

ORIGINAL ARTICLE

Factors associated with good adherence to self-care behaviours amongst adolescents with food allergy

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Keywords

adherence; adolescent; food allergy; health psychology; self-care behaviours

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Abstract

Background: Our understanding of factors which affect adherence to health sustaining self-care behaviours in adolescents with food allergy is limited. This study used the Health Belief Model to explore the relationship between food allergic adolescents' health beliefs, demographic, structural and social psychological factors with adherence to self-care behaviours, including allergen avoidance and carrying emergency medication.

Methods: A cross-sectional study of 188 13- to 19- olds identified from hospital prescribed auto-injectable epinephrine for food allergy. Data were collected on demographics, structural factors, social psychological factors, health beliefs and current adherence behaviour using a postal questionnaire.

Results: Full adherence was reported by 16% of participants. Multivariate analysis indicated that adherence was more likely to be reported if the adolescents belonged to a support group (OR = 2.54, (1.04, 6.20) 95% CI), had an anaphylaxis management plan (OR = 3.22, (1.18, 8.81) 95% CI), perceived their food allergy to be more severe (OR = 1.24, (1.01, 1.52) 95% CI) and perceived fewer barriers to disease management (OR = 0.87, (0.79, 0.96) 95% CI).

Conclusions: Membership of a patient support group and having an anaphylaxis management plan were associated with good adherence to self-care behaviours in adolescents with food allergy. Our results suggest that interventions to improve provision and utilisation of management plans, address adolescents' perceptions of the severity of anaphylaxis and reduce barriers to disease management may facilitate good adherence behaviours than focussing on knowledge-based interventions.

Food allergy is estimated to affect 1 in 40 adolescents and is thought to be increasing in prevalence (1, 2). Key to successful management of food allergy is avoidance of the allergen (3), but an allergic reaction may still occur because of either accidental or intentional allergen exposure. There is a wide range of allergic symptoms from mild and localised to severe, life-threatening multisystem reactions. Anaphylaxis, characterised as being rapid in onset with life-threatening airway, breathing or circulatory problems and usually associated with skin or mucosal changes (4), is the most serious form of allergic reaction but can be managed acutely by the prompt administration of epinephrine. Anaphylaxis can be fatal and a review

of deaths highlighted that most victims are adolescent or young adults (5, 6) who have died as a result of delayed or non-administration of epinephrine in the emergency situation (5–8). Anaphylaxis management guidelines recommend that at risk patients carry their auto-injectable epinephrine (AIE) at all times (4, 9).

Lack of adherence to recommended treatment and self-care is not unique to allergy; it is common in all disease processes. A World Health Organization study estimated that only 50% of patients in developed countries adhere to treatment guidelines (10). Adherence is particularly troublesome amongst adolescents, with levels as low as 10% reported for some chronic

conditions (11). There are no good quantitative estimates of adolescent adherence to carrying AIE, but estimates for patients of all ages range from 30% to 78% (12, 13). Barriers to using AIE in adolescents include not being able to decide when it is necessary to administer the device, unawareness of the severity of reactions, inappropriate optimism that the reaction will resolve on its own, fear and anxiety (14). Some adolescents also take risks by continuing to eat foods containing the allergen, not informing friends or peers of their food allergy or how they could help in the event of an acute reaction (15).

Traditionally, interventions to improve adherence to medication and self-care behaviours have been largely educational, aiming to improve patient knowledge. In these instances, the health professional is seen as the expert who is there to impart knowledge to the patient, and the patient as the obliging and willing recipient of this knowledge, who will comply accordingly (16, 17). Whilst research has shown that adherence is positively related to a patient’s understanding of their disease and its management (18, 19), it is now widely recognised that knowledge alone is insufficient to change complex behaviours (20, 21). A review of strategies used to improve adherence concluded that for complex behaviours requiring lifestyle changes, addressing patients’ health beliefs alongside providing patient education is a superior approach (19).

As adherence to self-care behaviours for individuals with food allergy involves a set of complex behaviours and lifestyle changes (such as avoiding foods and certain situations, in addition to carrying medication) prior to developing new initiatives to promote adherence amongst adolescents it is important to better understand the range of factors which are associated with good adherence as well as those that act as a

deterrent (11). A number of theories of health behaviour have been developed and one model used extensively to help understand patients’ behaviour and treatment choices is the Health Belief Model (22) (Fig. 1). This model has been used in understanding parental adherence in two other atopic conditions, asthma (23) and atopic dermatitis (24) and has been successfully applied to adolescents with chronic conditions, particularly focussing on those with diabetes (25–28).

Methods

Study design and procedure

In this cross-sectional study, adolescents aged 13–19 with a diagnosis of food allergy and AIE for management of severe allergic reactions were recruited from two paediatric allergy outpatient clinics in the south-east of England, UK. Participants unable to read, write or speak English were excluded. Participants were sent an invitation, participant information sheet, consent form and questionnaire. Individuals over 16 old were sent these documents directly but for younger participants, this pack was sent to their guardians with an assent form for the child. Questionnaires were returned to the research team by freepost. The South East Research Ethics Committee provided ethical approval (ref: 09/H1102/100).

The Health Belief Model proposes that adherence is mediated through demographic, social psychological (personality) and structural variables (knowledge about the condition, prior experience), in addition to specific health beliefs (22). The health beliefs *perceived severity* (beliefs about how serious the condition is and the related consequences of the condition) coupled

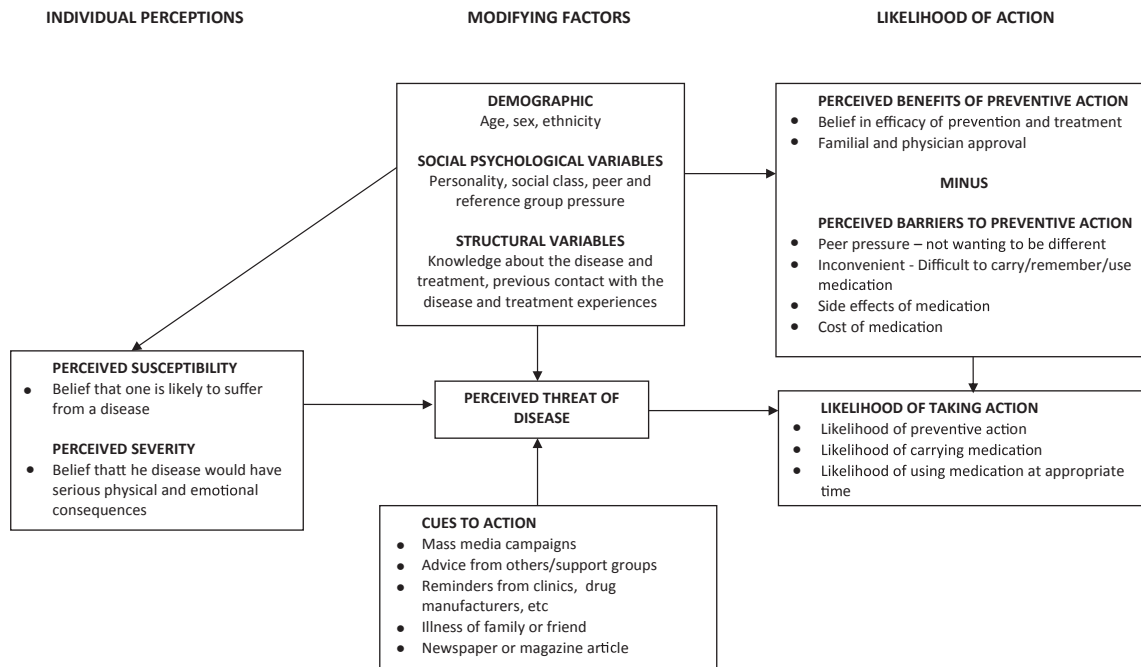


Figure 1 The Health Belief Model.

with *perceived susceptibility* (the extent to which the individual feels at risk of being exposed/suffering from the condition) and *cues to action*, all contribute to the individual's perception of threat. The cues to action may be internal (e.g. bodily state or symptom) or external (e.g. reminder about doctor's appointment). The individual's perception of threat of a condition plus the *perceived benefits* (the effectiveness and availability of taking a particular course of action) and the *perceived barriers* (the negative aspects related to following the course of action) all contribute to the likelihood of adherence (Fig. 1).

Questionnaire content

Health beliefs

The HBM items included in this study were adapted from a widely used and validated questionnaire (29). This questionnaire includes 26 items measuring the five constructs identified in the model – perceived severity (three items), perceived susceptibility (three items), perceived benefits (six items), perceived barriers (seven items) and cues to action (seven items). All items were measured on a 5-point scale, anchored 1 (strongly disagree) and 5 (strongly agree) and summed across each construct, so that higher scores represented more strongly held beliefs. Validation of the factor structures has been reported previously (30).

Demographic, structural and social factors

Participants were asked about their demographic characteristics (age, gender and ethnicity).

Structural factors collected were food allergens, age at diagnosis, presence or not of concomitant asthma, date last seen by allergy specialist, anaphylaxis history (number of severe allergic reactions) and auto-injector use (number of occasions used and whether self-administered). Knowledge of correct management of an acute anaphylactic reaction with AIE was assessed by nine questions derived from manufacturer's guidelines. Correct responses were summed to provide a score for managing an acute serious reaction (range 0–9), higher scores greater knowledge (Fig. 2). The questions related to recognition of anaphylaxis, preparing the AIE for use (checking expiry date, removing cap), and administration (holding AIE correctly, possible use through clothing, injection site, length of time AIE should be held in place) and follow-up care. Participants were also asked about additional support (including possession of an anaphylaxis management plan and membership of an allergy or anaphylaxis patient support group). Confidence in using AIE was measured with a modified confidence scale, which included five-items about AIE administration (confidence in correct use, use without hesitation, demonstration to doctor, practising administration and ability to use) measured on a five-point Likert scale ranging from 'not sure at all' to 'absolutely sure' (31). The confidence scale ranged from 5 to 25 with high scores indicating greater confidence in using the device. The measure demonstrated good internal reliability (Cronbach's $\alpha = 0.91$).

The social psychological factor assessed was optimism, this was chosen as optimism has been linked to taking proactive

steps to protecting one's health, leading to better subjective wellbeing and physical health (32). Optimism was assessed using the revised Life Orientation Test (LOT-R) (33), but to minimise participant burden, four filler statements were excluded. This shortened version maintained good internal reliability (Cronbach's $\alpha = 0.80$). Higher scores indicated greater optimism (range 0–24).

Adherence to self-care behaviours

Participants were asked to respond to the statement 'I carry my auto-injector with me at all times' on a five-point Likert scale from 'always true' (1) to 'never true' (5). Adherence to carrying AIE is often used as a single-item measure of self-care (11–13). In food allergy, avoidance of the allergen is also an essential element of preventive self-care behaviours. So using the same Likert scale, we assessed the extent to which participants avoided allergen containing foods, enquired about ingredients when eating in restaurants and enquired about ingredients when eating at friends' houses. The score from the four items were then summed (range 5–20) with higher scores reflecting greater adherence. The internal reliability of this multi-item measure of self-care was acceptable (Cronbach's $\alpha = 0.65$).

Statistical analysis

Statistical analyses were performed using SPSS version 15.0 SPSS Inc. Chicago, Illinois, USA. for Windows. Data imputation was used when scales had over half of the items present, but if more than half were missing that scale was not analysed for that participant. Imputation was achieved by calculating the mean of items present and substituting this value for the missing item. Kolmogorov–Smirnov and Shapiro–Wilk tests showed that even after logarithmic transformation the dependent variable (adherence to self-care behaviours) was not normally distributed. To enable multivariate analysis, adherence to self-care was converted into a binary measure with adherence defined as those who responded 'always true' to all self-care behaviour items. Nonparametric bivariate associa-

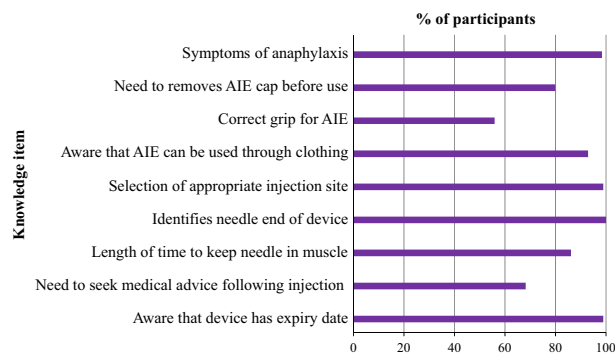


Figure 2 Percentage of participants responding correctly to each knowledge item ($n = 188$).

tions (Spearman's point-biserial) were conducted between adherence to self-care behaviours and demographic characteristics, social psychological factors, structural factors and health beliefs. To explain variance in adherence to self-care behaviours, a stepwise logistic regression was conducted. To maximise the ratio of sample size to variables, only those variables which showed significant bivariate associations were included in the regression analysis. Effect sizes generated by the models were assessed using Nagelkerke's R^2 and the classification tables. The Hosmer and Lemeshow test of goodness of fit and chi-square test were used to assess overall fit of the model. To ensure that the parameters of the regression models had not been affected by multicollinearity, the tolerance and VIF statistics were tested by linear regression analysis.

Results

Of the 558 adolescents contacted, 204 questionnaires were returned, of which 16 were ineligible (eight were unknown at address, three had outgrown their food allergy, and five had no prescription for AIE) giving an adjusted response rate of 34% (188/542).

Descriptive results

Demographic factors

The mean age of participants was 15 (s.d. = 1.7) with an equal distribution of males and females (50%). The majority of patients (82%) described themselves as white (Table 1).

Structural factors

The most frequently reported food allergies were nuts (tree nut 79%, peanut 73%), less common were egg (20%), fish (13%), shellfish (9%), dairy (7%), wheat (3%) and soya (1%). Two or more food allergies were reported by 59% of adolescents (n = 111). Age at diagnosis, presence of concomitant asthma, date last seen by allergy specialist, anaphylaxis history and auto-injector use (number of occasions used and whether self-administered) are reported in Table 1.

Knowledge of how to use auto-injectable epinephrine. Knowledge scores were high with a mean of 7.78 (s.d. = 0.95, range = 5–9). 18% (n = 34) participants were able to identify correctly all steps correct administration and scored the maximum of nine. Poor knowledge was particularly prevalent in two areas, knowing how to hold the AIE (44% incorrect) and the need to always seek medical advice following administration of AIE in case of a biphasic reaction (32% incorrect) (Fig. 2).

Confidence in using auto-injectable epinephrine. Participants reported high confidence in their ability to use AIE, with 40% feeling 'sure' and 37% feeling 'absolutely sure' of their ability to correctly use AIE (M = 18.63, s.d. = 4.53).

Support. Over half (56%) of adolescents reported having an anaphylaxis management plan and almost a third (31%) belonged to an anaphylaxis or allergy support group (Table 1).

Table 1 Demographic, structural and adherence characteristics of participants (n = 188)

Demographic	
Gender (% male)	50
Age (yr) Mean (s.d.), range	14.96 (1.66), 13–19
Ethnicity (%)	
White	81.5
Black	6.0
Mixed Race	7.0
Asian	3.7
Other	1.6
Structural	
Age of food allergy diagnosis (yr)	
Mean (s.d.), range	4.74 (4.50), 0–17
Last saw a doctor about food allergy (months)	
Mean (s.d.), range	12.43 (9.87), 1–48
Experienced anaphylaxis (% yes)	57
Number of anaphylactic reactions	
Mean (s.d.)	1.12 (1.68)
0 anaphylactic reactions (%)	43
1 anaphylactic reactions	33
2 or more anaphylactic reactions	24
Personal use of AIE (% yes)	4
Number of times self-administered AIE	
Mean (s.d.)	0.10 (0.66)
Range	0–8
AIE administered by others (% yes)	18
Number of times other has administered AIE for them	
Mean (s.d.)	0.27 (0.72)
Range	0–5
Diagnosis of asthma (% yes)	63
Member of an anaphylaxis or allergy support group (% yes)	31
Has a management plan for their anaphylaxis (% yes)	56
Adherence	
Carries AIE at all times (% 'always true')	41
Adherent to all self-care behaviours (% always adherent)	30

Social psychological factors

Personality. Higher scores on the LOT-R indicate greater optimism. In our sample, moderate levels of optimism were reported with a mean of 14.63 (s.d. = 4.00, range 4–24).

Health Beliefs

Perceived severity. Participants viewed their food allergy to be relatively severe with a mean of 11.40 (s.d. = 2.55, range 3–15).

Perceived susceptibility. Participants perceived themselves to be at moderate risk of suffering a serious allergic reaction (mean = 9.64, s.d. = 2.60, range 3–15).

Perceived benefits. Participants were largely able to see the benefits of their medication and following avoidance advice (mean = 20.81, s.d. = 3.23, range 11–30).

Perceived barriers. Participants reported strong feelings towards the barriers regarding the management of food allergy and medication (mean = 20.09, s.d. = 4.75, range 7–31).

Cues to action. Participants agreed with the statements that prompts or cues were likely to improve adherence (mean = 22.16, s.d. = 6.53, range 7–35).

Adherence to self-care behaviours

Full adherence was reported by 30 (16%) adolescents, who responded 'always true' to each of the four self-care behaviours measured. (Table 2).

Inferential results

Relationships between adherence to self-care behaviours and explanatory measures

Adherence to desirable self-care behaviours were correlated with being a member of a support group ($r_{pb} = 0.25$, $p = 0.001$), having an anaphylaxis management plan ($r_{pb} = 0.22$, $p = 0.003$), having greater confidence in using their AIE ($r_{pb} = 0.23$, $p = 0.002$), perceiving food allergy to be more serious ($r_{pb} = 0.19$, $p = 0.010$) and perceiving fewer barriers to management ($r_{pb} = -0.23$, $p = 0.002$). Variables not correlated with reported adherence included demographic factors (age, gender, ethnicity), structural factors (age at which food allergy diagnosed, allergy specialist consultations, number of anaphylactic reactions, previous AIE use, knowledge of AIE and co-morbid asthma), social psychological factors (optimism), and the health beliefs related to perceived susceptibility, benefits and cues to action (Table 3).

Multivariate associations of adherence to self-care behaviours

A logistic regression analysis was performed using the five factors identified as being significantly correlated with adherence to self-care behaviours (belonging to an allergy/anaphylaxis support group, having an anaphylaxis management plan, confidence in using AIE, perceived severity and perceived barriers) (Table 4). This further analysis demonstrated that adherence to self-care behaviours was greater in those who belonged to a support group (OR = 2.54, (1.04, 6.20) 95% CI), had an anaphylaxis management plan (OR = 3.22, (1.18, 8.81) 95% CI), perceived their food allergy to be more severe (OR = 1.24, (1.01, 1.52) 95% CI) and perceived fewer barriers to disease management (OR = 0.87, (0.79, 0.96) 95% CI).

Table 2 Response to individual items on adherence scale (n = 188)

Adherence item	% responding always true
I try to avoid foods which I know I am allergic to	85
When I eat in a restaurant I ask about the ingredients which have been used	42
When I eat at a friend's house I ask about ingredients which have been used	35
I carry my auto-injector with me at all times	41

However, confidence in managing an allergic reaction was no longer found to have significant associations with adherence. There was no evidence of collinearity between independent variables and the Hosmer and Lemeshow test provided evidence of good model fit ($\chi^2(8) = 6.02$, $p = 0.65$).

Discussion

In this study, food allergic adolescents reported varying levels of adherence to the different self-care behaviours necessary to avoid allergic reactions. Whilst most generally tried to avoid foods which they knew they were allergic to (85%), less were adherent to asking about ingredients when eating in restaurants (42%) or at friends' houses (35%). Forty-one per cent reported carrying their AIE at all times. Overall adherence was poor; only 16% of participants were adherent to all the aspects of self-care investigated. Using the Health Belief Model, we explored the relationship between health beliefs and demographic, structural and social psychological factors and adherence to self-care behaviours. Two structural factors were associated with better adherence; having an anaphylaxis management plan was associated with threefold better adherence to self-care behaviours and being a member of an anaphylaxis, and/or allergy support group was associated with over twofold better adherence. Adolescents who perceived their food allergy to be more severe and reported fewer barriers to managing their food allergy, also tended to report good adherence.

Current guidelines advise health professionals to provide anaphylaxis management plans (4, 9, 34) to promote patient empowerment and better health outcomes. There is no robust trial evidence for the utilisation of management plans in anaphylaxis, but there are case series to justify their use and our data add further supportive evidence (35). Whilst use of management plans is advocated in guidelines and clinical texts, less than three-fifths (56%) of adolescents surveyed had one highlighting the need for health professionals to improve provision of anaphylaxis management plans. The under-promotion of management plans by clinicians has been documented in other conditions, for example asthma (36). Given the serious and potentially life-threatening consequences of anaphylaxis, research is needed to understand why anaphylaxis management plans are sometimes not provided and to identify ways to encourage health professionals to initiate and monitor the use of anaphylaxis management plans.

Amongst participants in our study we found no association between their knowledge of adrenaline use and their self-adherence, challenging the commonly held assumption that it is poor knowledge of managing anaphylaxis that is the underlying reason for non-adherence. Instead our psychological approach identified how adolescents' perceptions of disease severity and the barriers to managing food allergy influenced adherence. Although this is the first study to directly assess the health beliefs of patients with atopy, perceptions of disease severity have been identified as an important predictor of parental adherence in asthma (23) and atopic dermatitis (24) suggesting that this psychological construct may be particu-

Table 3 Spearman's correlations between independent measures and adherence to self-care behaviours

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Adherence	0.01	0.11	-0.05	-0.13	-0.12	0.07	0.14	0.08	0.25***	0.22**	0.004	0.02	0.23**	0.12	-0.10	0.19**	0.10	-0.23**	-0.14
1. Age	-	0.03	0.08	0.07	0.06	0.05	0.11	0.08	-0.02	-0.18*	-0.02	-0.20*	0.09	-0.08	-0.03	0.01	-0.06	0.06	-0.15*
2. Gender	-	-	0.07	0.09	-0.03	-0.05	0.09	0.01	-0.06	0.07	0.04	-0.04	-0.13	-0.12	0.00	0.16*	-0.003	-0.17*	0.09
3. Ethnicity	-	-	-	0.02	-0.07	-0.04	-0.03	-0.03	-0.10	0.03	0.14	-0.17*	0.04	-0.01	-0.02	0.08	-0.01	0.07	0.07
4. Age of diagnosis of food allergy	-	-	-	0.003	0.003	0.01	-0.02	-0.18*	0.26***	-0.07	-0.15	-0.16	-0.13	-0.09	0.03	-0.11	0.11	0.02	0.01
5. Last seen by an allergist	-	-	-	-	-	0.02	-0.19*	0.003	-0.17*	-0.09	0.06	-0.004	-0.25***	-0.02	-0.17*	-0.20**	0.02	0.02	0.05
6. Experienced anaphylaxis	-	-	-	-	-	-	0.09	0.34***	0.08	0.01	0.08	-0.04	-0.01	-0.01	0.25**	0.12	-0.05	-0.07	-0.09
7. Previous AIE use on self	-	-	-	-	-	-	-	0.13	-0.07	-0.05	-0.08	-0.13	0.10	-0.03	0.08	-0.01	-0.15*	-0.05	-0.04
8. Treated with AIE by other	-	-	-	-	-	-	-	-	0.01	-0.02	0.09	0.10	0.04	-0.07	0.21**	0.14	-0.05	-0.04	-0.05
9. Member of a support group	-	-	-	-	-	-	-	-	-	0.20**	0.04	0.15	0.38***	0.02	0.10	0.22**	-0.12	-0.14	-0.03
10. Anaphylaxis management plan	-	-	-	-	-	-	-	-	-	-	0.07	0.05	0.21**	0.03	0.06	0.11	0.04	-0.02	0.11
11. Has asthma	-	-	-	-	-	-	-	-	-	-	-	-0.01	0.10	-0.05	0.07	0.07	0.10	-0.16*	-0.13
12. Knowledge of AIE use	-	-	-	-	-	-	-	-	-	-	-	-	0.15	-0.01	-0.06	-0.03	-0.02	-0.05	0.10
13. Confidence	-	-	-	-	-	-	-	-	-	-	-	-	-	13	-0.02	0.09	0.03	-0.23**	-0.09
14. Optimism	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-0.13	-0.17*	0.11	-0.16*	0.03
15. Perceived susceptibility	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.41***	-0.06	0.12	0.10
16. Perceived severity	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-0.13	0.09	0.06
17. Perceived benefits	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-0.10	0.01
18. Perceived barriers	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.08
19. Cues to action	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

p < 0.05*, p < 0.01**, p < 0.001***.

Table 4 Logistic regression for explanatory variables and adherence to self-care behaviours

	B (s.e.)	Wald	OR	95% CI for OR	
				Lower	Upper
Explanatory factors					
Member of a support group	0.93 (0.46)	4.17*	2.54	1.04	6.20
Anaphylaxis management plan	1.17 (0.51)	5.20*	3.22	1.18	8.81
Perceived severity	0.21 (0.11)	4.04*	1.24	1.01	1.52
Perceived barriers	-0.14 (0.05)	8.33**	0.87	0.79	0.96

$R^2 = 0.26$ (Nagelkerke), 0.16 (Cox & Snell). Model $\chi^2 = (4, 170) = 28.65^{***}$.
 $p < 0.05^*$, $p < 0.01^{**}$.

larly pertinent to those managing atopic conditions. Perpetuating the belief that lack of knowledge is the problem, and corrective education is the solution risks the development of misguided educational interventions when in fact what we need are more sophisticated interventions that change perceptions and ultimately behaviour.

No guidelines explicitly recommend membership of a patient support group, but our observations may suggest potential benefit that is worthy of further exploration, to ascertain which activities and resources are particularly influential in promoting adherence. It is important to recognise that whilst our data are supportive of patient support groups, causality cannot be concluded given the cross-sectional design of our study. The observed association may arise because the patient's own motivation to join a support group is the same as that which leads them to engage in desirable self-care behaviours. Further research is needed to explore how and why adolescents interact with support groups and what they perceive as the helpful aspects. To establish the true effectiveness of membership would require appropriate evaluation using a randomised trial design.

The anaphylaxis management plans available to our adolescents were knowledge-centric, focussing on correct administration of AIE and which symptoms to identify when deciding to administer. If management plans were more holistic, including ways to overcome specific barriers to managing food allergy, results regarding their effectiveness may be even greater. This is especially pertinent given our findings which suggest that greater barriers to self-care are associated with worse adherence. Understanding these barriers and developing management plans to provide solutions to these are vital to improve self-care behaviours amongst this population and should be the direction for future research. Both patients and health professionals should be involved in the design, content and format of future anaphylaxis management plans, before rigorous randomised trials comparing content of existing management plans with newly designed management plans can be carried out and provide us with much needed robust and prospective evidence for their use.

References

- Pereira B, Venter C, Grundy J, Clayton B, Arshad SH, Dean T. Prevalence of sensitization to food allergens, reported adverse reaction to foods, food avoidance, and food hypersensitivity among teenagers. *J Allergy Clin Immunol* 2005; **116**: 884–92.
- Sicherer SH, Munoz-Furlong A, Sampson HA. Prevalence of peanut and tree nut allergy in the United States determined by a

As well as being the first study to quantify adolescent adherence to self-care behaviours related to food allergy, this study also applied a psychological model, the Health Belief Model to further our understanding of adherence behaviours in this population. However, this exploratory study is not without limitations. The low response rate to the questionnaire (34%) raises concerns over responder bias, but it is comparable with previous published postal surveys amongst adolescents and those with food allergy (37, 38), and our responders and non-responders were comparable in gender, with only an average difference in age of 6 months. Selection bias may persist especially in regard to other demographics which were not known for non-responders, such as ethnicity. It is reassuring that the respondents were representative of the ethnic diversity found in the City of London from where the majority of participants were recruited. Using self-reporting to measure adherence to self-care behaviours risks overinflated estimates due to social desirability bias. To minimise this, we used anonymised questionnaires which were returned directly to the researcher rather than the clinician. The accuracy of adolescent reported information about childhood events could be challenged. Whilst we encouraged adolescents to complete the questionnaires with parental/guardian assistance, there was no formal assessment of this and adolescents may have poor recall of events from their early childhood. Finally, the generalisability of these findings could be limited as participating adolescents were recruited from specialist paediatric allergy clinics and therefore their disease characteristics may be more severe than those managed with food allergies in primary care.

In conclusion, this study highlights the need to be alert to the high prevalence of low adherence to self-care behaviours amongst adolescents with food allergy. This study has highlighted factors, other than knowledge, that may improve health and wellbeing in the adolescent with food allergy.

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- random digit dial telephone survey: a 5-year follow-up study. *J Allergy Clin Immunol* 2003; **112**: 1203–7.
3. Dinakar C. Anaphylaxis in children: current understanding and key issues in diagnosing and treatment. *Curr Allergy Asthma Rep* 2012; **12**: 641–9.
 4. Muraro A, Roberts G, Worm M, et al. Anaphylaxis: guidelines from the European academy of allergy and clinical immunology. *Allergy* 2014; **69**: 1026–45.
 5. Bock SA, Munoz-Furlong A, Sampson HA. Fatalities due to anaphylactic reactions to foods. *J Allergy Clin Immunol* 2001; **107**: 191–3.
 6. Pumphrey RS. Lessons for management of anaphylaxis from a study of fatal reactions. *Clin Exp Allergy* 2000; **30**: 1144–50.
 7. Sampson HA, Mendelson LM, Rosen JP. Fatal and near fatal anaphylactic reactions to food in children and adolescents. *N Engl J Med* 1992; **327**: 380–4.
 8. Yunginger JW, Sweeney KG, Sturmer WQ, et al. Fatal food-induced anaphylaxis. *J Am Med Assoc* 1988; **260**: 1450–2.
 9. Resuscitation Council (UK). Emergency treatment of anaphylactic reactions. Guidelines for healthcare practitioners. Resuscitation Council (UK), 2008. Available at: <http://www.resus.org.uk/pages.reaction.pdf>
 10. Sabaté E. Adherence to long-term therapies. Evidence for action. World Health Organisation, 2003. Available at: http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf
 11. Taddeo D, Egedy M, Frappier JY. Adherence to treatment in adolescents. *Paediatr Child Health* 2008; **13**: 19–24.
 12. Goldberg A, Confino-Cohen R. Insect sting-inflicted systemic reactions: attitudes of patients with insect venom allergy regarding after-sting behaviour and proper administration of epinephrine. *J Allergy Clin Immunol* 2000; **106**: 1184–9.
 13. Kim JS, Sinacore JM, Pongracic JA. Parental use of EpiPen for children with food allergies. *J Allergy Clin Immunol* 2005; **116**: 164–8.
 14. 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**: 869–77.
 15. 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**: 1440–5.
 16. Rollnick S, Mason P, Butler C. *Health Behaviour Change: A Guide for Practitioners*. Edinburgh, UK: Churchill Livingstone, 1999.
 17. Delamater AM. Improving patient adherence. *Clin Diabetes* 2006; **24**: 71–7.
 18. Burgoon JK, Pfau M, Parrott R, Birk T, Coker R, Burgoon M. Relational communication, satisfaction, compliance gaining strategies and compliance in communication between physicians and patients. *Commun Monogr* 1987; **54**: 307–24.
 19. Atreja A, Bellam N, Levy SR. Strategies to enhance patient adherence: making it simple. *Med Gen Med* 2005; **7**: 4.
 20. Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. *Med Care* 1998; **36**: 1138–61.
 21. Raynor DK, Booth TG, Blenkinsopp A. Effects of computer generated reminder charts on patients' compliance with drug regimens. *BMJ* 1993; **306**: 1158–61.
 22. Rosenstock IM. Why people use health services. *Milbank Mem Fund Q* 1966; **44**: 94–127.
 23. Conn KM, Halterman JS, Fisher SG, Yoos HL, Chin NP, Szilagyi PG. Parental beliefs about medications and medication adherence among urban children with asthma. *Ambul Pediatr* 2005; **5**: 306–10.
 24. Ohya Y, Williams H, Steptoe A, et al. Psychosocial factors and adherence to treatment advice in childhood atopic dermatitis. *J Invest Dermatol* 2001; **117**: 852–7.
 25. Gillibrand R, Stevenson J. The extended health belief model applied to the experience of diabetes in young people. *Br J Health Psychol* 2006; **11**: 155–69.
 26. Pantino AM, Sanchez J, Eidson M, Delamater AM. Health beliefs and regimen adherence in minority adolescents with type 1 diabetes. *J Pediatr Psychol* 2005; **30**: 503–12.
 27. Bond GG, Aiken LS, Somerville SC. The health belief model and adolescents with insulin-dependent diabetes mellitus. *Health Psychol* 1992; **11**: 190–8.
 28. Brownlee-Duffeck M, Peterson L, Simonds JF, Goldstein D, Kilo C, Hoette S. The role of health beliefs in the regimen adherence and metabolic control of adolescents and adults with diabetes mellitus. *J Consult Clin Psychol* 1987; **55**: 139–44.
 29. Champion VL. Instrument development for Health Belief Model constructs. *Adv Nurs Sci* 1984; **6**: 73–85.
 30. Jones CJ, Smith HE, Frew AJ, Toit GD, Mukhopadhyay S, Llewellyn CD. Explaining adherence to self-care behaviours amongst adolescents with food allergy: a comparison of the health belief model and the common sense self-regulation model. *Br J Health Psychol* 2014; **19**: 65–82.
 31. Grundy SE. The confidence scale: development and psychometric properties. *Nurse Educ* 1993; **18**: 6–9.
 32. Carver CS, Scheier MF, Segerstrom SC. Optimism. *Clin Psychol Rev* 2010; **30**: 879–89.
 33. Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a re-evaluation of the Life Orientation Test. *J Pers Soc Psychol* 1994; **67**: 1063–78.
 34. National Institute for Health and Care Excellence. *Anaphylaxis: Assessment to Confirm an Anaphylactic Episode and the Decision to Refer After Emergency Treatment for a Suspected Anaphylactic Episode: Nice Clinical Guideline*. London: National Institute for Health and Care Excellence, 2011.
 35. Choo K, Sheikh A. Action plans for the long-term management of anaphylaxis: systematic review of effectiveness. *Clin Exp Allergy* 2007; **37**: 1090–4.
 36. Ring N, Malcolm C, Wyke S, et al. Promotion the use 450 of personal asthma action plans: a systematic review. *Prim Care Respir J* 2007; **16**: 271–83.
 37. Richards J, Wiese C, Katon W, et al. Surveying adolescents enrolled in a regional health care delivery organization: mail and phone follow-up – what works at what cost? *J Am Board Fam Med* 2010; **23**: 534–41.
 38. Knibb RC, Horton S. Can illness perceptions and coping predict psychological distress in allergy sufferers? *Br J Health Psychol* 2008; **13**: 103–19.