

Mental health assessment of youth with sickle cell disease and their primary caregivers during the COVID-19 pandemic

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Abstract

Youth with sickle cell disease (SCD) and their caregivers are susceptible to stress and depression, perhaps exacerbated by pandemic-associated health and economic concerns. Most of the 50 youth-caregiver dyads enrolled in the multisite trial, Hydroxyurea Adherence for Personal Best in Sickle Cell Treatment (HABIT), took an online survey of self-reported mental health symptoms and food insecurity during the 2020 COVID-19 pandemic. Compared to largely pre-pandemic results, prevalence of mental health symptoms in dyad members appeared to have shifted: fewer youth and more caregivers were affected during the pandemic; many of both groups lacked optimism. Pandemic/post-pandemic screening of youth with SCD for mental health symptoms and food insecurity appears warranted.

KEYWORDS

anxiety, depression, mental health, pandemic, sickle cell disease, youth

1 | INTRODUCTION

Most people living with sickle cell disease (SCD) in the United States identify as Black and/or Latino,¹ whose communities are disproportionately

underresourced and vulnerable to adverse social factors.²⁻⁴ Social, economic, and disease-related factors render youth with SCD and their caregivers susceptible to mental health issues; for example, depression and anxiety.⁵⁻¹¹ Among adolescents with chronic health conditions, depressive symptoms are associated with less disease self-management and more disability and hospitalization.¹²

Abbreviations: HABIT trial, Hydroxyurea Adherence for Personal Best in Sickle Cell Treatment; SCD, sickle cell disease; SVI, Social Vulnerability Index.

Societal disruptions during the 2020 COVID-19 pandemic disproportionately affecting communities with lower socio-economic and greater minority status, included prolonged school and workplace closures, social isolation, economic insecurity, and impaired mental health, such as depression, anxiety, loneliness.¹³⁻¹⁶ Blacks with SCD and COVID-19 infection experienced disproportionately more hospitalizations and pneumonias compared to other Black Americans.^{17,18} Pandemic-related health concerns of SCD-affected families may have augmented their pre-existing risks to mental health.

Fifty dyads of youth with SCD ages 10–18 years and their primary caregivers enrolled in our multi-site randomized, controlled trial, HABIT (“Hydroxyurea Adherence for Personal Best in Sickle Cell Treatment”) aimed at improving youth’s adherence to hydroxyurea therapy, based on their flagging fetal hemoglobin levels.¹⁹ The HABIT trial was conducted from 2018 through 2021 at four pediatric SCD centers located in New York City and Philadelphia. Trial enrollment occurred between May 2018 and December 2020, with 89% enrolled prior to onset of the COVID-19 pandemic. Participants completed the pediatric or adult PROMIS multi-question measure of depressive symptoms at trial enrollment.²⁰ At pandemic onset, study visits were largely conducted virtually.

The Social Vulnerability Index (SVI) is a composite scale developed by the Centers for Disease Control and Prevention for estimating vulnerability to social adversity by United States census tract. The SVI was calculated for our sample using pre-pandemic standards. SVI ranges 0–1.0; higher values represent greater vulnerability.²¹ Nationally, high SVI was associated with higher prevalence of COVID-19 infections.²²

We hypothesized that (a) our sample had high SVI; (b) mental health symptoms, including depressive symptoms, were common among HABIT dyads during the early months of the COVID-19 pandemic; and (c) food insecurity, a measure of economic instability, was frequently experienced.³ From June to October 2020, enrolled dyads were offered participation in an open-access online survey of standardized adult core mental health symptoms, which focused on how the COVID-19 pandemic may have affected them personally.²³

We minimally adapted survey questions for study of youth. Like the PROMIS tool, the pandemic-focused survey asked about mental health symptoms over the preceding week. PROMIS asked multiple questions about depressive symptoms. The pandemic-focused survey included one question per symptom for five symptoms, including depression and hopelessness (listed in Table 2). Responses of symptoms for one or more days over the preceding week were scored as having symptoms. Questions also gauged changes in school or work arrangements, history of mental health conditions, current substance and/or verbal abuse. We added two validated screening questions about food insecurity.²⁴ Spanish survey translations were available as preferred. Participants identifying specific “red flag” issues (frequent mental health symptoms, food insecurity, or substance abuse) were referred to their site’s social services. Dyad responses were compared using McNemar’s test. Institutional review board approval was obtained at each study site.

2 | RESULTS

Of 50 HABIT trial dyads, 36 (72%) youth and 38 (76%) caregivers completed the pandemic-focused survey.

2.1 | Pre-pandemic

Demographic features are as shown at HABIT trial enrollment (Table 1). No significant demographic differences were found compared to non-participating dyads. Most (81.6%) primary caregivers were female. Social vulnerability was high (SVI 0.81 ± 0.20). Using the PROMIS measure (mean 11.8 ± 5.4 months prior to the pandemic survey), youth (mean age 14.2 ± 1.9 years) reported depressive symptoms more frequently than their caregivers: 58.3% versus 15.8%, $p < .01$.

2.2 | Pandemic

In the pandemic survey, eight (22.2%) youth reported having experienced one or more of the mental health symptoms asked about, most frequently loneliness (Table 2). Compared to depressive symptoms reported pre-pandemic, fewer youth than caregivers reported depressive symptoms (5.6% vs. 21.1%, $p = .02$) or anxiety (2.8% vs. 23.7%, $p < .01$) during the pandemic. Among caregivers with PROMIS scores indicating depressive symptoms, approximately half also reported symptoms during the pandemic. In contrast, only two youth reported depressive symptoms on the pandemic survey. Despite these differences, approximately half of both groups lacked optimism about the future (“not feeling hopeful”). More youth than caregivers had experienced changes in work or school routines (83.3% vs. 52.6%, $p < .01$).

Two youth (5.6%) and five caregivers (13.2%) had history of a mental health or behavioral (e.g., substance abuse) condition. Two youth and four caregivers (10.5%) reported use of a nonmedical substance (alcohol, marijuana, and/or nonmedical drug), and two from each group had experienced verbal abuse from a parent/partner. Three youth (8.4%) and five caregivers (13.2%) reported food insecurity. In total, six dyads (17.6%) had one or both members report at least one “red flag” issue, specifically daily mental health symptoms, substance or verbal abuse, and/or food insecurity. Those dyads were referred to their site’s social service resources for follow-up and intervention.

3 | DISCUSSION

Using a self-administered standardized assessment of mental health symptoms during the initial months of COVID-19 pandemic, we assessed youth with SCD and their caregivers from a sample of dyads enrolled in our hydroxyurea adherence trial. We had hypothesized that pandemic-related social and health concerns would be associated

TABLE 1 Sample demographics of 36 youth and 38 caregivers at HABIT trial enrollment^a

Youth (N = 36)			Caregivers (N = 38) ^b		
Variable	N	%	Variable	N	%
Age, years (mean ± SD)	14.2 ± 1.9		Age, years (mean ± SD)	43.9 ± 9.1	
Sex (female)	15	41.7	Sex (female)	31	81.6%
Race			Race		
White	1	2.8	White	1	2.6
Black	29	80.6	Black	32	84.2
Mixed race/other	6	16.7	Mixed race/other	5	13.2
Ethnicity (Latino/a)	6	16.7	Ethnicity (Latino/a)	8	21.1
			Education level		
			High school graduate or less	18	50.0%
			Some college	5	13.1
			College graduate or higher	15	39.5
Depressive symptoms ^c	21	58.3	Depressive symptoms ³ the superscript should be 9c) not (3)	6	15.8
Social Vulnerability Index ^d (mean ± SD)	0.81 ± 0.20				

^aMean 11.8 ± 5.4 months prior to survey period.

^bAmong caregivers, 39.5% reported married/living with a partner; the rest were single/divorced/separated.

^cPROMIS self-reported or pediatric or adult measures for depressive symptoms were scored as per <https://staging.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points> (accessed April 15, 2022); youth versus caregivers, $p < .01$.

^dSocial Vulnerability Index score of 0–1, with higher number representing greater vulnerability.^{21,22}

with social vulnerability, food insecurity, and mental health symptoms. Despite high SVI, only a modest proportion of dyads reported food insecurity, in contrast with our 2018 single-site assessment and a national pandemic survey.^{3,15} Comparing largely pre-pandemic results from a different measure of depressive symptoms, prevalence of mental health symptoms appeared to have shifted over time: fewer youth and more caregivers were affected during the pandemic, but they were not the same participants over time. Nonetheless, a substantial proportion of both groups lacked optimism about the future. Despite use of different instruments, shifts in depressive symptoms at two time points suggest that different pandemic-associated stressors affected youth and caregivers in diverse ways.

Mental health responses may have reflected the addition of pandemic-associated burdens on caregivers and youth living with SCD and stressors associated with high social vulnerability.²⁵ A survey of adult childhood cancer survivors reported more frequent pandemic-related health concerns and social isolation compared to unaffected siblings. Those data suggest that mental health concerns may have been exacerbated during the pandemic by feelings of vulnerability from chronic illness.²⁶

Established associations exist between depression and medication nonadherence in chronic illnesses of youth and adults, including adolescents with SCD.^{12,27,28} Hence, the finding of frequent depressive symptoms in youth at trial enrollment was not surprising. Interestingly, their scores at trial enrollment were only modestly higher than those reported in a similarly aged SCD sample prescribed hydroxyurea at another pediatric SCD center.²⁹ These similarities in findings suggest that depression in adolescents with SCD is common, as was recently reported from a large multinational survey of adults with SCD.³⁰

A systematic review performed pre-pandemic confirmed adolescents' mental health as being sensitive to social isolation.³¹ Interestingly, in our sample fewer youth reported mental health symptoms in the pandemic survey. We speculate that some social stressors may have lessened during the pandemic, even though affecting more caregivers. For example, youth may have experienced less school-related social and/or physical stressors or acute complications triggered by common respiratory infections.^{32,33} Alternatively, resiliency from living with SCD may have dampened pandemic effects on mental health.³⁴

Consistent with our finding of more pandemic-associated depressive symptoms in caregivers, mental health symptoms among US adults significantly increased compared to pre-pandemic levels; especially high frequencies were reported among those of minoritized racial and ethnic groups.^{15,35,36} Adolescents overall appear to be sensitive to the pandemic's social impacts, and families affected by SCD and high SVI may be especially vulnerable.³¹

Study limitations included the modest sample size with limited statistical power to detect differences. Survey participation was offered to a convenience sample of HABIT participants rather than broadly to youth and their primary caregivers at participating clinical sites. As HABIT trial eligibility for youth included inadequate hydroxyurea adherence, our findings of depressive and/or other mental health symptoms may not be generalizable across youth with SCD. Nonetheless, the report of similar scores from an independent study of adolescents with SCD prescribed hydroxyurea²⁹ suggest that depressive symptoms in adolescents with SCD are common, and may persist in adults with SCD.³⁰ SVI national indexing may not have applied uniformly across the sample. Use of two different self-reported assessment tools pre- and during the pandemic prevented direct comparisons

TABLE 2 Mental health symptoms and stressors in youth with SCD compared to their primary caregivers, as dyads, during the COVID-19 pandemic

Symptom	Youth vs. parent, by %	p-Value ^a
<i>Core mental health symptoms^b</i>		
Depressed	5.6 vs. 21.1	.02
Nervous, anxious or on edge	2.8 vs. 23.7	<.01
Lonely	19.4 vs. 18.4	1.0
≥1 of the above symptoms	22.2 vs 34.2	.32
Not feeling hopeful about the future	50.0 vs. 44.7	.78
Physical reactions when thinking about experiences and concerns with the pandemic ^c	0 vs. 7.9	
Change of school or work arrangements	83.3 vs. 52.6	<.01
History of a mental health condition or serious behavior problem (youth) ^d	2.8	
History of a mental health condition (adult)	13.2	
Substance use/abuse (alcohol, marijuana, and/or nonmedical drug use) ^b	5.6 vs. 10.5	.32
Verbal abuse parent/partner or other person ^b	5.6 vs. 5.3	1.0
Food insecurity ^e	8.4 vs. 13.2	.41

Note: Paired analysis based on 36 dyads.

^aMcNemar's test, *p*-values of <.05 are in bold.

^b"In the past 7 days, how often..." scored as positive if reported 1 or more days.

^cSuch as sweating, trouble breathing, nausea, pounding heart."

^dBy caregiver report.

^e"Over the past week"... (*paraphrased*) was there either worry about or experience of inadequate money for food?

between the two time points. Survey questions adjusted for youth participants lacked independent validation. Survey responses, particularly for sensitive topics like mental health symptoms and food insecurity, may have been influenced by social desirability. Our methodology precluded further probing about the mental health symptoms and their potential impact on health, quality of life, or other features.

In conclusion, routine screening for mental health symptoms, social disruption, verbal abuse, and food insecurity may be especially important during the pandemic for this group at risk for social and medical vulnerability.³⁷ Identifying these issues may help to focus attention on the need for interventions for families; for example, state or federal aid programs and/or available mental health services to support the health and mental health of youth with SCD and their caregivers.

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CONFLICT OF INTEREST

The authors declare that there is no relevant conflict of interest.

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