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Original Article

Food insecurity in households of children with ASD in COVID-19 pandemic: A comparative analysis with the Household Pulse Survey data using stabilized inverse probability treatment weights

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ABSTRACT

Background: Before the COVID-19 pandemic, households of children on the autism spectrum were more likely to be food insecure than households of children without disabilities. With the unprecedented social, public health, and economic disruption caused by the pandemic, food insecurity has likely increased among families of children on the autism spectrum.

Objective: This analysis aims to compare the prevalence of food insecurity between the Autism Speaks' Food Insecurity Survey (ASFIS) administered during the Fall of 2020 and a nationally representative sample from the Household Pulse Survey (HPS) data collected during a similar timeframe.

Methods: A propensity score analysis was utilized to create stabilized inverse probability treatment weights for adjusting background differences between the two groups. A logistic regression model was computed to estimate the odds of food insecurity in the ASFIS participants compared with those in the HPS data.

Results: After adjusting for background differences, households of children on the autism spectrum in the ASFIS were about four times more likely to be food insecure than households in the general population contained in the HPS data (OR = 3.7; 95% CI: 3.1–4.4).

Conclusions: The breakdown of social and economic supports during the COVID-19 pandemic contributed to a significantly higher likelihood of food insecurity among families of children on the autism spectrum.

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The COVID-19 pandemic has exacerbated food insecurity (defined as uncertainty in access to adequate food) in the United States, with the rate of food insecurity increasing in households with children from 13.6% in 2019 to 17.5% in December 2020.^{1,2} Further, the pandemic disproportionately impacted vulnerable populations. For example, Black and Hispanic households with children were significantly more likely to be food insecure than the households with White, non-Hispanic children ($\beta = 0.074$ and $\beta = -0.091$, respectively).³ The pandemic also made food sufficiency (a concept related to food insecurity) difficult for people with disabilities. Compared with adults without disabilities, a significantly larger share of working-age adults with disabilities reported sometimes or often not having enough to eat (8.1% versus 16.6%, respectively).⁴

Food insecurity was shown to disproportionately impact households of children on the autism spectrum. Based on the analysis of the National Survey of Children's Health (NSCH), children on the autism spectrum and children on the autism spectrum with intellectual disabilities had the highest likelihood of experiencing food insecurity (odds ratio (OR) = 1.5 and OR = 1.9, respectively), compared with households without children without disabilities before the pandemic.⁵ The COVID-19 pandemic could negatively impact the food security status of households of children on the autism spectrum by exacerbating existing social, economic, behavioral health vulnerabilities.⁶

Literature review

Increase in awareness and service systems for identification of autism spectrum disorders (a life-long neurodevelopmental condition characterized by social and communication disorders) has led to a substantial increase in the prevalence of children on the

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autism spectrum from 1 in 150 among 8-year old children in 2000 to 1 in 54 among 8-year old children in 2016.^{7,8} Based on parent's self-report in a nationally representative survey, it was estimated that in 2016 about 1.5 million U.S. children between the ages of 3–17 years were on the autism spectrum. Further, 5.4 million adults between the ages of 18–84 years are estimated to be on the autism spectrum, resulting in an estimated population of about 6.9–7 million individuals on the autism spectrum in the U.S.

An estimated 55% of persons on the autism spectrum experience co-occurring conditions such as intellectual disabilities, epilepsy, mental health conditions, gastrointestinal disorders, sleep disorders, etc., needing access to specialists and other forms of high-cost services.^{9,10} Further, children on the autism spectrum have a higher probability of exposure to adverse childhood experiences or ACEs (e.g., witnessing domestic violence, parents with a history of incarceration, experiencing discrimination, etc.), which predisposes them to additional health risks, including food insecurity.^{11–14} Families of person on the autism spectrum incur an additional \$4000 annually in out-of-pocket health care expenses than those without disabilities.¹⁵ The families also experience substantial economic loss from lost productivity,^{15–17} and experience social isolation and stigma.^{18–20}

In addition to these existing support needs, the COVID-19 pandemic exacerbated the physical and behavioral health challenges among children on the autism spectrum.^{21,22} Increased propensity of food selectivity coupled with challenges in getting out for shopping, likely, posed barriers in access to food during the pandemic.^{23,24} However, data on experiences in access to food during the pandemic for children on the autism spectrum is limited.

Therefore, this study aimed to explore food security status in households of children on the autism spectrum compared with a nationally representative sample of the general population during the height of the COVID-19 pandemic.

Methods

This study was approved as exempt by the Institutional Review Board at the John Carrol University.

Comparison groups

The Autism Speaks' Food Insecurity Survey (ASFIS) was administered as an anonymous, online survey on a SurveyMonkey platform from November 18 through December 7, 2020. The study used a national convenience sample of households of person on the autism spectrum. All individuals with a valid email address that contacted the Autism Speaks' call center or participated in outreach activities received an email link to participate in the survey. A total of 26,386 emails with the survey link were sent, out of which 11,865 individuals opened their email messages, and 1515 completed the survey. A random draw of ten percent of the survey respondents who completed the survey were offered a \$10 e-gift card.

A general population comparison data was derived from Phase 3 of the Household Pulse Survey (HPS) HPS. Weeks 19 and 20 of the HPS data were selected as they corresponded with the administration time of the ASFIS. The response rate for the HPS data used for this analysis was 6.6 and 6.7%, comparable to the ASFIS. The Census Bureau administers the bi-weekly HPS to a nationally representative sample of households to collect pertinent data measuring household experiences during the COVID-19 pandemic.²⁵ The HPS covered several topics, including access to supports and services for children, and adults, employment status, food security, housing, physical and mental health well-being. Appropriate sampling weights are assigned to account for non-response bias and other non-sampling errors.

The ASFIS and HPS data were concatenated to create an analytical data file for this study. The ASFIS consisted of 1515 records, and the HPS data consisted of 144,423 records yielding a combined data file with 145,938 records.

Dependent variable: Food insecurity

Seven items from the USDA's 10-item food security survey module were included in the ASFIS for this study. Further, three items from the 18-items USDA food security module specific for children were added with modification for children on the autism spectrum (Supplement 1). All items were modified to inquire about food situations within the last 30 days. Responses of "yes," "often," and "sometimes" were coded as affirmative with a value of 1 and 0 otherwise. A total score based was computed by adding scores for each of the items. Respondents with scores of 0–2 were classified as "food secure," 3–5 were classified as "food insecure," and respondents with a score of 6 or more were coded as experiencing "very low food insecurity." This method was similar to the USDA's approach in reporting food insecurity for the general population.²⁶ One hundred and forty-six responses had missing data for the outcome variable. As there were no differences in frequency distribution of background variables between observations with missing and non-missing data on food insecurity, the missing records were considered missing at random and were excluded from the analysis.

The HPS inquired about food sufficiency within the last seven days based on one item. The response options from the HPS included: 1) have enough of the types of food wanted; 2) have enough food, but not always the types wanted; 3) sometimes do not have enough to eat; or 4) often do not have enough to eat. Respondents who indicated that they "sometimes" or "often" did not have enough to eat were coded as food insecure.

The ASFIS collected information on the experience of food insecurity, whereas the HPS data collected information on a conceptually related concept of food sufficiency. The measure of "very low food insecurity" in the ASFIS is conceptually closer to the food insufficiency measured in the HPS, and it was utilized as the outcome variable in the analysis.^a

Coping in food insecurity

Like the HPS, the ASFIS asked the respondents about reasons for not getting enough to eat. Respondents could choose all that applied: 1) couldn't afford to buy more food; 2) couldn't get out to buy food; 3) afraid to go or didn't want to go out to buy food; 4) couldn't get groceries or meals delivered to me, and 5) the stores didn't have the food I wanted. Additionally, the questionnaire inquired respondents where they got free groceries or free meals. Respondents could choose all that applied: 1) did not get free groceries or free meals; 2) free meals through the school or other programs aimed at children; 3) food pantry or the food bank; 4) home-delivered meal service like Meals on Wheels; 5) church, synagogue, temple, mosque or other religious organization; 6) shelter or soup kitchen; 7) other community programs; and 8) family, friends, or neighbors.

Finally, the authors asked about an unmodified HPS item that asked how confident the respondent would be in the next four weeks to afford the kinds of food they'll need. Responses were dichotomized into "not at all and somewhat confident" and "moderately and very confident."

^a <https://www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us/measurement/#comparison>.

Background variables

Demographic variables included: age of respondents, gender, race/ethnicity, state of residence, current marital status, the highest level of education attained, approximate annual household income, type of health insurance, and if anyone in the house received Supplemental Nutrition Assistance Program (SNAP) benefits. Key differences in the frequency distribution of the confounding variables were identified between the ASFIS and the HPS data (Table 1). A greater proportion of ASFIS respondents were female, Black non-Hispanic, Hispanic, attained high school or less education, had public insurance, belonged to the low-income group, and received SNAP benefits compared with individuals in the HPS data. Prior studies have indicated a strong association between these demographic variables and food insecurity prevalence.¹ Additionally, Kogan et al. (2018) have also illustrated a significant association between these demographic variables to the prevalence of ASD in a national sample of households.²⁷ Balancing the distribution across these key variables could provide meaningful estimates of the relative distribution of food insecurity in the ASFIS group compared with those in the HPS data.

Statistical analysis

A propensity score method for balancing key demographic differences between the two sources of data was adopted.²⁸ An estimated propensity score reflects the probability of being assigned to treatment (ASFIS) or comparison (HPS data) conditions based on a set of observed characteristics. Once estimated, the propensity scores are used in various ways (i.e., regression adjustment, matching, stratification, and weighting) to balance differences between the comparison groups. This analysis utilized weighting to study differences in the prevalence of food insecurity among survey respondents and those from the national sample survey based on the HPS data.

Table 1
Frequency distribution of respondent characteristics comparing participants in the ASFIS with the HPS Survey.

	ASFIS	HPS Survey	P-value for Chi-square
Age group			
Less than 45 years	57.5	37.2	< 0.0001
Greater than 45 years	42.5	62.8	
Gender			
Female	85.4	60.3	< 0.0001
Race			
White, non-Hispanic	65.0	76.2	< 0.0001
Black, non-Hispanic	15.0	6.8	
Hispanic	14.5	9.0	
Other, non-Hispanic	5.5	8.0	
Marital status			
Married	56.6	58.0	0.286
Single/unmarried	43.4	42.0	
Education			
High school graduate or less	34.9	13.2	< 0.0001
More than high school	65.1	86.8	
Income			
Less than equal to \$49,000	47.3	29.2	< 0.0001
Between \$50,000 and \$74,999	16.8	17.5	
Greater than \$75,000	35.9	53.3	
Health Insurance Status			
Private insurance	48.4	56.9	< 0.0001
Public insurance	48.4	37.0	
No insurance	3.2	6.1	
Received SNAP	35.1	7.5	< 0.0001
Very low food secure	32.3	7.9	< 0.0001

Note: HPS = Household Pulse Survey; SNAP = Supplemental Nutrition Assistance Program

Specifically, a logistic regression model was computed to estimate the propensity scores. The probability of belonging to the ASFIS relative to the HPS data was calculated based on the background characteristics common between the two data sets. The stepwise forward selection method was utilized to compute the propensity score model with the entry criteria value of 0.15 and stay criteria value of 0.20. Since the purpose of this step in modeling is not to develop a parsimonious model for prediction, interaction effects were also entered along with the main effects to build a saturated model predicting the probability of belonging to the ASFIS data set compared with the HPS data.²⁹ Further, such an approach is shown to improve any unobserved imbalance in covariate distribution across two different data sources. A c-statistic value of 0.91 accompanied by a balance in the distribution of frequencies for the key confounding variables (Table 2) indicated that the propensity score model adjusted for a substantial imbalance between the two groups (i.e., ASFIS group and the HPS data). Any missing propensity score data were replaced with the group's median propensity score value before computing the weights. This approach helps prevent any data loss or bias.³⁰ Once the propensity scores were calculated, the next step utilized the inverse probability treatment weights (IPTW) approach to estimate the differences in the likelihood of being food insecure in the ASFIS group versus the HPS data.²⁸ Further, stabilized IPTW were computed to reduce bias resulting from the tails of propensity score distributions.³¹

The stabilized weights were utilized in a weighted logistic regression model estimating the difference in odds of food insecurity among individuals in the ASFIS group compared with the HPS data. The demographic variables likely to be associated with being food insecure were also included in the weighted logistic regression model to control for any residual group imbalance.

Results

Unweighted frequency analysis indicated that more than 32% of the ASFIS respondents were very low food secure, 20% were food

Table 2
Propensity-score adjusted frequency of respondent characteristics comparing participants in the ASFIS with the HPS Survey.

	ASFIS	HPS Survey	P-value for Chi-square
Age group			
Less than 45 years	38.6	61.4	0.39
Greater than 45 years	37.4	62.6	
Gender			
Female	60.5	60.3	0.97
Race			
White, non-Hispanic	72.9	76.2	<0.001
Black, non-Hispanic	6.8	6.9	
Hispanic	9	7.9	
Other, non-Hispanic	11.2	9	
Education			
High school graduate or less	14.4	13.3	0.26
More than high school	85.6	86.7	
Income			
Less than equal to \$49,000	30.8	29.4	0.3
Between \$50,000 and \$74,999	16	17.4	
Greater than \$75,000	53.2	53.2	
Health insurance status			
Private insurance	56.4	56.9	<0.01
Public insurance	35.5	37.1	
No insurance	8.1	6	
Received SNAP	13.2	7.8	< 0.0001

Note: HPS = Household Pulse Survey; SNAP = Supplemental Nutrition Assistance Program

insecure, and 48% were food secure. Compared with this, only 8% of respondents with children in the HPS data were very low food secure. Adjusting for the stabilized IPTW indicated that 22% of the respondents in the ASFIS were very low food secure compared with about 8% of the respondents in the HPS data. The multiple logistic regression model utilizing stabilized IPTW indicate (Table 3) that respondents in the ASFIS were nearly four times more likely to be very low food secure compared with their peers in the HPS data (OR = 3.7; 95% CI: 3.1–4.4). Examining other covariates in the model indicate that individuals belonging to low-income and racial/ethnic minorities, uninsured or receiving public insurance, SNAP benefits, and living in larger households were more likely to be very low food secure.

A stabilized IPTW-weighted frequency analysis indicated that a greater proportion of respondents in the ASFIS indicated that they couldn't get out to buy food (21% vs. 18%) or were afraid to go/didn't want to go out to buy food (38% vs. 24%) or couldn't get groceries delivered (24% vs. 9%) compared with those in the HPS data (Table 4). A greater proportion of individuals in the HPS data indicated that they could not afford food than those in the ASFIS (86% vs. 72%).

A higher proportion of individuals in the ASFIS data received their food from schools (42% vs. 38%) than individuals in the HPS data. Further, individuals in the HPS data were more likely to receive food from food banks, religious institutions, shelters, and soup kitchens (Table 5).

Further, about 30% of ASFIS respondents were confident that they would be able to get the food that they need in the next four weeks compared with 14% of individuals in the HPS data (p < 0.001).

Table 3
Multiple logistic regression model predicting the odds of very low food security in the study dataset utilizing stabilized IPTW.

	Adjusted OR	95% CI
Study groups		
HPS Survey	REF	
ASFIS	3.7	(3.1–4.4)
Respondent age group		
Greater than 45 years	REF	
Less than 45 years	1.5	(1.4–1.5)
Respondent race		
White, non-Hispanic	REF	
Black, non-Hispanic	1.5	(1.4–1.6)
Hispanic	1.2	(1.1–1.3)
Other, non-Hispanic	1.2	(1.1–1.4)
Respondent income		
Greater than \$75,000	REF	
Less than equal to \$49,000	7.0	(6.5–7.5)
Between \$50,000 and \$74,999	3.1	(2.9–3.4)
Respondent education		
More than high school	REF	
High school graduate or less	1.5	(1.4–1.6)
Respondent marital status		
Married	REF	
Single	1.5	(1.4–1.6)
Respondent health insurance status		
Private insurance	REF	
Public insurance	1.2	(1.2–1.3)
No insurance	2.8	(2.6–3.1)
Family receipt of SNAP benefits		
Did not receive SNAP	REF	
Received SNAP	2.1	(2.0–2.2)
Census region		
Northeast	REF	
Midwest	1.0	(0.9–1.1)
South	1.0	(1.0–1.1)
West	1.0	(0.9–1.0)
House size	1.2	(1.1–1.2)
C-statistic	0.835	

Note: HPS = Household Pulse Survey; SNAP = Supplemental Nutrition Assistance Program; IPTW = Inverse Probability Treatment Weights

Table 4
Why survey respondents were food insecure?

	ASFIS	HPS Survey	P-value for Chi-square
Couldn't afford to buy more food	71.6	85.7	< 0.0001
Couldn't get out to buy food	20.9	17.7	0.18
Afraid to go or didn't want to go out to buy food	37.9	24.2	< 0.001
Couldn't get groceries or meals delivered to me	26.5	9.3	< 0.0001
The stores didn't have the food I wanted	20.6	16.1	0.05

Note: HPS = Household Pulse Survey

Table 5
Where food insecure respondents got free food.

	ASFIS	HPS Survey	P-value for Chi-square
School	41.5	38.3	0.5
Food bank	31.0	49.1	< 0.001
Food delivery service like meals on wheels	4.1	4.3	0.93
Religious institution	9.2	24.9	< 0.001
Shelter or soup kitchen	0.7	4.8	0.043
Other community program	19.3	20.1	0.85
Family/friend's house	37.4	40.9	0.467

Note: HPS = Household Pulse Survey

Discussion

This analysis indicates that households of person on the autism spectrum in the ASFIS were nearly four times more likely to be very low food secure during the COVID-19 pandemic in comparison with the general population. The propensity score modeling approach of utilizing the stabilized IPTW helped mitigate some differences in the distribution of the background variables. Stabilized IPTW reduced observations with along the long tails of propensity distribution allowing for utilization of the complete data set without trimming.³² This approach is shown to satisfy the positivity assumption underlying the principle of the propensity score, where individuals in both groups have a non-zero probability of belonging to the treatment condition.³¹ Additionally, the modeling approach also adjusted for key covariates that demonstrated modest balance after propensity score weighting. However, the observed differences between the two groups in food insecurity are substantially higher and are likely due to different experiences in community-based settings.

Prior research based on the analyses of the NSCH data by the authors identified various factors at individual-, family-, and community-levels contributed in predicting higher levels of food insecurity in households of children on the autism spectrum.⁵ For example, children on the autism spectrum were more likely to use emergency room services, missed several days of school, and were more likely to be exposed to adverse childhood experiences. These variables also strongly predicted food insecurity in the multivariate regression models. Similarly, families of children on the autism spectrum experienced low family cohesion and lacked access to emotional and social support, including living in less supportive neighborhoods. These factors were strongly associated with predicting higher levels of food insecurity. Unfortunately, due to lack of data, these variables were not controlled for in the propensity score model when comparing food insecurity in the ASFIS participants

and HPS data in this analysis. Note that a prior study identified that 60% of the probability of food insecurity resulted from family-, and community-level factors. Similar mechanisms resulting from social, psychological, and economic stress are likely to play a predictive role in explaining substantially higher food insecurity in the ASFIS participants than those in the HPS data.

Higher confidence in emerging out of very low food security status among the ASFIS respondents was a positive finding. Research has shown the critical role of self-efficacy in managing food resources as a key predictor in improving food security among families.³³ As several state and federal interventions to improve the economic conditions of families are winding down,³⁴ it is essential to ensure that programs improving access to food resources and build capacities to manage food resources are extended to families of person on the autism spectrum.

A higher proportion of the ASFIS obtained food from their schools (nearly 42%), whereas the HPS data respondents were more likely to receive food from food banks, religious institutions, other community-based programs, including supports from friends and families. These data point towards the continued need for the Pandemic Electronic Benefits Transfer Program that provided monthly benefits equivalent to the value of school meals to the families for children eligible for free and reduced-price lunch through their schools. This program extended benefits through the summer months in states that declared a public health emergency in 2020. With the lifting of public health emergency throughout the U.S., families of children on the autism spectrum may likely experience higher levels of difficulty in access to food.

In preparation to update the Thrifty Food Plan (TFP)^b the USDA held listening sessions where advocates, researchers, and SNAP recipients, shared that SNAP benefits, based on the earlier plan determined in 2006, were inadequate to meet the nutritional needs of families including forcing the beneficiaries to make unhealthier choices to make ends meet. The pandemic, the 2018 Farm bill, and continued advocacy paved way for the federal government to update the TFP in 2021 by increasing SNAP benefit by an average 21%. Additionally, in 2020 the pilot program for purchasing food online for SNAP benefits was expanded to include 47 states including the District of Columbia. These resulting updates to the SNAP programs are a welcome change to advancing food security among families of children on the autism spectrum. However, it will be useful to understand the impact of these changes given continued challenges in online access to a healthy diet.

The reopening of the U.S. economy with increasing opportunities in the labor market could improve food insecurity among these families. Recent reports of a lower return to work among individuals and households of people with disabilities point to the need to prioritize the labor market inclusion of person on the autism spectrum and their families.³⁵

Given that food insecurity is associated with worse physical and mental health,³⁶ it is essential for clinicians to screen for food insecurity during regular checkups. For example, the American Academy of Pediatrics promotes a two-item screening tool for clinicians to identify, screen, and connect eligible families to public-funded programs such as SNAP, WIC, and school food programs.³⁷ Given that during COVID-19, many clinical visits were switched to tele-visits, future studies should explore if early screening and referral to mitigate food insecurity in children, especially among those with ASD and other developmental disabilities, were impacted.

Limitations and future directions

Firstly, the current analysis is limited by the observational nature of the data, lack of access to a broader set of variables to control for possible differences between the ASFIS respondents and HPS data. Deploying stabilized IPTW provided a helpful remedy to reduce imbalances between the comparison population for the weighted analyses. Additionally, the ASFIS respondents consisted of a self-selected sample of parents/caregivers of children on autism spectrum. In comparing the distribution of race/ethnicity characteristics of parents/caregivers of children on autism spectrum in the National Survey of Children's Health data,³⁸ the ASFIS respondents had higher proportion of NHW and a lower proportion of families that identified themselves as Hispanic. These differences result from self-selection of the survey participants, and the study design limitations make it difficult to compute selection probabilities due to lack of access to respondent background characteristics who got the survey links. The ASFIS contact information included valid email address that were collected as part of the call center support and it did not capture valid background data that could have been used to create a weighted sample for the analysis. This limits the generalizability of the findings to the entire population of children on the autism spectrum. This limitation also highlights overall challenge of collecting nationally representative data for persons on the autism spectrum in the U.S. In fact, the national prevalence data on autism spectrum disorders is based on passive surveillance from a handful of states in the U.S.³⁹ Many national survey data, while are increasingly incorporating measures identifying disabilities and functional limitations, are not able to characterize the type of impairments to help identify people on the autism spectrum. Therefore, reliance on convenience sample surveys is inevitable.

Secondly, there are minor differences in the approach to measuring food security. The ASFIS used a modified version of the USDA's 10-item food insecurity questionnaire, while the HPS used a single item measuring food sufficiency. However, to ensure equitable outcome measures, this analysis compared the more extreme level of stress experienced in the form of "very low food security" in the ASFIS with the corresponding construct in the HPS data. While the conceptual difference is minimal across the constructs, it could still contribute to the observed differences. Additionally, the data on identifying people with disabilities was incorporated later in the HPS and was not used as it could not align with the time-period of the ASFIS. Concerns regarding a generic approach to identifying individuals with disabilities continue to limit the utility of HPS for understanding distribution of food insecurity in people on the autism spectrum.

The final limitation of this analysis is that the mechanisms leading to food insecurity among individuals in the ASFIS are not explicit. Future research should leverage approaches such as mixed methods to uncover unique challenges to identify locally relevant strategies and policies to mitigate food insecurity among person on the autism spectrum. Additionally, future research should examine the increase in food insecurity resulting from the COVID-19 pandemic utilizing longitudinal survey data to better characterize the problem and understand putative mechanisms to increase the acceptance and awareness about the needs of person on the autism spectrum.

Conclusion

This study is the first to estimate food security amongst a large sample of households of children on the autism spectrum during the COVID-19 pandemic. Households of children on the autism spectrum were nearly four times more likely to be food insecure than the general population. There could exist numerous

^b Thrifty Food Plan is a formula that underlies how USDA estimates cost of healthy food that determines SNAP benefit amount.

breakdowns in social and economic supports, explaining the disparity in food security.

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Conflicts of interest

The authors do not have any conflict of interest to report.

Author contributions

AK conceptualized the study, analyzed data, wrote the manuscript; VV conceptualized the study, supported analysis, and contributed to writing the manuscript. AS and TF helped with conceptualization of the study.

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