Strategies for living with the risk of anaphylaxis in children: qualitative study of young people and their parents

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Background: There is an increase in occasions when young children have had severe anaphylaxis reactions. As a result, children and their parents are being given Epi-pens to treat these reactions and have to learn self-management in these circumstances.

Aims: To explore the healthcare adaptations and information needed for children living with the risk of anaphylaxis; to understand the different perspectives between the parent and the child and how the Epi-pen can be improved and modified to meet the needs of children.

Methods: A qualitative study was undertaken using an in-depth interview with a child with a recent experience of severe allergic reactions and a separate interview with one of her parents.

Results: The 7-year old child and her parent took part in separate interviews discussing their experiences with the Epi-pen, how they found out she had an allergy and how they were introduced to it.

Both the mother and the child had similar responses to the questions asked. What we discovered is that they both reported not being instructed how to use it properly by the doctor but by the daughter’s school, although they were told how to manage the allergy by a dietician. We discovered that the situation did not dominate their lives and that they showed a moderate amount of confidence. The mother reported that she sometimes did not remember to inform others about her daughter’s allergy and how to instruct others about how to administer the Epi-pen.

Conclusion: A child who is fully aware of the risks of their allergy and is instructed how to use the Epi-pens (safely and responsibly) themselves, will manage well with the device. This study has highlighted the need for more Epi-pen training and better labelling of food products.

Introduction

Automatic adrenaline injectors are medical devices that contain a single, pre-measured dose of adrenaline. Also known as auto-injectors, Epi-Pens or AnaPens, they are the first line emergency treatment for anaphylaxis (potentially life threatening severe allergic reaction). Adrenaline works rapidly to reduce throat swelling, open up the airways and maintain blood pressure. These devices are prescribed for individuals who are at risk of anaphylaxis due to allergies to insect bites and certain foods such as nuts. Automatic adrenaline injectors are designed to be used by people who are not medically trained, and only for emergencies. They may be used by the person experiencing anaphylaxis themselves, or if they are unable to, then they may be used by a friend, family member or even a passer-by. These devices
are becoming more commonly prescribed and used due to recent increases in incidence of anaphylaxis\(^1\). Our aims are to learn about how a child with a risk of severe allergic reactions can manage their environment accordingly and how they get the balance, not only between safety and responsibility, but letting it dominate their lives and remembering whether to take it everywhere with them. A secondary aim is to understand the experiences of a parent of a child with anaphylaxis. This study is part of a larger body of research being conducted by the MATCH research programme at the University of Nottingham questioning adherence of these medical devices and their safety for their users.

Previous research has focused on adult and adolescent users of these devices. For example, Money et al\(^2\) found that adult users required more training by healthcare professionals. They also investigated ideas to improve the design of the device to encourage adherence and safety of the Epi-pen. However, until now, little research has focused on the experiences of younger users of these devices and their parents.

**Methods**

We were given permission to interview a girl of 7 years by the mother to explain in her own words what her allergy was and her attitudes not only to this but also the Epi-pen. We also separately interviewed the mother, to compare the responses of each of them. A semi-structured interview was undertaken to produce data based on the child’s attitude and understanding of having an Epi-pen for their allergy. We did this to see if the 7 year old understood how to administer the Epi-pen and could take any responsibility to tell people about the allergy, and how to be safe with it. We also asked if they had any ideas about how to redesign the Epi-pen so that it was more child-friendly and not too intimidating, or, if it was smaller and more compact it could be safer. The interviews were approximately 30 minutes long and took place in the participants’ home. At the start of the interview we gave the parent an information sheet and consent form to ensure that she was totally comfortable with us interviewing her daughter. We also explained that she didn’t have to answer all or any of the questions if she became uncomfortable. For the full interview schedule please refer to Appendix I.

Ethical approval was obtained from The University of Nottingham (MATCH). Once the recordings were made they were confidentially stored for the use of interviewer only.

**Results**

We interviewed a child, who was 7 years old, who has an allergy to walnuts and pecans. Her anaphylaxis reactions are severe and her allergy is on the increase (medically). We also interviewed her mother, to compare the differences in responses.

1. They found out about the child’s allergy when on a car journey to her grandparents’ house. She tried some mixed nuts and when she consumed the walnuts and pecans she started having a reaction, and immediately spat them out. The anaphylaxis symptoms developed when proceeding with their journey. The daughter complained of her tongue tingling and difficulties breathing. By the time they arrived at the grandparents’ house the daughter’s eyes had swollen and she was given antihistamines and an inhaler which eased the reaction slightly. After 20 minutes the state of the daughter’s reaction had not improved and she went to the local hospital. The hospital took a prick test and they discovered her allergy.

2. They both revealed that once given the Epi-pen they were not fully instructed by the doctor how to use it. They did, however, get referred to a dietician who told them how to manage the allergy.

3. Both the child and parent expressed how good the school were at cooperating and managing the food allergy. The school also instructed the parent how to administer the Epi-pen, as she had
previously only been told to read the unclear instructions on the Epi-pen.

4. The parent said that she was confident that her daughter could be responsible and safe if left with the Epi-pen. She admittedly said “My daughter knows more than I do about her allergy and remembers (when appropriate) to tell people outside the family and school situation, about the allergy. I sometimes forget to tell others and have never told another how to use the Epi-pen”. However, her decision about whether to tell people or not appeared to be influenced by the fact that she did not want people to label her daughter as another person with an allergy.

5. It was clear that even though they were only given one Epi-pen, they always kept it safely in a bag in the car with the parents’ contact details, if needed.

6. They both agreed that shop labelling of products that contain nuts or have a warning, should be more specific on what is actually inside and what food it was processed near (e.g. ‘walnuts’ rather than just ‘nuts’).

7. The daughter had a lot of ideas and ways to improve the Epi-pen’s design:
   - “Make it smaller and more compact so that children who have them can use them themselves, and more child-friendly”
   - “Make them safer for children by putting child locks on them

Discussion

This study found a number of interesting pointers of managing the risk of anaphylaxis reactions.

The mother reported that she did not receive training from the hospital on how to administer the device. She was simply told to “read the instructions at the time”. It is intriguing to think that this instruction and training is not compulsory for the doctors to supply to new users of the Epi-pen. She found this unacceptable and she relied on training from her daughter’s school. This supports previous research with adult users of Epi-pens.

It is also interesting that the mother was hesitant in telling a lot of people. For example her daughter’s dance school (if they have refreshments) because she was afraid that they would make a big deal about it and would label her as “another child with an allergy and a DANGEROUS Epi-pen”. The mother does not let the allergy dominate their lives (unlike some who would if they were more serious). This suggests that there is stigma associated with allergies.

Epi-pens are given to treat anaphylaxis, however, our study suggests that it is managing living with allergies and preventing reactions from occurring that is the important factor. Our participants appeared to be affectively managing the condition; evidence of this is the fact that she has not had another reaction since the diagnostic one. Strategies reported by the participants were:

- The daughter’s confidence in telling people about her allergy and that she has an Epi-pen at all times.
- The Epi-pen is always in the car which means that wherever the daughter goes the Epi-pen does.
- The daughter’s ability to report what she would do if she had a reaction. “I would go and get my bag with the Epi-pen and go to a member of staff (if I was out without my parents) and try and tell them to ring my parents and describe to them what to do with the Epi-pen, before the reaction got really bad.”

Study Limitations

This was a small study, consisting of interviews with just one child and one parent. We cannot therefore claim that the results are generalisable to all children and parents living with anaphylaxis. However, our findings do support the work of others in this field, suggesting that the experiences of our participants are likely to be faced by many other people.

In addition, as this was a project carried out by a school student and therefore her first time performing an interview, it is possible that a more skilled or experienced
interviewer would have identified additional issues, or been able to collect richer data. If we did the interview again we would interview more people and interview different children at different ages.

**Recommendations**

Due to our study we think that doctors and hospitals should provide training to all people who are prescribed Epi-pens because there is an increase in people who have severe anaphylaxis and it could be dangerous for the user if not introduced fully to auto-injectors. The increase in food-related anaphylaxis has raised the issue of it not being clear on labels what produce in shops contains or could have been near, on labels, so the risk for the anaphylaxis may increase further.

**References**

Interview questions (bullet points were prompts that were used when necessary)

You don’t have to answer any of the questions if you don’t want to.

**Mother**

Can you tell me about your daughter and her Epi-pen?
- Allergy
- Training
- Dangers/risks?
- School/(brief responsibility)

Have you used it yet?
- Where/when
- Symptoms/signs/signals
- Safety around others and herself
- How they felt when using it
- If not do (see bullet point 5 of last question)

Who takes responsibility for it at home/school/groups/friends’ house/parties/restaurants?
- Does everyone know how to use it?
- How does it make you feel (risks and dangers)
- At what age do you think your child would be responsible for taking the device with her (school or when older out with friends) by herself?
- Can she be trusted to be responsible and safe when not with you? Does she know how to use it?

How do you try to control situations in which there may be a risk of her having an allergic reaction?
- Talked to doctor/specialist? How often?
- Do you ever question whether to take a risk and not take the device out with you?
- Chances of risk?
- Do you know how to recognise the signs that she might be having a reaction and may need the Epi-pen?
- How would you decide when to use it? (seriousness)

**Daughter**

Describe you and your allergy for me please [name]?
- Allergy
- Did the doctor/parent tell you how to use it?
- Explain what you do if you have an allergic reaction
- Have you ever had one?

Who does the injecting if you are at home/school/groups/parties and you have a reaction?
- Do they/you know what to do and the signs to look out for?
- Do you know how to be safe with it? Where not to go or do with it (messing around)?

How does it make you feel knowing you have an allergy and have to have the Epi-pen?
- Do you know to tell people and your friends about it if you are not with your mummy?
- Do you go to see the Doctor about your allergy?
- Do you remember what foods and things not to eat or avoid?
- Have you told your friends about it?

Do you think when your older you will remember to take it out with you to school/groups/parties by yourself?

(I then give the daughter strips of paper with the following on to put in order of importance for her):

- More awareness in schools/doctors/restaurants etc.
- Supermarket labelling improvements
- Re-test for allergy?
- Re-told what to do? Instruction video
- Design/draw your own EpiPen
- Talk to friends about allergy
- Written plan for what to do in emergencies

Appendix I

What do you think about the design of the Epi-pen?
- Improvements?
- Too Big/Small
- Rough/smooth/Colours?
- Safe for all?