Feed First, Ask Questions Later: Alleviating and Understanding Caregiver Food Insecurity in an Urban Children's Hospital

Jennifer A. Makelarski, PhD, MPH, Daniel Thorngren, MD, and Stacy Tessler Lindau, MD, MAPP

Objectives. We estimated the prevalence of caregiver hospital food insecurity (defined as not getting enough to eat during a child's hospitalization), examined associations between food insecurity and barriers to food access, and propose a conceptual framework to inform remedies to this problem.

Methods. We conducted a cross-sectional study of 200 caregivers of hospitalized children in Chicago, Illinois (June through December 2011). A self-administered questionnaire assessed sociodemographic characteristics, barriers to food, and caregiver hospital food insecurity.

Results. Caregiver hospital food insecurity was prevalent (32%). Caregivers who were aged 18 to 34 years, Black or African American, unpartnered, and with less education were more likely to experience hospital food insecurity. Not having enough money to buy food at the hospital, lack of reliable transportation, and lack of knowledge of where to get food at the hospital were associated with hospital food insecurity. The proposed conceptual framework posits a bidirectional relationship between food insecurity and health, emphasizing the interdependencies between caregiver food insecurity and patient outcomes.

Conclusions. Strategies are needed to identify and feed caregivers and to eradicate food insecurity in homes of children with serious illness. (*Am J Public Health.* 2015;105:e98–e104. doi:10.2105/AJPH.2015.302719)

In 2009, a pediatric hospital chaplain, distressed by signs of hunger among her patients' caregivers, shared her concerns with physician leaders of an effort to improve local urban health conditions. She related her observations of hungry parents asking nurses, residents, and medical students for food. She witnessed the kindness of many providers who shared their own sandwich or a few dollars. She also described what she perceived to be a loss of dignity on the part of the person asking for food and the painful resignation of those who were unable to help. She worried that caregiver hunger could be an impediment to a child's recovery.

Food insecurity is a major public health problem in the United States. One in 5 US households with children is food insecure.[1] Household food security is defined as having "access at all times to enough food for an active, healthy life for all household members."[1(p4),2] Acute symptoms of household food insecurity include hunger, depression, fatigue, and lack of control.[3–6] Furthermore, people with household food insecurity can experience "alienation" and related feelings including "embarrassment and shame" and a sense of "powerlessness."[3] A qualitative study reported that adults and children with household food insecurity have difficulty concentrating and an impaired ability to learn.[4] Hungry children are more likely to suffer from psychosocial problems, receive special education services, and fail a grade.[7]

The long-term outcomes of food insecurity include increased risk of poor physical and mental health in children[8–11] and adults.[12,13] Food insecurity is also associated with poor disease management and medication nonadherence.[12,14,15] The prevalence of household food insecurity has been assessed in inpatient and outpatient populations; the prevalence in these populations frequently exceeds national population-based averages.[16–20]

Although household food insecurity is a known risk factor for poor health, chronic disease, and hospitalization in children,[10,11,21,22] very little is known about the patterns and prevalence of food insecurity in the hospital setting. Results from a single qualitative study of 24 caregivers of hospitalized children found that among the personal, financial, and social costs of a child's hospitalization, "parents experienced difficulty providing themselves with adequate and affordable food and drink. . . ."[23(p748)] We found no published studies examining how the symptoms of food insecurity might be associated with a caregiver's ability to play an active role in the care of a hospitalized child. Little evidence was found to inform a rapid, sustainable remedy to the problem of food insecurity among caregivers of hospitalized children.

At the time the chaplain approached us, the hospital's policy permitted social workers to provide 1 free food tray per stay to families in need, regardless of the length of the patient's stay. The chaplain's concerns were validated by other professionals with experience as providers, caregivers, or both in the children's hospital. Given the acuity of the situation, we opted for a "feed first, ask questions later" approach in alignment with the ethical principle of beneficence in research[24] and the principles of our community-engaged research model.[25] We marshaled medical students, other faculty, hospital personnel, and existing relationships with the Greater Chicago Food Depository to deploy the area's first hospital-based food pantry.

After we implemented the food pantry, we launched a study to test the hypothesis that food insecurity among caregivers of hospitalized pediatric patients ("hospital food insecurity") would be prevalent and associated with potentially mutable barriers to food access. We used these empirical findings to develop a conceptual framework to facilitate future study of

the impact of hospital food insecurity on pediatric health and health care outcomes.

METHODS

This study was conducted at a 155-bed academic children's hospital in Chicago, Illinois. The hospital admitted approximately 5000 patients annually; an estimated 60% were Medicaid beneficiaries. The hospital's dining options included commercial cafés and a hospital-run cafeteria. A meal (e.g., sandwich, fruit, and drink) cost $10 to $12 per person. Few low-cost, nutritious alternatives were available within walking distance.

Participants

Participants included a convenience sample of caregivers of pediatric patients admitted to the general pediatric and oncology units from June through December 2011. To reduce medical risk to the patients and the research recruiters, especially to minimize the risk of infection, we excluded caregivers of patients admitted to intensive care units and patients diagnosed with a multidrug-resistant organism. Because of the focus on caregivers of hospitalized children, we also excluded caregivers of patients aged 19 years and older.

We recruited participants from patient rooms 1 to 3 days after admission. Following consent, caregivers were given a 27-item self-administered paper survey. The survey was designed for self-administration to minimize risk of respondent stigma and social response bias. The survey content and length were designed with input from health literacy experts to be understandable at a fifth grade or below literacy level. All caregivers approached for participation were provided information about the hospital's food pantry, regardless of participation. Data collection was scheduled for a 6-month period with the expectation of volunteers recruiting at least 200 participants. With a sample size of 200, the precision (i.e., half-width of the 95% confidence interval) of the estimated prevalence of food insecurity would be no larger than plus or minus 7 percentage points.

Measures

We assessed the prevalence of hospital food insecurity by using a survey item consistent

TABLE 1—Food Insecurity and Sociodemographic Characteristics of Caregivers of Hospitalized Pediatric Patients: Chicago, IL, June–December 2011

Characteristic	Total,[a] No.	No FI,[b] No.	FI During Hospital Stay	
			No. (%)	OR (95% CI)
Age, y				
18–24	24	12	12 (50)	2.8 (1.1, 7.1)
25–34	58	38	20 (35)	1.5 (0.7, 3.0)
> 34	96	71	25 (26)	1.0 (Ref)
Race/ethnicity				
Non-Hispanic Black	87	46	41 (47)	4.4 (2.0, 9.7)
Non-Hispanic White (Ref)	59	49	10 (17)	1.0 (Ref)
Hispanic	30	25	5 (17)	1.0 (0.3, 3.2)
Other	12	10	2 (17)	1.1 (0.2, 5.2)
Marital status				
Married	97	79	18 (19)	1.0 (Ref)
Single	74	41	33 (45)	3.5 (1.8, 7.0)
Divorced or separated	18	10	8 (44)	3.5 (1.2, 10.1)
Education				
Elementary or some high school	23	13	10 (44)	2.8 (1.0, 7.8)
High school or GED	49	30	19 (44)	2.3 (1.1, 5.4)
Some college	61	41	18 (30)	1.5 (0.6, 3.5)
College graduate	55	43	12 (22)	1.0 (Ref)
Insurance				
Yes	179	124	55 (31)	NC
No	5	2	3 (60)	NC
Household food insecure in past 12 mo				
Yes	81	42	39 (48)	3.9 (2.1, 7.6)
No	105	85	20 (19)	1.0 (Ref)
Received food stamps or WIC in past 12 mo				
Yes	74	38	36 (49)	3.8 (2.0, 7.3)
No	116	93	23 (20)	1.0 (Ref)
Got food donation in past 12 mo				
Yes	32	16	16 (50)	2.7 (1.2, 5.9)
No	155	113	42 (27)	1.0 (Ref)
Have enough money to buy food at the hospital				
Strongly disagree or disagree	82	37	45 (55)	8.2 (4.0, 16.6)
Strongly agree, agree, or neutral	108	94	14 (13)	1.0 (Ref)
Have transportation to get food while at the hospital				
Strongly disagree or disagree	67	32	35 (19)	4.6 (2.4, 8.8)
Strongly agree, agree, or neutral	124	100	24 (52)	1.0 (Ref)
Will lose income from your job because of hospital stay				
Strongly agree or agree	69	49	20 (29)	0.9 (0.4, 1.7)
Strongly disagree, disagree, or neutral	123	84	39 (32)	1.0 (Ref)
Know where to get food in or near the hospital				
Strongly disagree or disagree	34	19	15 (44)	2.1 (1.0, 4.4)
Strongly agree, agree, or neutral	155	112	43 (28)	1.0 (Ref)
Child will be OK if you leave the hospital				
Strongly disagree or disagree	91	57	34 (37)	1.8 (1.0, 3.3)
Strongly agree, agree, or neutral	100	75	25 (25)	1.0 (Ref)

Continued

TABLE 1—*Continued*

How likely to leave the hospital during child's stay				
Very unlikely or unlikely	129	86	43 (33)	1.5 (0.8, 3.1)
Very likely, likely, or neutral	57	43	14 (25)	1.0 (Ref)

Note. CI = confidence interval; FI = food insecurity; GED = general equivalency diploma; NC = not calculated because of small cell counts; OR = odds ratio; WIC = Special Supplemental Nutrition Program for Women, Infants, and Children.
[a]Numbers may not sum to group totals because of missing data.
[b]This category includes individuals who were classified as having neither household nor hospital food insecurity.

with the US Department of Agriculture definition of household food security, designed to focus specifically on the caregiver and the hospital context: "You have enough food to eat while your child is at the hospital: strongly agree, agree, neither agree nor disagree [neutral], disagree, and strongly disagree." We classified respondents as hospital food insecure (strongly disagree or disagree) or hospital food secure (neutral, agree, or strongly agree). We measured household food insecurity in the past 12 months by using a validated 2-item screen derived from the 18-item US Household Food Security Screen (affirmative responses to either survey item indicated a positive screen for household food insecurity).[26]

Survey items also ascertained sociodemographic characteristics (age, race/ethnicity, marital status, education, and insurance) and potential financial and caregiving barriers to food access.

Statistical Analysis

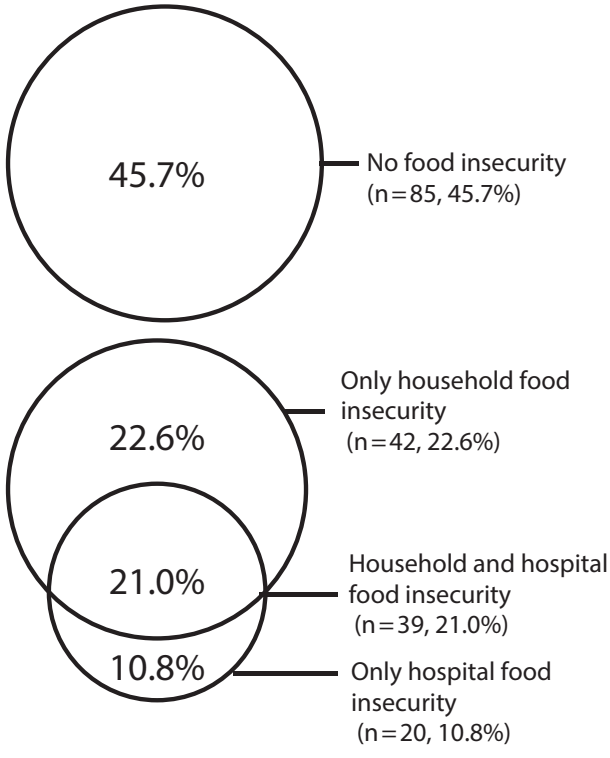
We calculated descriptive statistics for sociodemographic characteristics and barriers to food access by hospital food security status. We estimated the odds of experiencing hospital food insecurity by sociodemographic characteristics and barriers to food access by using logistic regression (and expressed as odds ratios) for the purposes of detecting variables associated with hospital food insecurity that could be used in routine clinical work flows to identify caregivers who might benefit from the hospital-based food pantry.

In addition, to identify variables independently associated with hospital food insecurity on which we might intervene, we estimated adjusted odds ratios for individual barriers to food access with multivariable logistic regression. We included the following covariates: age (continuous), race/ethnicity (non-Hispanic Black, Hispanic, non-Hispanic White, or other), marital status (married, single, or divorced or separated), and education (high school or less vs some college or college graduate). We also examined the odds of experiencing hospital food insecurity by race/ethnicity independent of receipt of government food assistance (used as a proxy for income; income data were not collected in this survey). We conducted analyses with Stata version 13 (StataCorp LP, College Station, TX).

RESULTS

Of 234 eligible caregivers approached for this study between June and December 2011, 200 participated (cooperation rate 85%). No additional data on those who refused or who were not approached for participation were available. We excluded 8 participants from this analysis because they did not answer the hospital food insecurity survey item. Table 1 summarizes sociodemographic characteristics of caregivers. The vast majority of caregivers identified themselves to survey staff as a parent of the hospitalized child (relationship to the child was not ascertained on the survey).

A third of caregivers screened positive for hospital food insecurity; 66% of these caregivers also met criteria for household food insecurity in the previous 12 months (Figure 1). Odds of hospital food insecurity were significantly higher among caregivers who were Black or African American, single or divorced, less educated, had household food insecurity,



Note. Percentages do not total 100 because of rounding.

FIGURE 1—Prevalence of food insecurity in caregivers of hospitalized pediatric patients: Chicago, IL, June–December 2011.

TABLE 2—Odds of Food Insecurity in Caregivers of Hospitalized Pediatric Patients: Chicago, IL, June–December 2011

Variable	Total,[a] No.	No FI, No.	FI During Hospital Stay	
			No.	AOR (95% CI)
Household food insecure in previous 12 mo				
Yes	81	42	39	3.1 (1.5, 6.5)
No	105	85	20	1.0 (Ref)
Received government food assistance in past 12 mo				
Yes	74	38	36	2.3 (1.0, 5.2)
No	116	93	23	1.0 (Ref)
Got food donation in past 12 mo				
Yes	32	16	16	2.1 (0.9, 5.0)
No	155	113	42	1.0 (Ref)
Have enough money to buy food at the hospital				
Strongly disagree or disagree	82	37	45	7.0 (3.2, 15.3)
Strongly agree, agree, or neutral	108	94	14	1.0 (Ref)
Have transportation to get food while at the hospital				
Strongly disagree or disagree	67	32	35	4.4 (2.1, 9.3)
Strongly agree, agree, or neutral	124	100	24	1.0 (Ref)
Will lose income from your job because of hospital stay				
Strongly agree or agree	69	49	20	1.0 (0.5, 2.0)
Strongly disagree, disagree, or neutral	123	84	39	1.0 (Ref)
Know where to get food in or near the hospital				
Strongly disagree or disagree	34	19	15	1.7 (0.7, 4.3)
Strongly agree, agree, or neutral	155	112	43	1.0 (Ref)
Child will be OK if you leave the hospital				
Strongly disagree or disagree	91	57	34	2.4 (1.1, 5.3)
Strongly agree, agree, or neutral	100	75	25	1.0 (Ref)
How likely to leave the hospital during child's stay				
Very unlikely or unlikely	129	86	43	2.2 (1.0, 4.0)
Very likely, likely, or neutral	57	43	14	1.0 (Ref)

Note. AOR = adjusted odds ratio; CI = confidence interval; FI = food insecurity. Independent of age (continuous), race/ethnicity (non-Hispanic Black, non-Hispanic White, Hispanic, or other), marital status (married, single, or divorced or separated), and education (high school or less, some college, or college graduate).
[a]Numbers may not sum to group totals because of missing data.

received government food assistance (e.g., food stamps, Supplemental Nutrition Assistance Program), and who received a food donation in the previous 12 months. The odds of experiencing hospital food insecurity remained significantly higher for those identifying as Black or African American compared with Whites (adjusted odds ratio = 2.7; 95% confidence interval = 1.1, 6.6) when we controlled for receipt of government food assistance.

Financial barriers to food access were prevalent: 43% of all caregivers reported not having enough money to buy food in the hospital. These caregivers, as well as those who did not have reliable transportation, were significantly more likely to have experienced hospital food insecurity. Most caregivers reported that they were unlikely to leave the hospital during their child's stay (69%) and nearly half felt that their child would not be OK if the caregiver left the hospital (48%). These barriers were not significantly associated with hospital food insecurity in bivariate analyses (Table 1).

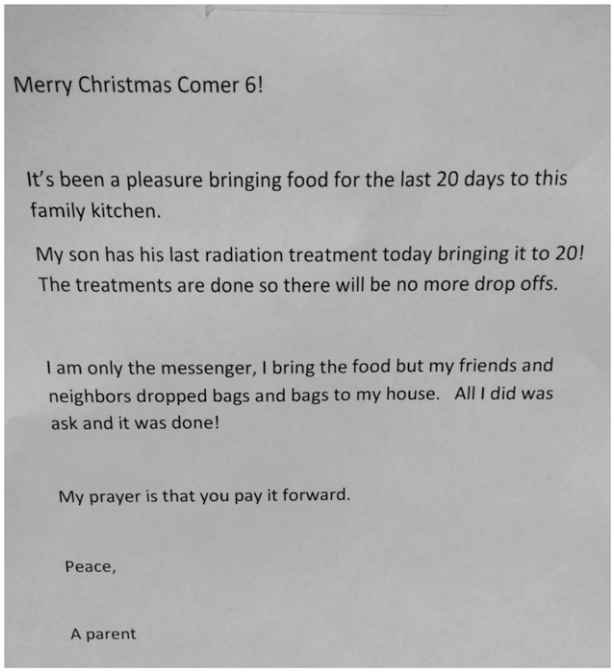
In multivariable analysis (Table 2), odds of experiencing hospital food insecurity were significantly elevated for those who thought their child would not be OK if the caregiver left the hospital. Other factors independently associated with a higher odds of hospital food insecurity included household food insecurity in the previous 12 months, receipt of government food assistance in the previous 12 months, not having enough money for food in the hospital, and lacking reliable transportation.

DISCUSSION

To our knowledge, this is the first study to describe the prevalence of hospital food insecurity among caregivers in the pediatric hospital setting. At this urban academic children's hospital, a third of caregivers met criteria for hospital food insecurity. More than 40% of caregivers in this study met criteria for household food insecurity in the previous 12 months, a prevalence similar to that reported for US households with children with income below the poverty level (45%) and households with children headed by single women (35%).[1]

Hospital food insecurity was associated with sociodemographic characteristics as well as with mutable factors, including having enough money to buy food at the hospital, having transportation to get food while at the hospital, and knowing where to get food while at the hospital. Although there were no previous studies of hospital food insecurity to corroborate these findings, the associations we found between household food insecurity and sociodemographic characteristics mirror associations reported for household food insecurity, including higher prevalence among people who are Black or African American, single or divorced, or less educated.[1,12] Low income status could explain these sociodemographic associations with hospital food insecurity. When we used government food assistance as a proxy to adjust for income status, African American or Black race was independently associated with hospital food insecurity. This finding suggests, as has been found in previous studies of the relationship between race and other health outcomes,[27,28] that factors more common to the experience of being African American or Black, including discrimination or racism, could be contributing to these racial differences in hospital food insecurity.

Previous studies found food insecurity in adults to be associated with symptoms including hunger, depression, fatigue, lack of


Merry Christmas Comer 6!

It's been a pleasure bringing food for the last 20 days to this family kitchen.

My son has his last radiation treatment today bringing it to 20! The treatments are done so there will be no more drop offs.

I am only the messenger, I bring the food but my friends and neighbors dropped bags and bags to my house. All I did was ask and it was done!

My prayer is that you pay it forward.

Peace,

A parent

FIGURE 2—Note received from caregiver contributing to the food pantry at a Chicago, IL, pediatric hospital.

concentration, lack of control, and impaired learning.[3–6] Although beyond the scope of our study, these kinds of symptoms could impair caregiver decision-making and be misunderstood by health care providers as disinterest in, distrust of, or lack of cooperation with the child's medical care. We found it interesting that a caregiver's worry that the child would not be OK if left alone at the hospital was independently associated with hospital food insecurity. Whether worry about the child's well-being prevents the caregiver from leaving to find food, or hunger promotes feelings of worry or distrust in the hospital care, cannot be discerned from this cross-sectional observation. However, it seems plausible that interventions to prevent and alleviate caregiver hunger in the hospital setting could promote trust between caregivers and staff. A prospective study is needed to assess the impact of the hospital food pantry or other hunger-prevention interventions on pediatric, caregiver, and even health provider outcomes.

The path to most health care interventions begins with research; however, the urgency of need and our capability to quickly respond warranted the "feed first, ask questions later" approach. Operating through volunteers and purchasing food with modest grant and philanthropic funds, our hospital-based pantry served approximately 10% of families of all children hospitalized during the study period (about a third of those in need, according to the findings of this study). Recipients expressed appreciation; 1 person called the program a "blessing" and another said it enabled him or her to "get through" the child's hospital stay. In 1 instance, during a child's hospitalization for 20 days of radiation therapy, an anonymous parent contributed donations supplied by supportive friends and neighbors and posted a letter encouraging other families to "pay it forward" (Figure 2).

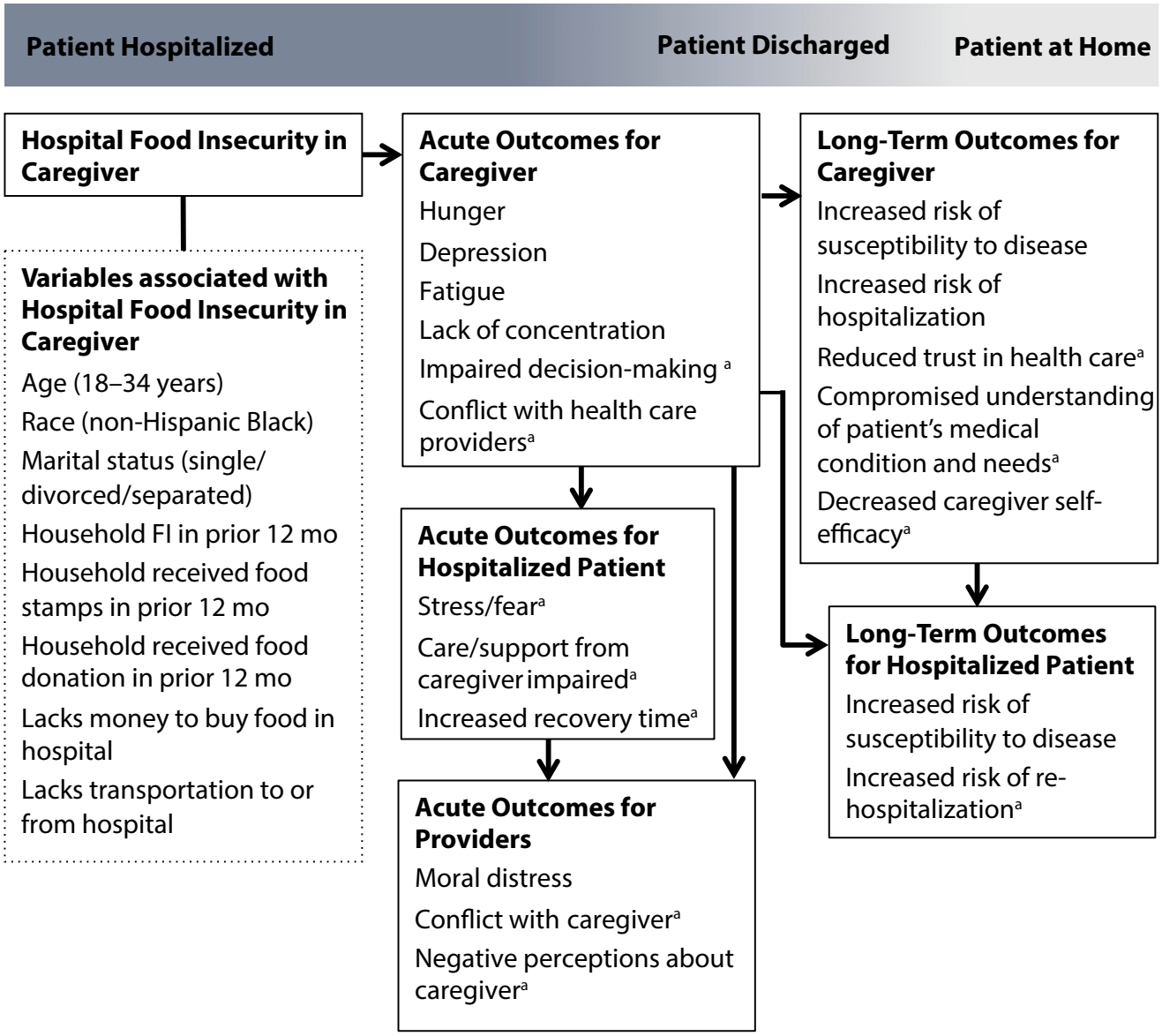
Nearly 40% of caregivers were receiving government food assistance suggesting that, in addition to, or as an alternative to, a food pantry, hospitals could work with their food vendors to provide items eligible for food stamp purchase. Since we began this work, we have identified 2 other hospital-based pantries, including the pediatric clinic at Hennepin County Medical Center[29] and the Preventive Food Pantry at Boston Medical Center.[30] Unlike our pantry, which focuses on feeding caregivers while their child is hospitalized, these pantries provide households with food to take home. Ideally, a hospital-based food pantry would offer both services.

On the basis of this study's findings, the published literature, and expert opinion, we propose a preliminary conceptual framework to facilitate future research and the design of effective interventions to address hospital food insecurity (Figure 3). This framework highlights gaps in the current evidence base and informs future intervention by showing that a holistic intervention would connect caregivers to food in the hospital and then extend into the home (more than 40% of children were discharged to food-insecure homes) to prevent caregiver and child food insecurity after a child's hospitalization.

Limitations

Several limitations should be considered in interpreting this observational study. The study was conducted in an urban, high-poverty community. Although food insecurity in the United States is concentrated in urban areas, generalizability of the study results to other populations may be limited for several reasons. The study was performed at a single center and used a convenience sampling design. This strategy, used in part to preserve participant dignity, confers a risk of selection bias; individuals willing to participate in the survey may have been systematically different from those unwilling or unavailable.

Furthermore, we excluded caregivers in the neonatal and pediatric intensive care units from the study (not from access to the food pantry) to protect patients from unnecessary exposure to the research team. We hypothesize that these caregivers are at even higher risk of hospital food insecurity because of the acuity and duration of the child's hospitalization. Also, the hospital food insecurity measure was not validated; we were unable to find a validated measure in the published literature. The measure used was a single survey item that, consistent with US Department of Agriculture's definition of food security,[1] assessed whether caregivers were getting "enough food" during their hospital stay, but did not define what constitutes "enough." Finally, because this was a cross-sectional study, we are limited in our



Note. FI = food insecurity.
[a]Outcomes supported by expert opinion and clinical experience; additional research needed.

FIGURE 3—Preliminary conceptual framework for risks for, and the acute and long-term outcomes of, hospital food insecurity in caregivers of hospitalized patients derived from literature, study results, and expert opinion: Chicago, IL, June–December 2011.

ability to make causal inferences about the relationship between caregiver characteristics and hospital food insecurity.

Conclusions

Episodes of hospital food insecurity in caregivers of hospitalized children likely have acute and long-term impacts on the health outcomes of the caregiver and the patient, and deleterious effects on health care delivery. The proposed conceptual framework can be used by others to inform preventive interventions and elucidate mechanisms through which hospital food insecurity affects important health outcomes. Alleviating caregiver hunger through a volunteer food pantry in the hospital could strengthen the therapeutic alliance between providers, caregivers, and children, and create opportunities for caregivers and families to support one another, while evidence is generated to determine a more holistic solution for hunger that optimizes outcomes for children and caregivers during and after a child's hospitalization. ■

About the Authors

Jennifer A. Makelarski and Stacy Tessler Lindau are with Department of Obstetrics/Gynecology and The University of Chicago Medicine Urban Health Initiative, The University of Chicago, Chicago, IL. Stacy Tessler Lindau is also with

Department of Medicine-Geriatrics, The University of Chicago, and the MacLean Center for Clinical Medical Ethics, Chicago. Daniel Thorngren is with the Pritzker School of Medicine, The University of Chicago.

Correspondence should be sent to Jennifer Makelarski, PhD, The University of Chicago, Department of Ob/Gyn, 5841 S Maryland Ave, MC 2050, Chicago, IL 60637 (e-mail: jmakelarski@babies.bsd.uchicago.edu). Reprints can be ordered at http://www.ajph.org by clicking the "Reprints" link.

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Contributors

J. A. Makelarski led the literature review and synthesis, wrote the initial draft of the article, led the analysis, and created the tables and figures. All authors designed the survey questionnaire. J. A. Makelarski and D. Thorngren implemented the survey questionnaire. S. T. Lindau oversaw the study and guided its execution, and obtained funding for and provided overall supervision of the study. D. Thorngren and S. T. Lindau contributed critical content, editing, and review of the article.

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Human Participant Protection

A protocol for the study was submitted to the University of Chicago institutional review board and was determined to be exempt from the requirement for review under category 45 CFR 46.101(b)(2). Even with this exemption, all individuals participated in an informed consent process before participation in the study.

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