

Clinical Communications

Low caregiver health literacy among pediatric food-allergic patients is associated with poorer food allergy management knowledge

Maureen Egan, MD^a, H. Shonna Yin, MD, MSc^b,
Matthew Greenhawt, MD, MBA, MSc^a, and
Julie Wang, MD^c

Clinical Implications

- Lower health literacy in caregivers of children with food allergies is associated with deficiencies in demonstrating correct use of an epinephrine autoinjector, increased reactions to foods in the past 12 months, and knowledge gaps on treatment of allergic reactions.

TO THE EDITOR:

Food allergy affects up to 10% of young children in Western countries.¹ Despite parental education, a high frequency of reactions are caused by accidental ingestions (annualized reaction rate of 0.81), and severe reactions may often be undertreated (~30% of severe reactions treated with epinephrine).² Barriers to optimal parental management include knowledge gaps in treatment of allergic reactions, failure to carry an epinephrine autoinjector (EA), and lack of knowledge on appropriate use of an EA.^{3,4} A national assessment of adults found that 44% have basic or below basic health literacy,⁵ which is associated with worse health outcomes in adult patients, including reduced health-related knowledge, poor chronic disease management, increased health care utilization (emergency department [ED] visits, hospitalizations), and decreased use of preventative services.⁶ Limited parent/caregiver literacy has also been associated with poor outcomes in children.⁷ However, few previous studies have evaluated the impact of parent health literacy on children with food allergies specifically.

This study aimed to explore the relationship between health literacy and food allergy management. Associations between caregiver health literacy and correct EA use, food allergy reaction rates, health care utilization, and knowledge on food allergy management were assessed. A cross-sectional survey was administered to a convenience sample of English- and Spanish-speaking parents/legal guardians (caregivers) of food-allergic children from the Mount Sinai Hospital pediatric allergy clinic between June 2015 and September 2016, who had an allergy follow-up visit and had previously been prescribed an EA. The Mount Sinai Hospital pediatric allergy clinic serves a population with predominately government-provided or subsidized health insurance (such as Medicaid) where patients are primarily seen by fellows who are supervised by Mount Sinai Pediatric Allergy & Immunology faculty. Although there are multiple providers in this clinical setting, continuity between fellows and patients is typically maintained and supervision is by a senior faculty member, which limits variability. Education provided at initial food allergy consultation includes written education in the form

of a standardized food allergy action plan as well as hands on training with an EA trainer. It is standard practice in the Pediatric Allergy & Immunology Division at Mount Sinai Hospital that fellows provide food allergy education to families and are trained to provide similar and consistent education. However, given there were multiple providers it is possible that differing educational and/or communication styles impacted results.

Health literacy was assessed using the Newest Vital Sign (NVS), a validated index consisting of 6 questions regarding an individual's ability to read an ice cream label.⁸ Higher scores reflect higher health literacy. Appropriate use of the EA (EpiPen) was assessed using a previously described 6-step checklist, with correct use being defined as completion of all steps based on parental demonstration using an EA trainer.³ All participants carried an EpiPen. Also administered were a demographic form and food allergy history survey, which was abstracted from a commonly used set of questions used in multiple other divisional studies. The food allergy history survey addressed the child's history of allergic reactions and health care utilization, specifically, the number of phone calls to pediatricians and allergists and emergency department visits in the previous 12 months. Two vignettes with hypothetical case presentations, 1 with very mild urticaria only and 1 with clear anaphylaxis, were used to assess how the caregiver would manage allergic reactions. Multiple answer choices were allowed. This study was approved by the Icahn School of Medicine at Mount Sinai Institutional Review Board.

Data were analyzed using Stata SE, Version 13.1 (College Station, Texas). These data were analyzed using frequency analysis for demographic trends and descriptive statistics. For inferential statistical comparisons, independent Student *t* tests, 1-way ANOVA, and Fisher exact tests were used to compare means and proportional differences. In addition, logistic and linear regression, including multiple linear regression, were used for predictive inferences regarding the relationship between key predictors and outcome variables, and adjusted predicted probabilities were calculated using the Stata margins command.

A total of 102 families were approached, 2 declined participation. Table I lists the key demographic characteristics of the sample. The NVS scores revealed that approximately half (51%) of the caregivers had either a high likelihood of limited health literacy (15%) or possible limited health literacy (35%), which parallels national statistics. Middle-income tier (defined as \$50,000-\$150,000 household income/y) to high-income tier (defined as >\$150,000 household income/y) was significantly associated with higher NVS score versus being in the lower income tiers (<\$50,000 household income/y) ($P = .004$ and $.00$, respectively). Race/ethnicity was significantly associated with the NVS score, with significant differences noted between white and black (higher for white race; $P = .00$) and Hispanic and white (lower for Hispanic ethnicity; $P = .00$). Health literacy was not associated with reported number of food allergies or any other demographic data, which may be due to the small number of participants.

Table II demonstrates key associations between food allergy and health literacy. Although there was no significant association between correct caregiver demonstration of EA use and the NVS

TABLE I. Study population characteristics (n = 100)

Characteristic	Value
NVS score (caregiver), mean \pm SD	3.4 \pm 2.0
0-1 (high likelihood of limited literacy)	16%
2-3 (possible limited literacy)	35%
4-6 (almost always adequate literacy)	49%
Age of child (y), median (IQR)	7 (5.5)
Gender of child, %	
Female	37
Male	63
Language spoken at home, %	
English	90
Spanish	9
No answer	1
Ethnicity of parent, %	
Black, non-Hispanic	26
White, non-Hispanic	33
Hispanic	35
Asian, non-Hispanic	3
Hawaiian/Pacific Islander, non-Hispanic	1
Other	2
Relationship to child, %	
Mother	77
Father	20
Guardian	3
Age of parent/guardian (y), median (IQR)	38.0 (12.0)
Parental/guardian education, %	
Less than high school	4
High school/GED	37
2-y college	18
4-y college	26
Graduate school	15
Annual household income, %	
<\$10,000	10
\$10,000-\$25,000	11
\$25,000-\$50,000	30
\$50,000-\$75,000	6
\$75,000-\$100,000	6
\$100,000-\$150,000	3
>\$150,000	13
Unsure	21
No. of food allergies of the child, mean \pm SD	3.0 \pm 1.8
Other atopic conditions of the child, %	
Atopic dermatitis/eczema	83
MD-diagnosed asthma	60
Allergic rhinitis	66

GED, General Equivalency Diploma; IQR, interquartile range; MD, doctor of medicine.

score, in an adjusted regression model, increased NVS score was associated with each additional step in EA use correctly demonstrated (model R^2 , 0.42). Caregivers who had their child's EA present at the time of assessment had significantly higher NVS scores. Lower health literacy (lower NVS score) was associated with a reported increase in food allergy reactions rates in the previous 12 months. In addition, a higher NVS score was associated with lower odds of reporting a child with anaphylaxis.

In regard to health care utilization, although the NVS score was not associated with the frequency of food allergy-related calls to the pediatrician in the past year or ED visits, the NVS score increased for every additional call to the allergist in the past year. Regarding assessment of food allergy management knowledge, the mean NVS score was lower among caregivers who denoted in a vignette detailing a mild reaction with "hives only" that they would take their child to the ED or would call 911. Surprisingly, the NVS score was lower among those who reported that they would take their child to the ED in a vignette describing an anaphylactic reaction.

In this exploratory study, within this convenience sample, key deficits were identified that disproportionately affect caregivers with lower health literacy. These included improper use and failure to carry an EA, increased allergic reactions to foods, and knowledge gaps on treatment of reactions based on hypothetical vignettes, specifically with those with lower health literacy being more likely to call 911 or visit the ED for mild allergic symptoms only. We argue that participants with higher versus lower health literacy may have differing knowledge of or practice habits regarding appropriate use of health care services. This is supported by those with higher health literacy in this sample reporting that they were more likely to call an allergist, compared with those with lower health literacy who reported that they were more likely to call 911 or visit the ED for mild allergic symptoms, which is not typically medically indicated. This shows a compounded potential risk of poor understanding of the underlying medical issue and choice of a less appropriate health care setting for its management. This study showed no correlation between the NVS score and ED visits over a 12-month basis. However, a longer study period may reveal differences in ED utilization. There is a paucity (or possible drought) of work evaluating how to best provide parent food allergy education to any population, let alone low health literacy populations given this is just the second study of health literacy in food allergy to our knowledge. Studies in asthma have demonstrated that implementation of a low literacy asthma action plan has improved both provider asthma counseling without any increase in time⁹ and parental understanding of asthma management.¹⁰ These studies suggest that similar educational tools that use low literacy education principles may be beneficial for food-allergic patients, ideally targeting key deficiencies in food allergy knowledge and management identified in this study.

This study has several limitations. First, this was a convenience sample of participants recruited from a referral population at an academic medical center, so results may not be generalizable. Correct EA use was defined as completion of all 6 steps based on previous literature,³ but it is possible that the medication could be successfully delivered with a fewer number of steps and the index used is a clinical tool that has not undergone robust validation. Key items on the survey were subject to recall bias, and the period of recall may be subject to spectrum bias in assessing only the past year, which may or may not be an appropriate recall period for a food allergy. Finally, food allergy management knowledge was based on 2 vignettes, which may not represent real-life management behaviors.

In conclusion, this study highlights the potential for an association between lower health literacy among caregivers of children with food allergy and an increase in incorrect EA use, failure to carry an EA, an increase in the number of allergic reactions to food in the past 12 months, and knowledge gaps on

TABLE II. Results for all participants and key findings associated with health literacy

Outcome assessed	All participants	Health literacy association
Demonstrated correct use of EA (caregiver), mean \pm SD	- Yes: 31% - No: 69% - No. of correct steps: 4.01 \pm 1.93	- Every 1-point increase in the EA score was associated with a 0.3 increase in the NVS score ($P = .002$)
Unexpired EA present at visit*	- Yes: 42.5% - No: 57.5%	- Device being present was associated with a 1.5-point increase in the NVS score ($P = .001$)
Food allergy reaction rates (no. of events in the past 12 mo), mean \pm SD	- Allergic reactions: 2.87 \pm 7.35	- The NVS score decreased by 0.46 for every additional allergic reaction ($P = .002$)
History of anaphylaxis	- Yes: 37% - No: 63%	- Those with a higher NVS score were less likely to have a history of anaphylaxis (OR, 0.76; 95% CI, 0.61-0.94)
Health care utilization (no. of events in the past 12 mo), median (IQR)	- Calls to pediatrician: 1.25 (2) - ED visits: mean \pm SD: 0.67 \pm 3.21 - Calls to allergist: 2.0 (2.0)	- No association with calls to pediatrician - No association with ED visits - For every additional allergy call, the NVS score increased by 0.46 ($P = .002$)
Clinical vignette: Treatment of mild hives† (participants able to select multiple answers)	- Oral antihistamine: 88.7% - Use of EA: 15.3% - Go to ED: 24.4% - Call MD: 54% - Call 911: 14.3% - Supine position: 15.3% - Unsure: 1% - Other: 15.3%	- The mean NVS score was lower among patients reporting taking child to the ED ($P = .003$) or calling 911 for hives ($P = .008$)
Clinical vignette: Treatment of anaphylaxis‡ (participants able to select multiple answers)	- Oral antihistamine: 40.1% - Use of EA: 94.9% - Go to ED: 88.8% - Call MD: 64.2% - Call 911: 80% - Supine position: 21.4% - Other: 5.1 %	- The NVS score was lower in patients who would take child to the ED for anaphylaxis ($P = .05$)

IQR, Interquartile range; *MD*, doctor of medicine; *OR*, odds ratio.

Total number participants 100 (unless otherwise specified).

*A total of 80 patients.

†Correct response is use of oral antihistamines.

‡Correct response must include use of EA, call 911, and go to ED. Responses that are not incorrect but not required are oral antihistamines, supine position, and call MD.

treatment of allergic reactions. These results merit further study in a larger population. Although all patients and families would benefit from improved education on use of EAs and management of food allergies, these results demonstrate that caregivers with low health literacy, and subsequently patients under that care, have some potential to be disproportionately impacted by these key issues, highlighting a need for the development of health literacy-informed education materials addressing food allergies.

^aSection of Pediatric Allergy and Immunology, Department of Pediatrics, Children's Hospital of Colorado, Aurora, Colo

^bDepartments of Pediatrics and Population Health, New York University School of Medicine, New York, NY

^cDivision of Pediatric Allergy and Immunology, Department of Pediatrics, The Icahn School of Medicine at Mount Sinai, New York, NY

Conflicts of interest: M. Egan has received consulting fees from Nestle. H. S. Yin has no conflicts of interest to disclose. M. Greenhawt is supported by the Agency for Healthcare Quality and Research (grant no. 1K08HS024599-01); is an expert panel and coordinating committee member of the National Institute of Allergy and Infectious Diseases (NIAID)-sponsored Guidelines for Peanut Allergy Prevention; has served as a consultant for the Canadian Transportation Agency, Thermo Fisher, and Aimmune Therapeutics; is a member of physician/medical advisory boards for Aimmune Therapeutics, DBV Technologies, Nutricia, Kaleo Pharmaceutical, Nestle, and Monsanto; is a member of the Scientific Advisory Council for the National Peanut Board; has received honorarium for lectures from Thermo Fisher and multiple state allergy societies, the American College of Allergy, Asthma & Immunology, and the European Academy of Allergy and Clinical Immunology; is an associate editor for the *Annals of Allergy, Asthma, and*

Immunology; and is a member of the Joint Taskforce on Allergy Practice Parameters. J. Wang receives research support via grants to her institution (from the NIAID, Aimmune, and DBV Technologies); has received consulting fees from Aimmune, DBV Technologies, and ALK Abello; and receives royalties from UpToDate.

Received for publication March 23, 2018; revised May 15, 2018; accepted for publication May 16, 2018.

Available online ■ ■

Corresponding author: Maureen Egan, MD, Section of Pediatric Allergy & Immunology, Children's Hospital of Colorado, Colorado University, 13123 E 16th Ave, Box 518, Aurora CO 80045. E-mail: Maureen.Egan@childrenscolorado.org. 2213-2198

© 2018 American Academy of Allergy, Asthma & Immunology

<https://doi.org/10.1016/j.jaip.2018.05.021>

REFERENCES

1. Sicherer SH, Sampson HA. Food allergy: a review and update on epidemiology, pathogenesis, diagnosis, prevention, and management. *J Allergy Clin Immunol* 2018;141:41-58.
2. Fleischer DM, Perry TT, Atkins D, Wood RA, Burks AW, Jones SM, et al. Allergic reactions to foods in preschool-aged children in a prospective observational food allergy study. *Pediatrics* 2012;130:e25-32.
3. Sicherer SH, Forman JA, Noone SA. Use assessment of self-administered epinephrine among food-allergic children and pediatricians. *Pediatrics* 2000;105:359-62.
4. Gold MS, Sainsbury R. First aid anaphylaxis management in children who were prescribed an epinephrine autoinjector device (EpiPen). *J Allergy Clin Immunol* 2000;106:171-6.
5. Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America's Adults Results From the 2003 National Assessment of Adult Literacy. Available from: <https://nces.ed.gov/pubs2006/2006483.pdf>. Accessed June 6, 2018.

6. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011;155:97-107.
7. DeWalt DA, Hink A. Health literacy and child health outcomes: a systematic review of the literature. *Pediatrics* 2009;124:S265-74.
8. Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: the newest vital sign. *Ann Fam Med* 2005;3:514-22.
9. Yin HS, Gupta RS, Tomopoulos S, Mendelsohn AL, Egan M, van Schaick L, et al. A low-literacy asthma action plan to improve provider asthma counseling: a randomized study. *Pediatrics* 2016;137:468.
10. Yin HS, Gupta RS, Mendelsohn AL, Dreyer B, van Schaick L, Brown CR, et al. Use of a low-literacy written action plan to improve parent understanding of pediatric asthma management: a randomized controlled study. *J Asthma* 2017; 54:919-29.