

ORIGINAL ARTICLE

Epinephrine auto-injector use in adolescents at risk of anaphylaxis: a qualitative study in Scotland, UK

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Summary

Background Adolescents with severe allergies are at particular risk of severe and fatal anaphylactic reactions. Epinephrine (adrenaline) is known to be under-utilized by teenagers.

Objective We sought to gain knowledge of adolescents' attitudes towards and experience of epinephrine auto-injectors in order to inform improvements in patient education.

Methods A qualitative study of adolescents in Scotland, UK with a history of anaphylaxis and their parents. In-depth interviews explored adolescents' accounts of anaphylactic reactions, including issues related to using epinephrine auto-injectors. Focus groups with adolescents and parents were used to discuss interventions to improve adolescent self-management of anaphylaxis.

Results Twenty-six adolescents and 28 parents were interviewed. Eight adolescents and 10 parents participated in separate focus groups. Most adolescents had not used the auto-injector in an anaphylactic emergency. We identified multi-faceted barriers to use, including: failure to recognize anaphylaxis; uncertainty about auto-injector technique and when to administer it; fear of using the auto-injector. Most adolescents reported carrying auto-injectors some of the time, though several found this inconvenient due to the size; only one reported non-use of an auto-injector because it had not been carried.

Conclusion and Clinical Relevance Adolescents and parents reported under-use of epinephrine auto-injectors. Carriage is insufficient to ensure that auto-injectors are used. Barriers to use are multiple and complex, and unlikely to be overcome using simple educational interventions. Auto-injector training currently offered is often inadequate preparation for an emergency. A more comprehensive approach is needed, addressing the psychosocial dimensions of anaphylactic emergencies as well as treatment. Training should ideally be provided by specialist allergists or nurses, but can also be provided and reinforced in primary care.

Keywords adolescent health, adrenaline, anaphylaxis, auto-injector, epinephrine, patient education

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Introduction

Adolescents with severe allergies are at particularly high risk of severe and fatal anaphylactic reactions [1–7]. The factors contributing to this are unclear as there has been no systematic research into the attitudes and experiences of this group. The observed high rates of morbidity and mortality may be due to a combination of limited allergen avoidance and poor emergency management amongst adolescents [4, 8, 9].

Intra-muscular injection of epinephrine (adrenaline) is the treatment of choice for anaphylactic emergencies.

Non-injection or delayed injection of epinephrine increases the risk of death [2, 6, 7, 10, 11]. Because anaphylaxis is sudden, rapid and usually unexpected, those believed to be at risk are commonly prescribed auto-injector devices for the administration of epinephrine in the community. Auto-injectors are not a panacea for anaphylaxis [7, 12] but, on the occasions when allergen-avoidance strategies fail, they can prevent fatalities if used correctly [13–16].

There is clear consensus in the research literature that auto-injectors are under-used by patients of all ages [3, 6, 13, 17–23]. The reasons for this have yet to be fully

explored. A recent paper [21] suggested that auto-injector under-use is commonly due to patients preferring to take antihistamines or not having auto-injector prescriptions, but more detailed research on this issue is urgently needed to inform improvements to clinical practice.

In particular, no studies to date have adequately investigated the non-use of auto-injectors by adolescents [22]. Because auto-injectors are central to the emergency management of this high-risk group, ensuring their correct use is a priority for clinicians. To do so, clinicians need to understand how and why adolescents respond in the way they do, taking account of the social context and the developmental transitions of adolescence. We set out to conduct an in-depth exploration of the barriers to auto-injector use amongst adolescents at risk of anaphylaxis and to investigate ways of overcoming those barriers to improve anaphylaxis management.

Methods

We undertook a qualitative study of 26 adolescents at risk of anaphylaxis and their parents ($n = 28$), living in locations across Scotland. A qualitative design was essential to generate detailed data about adolescents' experiences and attitudes and provide insights beyond the known general picture of auto-injector under-use [24, 25]. Our sample size was adequate to achieve data saturation, indicated by no novel information being gathered from the last three interviews [26].

Participants were purposively recruited from locations across Scotland through school nurses, allergy specialists, primary care, a patient support group, and via a press release. We sought adolescents at high risk of anaphylaxis, indicated by: (i) anaphylaxis in the last 5 years; or (ii) an earlier reaction and/or testing indicating high risk. We used the UK Resuscitation Council definition of anaphylaxis as a severe hypersensitivity reaction involving airway problems and/or circulatory problems [27]. Those who had experienced only mild reactions or reactions in early childhood were excluded. These criteria were designed to ensure the sample included those for whom anaphylaxis management was ongoing, and who were able to provide retrospective accounts of emergency management. This was essential to provide data about auto-injector use and non-use.

In-depth, semi-structured interviews, approximately 1 h long, were carried out with participants to explore their individual experiences of anaphylaxis and its management. Interview guides were devised around key ideas in the literature on anaphylaxis management and discussions about key issues for adolescents with several professional and patient/family contacts who had experience in this field. Interview topics relevant to auto-injector use included accounts of reactions, emergency management and what might improve management.

Interviews were carried out face-to-face (except one parent telephone interview) at the participant's place of choice, usually their home. Most chose to be interviewed alone, but in some cases parents, siblings and/or partners were present (32% of adolescent interviews; 38% of parent interviews).

Following preliminary analysis of the interview data, those who had been interviewed were invited to participate in focus groups to discuss possible interventions, including improvements to auto-injector design and training. Eight adolescents and 10 parents took part in the focus groups. Focus groups were chosen to enable the team to gauge the level of consensus and dissent amongst adolescents and parents about which interventions would be useful. The element of group discussion also allowed participants to debate, challenge and revise their views in ways which had not been possible in the interviews.

All interview and focus group recordings were transcribed verbatim, anonymized, entered into Nvivo [28], a computer programme which aids the organization and management of qualitative data, and thematically coded. Analytical validity was ensured through:

- Regular discussion of emerging themes and coding at multi-disciplinary project meetings.
- Comparison of transcripts coded independently by two researchers (M. G. and A. W.) during the development of the coding framework. Coding only began when they achieved a high level of agreement between their interpretations.
- Careful searching for data contradicting emerging findings.

Ethical approval for the study was granted by Fife and Forth Valley Research Ethics Committee (ref 08/S0501/24) and by Lothian and Greater Glasgow and Clyde Research and Development Offices. Informed consent was negotiated at the start of each interview/focus group. The nature of the study was discussed verbally with participants; the voluntary nature of participation was emphasized, and an opportunity was given to ask questions.

Results

Of 45 adolescents identified as potential participants, 29 were eligible. Three of these decided not to participate. Details of the 26 interviewees are presented in Table 1. Participants were aged 13–19 years; 54% were male. The majority were allergic to foods, predominantly peanuts and tree nuts. All but one had been prescribed an auto-injector at the time of the interview. The number of references to auto-injectors in both adolescent and parent interviews suggested that auto-injectors were central to the participants' experiences of anaphylaxis. Themes identified from the data in relation to auto-injector use

Table 1. Participant characteristics

ID no.	Anaphylaxis trigger	Gender	Age	Previous experience of anaphylaxis	Previous experience of AI	Referrer
002	Peanuts, fish, shellfish	M	19	Twice in last 5 years	Prescribed, available during reactions, not used	Allergy specialist
004	Peanuts, tree nuts	M	16	Twice in last 5 years	Prescribed, available during reactions, not used	School nurse
006	Peanuts	M	17	At least once in last 5 years	Prescribed, available during reactions, not used	School nurse
007	Trigger unidentified. Possibly idiopathic	F	13	Three reactions 2 years ago	Prescribed, never used	School nurse
008	Peanuts	M	14	Last reaction 7 years ago	Only prescribed following last reaction, so never used	School nurse
009	Peanuts	M	13	Last reaction 7 years ago	Prescribed, available during last reaction, not used	School nurse
011	Peanuts, tree nuts, sesame	F	15	Once in last 5 years	Prescribed, available during last reaction, not used	Patient support group
012	Peanuts, tree nuts	M	16	Last reaction 7 years ago	Parent attempted to administer AI in last reaction but it discharged spontaneously	Patient support group
013	Peanuts, tree nuts, insect stings	F	19	Once in last 5 years	Prescribed, available during last reaction, not used	Patient support group
014	Peanuts	F	13	Once in last 5 years	Administered effectively by school staff on two occasions	Patient support group
015	Peanuts	M	14	None, diagnosed as high risk by challenge test	Prescribed, never needed	Patient support group
016	Peanuts, dairy	M	13	Once in last 5 years	Only prescribed following last reaction, so never used	Family physician/school
017	Peanuts, dairy	M	13	None, diagnosed as high risk by specialist	Prescribed, never needed	Family physician/school
018	Peanuts, tree nuts	M	19	Last reaction 13 years ago	Only prescribed following last reaction, so never used	Patient support group
031	Lentils	F	19	Three reactions in last 5 years	Administered by friend of mother on one occasion but was ineffective (suspect due to delayed administration). Not used because not carried on another occasion	Allergy specialist
034	Peanuts	F	17	Once in last 5 years	Prescribed, available during last reaction, never used	University website
036	Peanuts, tree nuts	M	16	At least twice in last 5 years	Administered effectively himself on three occasions and by school nurse on one occasion	Press
039	Horses	F	19	Once in last 5 years	Not prescribed, never used	Press
041	Peanuts, tree nuts	M	19	Once in last 5 years	Administered effectively himself during last reaction	University website
043	Milk, eggs, nuts, sesame	F	15	Twice in last 5 years	Prescribed, available during reactions, never used	University website
044	Idiopathic	F	16	Twice in last 5 years	Prescribed, available during last reaction, never used	Allergy specialist
046	Tomatoes and other fleshy fruits	F	16	Three times in last 5 years	Prescribed, available during reactions, never used	Allergy specialist
052	Peanuts	F	14	Once in last 5 years	Only prescribed following last reaction, so never used	Allergy specialist

Table 1. continued

ID no.	Anaphylaxis trigger	Gender	Age	Previous experience of anaphylaxis	Previous experience of AI	Referrer
053	Milk, peanuts, egg	M	13	Once in last 5 years	Administered effectively by mother during last reaction	Public health nurse
055	Peanuts	M	14	At least once in last 5 years	Attempted to administer himself during last reaction but ineffective due to incorrect technique	Allergy specialist
067	Peanuts, legumes	F	17	Once in last 5 years	Prescribed, available during last reaction but not used. Administered effectively by mother on a previous occasion	Allergy specialist

AI, auto-injector.

included: carriage and storage of auto-injectors; desired improvements to auto-injector design; the difficulty of making the decision to use an auto-injector; experiences of training; and auto-injector technique.

The majority of adolescents had neither self-administered nor been given epinephrine via auto-injector, despite having experienced reactions that warranted this treatment according to current clinical guidelines. In most cases, this was not due to auto-injectors being unavailable: 18 adolescents reported anaphylactic reactions in which auto-injectors were close at hand and of these 11 reported not using their auto-injector. Only four had experienced an effective auto-injector administration in the community. Three reported ineffective use of an auto-injector. Only one participant recounted a reaction where an auto-injector was not used because it was not being carried at the time. Several of the participants who had not self-administered the auto-injector reported receiving epinephrine from ambulance staff, in the Accident and Emergency room or from school staff or a family member.

Approaching our data from a medicines management perspective [29], the correct use of an epinephrine auto-injector can be viewed as a process with several stages, beginning when the patient receives an auto-injector. Ideally, the person would then:

- undergo training in auto-injector technique,
- carry and store the auto-injector appropriately, so it is available for use at all times,
- identify an anaphylactic reaction when it takes place,
- know at what point in the reaction to use the device,
- make the decision to administer it,
- administer the auto-injector using the correct technique.

Our analysis identified barriers at all stages of this process, as illustrated below.

Training in auto-injector technique

The need for improvements to auto-injector training has been emphasized repeatedly [2, 4, 6, 13, 17, 18, 30, 31]. The extent and quality of the auto-injector training reported by adolescents in our study varied greatly. Some had regular reviews with specialists, at which they received training. Other participants reported having had training when the auto-injector was initially issued, but no follow-up since then. Even when provided, training did not always appear to be effective. Of the 11 adolescents who had experienced reactions in which auto-injectors were readily available but not used, six reported seeing an allergy specialist regularly at the time of the reaction. Similarly, of the three who reported ineffective use of an auto-injector, two were seeing an allergy specialist at the time of the reaction. These data suggest that even the auto-injector training currently offered by specialists may be inadequate preparation for an emergency.

Carrying and storing auto-injectors

Research suggests that many patients do not always carry their auto-injectors [6, 13, 17, 32]. Parents placed strong emphasis on carrying auto-injectors at all times, and this created some parent-adolescent conflict on occasions, as adolescents did not always wish to carry their auto-injectors if they perceived risk as low. There were sometimes differences in perceptions between parents and adolescents regarding the degree to which adolescents were in control of their anaphylaxis management, some parents perceiving a lack of risk-awareness in their teenage children. Contrary to common stereotypes, most adolescents we interviewed carried their auto-injectors at least some of the time (Table 2). Several participants, mostly females, reported carrying the devices at all times. At the other end of the spectrum, one young man said that he rarely carried his auto-injectors. Many said that they

Table 2. Carrying and storing auto-injectors

<i>I always carry two with me . . . we know it's really serious and we've basically got to carry our EpiPens all the time (Sophie, 19)</i>
<i>I've always got it in my school bag, like if I go it's in my fitba [football] bag and if I'm going out [out] I give it to my pal to watch or something if they've got pockets or that, so I'm alright with that (Kevin, 13)</i>
<i>I think they're just too big, I've got to carry enough as it is and I'd usually check before I eat stuff and if I didn't know about it so it's usually OK . . . If I'm with my parents they'll have it usually, but apart from that no, it usually just stays in the cupboard (John, 16)</i>
<i>I carry it most of the times when I'm out of the house, most of the times when I'm like going into town or going to parties and such like, but if I'm just going like down to the shop or something like that I don't normally take it because it's just like an encumbrance generally (Chris, 16)</i>
<i>It's just the sheer hassle of having to take it, you know, it's like, I mean they're quite big and they don't fit in any of my pockets (Steven, 19)</i>
<i>It can be quite awkward at times to carry . . . I don't mind though, it's important obviously so it's one of the things you just have to deal with (Rebecca, 17)</i>
<i>It's big and bulky but it's better than not having them. I know somebody who has an allergy to peanuts and he doesn't carry EpiPens at all because they stick out in his trousers or something daft like that, but he's a bit silly about it. Funnily enough he was in hospital a couple of weeks ago because of a reaction, so he doesn't learn . . . They're a wee bit uncomfortable when I'm sitting down sometimes but usually it's fine. So yeah, I'm not overly bothered about carrying EpiPens (Ben, 19)</i>

carried their auto-injectors in some situations – particularly at school and when going out to restaurants – but not others, such as when playing sport or at a friend's house close to home, where they perceived less risk. Many interviewees complained that the auto-injector is bulky and cumbersome to carry. Some, particularly males, said that this influenced them to carry their auto-injector less frequently. Not all shared this attitude, however. Some adolescents acknowledged the annoyance of having to carry an auto-injector, but said that its potential benefits outweighed the inconvenience.

It is noteworthy that, although adolescents and their parents discussed carriage of auto-injectors at length, only one young person reported not using an auto-injector due to failure to carry it. By contrast, 11 participants reported non-use even where an auto-injector was on hand. Carriage, though important, was clearly insufficient to ensure that auto-injectors were actually used when needed.

Identifying an anaphylactic reaction

Deciding to administer an auto-injector depends upon patients or their family/friends recognizing that an anaphylactic reaction is taking place. This is not straightforward as symptoms can vary between reactions. Two adolescents reported not using an auto-injector, despite having one available, because they did not realize that

they were having anaphylactic reactions. In both these cases, the adolescents had thoroughly checked the ingredients of the food that had triggered the reaction. Anaphylaxis therefore seemed to them to be unlikely, further hindering their self-diagnosis (Table 3).

Knowing when to use an auto-injector

Assuming that an in-date auto-injector is available and an anaphylactic reaction has been identified, the person needs to know at what point to use the auto-injector. Some adolescents seemed clear about this. However, several young people and parents expressed confusion over when to use the auto-injector. Of particular concern is the finding that, contrary to current clinical recommendations [21, 27], several young people thought that an auto-injector should be used only in the late stages of a reaction (Table 3).

Even where a reaction was recognized as anaphylactic and an auto-injector was readily available, adolescents and their parents did not necessarily take the decision to use it. Several expressed a sense that, looking back, they should have used the auto-injector but did not. The reasons for this reluctance were multiple and complex, including denial about the severity of the reaction, optimism that the situation would resolve without treatment, fear and anxiety about how the auto-injector would feel and what its effects might be, and panic during a reaction. Some parents provided stark descriptions of the emotional dimensions of using an auto-injector, the sense of responsibility a parent may feel in a 'life or death' situation, and the disparity between theoretical knowledge of how to deploy the auto-injector and the reality of doing so in a genuine emergency (Table 4).

Administration technique

The final stage of the auto-injector process requires patients, or someone else present, to be able to administer the auto-injector correctly. Our study reinforces previous findings that many patients are unable to demonstrate correct auto-injector technique [17, 18, 30]. Some expressed a lack of confidence in their auto-injector technique, despite having received training. Even where specialist training is provided initially, auto-injector technique may be forgotten over time. Training using plastic 'dummy' auto-injectors (training devices with no needle or epinephrine) was seen by some as inadequate preparation for a real emergency (Table 5).

Potential interventions to improve epinephrine auto-injector use among adolescents

Focus group participants discussed a range of interventions to support self-management, based on themes

Table 3. Recognising anapylaxis and knowing when to use the auto-injector

<i>I was finding it really difficult to breathe and I just, and I thought, 'oh I need my EpiPen, I really, really need it'. So I just went to the [school] office and they gave me it . . . I automatically knew I need to take my EpiPen now kind of thing (Karen, 13)</i>
<i>I thought I was having an asthma attack, which is really scary because like I thought if I had an anaphylactic shock I would be throwing up, because that's what it was when I was little, that's why I didn't use the EpiPen because I didn't know what I was having (Sophie, 19)</i>
<i>I had plenty [of auto-injectors available]. But because that time the symptoms were different, the time before it had been sore throat, feeling sick, vomiting then a rash and then feeling light headed at the same time, and this time it was just the sore throat and struggling breathing . . . it wasn't until we got into the car I suddenly thought no this is the same thing (Rebecca, 17)</i>
<i>If it was like really, like really starting to affect my breathing and I was like nearly passing out maybe, then like hopefully just before that then I would take it then, like if I couldn't stand up any more (Alison, 15)</i>
<i>Just if I felt that things were getting a wee bit scary kind of thing . . . Like my throat, like my breathing getting really bad. (James, 17)</i>
<i>I assumed that I would just be knocked out [out], and would black out and someone else would have to use it. But I didn't realise that I could use it if I was just going into it [the reaction] (Fiona, 17)</i>
<i>Would you take it when you feel it coming on or when it's there? . . . you don't know if I should take it now or if I should wait till it develops and then see how it goes, if it's going to calm down and if it doesn't calm down should I take it then, or do it before, like nip it in the bud (Lisa, 16)</i>
<i>Are you bad enough to use it, that's the big issue . . . she had a couple of times where she probably should have took it and she's asking me and I hadn't a clue, I didn't know (Mother of Lisa, 16)</i>

identified in the interviews. The most popular potential intervention was effective treatment for allergies, such as immunotherapy. Participants also expressed a wish for more specialist allergy services, particularly to support the transition from childhood to independent self-management through adolescence and into adulthood. Improved public awareness of anaphylaxis, the use of social networking sites for virtual support and better food labelling were all identified by participants as potentially useful strategies to prevent and manage anaphylaxis.

In relation to auto-injector use, many adolescents expressed the desire for a less bulky auto-injector design. There was unanimous support amongst participants for a new product, currently in development by US company Intelliject (Richmond, VA), which, unlike the current cylindrical designs, has a cuboid shape designed to fit easily into a pocket [33].

There was consensus within the focus groups that improved auto-injector training, including regular refresher training and supportive follow-up, could help to improve management. Some participants thought more follow-up could be provided in primary care, but others thought this was a specialist role. The possibility of

Table 4. Emotional barriers to effective auto-injector use

<i>I mean to be honest I would hesitate, I'd like to think I wouldn't but I probably would, I'd try not to [use the auto-injector] . . . I don't know if it's a kind of denial thing if you don't want to think you're having a reaction or what it is I'm not sure (Darryl, 14)</i>
<i>I'm worried about if it's going to hurt or that because I've never actually had to take it and I'm not very fond of getting needles or that (James, 17)</i>
<i>I'm quite feart tae [scared to] use it to be honest with you, like I don't know, like people say I thought they caused irregular heart beat but I don't know . . . something just scares me about it . . . I don't think I'd be able to do it myself, because I'd go to do it and stop because I know what's coming . . . there's something really about [about] taking this EpiPen that just, I'm terrified, I don't know why, so I just try to avoid it at all costs (Lisa, 16)</i>
<i>'I don't want the pen, I don't want the pen,' she just kept screaming . . . there was no way that I could have safely gave her the EpiPen in the situation. There was too much panic, she was hysterical, I was kind o hysterical myself, no that I was screaming or anything, you know, but I thought if I give her this am I going to hurt her or am I going to put it in a vein, it was all going through my head because there was too much panic in the bedroom (Mother of Catriona, 19)</i>
<i>I hope I never, ever have to dae [do] this again, it was the most frightening experience I've ever lived wi' . . . although I knew how tae dae [to do] it I didn't know if I could actually dae it or no because I was absolutely terrified . . . he was screaming and I was shaking . . . I thought oh my God what's going to happen when I gie [give] him this? That was my fear that I wouldn't have gave him it properly and he could have died . . . if I didn't dae that right, how could any parent live wi' themselves knowing they never gave their child that, you know . . . it was just total panic, panic in my case and I think when you panic the kids panic even worse . . . I was confident that if I ever had to use it I would know how tae dae it but when it actually occurred then I just total froze, I just thought oh my God I don't know if I can dae this . . . I literally thought oh my God if I dae this wrang [wrong] my child could be dead and it's my fault (Mother of Kevin, 13)</i>

providing refresher training each time a patient received a new auto-injector prescription also received some support in focus groups.

Discussion

Summary of main findings

Our study demonstrates that the barriers to effective use of auto-injectors by adolescents and their parents are multi-ple and complex. In addition to the technical ability to use an auto-injector, patients require the motivation and self-discipline to carry the medication, the ability to identify a reaction, knowledge of when to use the device and preparation for managing the challenging emotions which tend to accompany anaphylactic emergencies. Interventions are unlikely to succeed unless these diverse barriers are addressed.

Table 5. Auto-injector administration technique

<i>I just think I'd do it wrong . . . I don't feel confident about stabbing myself with a needle (Callum, 13)</i>
<i>At first when I got given it I was, I couldn't get ma head round it . . . I thought you had to press a button, they're like no you don't press that, it'll go through your bloody thumb (Catriona, 19)</i>
<i>They showed us how to use it but I think that's how many years noo [now], three or four years? I mean I'd be struggling to remember exactly what tae dae [to do] . . . I would say maybe going back and getting trained maybe once a year or something because I honestly widnae ken [wouldn't know] what tae dae. (Father of Theodore, 13)</i>
<i>I thought it was just like a wee tiny needle that you wouldn't actually feel and it would just go in you, but when I actually found out the truth it was just like a huge thick needle and that's the part where I really panicked . . . I sort of pushed it against my leg and then it just sort of bounded back . . . The needle just bounced back off my leg . . . I pressed it but it just went boom, just bounced back. I must be made of iron or something (Antony, 14)</i>
<i>Because it's always been . . . using the dummies and then when, you know, it was for real it was still a shock even although he knew what to do, you know, the sort of mechanism to go through, etc, it was still a shock . . . don't do the dummies because I don't know, maybe it works for others, I don't know, but it certainly didn't work for him (Mother of Antony, 14)</i>

Strengths and limitations of the study

This research is the first in-depth study of adolescent attitudes and behaviours regarding auto-injector use. Both adolescents and their parents were interviewed at length, enabling the researcher to probe and discuss fully the issues surrounding auto-injector use. While previous studies have identified that adolescents tend not to use auto-injectors in an emergency, this is the first study that provides detailed explanations of why this happens.

The most obvious limitation of this study, as with most qualitative work, is the small number of participants. Inevitably, this restricts the generalizability of the findings and the opportunity for subgroup analyses, such as age and gender. However, qualitative research uses an intensive approach, exploring a topic in detail and developing insights into why people act in certain ways [25, 34]. This can usefully inform clinical practice by helping professionals to understand patients' perceptions and behaviour [34]. Larger surveys of this issue have already been carried out [21], but such methods provide only limited insights into the underlying reasons for under-use of auto-injectors. The qualitative design therefore complements and extends the understanding derived from quantitative studies [25, 35].

Comparison with existing literature

Our findings reinforce the message from previous studies that auto-injectors are under-used in anaphylactic emergencies [3, 6, 13, 17–22], and that training is currently

inadequate. However, the detailed qualitative data provide a range of additional clinically important insights. Our study highlights that, contrary to the stereotype, many adolescents are often conscientious about carrying emergency medication but lack confidence in using it. Previous surveys have identified psychological barriers, which contribute to self- and parental administration of auto-injectors [21, 22], but the emotional dimensions of their indecision have not previously been detailed. We suggest that these are key factors for clinicians to take into account when discussing anaphylaxis management with young people and parents.

Implications for future research or clinical practice

There appears to be a tendency for adolescents, parents and professionals to focus on ensuring frequent carriage of auto-injectors, while neglecting the fundamental issue of whether adolescents and those around them can use auto-injectors when anaphylaxis occurs. Several participants in our study who reported carrying their auto-injectors at all times also reported not using them in emergencies. We suggest that, while carriage is clearly important, far greater emphasis should be placed on ensuring that adolescents and their parents are prepared to use their auto-injectors.

The need for improved auto-injector training has been a recurring theme in the literature on anaphylaxis [2, 4, 6, 13, 17, 18, 30, 31]. Our study suggests that, in addition to demonstrating injection technique, such training should:

- ensure that patients understand that auto-injectors should be used swiftly rather than waiting, even if in doubt about the severity of a reaction,
- address the fear and panic commonly associated with using an auto-injector,
- train patients in recognizing anaphylaxis, taking into account the wide variability of symptoms, especially between different episodes in the same person,
- inform patients about possible side effects of epinephrine, offering reassurance about its safety if used unnecessarily,
- take account of individual differences, developmental stages [36] and differences in allergens in tailoring training to patients' and families' specific needs and preferences,
- be followed up with at least annual 'refresher' sessions, either by a specialist nurse or allergist or in primary care.

One way of addressing training needs is through online training in auto-injector use, available at <http://etraining.allergy.org.au/index.php> and <http://www.anaphylaxis.org.uk>. Health professionals may wish to work through such resources with patients and family members to ensure understanding and answer any questions.

Our study suggests that simulated auto-injector use with training pens or using expired auto-injectors to practice an injection into fruit was not necessarily helpful in preparing people to self-inject. Real self-administration of epinephrine auto-injector under clinical supervision has been tried in clinical practice, with reported increase in confidence among patients that they would use their auto-injector if needed in the future [37]. Our focus group participants were divided about whether this would help, but some felt strongly that it would. This form of training therefore deserves to be trialled and properly evaluated.

Research and development of improved emergency treatments is also warranted. An auto-injector that is smaller, easier to carry and administer would be welcomed by many patients [23]. Alternative methods of dose-equivalent epinephrine delivery, such as the sublingual route [38], should be explored further.

Finally, it should be emphasized that prevention of anaphylaxis remains crucial for good management. Regular discussion of strategies for avoidance is recommended, particularly for adolescents, who are experiencing new social situations. This will vary considerably depending on the allergen.

Clinical relevance

The under-use of epinephrine auto-injectors in anaphylaxis is likely to contribute to fatalities. Improving the

readiness of patients and families to use emergency medication is therefore vital. This study shows that barriers to use are multiple and complex and unlikely to be overcome using simple educational interventions. A more comprehensive approach to auto-injector training is needed, addressing the psychosocial dimensions of anaphylactic emergencies. Training should ideally be provided by specialist allergists or nurses, but can also be provided and reinforced in primary care.

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