The Royal Society of Medicine

Journal of the Royal Society of Medicine Open;
6(7) 1–6
DOI: 10.1177/2054270415593443

Anaphylaxis in the community: a questionnaire survey of members of the UK Anaphylaxis Campaign

Aadam Sheikh[1], Sangeeta Dhami[2], Lynne Regent[3], Moira Austin[3] and Aziz Sheikh[4]
[1]University College London, London WC1E 6BT, UK
[2]Edinburgh EH17 8UD, UK
[3]Anaphylaxis Campaign, Farnborough GU14 6BU, UK
[4]Professor of Primary Care Research & Development, Allergy & Respiratory Research Group, Centre for Population Health Sciences, The University of Edinburgh, Edinburgh EH8 9AG, UK
Corresponding author: Aziz Sheikh. Email: aziz.sheikh@ed.ac.uk

Summary

Objectives: To examine the circumstances, features and management of anaphylaxis in children and adults.
Design: Self-completed questionnaire.
Participants: The age of participants ranged from 0 to 72 years.
Setting: We analysed data from self-completed questionnaires collected over a 12-year period, i.e. 2001–2013, available to people by phone and, since 2012, for online completion through the Anaphylaxis Campaign.
Main outcome measure: We analysed data from self-completed questionnaires collected over a 12- year period, i.e. 2001-2013, available to people by phone and, since 2012, for online completion through the Anaphylaxis Campaign
Results: In total, 356 questionnaires were submitted, of which 54 did not meet the criteria for anaphylaxis. The remaining 302 anaphylactic reactions originated from 243 individuals; 193 (64%) of these reactions were in children. Approximately half of all reactions occurred at home ($n = 148$; 49%); 61% ($n = 193$) of reactions occurred in those reporting a history of asthma, and many ($n = 76$; 41%) of these individuals had asthma that they classified as being severe. In 57% ($n = 173$) cases, the respondent reacted to a known allergen. Self-injectable adrenaline (epinephrine) was available in 79% of the cases, and it was only used in 38% of episodes. The usage of self-injected adrenaline was lower in children (30%) than in adults (54%), even though 82% of children had adrenaline available at the time of the reaction compared to 74% of adults.
Conclusions: These data suggest that the majority of anaphylaxis reactions are triggered by exposure to known food allergens and that approximately half of these reactions occur at home. Access to self-injectable adrenaline was sub-optimal and when available it was only used in a minority of cases. Avoiding triggers, access to self-injectable adrenaline and its prompt use in the context of reactions need to be reinforced.

Keywords

anaphylaxis, allergy, asthma, adrenaline, food allergens, prevention, self-management

Introduction

There have been substantial increases in the numbers of hospital admissions from anaphylaxis noted in the UK over recent decades,[1–3] thus reflecting a probable increase in lifetime risk.[4] Similar increases have been noted in other parts of the world.[5,6] Many of these reactions occur in those with known allergies and thus reflect failures in prevention and/or appropriate emergency when reactions occur.[7] It is now recognised that these reactions commonly occur in community settings.[8] In order to inform deliberations on how best to minimise the risk of anaphylaxis and optimise the self-management of reactions, it is therefore important to understand patient perspectives and experiences of such reactions.[9] We sought to obtain such insights through analysis of a unique dataset compiled by the Anaphylaxis Campaign, a UK-wide patient charity that provides advice and support to patients/carers experiencing anaphylaxis and their healthcare professionals.

This work builds on a previous report by Uguz et al.,[10] which reported an analysis of 109 individuals who reported on 126 reactions up until April 2001. The previous study concluded that the presence of asthma in children led to particularly severe reactions and that self-injectable adrenaline (epinephrine) was under-used, even when readily available. In the present study, we analysed data collected by the Anaphylaxis Campaign over the following 12-year period, i.e. 2001–2013.

Methods

Ethical considerations

The study was processed and approved by the University of Edinburgh's ethical committee. The Medical Advisory Committee of the Anaphylaxis Campaign had previously approved the format of the final version of the questionnaire used in this study.

© 2015 The Author(s)

Creative Commons CC-BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 3.0 License (http://www.creativecommons.org/licenses/by-nc/3.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access page (http://www.uk.sagepub.com/aboutus/openaccess.htm).

Downloaded from shm.sagepub.com at Queen's Univ Belfast on 30 June 2015

Recruitment and data collection

We used the same self-completed questionnaire that was used in the earlier survey.[10] These self-completed questionnaires were collected over the period May 2001–September 2013.

Individuals calling the Anaphylaxis Campaign's Helpline were made aware of the survey, and a copy was sent by post for carer/self-completion to those expressing an interest in participating. From 2012 onwards, it was also made available for online completion through the Anaphylaxis Campaign's website (www.anaphylaxis.org.uk/).

The questionnaire comprised 41 questions, of which approximately half were multiple choice in nature (see Appendix 1). These questions enquired about demographic information and relevant health and medical considerations such as the presence of known allergies. Participants were also asked to provide a description of the reaction that they were reporting; this description included details of the suspected allergen, the symptoms experienced, available treatments, treatments used and whether the reaction resulted in a hospital attendance.

Data processing and analysis

We first sought to determine if the reaction that was described was likely to have been anaphylaxis. This assessment was made by establishing whether there was evidence of a systemic allergic reaction in which respiratory and/or cardiovascular symptoms were also present.[11] Those responses that were judged unlikely to represent anaphylaxis were not interrogated any further.

Data from probable reports of anaphylaxis were entered into and analysed using Microsoft Excel. For the purposes of this study, children were defined as those aged 0–16 years and adults were defined as those aged 17 years and over. Co-existent asthma was categorised as being severe if it was reported as causing waking at night; it was otherwise classified as mild-to-moderate.

Data were summarised using counts and percentages with accompanying 95% confidence intervals (CIs), where appropriate.

Results

In total, 356 questionnaires were submitted to the Anaphylaxis Campaign; 54 of these reports were excluded as they were judged unlikely to be reports of anaphylaxis. The following sections relate to the 302 reports that were judged to describe anaphylaxis. These 302 reports came from 243 unique individuals. Of these, 228 individuals provided a single report; the remaining 15 individuals provided a total of 74 reports with these individuals submitting between 2 and 25 incident reports.

Demographic characteristics of respondents

The age of those experiencing reactions ranged from 0 to 72 years with a mean age of 19.1 years (SD 16.6). Sixty-four percent ($n = 193$; 95% CI 0.58–0.69) of responses related to children; the remaining 36% of reports ($n = 109$; 95% CI 0.31–0.42) were in adults (i.e. aged 16–72 years).

Of the 243 *unique respondents*, 58% ($n = 140$) were female and of these 42% ($n = 59$) occurred in girls. Of the 103 (42%) unique male respondents, 80% ($n = 82$) of reactions occurred in boys.

In total, 53% ($n = 160$) of the *reactions* were reported by females; there were comparatively fewer reports of reactions in girls ($n = 72$; 37%) than boys ($n = 121$; 63%), but this pattern reversed in adults with women reporting a greater proportion of reactions ($n = 88$; 81%) than men ($n = 21$; 19%).

Presence of coexistent asthma

Sixty-one percent ($n = 185$; 95% CI 0.56–0.67) of all reports involved people with co-existent asthma; in 41% of these reports ($n = 76$; 95% CI 0.34–0.49), the asthma was categorised as being severe.

Setting of reaction and triggers

Forty-nine percent ($n = 148$) of reactions occurred whilst at home. Similar proportions of children and adults experienced reactions whilst at home (children: 53%, $n = 103$; 95% CI 0.46–0.61; adults: 41%, $n = 45$; 95% CI 0.32–0.51).

Of the 90 children's reactions that occurred outside of the home environment, 26% ($n = 23$; 95% CI 0.17–0.36) occurred whilst at nursery or school. A further 18% of reactions ($n = 16$; 95% CI 0.11–0.27) occurred whilst eating out at a café or restaurant and four reactions (4%; 95% CI 0.01–0.11) occurred in hospital.

Sixty-four reactions in adults occurred outside of their homes; 31% ($n = 20$; 95% CI 0.20–0.44) occurred in a café or restaurant; 13% ($n = 8$; 95% CI 0.06–0.23) occurred whilst at work and 6% ($n = 4$; 95% CI 0.02–0.15) occurred whilst in hospital.

Fifty-seven percent (173; 95% CI 0.51–0.63) of reactions were triggered by exposure to a known allergen. The most common known allergen was tree nuts, which accounted for 39% ($n = 67$) of these reactions to known triggers. Peanuts accounted for 29% ($n = 51$) of these reactions, milk/dairy

Downloaded from shr.sagepub.com at Pareto Lib/Opt1A121 on July 30, 2015

products for 11% ($n = 19$) and egg for 9% ($n = 16$). Non-food triggers described included inhalant allergens (grass, dust, cat, dog and horse), stinging insects (wasp and mosquito), drugs (antibiotics, aspirin, paracetamol and anaesthetics) and latex.

Self-management, hospital attendance/admission and outcomes

Although in the majority of cases ($n = 240$; 79%, 95% CI 0.74–0.84), self-injectable adrenaline (epinephrine) was available, it was only administered in 38% ($n = 92$; 95% CI 0.32–0.45) of cases.

Availability of self-injectable adrenaline was comparable in children ($n = 159$; 82%, 95% CI 0.76–0.87) and adults ($n = 81$; 74%, 95% CI 0.65–0.82). Children with available adrenaline were however less likely to receive/use it ($n = 48$; 30%; 95% CI 0.23–0.38) than adults 54% ($n = 44$; 95% CI 0.43–0.65).

Adults were more likely ($n = 64$; 59%, 95% CI 0.49–0.68) to be treated in hospital than children ($n = 79$; 41%, 95% CI 0.34–0.48). Twenty percent ($n = 39$; 95% CI 0.15–0.27) of children and 28% ($n = 31$; 95% CI 0.20–0.38) of adults were admitted to hospital.

There were no fatalities reported in this dataset.

Discussion

Statement of principal findings

This study has found that most cases of anaphylaxis being reported to the Anaphylaxis Campaign followed exposure to known food triggers at home or in other community settings. Reactions were more common in children, with important age-sex differences being found such that reactions were more common in male children and in adult females. Although there was access to self-injectable adrenaline in the majority of cases, it was only used in a minority of cases. Overall, under half of all reactions involved hospital attendance with fewer still resulting in admission. There were no fatalities reported.

Strengths and limitations

A key strength of this study is that it involved carers/individuals personally reporting details of their reactions onto a standard data collection form that had been previously scrutinised by a scientific committee and used in an earlier investigation.[10]

There are however a number of limitations that need to be considered when interpreting the findings from this research. Key amongst these was that the sample was self-selected raising concerns about the generalisability of the findings. Furthermore, it was not possible within the context of this study to validate the carer/self-reports of triggers, clinical features or self-management.

Interpretation of the findings in the light of previous research

This study echoes the findings from earlier research that the majority of reactions occur in community settings following exposure to known triggers.[7,8,10] In keeping with previous research, reactions were common in males in childhood, with this pattern reversing in adults.[12] It was of concern that approximately half of all reactions occurred in individuals with a history of asthma; this is because co-existent asthma is known to substantially increase the risk of poor outcomes from anaphylaxis.[13,14] A relatively high proportion of individuals had access to adrenaline, this possibly reflecting the fact that this study was undertaken in those who were aware of/members of the Anaphylaxis Campaign – but this only translated into use of self-injectable adrenaline in a minority of cases.[15] Further studies are needed to explore why patients do not readily use adrenaline and why they are reluctant to present at hospital. That all individuals survived, despite sub-optimal management in a number of cases, reflects the now known low case fatality ratio from anaphylaxis.[16]

Implications for policy, practice and future research

This work highlights the importance of providing patients with appropriate allergen advice and furthermore the need for support that will help them to implement this in the context of the complexities of everyday life. UK, European and international anaphylaxis guidelines all make clear the importance of having access to and prompt use of self-injectable adrenaline in the context of reactions, and there is therefore a need for health professionals to reinforce this message at regular intervals.[17–21] This is important because the severity of reactions and fatalities can be difficult to predict, hence the need for prompt self-treatment.[22,23] Guidelines also encourage a period of observation under medical care following a reaction and so individuals experiencing reactions should be advised to seek urgent medical attention whenever they experience anaphylaxis.[17–21]

Further research is needed to assess the generalisability of the findings from this work and this would ideally be done by prospectively following a cohort of individuals who record their reactions. This work also suggests that many episodes of anaphylaxis go unreported to medical attention. Such episodes need

Downloaded from shr.sagepub.com at Pareto Lib/Opt1A121 on July 30, 2015

therefore to be taken into account in future studies into the epidemiology of anaphylaxis using routinely collected healthcare data. Finally, there is a need for further interventional studies which aim to improve the effectiveness of avoidance measures and self-care when avoidance measures fail.[24]

Conclusions

Many of the concerns highlighted by the previous survey persist, these including the failure of avoidance measures and inadequate carer/self-management in the context of experiencing anaphylaxis. There is a need for intervention studies designed to reduce the risk of recurrent reactions and to optimise self-management in the event of further reactions.

Declarations

Competing Interests: AaS and SD have a history of anaphylaxis. LR is Chief Executive of the Anaphylaxis Campaign. AzS has served as a consultant to ALK-Abello and Meda and is a member of the Anaphylaxis Campaign's Clinical and Scientific Panel.

Funding: None declared

Ethical approval: The study was processed and approved by the University of Edinburgh's ethical committee. The Medical Advisory Committee of the Anaphylaxis Campaign had previously approved the format of the final version of the questionnaire used in this study.

Guarantor: SD

Contributorship: The idea was conceived by the Anaphylaxis Campaign; LR and MA had the idea to analyse the questionnaires and commented on a draft of the paper. The manuscript was drafted by AaS and SD and revised in the light of critical comments from AzS.

Acknowledgements: We wish to express our gratitude to Anaphylaxis Campaign Helpline staff and to the individuals and carers who completed the questionnaire.

Provenance: Not commissioned; peer reviewed by Liz Angier

References

1. Sheikh A and Alves B. Hospital admissions for acute anaphylaxis: time trend study. *BMJ* 2000; 320: 1441.
2. Wilson R. Upward trend in acute anaphylaxis continued in 1998–9. *BMJ* 2000; 321: 1021–1022.
3. Gupta R, Sheikh A, Strachan DP and Anderson HR. Time trends in allergic disorders in the UK. *Thorax* 2007; 62: 91–96.
4. Sheikh A, Hippisley-Cox J, Newton J and Fenty J. Trends in national incidence, lifetime prevalence and adrenaline prescribing for anaphylaxis in England. *J R Soc Med* 2008; 101: 139–143.
5. Decker WW, Campbell RL, Manivannan V, Luke A, St Sauver JL, Weaver A, et al. The etiology and incidence of anaphylaxis in Rochester, Minnesota: a report from the Rochester Epidemiology Project. *J Allergy Clin Immunol* 2008; 122: 1161–1165.
6. Simons FE and Sampson HA. Anaphylaxis epidemic: fact or fiction? *J Allergy Clin Immunol* 2008; 122: 166–168.
7. Meh A, Wahn U and Niggemann B. Anaphylactic reactions in children – a questionnaire-based survey in Germany. *Allergy* 2005; 60: 1440–1445.
8. Beyer K, Eckermann O, Hompes S, Grabenhenrich L and Worm M. Anaphylaxis in an emergency setting – elicitors, therapy and incidence of severe allergic reactions. *Allergy* 2012; 67: 1451–1456.
9. Gallagher M, Worth A, Cunningham-Burley S and Sheikh A. Strategies for living with the risk of anaphylaxis in adolescence: qualitative study of young people and their parents. *Prim Care Respir J* 2012; 21: 392–397.
10. Uguz A, Lack G, Pumphrey R, Ewan P, Warner J, Dick J, et al. Allergic reactions in the community: a questionnaire survey of members of the anaphylaxis campaign. *Clin Exp Allergy* 2005; 35: 746–750.
11. Sampson HA, Munoz-Furlong A, Campbell RL, Adkinson NF Jr, Bock SA, Branum A, et al. Second symposium on the definition and management of anaphylaxis: summary report. Second National Institute of Allergy and Infectious Disease/Food Allergy and Anaphylaxis Network symposium. *J Allergy Clin Immunol* 2006; 117: 391–397.
12. Sheikh A and Alves B. Age, sex, geographical and socio-economic variations in admissions for anaphylaxis: analysis of four years of English hospital data. *Clin Exp Allergy* 2001; 31: 1571–1576.
13. Calvani M, Cardinale F, Martelli A, Muraro A, Pucci N, Savino F, et al. Risk factors for severe pediatric food anaphylaxis in Italy. *Pediatr Allergy Immunol* 2011; 22: 813–819.
14. Gonzalez-Perez A, Aponte Z, Vidaurre CF and Rodriguez LAG. Anaphylaxis epidemiology in patients with and patients without asthma: a United Kingdom database review. *J Allergy Clin Immunol* 2010; 125: 1098–1104.
15. Gallagher M, Worth A, Cunningham-Burley S and Sheikh A. Epinephrine auto-injector use in adolescents at risk of anaphylaxis: a qualitative study in Scotland, UK. *Clin Exp Allergy* 2011; 41: 869–877.
16. Panesar SS, Javad S, de Silva D, Nwaru BI, Hickstein L, Muraro A, et al. The epidemiology of anaphylaxis in Europe: a systematic review. *Allergy* 2013; 68: 1353–1361.
17. Alrasbi M and Sheikh A. Comparison of international guidelines for the emergency medical management of anaphylaxis. *Allergy* 2007; 62: 838–841.
18. Soar J, Pumphrey R, Cant A, Clarke S, Corbett A, Dawson P, et al. Emergency treatment of anaphylactic reactions – guidelines for healthcare providers. *Resuscitation* 2008; 77: 157–169.
19. Simons FE, Ardusso LR, Bilò MB, El-Gamal YM, Ledford DK, Ring J, et al. World Allergy Organization anaphylaxis guidelines: summary. *J Allergy Clin Immunol* 2011; 127: 587–593.e1–22.
20. Muraro A, Roberts G, Worm M, Bilò MB, Brockow K, Fernández Rivas M, et al. Anaphylaxis: guidelines from the European Academy of Allergy and Clinical Immunology. *Allergy* 2014; 69: 1026–1045.

Downloaded from shr.sagepub.com at Pareto Lib/Opt1A121 on July 30, 2015

21. Simons FE, Ardusso LR, Bilò MB, Cardona V, Ebisawa M, El-Gamal YM, et al. International consensus on (ICON) anaphylaxis. *World Allergy Organ J* 2014; 7: 9.
22. Pumphrey RS. Lessons for management of anaphylaxis from a study of fatal reactions. *Clin Exp Allergy* 2000; 30: 1144–1150.
23. Pumphrey R. Anaphylaxis: can we tell who is at risk of a fatal reaction? *Curr Opin Allergy Clin Immunol* 2004; 4: 285–290.
24. Dhami S, Panesar SS, Roberts G, Muraro A, Worm M, Bilò MB, et al. Management of anaphylaxis: a systematic review. *Allergy* 2014; 69: 168–175.

Appendix 1: Allergic reaction record

How you can help the Anaphylaxis Campaign and aid research into allergies

This form has been designed to help the Campaign gain a fuller understanding about allergic reactions, what causes them, and what is the best treatment. If you, or a family member, has an allergic reaction to a food or substance, however minor, would you please fill in the form as soon as possible after the reaction has occurred - and after the patient has recovered - and send it to: The Anaphylaxis Campaign, PO Box 275, Farnborough, Hants GU14 6SX or email to info@anaphylaxis.org.uk.

The identity of the person who has had the allergic reaction will be kept confidential, unless permission has been obtained first. Please photocopy this form so it can be used more than once, should further incidents occur. Alternatively we can supply more forms if needed. **Please call us on 01252 542029 if you need help filling in this form.**

1. Name of person who had reaction……..……

2. Sex: Male ❑ Female ❑ Please tick box.

3. Age at time of this reaction ……

4. Age at which patient first suffered an allergic reaction.……...

5. Address……

……..……..Postcode……...

6. Phone number for contact…….…….

7. Patient's allergies (e.g. peanut, cat, wasp stings)?

……..……..……..
8. Does the patient have

Eczema ❑ Rhinitis (constantly runny nose) ❑ Hay fever ❑ Asthma ❑

9. If you have ticked asthma, did the patient suffer asthma symptoms during the week before the allergic reaction now being reported? Yes ❑ No ❑

10. How many times a day was the patient using their reliever (blue puffer) in the week before the reaction?

11. Does he/she get symptoms of asthma when exercising? Yes ❑ No ❑

12. Does the patient's asthma wake them at night? Yes ❑ No ❑

13. If so, how often? Nightly ❑ Weekly ❑ Monthly ❑

Details of the reaction you are reporting

14. Date reaction occurred……..

15. Time symptoms began……

16. Location where symptoms began (e.g. restaurant, home) ……..

17. Allergen thought to have caused the reaction (e.g. peanut, egg, latex) ……

18. Was patient known to be allergic to this allergen? Yes ❑ No ❑

19. Has this been verified by skin prick testing, blood testing (e.g. RAST) or challenge testing? Yes ❑ No ❑

20. Please state which: Skin ❑ Blood ❑ Challenge ❑

21. How did patient come into contact with the allergen? Smell ❑ Touch ❑ Eat ❑ Drink ❑ Sting ❑

Downloaded from shr.sagepub.com at Pareto Lib/Opt1A121 on July 30, 2015

22. If eaten or drunk, state quantity consumed, if known ……

23. Food product in which ingredient was a part (where applicable). State brand name if known

……

24. Where was the food obtained (e.g. supermarket, restaurant, in-store bakery, school)?

……

25. Length of time between contact with, or consumption of allergen and the onset of symptoms

……

26. Did patient have: Swelling of throat or mouth ❑ Difficulty breathing ❑ Collapse ❑

Severe abdominal pain ❑ Other (e.g. rash, hives) Give details ……

……

27. Had the patient been prescribed medication for allergic reactions? Yes ❑ No ❑

28. If so, please tick:

Adult EpiPen ❑ Junior EpiPen ❑ Adult Anapen ❑ Junior Anapen ❑ Mini-I-jet ❑

Anakit ❑ Antihistamines ❑ Inhaled adrenaline (epinephrine) ❑ Hydrocortisone ❑

Bronchodilators (e.g. Ventolin, Bricanyl) ❑ Other ……

29. Was self-injectable adrenaline (epinephrine) available at time of reaction? Yes ❑ No ❑

30. If so, was it administered? Yes ❑ No ❑

31. By whom? (e.g. self, parent, friend, GP) ……

32. How long after symptoms began was self-injectable adrenaline (epinephrine) administered?

0-5 mins ❑ 5-15 mins ❑ 15-30 mins ❑ Other (please state)……

33. If patient had been prescribed other medicine, was this given? Yes ❑ No ❑

34. State which medicine: ……

35. How long after symptoms began was this given?

0-5 mins ❑ 5-15 mins ❑ 15-30 mins ❑ Other (please state)……

36. If patient received self-injectable adrenaline, was patient's second injection administered? Yes ❑ No ❑

37. If yes, how long after the first injection was the second given? 0-5 mins ❑ 5-15 mins ❑ 15-30 ❑ mins

Other ……

38. How soon was improvement noticed after treatment began? 0-5 mins ❑ 5-15 mins ❑ 15-30 mins ❑

Other …… **Further details about effectiveness of treatment can be written on a separate sheet.**

39. Was patient treated at hospital? Yes ❑ No ❑

40. Was patient admitted to hospital? Yes ❑ No ❑

41. Might there have been factors which made the allergic reaction worse (e.g. exercise, alcohol, stress, temperature, presence of infection, menstrual period)? Please give details

……

Please include further relevant information on a separate sheet (e.g. relating to the effect of the treatment). Was there anything you would like to have done differently? Were you well prepared to cope?

Downloaded from shr.sagepub.com at Pareto Lib/Opt1A121 on July 30, 2015