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BRIEF REPORT

Food insecurity and quality of life in patients with sickle cell disease

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Abstract

Little is known about the relationship between quality of life (QOL) and food insecurity (FI) among patients with sickle cell disease (SCD). We hypothesized FI is associated with lower QOL in children and young adults with SCD. Overall ($N = 99$), 22% screened positive for FI. Supplemental Nutrition Assistance Program (SNAP) enrollment was 50 and 71% among people from food secure and FI households, respectively. A higher FI score was correlated with lower overall QOL ($r = -0.22$, $p = .03$), specifically lower QOL in worry and communication domains. Interventions for FI beyond SNAP may be important for QOL among people living with SCD.

KEYWORDS
child, food insecurity, hemoglobin, quality of life, sickle, young adult

1 | INTRODUCTION

Sickle cell disease (SCD), a genetic disorder, affects approximately 100,000 individuals in the United States.[1–3] Diagnosed in early childhood, it is a debilitating chronic disease characterized by recurrent episodes of acute vaso-occlusion manifesting as severe pain, neurovascular defects, acute chest syndrome, renal failure, and premature death.[4–6] The Cooperative Study of Sickle Cell Disease estimates life expectancy of 45 years for patients with Hb SS and 65 years for those with Hb SC.[3,7] Advances in care, including disease modifying drugs, routine use of hydroxyurea, antimicrobial prophylaxis, and comprehensive care by specialized centers, have contributed to an increase in overall life expectancy.[1] However, quality of life (QOL) in the majority of patients with SCD remains poor and lower than in other chronic conditions, particularly in psychological well-being, scholastic attainment, and ability to work domains.[8–10] Identification of modifiable factors affecting QOL is critical to improve the lives of people with SCD.

Household material hardships (HMH), including difficulty accessing food, housing, transportation, and basic utilities, have long been understood to impact health related QOL and outcomes among

Abbreviations: CRA, clinical research assistant; FI, food insecurity; FS, food security; HMH, household material hardship; PYA, pediatrics and young adult; QOL, quality of life; SCD, sickle cell disease; SNAP, supplemental nutrition assistance program; USDA-FSSF, United States Department of Agriculture-Food Security Short Form.

children.[11–14] Identification of HMHs at the point of care enables social care interventions, adjustment of therapies, and linkage to community-based supports, allowing data generation for resource alignment and advocacy.[15,16] In other pediatric populations, including those with chronic disease, food insecurity (FI)—the most prevalent HMH—has been associated with poor physical and mental health.[16–18] While pediatric and young adult (PYA) patients with SCD are more likely than their peers to live in a food insecure household, little is currently known about the relationship between FI and QOL in this population.[19]

Prior studies of households with a child hospitalized or seen in the emergency department at an urban academic pediatrics hospital yielded 12 month FI rates of 32 and 45%, respectively.[20,21] These rates were threefold to fourfold higher than national estimates for the general population of US households with one or more dependents. Rates of Supplemental Nutrition Assistance Program (SNAP) participation, which provides food benefits to households of low income, elderly, or disabled persons, were also high compared with national samples.[22,23] This study was designed to estimate, among PYA SCD patients, household FI rates, and the relationship between FI and QOL. We hypothesized PYAs with SCD living in food insecure households would have lower QOL than peers.

2 | METHODS

We performed a single center, cross-sectional observational study from July 2015 to July 2019 of SCD patients treated as outpatients at an urban academic pediatric medical center. Patients aged 5–24 years were approached for participation and consented during a routine SCD clinic visit. Parents provided documentation of the informed consent process for patients <18 years, with assent for participants 9–17 years. The protocol was approved by the IRB (#14-0963) and was conducted in accordance with Declaration of Helsinki guidelines.

2.1 | Data collection

A clinical research assistant (CRA) approached all eligible patients and administered the informed consent process and survey. Enrolled patients ($N = 99$) completed a baseline interview with the CRA ascertaining sociodemographic characteristics, FI (United States Department of Agriculture Food Security Short Form [USDA-FSSF])) and QOL ($PedsQL_{TM}$ Sickle).[24–26] For patients <18 years, the survey was administered to the parent/caregiver; patients 18+ years self-responded.

2.2 | Statistical methods

The USDA-FSSF with a 12-month look back period was scored 0–6, and categorized: food secure (score = 0), marginal food security [FS] (= 1), moderate FI (= 2–4), or high FI (= 5–6). Dichotomous analysis compared FS (score = 0–1) to FI (≥ 2). $PedsQL_{TM}$ Sickle (score 0–100, <60 indicates clinically significant low QOL) is validated for patients with SCD and queries SCD-specific domains of Pain, Worry I (worry about pain, need for emergency care or hospitalization), Worry II (worry about stroke or acute chest syndrome), Emotions, Treatment and Communication (difficulty expressing concerns regarding SCD with healthcare team).[25,27] Associations between FI and QOL scores (overall and domain-specific) were evaluated using Spearman rank correlations and chi-squared tests or Fisher's exact tests. Statistical analyses were performed using Stata Version 16.[28]

TABLE 1 Demographic and health characteristics of study population. *p* Values from chi-squared tests unless otherwise noted (FET, Fisher's exact test).

	Total	FS (score 0–1)	FI (score 2+)	*p* Value
Gender, *n* (%)				.79
Female	52 (53%)	41 (53%)	11 (50%)	
Male	47 (47%)	36 (47%)	11 (50%)	
Race, *n* (%)				>.99 (FET)
Non-Hispanic Black	95 (96%)	73 (95%)	22 (100%)	
Hispanic Black	1 (1%)	1 (1%)	0 (0%)	
Mixed race	3 (3%)	3 (4%)	0 (0%)	
Age (y), *n* (%)				.71
5–7	17 (17%)	12 (16%)	5 (23%)	
8–12	30 (30%)	24 (31%)	6 (27%)	
13–17	27 (27%)	20 (26%)	7 (32%)	
18–24	25 (25%)	21 (27%)	4 (18%)	
Genotype, *n* (%)				>.99 (FET)
Hgb SS	75 (76%)	57 (74%)	18 (82%)	
Hgb SC	18 (18%)	14 (18%)	4 (18%)	
Hgb SB+	3 (3%)	3 (4%)	0 (0%)	
Hgb SB−	3 (3%)	3 (4%)	0 (0%)	
SNAP, *n* (%)				.08
No	43 (45%)	37 (50%)	6 (29%)	
Yes	52 (55%)	37 (50%)	15 (71%)	

3 | RESULTS

Table 1 summarizes sociodemographic characteristics, stratified by FS status. Among 22% of patients with FI, 64% ($n = 14$) were moderately food insecure and 36% ($n = 8$) had high FI. Among 78% who were food secure, 17% were marginally food secure. The rate of SNAP enrollment in the previous 12 months was 50% among those food secure and 71% among food insecure participants ($p = .08$). Higher FI score was associated with lower overall QOL score ($r = -0.22$, $p = .03$; Figure 1) as well as lower QOL in the Worry sub-domains Worry I ($r = -0.30$, $p = .002$), Worry II ($r = -0.25$, $p = .03$), and the communication sub-domain ($r = -0.30$, $p = .003$).

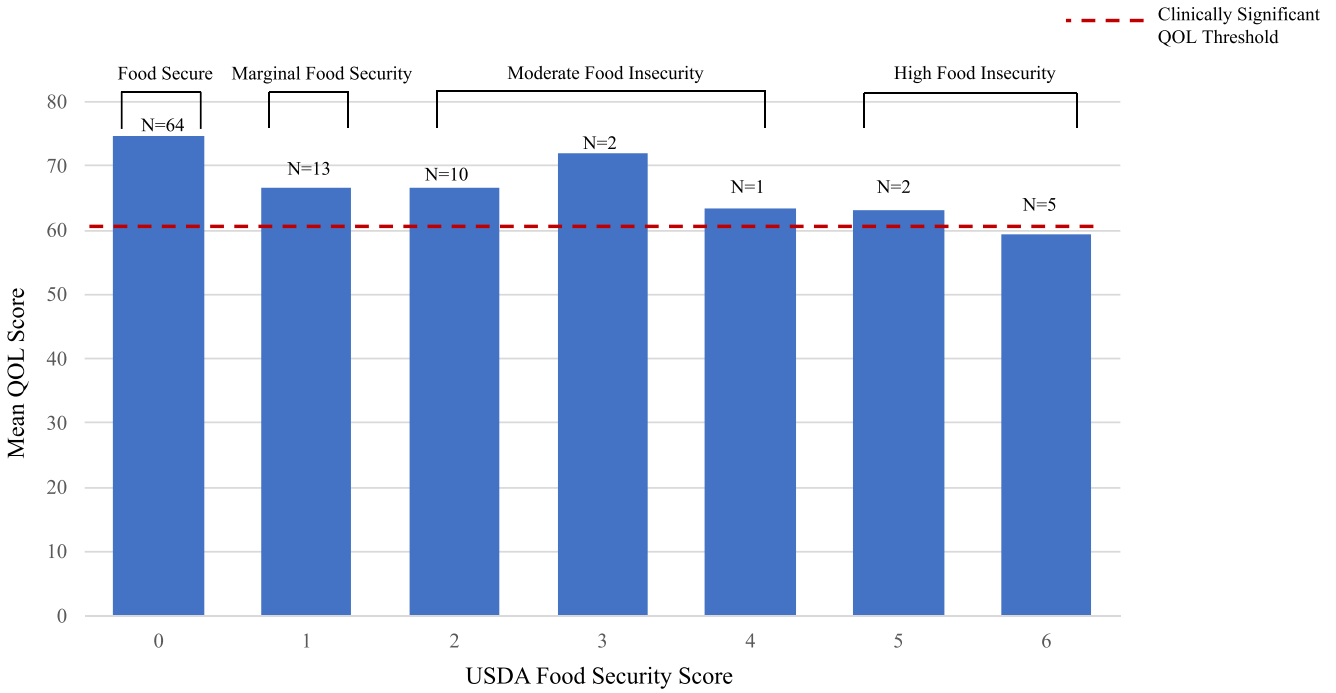

FIGURE 1 PedsQL™ sickle mean quality of life scores by patient reported United States Department of Agriculture Food Security short form scores. The food security score can be categorized as food secure (FS) (score of 0), marginal FS (score of 1), and moderate food insecurity (FI) (score of 2–4) or high FI (score of 5–6). $N = 97$ due to two patients missing the QOL score. The red dashed line indicates a mean QOL score of 60 (the clinically significant threshold for low quality of life).[25]

4 | DISCUSSION

In this study, more than one in five PYA SCD patients seen in the ambulatory setting had FI and another 37% of patients were food secure with SNAP benefits. In general populations, SNAP is a proven, effective intervention for FI that can reduce the severity of FI and, for some, is sufficient to achieve FS.[22,23] Our study corroborates high FI rates seen in acute pediatric SCD care settings.[29–31] It is also consistent with a prior report showing higher rates of FI among children with special healthcare needs, including households receiving governmental support like WIC, SNAP, housing assistance, and Federal Supplemental Security Income.[32]

As hypothesized, higher levels of FI were associated with overall poorer QOL, more worry about SCD complications and need for acute hospitalizations, and poorer communication with members of the healthcare team about symptoms and questions regarding SCD. These findings corroborate evidence that FI can compromise QOL, interpersonal communication and trust, including in the healthcare setting.[33] FI has also been associated with more frequent experiences of discrimination in the pediatric care setting and is known to be a stressful and stigmatizing condition, especially for families with children.[33,34] Lack of clinician awareness of FI may impede effective SCD care at the population level, compromise parent and child QOL, and demoralize individual patients, especially if they disclose FI in the clinical setting but receive no support. FI is a known and modifiable threat to physical, mental, and social health of children and young adults.[16,18] The high rate of FI in our SCD population supports the call by National Academies of Science, Engineering and Medicine and others for integration of social with medical care for SCD.[15]

Study findings should be interpreted in light of certain limitations. Data were collected over a several year period prior to the COVID-19 pandemic, an event that had a major impact on national and local FI rates. Participants were enrolled from a geography with a high proportion of people living with poverty, which may limit generalizability. However, the predominantly African American and Black population in this geography and study sample reflect the demographic distribution of SCD. Additionally, study findings are limited due to performing bivariate cross-sectional analyses that did not account for potential confounders that could influence both FI and QOL.

A recent randomized trial at the study site found FI can be addressed without exacerbating experiences of discrimination using a universal intervention approach.[35] Still, many programs are using FI screening to drive social care. Our work depicts the relationship between lower QOL and higher FI among people with SCD, especially in the worry and communication domains. Providers should be trained and prepared to respond in a nonstigmatizing manner before implementing routine assessment for FI in SCD practice.[36,37] Additional analysis, including multivariate analysis with potential confounders, is planned moving forward to help inform interventions in this important space.

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CONFLICT OF INTEREST STATEMENT

Dr Lindau discloses that under the terms of Grant Number 1C1CMS330997-01-00 (ST Lindau, PI) from the Department of Health and Human Services, Centers for Medicare & Medicaid Services, recipients were expected to develop a sustainable business model to continue and support the model that we tested after award funding ended. Dr. Stacy Lindau was the founder and owner of a social impact company, NowPow, LLC, which was acquired by Unite USA Inc. in 2021. Dr. Lindau is an unpaid advisor to and holds stock in Unite USA Inc. Neither the University of Chicago nor UChicago Medicine is endorsing or promoting Unite USA Inc. or its business, products, or services. Dr. Lindau is an editor on Female Sexual Dysfunction for UpToDate, Inc. and received royalties <$100/year in 2019, 2020 for this work. Subsequent royalties have been paid to the University of Chicago. Dr. Lindau and her spouse own equity in Glenbervie Health, LLC.The University of Chicago has filed patents (pending) for the Bionic Breast Project, a project led by S.T.L. The other authors declare no conflict of interest.

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