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Title	Green, Yellow, and Red risk perception in everyday life - a communication tool
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Publication date	2017-01-24
Original Citation	Stensgaard, A., Dunn Galvin, A., Nielsen, D., Munch, M. and Bindslev-Jensen, C. (2017) 'Green, Yellow, and Red risk perception in everyday life - a communication tool', Allergy, 72 (7), pp. 1114-1122. doi:10.1111/all.13095
Type of publication	Article (peer-reviewed)
Link to publisher's version	10.1111/all.13095
Rights	This is the peer reviewed version of the following article: Stensgaard, A., Dunn Galvin, A., Nielsen, D., Munch, M. and Bindslev-Jensen, C. (2017) 'Green, Yellow, and Red risk perception in everyday life - a communication tool', Allergy, 72 (7), pp. 1114-1122, which has been published in final form at http://dx.doi.org/10.1111/all.13095. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.
Download date	2026-11-17 12:34:34
Item downloaded from	https://hdl.handle.net/10468/4069

UCC
University College Cork, Ireland
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Received Date : 20-May-2016
Revised Date : 07-Oct-2016
Accepted Date : 21-Nov-2016
Article type : Original Article: Anaphylaxis

Green, Yellow and Red risk perception in everyday life – a communication tool

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Abstract

Background: Adolescents have the highest risk for food allergy-related fatalities. Our main aim was to investigate the level of risk in everyday social situations as perceived by adolescents/young adults with peanut allergy, their families and their friends.

Methods: The web-based 'Colours Of Risks' (COR) questionnaire was completed by 70 patients (aged 12-23 years), 103 mothers and fathers, 31 siblings (aged 12-26 years), and 42 friends (aged 12-24 years). COR deals with six main contexts (home, school/university, work, visiting/social activities, special occasions/parties, and vacations), each with 1-12 items. Response categories are green (I feel safe), yellow (I feel uncertain), or red (I feel everything is risky).

Results: There was a high level of agreement between participants in defining situations as safe, uncertain, or risky, but female patients and mothers rated fewer situations as safe compared to

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/all.13095
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male patients and fathers. Being with close friends and family, and attending planned parties without alcohol were perceived as situations of low risk. While 94% of patients took an epinephrine auto-injector (EAI) into risky situations, only 65% took it into safe situations. In contrast to the close family, 31% of the friends did not know the patient had an EAI, and fewer knew how to administer the EAI.

Conclusion: Young adults with peanut allergy face challenges when moving from the safe home with ready assistance if needed, to independence with unpredictable surroundings and less certain help. Perceived 'safe' situations may in fact be the riskiest, as patients often do not take the EAI with them.

Keywords

Adolescents/young adults, food allergy, health-related quality of life, risk/safety perception, self-management

Introduction

Food allergy is unusual in that the individual has a chronic condition but remains well with the potential to contract severe acute illness (1). Everyday life involves the risk of life-threatening anaphylactic shock with each food intake, and management is restricted to avoidance of the implicated food through elimination diet (1, 2). Avoidance in the case of peanut allergy is not clear-cut, however, as peanut and its derivatives are present in many food products, and food can also be contaminated with peanut protein during manufacturing. This is further complicated by inconsistent precautionary labeling, which families describe as often inadequate or difficult to understand (14). The patient must be able to identify situations with high risk of inadvertent intake ("red zones") where maximum alert is required in contrast to low risk zones ("green zones") where the risk is minimal.

Food allergy is known to negatively impact psycho-social aspects of health-related quality of life (HRQL) irrespective of patient age (1-9). It affects not only the individual but also their families, with higher levels of stress and anxiety described in families living with the risk of anaphylaxis (10-12). The lifetime prevalence and point prevalence of self-reported food allergy in Europe are around 17% and 6%, respectively (13). In contrast to other food allergies such as egg and milk, peanut allergy is rarely outgrown (14). Individuals with peanut allergy reported less control over their disease compared to patients with diabetes (8).

Adolescents have a high risk of food allergy fatality (15, 16) and thus of (fatal) anaphylaxis. This may be due the increasing desire for autonomy, making them more vulnerable but also leading to riskier allergy management strategies (10, 17, 18). The change in lifestyle, where adolescents tend to socialize with friends rather than family, increases their exposure to risk. When investigating adolescents' perception of risk related to food allergy, it is thus essential to take into account the impact of social context and peer relationships. Adolescents often feel a need to conform and can engage in risky behaviors such as eating food that "may contain traces of nuts". Although those with

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food allergy are advised to always carry an epinephrine auto-injector (EAI) with them (19, 20), adolescents do not always do this (19, 21-23).

Although it is recognized that peanut allergy impacts on the HRQL of adolescents/young adults, more is needed from a health care professional perspective to help them manage the burden of everyday vigilant management (28). Very little research has investigated any gender differences and what impact these may have (24).

The aim of the current study was to learn more about the risk perception in everyday life of adolescents/young adults diagnosed with peanut allergy. Specifically, we sought 1) to investigate the level of risk in various everyday social situations as perceived by adolescents/young adults with peanut allergy, their families and their friends,
2) to investigate the participants' knowledge about anaphylaxis and rescue medication, 3) to determine if there were gender differences in the perception of safe and risky situations, and 4) to examine the relationship between self-reported HRQL and the number of perceived safe and risky situations.

Methods

Study design

Quantitative survey data were collected from May 2013 to May 2014 using a validated allergy-specific HRQL questionnaire and a newly developed computer-based communication tool, the 'Colours Of Risks' (COR) questionnaire that asked about perception of risk in everyday life due to food allergy. The participants were adolescents/young adults with peanut allergy, their families, and their close friends.
The study was approved by the local medical ethics review commission.
For the purposes of this paper, we refer to the adolescents/young adults with peanut allergy as "patients" to distinguish them from their peers and relatives.

Participant recruitment

Participation was completely voluntary. Patients were recruited from the Allergy Center at Odense University Hospital, Denmark. Inclusion criteria were age 12-23 years and a positive oral challenge to peanut. Exclusion criteria were any diagnosed psychiatric disorder, intellectual disability, other major illness, or inability to read or fluently speak Danish.

Patients were invited to take part in the study when they attended their planned check-up at the Allergy Center. If they expressed an interest in participating and their parents accepted, they were fully briefed on the study purpose and method, after which they completed the study questionnaire on a laptop in a quiet room in the clinic. They were also asked to invite their mother and father, siblings (>12yrs) and two of their friends to participate in the study. All were told not to disclose their own answers to the questionnaire until their family and friends had completed it. They were given letters for their family and friends with information about the study (including a link to the homepage www.datafabrikken.dk) and a code to access the questionnaire. Recruitment of family and friends was done in this way to respect patient autonomy, and the patients decided themselves which of their relatives and friends they would like to include.

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Measures

'Colours Of Risks' (COR) questionnaire

A communication tool, 'Colours Of Risks' (COR), was developed to assess the everyday challenges faced by adolescents/young adults with food allergy. Items for the questionnaire were generated by interviewing 20 patients (aged 12-23 years) and their parents in the clinic. Main themes were identified from the responses and discussed in depth within the research team. The resulting tool was then pilot-tested. The COR was developed as web-based questionnaire using SurveyXact.
The final version of COR comprises six main themes/subscales on risk perception in various settings: home (1 question), school/high school/university (6 questions), work (3 questions), visiting and social activities (12 questions), special occasions and parties (8 questions), and vacations (10 questions). Respondents are asked to indicate their perception of risk according to the response options: green ('I feel safe'), yellow ('I feel uncertain'), or red ('I feel everything is risky'). Respondents are then asked if they would spend more time in the yellow or red zones if they did not suffer from peanut allergy.

The study questionnaire also asked about knowledge of anaphylaxis and use of the epinephrine auto-injector (EAI), i.e. *Do you know what a severe allergic reaction/anaphylaxis is?; Do you know what an EAI is?*. If they had an EAI, they were also asked if they knew how to use it, whether they took it with them into green, yellow, or red zones, and if they had ever used it. The response categories to these items were Yes, No, Don't know.

Family and friends answered the same questions, but from the patient´s perspective. At the end they were asked about their own knowledge of anaphylaxis, if they knew how to use the EAI, and whether they had helped the patient to use it.

HRQL and FAIM measure

A subset of patients (N=45) and their parents (N=64) had participated in an earlier study and had completed six months previously the Food Allergy Quality of Life Questionnaire (FAQLQ) and the Food Allergy Independent Measure (FAIM).

We used age-appropriate forms of the FAQLQ to measure health-related quality of life of people with food allergy. For adolescents aged 13-17 years had completed the teenage form (25), adult patients aged 18 years and above had completed the adult form (26), and parents completed the parent form (27). FAQLQ items were scored on a 7-point scale, where 1 was the best possible score. Thus the higher the score, the worse the HRQL.

The FAIM consist of six questions in total (27). We used the four questions deal with the perceived chance of accidental exposure to allergens and the likelihood of severe reaction, i.e. How great do you think the chance is that you: 1) Will accidentally eat something to which you are allergic? 2) Will have a severe reaction if you accidentally eat something to which you are allergic? 3) Will die if you accidentally eat something to which you are allergic? 4) Cannot effectively deal with an allergic reaction should you accidentally eat something to which you are allergic? Each of these exposure questions was scored on a scale from 1 (0% chance) to 7 (100% chance).

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Statistical analysis

We examined the proportion of everyday situations that were rated by adolescents/young adults and their family and friends as green, yellow, or red zones. Stuart-Maxwell chi square test was used for pairwise comparisons between types of situations as perceived by the different participant groups. Univariate analysis was used to examine the relationship between gender and number of red and green zones. Univariate analysis were also used to assess the relationship between the number of safety zones and self-reported HRQL and FAIM for patients and their parents (these results were not analyzed for siblings and friends as validated HRQL questionnaires are not available for these groups).

Cronbach's alpha (28) was used to evaluate the reliability of the COR total scale and the four subscales. Analyses were performed using STATA version 14.0.

Results

Seventy patients (59% female) agreed to participate in the study. The questionnaire was also completed by 103 parents (57% mothers), 31 siblings (71% female), and 42 friends (52% female), giving a total of 246 participants. Patients were aged 12-23 years (mean 15, SD=3.14), siblings were aged 12-26 years (mean 18, SD=4.48), and friends were aged 12-24 years (mean 15, SD=3.42) (Table 1). 12% of the parents, 16%of the siblings and 5% of the friends had food allergy themselves.

We found good reliability of the COR total scale and the four subscales. Cronbach´s alpha for the total scale was 0.94 for patients, 0.95 for parents, 0.87 for siblings, and 0.93 for friends (Table 1).

Green, yellow, and red zones as defined by the patients

When asked whether 'home' was a green, yellow or red zone, nearly all respondents reported that home was a green (safe) zone. The expectations were one patient (red zone), four parents (3 yellow and 1 red), one sibling (yellow), and three friends (yellow).

Only 24 (35%) of patients reported they had jobs. These were mainly leisure jobs such as babysitting, dishwasher at a restaurant, and paper delivery, and only one patient had a full-time job. All but one of these patients with a job reported the job to be a green zone (1 reported it as yellow).

As shown in Table 1, patients felt safest in situations where they could maintain a high degree of control, such as in their home or with close family and friends (0% red), planned classroom activities (3% red), or in a familiar restaurant (1% red). In contrast, situations with little control were perceived as risky e.g. visiting ethnic restaurants (54% red), unfamiliar restaurants (37% red), unplanned parties with serving of alcohol (27% red), or travelling abroad alone (27% red). Activities where food or drink was provided were perceived as riskier than activities without such provision, e.g. special events without food such as a graduation (9% red) and parties without alcohol (7% red).

Pairwise comparisons showed that for all participants, i.e. patients, parents, siblings, and friends, familiar situations were perceived as significantly safer than unfamiliar situations, including classroom activities vs canteen or school outings, being with close friends or family vs being with less close friends or family, own vs others' birthday party, planned vs unplanned parties, without alcohol vs with alcohol, vacation at home vs abroad, as well as car travel vs air travel (all $p<0.001$). Patients

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were thus limited in the more spontaneous activities that can be important in forming new relationships. While the patients did not express a desire to spend more time at home, at work or at school, 20-30% of them reported that they would spend more time in zones they rated as yellow or red i.e. social activities, parties, and vacations, if they did not have peanut allergy ($p<0.05$).

Knowledge of the EAI

Although only 8% of patients had actually used an EAI, 94% reported that they knew what a severe allergic reaction/anaphylactic reaction was, and 97% knew what an EAI was. Of the 94% (66/70) who had an EAI, 97% knew how to use it. The proportion of patients carrying the EAI with them into everyday situations was dependent on whether they rated the situation as green (65% brought the EAI with them), yellow (85%), or red (94%). Knowledge and behavior regarding the EAI are presented in Table 2.

Family and friend responses

No significant differences were found between the patient's perception of green, yellow, and red zones in everyday life and the parents', siblings', and friends' responses on their behalf ($p=0.07$). The relatives appeared to have a good insight into when their child, sibling, or friend felt safe, uncertain, or that everything was risky. However, 31% of the friends did not know that the patient had an EAI, in contrast to 100% of the family members knew it, and friends also knew less about how to administer the EAI. Only 4% of the parents, and none of the siblings or friends, had assisted with the EAI during an allergic reaction.

Gender differences, HRQL and FAIM

In these univariate analyses, the responses to the 'home' and 'work' variables were not included as they were nearly always green zones. Female patients rated fewer situations as green zones than male patients ($p<0.008$). Similarly, mothers rated fewer situations as green zones than fathers ($p<0.01$].

The number of red and green zones reported from patients and their parents was plotted against their mean FAQLQ score (Figure 1) and mean FAIM score (Figure 2). A significant correlation between the number of green zones and impact on HRQL was seen, i.e. the more green zones, the less impact on HRQL (patients $p=0.006$, fathers $p=0.003$, mothers $p=0.042$). No correlation between number of green zones and FAIM was found (patients $p=0.630$, fathers $p=0.602$, mothers $p= 0.274$).

Similarly, a greater number of red situations in everyday life was associated with worse HRQL ($\beta=0.12$). For example, patients and parents with the worst HRQL (mean FAQLQ score >6) rated up to 19 of 37 situations as red. This was a significant difference for patients [$F(1.43)=6.53$, $p<0.01$].

Discussion

Results showed that adolescents/young adults with peanut allergy feel safe in everyday life when socializing with close friends and family, but feel uncertain or at risk when engaging in unplanned and unfamiliar social situations. This affects the quality of their life, as spontaneity is an important element of young adulthood. They appeared to take calculated risks with respect to their allergy, where 65% of patients took the EAI with them into green (safe) zones, but nearly all took the EAI

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with them to red (risky) zones. The zones perceived as green (safe) are thus in fact the riskiest zones for these patients with allergy if they develop an anaphylactic reaction.

Food allergy affects the quality of life of adolescents and young adults (1, 9, 15, 17, 18, 23, 29-32). Our study is the first to examine the perception of risk in various everyday social situations from the perspective of the adolescents/young adults with food allergy and the perspective of their family and friends. The results reinforce the need for allergy consultations in this age group to be more focused on individual patient needs and to help prepare young people for the practical and social challenges when they leave home. Adolescence is a period of increasing autonomy and rapid physical, cognitive, psychological, and social development (33). Young people must adapt to new rights and responsibilities and develop greater self-reliance, as the responsibility moves from parent to adolescent. We found good agreement between patients' perception of green, yellow and red zones in everyday life and the perception of parents, siblings, and friends on their behalf. This suggests that family and friends have a good insight into when the person with food allergy feel safe, uncertain, or at risk in different social contexts.

Adolescents with food allergy were significantly less likely to take the EAI with them when visiting what is perceived as a green (safe) zone. It is known that food allergic adolescents take risks in relation to their food allergy, including not carrying their EAI at all times (19, 34). The first-line treatment for anaphylaxis is intramuscular adrenaline (20, 35), for example through an EA, and non-injection or delayed injection of epinephrine increases the risk of death (16, 34-36). Under-use of the EAI by patients of all ages is well known (16, 18, 21, 23, 37), and may be due to patients preferring to take antihistamines or not having EAI prescriptions (37), or a lack of recognition of its usefulness (21). Saleh-Langenberg et al. reported that the burden of treatment was higher in food-allergic adolescents who were prescribed an EAI but did not carry it at all times (19). We found that one-third of friends did not know that the patient had an EAI, and many did not know how to administer it. Although only 10% of parents had helped the patient to use the EAI, they knew about the EAI and how to use it. This highlights the change in environment for the adolescent when moving from the safe home with ready assistance if needed, to more unpredictable surroundings and less certain help.

We found that female patients rated fewer social situations as green (safe) compared to male patients. A similar pattern was found for parents, where mothers rated fewer social situations as green compared to fathers. Gender differences have been noted before in food allergy, where girls reported a more negative impact on HRQL than boys (38, 39). Studies have typically only included the mother's perspective, and only few studies have included the father's perspective on living with a child with food allergy (6, 40-42).

The strengths of this study are the patient recruitment based on confirmed IgE-mediated systemic peanut allergy, the inclusion of both family and friend perspectives, and that both mothers and father were included. The COR tool performed well and was clearly relevant and useful for the participants. However the limitations was that, it was sometimes difficult for the respondent to choose only one color zone for a particular social situation, as the situation could be more or less risky depending on other factors. It is also likely that the friends who participated in the study were the patients' closest friends, and that other friends and acquaintances would have much less knowledge about the patient's peanut allergy and using the EAI. In future studies using the 'Colors

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Of Risk' questionnaire among younger respondents it would be useful to ask separately about part-time and full-time jobs.

Health professionals should be prepared to discuss behavior strategies with the adolescent patient in a concise, but balanced fashion to help prepare for the transition to independent living. Adolescents and their families will vary in their ability to develop coping strategies and to face the challenges of food allergy. The COR tool is recommended as a communication tool for the adolescent at risk of anaphylaxis, as it raises the issue of safe and risky social contexts, focuses on the individual patient's needs, and helps to encourage self-management. A shorter, app-based version of the COR tool would allow patients to complete the questionnaire before the consultation, thus providing the health professional with a basis for discussion and information on the main type of help needed. Careful involvement of close friends in management strategies would also strength the intervention.

Our intention with this study was to investigate how young adults with peanut allergy and their friends and family perceive the risk from allergic reactions in social situations outside the traditionally safe zones of the home. Social interaction with (new) friends is important for shaping the young adult's identity, and unknown and unplanned situations are inevitable. Such situations are perceived as highly risky, however, and can be a challenge for young adults with peanut allergy. Further use is recommended of the COR questionnaire as a communication tool between health professionals and patients with allergy in developing effective management strategies for allergy.

Our results can be generalized to other food allergies where it is important to focus on risk when communicating and guiding patients and their families. They may also be relevant in other chronic illness, such as diabetes with the risk of hypoglycemia, where health professionals aim to help patients and their families to handle chronic illness in everyday life.

The "Colours of Risk" tool appears to be a relevant way of collecting information about the patient's perspective of everyday life with food allergy and the risk associated with this. Use of the questionnaire as a communication tool puts focus on the patient rather than the biomedical perspective and can help to improve social and emotional outcomes of young people with a chronic disease and to better support young people's emerging capacity for self-management.

Acknowledgments
We thank our participating patients, parents, siblings, and their friends.

Conflicts of interest
The authors declare no conflict of interests in relation to this study.

Author contributions
AS, CBJ, AD, DN contributed to study conception, design and management. AS collected data and wrote the first draft. All authors analyzed and interpreted the data. All authors approved the final draft.

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References

1. Cummings AJ, Knibb RC, King RM, Lucas JS. The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: a review. *Allergy*. 2010;**65**:933-945.
2. Knibb RC, Ibrahim NF, Stiefel G, Petley R, Cummings AJ, King RM, et al. The psychological impact of diagnostic food challenges to confirm the resolution of peanut or tree nut allergy. *Clin Exp Allergy*. 2012;**42**:451-459.
3. Roy KM, Roberts MC. Peanut allergy in children: relationships to health-related quality of life, anxiety, and parental stress. *Clin Pediatr (Phila)*. 2011;**50**:1045-1051.
4. King RM, Knibb RC, Hourihane JO. Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy*. 2009;**64**:461-468.
5. Primeau MN, Kagan R, Joseph L, Lim H, Dufresne C, Duffy C, et al. The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children. *Clin Exp Allergy*. 2000;**30**:1135-1143.
6. Marklund B, Ahlstedt S, Nordstrom G. Health-related quality of life in food hypersensitive schoolchildren and their families: parents' perceptions. *Health Qual Life Outcomes*. 2006;**4**:48.
7. de Blok BM, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, DunnGalvin A, Hourihane JO, et al. A framework for measuring the social impact of food allergy across Europe: a EuroPrevall state of the art paper. *Allergy*. 2007;**62**:733-737.
8. Avery NJ, King RM, Knight S, Hourihane JO. Assessment of quality of life in children with peanut allergy. *Pediatr Allergy Immunol*. 2003;**14**:378-382.
9. Flokstra-de Blok BM, Dubois AE, Vlieg-Boerstra BJ, Oude Elberink JN, Raat H, DunnGalvin A, et al. Health-related quality of life of food allergic patients: comparison with the general population and other diseases. *Allergy*. 2010;**65**:238-244.
10. Akeson N, Worth A, Sheikh A. The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy*. 2007;**37**:1213-1220.
11. Mandell D, Curtis R, Gold M, Hardie S. Anaphylaxis: how do you live with it? *Health Soc Work*. 2005;**30**:325-335.
12. Gillespie CA, Woodgate RL, Chalmers KI, Watson WT. "Living with risk": mothering a child with food-induced anaphylaxis. *J Pediatr Nurs*. 2007;**22**:30-42.
13. Muraro A, Dubois AE, DunnGalvin A, Hourihane JO, de Jong NW, Meyer R, et al. EAACI Food Allergy and Anaphylaxis Guidelines. Food allergy health-related quality of life measures. *Allergy*. 2014;**69**:845-853.
14. Anagnostou K, Clark A. The management of peanut allergy. *Arch Dis Child*. 2014.
15. Monks H, Gowland MH, MacKenzie H, Erlewyn-Lajeunesse M, King R, Lucas JS, et al. How do teenagers manage their food allergies? *Clin Exp Allergy*. 2010;**40**:1533-1540.
16. Bock SA, Munoz-Furlong A, Sampson HA. Further fatalities caused by anaphylactic reactions to food, 2001-2006. *J Allergy Clin Immunol*. 2007;**119**:1016-1018.
17. Gallagher M, Worth A, Cunningham-Burley S, Sheikh A. Strategies for living with the risk of anaphylaxis in adolescence: qualitative study of young people and their parents. *Prim Care Respir J*. 2012;**21**:392-397.
18. Greenhawt MJ, Singer AM, Baptist AP. Food allergy and food allergy attitudes among college students. *J Allergy Clin Immunol*. 2009;**124**:323-327.
19. Saleh-Langenberg J, Flokstra-de Blok BM, Goossens NJ, Kemna JC, van der Velde JL, Dubois AE. The compliance and burden of treatment with the epinephrine auto-injector in food-allergic adolescents. *Pediatr Allergy Immunol*. 2015.
20. Sampson HA. Anaphylaxis and emergency treatment. *Pediatrics*. 2003;**111**:1601-1608.
21. Gallagher M, Worth A, Cunningham-Burley S, Sheikh A. Epinephrine auto-injector use in adolescents at risk of anaphylaxis: a qualitative study in Scotland, UK. *Clin Exp Allergy*. 2011;**41**:869-877.

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Accepted Article

22. Marrs T, Lack G. Why do few food-allergic adolescents treat anaphylaxis with adrenaline?--Reviewing a pressing issue. *Pediatr Allergy Immunol*. 2013;**24**:222-229.
23. Sampson MA, Munoz-Furlong A, Sicherer SH. Risk-taking and coping strategies of adolescents and young adults with food allergy. *J Allergy Clin Immunol*. 2006;**117**:1440-1445.
24. DunnGalvin A, Hourihane JO, Frewer L, Knibb RC, Oude Elberink JN, Klinge I. Incorporating a gender dimension in food allergy research: a review. *Allergy*. 2006;**61**:1336-1343.
25. Flokstra-de Blok BM, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, Hourihane JO, et al. Development and validation of the self-administered Food Allergy Quality of Life Questionnaire for adolescents. *J Allergy Clin Immunol*. 2008;**122**:139-144, 144 e131-132.
26. Flokstra-de Blok BM, van der Meulen GN, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, et al. Development and validation of the Food Allergy Quality of Life Questionnaire - Adult Form. *Allergy*. 2009;**64**:1209-1217.
27. van der Velde JL, Flokstra-de Blok BM, Vlieg-Boerstra BJ, Oude Elberink JN, DunnGalvin A, Hourihane JO, et al. Development, validity and reliability of the food allergy independent measure (FAIM). *Allergy*. 2010;**65**:630-635.
28. Fayers P.M. MD. Quality of Life. The assesment, analysis and interpretation of patient-reported outcomes. Second Edition ed: Wiley; 2009. 83-91 and 123-127 p.
29. DunnGalvin A, Gaffney A, Hourihane JO. Developmental pathways in food allergy: a new theoretical framework. *Allergy*. 2009;**64**:560-568.
30. Flokstra-de Blok BM, van der Velde JL, Vlieg-Boerstra BJ, Oude Elberink JN, DunnGalvin A, Hourihane JO, et al. Health-related quality of life of food allergic patients measured with generic and disease-specific questionnaires. *Allergy*. 2010;**65**:1031-1038.
31. Goossens NJ, Flokstra-de Blok BM, van der Meulen GN, Arnlind MH, Asero R, Barreales L, et al. Health-related quality of life in food-allergic adults from eight European countries. *Ann Allergy Asthma Immunol*. 2014;**113**:63-68 e61.
32. MacKenzie H, Dean T. Quality of life in children and teenagers with food hypersensitivity. *Expert Rev Pharmacoecon Outcomes Res*. 2010;**10**:397-406.
33. Christie D, Viner R. Adolescent development. *BMJ*. 2005;**330**:301-304.
34. Pumphrey RS, Gowland MH. Further fatal allergic reactions to food in the United Kingdom, 1999-2006. *J Allergy Clin Immunol*. 2007;**119**:1018-1019.
35. Muraro A, Roberts G, Worm M, Bilo MB, Brockow K, Fernandez Rivas M, et al. Anaphylaxis: guidelines from the European Academy of Allergy and Clinical Immunology. *Allergy*. 2014;**69**:1026-1045.
36. Gowland MH. Food allergen avoidance--the patient's viewpoint. *Allergy*. 2001;**56 Suppl 67**:117-120.
37. Simons FE, Clark S, Camargo CA, Jr. Anaphylaxis in the community: learning from the survivors. *J Allergy Clin Immunol*. 2009;**124**:301-306.
38. Wassenberg J, Cochard MM, Dunngalvin A, Ballabeni P, Flokstra-de Blok BM, Newman CJ, et al. Parent perceived quality of life is age-dependent in children with food allergy. *Pediatr Allergy Immunol*. 2012;**23**:412-419.
39. Marklund B, Ahlstedt S, Nordstrom G. Health-related quality of life among adolescents with allergy-like conditions - with emphasis on food hypersensitivity. *Health Qual Life Outcomes*. 2004;**2**:65.
40. van der Velde JL, Flokstra-de Blok BM, Dunngalvin A, Hourihane JO, Duiverman EJ, Dubois AE. Parents report better health-related quality of life for their food-allergic children than children themselves. *Clin Exp Allergy*. 2011;**41**:1431-1439.
41. van der Velde JL, Flokstra-de Blok BM, Vlieg-Boerstra BJ, Oude Elberink JN, Schouten JP, Dunngalvin A, et al. Test-retest reliability of the Food Allergy Quality of Life Questionnaires (FAQLQ) for children, adolescents and adults. *Qual Life Res*. 2009;**18**:245-251.

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42. Goossens NJ, Flokstra-de Blok BM, van der Meulen GN, Botjes E, Burgerhof HG, Gupta RS, et al. Food allergy knowledge of parents - is ignorance bliss? *Pediatr Allergy Immunol*. 2013;**24**:567-573.

Table 1. Descriptive characteristics of included participants, and zones in everyday life where they felt safe (Green), uncertain (Yellow), or that everything was risky (Red).

	Patient (n=70)			Parent (n=103)			Sibling (n=31)			Friend (n=42)		
Gender (male/female)	29/41			44/59			9/22			20/22		
Mean age (SD)	15.15 (3.14)			46.03 (5.91)			18.43 (4.48)			14.51 (3.42)		
Overall reliability (Cronbach's alpha)	0.94			0.95			0.87			0.93		
(High) school/university (%)	**Zones**			**Zones**			**Zones**			**Zones**		
Outings/study tours	23%	59%	19%	18%	63%	18%	3%	84%	13%	26%	57%	17%
School sports events	61%	29%	10%	63%	35%	2%	65%	32%	3%	52%	43%	5%
Canteen/places to buy food	39%	49%	13%	32%	56%	12%	13%	65%	23%	45%	31%	24%
Classroom/places with lectures	74%	23%	3%	80%	20%	0%	65%	35%	0%	76%	24%	0%
Studying with other students	63%	33%	4%	71%	26%	3%	68%	29%	3%	74%	24%	2%
Teaching involving cooking	50%	41%	9%	48%	45%	8%	23%	61%	16%	48%	52%	0%
Subscale reliability (Cronbach's alpha)	0.82			0.83			0.62			0.75		
Visiting and social activities (%)	**Zones**			**Zones**			**Zones**			**Zones**		
Socializing with good friends	84%	16%	0%	88%	12%	0%	90%	10%	0%	88%	10%	0%
Socializing with acquaintances	19%	64%	17%	17%	74%	9%	3%	87%	10%	17%	69%	14%
Familiar restaurants	64%	34%	1%	65%	31%	4%	61%	39%	0%	62%	33%	2%
Unfamiliar restaurants	11%	51%	37%	11%	57%	32%	0%	65%	35%	7%	62%	31%
Fast food	81%	16%	3%	76%	22%	2%	71%	26%	3%	57%	36%	5%
Ethnic food	4%	41%	54%	2%	49%	50%	10%	32%	58%	19%	48%	33%
Other places to buy food	21%	70%	9%	17%	60%	22%	13%	71%	16%	17%	69%	14%
Café	40%	54%	6%	31%	59%	10%	26%	68%	6%	36%	57%	7%
Spectator to sports events	80%	20%	0%	81%	19%	0%	77%	23%	0%	79%	19%	0%
Playing sports	81%	19%	0%	80%	20%	0%	81%	16%	3%	71%	29%	0%
Visiting close family	89%	11%	0%	90%	10%	0%	97%	3%	0%	93%	7%	0%
Visiting less close family	24%	66%	10%	17%	79%	5%	16%	74%	10%	21%	62%	17%
Subscale reliability (Cronbach's alpha)	0.86			0.86			0.67			0.83		
Special occasions, parties (%)	**Zones**			**Zones**			**Zones**			**Zones**		
Planned party	63%	34%	3%	70%	28%	2%	68%	29%	0%	74%	24%	2%
Unplanned party	23%	59%	19%	21%	61%	17%	29%	58%	13%	31%	40%	29%
Festivities (e.g. Christmas)	50%	43%	7%	66%	31%	3%	61%	29%	10%	67%	31%	2%
Own birthday party	99%	1%	0%	98%	1%	1%	100%	0%	0%	93%	5%	2%
Others' birthday parties	26%	69%	6%	31%	65%	4%	29%	68%	3%	29%	64%	7%
Special events (e.g. graduation)	34%	57%	9%	33%	60%	7%	19%	74%	6%	38%	55%	7%
Party with alcohol	33%	40%	27%	27%	47%	26%	26%	42%	32%	38%	43%	19%
Party without alcohol	64%	29%	7%	52%	43%	5%	58%	42%	0%	60%	36%	5%
Subscale realibility (Cronbach's alpha)	0.85			0.86			0.75			0.83		
Vacation (%)	**Zones**			**Zones**			**Zones**			**Zones**		
Vacation with family	76%	21%	3%	90%	10%	0%	74%	19%	3%	88%	10%	2%
Vacation with friends	39%	49%	13%	31%	65%	4%	19%	74%	6%	36%	57%	7%
Vacation alone	33%	40%	27%	18%	55%	26%	19%	55%	26%	21%	55%	24%
Vacation in own country	80%	19%	1%	64%	34%	2%	68%	32%	0%	67%	33%	0%
Foreign vacation	26%	57%	17%	19%	62%	18%	13%	74%	13%	24%	64%	12%
Transport by train	66%	34%	0%	66%	34%	0%	68%	32%	0%	67%	29%	5%
Transport by car	93%	7%	0%	92%	8%	0%	94%	6%	0%	90%	10%	0%
Transport by bus	71%	29%	0%	66%	32%	2%	77%	23%	0%	67%	33%	0%
Transport by plane	40%	50%	10%	37%	54%	9%	26%	68%	6%	45%	40%	14%
Transport by ferry	56%	43%	1%	61%	34%	5%	52%	48%	0%	57%	38%	5%
Subscale reliability (Cronbach's alpha)	0.86			0.88			0.74			0.82		

Percentages do not always add up to 100% due to missing responses

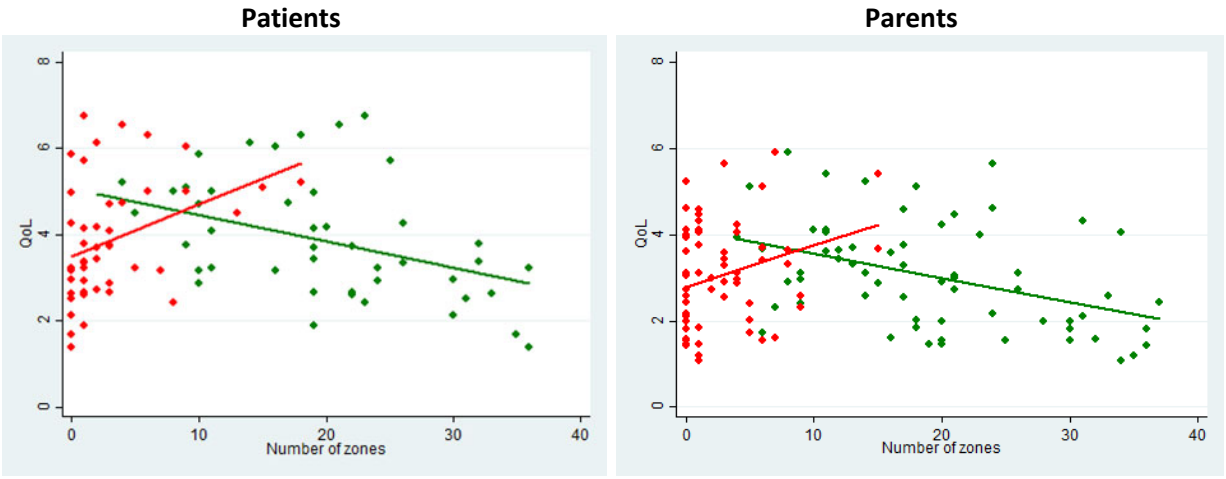
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Table 2. Knowledge of the epinephrine auto-injector (EAI) among patients, parents, siblings and friends

	Patients			Parents			Siblings			Friends		
	70			103			31			42		
	Yes N (%)	No n (%)	Don't know n (%)	Yes n (%)	No n (%)	Don't know n (%)	Yes n (%)	No n (%)	Don't know n (%)	Yes n (%)	No n (%)	Don't know n (%)
Does your child, sister/brother, friend know what a severe allergic/anaphylactic reaction is?				101(98)	0(0)	2(2)	28(90)	0(0)	3(10)	38(90)	0(0)	4(10)
Do you know what a severe allergical/anaphylactic reaction is?	66(94)	2(3)	2(3)	103(100)	0(0)	0(0)	25(83)	3(10)	2(7)	25(61)	11(27)	5(12)
Does your child, sister/brother, friend know what an EAI is?				98(95)	4(4)	1(1)	30(97)	1(3)	0(0)	28(68)	1(2)	12(29
Do you know what an EAI is?	68(97)	2(3)	0(0)	103(100)	0(0)	0(0)	31(100)	0(0)	0(0)	24(57)	15(36)	3(7)
Do you/your child, sister/brother, friend have an EAI?	**66(94)**	4(6)	0(0)	**96(93)**	7(7)	0(0)	**29(94)**	2(6)	0(0)	**26(62)**	3(7)	13(31
Participants answering "yes" to having an EAI, n (%)	**66(94)**			**96(93)**			**29(94)**			**26(62)**		
Do you/your child, sister/brother, friend bring the EAI with him/her in the green zones?	43(65)	20(30)	3(5)	71(74)	24(25)	1(1)	20(69)	6(21)	3(10)	15(58)	9(35)	2(8)
Do you/your child, sister/brother, friend bring the EAI with him/her in the yellow zones?	56(85)	8(12)	2(3)	90(94)	5(5)	1(1)	23(79)	1(3)	5(17)	20(77)	2(8)	4(15)
Do you/your child, sister/brother, friend bring the EAI with him/her in the red zones?	62(94)	2(3)	2(3)	96(100)	0(0)	0(0)	28(97)	0(0)	1(3)	24(92)	1(4)	1(4)
Does your child, sister/brother, friend know how to use it?				92(96)	1(1)	1(1)	25(86)	3(10)	1(4)	26(100)	0(0)	0(0)
Do you know how to use it according to your child, sister/brother, friend?	64(97)	2(3)	0(0)	94(98)	1(1)	1(1)	29(100)	0(0)	0(0)	20(77)	4(15)	2(8)
Have you/your child, sister/brother, friend used it?	5(8)	58(90)	1(2)	10(10)	86(90)	0(0)	1(4)	25(86)	3(10)	4(15)	18(69)	4(15)
Have you helped your child, sister/brother, friend to use it?				4(4)	92(96)	0(0)	0(0)	29(100)	0(0)	0(0)	26(100)	0(0)

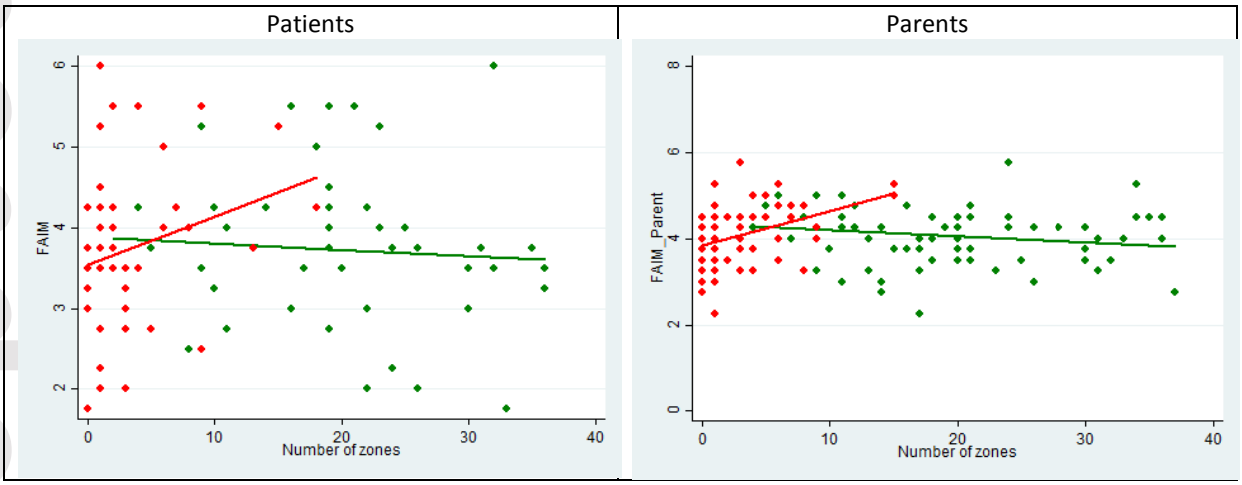
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Figure 1. Health-related quality of life (mean FAQLQ score) plotted against the number of red zones (highly risky situations) and green zones (safe situations) reported by patients with peanut allergy and their parents.



FAQLQ = Food Allergy Quality of Life Questionnaire

Figure 2. Food Allergy Independent Measure (mean FAIM score) plotted against the number of red zones (highly risky zones) and green zones (safe situations) reported by patients with peanut allergy and their parents.



FAIM = Food Allergy Independent Measure

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