1	TITLE PAGE
2	Original Article
3	Title: Parental self-efficacy in managing food allergy and mental health predicts food
4	allergy related quality of life.
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20	Word count: 2,701 Number of tables: 5 (plus one supplementary table)
21	
22	Statement of contribution of each author: R Knibb and C Barnes designed the study
23	protocol; C Stalker collected and inputted the data for the study; R Knibb analysed the data
24	and wrote the paper; all authors contributed to editing the paper and agreed the final version.
25	

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Parental self-efficacy in managing food allergy and mental health predicts food allergy related quality of life.

29 Pediatr Allergy Immunol

30

31 ABSTRACT

Background: Food allergy has been shown to have a significant impact on quality of life (QoL) and can be difficult to manage in order to avoid potentially life threatening reactions. Parental self-efficacy (confidence) in managing food allergy for their child might explain variations in QoL. This study aimed to examine whether self-efficacy in parents of food allergic children was a good predictor of QoL of the family.

37

38 **Methods**: Parents of children with clinically diagnosed food allergy completed the Food 39 Allergy Self-Efficacy Scale for Parents (FASE-P), the Food Allergy Quality of Life Parental 40 Burden Scale (FAQL-PB), the GHQ-12 (to measure mental health) and the Food Allergy 41 Independent Measure (FAIM), which measures perceived likelihood of a severe allergic 42 reaction.

43

Results: A total of 434 parents took part. Greater parental QoL was significantly related to greater self-efficacy for food allergy management, better mental health, lower perceived likelihood of a severe reaction, older age in parent and child and fewer number of allergies (all p<0.05). Food allergy self-efficacy explained more of the variance in QoL than any other variable and self-efficacy related to management of social activities and precaution and prevention of an allergic reaction appeared to be the most important aspects.

50

51 **Conclusions**: Parental self-efficacy in management of a child's food allergy is important and 52 is associated with better parental QoL. It would be useful to measure self-efficacy at visits to 53 allergy clinic in order to focus support; interventions to improve self-efficacy in parents of food 54 allergic children should be explored.

- 55 Key words: confidence; food allergy; parents; quality of life; self-efficacy
- 56

57 Abbreviations:

- 58 FAIM: Food Allergy Independent Measure
- 59 FASE-P: Food Allergy Self-Efficacy Scale for Parents
- 60 FAQL-P: Food Allergy Quality of Life Parental Burden Questionnaire
- 61 GHQ-12: General Health Questionnaire 12
- 62 QoL: Quality of Life
- 63
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- 69

70 INTRODUCTION

71 Food allergy affects approximately 5% of children and is often a life-long condition with about 72 20% not growing out of their allergy⁽¹⁾. Symptoms related to accidental ingestion of an 73 allergen can be severe and include urticaria, hives, swelling of lips, tongue and mouth and 74 anaphylactic shock. Optimal management of food allergy is complete avoidance of the 75 allergen and administration of antihistamine or adrenaline if accidental ingestion and a 76 reaction occurs ^(1,2). Parents and children have reported that food allergy has a significant 77 impact on quality of life compared to healthy controls⁽³⁾ and children with other chronic 78 conditions⁽⁴⁾. Quality of life is a multi-dimensional construct including emotional, social, 79 environmental and physical domains and should be viewed in the context of a person's 80 culture, value systems, goals, expectations, standards and concerns⁽⁵⁾. A number of domains 81 of quality of life appear to be affected in food allergy including social relationships, emotional, 82 school and financial⁽⁶⁾. The constant risk of a serious reaction is thought to be a major cause 83 of the burden of food allergy and an important factor in causing stress and worry in parents. 84 Parents, particularly mothers, have reported high levels of stress and anxiety⁽⁷⁾ and have also 85 reported high levels of worry about their child having an anaphylactic reaction and uncertainty 86 around what to do if their child does go into anaphylactic shock^(8,9).

87

88 Parental confidence in managing their child's food allergy may be an important factor to 89 consider in relation to the burden of food allergy and its impact on quality of life. Confidence 90 and the belief in your ability to carry out certain actions and manage situations has been 91 defined as self-efficacy⁽¹⁰⁾. Self-efficacy has been related to psychological wellbeing in 92 mothers of children with long term conditions such as Cerebral Palsy⁽¹¹⁾ and in parents of 93 children with diabetes, where it has been shown to relate to better management of the child's 94 condition regarding glycaemic control and better quality of life⁽¹²⁾. Interventions which seek to 95 enhance self-efficacy (e.g. delivered through education, training or self-management) lead to 96 improvements in quality of life, self-management and coping with asthma⁽¹³⁻¹⁵⁾ and other long-97 term conditions⁽¹⁶⁾. Self-efficacy has not been examined before in relation to food allergy. 98 Therefore, the aim of this study was to examine whether self-efficacy in parents of food

99	allergic children was a predictor of parental quality of life. As parents of children with food
100	allergy have reported high levels of distress ⁽⁷⁻⁹⁾ , mental health was also examined in order to
101	explore the unique contribution self-efficacy might make to quality of life relative to mental
102	health and food allergy characteristics.
103	
104	

106 METHODS

107 Ethical approval was provided by the Psychology Research Ethics Committee at the108 University (102-13-CB). All participants gave informed consent to take part.

109

110 Participants and procedure

111 Participants were recruited from the general population via advertisement of an online survey 112 through social media channels such as Facebook and Twitter and through the Anaphylaxis 113 Campaign's website. Emails advertising the study were also sent to all eligible members of 114 the Campaign although parents did not need to be members of the Campaign to take part. 115 Inclusion criteria for the study were that the participant was a parent who had at least one 116 child under the age of 18 years living in the family home who had a food allergy diagnosed by 117 a clinician at an allergy clinic. There were no exclusion criteria, although participants needed 118 to be able to understand written English in order to take part in the study as the scales used 119 were only validated in the English language. Participants completed the guestionnaires 120 anonymously.

121

122 Measures

123 The Food Allergy Self-Efficacy scale for Parents (FASE-P)⁽¹⁷⁾ is a 21 item scale measuring 124 parental self-efficacy or confidence in managing food allergy in their child. It is scored on a 0-125 100 scale with higher score representing greater confidence. It has five sub-scales: 126 managing social activities, precaution and prevention of an allergic reaction, identifying 127 allergens, treating an allergic reaction and seeking information about food allergy. The scale 128 has good to excellent internal consistency (alpha=0.88 for total scale; 0.63-0.89 for the sub-129 scales), excellent re-test reliability (r=.82) and has been shown to have good construct and 130 discriminative validity (17).

131

Food Allergy Quality of Life – Parental Burden (FAQL-PB) scale⁽¹⁸⁾ has 17 items and uses a
7-point Likert scale ranging from 1 (not troubled) to 7 (extremely troubled). Questions include
issues concerning going on vacation, social activities and worries and anxieties over the

135 previous week. A higher score indicates greater parental burden. Reliability has been 136 reported as excellent in a U.S. sample (Cronbachs α = 0.95) ⁽¹⁸⁾ and in a U.K. sample (α > 137 0.85) ⁽¹⁹⁾.

138

Food Allergy Independent Measure (FAIM) has 4 items which measure the severity of perceived risk of an accidental reaction to food and the perceived risk of not being able to treat a reaction appropriately. Items are answered on a 7-point Likert scale with a greater score indicating a higher level of perceived seriousness. It is a well used and valid means of measuring the perceived severity of food allergy ⁽²⁰⁾.

144

General Health Questionnaire – 12 (GHQ-12) ⁽²¹⁾ is a 12 item scale of current mental health which asks individuals to state how they have felt over the last few weeks. It uses a 4 point Likert scale from not at all (scored 0) to much more than usual (scored 3). Scores are summed and have a range from 0 to 36. Scores over 11-12 indicate a risk of being diagnosed with a mental illness. The scale has excellent reliability (Cronbach's $\alpha = 0.77$ -0.93) and good validity ⁽²¹⁾.

151

152 Demographic and food allergy questionnaire

A questionnaire to gather demographic information from the parent and food allergy information about their child was developed based on that used in previous published studies⁽²²⁾. Information collected included the type of food allergy, symptoms, how the allergy was diagnosed, medication, history of anaphylaxis and presence of other atopic conditions such as asthma, hay-fever and eczema.

158

159 Statistical analysis

160 Data analyses were conducted using SPSS version 21, and all tests were 2-tailed with a

161 significance level set at p<0.05. Missing demographic and food allergy information was

- 162 treated pairwise; there were no missing answers for any of the psychometric scales and
- 163 everyone who completed all questionnaires was included in the analysis. Tests for normality,

164	kurtosis and skew were conducted and showed the data to be within acceptable levels and
165	so parametric tests were conducted. Pearson's bivariate correlations were conducted to
166	examine relationships between quality of life and other continuous variables such as self-
167	efficacy and mental health. Independent t-tests were conducted to look at differences in
168	quality of life across demographic variables. Hierarchical regression was conducted to
169	examine which factors were predictive of quality of life.
170	

173 RESULTS

A total of 434 parents completed the questionnaires for 482 children with food allergy. Demographic information for participants can be found in Table 1 and food allergy information can be found in Table 2. Means and standard deviations of scores for each measure can be found in Table 3. Mean GHQ scores exceeded the cut-off score for being at risk of being diagnosed with a mental illness. Examination of mean scores of the sub-scales for selfefficacy showed that parents appeared to be least confident in managing social activities and seeking information about food allergy.

181

182 Relationships between quality of life, self-efficacy and mental health

183 Pearson's correlations between quality of life, self-efficacy, mental health and FAIM scores 184 can be seen in Table 4. Better quality of life was significantly related to greater self-efficacy 185 for food allergy management (p<0.001), better mental health (p<0.001) and lower perceived 186 likelihood of a severe reaction (p<0.001). The correlations with total mean self-efficacy were 187 particularly strong and there were also strong correlations between quality of life and selfefficacy for managing social activities (p<0.001). To explore whether mental health status 188 189 and FAIM scores were influencing the relationship between self-efficacy and quality of life, partial correlations were run. After controlling for mental health, the unique relationship 190 191 between quality of life and self-efficacy was still significant (-.512, p<0.001). After controlling 192 for FAIM scores, the unique relationship between quality of life and self-efficacy was also still 193 significant (-.533, p<0.001).

194

195 Relationships between quality of life, parent, child and food allergy characteristics

Greater quality of life was significantly related to older age in parent and child and fewer numbers of allergies (Table 4). Significantly poorer quality of life was reported in parents of children who had asthma (mean=75.88, s.d.=21.32) compared to children without (mean=69.03, s.d.=19.13), (t=2.76(399), p=0.006) and children who had eczema (mean= 75.46, s.d.=21.09) compared to children without (mean=68.67, s.d.=18.91), (t=2.18(415), p=.03). Significantly poorer quality of life was also reported in parents of children who had egg

allergy (mean=77.72 s.d.=20.50) compared to children without (mean=72.54, s.d.=21.06), (t=2.50(432), p=0.01), history of anaphylaxis (mean=76.03 s.d.=20.97) compared to children with no history (mean=71.68, s.d.=21.04), (t=1.94(369) p=0.05) and hospitalisation due to food allergy (mean=76.55, s.d.=21.02) compared to children who had no such history (mean=70.28, s.d.=20.29), (t=3.00(430), p=0.003).

207

As there was a significant relationship between quality of life and age of child, age might be a reason for the differences seen in children with egg allergy, which tends to affect younger children. To assess this, an Analysis of Covariance (ANCOVA) was run. After controlling for age of child there was still a significant difference in quality of life for parents of children with egg allergy or not (F=15.12, p<0.001).

213

214 Explaining variance in quality of life

215 Hierarchical regression models were run with variables that significantly related to quality of 216 life. Food allergy and demographic characteristics were entered in step one in order to 217 control for these variables; self-efficacy, GHQ-12 and FAIM scores were entered in step two. 218 In step one age of child, number of allergies and presence of asthma were significantly 219 related to parental quality of life, explaining 7% of the variance. In step two, age of child and 220 number of allergies retained their significance but with attenuated beta coefficients. Food 221 allergy self-efficacy, mental health and FAIM scores were all significantly related to parental 222 quality of life with 46% of the variance in quality of life explained, which was a significant 223 increase from step one (R² change=.385, p<0.001), (Table 5). Examination of the 224 standardized betas showed that self-efficacy explained the most variance in parental quality 225 of life.

226

A forced entry regression model was run with the sub-scales of the FASE-P to explore whether particular areas of parental self-efficacy were important in explaining quality of life. The FASE-P sub-scales together explained 35% of the variance in food allergy related quality of life. Examination of both standardized and unstandardized betas (as all predictors were

measured on the same scale) showed that confidence in managing social activities and precaution and prevention of allergic reactions appeared to be the most important aspects of in explaining food allergy related quality of life in parents (Table 5).

235 **DISCUSSION**

236 This is the first study to explore the contribution parental self-efficacy for managing food 237 allergy can make in explaining the impact of food allergy on quality of life in the parent. We 238 found that self-efficacy explained the greatest proportion of variance in parental quality of life. 239 The regression model which included just self-efficacy explained over a third of the variance 240 in quality of life and managing social activities and precaution and prevention of allergic 241 reactions appeared to be particularly important. Aspects of allergy such as history of 242 anaphylaxis, type of allergy, other atopic conditions, age of child and age of parent only 243 accounted for a small proportion of the variance. It appears then that parental self-efficacy is 244 an important construct to consider when offering advice and training in food allergy 245 management for the parent or psychological support.

246

247 Self-efficacy for managing social activities explained the greatest proportion of quality of life 248 when just self-efficacy sub-scales were examined. Interestingly this sub-scale also had the 249 lowest level of self-efficacy reported by parents. This sub-scale includes items such as going 250 out to a restaurant, planning a holiday and being on holiday in this country or abroad. Having 251 good self-efficacy to do these sorts of activities appears to be very important to having a good 252 quality of life. Ways in which we can support parents in growing confident in being able to do 253 these things should be explored further, which might include providing information and 254 helping parents with action plans for travelling in this country and abroad.

255

256 The age of the child, the number of food allergies they had and the presence of asthma were 257 all significantly related to parental quality of life, although they explained only a small amount 258 of its variance. Previous studies have also found that presence of other atopic conditions 259 such as asthma and eczema⁽²³⁾ and number of allergies⁽²⁴⁻²⁶⁾ reduces quality of life and these 260 findings therefore provide further evidence of the detrimental effect of multiple allergies on 261 quality of life. It is interesting that our study found that parental quality of life gets better as 262 the child gets older. This may be because parents become used to coping with their child's 263 allergy over time and develop good management strategies and as children get older they

take more responsibility for their own allergy management. The child may also grow out of some of their allergies as they get older, resulting in a better quality of life for the family. The relationship between quality of life and age is not consistent in the literature however, with Wassenberg et al⁽²⁶⁾ reporting that younger children (up to age 3 years) had better parental rated quality of life than older children, possibly due to older children taking part in more in social activities and having greater independence from parents. The relationship between age of child and quality of life would therefore benefit from further investigation.

271

There was a significant difference in levels of quality of life reported by parents of children with egg allergy compared to other allergies. Much attention has been placed on the impact of allergies such as peanut and nut ^(e.g. 4,6,22) and so this is a novel finding. The difference in quality of life found here may be because egg allergy is difficult to manage due to the number of foods that contain egg. It is also a good source of protein and a diet excluding egg would need to substitute other foods to ensure adequate nutritional content. This may be less of an issue when avoiding foods such as peanut and nut.

279

280 A strength of this study was the large sample size drawn from a general population, which 281 provided a sample of participants with a range of food allergy characteristics such as the type 282 of food allergen reported, the length of time since diagnosis and age of child. Nevertheless 283 the study was predominately completed my mothers, which limits any conclusions we can 284 make about what fathers experience, and does rely on parental reporting of a clinical 285 diagnosis in their child. The high proportion of children with prescribed adrenaline auto-286 injectors implies it is probable that these children had received a clinical diagnosis. It would 287 be useful to examine the relationship between self-efficacy and quality of life in a population 288 drawn from a clinical database to check that self-reporting of allergy has not affected the 289 results. This study is also cross-sectional in nature and so we cannot make any conclusions 290 about cause and effect to determine whether better self-efficacy for food allergy management leads to better quality of life or whether better initial quality of life supports parents to feel 291 292 more efficacious in how they are managing. It would be useful to conduct a longitudinal study

looking at food allergy self-efficacy and quality of life from the point of diagnosis and acrosstime in order to ascertain the causal relationships between these variables.

295

In conclusion, this study has shown that parental self-efficacy for food allergy management is important in explaining quality of life in parents of children with food allergy. Measurement of self-efficacy should be considered in addition to quality of life when parents attend allergy clinic with their child. Low scores in any domain of self-efficacy could help focus the content of a consultation or prompt a referral to a dietician or to psychological support. Interventions to improve self-efficacy in parents of children with food allergy should be explored as they may be able to improve food allergy related quality of life.

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304 Acknowledgements

The authors would like to thank the Anaphylaxis Campaign for their support in advertising this study and the parents who took part. This study was funded by pump priming money from the Health and Lifespan Research Group at Aston University.

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309 Conflicts of interest

310 There are no conflicts of interest.

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	Sample n=434404
	n/%
Parents age (mean, s.d.)	42.21 (6.41)
Gender of Parent completing survey	
Male	19 (4.4%)
Female	411 (94.7%)
Marital status	
Married/living with partner	393 (90.5)
Divorced	16 (3.7)
Single	17 (3.9)
Widowed	1 (0.2)
Employment status	
Working full-time	123 (28.3)
Working part-time	204 (47.0)
Full-time education	3 (0.7)
Not working or in education	102 (23.5)
Country of residence	
UK	410 (94.5)
Other EU	12 (2.8)
Non-EU	8 (1.8)
Number of children within family (mean, s.d.)	2.03 (1.12)
Number of children in family with a food allergy	
One	382 (88)
Two	44 (10.1)
Three	6 (1.4)

Table 1. Characteristics of respondents (n %) 403

405 406 Where % don't add up to 100 there are missing values

408 Table 2. Food allergy characteristics (n %).

	Sample n=482
	n/%
Child age in years (mean, s.d.)	9.47 (4.7)
Child age range (years)	1-18
Gender of child with food allergy	
Male	300 (62.2)
Female	170 (35.3)
Foods reported	
Peanut	354 (73.4)
Tree nut	302 (62.7)
Both peanut and tree nut	275 (57.1)
Egg	177 (36.7)
Cows Milk	128 (26.6)
Fruit	59 (12.2)
Sesame	45 (9.3)
Shellfish	36 (7.5)
Soya	34 (7.1)
Fish	34 (7.1)
Wheat	18 (3.7)
Symptoms reported	
Rash, hives, urticaria	346 (71.8)
Vomiting	247 (51.2)
Abdominal Pain	172 (35.7)
Swelling of face	296 (60.8)
Swelling of lips or tongue	270 (56.0)
Tingling or sore mouth	236 (49.0)
Breathing difficulties	224 (46.5)

Wheeze	217 (45.0)
Throat tightening	188 (39.0)
Other allergies	
Latex	15 (3.1)
Tree Pollen	122 (25.3)
Grass Pollen	134 (27.8)
Asthma	337 (69.9)
Eczema	403 (83.6)
Hayfever	264 (54.8)
History of Anaphylaxis	237 (49.2)
Prescribed Adrenaline Auto Injector	436 (90.5)
How allergy diagnosed	
Skin prick test	357 (74.1)
Blood test	290 (60.2)
Food challenge	73 (15.1)
Hospitalisation due to an allergic reaction	300 (62.2)

to food

Where % don't add up to 100 there are missing values; where % total more than 100 parents were able to select more than one answer. 410

413 Table 3. Means (and standard deviations) of scale scores

Scale	Mean (SD)
Quality of life (FAQL-PB)	74.47 (20.98)
Food Allergy Self-Efficacy (FASE-P)	76.07 (11.37)
FASE-P sub-scales	
Managing social activities	68.85 (20.50)
Precaution and prevention	81.22 (11.82)
Allergic treatment	88.60 (11.17)
Food allergen identification	87.41 (11.37)
Seeking information	64.11 (16.83)
General Health Questionnaire (GHQ12)	11.06 (5.1)
FAIM	3.32 (.97)

416 Table 4. Relationships (Pearsons r) between quality of life, self-efficacy, mental health, FAIM

417 scores and demographic and food allergy characteristics

Scale	Quality of life
	(FAQL-PB)
Age of parent	205**
Age of child	257***
Number of allergies	.130*
Food Allergy Self-Efficacy (FASE-P)	563***
FASE-P sub-scales	
Managing social activities	584***
Precaution and prevention	451***
Allergic treatment	243***
Food allergen identification	219***
Seeking information	280***
General Health Questionnaire (GHQ12)	.330***
FAIM	.447***
*p<0.05; **p<0.01; ***p<0.001	

422 Table 5. Hierarchical regression models showing significant predictors of parental quality of

423 life

	Standa	rdised β	
Predictors	Step 1	Step 2	
Age of parent	089	013	
Age of child	171*	115*	
Number of allergies	.158*	107*	
Egg allergy	.115	096	
Asthma	118*	003	
Eczema	027	029	
Anaphylaxis	061	088	
Hosptilisation Hospitalisation	046	041	
Food Allergy Self-Efficacy (FASE-P)		451***	
General Health Questionnaire (GHQ12)		.128**	
FAIM		.295***	
F value	3.77***	24.30***	
Adj R ²	.068	.457	

Predictors	Standardised	Unstandardized
FASE-P sub-scales	β	β
Managing social activities	467***	482
Precaution and prevention	159**	280
Allergic treatment	013	025
Food allergen identification	032	.058
Seeking information	066	081
F value	45.840***	
Adj R ²	.35	

424 *p<0.05; **p<0.01; ***p<0.001

426 <u>Table S1. Table of significant predictors of parental quality of life</u>

Predictors of Quality of Life

Age of child

Number of allergies

Food Allergy Self-Efficacy (FASE-P)

General Health Questionnaire (GHQ12)

Food Allergy Independent Measure

Predictors of Quality of Life - FASE-P sub-scales

Managing social activities

Precaution and prevention

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