

# Understanding Caregiver Perspective on Social Determinants of Health Interventions in Pediatric Primary Care

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## Abstract

Comprehensive social risk screening has become standard practice in primary care. Evidence is lacking, however, on whether and how interventions provided for positive screens are being utilized. This study aimed to create a standardized follow-up process to evaluate caregiver perspective and usage of community resources provided during well-child visits. Follow-up calls were made to families with positive screens for food insecurity (FI) and/or utility insecurity (UI) ( $n=347$ ). Phone interviews assessed resource usage, effectiveness, influence on stress level, and current insecurity status. Caregiver responses regarding barriers to resource usage were inductively analyzed and developed into major themes. The sample included 228 (65.7%) families with positive screens for FI and 166 (47.8%) families screening positive for UI. Of those who completed interviews ( $n=108$ ), 77 (71.3%) caregivers recalled being provided resources during their child's visit with only 33 (42.9%) reporting use of those resources. Twelve (36.4%) of those caregivers who used the resources confirmed that their insecurity was still a concern. Five major themes for barriers to resource usage emerged: (1) improved situation, (2) perception, (3) access barriers, (4) conflicting priorities, and (5) too busy/overwhelmed. The majority of caregivers (95.7% of asked) noted that their insecurity caused increased stress with 70.5% acknowledging decreased stress levels after discussion with a provider. Integrating caregiver input through a standardized follow-up protocol into provided interventions for screened social risks can improve not only the quality and effectiveness of provided resources, but also provide insight into the impact of those interventions on insecurity from the caregiver perspective.

**Keywords:** screening, social determinants, interventions, food insecurity, utility insecurity, pediatrics

## Introduction

**P**OVERTY AND ITS ASSOCIATED INSECURITIES are important contributors to social determinants of health (SDOH) for children and are connected to negative health outcomes that can persist into adulthood.<sup>1,2</sup> Living with unmet basic needs, such as food, housing, and utilities, especially during early childhood, can be detrimental to a child's health and well-being and adds to the development of child health disparities.<sup>3</sup> Food insecurity (FI), defined as inadequate access to affordable and nutritious food, is a growing population health concern in the United States that has been linked to many adverse health effects, such as obesity, toxic stress, mental health conditions, and developmental delays.<sup>4-6</sup>

Other increasingly common SDOH, such as housing insecurity and the lack of proper household utilities, also contribute to the growing health disparities found in communities with greater levels of poverty.<sup>7,8</sup> Housing insecurity, which encompasses all conditions that lead to an unreliable living environment, such as high housing cost compared with income, poor housing quality, overcrowding, and unstable neighborhoods, has been linked to poor health, growth, and development in children.<sup>7,9</sup>

Early identification and intervention of risk factors for SDOH are critical to reducing these detrimental health outcomes in children. The American Academy of Pediatrics and Academic Pediatric Association recommend the surveillance of risk factors related to SDOH during all patient encounters through a written or verbal screener for basic

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needs.<sup>1,10,11</sup> In current practice, hospitals and clinics respond to positive screens for these basic needs by linking families with resources and services provided by Healthcare and Community Based Organizations (CBOs).

Despite recent growth in health care screening practices, little research has been done to understand the caregiver's perceptions and experiences with interventions. Instead, focus has largely been placed on system-centric values that relate to the bottom line, such as health care cost and utilization. The few studies that have focused on person-centric impacts of linking caregivers to CBO resources and services have shown that caregivers often appreciate screens for resource insecurity as it helps them feel cared for and provides them with resources, even if they do not expect those resources to solve their resource insecurities completely.<sup>12–15</sup>

The goal of this study was to expand upon existing person-centric research and explore caregiver experience with insecurity screening and the impact of provided resources through the development of a standardized follow-up protocol. Using an iterative improvement methodology, this study sought to understand caregiver experience of receiving community resources in response to structured screening for social needs.

The 3 major aims of this study are as follows: (1) describe the development and implementation of a standardized process to evaluate the effectiveness of current interventions for responding to screened food and utility resource insecurities, (2) evaluate specific resource usage in patients with food and/or utility resource insecurity and understand barriers faced by caregivers that prevent them from accessing resources, and (3) evaluate the impacts of this intervention on caregiver stress.

## Materials and Methods

This project was reviewed by the Drexel University Institutional Review Board and deemed to not be human subjects research. The qualitative component was added after data collection was initiated to provide deeper understanding of caregiver reasoning to why provided community resources were not utilized.

### Setting

St. Christopher's Hospital for Children (SCHC) is an academic tertiary care facility that provides care to North Philadelphia's underserved pediatric population. Philadelphia is one of the poorest major cities in the country, and that poverty is concentrated primarily in North and West Philadelphia, with a poverty rate of 25%, child poverty rate of 39%, and a FI rate of 21% that has continued to grow despite national declines.<sup>16</sup> The SCHC outpatient practice sees ~30,000 patients annually, who are disproportionately aged 5 years or younger, Black (39.5%) or Hispanic (41.4%), and largely reliant on Medicaid insurance (90%).

In 2011, comprehensive social risk screening was implemented for all well-child visits through the Medical Legal Partnership that created a 14-item screening tool to assess SDOH. The resident continuity clinic, where this study's sample was derived, is staffed by ~75 residents who are precepted by ~15 attending physicians and screens ~600 well visits per month.

### Participants

Participants included a convenience sample of caregivers who presented to the resident clinic between December 2018 and January 2020 for well visits and completed social risk screening. Caregivers were included for follow-up if they had screened positive for at least 1 of the 2 most frequently positive insecurities on the screening tool: FI and/or utility insecurity (UI). FI and UI were selected for follow-up because (1) both are prevalent across the practice and (2) standardized interventions were already in place for both insecurities. FI was assessed using the validated 2-item Hunger Vital Sign tool.

A positive screen for FI was determined by affirmation of at least 1 of the following statements: (1) within the past 12 months we worried whether our food would run out before we got money to buy more; (2) within the past 12 months the food we bought just did not last and we did not have money to get more. UI screening was deemed positive if caregivers affirmed the following question: Have you received a shut off notice from any utility (gas, electric, and water) in the past 30 days?

Exclusionary criteria included non-English-speaking caregivers ( $n=8$ ), families with reported Department of Human Services Involvement ( $n=3$ ), and those screened in other departments ( $n=6$ ). Families with multiple child and/or sibling visits during the study time frame only completed 1 interview. Multiple interviews were not conducted for any caregiver.

### Procedure

Using an iterative process, a standardized follow-up protocol for phone interviews was developed.<sup>17,18</sup> The research team met on a monthly basis to discuss the previous month's results with the protocol subsequently updated and revised as necessary following research team consensus. Revisions included rewording of the interview script for increased clarity and caregiver comprehension and the addition of caregiver stress-related measures. A detailed description of changes is provided in Table 1.

During each cycle, phone interviews were conducted by 2 medical student interviewers (J.R.C. and P.A.) to qualify caregivers. Monthly data sets of positive screens from well visits were used to conduct the interviews, with interviews occurring an average of 63.3 days (standard deviation=20.7) after their patient visit. Interview responses were collected and managed using Research Electronic Data Capture (REDCap) tools hosted by Drexel University College of Medicine.<sup>19,20</sup> The final interview guide is provided in Table 2.

### Data analysis

Descriptive statistics of caregiver and child demographics, phone interview responses, and resource insecurity were conducted for quantitative analysis. Secondary qualitative analysis was applied to the responses caregivers provided for why they had not utilized resources provided to them during their child's appointment ( $n=41$ ). Responses that were recorded in REDCap<sup>19,20</sup> by medical student interviewers were independently coded by 2 members of the research team with qualitative research experience (J.R.C. and K.C.) in alignment with inductive thematic analysis principles.<sup>21</sup>

Incomplete responses that failed to capture explicit caregiver statements were excluded from qualitative analysis

TABLE 1. ITERATIVE CYCLE OBJECTIVES AND CHANGES

<i>Cycle</i>	<i>Objective</i>	<i>Changes</i>
1	To assess primary application of follow-up interview	Rewording of interview protocol script for increased clarity (eg, changing “resource” to “information”)
2	To address whether current interview protocol is meeting follow-up aims	Addition of stress-related questions
3	To assess effectiveness and clarity of new stress-related questions	Revision of stress-related measure protocol, asking secondary question regarding provider discussion to only those with increased stress
4	To evaluate qualitative analysis of caregiver responses to resource usage barriers	Development and application of coding scheme
5	To develop common themes from qualitative analysis and discuss application of protocol to include other departments and SDOH	Plans to include additional social needs, such as lack of transportation and medical insurance, and to expand into other departments

SDOH, social determinants of health.

(*n*=6). Early responses (*n*=25, 61%) were first openly coded to reflect expressed sentiments and later discussed to develop a coding scheme that was agreed upon by team consensus and applied to remaining responses. This coding scheme was used to develop common themes in caregiver responses. Common themes were continuously reviewed and revised during data acquisition until consensus was reached and themes appropriately exemplified caregiver statements.

**Results**

From December 2018 to January 2020, 400 eligible patients at SCHC screened positive for either FI and/or UI during their well-child visits with their primary care provider. Out of these 400 patients, there were 53 sibling visits identified, resulting in a total of 347 families with positive screens. FI was the primary insecurity with 228 (65.7%) families screening positive and UI being positively screened in 166 (47.8%) families. This pattern of prevalence in the sample population reflected that of the clinic population from which the sample was drawn (FI 5.6% and UI 3.2%). The majority of families with positive screens identified as Black (49.4%) and Hispanic (33.8%). In addition, over half of the sample population with positive screens (*n*=229, 66.2%) resided in zip codes with a poverty rate >20%.<sup>16,22,23</sup>

*Quantitative analysis*

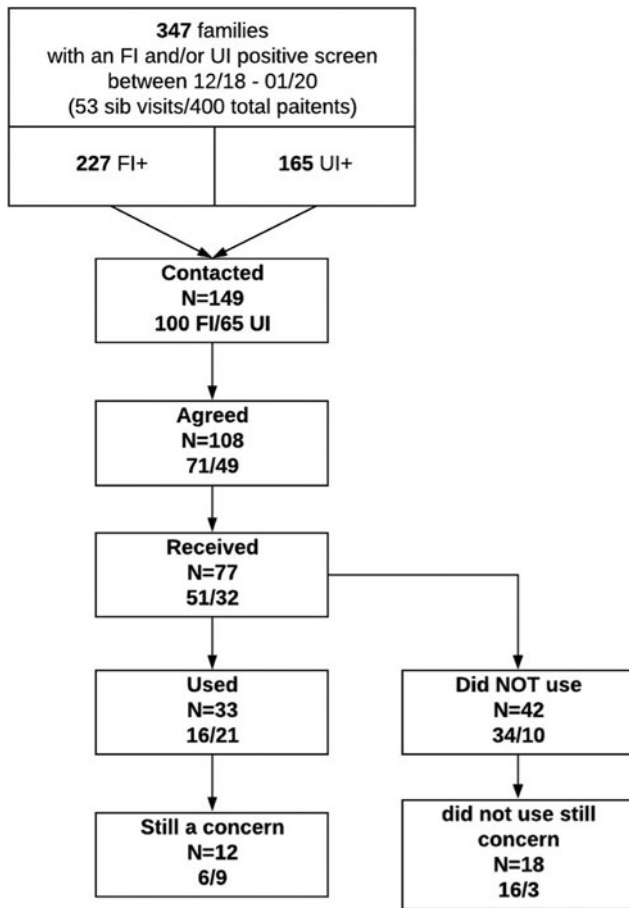
A total of 108 follow-up interviews were completed. The contact rate for conducted follow-up interviews was 42.9% with a 72.5% acceptance and completion rate (Fig. 1). This resulted in survey data originating from 31.1% of all the families that screened positive for FI and/or UI during the study time period. Of those who completed the survey, 77 (71.2%) caregivers stated that they had received resources for their identified insecurity from a member of the health care team. Although families with FI more frequently reported receiving resources (71.8%) than those with UI (65.3%), there was no significant difference (*P*=0.45).

Out of the 77 caregivers who were provided resources, only 33 (42.9%) stated that they had used the resources provided. Those with UI were more likely to use the resources than those with FI (*P*=0.002). Statements made by caregivers for reasons why they did not use the provided resources were qualitatively examined and common themes were developed.

During the second iteration, the follow-up interview protocol was modified to include measures of caregiver stress. Each caregiver (*n*=80) was asked whether they had experienced stress as a result of their resource insecurity. FI caregivers were no more likely to report stress due to their insecurity than their UI counterparts (*P*=0.75) (Table 3).

TABLE 2. FOLLOW-UP INTERVIEW PROTOCOL

<i>Main questions</i>	<i>Probes</i>
1. At your visit, it was noted that you may have had some recent difficulty with food (or utilities). Do you remember discussing this with a member of the health care team?	If no, do you remember marking this concern on a paper form during your visit?
2. Did you receive any information to help you address your concern?	This may have been a piece of paper with contact information. If yes, what was the resource provided? (List possible resources if cannot recall)
2a. If yes, have you had the opportunity to use the resource?	If yes, was it helpful? If no, why not?
3. Do you feel like this concern has caused you to have stress in your life?	Why or why not?
3a. If yes, how did discussing this concern with your provider affect your stress level?	Increased, decreased, or no change in stress?
4. Is food (or utilities) still a concern for you?	



**FIG. 1.** Call outcome flow diagram. FI, food insecurity; UI, utility insecurity.

Those who reported stress were asked an additional question about changes in their stress level after a discussion with their provider about their resource insecurities. The majority of caregivers (~80% for each resource) stated that they had decreased stress after their discussion with a provider. No caregivers reported increased stress after their provider conversation, although 5 FI and 3 UI caregivers expressed no change in stress level.

At the end of the interview, all caregivers were asked whether their identified resource insecurity was still a concern. A total of 41 caregivers (39.2%) stated their identified insecurity was still a concern, with no significant difference

**TABLE 3.** STRESS OUTCOMES

	FI, n (%)	UI, n (%)
Stress interviews	46	34
Insecurity causes stress	26 (56.5)	18 (52.9)
Provider discussion:		
Decreased stress	18 (78.3)	13 (81.2)
No change in stress	5 (21.7)	3 (18.8)
Increased stress	0 (0.0)	0 (0.0)

*Note:* Percentages for “insecurity causes stress” derived from “stress interviews,” percentages for “provider discussion” derived from total asked (FI n=23, UI n=16) as second stress question was added at a later iterative cycle.

FI, food insecurity; UI, utility insecurity.

between caregivers reporting FI or UI ( $P=0.61$ ). Twelve of the 33 caregivers (36%) who used the resources provided stated that their insecurity was still a concern and only 1 caregiver reported a new concern. There was no significant difference between FI and UI caregivers in reporting continued concern for their identified need after using the provided resources ( $P=0.74$ ).

*Qualitative analysis*

Caregivers expressed a variety of reasons for why they were unable or unwilling to use the provided community resources. These reasons can be described by 5 major themes: (1) improved situation, (2) perception, (3) access barriers, (4) conflicting priorities, and (5) too busy/overwhelmed. Each theme is discussed in succession hereunder.

**Improved situation.** When asked why they did not use the provided food and/or utility resource, many caregivers reported that their situation had stabilized in some capacity since their child’s appointment. Others went so far as to state that their insecurity had resolved. Often, caregivers explained that they had gained access to another tangible resource that they did not previously have access to at the time of their child’s appointment (ie, means of transportation, Supplemental Nutrition Assistance Program benefits, food stamps, and a new occupation). Others simply expressed that they were currently “doing better” and would use the resource in the future if the need should arise.

**Perception.** For some caregivers, the reasoning they gave for not using the resources provided revolved around their perceptions of need. These caregivers expressed a belief that the resources were not appropriate for them, whether it was because they did not believe they had a large enough need or that they believed others needed the resource more. One caregiver stated that they were “never completely without food,” whereas another stated, “others have it harder.” These sentiments were expressed by others as well, with some taking the resources simply for “future use,” in case their need became greater and the resource was more appropriate for their situation.

**Access barriers.** Multiple caregivers expressed the desire to use the community resources provided, but stated that a physical barrier prevented them from accessing these resources. These physical barriers included a lack of transportation, poor weather conditions, health concerns, and the location, or distance, of the resources. Primarily, these concerns revolved around the inability to travel to and from the resource location. Many of the caregivers with these access barriers suggested that they would use the resources provided if their travel concerns were met, such as having the resources closer to their home or within walking distance.

**Conflicting priorities.** Besides having physical barriers limiting resource usage, many caregivers noted conflicting responsibilities and social needs that took priority to accessing the provided resources. These caregivers specified a social factor, such as housing concerns (ie, moving and landlord issues), loss of a job, legal concerns, or lack of amenities, which took precedence and required their attention before they could attempt to access the resources. Some

caregivers expressed that the cost requirement of some of the provided resources was a deterrent of usage, stating they required the money for other needs.

**Too busy/overwhelmed.** Another common explanation for why resources were not being used was caregivers stating that they were simply “too busy.” They stated that they had “no time” to use the resource and often expressed feelings of overwhelm. Some even went so far as to state that they were currently in a stressful period and were struggling to manage all of their daily responsibilities with work and child care.

## Discussion

Systematic social risk screening has increasingly been incorporated into standard pediatric health care practices to identify unmet basic needs, and when possible, provide interventions to assist families. This study focused on 2 of the most prevalent social needs identified at SCHC, FI and UI, to create a standardized follow-up protocol for families with positive screens for these basic needs. Although positive social screens were routinely identified, discussed, and provided interventions by the health care team, less than half (42.9%) of those caregivers who were provided resources utilized them.

Moreover, the authors found that though FI was more common, those with UI were more likely to use the provided resources than those with FI, possibly due to the nature and accessibility of those resources. The primary UI resource included a temporary emergency shut off hold that the health care providers file on behalf of their patients, whereas the FI resources included a list of available food pantries and deliverable produce, some of which require a small fee. When the resources were utilized, almost all caregivers found the resources to be beneficial in some way.

Only 2 caregivers stated that they were unsuccessful in attempting to utilize the resource, whereas all others who had attempted to use the provided resources were successful. This is reassuring that the CBOs to which patient families are being connected are largely accessible and successful in addressing social needs. However, the fact remains that the majority of caregivers are not accessing the provided resources.

Based on the qualitative results, the authors found that barriers to accessibility, such as transportation and resource location, were major factors in determining whether caregivers utilized their provided resources. Since the main UI resource is directly administered by providers, it seems reasonable that those resources were utilized more often than the FI resources that require caregivers to access on their own. Caregiver perception of their current condition also often kept them from accessing the resources, whether based on tangible improvements to their condition or simply their understanding of “need.”

This may be reflective of the fluctuating nature of resource insecurity that contributes to the complexity of addressing social needs.<sup>24</sup> In addition, caregivers expressed a number of competing priorities that conflicted with resource usage. Presence of multiple social needs, time constraints, and general overwhelm often hindered resource usage as other needs had to be addressed before resource access. This feeling of overwhelm was expressed by most caregivers as the majority of caregivers expressed stress as a result of their insecurity. This stress experienced by caregivers is a potential target for reducing potentially harmful “toxic stress” exposure in their

children, which can have life-long negative effects on learning, behavior, and physical and mental health.<sup>25–27</sup>

This lack of resource utilization and increased caregiver stress provides an opportunity for improvement and provider outreach. The authors found that caregivers often expressed decreased stress after discussions with their health care provider about their identified needs, suggesting that simply having conversations and discussing possible resources are enough to lift some of the emotional burden left by limited social needs. Future studies may look into developing a standardized protocol of screening for chronic caregiver stress within SDOH screening initiatives as a means to mitigate toxic stress exposure in children and start conversations around resource insecurities that may act as a first step to intervention.

It is the authors’ recommendation that health care workers create personalized action plans with caregivers when providing external resources. Action plans can help caregivers address potential barriers to resource usage and, together, caregivers and providers can identify which resources may be most accessible. Similar recommendations have been made by Swavely et al who also qualitatively analyzed FI screening and community resource utilization in discharged adult patients from a comparable population.<sup>24</sup>

This study builds upon this prior study by specifically addressing FI and UI affecting the pediatric population. The simplicity of the follow-up protocol the authors developed with phone interviews creates a straightforward and manageable approach to directly assess caregiver perspective on resource effectiveness.

Although this study has many strengths and provides recommendations for future screening and resource evaluation practices, there are a few limitations to note. The first includes the study population, which, although representing the screening and resource intervention practices of a single urban children’s hospital, may not be reflective of all pediatric health care communities. The sample population was also limited to only English-speaking caregivers. Although this helped to limit language barriers and translational errors for this pilot sample, potentially important feedback from a particularly vulnerable population has been missed.

Future efforts should be made to include this population for further quality improvement endeavors. In addition, not all screening forms during the study time period were identifiable and able to be correctly recorded for an identified need. Some forms (~30%) lacked the necessary medical record number, which prevented them from being linked to the correct patient and, therefore, unable to be contacted and incorporated into this study sample.

Improvements can be made with systematic checks to increase correct filing. Lastly, although this study does use qualitative analysis to explore barriers to resource usage, this was not a primary aim of the study. Future studies should make qualitative analysis a primary focus and include further in-depth examination of caregiver responses for a more robust understanding of the caregiver perspective to social need interventions in health care practice.

## Conclusion

SDOH are a major concern for impoverished communities, particularly for children. Screening practices have been incorporated into pediatric health care for early identification

and intervention of unmet basic needs. However, follow-up exploring caregiver perspective and utilization of provided community-based interventions remains challenging. In this study, the authors created a standardized follow-up protocol to assess ongoing caregiver insecurity status and ability to access provided resources after positive screens.

Implementing such protocols presents unique insights into the caregiver perspective of resource acceptance and usage and provides opportunities for improved care. Addressing caregiver concerns and barriers to access, including location, competing priorities, and perceptions of need, through personalized action plans may increase positive outcomes and partially alleviate caregiver stress when attempting to reduce the negative effects associated with unmet basic needs. Future studies are needed to expand follow-up protocols to other unmet social needs and reach populations not addressed in this study.

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