

# Barriers and Challenges Affecting Parents Use of Adrenaline auto-injector in Children at Risk of Anaphylaxis

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## Abstract

**Background:** Anaphylaxis is a life-threatening condition. As accidental exposure to the offending allergens usually happens in the community, in absence of medical personnel, adrenaline auto-injector (AAI), carried by parents, remains the first and only drug of choice. As studies have shown that AAI is commonly underused by parents, this study was undertaken to elucidate the causes of its underutilization in our community. **Methods:** A cohort of parents attending the paediatric allergy clinic at Al Ain hospital, in the United Arab Emirates (UAE), completed a questionnaire survey aimed to assess their understanding and knowledge of their child's allergy management, including their aptitude with the use the AAI, as well as their competence and comfort to provide this treatment in an emergency. **Results:** A total of 47 parents, 83% of whom were Emirati, including 66% of mothers, participated in the study. Food allergy was the main indication for AAI prescription, with tree nuts 62%) and peanuts (38%) being the main culprits. The majority (94%) of parents were trained by a doctor on using the AAI, with most (79%) demonstrating a good knowledge of indications for administering the AAI. Although all parents expressed satisfaction with the training that they had received, they still admitted to a remaining lack of confidence with using an AAI. **Conclusions:** The continuous education and training of parents on how to use an AAI, still requires supplementary psychological support to overcome their fear and anxiety with using the device in an urgent situation. More research is needed to explore the reasons behind their fear and anxiety to plan effective interventions. **Abbreviations:** (AAH), Al Ain Hospital, (AAI) adrenaline auto-injector **Keywords:** Anaphylaxis, Adrenaline, Food allergy, Barriers, Education, Management

## Introduction

Anaphylaxis, a rapid-onset allergic reaction involving multiple body systems, is a serious and potentially lethal condition [1]. Adrenaline is the immediate and only drug of choice to treat it, in all ages, in health care settings as well as in the community. Food allergy is the leading cause of anaphylaxis in children, with common triggering allergens such as peanut, tree nuts, egg, cow's milk, sesame, fish, shrimp and wheat, although they vary in different populations. In our paediatric allergy clinic, we manage children of all ages up to 16 years of age, from different ethnicities and with different underlying allergic conditions. The prevalence of food allergy in children in Al-Ain city has been reported to be 8%, with egg, fruit and fish being the main culprits [2]. A systematic review indicated that the global incidence of food-induced anaphylaxis in children was between one and seventy-seven per 100,000 person-years, with anaphylaxis of any cause ranging from one to seven hundred and sixty-one per 100,000 person-years [3].

After the diagnosis and the effective management of the first episode of anaphylaxis, the affected children are usually referred to a paediatric allergy clinic where the parents and age-appropriate children, are advised on allergens avoidance with a personalized allergy action plan. As the main characteristic of anaphylaxis secondary to food allergy in children is that it almost always happens in the community where no medical personnel are present [4]. It is crucial for the parents, caregivers and teachers of these children to be provided

with an adrenaline auto-injector(AAI), to always be available and ready for use. Instructions on the indications for using the device are provided, including the technique for administering it immediately into the mid-outer thigh, by intramuscular injection as the preferred route, if the child is having anaphylaxis or if the condition is likely to progress to anaphylaxis. [4]. As per the European Academy of Allergy and Clinical Immunology (EAACI) guidelines, the indications for prescribing AAI are either absolute (previous anaphylaxis to food or other allergens, previous exercise-induced anaphylaxis, previous idiopathic anaphylaxis, underline mast cell disorder with high baseline serum tryptase, moderate to severe persistent asthma with food allergy and venom allergy in adults), or relative ( previous mild-moderate reaction to nuts, teenager, previous mild-moderate reactions to trace of food or mild reaction to food and remoteness from medical help) [4]. In our practice, we usually prescribe two AAI devices; one to keep at home and one at school. This number may change in some special circumstances, such as if a child had needed two injections in an earlier episode, or as per the family living circumstances, such as separation or divorce. In addition to the medical and technical information provided and repeated at each clinic visit, the parents should demonstrate competence and be made to feel comfortable using the AAI.

However, despite the availability and the ease of prescription of AAI in the community[5], we have observed that many of our patients, parents and caregivers either do not refill the prescription or do not appreciate the need to administer the AAI at the scene of anaphylaxis. They prefer instead to go to the emergency department, which is at the very end of the written allergy action plan, is only advised as a last resort. Such resulting delay in providing immediate life-saving treatment is potentially very dangerous. Other parents may not even know how to properly use the device, or may not carry it with them at all times [6]. In previous studies of case fatalities due to anaphylaxis, underusing, delaying, or using a faulty technique in administering the AAI, have been linked to mortality [7]. Even in those who had survived anaphylaxis, more than 50% did not receive AAI as and when required [8,9].

Our population is different from those from previous reports, with different nationalities, cultures and traditions. As a result, we cannot assume that the underlying factors behind difficulties identified in previous studies are necessarily the same in our environment. Furthermore, the common allergens triggering anaphylaxis vary geographically and genetically among different countries and races (e.g. peanut allergy, common in the western world, is uncommon in the Far East.). We have therefore developed this study to analyse, in our environment, the extent of inadequate or improper use of AAI by parents and to identify the underlying causes to implement appropriate interventions.

## Methods

Parents of children who have been diagnosed with anaphylaxis, or at risk of developing anaphylaxis, and who had already been provided with an AAI, were invited to participate in the study. There were no exclusion criteria. Parents were informed that they can opt-out of the study at any time, without explanations, and without compromising the care that their child was receiving.

The study was conducted at the paediatric allergy clinic of Al Ain hospital (AAH), between January and March 2020. AAH is a teaching hospital in Al Ain City, United Arab Emirates (UAE) with a multi-national population of approximately 500,000. It has a capacity of 324 total beds, including 54 paediatric beds, and provides general and specialised services. With approximately 700 outpatient visits per year, the paediatric allergy clinic provides care for different allergic conditions such as food allergy, drug allergy, insect and venom allergy, atopic dermatitis, allergic rhino-conjunctivitis, allergic asthma, chronic spontaneous urticaria and other types of childhood allergic diseases.

Ethical approval for the study was granted by the Institute's Board of Ethics. The information document describing the study to the parents and the written informed consent forms were made available in both Arabic and English to suit the parents' preferences. After reading the study information and signing an informed consent form, the parents or caregivers completed a short survey. This consisted of a questionnaire regarding their understanding of their child's allergy/anaphylaxis, and the treatment including the AAI as part of the individualized allergy action plan provided to them. The survey also included their perception of the quality

of the teaching provided at the clinic and their competence and comfort in administering AAI (Appendix 1). The questions were easy and straightforward, not requiring any special preparation or revision. The survey aimed to assess the parents' factual knowledge, competency and empowerment with using an AAI device for immediately treating their child's anaphylaxis.

## Statistical analysis

Groups were reported as numbers and percentages. A Likert scale was used to quantify the answers for the qualitative questions. The univariate association between the explanatory variables and the outcomes of interest was compared with the unpaired Student's t-test between 2 variables, and analysis of variance (ANOVA) when comparing 3 groups or more. An ordered logistic model tested the association of the outcomes with the explanatory variables while correcting for potential confounders. All analyses were performed in the STATA 15.0 software (StataCorp, Texas, USA) and a two-tailed P value < 0.05 defined statistical significance.

## Results

A total of 47 questionnaires were completed mainly by mothers (66%), with the majority of families (n=39, 83%) being Emirati. Nearly half of the affected children (n=21, 45%), were under five years of age and the majority (n=42, 89%) had the AAI prescribed for food allergy (Table 1). The majority of parents (n=37, 79%) correctly stated that they would use AAI in case of an accidental allergic reaction if their child developed a rash with other system involvements such as a cough and breathing difficulty. Nine (19%) stated that they would use the AAI device in case of a rash associated with lips swelling, and one parent (2%) declared that she was not sure when to use it. The allergy doctor had trained 44 (94%) parents, and 17 parents (36%) reported previous real-life experience of using an AAI. The majority (n=33, 70%) of children had two AAIs prescribed (one for home and one for nursery or school).

The most common food allergen reported (Table 2) was tree nuts (62%), followed by peanuts (38.5%).

Parental perceptions of their comfort, competency and satisfaction with the training on using the AAI are detailed in Table 3 and Fig. 1. When asked about how comfortable they feel when using the AAI device, 34 (72%) parents strongly agreed, of whom 28 (59.6%) moderately agreed, six (12.8%) strongly agreed, nine (19%) were unsure and four (8.5%) remained uncomfortable with the device. Overall competency in using the AAI was expressed by 38 (80.8%) parents, seven of whom (14.9%) felt very competent and 31 (66%) moderately competent, while nine (19%) were unsure. Overall satisfaction with the training on using the AAI was expressed by 42 (89%) parents of whom 26 (55%) were moderately satisfied, 15 (31.9%) were strongly satisfied, while five (10.6%) were unsure and only one (2%) remained very unsatisfied.

In the univariate analysis, there was no significant difference in the parental level of comfort in using the AAI, their competency in using it, or their satisfaction with the training received, when compared between fathers and mothers, or having used AAI in the past, or having been trained by a physician versus non-physician, nor when compared between children's gender, their age or the aetiology of their anaphylaxis (Table 3).

After adjusting for potential confounders in the ordered logistic regression model looking at the association of the baseline characteristics with the parents' level of comfort in using the AAI, their competency in using it and their reported satisfaction with the training received, only the competency in using the AAI was significantly associated with prior use of the device (Table 4).

## Discussion

To our knowledge, this is the first study carried out in the United Arab Emirates to look at factors influencing parental use of AAI for children at risk of anaphylaxis.

In our population, most cases of anaphylaxis in children were triggered by the common offending food allergens, in addition to sesame, responsible for 15% of the cases and previously unreported in local studies [2].

Despite the training provided and persisting doubts on when to administer the AAI, the parents' self-perceived technical competency and comfort level in using the device are less than desired. Regardless of all being trained by the allergy specialist, and although 36% of parents had the experience of administering AAI during an acute episode, 21% still had incomplete knowledge of the situations when they must use the AAI, and 2% were still not sure.

The level of comfort in injecting the AAI was inadequate or uncertain in 27.5% of the respondents and 19% remained undecided about their competency in administering the AAI. Results from a previous study revealed that only 30% of parents of children aged 0-18 years with food allergy and anaphylaxis, dared to use an AAI. Moreover, only 75% of the users demonstrated good skills and technique on using the autoinjector device [11]. Two-third of the respondents in our study were mothers, on whom the psychological effects, mainly anxiety, mental functioning when having a child with a food allergy or anaphylaxis, and their effect on the child's medical care has been well documented [10] and it may even exceed the amount of stress encountered by having a child with diabetes [11]. Reassuringly, parents who had previous experience in using the AAI expressed a higher level of comfort to use it again.

The perception of the quality of training revealed uncertainty or a clear negative opinion in 12.5% of the parents. Despite efforts to adequately train the parents on the management of anaphylaxis in their children, difficulties with the training remain, as highlighted by their perception of the quality of that training. Although it has been argued that it is not the knowledge of the previous experience of anaphylaxis which raises parents' comfort in using AAI, it was the empowerment, instead, with the continuous instruction and education on using AAI correlating significantly with the parents' level of comfort, in defiance of the presence of undefined psychological factors undermining parents use of the device [10]. For all these reasons, we believe that parents and caregivers should be encouraged to periodically use the expired unused auto-injector on inanimate objects such as cardboard, apple, orange, before discarding it. Such regular practical experiences would give them a real-time tactile and visual experience, as well as boost their confidence.

The range and magnitude of the psychological stressors that parents encounter seem to have been often overlooked and, as they have an impact on the outcome of any training and the parental empowerment, they need to be dealt with by consistently providing psychological support [12, 13]. Parent support groups where parental anxiety, fears and experience with the AAI when shared among parents would also be of help [12].

Like any self-administered questionnaire, our survey might have included parental recall bias or their selection of answers aiming to please the treating physician. These limitations might have been alleviated by a direct face to face interview, as well as asking the parents to demonstrate on an inanimate object or simulation mannequin how to administer the AAI. This would objectively assess the parents' confidence and competence better than simple parental recall or perception of the events. However, in an attempt to minimise the aforementioned bias, instead of using the time regularly allocated to review and consolidate parental knowledge and confidence with the AAI at the end of each clinic visit, we used it for the survey on that day, preventing, therefore, any, immediate, prior teaching to influence parental responses.

Another limitation is the small sample size and a single-centre experience, limiting the generalisation of our results. A larger multicenter study across the other regional paediatric clinics would have helped to overcome those limitations.

To better understand the parents' underlying beliefs and attitude in managing anaphylaxis in their child, a qualitative study will be needed by face to face interview. The aim would be to elicit, record and analyse their responses, comments and feelings about the psychological effect they endure and on their thought process when their child develops anaphylaxis. Such information would be helpful to clinicians and psychologists for developing appropriate interventions to help the families.

## Conclusions

There is a constant need to improve the educational and especially the psychological support to parents of children at risk of anaphylaxis. AAI trainer devices, useful as a tactual and visible tool, should be made

available to parents for periodical practice at home, to help to build their confidence. Using the expired AAI on objects, such as cardboard, apple or orange, may also help them to achieve the required confidence and alleviate their fears. Besides, the often lacking psychological support remains a crucial element to always include alongside the educational efforts for the parents and the child alike.

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### **Conflict of interest.**

The authors have nothing to disclose.

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### **Compliance with ethical principles:**

The study was conducted per the principles of the Declaration of Helsinki (2013). Ethics approval was granted by the Al Ain Hospital Research IRB Committee.

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