# Prevalence, perception, experience...

Clarke, Elliott & Team

## How is food allergy experienced?

#### Illustrating Risk: Anaphylaxis Through the Eyes of the Food-Allergic Child

Nancy Elizabeth Fenton<sup>†,\*</sup>, Susan J. Elliott<sup>‡</sup>, Lisa Cicutto<sup>§</sup>, Ann E. Clarke<sup>¶</sup>, Laurie Harada<sup>∥</sup> and Elizabeth McPhee<sup>††</sup>

Article first published online: 15 SEP 2010

DOI: 10.1111/j.1539-6924.2010.01488.x

© 2010 Society for Risk Analysis



**Risk Analysis** 

Volume 31, Issue 1, pages 171–183, January 2011

## How is food allergy experienced?

- \*Children at risk
- \*School environments
- \*Interrupted social spaces
- \* Emotional disruption

# What is it like to live with a severe food allergy?



## Stigma, social isolation



## Disclosing food allergy status in schools: health-related stigma among school children in Ontario

Jennifer Dean MA PhD<sup>1,\*</sup>, Nancy E. Fenton MEd PhD<sup>2</sup>, Sara Shannon Anaphylaxis Advocate<sup>3</sup>, Susan J. Elliott MA PhD<sup>1</sup> and Ann Clarke MSc MD<sup>4</sup>

Article first published online: 4 MAY 2015

DOI: 10.1111/hsc.12244

© 2015 John Wiley & Sons Ltd

Issue



Health & Social Care in the Community

Early View (Online Version of Record published before inclusion in an issue)

Table 1: Demographic characteristics of SCAAALAR, SPAACE, and Canadian population

	SCAAALAR	SPAACE	Canada*	
	(n=9,667)	(n=15,022)	(n=31,612,897)	
Immigrant status				
Immigrated <10 yrs	1.9%	11.8%	7.2%	
Immigrated ≥10 yrs	12.5%	19.1%	12.6%	
Canadian-born	85.6%	69.1%	80.2%	
Household income				
< LICO	8.9%	22.8%	15.7%	
≥ LICO	91.1%	77.2%	84.3%	
Education				
<post-secondary degree<="" td=""><td>39.5%</td><td>50.5%</td><td>49.4%</td></post-secondary>	39.5%	50.5%	49.4%	
≥Post-secondary degree	60.5%	49.5%	50.6%	
Aboriginal status				
Aboriginal person	Data not collected	15.1%	3.8%	
Non-aboriginal person	Data not collected	84.9%	96.2%	
Area of residence				
Provinces	100%	66.2%	99.7%	
Territories	0%	33.8%	0.3%	

<sup>\*</sup>Data from 2006 Canadian Census

Table 2: Prevalence of allergy to any food in SPAACE			
	Prevalence	95%-CI	
Overall	7.49%	(6.88,8.10)	
Immigrant status			
Immigrated <10 yrs	3.22%	(2.18,4.26)	
Immigrated ≥10 yrs	5.45%	(4.47,6.44)	
Canadian-born	8.23%	(7.42,9.05)	
Household income			
< LICO	7.16%	(5.74,8.57)	
≥ LICO	7.76%	(6.85,8.67)	
Education			
<post-secondary degree<="" td=""><td>6.33%</td><td>(5.45,7.21)</td></post-secondary>	6.33%	(5.45,7.21)	
≥Post-secondary degree	8.70%	(7.55,9.84)	
Aboriginal status			
Aboriginal person	8.49%	(5.33,11.64)	
Non-aboriginal person	7.42%	(6.74,8.10)	
Area of residence			
Provinces	7.48%	(6.81,8.14)	
Territories	5.31%	(4.52,6.09)	

Prepared by Lianne Soller

#### "THEY THOUGHT I WAS JUST JOKING": EXPERIENCES AND PERCEPTIONS OF FOOD ALLERGY IN NEW CANADIANS FROM ASIA

AllerGen 2013 Scientific Meeting Stephanie Lu MSc, Applied Health Sciences University of Waterloo

## What about our new Canadians?

Journal of Allergy Volume 2014 (2014), Article ID 964504, 7 pages http://dx.doi.org/10.1155/2014/964504

#### Research Article

## Exploring Perceptions and Experiences of Food Allergy among New Canadians from Asia

Stephanie K. Lu, 1 Susan J. Elliott, 1 and Ann E. Clarke 2

<sup>1</sup>School of Public Health and Health Systems, University of Waterloo, 200 University Avenue West, Waterloo, ON, Canada N2L 3G1 <sup>2</sup>Department of Medicine, University of Calgary, Calgary, AB, Canada T2N 1N4

## Methods

- Qualitative interviews with key informants (n=3) and allergic individuals (n=18) in Waterloo Region
- Interviews tape recorded and transcribed verbatim for subsequent thematic analysis in *NVivo 9*
- Inter- and intra-rater reliability tests to establish rigour
- Policy documents and web pages also searched for food allergy content specific to new Canadians

## Results

- \* No resources on food allergies have been specifically created for new Canadians
- \* Although food allergies are not a primary health concern for immigrants, they are often surprised or skeptical of its severity
- \* Allergic participants perceive the prevalence of food allergies to be higher in Canada than in Asia, citing differences in diet (more processed foods in Canada), environment (less pollution in Canada), and education

## Results, cont'd

- \* Food labelling, school policies, and social acceptability of having a food allergy in Canada has lessened its impact on quality of life in new Canadians
- \* Food allergies are not a part of the everyday language in Asia; participants were unfamiliar with differences between intolerance, allergy, and anaphylaxis
- \* Key informants believe that the public's unfamiliarity with food allergies is still breeding misconception
- \* Efforts to improve health literacy amongst new Canadians is a necessary step to increasing awareness

## One step further.... Intervention Science

"We don't have such a thing, that you may be allergic": Newcomers' understandings of food allergies in

Canada

Daniel W Harringtor

Jennifer Dean2

Kathi Wilson3

Zafar Qamar3



- \* Dan Harrington, PHIRNET PDF, U of T (now Lead Epidemiologist for Public Health Ontario)
- Focus groups with directly and indirectly affected newcomers in Mississauga
  - In collaboration with community partners
- \* Pilot a dual-component intervention for (1) increasing knowledge/awareness about food allergies in Canada, and (2) assist with allergen-safe food purchasing

## Research Protocol

#### Phase 1 Focus Group goals

- Establish baseline perceptions and examine strategies for allergen-safe food purchasing
- 2. Pilot the intervention: Informational presentation with handouts; resource cards designed to assist with reading and interpreting labels and precautionary statements

Reconvene ~ 30 days later

#### Phase 2 Focus Group goals

- 1. Explore expressed changes in perceptions and/or food purchasing practices
- 2. Allow participants to evaluate the strengths and weaknesses of the intervention

## RESULTS

\* "Results indicate unique challenges and understandings of food allergies as a new and unfamiliar risk for most newcomers, particularly as the indirectly affected participants negotiate the policy landscape. The directly affected group highlights the supportive environment in Canada resulting from the same policies and increased awareness in the general population"

## What about our Aboriginal Peoples?

- \* SPAACE to SPAACE data...
- \* Aboriginal Peoples Survey

## Using the Aboriginal Peoples Survey

## Diagnosis and treatment of food allergies in off-reserve Aboriginal children in Canada

Daniel W. Harrington<sup>1,\*</sup>, Kathi Wilson<sup>1</sup>, Susan J. Elliott<sup>2</sup> and Ann E. Clarke<sup>3</sup>

Article first published online: 30 SEP 2013

DOI: 10.1111/j.1541-0064.2013.12032.x

© 2013 Canadian Association of Geographers / L' Association canadienne des géographes Issue



The Canadian Geographer /
Le Géographe canadien

Volume 57, Issue 4, pages 431–440, Winter / hiver 2013

## Findings...

\* "Estimates of prevalence (2.9%) appear lower than the general population in Canada. Controlling for demographic and socioeconomic factors, co-morbidity of asthma and access to family physicians and specialists (e.g., allergists) most strongly predicted both prevalence and treatment. Lower prevalence rates suggest either truly lower rates or lower rates of detection in this population. Access to treatment appears most significant for diagnosis and treatment for this population, raising important directions for future research addressing disparities in the management of food allergies among Aboriginal children"

Journal of Allergy Volume 2014 (2014), Article ID 160363, 7 pages http://dx.doi.org/10.1155/2014/160363

#### Research Article

#### Exploring Low-Income Families' Financial Barriers to Food Allergy Management and Treatment

Leia M. Minaker, <sup>1</sup> Susan J. Elliott, <sup>2</sup> and Ann Clarke <sup>3</sup>

Critical Public Health





Low income, high risk: the overlapping stigmas of food allergy and poverty

# Low income families: experiences, management, coping

- Leia Minaker, PDF, Applied Health Sciences, University of Waterloo (now a senior scientist with PROPEL)
- \* In-depth, semi-structured interviews with 23 participants
  - \* 13 low-income individuals
  - \* 10 key informants
- \* Interviews were transcribed verbatim for subsequent thematic analysis

## Preliminary findings

#### \* Direct costs:

- health care costs, costs of procuring safe and healthy foods, costs incurred because of misinformation
- \* Indirect costs:
  - \* inconsistent family doctor
- \* Intangible costs:
  - stress related to the difficulty of obtaining safe foods at the food bank, feeling unsafe at discount supermarket

"And so it is like sometimes it is like wasting money I know but I think as an adult now I will take much better

"... for folks who are dependent on urgent

"I find people on low income they are kind of forced to shop at certain stores. They don't have a choice, like [discount supermarket]... It is cheap. You can get the most food for your money. They are the ones that are most laziest about their food

## Especially "at risk" populations

- \* Working poor
- \* Newcomers
- \* Food bank users
- \* Youth living in poverty

I think it is embarrassment for a lot of the kids. 'I don't want to ask for food from you, because I don't want you to know I am hungry, like that I have no money, and that my parents have kicked me out.' A lot of them don't know a nice way of saying, just tell me what is in this, you know, so they don't. because they are just too expensive.

## Why is all this relevant?

- \* Food allergies are experienced differently in different contexts; there is NOT just ONE public
- \* Impacts on the design and implementation of the quantitative data collection tool