A Psychological Perspective on Food Allergies: Global Burden, Causes, Treatment, Prevention & Public Policy

Audrey DunnGalvin
Why do we need a psychological perspective on the causes, treatment, and prevention of food allergies?
- Food allergy is influenced by biological, psychological and environmental factors

- It can best be understood by considering the interactions of variables that cut across multiple levels

‘.. the whole emerging out of dynamic interactions of its parts’.
In food allergy - threat is ever present but the timing is unpredictable
‘Avoidance is the cornerstone of therapy’

secondary prevention & management:
avoidance of allergens, continual risk assessment
emergency treatment
‘Avoidance is the cornerstone of therapy’

secondary prevention & management:
  avoidance of allergens, continual risk assessment
  emergency treatment
BUT avoidance is not easy…
‘Avoidance is the cornerstone of therapy’

secondary prevention & management:
avoidance of allergens, continual risk assessment
emergency treatment
BUT avoidance is not easy...

...or always successful
Schoolboy, 12, died of severe allergic reaction to curry containing peanuts (April, 2014, N.Yorkshire)

Two Indian takeaway workers arrested after father, 38, dies from severe allergic reaction from curry containing peanuts (April, 2014, N.Yorkshire)

Nut allergy teenager, 15, dies after two bites of Chinese takeaway spare ribs marinated in peanut sauce.

Mother’s agony as teenage girl dies from peanut allergy on city street (December 2013, Dublin)

Curry sauces in restaurants across UK being tested after three deaths linked to peanut allergy. Fears ground peanuts are being used to thicken sauces rather than almond powder (March, 2014)
Schoolboy, 12, died of severe allergic reaction to curry containing peanuts after takeaway staff assured his family it was nut-free. (October, 2013, Manchester)

- 61.8% (12,560) emergencies due to allergic reactions
- 1/5 (4070) were for anaphylactic reactions, an increase of 10% per cent NHS, UK (2014)
- 10,000 hospitalizations annually among patients <18 years of age US CDC 2011-2012
- Initial allergic reactions occurring at earlier ages Green et al., 2007
‘living worried’

Parents, children, teens, families & adults report that their feeling of risk is always present

- Avery, King, Knight, and Hourihane 2003
- Primeau et al. 2000
- Rosa et al., 2004,
- Rashid et al.2005
- Furlong&Sicherer 2006
- Leffler et al., 2007
- Whitaker, et al.,2009
- Grimshaw et al. 2010
- DunnGalvin, et al., 2010
- Flokstra deBlok et al., 2010
- Roma et al. 2010
- Barnett et al., 2011
- Ostblom, et al. 2008
- Hattersler&Ward 2013
- DunnGalvin & Hourihane 2015
‘living worried’

Parents, children, teens, families & adults report that their feeling of risk is always present.

‘I remember his first reaction very clearly... he was just six months old... I have nightmares about it since ....... by the time I got to the hospital, I had my fingers down his throat to try to keep it open.

…I thought I was going to lose him... you never get over that feeling, ever....’

Jacinta, mother of Colm, age 3

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› Primeau et al. 2000
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› Roma et al. 2010
› Barnett et al., 2011
› Ostblom, et al. 2008
› Hattersler & Ward 2013
› DunnGalvin & Hourihane 2015
How do food allergies affect psychological development and quality of life in children, teens & adults?
The developmental process shapes physical and psychological health and health related quality of life over the life course.

‘the boundaries between what is innate and what is acquired become so blurred as to be at the very least uninteresting compared to the powerful questions of developmental process’.

*Thelen and Smith 2008*
Neurobehavioral Development in Children

‘Development’ and ‘Food allergy’ combine to increase stress

- physiological and psychological stressors activate similar neural circuitry... which regulates inflammation
- Inflammation (PIM) influences emotions and cognitions
Neurobehavioral Development in Children

‘Development’ and ‘Food allergy’ combine to increase stress

- Does immune *activation* -together with the *experience* of having FA - influence the responsiveness of the HPA axis?

- Physiological and psychological stressors activate similar neural circuitry... which regulates inflammation

- Inflammation (PIM) influences emotions and cognitions
Search for Normality

Maximisation
Balanced Adaptation
Minimisation

Perceived Benefits and Risks
Self Identity
Self Efficacy
Perceived health related quality of life

Context
Transition Point
Developmental stage

Parent/Peer/Public/Health Professional/Food Producers & Providers
Gender Culture Norms Education

EXPERIENCE /EMOTIONS

Disease identity
Perceived control
Perceived Threat

Living with the Rules
Living with Uncertainty
Living with Difference

COPING /COGNITIONS & BEHAVIOURS

Perceived Barriers and Supports

Perceived health related quality of life
Developmental pathways in food allergy: a new theoretical model. DunnGalvin, Gaffney Hourihane. Allergy, 2009; 64, 560-568

Pathways to anxiety or risk in five countries: The developmental model in food allergy. DunnGalvin Polloni, Le Bovidge, Muraro Greenhawt Taylor Burks Allen Hourihane Tang. submitted
Growing up with food allergy: *Living with the Rules*

‘you can’t really relax at a party because it’s there all the time… people are eating all the time and not just when the cake comes out’

‘you always have to read the label but everything says may contain so what’s the point?’

‘I forget the pen sometimes on purpose because I get angry…and because MUM nags me so much about it’

Growing up with food allergy: *Living with the Rules*

‘I went to a birthday party ...the lady kept saying ‘don’t touch this’, ‘don’t touch that’”

“sometimes they just joke around and they say ‘ohh, there’s nuts in this....it makes me sad...I ask them to stop. ...and sometimes they don’t stop

‘...they were making fun of something that could kill me’

‘he asked me ‘when will I be normal’ and I was shocked, I didn’t realise he felt like that’

Growing up with food allergy: Living with Uncertainty

‘I need to kind of live my life on the risk that something is going to happen or something might never happen.

‘like sometimes you can’t find the cause [of a reaction] …it just happens, you know…not knowing makes you worried and unsure of yourself’

You tell them in a restaurant but sometimes they listen and it’s safe and sometimes you get really really sick....

Challenges in ‘Growing up and Living with food allergy ’ is compounded by a low level of awareness among the general public.

Acts as a barrier to constructive management and promotes a negative sense of food allergy in everyday life.

‘I don’t know what would happen if he got a reaction..’ maybe he would start having breathing problems, like they start gasping or something...it’s a bit of a mystery..food allergy ‘

Calum, age 12, Australia

‘ To be honest, I really don’t want her at the house...what do you do ? Wrap her up in cellophane and put her in the wardrobe !’

Anne, age 32, Ireland
Emma (8 years) presented as an anxious child, very dependent on Mum.

Mum scored Emma very highly on the ‘Food anxiety’ subscale of the FAQLQ-PF (6 out of 7). She was very fearful of the possibility of a reaction and would interpret many social situations (e.g. going to the cinema) as ‘scary’. When she was 5, she had an ice cream that appeared to Mum to be safe but she experienced a moderately severe reaction immediately on eating it. She now asks Mum to check again and again to see if the packaging is ‘safe’.

Mum is also very anxious, and scores highly on the FAIM (i.e. for Emma, chance of an accidental ingestion, severe reaction and death ‘extremely’ likely)

We describe Emma as ‘anxious/avoidant’ and the emotions and behaviours associated with being careful about food are now generalising to all life situations, so that she was fearful of any ‘new’ people and places. Both Mum and Emma cried as they described what it was like to live with food allergy. Neither felt that they were ‘in control’ of the everyday management of allergy.

‘Food Allergy Matters’: Evidence-based efficacy of an intervention developed to moderate the psychological impact of food allergy, using a controlled design. DunnGalvin & Hourihane (submitted).
Living in a constant state of fear of an accidental food reaction can have a major impact on an individual’s quality of life.

Food allergic individuals can experience food fears 24 hours a day, 7 days a week ...

........while on vacations, at parties, using public transportation, at school, at work, at the restaurant, and even at home.

Pathways to anxiety or risk in five countries: The developmental model in food allergy. DunnGalvin Polloni, Le Bovidge, Muraro Greenhawt Taylor Burks Allen Hourihane Tang. submitted

Fear

Living in a constant state of fear of an accidental food reaction can have a major impact on an individual’s quality of life.

Food allergic individuals can experience food fears 24 hours a day, 7 days a week while on vacations, at parties, using public transportation, at school, and even at home.

In the US, 41.8% of the participants are not comfortable going on vacation during which they spend a night away from home.

Koman, E; RaverEAdamsDunn Galvin, A. Quality of Life Impact in living with and managing food allergies (in preparation).

Eating out

- Adults & Parents reported that their feeling of risk and fear was ever-present when eating out.

...you tell them you have an allergy .. And you ask for, you know, “What’s in the sauce – are there any nuts?” Oh, no, no, no, you’re absolutely fine!” and, sure enough, there are [nuts]......I think, with people with severe allergies, you take a bit of a punt any time you go out, for any meal really.

When you go and eat out ...it’s like playing roulette.

The restaurants, hundred percent, even if they say it’s nut free I mean you can’t tell ... If say they shove some cashew nuts in a wok, shove the dish out and then my dish goes in there’s going to be some bits of the cashew nuts still left’

The preferences of those with food allergies and/or intolerances when eating out

DunnGalvin, A (2015) FSA workshop, Surrey, UK
Bullying

- In the US, 35% of children and adults report being bullied
- Of these, 57% report a physical event.
- >20% were “bullied, teased or harassed by a teacher or other school staff”
- In EU and US, children and teens report
  - being threatened with or being chased with an allergen, having their safe food removed or contaminated, and threats to use or break their auto injectors
  - being called “weird,” or ‘wimps’, blamed for not being allowed to have food at parties, and excluded from activities.
- 31% reported the bullying, teasing, or harassment
- 12% reported that the bullying had been punished or disciplined
- 30% tried to hide their food allergies because of past bullying, teasing, or harassment

- Lieberman et al. 2010
- Sicherer, Burks, & Sampson, 1998.
- DunnGalvin The Validation of the Food Allergy Quality of Life Questionnaire-Parent Form (FAQLQ-PF) in an American Sample of Children between 0-12 Years. Submitted.
- Koman, E; RaverEAdams Dunn Galvin, A. Quality of Life Impact in living with and managing food allergies (in preparation).
Peter (12 years) had experienced anaphylaxis twice in the relatively recent past, and Mum was very worried. Peter scored highly (5.2) on the third subscale of the FAQLQ-PF impact of ‘social and dietary restrictions’.

He has been bullied in the past and has internalised the negative reactions of others. Bullying made Peter feel angry, isolated, vulnerable and confused as to why he was targeted.

He thinks wishfully of food he would like to eat and no longer having food allergy. He is very frustrated by the ‘rules’ and compares his life very unfavourably with other children.

He moved school and is now very reluctant to tell any of his classmates that he has food allergy, and will share and accept food from peers so that he is not seen as ‘different’. He is angry at his Mum if she mentions his food allergy in social contexts. He sometimes ‘forgets’ his pen and does not like his parents ‘nagging’ him to remember it.

‘Food Allergy Matters’: Evidence-based efficacy of an intervention developed to moderate the psychological impact of food allergy, using a controlled design. DunnGalvin & Hourihane (submitted).
Tom is 16 years, has peanut allergy and has had one or two ‘scares’ quite recently. He rarely mentions his food allergy in social contexts. ‘I do ask in restaurants about what’s in [the food] but sometimes I let it go so not to make a fuss.. He eats ‘may contain stuff’ and doesn’t usually have a reaction so he is uncertain whether he is now tolerant, although his last FC suggests he is not.

He was ‘fine with it’ when he was younger but now faces an uncomfortable cognitive dissonance (or tension), particularly in social situations.

‘There is this awful moment when you know you need to say or do something to keep yourself safe and you are torn because you don’t want to embarrass yourself or break up the party’

With regard to carrying the autoinjector ‘It’s just the sheer hassle of having to take it, although I know I should, but...I have been fine so far....If I bring it along and I don’t need it (again !), I feel it’s been a complete waste of time and a bit stupid’
A substantial proportion of FA consumers regularly take risks

38% do not have an AI with them during severe reactions

Cochrane et al, UK, 2013 characteristics and buying behaviours of food-allergic consumers in UK

Monks et al (2010) CEA; How do teenagers manage their food allergies

MacKenzie et al (2010) PAI; Teenagers experiences of living with food allergy

Consumer choice and risk reasoning
Confidence in managing food allergy?

DunnGalvin, Hourihane, Greenhawt, et al., Assessment of Self-Efficacy in Food Allergy
## Confidence in managing food allergy?

<table>
<thead>
<tr>
<th></th>
<th>Level of stress</th>
<th>Expectation of outcome</th>
<th>Confidence in managing a reaction</th>
<th>Trust in reliability of labelling</th>
<th>Eat a wide variety of foods</th>
<th>Trust in restaurant s and chefs etc.</th>
<th>Enjoymen t in eating out</th>
<th>Safety in eating out</th>
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<tr>
<td>Adults*</td>
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DunnGalvin, Hourihane, Greenhawt, et al., Assessment of Self-Efficacy in Food Allergy
DunnGalvin et al. Pathways to anxiety or risk in five countries: The developmental model in Food Allergy (submitted).

Living with the Rules
Living with Uncertainty
Living with Difference

Perceived Threat
Perceived control
Perceived Barriers and Supports

Parent/Peer/Public/Health Professional/Food Producers & Providers

Gender Culture Norms Education

Minimisation
Balanced Adaptation
Maximisation

EXPERIENCE /EMOTIONS

Search for Normality

COPING /COGNITIONS & BEHAVIOURS

Beliefs
Self Identity

Self Efficacy

Health related quality of life

Developmental stage
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EXPERIENCE /EMOTIONS

Balanced Adaptation
Maximisation
Minimisation

Disease identity

Perceived Threat
Children, teens and parents need to cope with normal developmental changes

Food challenge as diagnosis vs safe level threshold

Confusion on how much allergen is required to cause a reaction
Confusion on how severe this reaction might be.

Allergic reactions unpredictable

Low level of control/
High level of uncertainty/frustration/fear

Low confidence in coping, decision making, and management

Search for control/certainty

Increased Risk/Anxiety/Reduced Choice/QoL

Children, teens and parents need to cope with constant vigilance & avoidance

Inconsistency in application of PALs and in advice given by HCPs

PALs & information unreliable

Reduced public trust in food safety/information

Deliberate/Accidental Risk:
Discount PALs, define own thresholds, and/or interpret PAL wording as implying a level of risk
Consumer choice & risk reasoning

Why hypersensitive consumers do not read labels

- **Past experience:**
  - If safe to eat in the past, then safe to eat

- **Sensory appreciation:**
  - If it looks, smells, tastes and feels safe, then it is safe to eat

- **Desire for the product**
  - Taste, cost, quality, health, convenience and ethics

- **Labelling not clear, trustworthy, regulated**
  - Desentisation, discounting, cynicism

- **Labelling non-directive**

- **Context**
  - Trust in brands, big companies and supermarkets.
  - The needs of other people for whom they were shopping
  - The presence of other people when shopping
  - Shopping for themselves only

- **Physiological/Psychological**
  - Stress, tiredness, hunger, embarrassment, time constraints, risk orientation, values, personality, age, gender
Feeling informed & in control of risk management

Consumers understand that zero risk is not possible...but they do want more control

‘A safe level to tell friends, you can’t give a life time of knowledge in a hour’

Kate, Age 20, UK.

‘You have to take risks but ... this would be a calculated risk ... which would give you a lot more control’

Mum of Caoimhe & Brian, Ireland

‘The more precise and consistent information you have, the better the decisions you can make’

Isobell, Age 20, Ireland

‘If the threshold at which he reacts could be used in a practical way, then far more helpful than the labelling we have now’

Dad of Jamie, Age 4, UK.

‘I want to be in control of my health and wellness, to manage or improve it through making better choices’

Andy, Age 30, US

‘Life is long. I hope my child lives longer as an adult than a child. If there were a safe min level on shared equipment, it would open up a universe of food for her.’

Helen, Mum of Danni, US

Food Allergy Research and Resource Program (FARRP) 2015 unpublished report
Feeling informed & in control of risk management

Consumers understand that zero risk is not possible...but they do want more control.

“A safe level to tell friends, you can’t give a lifetime of knowledge in an hour”

“You have to take risks but...this would be a calculated risk...which would give you a lot more control”

The more precise and consistent information you have, the better the decisions you can make.

“I want to be in control of my health and wellness, to manage or improve it through making better choices.”

Aligning precautionary statements with level of risk would enhance patients’ management of food allergy by allowing them to make informed decisions & choices.

“Life is long. I hope my child lives longer as an adult than a child. If there were a safe min level on shared equipment, it would open up a universe of food for her.”

Food Allergy Research and Resource Program (FARRP) 2015 unpublished report
Common themes from key stakeholder groups

Labelling

- must reflect actual risk
- absence should imply a clear level of safety
- should be governed by legislation and be consistent and meaningful.
- should be based on agreed reference doses, derived from the distribution of individual allergen threshold doses in the allergic population.
- must be transparent in reasoning, workings, and rules on decision making.

Precautionary (‘may contain’) allergen labelling: perspectives from key stakeholder groups (EAACI)
Recommendations
In policy

- Criteria should be established for the FA definition, diagnosis and stratification
- Models of shared care (primary/specialist) integrated across organisational boundaries
- Agreed management plan for each patient with active patient participation
- A monitoring and evaluation framework for programmes.
- Raise awareness among public – ‘keeping it real’ as part of overall school policy on health and well being for all students
- Management programmes should recognise the nature of the interdisciplinary work concerned and comprise the total developmental course of FA
In research

- Determine the proportion of the general population at risk to each food allergen.

- Determine the reference doses that are reliably associated with severe reactions for different allergens and different types of food hypersensitivity.

- Develop educational approaches that provide patients with the ability to undertake an individualised risk assessment and a management plan that works for them.

- Examine the interaction of genetic, psychosocial and environmental risk factors in causal/predictive models.

- OIT trials - recruit larger numbers of participants, from diverse geographic, socioeconomic, and racial/ethnic backgrounds.

- Investigate how consumers incorporate competing values & how these influence decision making, choice, trust, and quality of life.

- Develop Models and techniques for translating consumer information/attitudes into product specifications (e.g. labelling).
Routine oral food challenge improves Health Related Quality of Life


Good communication and clinical support improves Quality of life and confidence in decision making and management


Learning to cope constructively with food allergy improves perception of control and quality of life

‘Food Allergy Matters’: Evidence-based efficacy of an intervention developed to moderate the psychological impact of food allergy, using a controlled design. DunnGalvin & Hourihane (submitted).

Translating science into meaningful strategies for consumers, clinicians and industry. DunnGalvin, Baumert, Taylor, (in preparation)
Thank you!

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