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Association of Food Insecurity With Disease-Related Complications and Healthcare Utilization for Patients With Sickle Cell Disease

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ABSTRACT

Background: Food insecurity is one of several household material hardships (HMH) recognized for their impact on disease severity and healthcare utilization in patients with chronic disease. Sickle cell disease (SCD) is a chronic disease, disproportionately affecting patients of lower socioeconomic status, that results in high rates of disease-related complications and high healthcare utilization. This study examines the relationship between food insecurity and SCD-related complications and healthcare utilization.

Methods: Patients (ages 2–24 years) and/or their parents were surveyed to assess food insecurity status during routine SCD clinic visits from July 2015 to July 2019. Food insecurity status was assessed using the United States Department of Agriculture (USDA) Food Security Short Form (six-item), with a lookback period of 12 months. Sociodemographic characteristics, disease-related complications, and healthcare utilization were abstracted from electronic health records.

Results: Overall, 22% ($n = 25$) of participant households were food insecure. Food insecurity was associated with significantly higher annual rates of acute chest syndrome (aOR = 3.12, 95% CI: 1.27–7.67), prevalence of cholecystectomy (aOR = 6.29, 95% CI: 1.66–23.80), and a higher number of hospitalizations (aOR = 2.40, 95% CI: 1.04–5.52).

Conclusions: The rates of food insecurity among sampled households of pediatric and young adult patients with SCD were much higher than national (13.4%) and local county rates (13%). Food insecurity was independently associated with more disease-related complications and higher healthcare utilization even after adjusting for age, sex, and sickle cell type. These results suggest food insecurity may be a modifiable contributor impacting morbidity in patients with SCD and should prompt further study into these relationships.

Abbreviations: AAP, American Academy of Pediatrics; ACS, acute chest syndrome; HMH, household material hardships; PYA, pediatric and young adult; QOL, quality of life; SCD, sickle cell disease; SNAP, Supplemental Nutrition Assistance Program; USDA, United States Department of Agriculture; VOE, vaso-occlusive episode.

1 | Introduction

Sickle cell disease (SCD) is an inherited genetic disorder that impacts over 100,000 people in the United States [1]. It is a debilitating condition characterized by painful vaso-occlusive episodes (VOEs) and additional disease-related complications like acute chest syndrome (ACS), chronic kidney disease, stroke, blood clots, splenic sequestration, cholelithiasis, and recurrent infections; additionally, either due to such complications or as a preventive strategy, patients with SCD often require procedures like splenectomy, cholecystectomy, and tonsillectomy [1–3]. These complications contribute to high morbidity and mortality, with a reduction in average life expectancy by approximately 25–30 years when compared to the general population [4].

SCD-related complications often require urgent and emergency care visits that can result in hospital admissions [5, 6]. Thus, healthcare utilization, when defined as the annual number of emergency department visits, hospitalizations, and/or acute outpatient visits, is higher in patients with SCD than in patients with other chronic diseases [7]. Prior retrospective, prospective, and cross-sectional studies have shown that increased healthcare utilization is independently associated with poor quality of life (QOL), including among pediatric and young adult (PYA) patients with SCD [8–10]. Additionally, high rates of healthcare utilization contribute to patients' financial burden [10, 11]. A study analyzing commercial claims from 2007 to 2018 found that average lifetime spending attributable to SCD-related treatment among privately insured patients was $1.7 million, of which $44,000 were out-of-pocket expenses [11]. Between 2013 and 2019, annual average spending by Medicaid for patients with SCD was nearly 10-fold that of all other enrollees ($63,436 vs. $6636) [11]. Among patients with SCD, studies have suggested that higher costs can be attributed in large part to higher healthcare utilization [10]. Thus, reducing healthcare utilization can potentially benefit QOL and the financial burden among a patient population with a high burden of socioeconomic disadvantage.

Few disease-modifying therapies for SCD are currently available to reduce disease-related complications and healthcare utilization [12]. Hydroxyurea, first approved for SCD in 1998, has faced barriers to adoption, such as costs, lack of patient and clinician knowledge, and negative perceptions of risks and side effects [13]. Newer approved therapies, including L-glutamine and crizanlizumab, are also difficult to access for patients due to cost and requirements by Medicaid for prior authorization; additionally, in the case of monthly infusions required for crizanlizumab, patients commonly face transportation barriers [14]. These barriers are also present for gene therapy, which is a potentially curative option for patients with SCD [15]. Addressing the barriers that limit benefit from these therapies is important; however, concurrently identifying other modifiable contributors to disease-related complications and healthcare utilization in SCD may be beneficial to pursue.

Indeed, studies in patients with diabetes have shown that household material hardships (HMH) like food insecurity are independently associated with disease complications and healthcare utilization; furthermore, interventions targeted at reducing food insecurity in these patients have shown a reduction in disease-related complications and healthcare utilization (independent of other medical interventions) [16]. Relatedly, HMH, such as lack of access to transportation, unstable housing, and inadequate nutrition, have been shown to significantly impact disease-related complications in patients with SCD as well [17–21].

In particular, poor nutritional status has been associated with lower patient QOL, more disease-related complications, and higher healthcare utilization in patients with SCD [22–26]. However, nutritional status is not consistently defined or easily screened [27]. Alternatively, food insecurity is defined by the United States Department of Agriculture (USDA) as a lack of access to enough food for individuals to live an active, healthy life; survey tools that operationalize this construct, while not entirely comprehensive assessments of nutritional status, do provide a longitudinal measure that has shown to correlate with socioeconomic well-being and has been studied as a modifiable risk factor of chronic disease [27–29]. However, food insecurity's relation to disease-related complications and healthcare utilization has not been studied specifically in patients with SCD. Furthermore, considering that patients with SCD in the United States are predominantly Black, any question regarding HMH must acknowledge the long history of institutional racism, including within the healthcare complex, that drives a disproportionate burden of HMH, like food insecurity in this population, and makes such inquiries even more important to investigate [30].

Relatedly, a 2019 study of PYA patients with SCD seen at our urban academic pediatric hospital on Chicago's South Side screened for food insecurity and found a rate of 35% amongst respondents [31], which was nearly three-fold the estimated rate of pediatric food insecurity in our county that same year [29, 31, 32]. Given the high prevalence of food insecurity in prior sampled patients and the imperative to identify modifiable risk factors for SCD-related morbidity, we studied whether food insecurity among our PYA patients with SCD was correlated with more disease-related complications and higher acute healthcare utilization.

2 | Methods

2.1 | Study Design

This single-center, prospective observational study, from July 2015 to July 2019, enrolled patients with SCD at an urban academic pediatric medical center. During routine SCD clinic visits, all patients with SCD types of hemoglobin (Hgb) SS, Hgb SC, Hgb SB^+, and Hgb SB^0, aged 2–24 years, were approached for study participation and consent. This age range was selected to accommodate the age range constraints of survey tools utilized for a larger study library by our group. For patients under age 18, parents provided written documentation of the informed consent process. Additionally, assent was obtained for patients ages 9–17. The study protocol was approved by the University of Chicago Institutional Review Board.

2.2 | Data Collection

To measure food insecurity, a clinical research assistant administered the United States Department of Agriculture

(USDA) Food Security Short Form (six items), which has a lookback period of 12 months [33]. Responses for the USDA Food Security Short Form were collected from parents/guardians for patients less than 18 years of age and from patients directly if aged 18 or older. Sociodemographic characteristics (such as age, sex, and SCD type), SCD-related complications, and healthcare utilization were obtained via retrospective chart review of all available data from the electronic health record (EHR). SCD-related complications were reported either as annual rates (VOE and ACS) calculated as averages over the 4-year study period or they were reported as binary variables (stroke, deep venous thrombus, pulmonary embolus, priapism, avascular necrosis, asthma, obstructive sleep apnea, cholecystectomy, and splenectomy) defined by their presence/absence by the end of the study period. These diagnoses were made by treating physicians and verified by the investigators (board-certified hematologists and internists). Healthcare utilization variables included separate counts for acute outpatient visits, emergency room encounters, and hospitalizations due to any of the SCD-related complications listed above. These were reported as the total number of each that occurred during the full 4-year study period.

2.3 | Statistical Analysis

The USDA Food Security Short Form was scored 0–6 per standard guidelines, where 0 = food secure, 1 = marginal food security, 2–4 = moderate food insecurity, and 5–6 = high food insecurity. Food insecurity was defined as a score of ≥2 [33]. Bivariate associations between food insecurity and SCD-related complications were evaluated using chi-square or Fisher's exact tests, depending on expected cell frequencies. Wilcoxon rank-sum tests were used to assess associations between food insecurity and VOE and ACS annual rates, as well as healthcare utilization variables. Multivariable logistic and ordinal logistic regression models with SCD-related complications, VOE/ACS annual rates, or healthcare utilization as the dependent variable and food insecurity as the independent variable, also adjusted for age (continuous), sex (male vs. female), and sickle cell type (Hgb SS vs. Hgb SC vs. Other), chosen a priori based on known associations with outcomes. No adjustment for multiple comparisons was made. Statistical significance was defined as $p < 0.05$, and statistical analyses were done using Stata Version 17 (StataCorp LLC, College Station, TX).

3 | Results

Among 115 participants, 56% were female, the mean age was 11 years (standard deviation = 6), and the distribution of SCD types was 77% Hgb SS, 18% Hgb SC, 4% Hgb SB^+, and 1% Hgb SB^0. Of the 22% (25/115) of participants from food-insecure households, 64% (16/25) were classified as moderate and 36% (9/25) as having high food insecurity (Table 1).

Food insecurity was associated with significantly higher annual rates of ACS (0.13 vs. 0.07; aOR = 3.12, 95% confidence interval [CI]: 1.27–7.67, $p = 0.013$; Table 2) and an approximately four-fold increased prevalence of cholecystectomy (28% vs. 7%) (aOR = 6.29, 95% CI: 1.66–23.80, $p = 0.007$). There were no significant associations between food insecurity and development of other SCD-related complications, including rates of VOE (0.50 vs. 0.28; aOR = 1.47, 95% CI: 0.65–3.29, $p = 0.352$; Table 2). When restricting SCD-related complication events to those developed after FI status was assessed, no difference in results was observed (Table S1).

TABLE 1 | Demographic data by food insecurity status.

	Food secure ($n = 90$)	Food insecure ($n = 25$)	p-value
Sex, *n* (%)			
Male	39 (43%)	12 (48%)	0.68[a]
Female	51 (57%)	13 (52%)	
Age (years), *n* (%)			
2–4	19 (21%)	4 (16%)	0.87[b]
5–7	11 (12%)	4 (16%)	
8–12	23 (26%)	6 (24%)	
13–17	18 (20%)	7 (28%)	
18–24	19 (21%)	4 (16%)	
Mean age (SD)	11 (6)	11 (6)	0.96[c]
SCD type, *n* (%)			
Hgb SS	67 (74%)	21 (84%)	0.48[b]
Hgb SC	17 (19%)	4 (16%)	
Other	6 (7%)	0 (0%)	

Abbreviation: SCD, sickle cell disease.
[a]From chi-square test.
[b]From Fisher's exact test.
[c]From *t*-test.

Food insecurity was also associated with a higher number of SCD-related hospitalizations (5.6 vs. 2.6; aOR = 2.40, 95% CI: 1.04–5.52, $p = 0.040$) over the study period (Table 3). Food insecurity status had no statistically significant association with the number of SCD-related emergency room encounters or acute outpatient visits. The former remained true even after excluding one patient with over 100 emergency room visits over the study period. When restricting healthcare utilization events to those occurring after FI status was assessed, no difference in results was observed aside from a loss of statistical significance in the difference in SCD-related hospitalizations by FI status (Table S1).

4 | Discussion

Consistent with our prior studies, we report high levels of food insecurity amongst our study sample of PYA patients with SCD [31]. The results of food insecurity correlating to greater disease severity in our patients with SCD mirror similar relationships observed in other chronic conditions like asthma, ADHD, and diabetes [34–36]. Within the SCD literature, our findings regarding food security, a potential indicator for poor nutritional status, are also similar to prior studies demonstrating associations between poor nutritional status and greater SCD complication severity, which is often represented by higher VOE and ACS incidence [37–39]. For example, Kamal et al. assessed the Subjective Global Assessment, a validated nutrition tool

TABLE 2 | Clinical outcomes by food insecurity status.

	Food secure ($n = 90$)	Food insecure ($n = 25$)	Chi-square p-value	Adjusted OR (95% CI) p-value[a]
Splenectomy, n (%)	12 (13%)	5 (20%)	0.41	1.63 (0.50–5.29) 0.41
Cholecystectomy, n (%)	6 (7%)	7 (28%)	**0.003**	**6.29 (1.66–23.80) 0.007**
OSA, n (%)	21 (23%)	3 (12%)	0.22	0.48 (0.13–1.80) 0.28
Asthma, n (%)	23 (26%)	8 (32%)	0.52	1.37 (0.51–3.71) 0.54
Asthma tx, n (%)	21 (23%)	6 (24%)	0.95	1.05 (0.36–3.05) 0.93
AVN, n (%)	8 (9%)	3 (12%)	0.70[b]	1.63 (0.32–8.41) 0.56
Stroke, n (%)	5 (6%)	3 (12%)	0.37[b]	-[c]
DVT, n (%)	1 (1%)	1 (4%)	0.39[b]	-[c]
PE, n (%)	0 (0%)	1 (4%)	0.22[b]	-[c]
Priapism[d], n (%)	5 (13%)	2 (17%)	0.66[b]	-[c]
	Food secure ($n = 90$)	**Food insecure ($n = 25$)**	**Wilcoxon rank-sum p-value**	**Adjusted OR (95% CI) p-value[a]**
Annual rate of VOE, mean (SD)	0.28 (0.38)	0.50 (0.89)	0.45	1.47 (0.65–3.29) 0.35
Annual rate of ACS, mean (SD)	0.07 (0.22)	0.13 (0.30)	**0.014**	**3.12 (1.27–7.67) 0.013**

Abbreviations: ACS, acute chest syndrome; AVN, avascular necrosis; CI, confidence interval; DVT, deep vein thrombosis; OR, odds ratio; OSA, obstructive sleep apnea; PE, pulmonary embolism; SCD, sickle cell disease; VOE, vaso-occlusive episode.

[a]From regression models adjusting for age, sex, and SCD type (logistic regression for complications and ordinal logistic regression for VOE and ACS).

[b]From Fisher's exact test.

[c]Multivariable logistic regression models were not fit for stroke, DVT, PE, and priapism due to a very limited number of events.

[d]Males only.

that incorporates various variables related to patient history, body composition, and physical exam into a "nourishment" score, in patients with SCD and correlated low nourishment scores to a five times higher incidence of VOE [38]. They and others have also correlated specific lab-measured micronutrient deficiencies, like zinc, to as much as 10 times higher incidence of VOE [38, 39].

Additionally, we found a striking increase (over four-fold) in cholecystectomy prevalence in patients with food insecurity. Potential mediators of this relationship could be the roles of a "Western diet" and associated metabolic syndrome, comprised of dyslipidemia, hyperinsulinemia, and obesity, which have consistently been demonstrated as predisposing factors for developing cholelithiasis and an eventual need for cholecystectomy [40, 41]. Also, many studies have shown that food-insecure individuals, particularly in the United States and including children with SCD, are at higher risk of being limited to consuming nutritionally deficient, high-calorie diets, and subsequently developing obesity and metabolic syndrome [42–45]. While this mechanism of gallstone formation is more relevant to gallstones composed of cholesterol, patients with SCD more typically have gallstones from excess bilirubin due to red blood cell destruction and higher turnover [46]. Nonetheless, nutritionally deficient diets have also been associated with greater red blood cell sickling and destruction, which could conceivably also contribute to the greater prevalence of cholelithiasis and need for cholecystectomy [47–49]. We did not collect information on lipid levels, diabetes status, body mass index, or gallstone composition amongst our patients, but this would be an area of research for future studies to explore.

Healthcare utilization amongst patients with SCD is variable, but on average, higher than for other chronic conditions afflicting PYA patients such as diabetes, inflammatory bowel disease, or cystic fibrosis [50–52]. Additionally, social determinants and HMH have increasingly been recognized as playing key roles in this variability amongst patients with SCD, and patients with more HMH experience higher healthcare utilization [52]. Relatedly, our patients experiencing food insecurity had more SCD-related admissions, but no difference in SCD-related emergency room and acute outpatient visits. A potential explanation

TABLE 3 | Healthcare utilization by food insecurity status.

	Food secure ($n = 90$)	Food insecure ($n = 25$)	Wilcoxon rank-sum p-value	Adjusted OR (95% CI)[a] p-value
Total emergency room visits, mean (SD); median [IQR]	3.5 (17.9)[b]; 0.5 [0–3]	1.0 (1.9); 0 [0–1]	0.35	0.70 (0.29–1.66) 0.42
Total admissions, mean (SD); median [IQR]	2.6 (5.9); 0 [0–2]	5.6 (11.4); 2 [0–5]	**0.045**	**2.40 (1.04–5.52)** **0.040**
Total clinic visits, mean (SD); median [IQR]	12.6 (7.8); 11 [7–18]	12.9 (6.1); 12 [8–17]	0.55	1.20 (0.56–2.56) 0.64

Abbreviations: CI, confidence interval; IQR, interquartile range; OR, odds ratio.

[a]From multivariable ordinal logistic regression adjusting for age, sex, and SCD type.

[b]Excluding 1 patient with >100 emergency room visits, the average (SD) total emergency room visits were 1.6 (2.3) for the food-secure group (adjusted OR = 0.72, 95% CI: 0.30–1.73, $p = 0.47$).

for this may be that food-insecure patients were more likely to have complications and disease severity that specifically required hospitalization.

Overall, these results suggest that in patients with SCD, there is potentially a relationship between food insecurity and the frequency of disease-related complications and healthcare utilization. Further study confirming this relationship and exploring its mediators could have an impact on overall patient morbidity. We attempted to explore the temporality of these relationships by conducting an additional sensitivity analysis in which data on disease-related complications and healthcare utilization were restricted to after FI status was assessed, and the data were consistent with our overall analysis. Furthermore, considering that other HMH, such as transportation barriers and health insurance status, have already been shown to limit patient knowledge of, access to, and adherence with disease-modifying treatments, it is worth exploring whether food insecurity plays a similar limiting role [9, 10]. If so, incorporating care that identifies and intervenes on barriers from HMH, like food insecurity, could help work synergistically with medical treatment to ultimately benefit patients. Such a model would be similar to how outpatient oncology clinics incorporate HMH interventions in a comprehensive care model for patients [53]; in fact, a recent 2022 study demonstrated improved cancer outcomes with interventions that specifically targeted food insecurity [36].

Similarly, national organizations like the American Society of Hematology, the National Academies of Sciences, Engineering, and Medicine, and the National Heart, Lung, and Blood Institute have specifically called for the creation of more SCD centers where multidisciplinary team members can identify and address HMH, such as food insecurity, in the care of patients [54–58]. In terms of screening, the Centers for Medicare & Medicaid Services (CMS), the Joint Commission, and the National Quality Forum are just a few of the regulatory agencies holding health systems accountable for food insecurity screening as part of an increasing recognition of its importance to patient care [59–61]. This aligns with the American Academy of Pediatrics' (AAP) recommendations on screening for food insecurity using a shortened version of the USDA Household Food Security Survey during routine health maintenance visits as a step in the process of mitigating food insecurity [62]. Additionally, the AAP recommends that clinicians obtain knowledge regarding local and federal programs for nutritional assistance, such as school lunch and the Supplemental Nutrition Assistance Program (SNAP), and also familiarize themselves with referral mechanisms to these programs [62]. Finally, the AAP recommends that clinicians allocate resources to educating trainees on food insecurity screening and referrals, advocate for increased funding for these programs at the government level, and support research that investigates associations between food insecurity and health outcomes, amongst other things, as this study intends [62]. Similar recommendations regarding screening and referrals to assistance programs have been made to general practitioners taking care of adult patients by independent investigators and the American Academy of Family Physicians [63, 64]. Given that many hematologists treating patients with SCD also serve as primary care physicians for both pediatric and young adult patients, this only reinforces the need for incorporation of food insecurity screening in their practice.

Being cognizant of, screening for, and addressing HMH like food insecurity in the care of patients with SCD should also be done with a conscious effort to understand why these patients face such a high burden of non-clinical determinants to their health in the first place: namely, the racial makeup and associated racism they are subject to. Even within healthcare, negative provider attitudes, biases, and stigma toward Black patients, lack of institutional investments into their care, or disproportionate shortage of national funding allocated to advancing SCD therapies are all forms of institutionalized racism that healthcare providers have long been complicit (or even active agents) in [30]. With this in mind, it is even more imperative for medical providers and researchers to make active efforts to investigate and address HMH such as food insecurity as outlined in the recommendations above.

Our study findings should be interpreted considering certain limitations. This was a single-center study conducted at an urban academic medical center with a longstanding, multi-site, self-serve food pantry program [59]. Estimates of food insecurity in this sample may not reflect those of other sites. Additionally, in the process of consenting patients, we experienced high turnover in clinical research assistants who approached patients, and thus, are not able to report on rates of non-consent, which could overlook

potential non-response bias. The sample size limits the power to detect smaller differences between food-secure and food-insecure groups. Inversely, results such as differences in cholecystectomy prevalence had large confidence intervals, which indicate wide variation from relatively small sample sizes. The lack of adjustment for multiple comparisons also limits the interpretation of the differences observed. Healthcare utilization data were limited to utilization events at our medical center. Care provided outside our healthcare system's EHR was not captured, which could bias estimates of differences between groups, especially if patterns of outside healthcare utilization differed by food insecurity status. We also were not able to collect information on body mass index (BMI), which limits the interpretation of the higher prevalence of cholecystectomy observed in our food-insecure patients.

We have previously shown an association between food insecurity and poorer QOL in our patients with SCD [65]. This study adds important clinical correlates of food insecurity for patients with SCD. Emerging evidence about the value and impact of food insecurity screening and intervention in the general pediatric and adolescent practice contexts should also inform SCD-specific interventions to improve patient outcomes.

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Conflicts of Interest

The authors declare no conflicts of interest.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Supporting Table 1: pbc32100-sup-0001-Tables.docx