



Timing the transfer of responsibilities for anaphylaxis recognition and use of an epinephrine auto-injector from adults to children and teenagers: pediatric allergists' perspective

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ABSTRACT

Background: The optimal time for transferring responsibilities for anaphylaxis recognition and epinephrine auto-injector use from adults to children and teenagers has not yet been defined.

Objective: To determine whether pediatric allergists have age-specific goals for beginning to transfer responsibilities for anaphylaxis recognition and epinephrine auto-injector use from parents and caregivers to children and teenagers at risk of anaphylaxis in the community.

Methods: Members of the American Academy of Pediatrics Section on Allergy and Immunology (AAP-SOAI) were surveyed about when they typically begin to transfer these responsibilities from adults to children and teenagers.

Results: Eighty-eight allergists responded to the survey, 97.7% of whom provided service to children and teenagers with food allergies. Few allergists expected to begin transferring responsibilities for anaphylaxis recognition and epinephrine auto-injector use to children younger than 9 to 11 years. By the time their patients reached age 12 to 14 years, however, most allergists expected them to be able to describe some anaphylaxis symptoms (95.4%), demonstrate how to use an epinephrine auto-injector trainer (93.1%), begin carrying self-injectable epinephrine (88.2%), recognize the need for epinephrine (88.1%), learn to self-inject epinephrine (84.5%), and be able to self-inject epinephrine (78.6%) (cumulative data). The allergists rated the following as “very important” readiness factors for beginning to transfer responsibilities: medical history, developmental level, and ability to demonstrate auto-injector technique.

Conclusion: Most pediatric allergists expected that by age 12 to 14 years, their patients should begin to share responsibilities with adults for anaphylaxis recognition and epinephrine auto-injector use; however, they individualized the timing based on assessment of patient readiness factors.

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Introduction

When anaphylaxis occurs in a community setting, prompt first-aid treatment from an epinephrine auto-injector is recommended. Important goals in anaphylaxis education are to teach children and teenagers at risk of anaphylaxis in the community and their parents or caregivers about recognition of anaphylaxis symptoms and correct use of an epinephrine auto-injector, in the context of a person-

alized written anaphylaxis emergency action plan.^{1–3} Age-specific goals for the optimal time to begin to transfer responsibilities for anaphylaxis recognition and treatment from an adult to a child or teenager have not been determined. Most anaphylaxis guidelines published in peer-reviewed journals by medical professional organizations are silent on this issue,^{4–8} although one guideline mentions that “children and young people” (age range not stated) should rehearse their anaphylaxis emergency action plan and practice their auto-injector technique at follow-up visits.⁹ Also, general guidelines about student self-carrying and self-administration of prescribed medications in schools do not provide any age-specific recommendations.¹⁰

In many areas in which legislation has been passed to allow children and teenagers to carry epinephrine auto-injectors in school, determination of the age of readiness to carry is left to the patient's personal physician. In other areas, legislation has been passed to permit all children as young as 8-years-of-age who are at risk of allergic reactions to food to carry epinephrine auto-injectors

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with them in school and potentially self-administer epinephrine.¹¹ Although this might help to solve the problem of limited access to epinephrine auto-injectors in the school setting,¹² in the absence of published data, the rationale for selecting a specific age of readiness is unknown.^{2,13}

Children and teenagers are seldom included in studies in which participants are asked to demonstrate knowledge of anaphylaxis symptoms and correct use of an epinephrine auto-injector trainer.¹⁴ In addition, there are practical concerns about their ability to use an epinephrine auto-injector correctly and safely during an anaphylactic episode. Young children might not be able to exert optimal pressure on their epinephrine auto-injector, based on the peak plasma epinephrine concentrations they achieved after self-injection of epinephrine in a non-emergency setting.¹⁵ More than half of the 15,951 unintentional injections from epinephrine auto-injectors (with or without injury to a digit or other body part) that were reported to US poison control centers from 1994 to 2007 occurred in patients aged 17 years or younger.¹⁶

In this pilot study, our objectives were to determine when pediatric allergists typically begin to transfer responsibilities for recognition of anaphylaxis symptoms and epinephrine auto-injector use from parents and caregivers to children and teenagers, and how they determine their patients' readiness to begin sharing these responsibilities with adults.

Methods

The study was approved by the Mount Sinai Program for the Protection of Human Subjects and by the American Academy of Pediatrics' Institutional Review Board.

Questionnaire development

We developed a questionnaire for members of the Section on Allergy and Immunology (SOAI) in the American Academy of Pediatrics (AAP) about the ages at which they begin to transfer responsibilities for recognition of anaphylaxis symptoms and epinephrine auto-injector use. We asked them to assess the relative importance of various factors influencing how they determine their patients' readiness for transfer of these responsibilities, using the 3-point Likert scale provided.

The questionnaire could not be validated against any previous prospective study of the timing of transfer of responsibilities for anaphylaxis recognition and auto-injector use, because no such study has been published. It was therefore field-tested for face validity by American Board of Allergy and Immunology (ABAI)-certified pediatric allergists practicing outside of the United States who were not members of the AAP-SOAI. Additionally, AAP-SOAI Executive Committee members reviewed the questionnaire before it was posted online but did not complete the online survey or contribute to the data collected.

Questionnaire distribution

Information was collected by using SurveyMonkey (www.surveymonkey.com), a confidential online instrument. An electronic invitation to participate in the survey and link to the

online questionnaire was sent to SOAI members at their e-mail address on record with the AAP. Participants were advised that the questionnaire would take approximately 5 minutes to complete and that the percentage of questions remaining could be ascertained by viewing the survey completion progress bar. At 2 and 4 weeks after the initial questionnaire distribution, SOAI members received follow-up e-mails with the link to the online questionnaire. Those who had completed the survey were thanked for their participation, and those who had not yet responded were asked to consider submitting replies at their earliest convenience. Questionnaires submitted through this link could not be traced to any individual participant or IP address.

Data management and analysis

The responses tabulated by SurveyMonkey for each question were downloaded into Microsoft Excel (Microsoft Corp., Redmond, Washington), imported into Stata 11.1 (Stata Corp., College Station, Texas), analyzed over all responders, and compared by practice demographics using the Fisher's exact test.

Results

The survey response rate was 42.0% (88 of 210 subscribers to the SOAI ListServ). Most (93.2%) responders were ABAI-certified allergists in active practice: 48.9% were in group private practice (single specialty or multi-specialty); 37.5% were in academic practice; 14.8% were in solo private practice; and 6.8% reported more than 1 type of practice. Of the responders, 97.7% provided service to children and teenagers with food allergies, and 95.4% completed the survey.

How pediatric allergists manage children and teenagers at risk of anaphylaxis in the community

Most (91.7%) of the allergists were directly involved in training children and teenagers to use epinephrine auto-injectors, along with other medical professionals in their practices such as fellows-in-training, residents, nurse practitioners, physician assistants, and medical assistants. Many (58.3%) of the pediatric allergists "always or often" asked to see the child's or the teenager's epinephrine auto-injector at visits (Table 1), to see whether they were actually carrying it (87.5%), to see whether the auto-injector appeared intact (42.5%), to check the expiration date (80.0%), and to check the appropriateness of the dose (52.5%). Other reasons for looking at the patient's auto-injector included using this inspection as a "jumping off" point for discussion of anaphylaxis; reinforcing how important it was to carry the auto-injector at all times; making sure the child or teenager was carrying the live auto-injector, not the trainer; and reviewing the use of the auto-injector.

Additionally, 92.8% of the allergists "always or often" recommended a written anaphylaxis emergency action plan for their patients (Table 1). A variety of plans were suggested, such as the Food Allergy & Anaphylaxis Network plan (67.5%), school plans (28.9%), the American Academy of Allergy Asthma and Immunology plan (26.5%), and allergist-designed plans (20.5%), including computer-generated plans personalized for each patient. Of those

Table 1
How pediatric allergists manage children and teenagers at risk of anaphylaxis in the community^a

	Always n (%)	Often n (%)	Sometimes n (%)	Rarely n (%)	Never n (%)
Inspect epinephrine auto-injector	17 (20.2)	32 (38.1)	24 (28.6)	7 (8.3)	4 (4.8)
Recommend a written anaphylaxis emergency action plan	62 (73.8)	16 (19.0)	4 (4.8)	1 (1.2)	1 (1.2)
Recommend medical identification, eg, an ID bracelet	29 (34.5)	29 (34.5)	18 (21.4)	6 (7.1)	2 (2.4)
Ask to see medical identification at every visit	4 (4.9)	16 (19.5)	16 (19.5)	26 (31.7)	20 (24.4)
Discuss the importance of control of asthma symptoms ^b	52 (61.9)	24 (28.6)	6 (7.1)	1 (1.2)	1 (1.2)

^aIn addition to direct involvement in training children and teenagers to use epinephrine auto-injectors.

^bIn patients with persistent asthma who are at risk of anaphylaxis recurrence.

Table 2

Timing: when pediatric allergists begin to transfer responsibilities for anaphylaxis recognition and epinephrine auto-injector use to children and teenagers

Age (years)	<6 n (%)	6–8 n (%)	9–11 n (%)	12–14 n (%)	15–18 n (%)	≥19 n (%)	Never n (%)
Describe some anaphylaxis symptoms	10 (11.6)	27 (31.4)	28 (32.6)	17 (19.8)	3 (3.4)		1 (1.2)
Recognize need for self-injectable epinephrine	4 (4.8)	9 (10.7)	32 (38.1)	29 (34.5)	10 (11.9)		
Demonstrate epinephrine self-injection using trainer	1 (1.2)	13 (15.1)	35 (40.7)	31 (36.0)	6 (7.0)		
Begin carrying self-injectable epinephrine	2 (2.4)	11 (13.1)	24 (28.6)	37 (44.0)	10 (11.9)		
Take responsibility for learning to self-inject epinephrine		5 (6.0)	29 (34.5)	37 (44.0)	13 (15.5)		
Self-inject epinephrine		3 (3.6)	24 (28.6)	39 (46.4)	16 (19.1)	2 (2.4)	
Use a live auto-injector to inject into an orange		5 (5.8)	13 (15.1)	15 (17.4)	7 (8.1)		46 (53.5)

Note. The age ranges for transferring responsibilities that were most frequently selected by the pediatric allergists are shown in bold. Cumulative data for each of the responsibilities, as presented in the text, were obtained by adding the percentages as listed horizontally for each age range.

who provided action plans, 81.9% reviewed and updated the plans annually. Although 69.0% of the allergists “always or often” recommended anaphylaxis medical identification (ID) such as an ID bracelet for at-risk patients, only 24.4% inspected medical IDs regularly. Most (90.5%) of the allergists “always or often” discussed asthma control with patients at risk of anaphylaxis who also had asthma, and with their parents.

Timing: when pediatric allergists begin to transfer responsibilities for anaphylaxis recognition and epinephrine auto-injector use to children and teenagers

The age groups at which allergists expect children or teenagers to begin to share various responsibilities with adults for anaphylaxis recognition and management are shown in Table 2. They most frequently selected 9 to 11 years as the age range when they expected their patients to begin to describe some symptoms of anaphylaxis, recognize the need for epinephrine, and demonstrate how to self-inject epinephrine using an auto-injector trainer. They most frequently selected 12 to 14 years as the age range when they expected their patients to begin carrying self-injectable epinephrine on their person or in a backpack or handbag, take responsibility for learning to self-inject epinephrine, and self-inject epinephrine. Many of the allergists did not expect children or teenagers at any age to use a “live” auto-injector to give an injection of epinephrine into an orange or similar object.

When the data were examined cumulatively, the allergists expected to begin transferring responsibilities from parents and care-

givers to most children and teenagers by age 12 to 14 years. By the time their patients reached this age, 95.4% of the allergists expected them to be able to describe some anaphylaxis symptoms; 93.1% expected them to demonstrate how to self-inject epinephrine using an auto-injector trainer; 88.2% expected them to begin carrying an epinephrine auto-injector on their person or in a backpack or handbag; 88.1% expected them to recognize the need for epinephrine; 84.5% expected them to begin to take responsibility for learning to self-inject epinephrine; and 78.6% expected them to be able to self-inject epinephrine.

Factors that influence readiness for transfer of responsibilities

Factors that 75% or more of the allergists considered to be “very important” for demonstrating readiness for transferring responsibilities included the child’s or teenager’s ability to demonstrate how to self-inject epinephrine using a trainer, ability to describe some symptoms of anaphylaxis, developmental level, history of severe or life-threatening anaphylaxis, more than 1 previous anaphylactic episode, request or expressed comfort level with epinephrine auto-injector use, and the presence or absence of a comorbidity such as developmental delay, attention deficit hyperactivity disorder, autism spectrum disorder, or depression (Table 3).

Additional factors that the allergists considered to be “very important” included anaphylaxis triggered by an allergen such as peanut that is known to cause fatality; a high level of sensitization to allergens that previously triggered anaphylaxis, child’s or teen-

Table 3

Readiness factors for beginning to share responsibilities for anaphylaxis recognition and epinephrine auto-injector use

	Very important ^a n (%)	Somewhat important ^a n (%)	Not important ^a n (%)
Child or Teenager: Medical history			
Severe or life-threatening anaphylaxis	75 (89.3)	7 (8.3)	2 (2.4)
More than 1 previous systemic allergic reaction (anaphylaxis)	67 (79.8)	14 (16.7)	3 (3.6)
Co-morbidity (cognitive or psychiatric) ^b	63 (75.0)	20 (23.8)	1 (1.2)
Anaphylaxis triggered by an allergen, eg, peanut, known to cause fatality	58 (69.0)	23 (27.4)	3 (3.6)
High level of sensitization to allergen(s) that previously triggered anaphylaxis	57 (67.9)	22 (26.2)	5 (6.0)
Persistent asthma	55 (65.5)	23 (27.4)	6 (7.1)
Other atopic disease (eg, allergic rhinitis, atopic dermatitis)	6 (7.1)	42 (50.0)	36 (42.9)
Child or Teenager: Other factors			
Can demonstrate technique with trainer	81 (96.4)	3 (3.6)	
Can describe reasons to inject	78 (92.9)	6 (7.1)	
Developmental level of child or teenager	78 (92.9)	6 (7.1)	
Child’s or teen’s request to use, or expressed comfort level with, use of the auto-injector	66 (78.6)	16 (19.0)	2 (2.4)
Age of child or teenager	56 (66.7)	28 (33.3)	
Child’s or teenager’s fear of needles or procedures	55 (65.5)	25 (29.8)	4 (4.8)
Can read and understand printed instructions and simple diagrams	53 (63.1)	29 (34.5)	2 (2.4)
Child’s or teenager’s need to be independent due to family circumstances	52 (61.9)	29 (34.5)	3 (3.6)
School grade of child or teenager	26 (31.0)	55 (65.5)	3 (3.6)
Other: Parental and institutional factors			
Parent’s request or comfort level	56 (66.7)	27 (32.1)	1 (1.2)
Institutional (eg, school) policy about carrying epinephrine auto-injector	31 (36.9)	45 (53.6)	8 (9.5)

^aTerminology used in the Likert scale.^bSuch as developmental delay, attention deficit hyperactivity disorder, autism spectrum disorder, depression.

ager's chronologic age, fear of needles or procedures, ability to read and understand printed instructions and simple diagrams, and need to be independent because of family circumstances.

Although persistent asthma was considered to be "very important," the presence of other allergic diseases such as atopic dermatitis and allergic rhinitis was not. Special circumstances were described; for example, "some children have long school bus rides during which they need to be protected," and "even if a school does not allow carrying, the child spends more time out of school than in school, and needs to be protected."

Association between practice demographics and responses

No associations were found between type of practice (private vs hospital-based) and the percentage of responders reporting discussion of the importance of asthma control in patients with asthma who are at risk for anaphylaxis ($P = .45$), provision of an anaphylaxis emergency action plan ($P = .41$), recommendation of a medical identification bracelet ($P = 1.00$), or auto-injector teaching by an allergist ($P = .73$). Associations between individual practitioner characteristics and assessment of readiness for gradual transfer of responsibilities could not be performed, because most responders were ABAI-certified allergists.

Discussion

This is the first prospective investigation of the optimal time to begin transfer of responsibilities for anaphylaxis recognition and management from parents and caregivers to children and teenagers. Pediatric allergists report individualizing their approach to timing, based on their assessment of a child's or teenager's readiness to begin to share the different responsibilities involved with an adult. Most of the allergists expected that, cumulatively, by age 12 to 14 years, their patients should be able to describe some anaphylaxis symptoms, recognize the need for epinephrine, demonstrate how to self-inject epinephrine using an auto-injector trainer, begin carrying self-injectable epinephrine, take responsibility for learning to self-inject epinephrine, and self-inject epinephrine. Although the transfer of these responsibilities was expected by age 12 to 14 years, the gradual process of teaching anaphylaxis recognition and management might have begun when the patients were considerably younger.

Readiness factors that influenced the allergists' timing of transfer of these responsibilities included the patient's ability to demonstrate how to self-inject epinephrine using an auto-injector trainer, ability to name some symptoms of anaphylaxis, and developmental level. Previous severe or life-threatening anaphylaxis and more than 1 previous systemic allergic reaction (anaphylaxis) were also considered to be "very important" factors. This possibly reflects a greater willingness or motivation of parents, children, and teenagers who have witnessed or experienced severe or frequent anaphylaxis to have the child or teenager begin to share responsibilities for recognition and management of anaphylaxis at a younger age.^{17,18} However, severity or frequency of past episodes does not necessarily predict severity or frequency of future episodes, and a mild systemic allergic reaction can be followed by a severe anaphylactic episode.¹⁸ The presence of persistent asthma was recognized as a "very important" factor for severe anaphylaxis by many of the allergists. The presence of other allergic diseases such as atopic dermatitis and allergic rhinitis were considered "somewhat important" or "not important," although these diseases have been associated with severe anaphylaxis to food,¹⁹ the commonest anaphylaxis trigger in children and teenagers.

The strengths of this study are that it is the first to provide a perspective on the time to begin transfer of responsibilities for anaphylaxis recognition and management from allergists in diverse practice settings who had high awareness of the key elements of anaphylaxis education for children and teenagers at risk of ana-

phylaxis recurrences in the community. Although the 42% response rate to the survey is a potential limitation, it is almost identical to the 41% response rate by pediatricians to a national survey about food-induced anaphylaxis.²⁰ It should lead to the generation of some interesting hypotheses; for example, "...that patients age 12 years and older should be able to recognize anaphylaxis symptoms and use an epinephrine auto-injector."

In this study, few allergists expected children younger than 9 to 11 years to begin to share responsibilities with an adult for injecting epinephrine. Anecdotally, a 3-year-old child has been reported to use an epinephrine auto-injector²¹; however, in contrast, in a qualitative study in which 45 teenagers described their most recent anaphylactic episode, despite the fact that most had auto-injectors available, only 3 (ages 14, 16, and 19 years) reported self-injecting epinephrine, and the 14-year-old reported problems in using the device.²²

Recognition of anaphylaxis symptoms and the need for epinephrine injection involves many complexities and can sometimes be difficult, even for experienced healthcare professionals.¹ Injection of epinephrine from an auto-injector during an anaphylactic episode requires the ability to recall many details in sequence while under stress, for example, whether to use the auto-injector, choosing the site on the thigh for the injection, and remembering to remove the safety release.²³

Adult supervision of a child or teenager is recommended even in diseases involving regular self-injection of medication, for example, self-injection of insulin for type 1 diabetes, which involves daily practicing and coaching and gradually leads to competence and confidence in self-management. Although school-age children can begin to assume some of the tasks involved in daily diabetes management, they still need significant assistance and supervision from a knowledgeable adult, especially with regard to management decisions.²⁴ Although many teenagers are considered competent to perform self-management activities in diabetes, it is strongly recommended that parents maintain some guidance and supervision.²⁵

Patients at risk for anaphylaxis in community settings who vigilantly avoid their anaphylaxis triggers might not have an anaphylactic episode for years, or even decades. For these patients, regular review of recognition of anaphylaxis symptoms and how to use an epinephrine auto-injector is therefore advised, in order to help them achieve and maintain competence and confidence.

A novel epinephrine auto-injector being introduced is reported to be easier to use than currently available auto-injectors such as EpiPen (Dey Pharma, Basking Ridge, New Jersey) and Twinject (Shionogi, Inc., Florham Park, New Jersey); however, in a comparative study of ability to use the trainers for EpiPen, Twinject, and an early prototype of this auto-injector, the children age 7 to 10 years performed significantly less well with all the devices than the teenagers and adults did.²⁶ Although a later prototype of the novel auto-injector might be even easier to use,²⁷ children and teenagers must also be able to perform the much more difficult task of recognizing anaphylaxis symptoms and the need for epinephrine injection, in addition to mastering the correct technique for using an epinephrine auto-injector.

Beyond the age-specific considerations reported and discussed in this study, during an anaphylactic episode, regardless of age, patients potentially have impaired recognition of what is happening to them and impaired ability to self-inject epinephrine correctly and safely, especially if symptoms progress rapidly, or if they are hypoxic or hypotensive. It is therefore recommended that backup and support from a responsible adult should be available to a child or teenager experiencing an anaphylactic episode.^{2,12,28}

Further studies of the optimal time to begin to transfer responsibilities for anaphylaxis management from adults to children are clearly needed. In the future, perspectives on this issue should also

be obtained from primary care physicians, allied health colleagues, parents, caregivers, and other adults with responsibilities for youth, as well as from at-risk children and teenagers themselves.

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