, Liu et al. examined the association between Medicaid status on health outcomes of patients after receiving bariatric surgery and found no association between Medicaid receipt and weight loss outcomes (Liu et al., 2021). Christopher et al. found similar results after investigating the connection between Medicaid status and the health outcomes of patients receiving clinical care and found no association between Medicaid receipt and control of diabetes (Christopher et al., 2016). The Oregon Health Insurance Experiment, which was a larger study that examined health outcomes of 6,387 adults receiving Medicaid, also found Medicaid receipt had no demonstrable effects on physical health (Finkelstein et al., 2012). The results of these studies may be surprising given that Medicaid status has been shown to increase healthcare utilization, access to specialty care and medications, and decrease mortality (Baiker et al., 2013; Sommers et al., 2014; Thompson, 2017; Torres et al., 2017; Wherry & Miller, 2016). Seemingly, youth with SCD who receive Medicaid would have favoring outcomes; yet, this association is not well established. Therefore, the current study aims to discover whether Medicaid receipt predicts the frequency of pain and disease-related symptoms among youth diagnosed with SCD. It is hypothesized that Medicaid receipt will be a predictor for a lower frequency of pain and SCD-

related symptoms. Discovering this connection may inform Medicaid policy and highlight avenues for improving said policies.

3. Methodology

3.1 Study Participants

The participants in our study consisted of patient/parent dyads from a comprehensive sickle cell program at a children's hospital in Southeastern Virginia. Following a review from two institutional review boards, Eastern Virginia Medical School and Norfolk State University, 150 patients aged 8–17 years old and their parents completed assent and consent forms, respectively. Patients had a diagnosis of SCD, spoke English fluently, and were absent of intellectual disabilities. Parents were above the age of 18 years old and spoke English fluently. I approached patients and parents to participate in the study during their regularly scheduled visits.

3.2 Measures

3.2.1 Medicaid coverage.

I created a demographic information form. On this form, parents indicated whether their child currently receives Medicaid.

3.2.2 Pain & disease-related symptoms.

The demographic information form completed by parents was used to gather the frequency of pain and disease-related symptoms. For pain, parents indicated whether their child experienced pain *never*, *sometimes*, or *often* over the past 30 days. Concerning disease-related symptoms, parents reported the number of times the patient experienced symptoms related to SCD, aside from pain, over the past 30 days. The *pain* variable was extracted from the *disease-related symptoms* variable to determine the independent association between Medicaid receipt and pain, the hallmark symptom of SCD.

3.2.3 Covariates.

Sociodemographic data was obtained to include patient age and self-identified gender. These were important to gather as age and gender impact patient well-being (Alberts et al., 2021).

3.3 Data Analysis

I used the Statistical Package for the Social Sciences to assist with data analysis. I conducted a univariate analysis to gather description details of the study participants and variables. Next, I deployed a linear regression model, while controlling for age and gender, to investigate whether the receipt of Medicaid predicts health outcomes in youth with SCD. In the model analyzing the association between Medicaid status and pain, I transformed the pain variable from the ordinal scale to three dummy variables for patients who experience pain *never*, *sometimes,* or *always*. In the model investigating the connection between Medicaid receipt and disease-related symptoms, the variable for *disease-related symptoms* is continuous and will not be transformed for this analysis. I used the coefficient on Medicaid to interpret the analysis outcome.

4. Results

4.1 Descriptive Results

Table 1 includes a full presentation of the study participants. Medicaid recipients represented 69% of the study sample. A small majority of patients self-identified as female (52%) and the mean age reported was 12 years old.

Table 1. Descriptive/Frequency Table for Sociodemographic Variables

Variable	Freq.	%	mean
Patient age (8-17 years)	150	-	12.45
Patient gender	-	-	-
Female	78	52	-
Male	72	48	-

The current study investigated the association between Medicaid receipt and health determinants of youth with SCD. A model that includes the receipt of Medicaid and patient covariates (e.g., patient age and dummy variable female gender) as predictors of not experiencing pain is statistically significant (F (3,146) = 6.07, p <.001). As shown in Table 2, I observed a statistically significant correlation between Medicaid receipt and patients who *never* experienced pain over the past 30 days (β = -.28, t = -3.66, p < .001). The model investigating the association between Medicaid receipt and patients who experienced pain *sometimes* was not statistically significant (F (3,146) = 1.37, p = .*25*), suggesting that the null hypothesis could not be rejected. Lastly, the model examining Medicaid as a predictor for patients who experience pain *often* shows

statistical significance (F (3,146) = 3.33, p <.05). The receipt of Medicaid was significantly related to whether the young person would experience pain *often* (β = .20, t = 3.15, p < .01). This would imply a 20-percentage point difference in the probability of experiencing pain *often* between those with Medicaid and those without. This differs from what I expected, as -.20 would be more reasonable.

Table 2. Multiple Regression to Predict Pain

Variable	*B*	β	*SE B*
Never Experiencing Pain (DV)	-	-	-
Medicaid Receipt	-.28***	-.29	.08
Patient age (8-17 years)	-.02	-.11	.01
Patient gender	-	-	-
Female	-.15*	-.17	.07
Male (referent)	-	-	-
Variable	*B*	β	*SE B*
Experiencing Pain Sometimes (DV)	-	-	-
Medicaid Receipt	.08	.08	.09
Patient age (8-17 years)	.02	.10	.02
Patient gender	-	-	-
Female	.16	.13	.13
Male (referent)	-	-	-
Variable	*B*	β	*SE B*
Experiencing Pain Often (DV)	-	-	-
Medicaid Receipt	.20**	.25	.06
Patient age (8-17 years)	.00	.01	.01
Patient gender	-	-	-
Female	.03	.04	.06
Male (referent)	-	-	-

Notes: *p < .05. **p < .01. ***p<.001.

To analyze whether the receipt of Medicaid is a predictor for the frequency of disease-related symptoms aside from pain, the regression model consisted of the variables for Medicaid receipt and patient covariates (e.g., patient age and dummy variable female gender) as predictors of disease-related symptoms. The model was statistically significant (p <.001). Based on the

regression analysis, Medicaid receipt is significantly related to disease-related symptoms after controlling for age and gender (β = .76, t = 4.10, p < .001.) This examination included results that were not expected, as the receipt of Medicaid predicted youth with SCD to experience more symptoms.

Table 3. Multiple Regression to Predict SCD-Related Symptoms

Variable	*B*	β	*SE B*
Medicaid Receipt	.77***	.32	.19
Patient age (8-17 years)	.05	.15	.03
Patient gender	-	-	-
Female	.28	.13	.17
Male (referent)	-	-	-

Notes: ***p<.001. SCD = sickle cell disease

5. Discussion

The current study was the first to examine whether the receipt of Medicaid predicted the frequency of pain and disease-related symptoms in youth diagnosed with SCD. The results of the study showed that Medicaid receipt is a predictor of increased pain and disease-related symptoms in youth with SCD. These results show the association between Medicaid and health outcomes of those with chronic illness, specifically youth with SCD, to be complex.

Prior research shows that receiving Medicaid is not enough to improve the health determinants of individuals with SCD (Desai et al., 2020; Grady et al., 2021). This may be, in part, due to the multifaceted nature of symptoms related to this illness. It has been well documented that the exacerbation of pain and other SCD-related symptoms is not one-dimensional; rather, it is caused by a series of factors (Myrvik et al., 2013; Porter et al., 1998; Takaoka et al., 2021). This suggests that, while the receipt of Medicaid may give patients access to healthcare to treat physical symptoms, other underlying issues may be present and influential. Living with a lower income and poor psychological well-being, for example, have been found to be predictors of SCD-related pain (Knisely et al., 2020; Leuche et al., 2022). More research is warranted to further understand potential mediating factors for Medicaid receipt and health outcomes in SCD.

Another idea to consider is the time in which children are enrolled in Medicaid. Selection into Medicaid is not random; therefore, youth with SCD must apply and are selected based upon a selection criterion (CMS, 2022). Perhaps by the time children qualify for Medicaid, they are already experiencing a more severe disease. This connection may explain how patients enrolled in Medicaid also receive more pain medication and have higher healthcare utilization in comparison to youth with SCD without Medicaid (Grady et al., 2021; Mikosz et al., 2020). Research examining Medicaid policies may provide more clarity.

5.1 Medicaid and SSA Policy Implications

Pediatric patients who receive supplemental security income (SSI) are also jointly qualified to receive Medicaid. Therefore, implications based on findings from the current study may be attributed to Medicaid and SSA policies. Efforts made by the CMS and SSA to improve health outcomes in individuals with SCD must be acknowledged. In 2005, CMS added the coverage of chronic transfusions, genetic counseling, and the Early and Periodic Screening, Diagnostic, and Treatment services (EPSDT), which provides comprehensive treatment for low-income youth. This has improved access to healthcare and increased the use of healthcare services (Perkins, 2017).

While efforts have been made by CMS and SSA program officials to advance policies, room for improvement remains. As previously mentioned, literature showing psychological and social constructs contribute to disease-related symptoms, so it's understandable that policies solely targeting symptoms are ineffective. Perhaps implementing policies targeting psychosocial factors may improve the association between Medicaid, SSI receipt, and health determinants. CMS has recognized this issue and has identified the development of effective benefit design for mental health services for children, youth, and their families as a priority over the next 3 years (CMS, 2005).

5.2 Limitations

Limitations within the current research study warrant mentioning and further discussion. First, the current study used a cross-sectional design, which does not allow for cause-effect interpretation and only captures Medicaid enrollment and disease status at the point parents completed the survey. A longitudinal study that also examines the state of the child's disease before and after Medicaid enrollment may be more informative. Also, a small sample size of 150 participants enrolled from one children's hospital limited generalizability. A multi-center research study may

yield better results. Finally, the current study did not include a control group to include children with SCD who lacked insurance or those who received public insurance for comparison.

6. Conclusion

The study findings highlight the complexities in understanding the association between Medicaid enrollment and health outcomes in youth with SCD. Medicaid receipt predicted increases in pain frequency and SCD-related symptoms, which opposes the study hypothesis that Medicaid receipt would predict a lower frequency of pain and SCD-related symptoms. It may be beneficial for future researchers to take a longitudinal approach such as examining how youth with SCD experienced health outcomes pre- and post-Medicaid receipt to further understand this connection.

7. References

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Center for Financial Security

School of Human Ecology
University of Wisconsin-Madison

1300 Linden Drive
Madison, WI 53706

608-890-0229
cfs@mailplus.wisc.edu
cfs.wisc.edu

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