Screening for Food Insecurity: Amplifying the Caregiver Perspective

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When kids go hungry, it takes a toll on nearly every aspect of their health. From increased risk of asthma and anxiety to cognitive delay and hospitalization, food insecurity is a strong predictor of poor health outcomes. In Philadelphia, nearly 1 in 4 children was food insecure in 2019, a number that continues to climb during the COVID-19 pandemic.

For these reasons, medical providers have been increasingly interested in screening for food insecurity and other social determinants of health. When armed with information about a family's circumstances, providers can serve as a source of support and connect caregivers to community resources that can help meet their needs. However, little is known about how to screen families for a social need like food insecurity in a way that is comfortable and elicits an accurate report of the challenges they face. Furthermore, few studies have examined why rates of engagement with resources are low even after a referral is provided.

We conducted a three-part study to learn more about these issues: first, randomizing caregivers arriving with pediatric patients to Children's Hospital of Philadelphia's (CHOP) Emergency Department (ED) to either a written, tablet-based screen for food insecurity, or the identical screening tool asked verbally; second, conducting surveys and telephone interviews to explore caregivers' experiences with food insecurity screening and resource referral; and third, partnering with a community food resource agency to provide a "warm handoff" through which caregivers were contacted directly within two weeks of the ED visit for resource navigation.

Our findings—particularly illuminating during Hunger Action Month—highlight caregiver preferences and perceptions related to screening and social resource referral, addressing three main questions:

1) How should we screen for social risk?

2) What gets in the way of engaging with social resources?

3) How do caregivers think the referral process could be improved?

How should we screen for social risk?

Use electronic tablet-based screening. Our randomized controlled trial found a significantly higher rate of reported food insecurity among caregivers screened by tablet (24%) compared to those screened verbally (18%). Caregivers shared during phone interviews that the tablet provided a level of anonymity that helped them feel less "judged," as food insecurity can be a stigmatizing condition and disclosure of this sensitive information can raise fears of negative repercussions such as the involvement of Child Protective Services. Some caregivers explained that they felt the tablet was a more private way to answer questions about sensitive subjects:

> I'm happy it was in a device and I didn't have to speak out loud in front of my child.

Leveraging screening location as an opportunity for enhanced anonymity. While there was a high level of comfort with screening regardless of the clinical setting, more participants reported comfort completing the screen in the ED compared to their child's doctor's office (86% vs. 80%). Caregivers described a close relationship with a physician as both a facilitator and a barrier to relaying social need. As one parent described:

> So, you get a relationship with that doctor. You really don't want them in your business or judging you or looking at you some kind of ways.

It is possible that, together with a tablet-based screen, the added level of anonymity inherent to being a patient in the ED enhanced participants' comfort levels.

What gets in the way of engaging with social resources?

Perception of need. Caregivers often refused resources because they did not see their situation as “bad enough” to require additional help. Many reported discomfort taking resources that other families might need more. One caregiver simply stated,

> I don't think that my family is as needy as other families could be.

Negative past experiences with social resources. Some caregivers reported negative past experiences with social resources and expectations that their income or employment status would disqualify them from receiving additional resources. One caregiver described his rationale for refusing resources:

> Once they see your income, they're going to say, ‘Oh you can afford this,’ not knowing that they don't take a consideration that you have to pay for your insurance. You have to pay for rent. You have to pay for all these things because the system won't help you. So, it's just like I didn't need to be contacted because they already shut me down.

Competing priorities. A common theme among caregivers who were food insecure and did not engage with resources was the presence of competing priorities: the inability to find time to make or return phone calls, visit websites, or travel to resource agencies because of other distracting or higher priority demands. Frequently, caregivers cited their child’s acute health complaint as the reason they did not engage with the referred resource.

Challenges with follow-up. Many families in our study (54%) who screened positive for food insecurity opted to receive a follow-up phone call from a food resource agency. However, only one-third were reached by phone, and many among this group (31%) no longer felt they needed or were no longer interested in help. This suggests that providing onsite resources at the time of screening could better serve families and avoid difficulties related to follow-up.

Caregiver suggestions for improving the referral process

Offer electronic modes of resource connection. Several caregivers suggested that keeping track of a physical list of resources was difficult for them and that electronic platforms provided an additional sense of privacy. One caregiver explained,

> The paper, people lose it. There's so many, bunch of stuff in the trash, but emails will always be there.

Provide resources that are geographically appropriate. Caregivers described frustration that resources were not geographically convenient and emphasized individualizing resources to a family's location. One caregiver explained her challenges accessing community resources:

> Being that I live basically on the other side of the city, and I don't have a vehicle, getting there to take advantage of that which I would love to do is very difficult.

Ensure that instructions for accessing resources are widely available. Many caregivers suggested that a generalized distribution of food access resources without associated screening processes might make it easier to connect families with services they need. Several different modes of communication were suggested such as television, phone calls, text messages, mailed letters or pamphlets.

Next Steps

These findings have influenced social risk screening protocols at CHOP and throughout southeast Pennsylvania via the COACH collaborative, with implementation of social risk screening tools using a tablet. While we found overall high reported comfort with screening, it is notable that comfort levels were lower among those reporting food insecurity, with caregivers expressing fear of stigma or negative repercussions as a consequence of reporting social risk. This and other emerging literature emphasize the potential for unintended consequences with social risk screening and have led to a growing interest in a model of universally offered social assistance, rather than one of screening and intervention. Our team will be launching a new study to further elevate the caregiver perspective, systematically exploring how screening affects families' acceptance, perception and engagement with social resources.

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