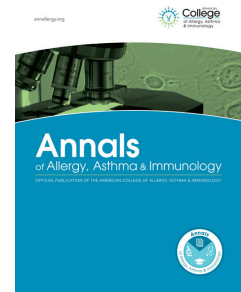


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The burden of food allergy (FA) among children in the United States has grown in recent decades, with low socioeconomic strata (SES) populations disproportionately affected.¹ In addition to demonstrating substantial variability in FA prevalence and severity across SES¹, data also indicate that important differences may exist with respect to food allergy management practices. For example, low SES patients are more likely to receive treatment in the emergency department for FA and report greater expenditures on FA-related emergency care.² Additionally, low SES families report spending less on FA clinic visits.¹ This may lead to suboptimal management, as allergists provide specific diagnostic, educational, and treatment-related services. Thus, low SES children with FA are less likely than their more affluent counterparts to obtain clinical confirmation of suspected FAs and education on how to manage them.

To date, limited qualitative work has attempted to characterize barriers to proper FA management amongst low SES patients. Our team aimed to fill this gap by using a qualitative approach to identify specific barriers to providing appropriate food allergy management and acute care to Medicaid-insured food allergic children in Chicago.

The questionnaire was developed by the study investigators (allergists, pediatricians, and psychologist) and piloted by research coordinators (trained in qualitative research methods). The interview guide included questions regarding their child's FA, in regards to: management (diagnosis, testing, and access to care), management at school or with other caregivers, and allergic reactions and treatment. Caregiver's knowledge and preparedness was assessed, and information regarding the emotional response of both the caregiver and child was documented.

Confusions, difficulties, and barrier to properly managing their child's FA were explicitly discussed. The in-person interviews were conducted by the primary research coordinator and lasted about an hour. Interviews were then transcribed, de-identified, and analyzed using NVivo software. A comprehensive codebook of key themes was then created and used to analyze the transcripts.

We completed 8 semi-structured qualitative interviews with primary caregivers of Medicaid-insured children in Chicago, Illinois. Participants were all English-speaking, female adults (18+), whose child had a physician-diagnosed FA. There were four Hispanic participants, three Black/African American participants and one White participant. A majority of participants (6) reported two or more potential caregivers over the age of 18 within the household. Five of the FA children were male, and half were under the age of seven years old. Six FA children had a physician-diagnosed FA established 3-9 years ago, and two children were diagnosed a year prior.

Our findings suggest that substantial barriers to proper FA management do exist within this population. Our analysis of interviews yielded three major themes (Figure 1). The first was (1) "*Limited caregiver knowledge*," as indicated by participant assertions of (a) faulty perceptions of risk, (b) uncertainty surrounding their child's specific allergens, and (c) confusion about symptoms, treatment, and aftercare of a reaction. For example, one participant described how she "think[s] that [the doctors] don't really tell you when to use [the epinephrine auto injector]. Now that I'm thinking about it, they don't tell you.... 'use it only if it's severe,' or 'use it at all times.' Like, actually, they don't say that." Despite the importance of patient education in the clinical treatment of FAs,³ our findings are consistent with existing literature that documents the pattern

of less adequate healthcare delivery provided to publicly insured patients than their privately-insured counterparts in the US.⁴

The second major theme identified from this analysis was (2) “*Poor inter-caregiver management.*” This reflected concerns regarding a secondary caregivers’ ability to (a) properly manage a child’s FA, (b) understand the severity of that child’s FA, and (c) treat a reaction should it occur. One participant described how she does not think physicians “fully understood the process [of] maintaining [a] child's eating habits when you're not around and you're a single parent ... [the physicians did not] give the best instructions on how to manage it other than [to] provide this list... but how does this really help?” Concern about secondary caregivers’ ability to manage FA is vital, given prior findings that a large proportion of children with FAs have allergic reactions outside of the home.⁵

The final major theme discussed by caregivers was (3) “*Insecure access to allergen-free foods.*” This theme was articulated in caregiver descriptions of how allergen-free meals are expensive, difficult to access, and time-consuming to prepare. “I would say the biggest challenge is finding food that fits ... all of his restrictions,” one participant told us. Another participant described how, “shopping can be quite an experience because sometimes you can afford the items and things that you use, and sometimes it is hard to afford them on a consistent basis.” These concerns are consistent with a national economic study of FA costs, which concluded that low SES and minority children spend less on separate allergen-free foods.² As food insecurity will often impact Medicaid-insured individuals,⁶ all clinicians should keep patients’ nutritional realities and budgetary constraints in mind during their treatment of FA.

70

71 In summary, these qualitative interviews identified three principal barriers to FA management
72 within this Medicaid-insured population: *Limited caregiver knowledge, inconsistency in FA*
73 *management attitudes and practices between the child's caregivers, and limited access to safe*
74 *foods*. While the study is limited by the small convenience sample utilized, the similarities of
75 their experiences indicate that the aforementioned barriers are likely shared by other low SES FA
76 patients in the US. We believe that the present qualitative findings complement existing work
77 describing FA management trends among low SES populations. Further evaluation of the
78 specific barriers to proper food allergy management amongst Medicaid-insured families is a
79 necessary first step in addressing health inequities. Importantly, we hope that these findings will
80 inform future interventions to improve management and outcomes among the low SES
81 populations disproportionately affected by this chronic condition.

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REFERENCES

1. Gupta RS, Warren CM, Smith BM, et al. The Public Health Impact of Parent-Reported Childhood Food 81 Allergies in the United States. *Pediatrics*. 2018;142(6):e20181235
2. Bilaver, Lucy A., et al. "Socioeconomic disparities in the economic impact of childhood food allergy." *Pediatrics* 137.5 (2016): e20153678.
3. Sampson, H. A., Aceves, S., Bock, S. A., James, J., Jones, S., Lang, D., ... Wallace, D. (2014). Food allergy: A practice parameter update - 2014. *Journal of Allergy and Clinical Immunology*. <https://doi.org/10.1016/j.jaci.2014.05.013>
4. Dayaratna, K. D. (2012). Studies show: Medicaid patients have worse access and outcomes than the privately insured. *The Heritage Foundation Backgrounder*, 2740, 669-682.
5. Nowak-Wegrzyn, A., Conover-Walker, M. K., Wood, R. A., M.K., C.-W., & R.A., W. (2001). Food-Allergic Reactions in Schools and Preschools. *Archives of Pediatrics & Adolescent Medicine*, 155(7), 790–795. <https://doi.org/10.1001/archpedi.155.7.790>
6. USDA. "Characteristics Of Supplemental Nutrition Assistance Program Households: Fiscal Year 2015 96 (Summary)." SNAP, 2015, fns-prod.azureedge.net/sites/default/files/ops/Characteristics2015-Summary.pdf.

FIGURE LEGEND

Figure 1: Barriers to Proper Food Allergy Management Among a Medicaid-Insured Population

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