

Perception of food allergy symptom severity differs across stakeholders

To the Editor,

Living with food allergy requires vigilance as patients and family members need to avoid allergenic food. However, mistakes can and do occur. To ensure patients and family members respond appropriately, medical professionals recognize the importance of classifying symptom severity as "mild, moderate, or severe."^{1,2} However, when confronted with an adverse allergic reaction its application is mixed and this can lead to delays in the administration of adrenaline.^{1,3,4} With international studies showing up to 60% of food allergy patients experiencing repeat adverse food-induced reactions in schools, restaurants, and at home, there is not only the need to recognize symptom severity,^{5,6} but also improve health literacy so those who live with food allergy are empowered to make informed decisions.^{7,8}

This study, conducted from 2015 to 2017 over three phases, explored how four different stakeholders: Teenagers living with food allergy, parents of children with food allergy, general public, and allergy specialists classified food allergy symptoms. Phase 1 (2015-16) of the study engaged teenagers and parents of children living with food allergy. To maximize participation, recruitment was Australia-wide, with advertisements mailed to over 700 randomly selected pre-schools as well as writing to 44 allergy specialists and the Australian patient support group, Allergy & Anaphylaxis Australia requesting promotion of the online survey.

Participation rates were calculated based on how many logged on compared with those who completed the online survey. For the teenager cohort, this was 72.5% ($n = 37/51$) with 41 commencing the survey and 37 completing it. For parents, the completion rate was 79.5% ($n = 318/400$), with 357 parents eligible for inclusion in the study, as they proceeded past the first question and resided in Australia (318/400). Demographic data are presented in Table 1. We also asked parents whether they lived in a capital city as regional participants may lack access to specialized medical services and this could influence health-literacy levels.

In 2017, Phase 2 involved contacting (phone/email) 15 Sydney-based allergy specialists and requesting their assistance in completing a short online survey (100% response rate). All had more than 10 years of clinical experience and were in either private practice or hospital funded allergy clinics (most with a mix of private and hospital practice). To facilitate the transfer of knowledge and improve health literacy of patients specialists can access the Australasian

Society of Clinical Immunology and Allergy (ASCI) e-training platform and print out the Australian Anaphylaxis Action Plan,⁹ a document outlining what parents and those with food allergy need to look for when confronted with an allergic reaction. This not only lessens the probability of conflicting advice, but also serves as a reference guide for the food allergy community and those responsible for providing care.

Phase 3 (2017) involved recruiting members of the public to gauge community perception and awareness. To ensure consistency, one researcher approached 150 members of the public and asked them whether they would be willing to complete a 5-minute survey on food allergy. Fifty-five agreed to participate (36.6% response rate) over three Sydney suburbs—Bondi Junction ($n = 15$), North Sydney ($n = 20$), and Parramatta ($n = 20$). These suburbs were chosen as they are major transport hubs, close to major shopping centers, have different socioeconomic and ethnic demographics and have a high thoroughfare of pedestrian traffic. Interviewee details are presented in Table 1.

Results from our study show allergy specialists were unanimous in the symptom classification of "hives" [mild] and "difficulty talking and swelling in the throat" [severe]. However, differences emerged for the multi-presentation of "hives, cough, and stomach cramps" as 64% ($n = 11$) classified this as severe and 36% ($n = 4$) chose moderate. For "cough/ wheeze," all but one identified this symptom as severe. Data were analyzed using a chi-square test. Highlighting discrepancies among allergy specialists shows symptom classification is not universal and can result in controversy. However, the literature implores agreement when managing patients, as failure to appreciate severity can lead to diagnostic delays.^{1,2,7,8,10} This was a key finding in the study by Vetander and colleagues.¹ In that study conducted in Sweden, they found allergy symptoms were misclassified by hospital emergency personnel as there was no universal understanding and this led to delays in administering adrenaline when patients presented to hospital with food allergy reactions.¹

While allergy specialists were in agreement for the symptom of "hives," this was not replicated across the food allergy community or members of the public as 65 (20%) parents ($\chi^2(2) = 1851.04$, $P < .001$), four (11%) teenagers ($\chi^2(2) = 213.03$, $P < .001$), and 13 (24%) members of the public ($\chi^2(2) = 567.37$, $P < .001$) thought this reaction was severe. Of the 65 parents who thought "hives" a severe allergic reaction, 14.3% ($n = 29/203$) were from capital cities and 24.6% ($n = 35/142$) from regional locations. No biographic data were available for one non-responder who declined to answer beyond the classification

TABLE 1 Characteristics of participants

Teenagers					
Participation rate		Allergies ^a			N = 41
Logged on	51	Peanut			30 (73.2%)
Started survey	41 (80.4%)	Tree nuts			24 (58.5%)
Completed survey	37 (72.5%)	Egg			9 (22.0%)
		Cow's milk			9 (22.0%)
Characteristics	N = 41	Multiple food allergies			
Male	17 (41.5%)	Peanut and tree nuts			20 (48.8%)
Female	20 (48.8%)	Peanut, tree nuts, and egg			5 (12.2%)
Unknown	4 (9.7%)	Egg and cow's milk			5 (12.2%)
Parents					
Participation Rate		Allergies ^a			N = 357
Logged on	400	Peanut			251 (70.3%)
Started survey	374 (93.5%)	Tree nuts			212 (59.4%)
Eligible for analysis	357 (89.3%)	Egg			166 (46.5%)
Completed survey	318 (79.5%)	Cow's milk			138 (38.7%)
Characteristics	N = 318	Multiple food allergies			
Male child	194 (61.0%)	Peanut and tree nuts			163 (45.7%)
Female child	123 (38.7%)	Peanut, tree nuts, and egg			91 (25.5%)
Unknown	1 (0.3%)	Egg and cow's milk			108 (30.3%)
Child's age		Location			
Under 8 y	177 (55.7%)	Capital city			203 (56.8%)
8-12 y	87 (27.4%)	Regional			142
Teenagers	51 (16.0%)	Unknown			12
Unknown	3 (0.9%)				
General public					
Characteristics	N = 55	Age group			
Male	29 (52.7%)	Under 20	20-29	30-39	40 y +
Female	26	11	25	7	12
Know someone with food allergy					
Yes	28 (51%)				
No	26				

^aAs multi-dichotomy responses permitted for the allergy question, percentages are not cumulative or add to 100%. Numbers based on eligibility.

questions. While distribution between capital cities and regional locations averaged 10% for "difficulty talking and swelling in the throat," this was more problematic as 34 (11%) parents, 19 from capital cities, and four (7%) members of the public reported this as a mild reaction.

Although significant disparity was found between the food allergy community and the general public compared with allergy specialists, Figure 1 shows teenagers performed better than parents in three of the four symptoms. This is also reflected in the data presented in Table 2 comparing significance, measured as $\alpha = 0.05$ to

allergy specialists. This awareness may be due to personal experience and/or parental influence. To test the hypothesis that symptom classification is the same among family members (teenagers and their parents), we were able to match 30 IP addresses and compare responses across all four symptoms. To determine whether correlation existed, we then conducted a Mann-Whitney *U* test and found all *P*-values above the significant threshold of .05: "difficulty talking and swelling in throat" ($P = .720$, Mann-Whitney test), "hives" ($P = .769$, Mann-Whitney test), "hives, stomach cramps, cough, and

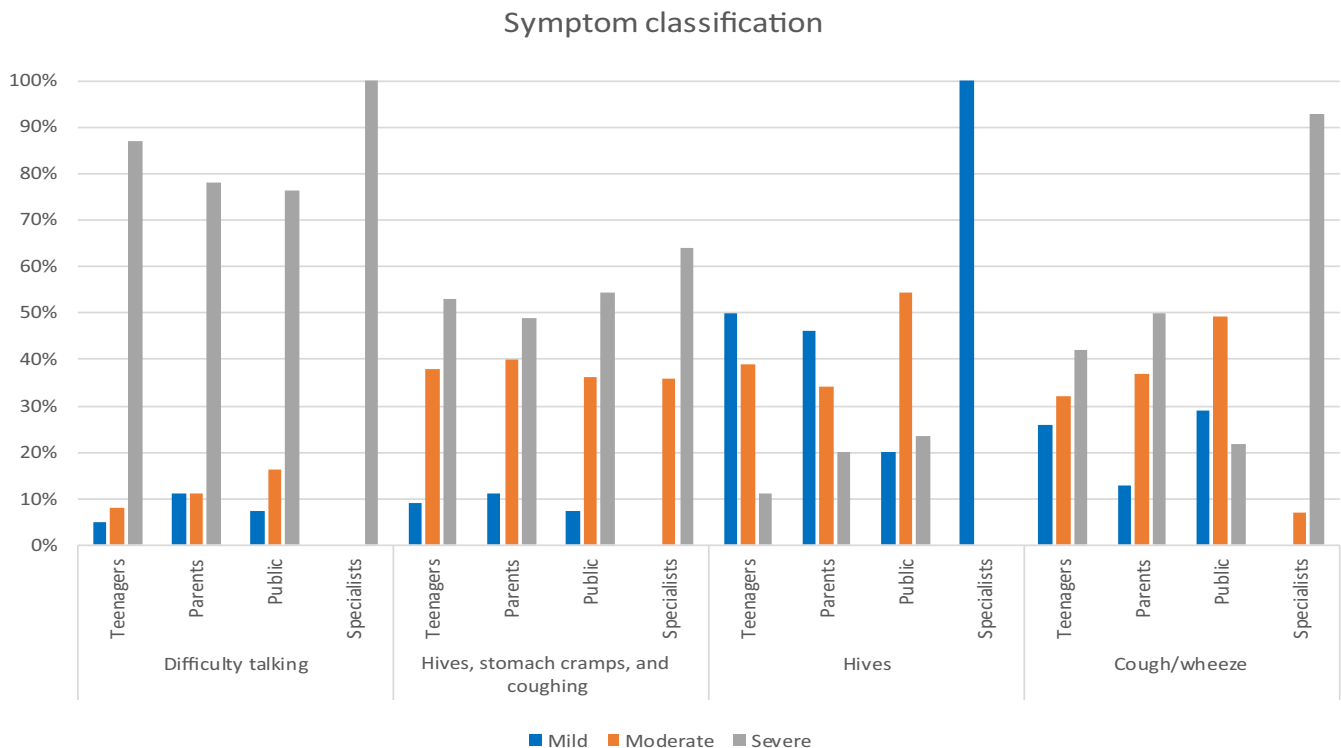


FIGURE 1 Classification of common food allergy symptoms across participant groups

hives" ($P = .470$, Mann-Whitney test), and "cough/wheeze" ($P = .541$, Mann-Whitney test). These results show there was no significant difference in the responses by members of the same family.

However, with disparity in identifying symptom severity there is always the risk that the food allergy community and members of the public delay using an adrenaline auto-injector and/or seeking medical help.^{3,4} This quandary is reflected in the following quote by one of the participants:

Hard to tell how severe the symptoms are as subtle/internal rather than overt. Do not necessarily exactly fit the Action Plan.

[Parent, regional location]

Although this uncertainty is not an isolated quote, it resonates in the literature.^{3,4,10} In a prospective study by Song and colleagues, they found 54.4% of patients (children and teenagers) from 14 UK allergic clinics failed to use an adrenaline auto-injector when confronted with a food-related allergic reaction.¹⁰ The common theme was that they "thought it was unnecessary."¹⁰ However, consequences for misjudging severity can be catastrophic. In a retrospective Australian study of reported fatalities between 1997 and 2013 where the cause of death was attributed to food allergy, 30% ($n = 7/22$) had been prescribed an adrenaline auto-injector and they may have underappreciated severity.¹¹

Failure to appreciate symptom severity is not only the realm of the food allergy community, as awareness of what constitutes a mild, moderate, or severe allergic reaction is also problematic in

the community—refer Figure 1. This is even for the 28 (50.9%) interviewees who reported knowing someone with food allergy. Further concerns exist as those aged under 20 years were less likely to recognize severity for the symptom "difficulty talking and swelling in throat" ($H(3) = 8.96$, $P = .03$) when compared to the other three age groups (20–29 years; 30–39 years; and 40 years plus). These results highlight not only the urgency for a simplified allergy symptom classification scheme but also the need for community education and awareness.¹²

In offering valuable insights into how different stakeholders classify allergy-related symptoms including the general public, there are of course limitations to our study. For those living with food allergy (teenagers and parents), there were two main limitations associated with the online platform. Firstly, we are unable to determine response rates and motivations of who responded and who the non-responders were and secondly the inability to clinically support the allergy status (eg, IgE levels) of participants. However, with 82.9% ($n = 34/41$) teenagers possessing an adrenaline auto-injector and 89.4% ($n = 319/357$) of parents reporting food allergy diagnosis through GPs, allergy specialists, or hospital staff, this may serve as a proxy measure of allergy status. For questions on symptom severity, another limitation was participants not having the option to answer "don't know" for some questions and this may have led to some guessing the "right" answer or leaving the question blank. Also as the survey was in English this may have discouraged participants from non-English-speaking backgrounds from logging on and completing the survey. To minimize possible exclusion in future studies, it would be useful to consider strategies to increase participants from

TABLE 2 Distribution and classification of symptoms by parents/teenagers (observed) and allergy specialists (specialist)

Symptoms	Parent/Teenager Public	Mild	Moderate	Severe	Total	Chi-square χ^2	P Value (2-tailed)
Difficulty talking/swelling in throat	Parent						
	Observed	34 (11%)	34 (11%)	233 (78%)			
	Specialist	5 (2%)	10 (3%)	286 (95%)	301	172.93	<.001
	Teenager						
	Observed	2 (5%)	3 (8%)	33 (87%)			
	Specialist	1 (2%)	1 (2.5%)	36 (95%)	38	5.25 ^a	.0724
	Public						
Cough/wheeze	Observed	4 (7%)	9 (16%)	42 (77%)			
	Specialist	1 (2%)	2 (3%)	52 (95%)	55	35.42 ^a	<.001
	Parent						
	Observed	41 (13%)	115 (37%)	156 (50%)			
	Specialist	5 (2%)	26 (8%)	281 (90%)	312	760.57	<.001
	Teenager						
	Observed	10 (26%)	12 (32%)	16 (42%)			
Hives, stomach cramps, and cough	Specialist	1 (2%)	3 (8%)	34 (90%)	38	117.53 ^a	<.001
	Public						
	Observed	16 (29%)	27 (49%)	12 (22%)			
	Specialist	1 (2%)	4 (8%)	50 (90%)	55	386.13 ^a	<.001
	Parent						
	Observed	34 (11%)	122 (40%)	149 (49%)			
	Specialist	5 (2%)	105 (34%)	195 (64%)	305	192.18	<.001
Hives ^b	Teenager						
	Observed	3 (9%)	13 (38%)	18 (53%)			
	Specialist	1 (2%)	12 (34%)	21 (64%)	34	4.51 ^a	.1049
	Public						
	Observed	4 (7%)	20 (37%)	30 (56%)			
	Specialist	1 (2%)	18 (34%)	35 (64%)	54	9.94 ^a	.0069
	Parent						
Hives ^b	Observed	150 (46%)	111 (34%)	65 (20%)			
	Specialist	310 (95%)	10 (3%)	6 (2%)	326	1851.04	<.001
	Teenager						
	Observed	19 (50%)	15 (39%)	4 (11%)			
	Specialist	36 (95%)	1 (2.5%)	1 (2.5%)	38	213.03 ^a	<.001
	Public						
	Observed	11 (20%)	30 (56%)	13 (24%)			
	Specialist	51 (95%)	2 (3%)	1 (2%)	54	567.37 ^a	<.001

^aFor the teenager and public chi-square results, there were two cells (66.67%) with expected ues less than 5.

^bAllergy specialists correctly identified symptom classification (100%). To measure statistical significance, the expected number assigned equates to 95% with an error of 5% distributed accordingly as 3% and 2%, respectively.

non-English-speaking backgrounds. Finally, for those interviewed there is the risk of interviewer and interviewee bias, including who was approached and why some agreed to the interview while others declined.

In conclusion, symptom classification is not only complicated, but also subjective and reliant on knowledge/health literacy. With results showing patients and family members assign their own

subjective rating, there is an urgent need for medical practitioners to clarify, reinforce, and regularly check the understanding of allergy symptom severity, as patient understanding cannot be assumed. Furthermore, with significant differences identified, our study also highlights the need to improve education across all stakeholders.^{5-7,12} Finally, what our study also shows is the need for community education, as members of the public may be the

first responders, particularly as global prevalence of food allergy diagnoses continues to increase.¹³

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CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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AUTHOR CONTRIBUTIONS

DS developed the idea of the study in consultation with CHK, MDS, and TV, and DS and CHK developed the study design and questions. DS, facilitated by CHK, was responsible for notification and awareness of survey via the medical fraternity, childcare providers, the food allergy community, and the patient organization, Australia Allergy & Anaphylaxis. DS performed the research and analysis and drafted the manuscript. DS together with CHK, MDS, and TV critically reviewed the draft manuscript. All gave approval of the submitted version of this manuscript.

ETHICAL APPROVAL

This research was approved by the Human Research Ethics Committee (Charles Sturt University, Australia). Approval Number is H2015004.

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