

Influence of health literacy and trust in online information on food allergy quality of life and self-efficacy

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ARTICLE INFO

Article history:

Received for publication March 25, 2016.

Received in revised form July 5, 2016.

Accepted for publication July 7, 2016.

ABSTRACT

Background: Health literacy among caregivers of food allergic individuals (FAIs) is poorly described, as are the information sources sought regarding food allergy.

Objective: To assess the association among health literacy, trust in online sources of information, and food allergy quality of life (QoL) and self-efficacy.

Methods: An online survey was administered to caregivers of FAIs assessing health literacy (Newest Vital Sign [NVS]) and the eHeals Internet health literacy index), trust in online information (Hargittai Internet credibility index and Annenberg National Health Communication Survey [ANHCS]), QoL (Food Allergy Quality of Life Parental Burden), and self-efficacy (Food Allergy Self-Efficacy Questionnaire [FASEQ]).

Results: Among 1562 respondents, 94.6% (NVS) and 61.1% (eHeals) had good health literacy, and 58% had high levels of trust in online information (both indexes). The NVS correlated poorly with the eHeals and Hargittai indexes. Hargittai and eHeals scores were moderately correlated ($r = 0.37$, $P < .001$). A high NVS score was significantly associated with reported anaphylaxis and high eHeals and Hargittai scores with advocacy group membership. In unadjusted analyses, FAQL-PB scores were worse with high Hargittai scores ($P = .05$) and ANHCS scores ($P < .001$). The FASEQ scores were better with high ANHCS scores ($P = .02$) and eHeals scores ($P < .001$). In an adjusted regression, high trust in online information (both indexes), worsening FASEQ score, blog readership, advocacy group membership, caring for multiple FAIs, and having milk or egg allergy were associated with worse FAQL-PB scores.

Conclusion: In this sample, health literacy and trust in online information sources were high, with high trust in online information sources negatively associated with QoL. Advocacy group membership had an independent negative association with QoL.

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Introduction

Food allergy (FA) affects approximately 8% of US children, accounting for an estimated 300,000 hospitalizations and 200,000 emergency department encounters per year.^{1–3} FA has an approximate socioeconomic effect of \$25 billion annually.⁴ FA is associated with deficits in health-related quality of life (QoL), spillover effect of

the child's illness into the caregiver QoL, and a high perceived burden of illness despite the fact that food allergic individuals (FAIs) rarely experience daily symptoms of disease and fatality is rare. These factors may be influenced by a lack of potentially curative treatment for FA and fear of unintended reactions.^{5–10} Although multiple studies have begun to elucidate factors associated with differences in FA QoL, our understanding of sources of variation, influencing caregiver QoL (and the effect of this), as a field is still limited.^{7,11–16}

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions and is defined by the sources and quality of available health information and the extent to which health information is sought and understood.^{17,18} In disorders such as asthma, cancer, diabetes, human immunodeficiency virus, and hypertension, there is correlation between low health literacy and a decrease in overall understanding of these medical conditions.^{18–26} Among caregivers of

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Disclosures: Authors have nothing to disclose.

Disclaimer: The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Funding Sources: This study was supported by grant 2KL2TR000434 from the National Centers for Advancing Translational Sciences and investigator institutional discretionary funding (Dr Greenhawt). Mr Ditzler participated in this project through the University of Michigan Undergraduate Research Program.

FAIs, it is unclear how health literacy may affect the ability to manage FA or influence caregiver QoL.

Understanding the sources of information caregivers and patients use to learn about a medical condition is equally relevant.^{27–29} The Internet, direct-to-consumer medical advertising, medical themed television and radio talk shows, programming within local and national news devoted to covering timely medical issues, and peer to peer (or family) discussions are available sources for health care information supplementing or even supplanting direct discussion with one's physician.³⁰ For FA, there are multiple online sources for information, including support and advocacy group websites and public and private chat rooms or forums enabling peer to peer interaction. Preference for particular information sources is likely highly individualized, based on one's personal experiences, medical condition, health beliefs, and social support systems. It is unclear whether there is an association between health literacy and FA medical information sources.

Given limited understanding of health literacy within FA and poor understanding of where caregivers of FAIs obtain sources of health information, we sought to assess the health literacy of caregivers of FAIs and describe sources from where medical information is obtained. Furthermore, we explored the influence that trust in information sources and health literacy may have on caregiver FA QoL and caregiver self-efficacy (a related measure of behavioral motivation to actualize change).

Methods

Caregivers of FAIs were recruited nationally for participation during the late fall of 2014 through the spring of 2015 by email contact list, social media feeds (including reposting and retweeting by users to other advocacy groups, including Food Allergy Research and Education and multiple FA blogs), and the websites of Kids with Food Allergies, a national FA advocacy group that is a subsidiary of the Allergy and Asthma Foundation of America. Eligible participants included caregivers identifying themselves as older than 18 years and caring for at least 1 FAI with a physician-diagnosed FA. Caregivers caring for more than 1 FAI were asked to retake the survey based on their experience with each FAI independently. The survey instrument consisted of the following: (1) a questionnaire assessing the history of allergy in FAIs, including past symptoms of the most severe reaction to the allergen, prior treatments, caregiver perception of reaction severity, follow-up care of their FA, medical comorbidities, training in anaphylaxis management, and socio-demographic information; (2) caregiver outcome measures, including the recently validated Food Allergy Self-efficacy Questionnaire (FASEQ)³¹ and the Food Allergy Quality of Life Parental Burden Questionnaire (FAQL-PB),³² assessing these trends cross-sectionally; (3) 2 measures of health literacy, including the Newest Vital Sign (NVS)³³ and the eHeals Internet health literacy index³⁴; and (4) 2 measures of trust in online information: the Annenberg National Health Communication Survey (ANHCS)³⁵ and the Hargittai index.³⁶

The NVS (Pfizer, New York, New York) is a short-form validated index that assesses health literacy through a series of 6 questions regarding an individual's ability to read an ice cream label. Higher scores reflect better health literacy. It has been used in more than 25 peer-reviewed studies, has a Cronbach α of 0.76, and has strong validity to distinguish good from poor health literacy.³³ Health literacy was additionally measured using the eHeals index, an 8-item index of 5-point Likert items specifically designed to measure electronic health resource literacy. Higher scores for this index indicate better electronic health literacy. It has a Cronbach α of 0.76, strong item-scale correlation ($r = 0.51$ – 0.76), and a single-factor solution that explains 56% of the variance in the sample.³⁴ Trust in online information was measured using a 13-question domain of

5-point Likert items from a survey instrument developed by Hargittai et al.³⁶ measuring user assessment of an Internet site credibility, which has a Cronbach α of 0.88. Lastly, trust in online information sources was also measured using the ANHCS, an 8-item index of 4-point Likert items used in multiple studies but not formally validated.³⁵

The FAQL-PB is a validated, 17-item, self-administered questionnaire that measures the effect of pediatric FA on caregiver QoL developed by Cohen et al.³² Its psychometric properties include an intraclass correlation coefficient of 0.93 and a Cronbach α of 0.95, indicating excellent validity and reliability for the cross-sectional assessment of QoL. Caregiver QoL was not assessed at a uniform time from diagnosis during the formulation and validation of this scale. The 17 questions are each 7-point Likert items, and the index is scored as a summated rating scale from 0 to 6, with a higher FAQL-PB score indicating a worse QoL.³² Dimensionality of the index was not investigated during its validation but has more recently been noted to have 2 dimensions: general health concerns and anxiety and social interaction with others. A minimal clinically important difference (the smallest difference in score that patients perceive as beneficial) for the FAQL-PB has ranged from 0.3 (established using the SEM) to 0.5 (generic for 7-point Likert scales), depending on the study.^{37–39}

The FASEQ is an 8-item caregiver self-efficacy questionnaire measuring confidence in the self-management of FA. The 8 questions are all 5-point Likert items, and the index is scored as a summated rating scale from 0 to 4, with lower score indicating better self-efficacy. It has a Cronbach α of 0.88, intraclass correlation coefficient of 0.75, minimal clinically important difference of 0.3 (calculated as described above), and a unidimensional factor structure. It has good discriminant validity and concurrent validity to differentiate allergen type, history of anaphylaxis, and epinephrine use (M.G., unpublished data, 2015).³¹

Data were analyzed for descriptive statistics; bivariate comparisons using logistic regression, χ^2 test, and independent-sample t tests; and comparisons using multiple linear regressions to explore a model predictive of FAQL-PB score using generation of robust SEs. Multicollinearity was assessed through inspection of variance inflation factor. The study had 80% power to find a 0.5 mean difference between groups at 65 patients per stratified arm and a 0.3 mean difference between groups at 123 patients per arm. The University of Michigan Medical School Institutional Review Board approved this study as exempt from ongoing review.

Results

Demographic Trends Within the Allergic Child Population

A total of 1562 caregivers of FAIs responded. Demographic trends for the population are detailed in Table 1. Within the population, most respondents were college educated, and approximately 20% cared for multiple FAIs. Overall, 76.5% specifically reported their child had experienced a severe allergic reaction that involved “2 or more organs (such as skin, airways, lung, stomach, heart, or blood pressure) within minutes to hours of eating a particular food,” although just 55.8% specifically indicated their child has experienced an anaphylactic reaction to a food in the past when the concept was posed using this wording (“Has your child experienced an anaphylactic reaction?”). Only 26% of caregivers reported that the FAI they cared for had ever received epinephrine, with 8.74% having received epinephrine multiple times. Among those indicating the FAI experienced reactions in 2 or more organ systems ($n = 1,108$), 55.8% indicated the FAI has never received epinephrine. Peanut ($n = 1,152$ [73.7%]), tree nut ($n = 940$ [60.2%]), egg ($n = 681$ [43.6%]), and milk ($n = 628$ [40.2%]) allergy were the most commonly reported allergens among the population.

Table 1
Characteristics of Caregivers of Food Allergic Children

Characteristic ^a	No. (%) of caregivers
Respondent is the mother (n = 1,446)	1,395 (96.5)
College graduate (n = 1,459)	1,162 (79.6)
White race (n = 1,459)	1,281 (87.8)
No. of food allergic children (n = 1,456)	
1	1,145 (78.6)
2	258 (17.7)
3	46 (3.16)
No. of food allergy support groups a member of (n = 1,459)	
0	450 (30.8)
≥1	1,009 (69.2)
Present age of allergic child, y (n = 1,462)	
0–5	685 (46.9)
6–10	555 (38)
11–18	222 (15.2)
Age of diagnosis, y (n = 1,464)	
0–1	675 (46.1)
1–2	424 (29)
2–3	187 (12.8)
3–4	75 (5.12)
4–5	27 (1.84)
Allergist diagnosed the food allergy (n = 1,516)	1,387 (91.5)
Other allergic conditions	
Asthma (n = 1,302)	690 (53)
Eczema (n = 1,385)	1,015 (73.3)
Allergic rhinitis (n = 1,316)	968 (73.6)

^aA total of 1,562 caregivers took the survey, but respondents were not required to answer every question.

Assessing the Credibility of Internet Medical Information Used by Caregivers

In exploring caregiver assessment of website credibility, only 660 of 1,359 respondents (48.7%) reported that knowledge of what businesses or organizations financially support a website was “very or extremely important,” 826 of 1,355 (60.8%) indicated that information regarding website ownership was “very or extremely important,” and 1,008 of 1,359 (74.2%) indicated that easily identifying information sources on the website was “very/extremely important.” When caregivers were queried regarding what was most important when considering sources of online information, 1,166 of 1,361 (85.7%) reported verification that the information displayed is current, 1,252 of 1,360 (92.1%) reported sources to validate the

information contained on the site, and 1,282 of 1,358 (94.4%) reported that the views represented on the site were considered fact vs opinion. Other considerations that were “very/extremely important” included the qualifications or credentials of the authors (n = 894 of 1,354 [66.0%]) and the “about us” page on the website (n = 959 of 1,354 [70.8%]). When specifically queried to describe their overall experience in using the Internet for health information, 1,065 of 1,360 (78.3%) agreed or strongly agreed the Internet was a useful tool in helping make decisions about their child’s health, and 1,201 of 1,359 (86.3%) agreed or strongly agreed that they know where on the Internet to locate “helpful” resources (Table 2).

Assessment of Health Literacy and Association With Trust in Online Information

Health literacy was high, with 94.6% of individuals scoring 4 or more of 6 on the NVS, with a mean score of 5.3 of 6. In addition, 954 (61.1%) had an eHeals score higher than 3 (mean score, 2.98 on a scale of 0–4, with 4 being the best), indicating good Internet health literacy. Moreover, 906 (58%) had a score greater than 3 (mean score, 2.94 of 4) on the Hargittai questionnaire regarding Internet credibility assessment, and 908 (58.1%) had a score greater than 3 (mean score, 3 on a scale of 0–4, with 4 being the best) on the ANHCS, indicating high levels of trust in online sources of information. The NVS correlated poorly with the eHeals index ($r = 0.07$) and Hargittai credibility assessment ($r = 0.06$), although there is no literature describing an association among these indexes or a priori presumption that there should be an association. However, the odds of having a high score on one health literacy index were significantly associated with odds of a high score on the other index, and a high NVS score was associated with higher odds of higher credibility assessment score on the Hargittai index. Hargittai and eHeals scores were moderately positively correlated ($r = 0.37$, $P < .001$), and a higher Hargittai score was associated with higher odds of a higher eHeals score.

No associations with health literacy or trust in online information were noted based on allergen type (peanut or tree nut and milk or egg), allergic comorbidity, reported anaphylaxis (≥ 2 organ systems), or reported epinephrine use. Significant associations ($P < .05$ or smaller) were seen with higher NVS score and those self-reporting their child had anaphylaxis (item specifically asking this), higher NVS score and college education, and higher eHeals

Table 2
Features of Trust in Online Health Care Information^a

Item	Not at all important	Somewhat important	Important	Very important	Extremely important
Being able to easily identify the source of information on the site (n = 1,359)	7 (0.52)	68 (5.00)	276 (20.31)	443 (32.60)	565 (41.57)
Knowing who owns the website (n = 1,359)	37 (2.72)	187 (13.76)	309 (22.74)	396 (29.14)	430 (31.64)
Knowing what businesses and organizations financially support the site (n = 1,355)	84 (6.20)	267 (19.70)	344 (25.39)	338 (24.94)	322 (23.76)
Item	Never	Rarely	Occasionally	Often	All the time
I check to see if information is current (n = 1,361)	9 (0.66)	28 (2.06)	158 (11.61)	583 (42.84)	583 (42.84)
I seek out other sources to validate the information (n = 1,360)	5 (0.37)	13 (0.96)	90 (6.62)	546 (40.15)	706 (51.91)
I consider whether the views represented are fact or opinions (n = 1,358)	3 (0.22)	6 (0.44)	67 (4.93)	514 (37.85)	768 (56.55)
I check to see who the author is (n = 1,358)	15 (1.10)	71 (5.23)	256 (18.85)	483 (35.57)	533 (39.25)
I check to see what other sites link to the website I am viewing (n = 1,352)	26 (1.92)	157 (11.61)	315 (23.30)	520 (38.46)	334 (24.70)
I check the qualifications or credentials of the author (n = 1,354)	30 (2.22)	138 (10.19)	292 (21.57)	488 (36.04)	406 (29.99)
I check if contact information is provided on the website (n = 1,354)	47 (3.47)	206 (15.21)	376 (27.77)	451 (33.31)	274 (20.24)
I frequently visit the “About Us” page on a website (n = 1,354)	33 (2.44)	89 (6.57)	273 (20.16)	556 (41.06)	403 (29.76)

^aRaw responses to questions that assess relative importance or lack of importance to the respondent regarding aspects of assessing online information source credibility.

and Hargittai score with membership in multiple advocacy groups (data not shown).

Effect of Health Literacy and Trust in Online Sources of Information on Caregiver FA Self-efficacy and Health-Related QoL

Within this population, the mean FAQL-PB score (scale range, 0–6, with lower score indicating better QoL) was 3.1 (95% CI, 2.94–3.1), indicating moderate QoL, and the mean FASEQ score (scale range, 0–4, with lower score indicating better self-efficacy) was 1.72 (95% CI, 1.67–1.75), indicating good self-efficacy. Figure 1 and eFigure 1 detail the FAQL-PB and FASEQ domain means. Mean FAQL-PB score was not different based on health literacy (both measures) but was significantly different based on higher vs lower Hargiatti score (3.09 vs 2.93; mean difference, 0.15; $P = .05$) and higher vs lower trust in online information (ANHCS) score (3.14 vs 2.88; mean difference, 0.27; $P < .001$). Mean FASEQ score was significantly lower (better) with higher vs lower ANHCS score (1.67 vs 1.77; mean difference, 0.1; $P = .02$), and mean FASEQ score was significantly lower based on higher vs lower eHeals score (1.61 vs 1.85; mean difference, 0.24; $P < .001$). No difference in FASEQ score was noted based on Hargiatti or NVS score (Fig 2).

Mean FAQL-PB score was significantly higher (worse QoL) among those reporting advocacy group membership vs non-members (3.17 vs 2.65; difference, 0.52; $P < .001$; also noted among 16 of 17 individual FAQL-PB domains). This trend was not noted for FASEQ domains. In an adjusted multiple regression analysis exploring predictors of FAQL-PB score, there were significant associations noted between higher (worsening) FAQL-PB score and high trust in online information (with the ANHCS and Hargittai scores), higher (worsening) FASEQ score, reported blog readership, advocacy group membership, caring for multiple FAls, and FAls with milk or egg allergies (Table 3).

Discussion

Health literacy is crucial in decision making in chronic disease management. Because FA preferentially affects children, the caregiver's health literacy is even more crucial given they make proxy decisions for the FAls they care for. Thus, poor health literacy may diminish an ability to provide competent care. We present the index study of FA health literacy within a population of caregivers of food allergic children and also describe the trust placed in the health information, most notably on-line information source, for these caregivers. Online FA education materials are a mainstay of how FA information is disseminated. A number of allergy specialist offices, large academic practices, specific FA support groups, advocacy organizations, message boards, and blogs have Internet sites or space dedicated to providing such information regarding FA management.

Health literacy is high within a population of caregivers of food allergic children. This is not surprising for several reasons. Foremost, the NVS involves reading a food label, something that the FA population should be well trained to do accurately. In addition, prior studies have noted that caregivers of FAls (participating in research studies) tend to be overrepresented by college-educated, middle class, or higher socioeconomic status caregivers—a group at baseline that is presumably less likely to have poor health literacy.^{16,32,37} Our population sampled was fairly representative of these individuals. Given some concerns that the NVS was particularly tailored to this population, we administered a second measure to assess online health literacy, on which performance was still good but not quite as strong. We had no a priori assumptions that there would (or should be) an association among these aspects of health literacy and included multiple measures to more broadly describe the concept. Similarly, it was also not surprising that in this sample there was a high level of reported trust in online

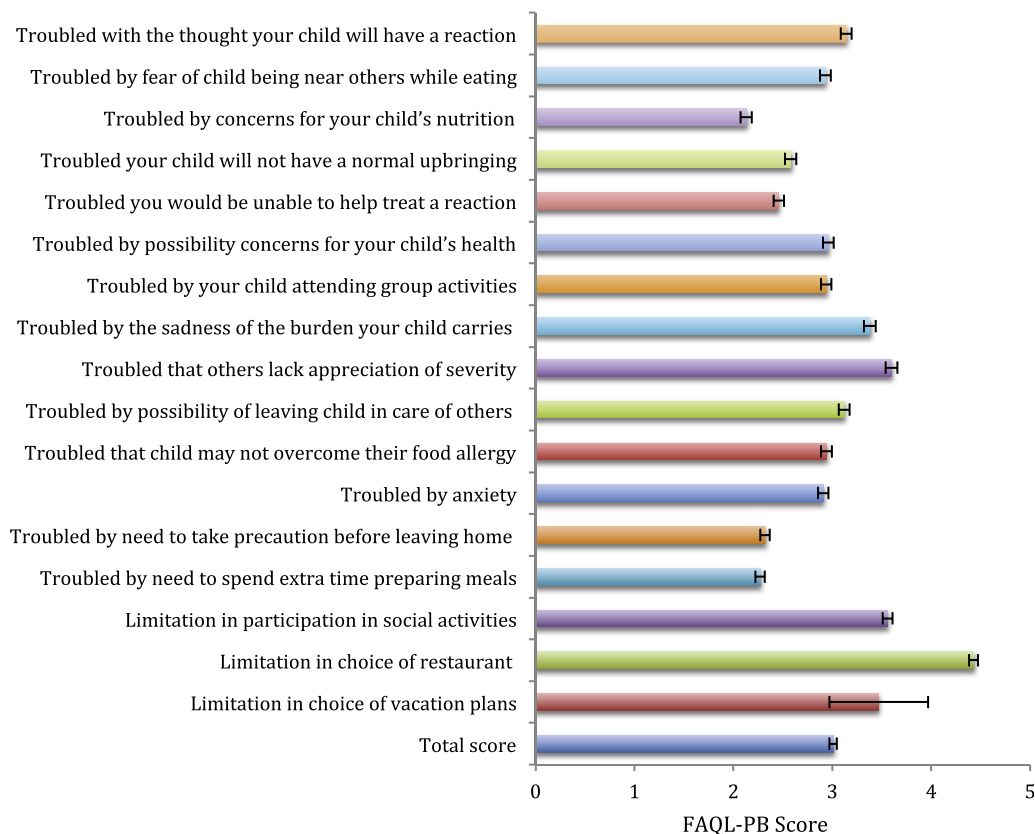


Figure 1. Mean Food Allergy Quality of Life Parental Burden (FAQL-PB) total and domain-specific scores.

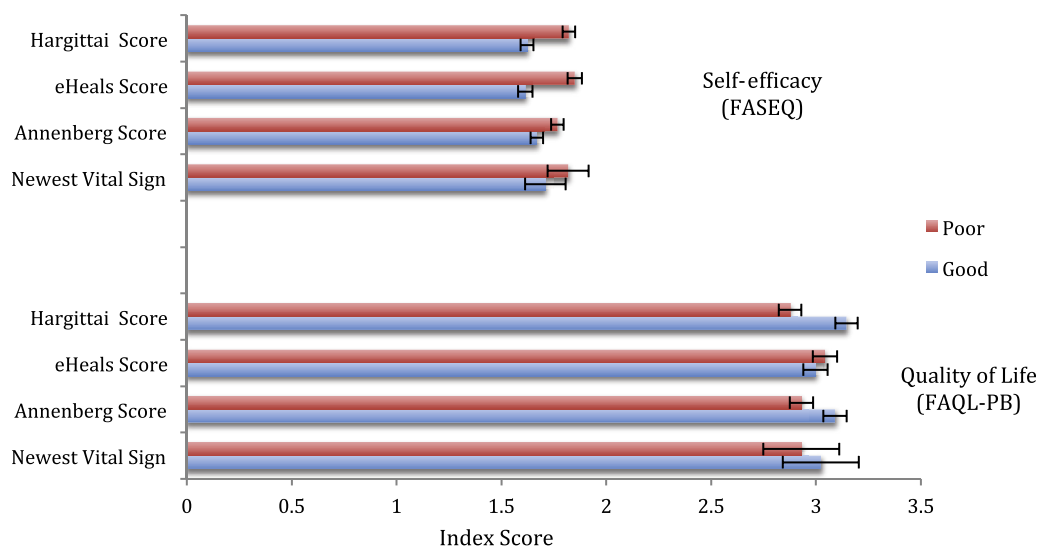


Figure 2. Mean quality-of-life and self-efficacy scores stratified by health literacy and trust in online information score. FAQL-PB, Food Allergy Quality of Life Parental Burden; FASEQ, Food Allergy Self-Efficacy Questionnaire.

information, noted in 2 measures. More than 75% verified that they use the Internet as a health care resource for medical decision making. Respondents affirmed that accuracy of the website content and that the content was fact rather than opinion were of high importance to the respondent's decision making.

Although no association was noted between QoL and health literacy (likely because of limited health literacy score variation in the sample), we observed significant differences in higher (worse) mean FAQL-PB scores and higher trust in online information. There was also an association between lower (better) FASEQ scores and higher trust in online information (ANHCS) and higher Internet health literacy score. These findings are not surprising, given that traits associated with developing a poor sense of trust in medical information may be highly similar to those that beget poor underlying self-management skills and anxiety that contributes to poor QoL. This is an area of future study that we intend to pursue because further understanding of these processes may enhance development of better tailored health information and materials for these individuals, which could lead to better disease management.

Most interestingly, we note clinically and statistically significant effects between reported advocacy group membership and a higher (worse) FAQL-PB score. This is of some importance because of the heavy online and social media presence of FA advocacy groups,

which do provide a significant amount of FA information and for many act as a significant resource. This association is tricky to interpret because we could not assess whether persons with worse baseline QoL are more likely at baseline to belong to advocacy groups or whether there is some sort of a moderating effect among advocacy group membership, QoL, and trust in online health care information sources. Moreover, we could not determine what aspects of the advocacy group membership may be most attributable to the worse QoL. To our knowledge, this is the first reported association between caregiver membership in advocacy groups and poor QoL, and this merits a more focused follow-up study profiling attributes that influence membership. We note this association in the setting of a cross-sectional, exploratory study examining health literacy, and it is unclear whether certain other facets of advocacy group membership not explored in this study may help to explain the QoL findings.

There are some limitations for this study. Most notably, we used self-reported data, which are subject to recall bias and questionable validity of the allergy, although methodologically no other feasible alternative was available to gather our data. Bias from selection may have occurred, given use of an Internet survey and solicitation through the use of social media. The respondents to this study may more likely represent individuals who may self-select for use of online health information or are more technologically savvy. However, Internet use in the United States is common and may occur at rates higher than in our sample. Recently, it was reported that 84% of Americans use the Internet (although this may differ slightly by age, race, income, and educational level) and 72% of adults have used the Internet as a source of health care information (which includes 58% of senior citizens, 78% of blacks, 81% of Hispanics, 85% of whites, 97% of English-speaking Asian Americans, and 78% of those living rurally).⁴⁰ Therefore, we believed an Internet sample was appropriate. Another limitation was use of participants with high rates of membership in FA advocacy groups. We did not assess the relative availability of other types of FA health information compared with that available on the Internet to determine whether there is a biasing preference for online material, if online material is an unavoidable necessity, or the degree to which paper and online information may duplicate one another in content. We would presume some baseline bias within this population toward using online health sources at baseline; however, this trend is increasing nationally as noted above. Importantly, we did not assess for the variability in the quality of the online information

Table 3
Factors Pertaining to Health Literacy and Trust in Online Information Predictive of Quality of Life (QoL)^a

QoL score	Coefficient (95% CI)	P value
Hargittai score	0.31 (0.01 to 0.61)	.04
Annenberg score	0.31 (0.17 to 0.46)	<.001
Self-efficacy score	0.55 (0.44 to 0.67)	<.001
Parent perceived anaphylaxis	0.22 (0.04 to 0.41)	.02
Age of diagnosis	−0.07 (−0.12 to −0.02)	.005
Blog readership	0.32 (0.14 to 0.5)	<.001
Advocacy group membership		
Single	0.29 (0.10 to 0.48)	.003
Multiple groups	0.48 (0.25 to 0.71)	<.001
Milk or egg allergic	0.33 (0.13 to 0.53)	.001
College education	−0.35 (−0.55 to −0.17)	<.001

^aAdjusted (for health literacy, child's reported epinephrine use, number of food allergic children, child having multiple food allergies, and comorbid atopy) multiple regression analysis of key predictors that influence Food Allergy Quality of Life Parental Burden (QoL) score. Positive coefficients indicate a net increase in score, indicating a worsening QoL, and negative coefficients indicate a net lowering in score, representing an improving QoL.

source or the nature of the information source (eg, advocacy group, blogger, academic medical center, or research program), both of which could have significant potential influence. A follow-up study is being planned to better determine these influences. Better understanding of which information sources have maximal resonance could be a major boon to providing high-quality FA education to caregivers. This study was intended as an exploratory study examining the potential range of and influencing factors of health literacy in a FAI caregiver population. Because this study was exploratory, we chose an observational and cross-sectional design within a large convenience sample, and no firm causal inferences should be assumed from our findings. The measures of health literacy and online information sources we used were previously validated but not used in a food allergic population, and there may be better measures for these concepts of which we were not aware.

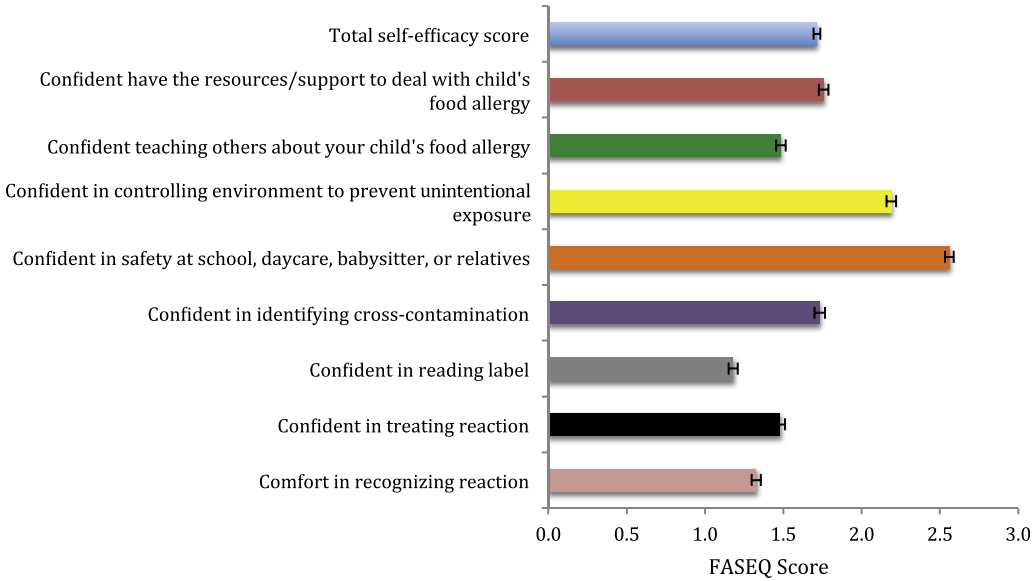
In summary, we present novel findings regarding the health literacy of caregivers of FAIs and note some innovative associations regarding their trust in online information, assessment of the credibility of this information, and how this affects outcomes such as QoL and self-efficacy. Health literacy should be a concern among caregivers of FAIs, given that such individuals are making proxy health care decisions for their children, and there is reliance on these individuals understanding information about the disease so their child's chronic health problem can be appropriately managed. Our data indicate that in this sample there is good health literacy and a strong use of the Internet to obtain health care information. This study better defines specific attributes of the level of trust that these caregivers have for the information available to them and how they assess whether this is credible—key points in understanding how parents make decisions. We found that there are associations between their trust and credibility assessment of this online information and their health-related QoL, which underscores the importance to more specifically identify factors within the delivery of this health care information that are most attributable to influencing QoL. Such understanding is of particular interest given the importance of the Internet in providing health care information and health care access now and in the coming future.

Supplementary Data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.anai.2016.07.011>.

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eFigure 1. Mean scores for the sample for the Food Allergy Self-Efficacy Questionnaire (FASEQ) and the individual index items. Lower scores indicate better quality of life. Error bars represent SE.