Coping with food allergy –
converting research to practice

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Food Allergy

Food allergy is associated with a poorer quality of life than other conditions such as diabetes or asthma, and is associated with greater psychological distress such as anxiety, worry and stress.

Unpredictability of food allergy
- Children are well the majority of the time
- Allergens hide!

Social and financial costs
- Eating out; reading food labels
- Parties/school trips
- Family holidays
- Dietary costs
- Unable to work

Cummings et al., Allergy, 2010, 65, 933-945
Food Allergy

An increasing range of research on the psychological impact of food allergy has been published

- QoL, anxiety and depression, worry and stress
- Knowledge and understanding of FA
- Coping and FA management in patients and parents
- Self-efficacy and confidence in managing food allergy
- Self-concepts, illness beliefs and using psychological models to predict intentions and behaviour
- Interventions: group support, online support, CBT
Food Allergy

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  – **Coping and FA management in patients** and parents
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Management of food allergy

- Research on coping and management of food allergy has mostly focused on children, adolescents and parents rather than on adults.
- There is a developmental aspect to allergy management with different strategies used depending on the age of the allergic patient.
Management of food allergy depends on age of the patient

DunnGalvin et al., (2009)

• 15 focus groups with children aged 6-15 years
• 6 themes identified:
  – Meanings of food
  – Autonomy, control and self-efficacy
  – Peer relationships
  – Risk and safety
  – Self identity
  – Coping strategies
Management of food allergy depends on age of the patient

DunnGalvin et al., (2009)

• Younger children were more confident in social situations as they relied more on parents to choose safe food and agreed that ‘you must not eat any food you are unsure about’.

• After the age of 8 years social occasions become a source of anxiety and uncertainty: ‘there is always food about…..when I take a first bite, there’s a moment when you think, is this it?’ (girl aged 10).
Management of food allergy depends on age of the patient

*DunnGalvin et al., (2009)*

- Older children realised parents can’t always provide a safe environment and their autonomy and need to control events in their life increases.
- Coping strategies were cognitive, emotional and behavioural
  - *Avoidance* strategies (40% of children and teens) to manage risk and anxiety/worry, e.g. avoid going to parties where there is food
  - *Cognitive minimisation* strategies (30% of children and teens), e.g. rejection of allergic identity to prevent teasing/bullying
  - *Adaptive* strategies (30% of children and teens), e.g. independence and self-management encouraged by the parents
Management of food allergy depends on age of the patient

Fenton et al., (2011)

- Interviewed 10 children (8-12 years) and 10 teenagers (13-18 years) in Canada and found similar results:
  - Younger children relied heavily on parents to manage risk
  - **Avoidance** of risky foods or places and educating others used as strategies to cope by children and teenagers
  - Adolescents described being **extremely vigilant**, being alert and on guard in order to overcome risk and risk related anxiety and fear
  - A few adolescents described giving in, **feeling helpless** and disempowered which was accompanied by overcompensating and obsessive behaviour such as hand washing
Management of food allergy

Adolescents experience of living with food allergy: MacKenzie et al. (2009).

• 21 teenagers (aged 13-18 years) interviewed
• Food allergy was a burden but a way of life
• Coping involved assessing acceptable risk or using willpower to avoid the food they are allergic to and try and find alternatives

‘it makes me more conscious of trying to be safe and trying to be prepared. But it doesn’t stop me doing these things’. (female aged 18).
Management of food allergy

Adolescents experience of living with food allergy: MacKenzie et al. (2009).

• Some teenagers (n=9) were very strict about managing their food allergy and not taking risks, **But** they had a high level of burden.

• Some teenagers (n=10) were more tolerant of risk and level of precautions depending on the situation, perceived severity of their own allergy and trust/distrust in information on food labels.

‘we are supposed to carry them [AAIs] around school but I don’t. I don’t think there is much point … because I have a packed lunch’. (female aged 14).
Management of food allergy

Adolescents experience of living with food allergy: MacKenzie et al. (2009).

- A minority of teenagers (n=2) were very tolerant of risk and took fewer precautions and may do things like eat food they haven’t eaten before without checking the label properly.
- This group experiences the lowest level of burden from their food allergy.

- Assessment of risk and decision on precautions to be taken is a common theme in the food allergy literature on adolescents.
How do children and adolescents cope with food allergy?

Hammond, Cooke and Knibb, 2017

- Systematic review of coping in children and adolescents with FA.

**Inclusion criteria**

- Aged 8-19 with a food allergy or food intolerance
- Outcomes related to coping behaviours
- All research designs for qualitative, quantitative and mixed-methods studies

**Exclusion criteria**

- Parents of children with a food allergy
- Adults with a food allergy
- Medical/nursing/school staff
- Studies with no outcomes related to coping e.g. QoL, anxiety, depression
- Studies not published in the English language
- Reviews/letter to the editor/abstracts
Studies included in qualitative synthesis (n = 10)

Records screened (n = 4487)
- Records after duplicates removed (n = 4487)
- Records excluded (n = 4405)
- Full-text articles excluded, with reasons (n = 72)
  - Participants (n = 14)
  - Not related to coping (n = 32)
  - Outside of the age range (n = 6)
  - Review/letter to editor (n = 20)

Full-text articles assessed for eligibility (n = 82)

Participants (n = 14)
- Not related to coping (n = 32)
- Outside of the age range (n = 6)
- Review/letter to editor (n = 20)

Additional records identified through other sources (n = 276)

Records identified through database searching (n = 4990)


Themes:
1. Coping with risk
2. Coping with emotions
3. Using AAs
4. Support of others
5. Education, knowledge and understanding
Coping with risk

Not carrying an EpiPen when assessing risk of reaction as low:
“We’re meant to carry them (EpiPens) around school but I don’t. I don’t think there’s much point … because I have a packed lunch… So I don’t eat anything that I know might have a nut in” (Mackenzie et al, 2010)

Selecting “safe” foods to eat to avoid an allergic reaction:
“Just, if I like it or not, I’ll just like see what I like and then if it’s got nuts in it, first, I won’t pick it all out with nuts first…” – Ryan, aged 14(Sommer et al, 2014)

Being prepared and carrying AAI
Female aged 15 “I’ve got a handbag that I take with me and I just keep them in there. So if I need to go out I know where they are” – Female, aged 15 (Monks et al, 2010)
Coping with emotions

Using avoidance to manage anxieties in social contexts e.g. birthday parties:
“\textit{I’ve missed out on 4 parties because I just don’t want to go}” – Female aged 13 (Mackenzie et al, 2010)

Using avoidance of discussing FA to manage feeling different from friends and peers
“I’d only mention something if it came up… if I had to say why I couldn’t have something, I’d say that I didn’t like it, or I wasn’t hungry.” Peter, aged 12  (Dunn-Galvin et al, 2009)

Using positive reinterpretation to manage emotions associated with FA
“There’s some people that have to be really aware because they can just smell it and have a reaction. I’m kind of grateful for that” Male, aged 14  (Mackenzie et al, 2010)
Using adrenaline auto-injectors

Uncertainty as a barrier to using AAI’s:

“Would you take it when you feel it coming on or when it’s there? . . . you don’t know if I should take it now or if I should wait till it develops and then see how it goes, if it’s going to calm down and if it doesn’t calm down should I take it then, or do it before, like nip it in the bud” – Lisa (Gallagher et al, 2011)

Avoidance in using an AAI due to fear:

“I know how to use it but I wouldn’t do it. I would do it if I needed to, but before I’d do it I’d get someone else to do it like my mum. . .because. . .I had a blood test and I fainted; I don’t like needles.” – Male, aged 16 (Monks et al, 2010.)
Support of others

Relying on parents to assess risk and manage FA:
“I guess I don’t check every single time, because my mom usually does that…” (Fenton et al, 2011)

Relying on parents to manage practicalities of social events e.g birthday parties:
“I’m fine because Mum brings my own food to parties” (Dunn-Galvin et al, 2009)
Education, knowledge and understanding

The impact of education and knowledge on managing FA:

“I thought I was having an asthma attack, which is really scary because like I thought if I had an anaphylactic shock I would be throwing up, because that’s what it was when I was little, that’s why I didn’t use the EpiPen because I didn’t know what I was having.” - Sophie (Gallagher et al, 2011).

How adolescents feel that their FA education could be enhanced to help that manage their FA better:

“I also think, like, maybe one of those Annies that you get, you know the ones you learn CPR on? Well if you can get, like, Annie legs and maybe do it on that and actually have, like, a real injector so you know what it feels like to do it” – Male, aged 13 (Monks et al, 2010)
How do children and adolescents cope with food allergy?

*Hammond, Cooke and Knibb, 2017*

- Interviewed 13 children (8-11 years) and 18 teenagers (13-16 years):

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<th>8-11 year olds</th>
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<td>Perception of risk</td>
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<td>The importance of knowledge</td>
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“I have to just watch where I am and where I’m sat and things, and like check that my food doesn’t touch someone else’s because that could make me have a reaction” – Hannah, age 9

“If I’m going to my friend’s house, he only lives down the road from me, I won’t really bother to carry my EpiPen on me because it’s normally fine when I go there” – Francis, age 10

“I’ll check the food labels when we’re at the supermarket if I want to try something new” – Millie, age 10
“my mum normally carries my EpiPen for me because she has a bag, so I don’t need to do anything” – Francis, age 10

“I’ll normally check with my mum first to see if its ok before I do anything, even if I think its ok I just want to make sure she thinks the same as well” Christopher, age 10

“Yeah, I speak to my mum like, I speak to my mum and say to her things like I’m quite worried about my food allergy, and she will always make me feel better.” Jacob, age 10
SR: Coping with emotions

8-11yr olds: Managing emotions

12-16 yr olds: The emotional experience of FA

- “Like sometimes I’m angry that it happened to me because my older brother he doesn’t have a food allergy, my mum and dad don’t have a food allergy, so I don’t know why I got it.” – Sarah, age 8

- “sometimes it’s made me angry because I can’t eat certain things and I uhmm I’ve gone to my room and thrown my things on the floor, which is really silly” – Mike, age 11

- “Uhmm I go to my room which I’m in now and have like a few moments to myself really just to get away from it all really” Jacob, age 10

- “I just uhmm, kind of forget about it and try to ignore it and I can do something else, like some things that make me happy, like drawing” Farina, age 9

- “I’d just distract myself and not really think about it and think about something else instead” – Francis, age 10
“well…I eat the foods that I know I can have because then it makes me feel happy that I can actually eat some foods that I want to. So, I sometimes think it’s not that bad when I can eat some of my favourite foods” Sarah, age 8

“because I could be allergic to so much more stuff and I’m not so it’s not that bad really. I think if maybe I was allergic to more stuff, I’d get really annoyed about it” Francis, age 10

“I try to feel grateful for what I can have because there will be others out there who have worse allergies or who have no food.” Hannah, age 9
Support for food allergy management - translating research into practice

• Interventions for food allergy are now being developed:
  – Educational – in clinic and online
  – Online and face-to-face support groups
  – Cognitive Behavioural Therapy
    • Primary care referrals
    • Secondary care referrals (Southampton Hospital; Guy’s and St Thomas)
    • Private route
Support for food allergy management - translating research into practice

• Interventions for food allergy have been shown to improve:
  – Quality of life for parents and children
  – Psychological outcomes such as stress, anxiety, worry and depression
  – Adaptive coping strategies for food allergy management
  – Knowledge about food allergy
  – Rates of allergic reactions
Targeting families for help with food allergy management

Can we identify those who may be at risk of poorer psychological health or less able to cope?

- Parents and children with high levels of stress and anxiety, especially if they often worry about many things in their life
- Parents and children with poor levels of knowledge or misperceptions about food allergy
- Parents and children with negative attitudes towards food allergy
- Parents of children who have experienced a severe anaphylactic reaction
Targeting families for help with food allergy management

Can we identify those who may be at risk of poorer psychological health or less able to cope?

• Not enough worry
• No assessment of risk
• No carriage of AAI
• Lack of understanding
• High risk of accidental reaction

• Good self-efficacy
• Carriage of AAI
• Knowledge and understanding of risk and use of AAI
• Good quality of life

• High stress, anxiety and worry
• Hypervigilance regarding risk
• Lack of understanding
• Poor quality of life
How can we help families to manage well?

Pillars of Food Allergy Management

Prevention

Emergency Preparedness

These must be applied at all times and in all settings
How can we help families to manage well?

- **Parents/patients need accurate information about food allergy and about risk of a serious reaction that they understand**
  - Risk ladders for anaphylaxis deaths related to other rates of death
  - Reliable web resources which use the information standard

- **Parents/patients should have a trainer pen**, and need to regularly re-train at home as they quickly forget

- **Families should be encouraged to talk about the allergy** and how to manage it as often and openly as possible
  - Avoidance increases anxiety
How can we help families to manage well?

- **Parents/patients should be helped to feel normal** – many parents/patients feel worried, anxious, stressed and this is normal; they should ask for help and support if they need it – they should not feel alone
  - A psychologist can listen to their worries and help them find better ways to cope with those worries and manage their allergy

- **Parent/patients should be encouraged to use the support of the Anaphylaxis Campaign and Allergy UK**
  - They have regional support groups and excellent trustworthy information on their websites
Thank you for listening
Any questions?

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