

Why do young people with allergies join support groups?

End of study report

Executive summary

Young people are frequently recognised as being most at risk of anaphylaxis. This may in part be due to difficulties in effectively managing severe allergy. It has previously been assumed that poor management was due to lack of knowledge, confidence and training in using auto-injectors (AIs). In a recent study of 188 young people, we found that better adherence to self-care behaviours (e.g. carrying an AI and avoidance of allergens) were associated with being a member of a support group. Among participants in our study we found no association between their knowledge of adrenaline use and adherence, challenging the commonly held assumption that it is poor knowledge of managing anaphylaxis that is the underlying reason for non-adherence.

No guidelines explicitly recommend membership to a patient support group but our observations suggest benefit that is worthy of further exploration. This is important in order to discover which activities and resources offered by support groups are particularly influential in promoting adherence. The aim of this qualitative study was to explore why young people with severe allergies join support groups, areas they find important and resources offered that influence and promote adherence.

In-depth, semi-structured interviews were conducted with young people (aged between 12-21 years old) with severe allergies who belonged to an allergy support group. Interviews were audiotaped, transcribed verbatim and analysed using a thematic approach. 21 young people with food, venom or latex allergies, were recruited from a range of physical and online support groups. Of these, 18 young people joined support groups on recommendation of their parents or self-referral.

Some participants highlighted that they previously had “never even realised there were support groups”, emphasising that such support for young people is not widely publicised. This lack of awareness caused many young people to experience severe isolation “if I say that I want to go to a sleepover... I can never go because my friend’s Mums aren’t willing to take that responsibility. So I am left out on most things.” Anticipating emotional and psychological benefits appeared to be the most fundamental reason for joining a support group, but young people were also interested in learning more about their allergies and how to manage these effectively. The importance of feeling included and sharing experiences was emphasised by the beliefs that support groups brought “unity” and comfort in meeting with those “who understand what you’re going through”. Confidence was felt to increase after support group involvement and this was highlighted by improved self-assurance when using their AIE (auto-injectable epinephrine), the ability to disclose their allergies in restaurants and to others without allergies.

This study highlights the role support groups play in aiding young people in managing their allergies and adhere to positive self-care behaviours. Participants expressed how groups provide positive experiences by reducing their isolation, connecting them with others in similar circumstances and improving their confidence in managing allergies. Young people

reported a need for increased awareness of support groups, as well as greater geographical distribution of groups.

Literature review/background

Allergy can be triggered by a number of substances such as pollen, dust mite, food, medications, insect venom and latex. There is a wide range of allergic symptoms from mild and localised to severe, life threatening multi-system reactions. Anaphylaxis, characterised as being rapid in onset with life-threatening airway, breathing, or circulatory problems and usually associated with skin or mucosal changes (1), is the most serious form of allergic reaction but can be managed acutely by the prompt administration of epinephrine. Anaphylaxis can be fatal and a review of deaths highlighted that most victims are adolescent or young adults (2, 3). Anaphylaxis management guidelines recommend that at risk patients carry their auto-injectable epinephrine (AIE) at all times (1, 4).

Lack of adherence to recommended treatment and self-care is not unique to allergy; it is common in all disease processes. A World Health Organization study estimated that only 50% of patients in developed countries adhere to treatment guidelines (5). Adherence is particularly troublesome amongst adolescents, with levels as low as 10% reported for some chronic conditions (6). A recent study reported the estimates of adolescent adherence to carrying AIE is 41% (7). Barriers to using AIE in adolescents include not being able to decide when it is necessary to administer the device, unawareness of the severity of reactions, inappropriate optimism that the reaction will resolve on its own, fear and anxiety (8). Some adolescents also take risks by continuing to eat foods containing the allergen, not informing friends or peers of their food allergy or how they could help in the event of an acute reaction (9).

Traditionally interventions to improve adherence to medication and self-care behaviours have been largely educational, aiming to improve patient knowledge. In these instances the health professional is seen as the expert who is there to impart knowledge to the patient, and the patient as the obliging and willing recipient of this knowledge, who will comply accordingly (10, 11). Whilst research has shown that adherence is positively related to a patient's understanding of their disease and its management (12, 13), it is now widely recognised that knowledge alone is insufficient to change complex behaviours (14, 15). As adherence to self-care behaviours for individuals with food allergy involves a set of complex behaviours and lifestyle changes (such as avoiding foods and certain situations, in addition to carrying medication) prior to developing new initiatives to promote adherence among adolescents it is important to better understand the range of factors which are associated with good adherence as well as those that act as a deterrent (6).

A recent study explored the factors which affect adherence to health sustaining self-care behaviours in adolescents with severe allergy (7). The results showed that good self-care behaviours were 2.5 times more likely when young people were members of an allergy or anaphylaxis support group. Although the results were supportive of patient groups, the cross-sectional design of the study impedes drawing conclusions on causality. The observed association may arise because the patient's own motivation to join a support group is the

same as that which leads them to engage in desirable self-care behaviours. Further research is needed to explore how and why adolescents interact with support groups and what they perceive as the helpful aspects.

Study aims and objectives

No guidelines explicitly recommend membership to patient support groups but these observations suggest benefit that is worthy of further exploration. This is important in order to discover which activities and resources offered by support groups are influential in promoting adherence.

The aim of this research was to understand young people's rationale for belonging to support groups and discover what activities or support they find particularly important. This information will be useful to support groups such as the Anaphylaxis Campaign and Allergy UK, to provide more tailored support to young people at greatest risk of anaphylaxis.

This study will build on the existing quantitative evidence and address four questions:

- 1) What motivates young people to join support groups?
- 2) What aspects of support groups are effective in encouraging individuals to adopt positive self-care behaviours?
- 3) How can young people and young adults be encouraged to join support groups?
- 4) What information/support/activities are currently not met by the support groups?

The information provided by participants will be used to provide feedback to support groups on what is currently working well and what aspects young people would like to see improved.

Methods

The research study is a qualitative study exploring young people's rationales for joining support groups and understanding what are the most influential resources for promoting adherence. The conceptual approach used was interpretivist/constructivist whereby the researcher relies upon the participants' views of the situation being studied and recognises the impact on the research of their own background and experiences (16). Interviews were semi-structured and focussed on what motivated the individual to join a support group initially, what aspects they find particularly helpful/unhelpful from their support groups, how they think management of their allergy is improved by their membership and what might attract others to join. Participants were also asked to identify areas for improvement regarding resources currently provided by their support group.

Participants and recruitment

Inclusion criteria

- Young people aged 12-21 years

- Physician diagnosis of allergy
- Current member of a support group
- Young person and/or parent guardian is willing and able to provide informed consent/assent
- Fluent in English

Exclusion criteria

- Young person and or parent/guardian is unwilling or unable to give informed consent/assent
- Unable to speak or understand English

Procedure and consent

Young people aged between 12-21 years with allergies and who were members of a support group were invited to participate. Participants were recruited through online social media support groups as well as physical support groups run by The Anaphylaxis Campaign. Allergy and anaphylaxis groups advertised the study on their websites, within their newsletters and through email to their current members providing information about the study and the contact information of the Principal Investigator. Potential participants had the opportunity to discuss the study with the Principal Investigator. If they remained interested, an age-appropriate participant information leaflet, consent/assent forms and freepost envelope was provided, either by post or by email dependent on participant preference prior to the commencement of arranging an interview time and date.

The study followed the Children's Research Network Standard Operating procedures for obtaining informed consent. In research studies where a person under the age of 16 is considered competent to give an informed view on the question of participating in a research study, they should be allowed, and facilitated to do so. All participants in this study consented for themselves where they were capable of understanding the nature, purpose and likely outcome of the research. Parental assent was obtained for young people aged under 16 years.

All participants opted for telephone interviews (a choice of telephone, online video and for those in Brighton-London area, face-to-face were offered. Interviews lasted between 30-60 minutes and followed a semi-structured guide aiming to cover four key areas, allowing the participant maximum freedom to discuss the issues of importance to them, and to avoid unintentional prompting. The interview guide was designed so as best to satisfy this structure, using participant-friendly phrases, and to achieve answers to our research questions.

Data analysis

A power calculation was not appropriate as the study is qualitative in nature. Recruitment continued until theoretical saturation was achieved, usually around 20-30 participants. Interviews were recorded and transcribed verbatim. Thematic content analysis was performed on the interview transcripts based on Burnard's structured approach (17). As per

protocol, transcripts were analysed manually, no computer software was used. Transcripts were analysed throughout the project so that emerging themes could be fed into subsequent interviews. These were triangulated between two researchers independently.

Results

Twenty one interviews were conducted. Respondents ranged between 12-21 years (mean 17 years, mode 15), 13 (62%) were female and came from across England and Scotland (Figure 1). Participants had a range of allergies including food, venom and latex, and were recruited from a range of physical and online support groups. Of these, the majority (86%) joined support groups on recommendation of their parents or self-referral. Only three participants were explicitly recommended to join an allergy support group by their health care professional (Table 1).



Figure 1. Geographic distribution of participants across UK

Table 1. Demographic and clinical characteristics

Age	Gender	Duration of membership (years)	Allergy	Experience of anaphylaxis
14	F	10	Nuts (desensitized to tree nuts), kiwi	Yes
15	F	2	Nuts, dairy, intolerant to wheat, soya and gluten	No
15	F	1	Nuts, peanuts, lupin, legumes	No
16	M	16	All nuts, sesame, lupin	Yes
18	M	8	Most nuts, eggs, sesame (anaphylaxis) aspiring, penicillin, elastoplast, strawberries (allergy)	Yes
14	F	10	Peanuts (avoids all nuts), allergic to animal dander	Yes
14	M	13	Nuts and eggs	Yes
15	F	2	Peanuts, most tree nuts	Yes
12	F	3 months	Eggs, all nuts, seeds, legumes, sesame, coconut, paprika	Yes
13	F	3	Peanuts (animals)	Yes
21	F	1	Peanuts (nut, pregabalin, gabapentin)	Yes
20	F	2	Peanuts (avoids all nuts)	Yes
12	F	9	Eggs, nuts, bananas, kiwi, latex	Yes
21	F	3	EiA to wheat, barley, rye, oats, allergic to celery, walnuts, cod, wasp venom, milk, seafood	Yes
16	F	6	Milk, eggs, nuts	Yes
15	M	6 months	Peanuts, almonds	Yes
12	M	3	Nuts, seeds, banana, kiwi, eggs, peanuts	Yes
15	M	5	Eggs, nuts, peanuts, wheat, gluten, most fruit and veg	Yes
19	M	12	Nuts, fish, milk, peas, sesame, poppy seeds	Yes
21	F	4-5 months	Milk, peanuts, all nuts, protein PR10, various medications, type 1 latex allergy, dust mite, mould, hayfever	Yes
14	M	10	Peanuts, raw eggs	Yes

Motivation for young people to join support groups

Whilst the majority of young people were members of support group by proxy through their parents, *the emotional and psychological benefits of membership* appeared to be the most fundamental reason for others to join or remain engaged with the groups. The benefits largely centred on the *appreciation of shared experiences and feelings of inclusivity*:

“It has just really helped to have someone to like ... who understands what you are sort of going through. And it is just really easy to talk to them about it” (Female, aged 15)

“A lot of times you just feel the ignorance from other people and people think you are just being a fussy eater, when they don’t understand the anxiety. You can just talk to them and they completely understand. And I think I just ... I felt quite relaxed when ... and not so alone with the allergy.” (Female aged 20)

"I don't feel like I am alone or anything. I feel like ... I don't know, it is easier to make friends with them because they know what ... like we all go through the same things" (Female, aged 14)

"But I also found it really useful just to meet other people and speak to them; because I didn't ... I was kind of in my own world as lots of 6 year olds are. And I didn't really realise that there are other people with allergies, doing the same things as I was. So that was useful just to meet other people" (Male, aged 19)

"And I think ... I think the thought of going somewhere where you are all the same and you are all equal, is quite nice; because I met like a girl who is at my age, and we had so much in common. It was like ... you think sometimes you are the only one who understands, but there are so many other people who are out there" (Female aged 12)

In addition to helping reduce feelings of isolation, support groups were also felt by young people to *improve their self-esteem and confidence* in both life generally and in managing their allergies:

"I now actually want to leave the house and I want to go out and sort of live life without feeling quite as bad as I was" (Female, aged 21)

"It made me feel more confident because I ... it would get to know and like speak to adults who are these big scary things (laughing) when I was a young kid" (Male, aged 19)

"When I go away from home I know how to take care of myself, I feel like I know what I am doing" (Male, aged 15)

Aspects of support groups which are valued and effective in improving self-care

Support groups were also seen as *useful sources of information*, where young people felt that *positive self-care behaviours were reinforced* such as carrying medication:

"I watched one [video] where a girl didn't take it [EpiPen] out because she decided to take lipstick out instead. And obviously a boy wouldn't do that but ... she kissed someone or something that had eaten peanuts and it shows you that it can happen if you don't take it out and you swap it for something else, just 'cos you want that instead in your bag.... you should always take it out. Even if you wanted to take something else it is probably more important" (Male aged 14)

"I think that made a massive difference with people sharing what they had been through with their anaphylaxis and how bad it can get, like with ITU and stuff. It made me think maybe I should carry my EpiPen with me everywhere" (Female aged 21)

"I just think it reinforces it so when you see posts you just ... like if there was any like ... if there was maybe a tiny bit of my mind thinking "Maybe today I will risk it and go out without my EpiPen" I would see this online and think "No."" (Female aged 21)

"But it is quite good I think support groups have helped me from that point of view – to actually sort it out and take my EpiPens and things like that." (Female aged 21)

“Well I myself know the importance of always carrying it, but definitely reinforces it, because you hear all the other things that other people go through, all the things that can happen.” (Male aged 15)

*“Yeah well that is what I was doing beforehand, because to be honest with you before I joined these groups I didn’t really kind of take my allergy seriously. I would go out and not take my EpiPen like ... I would eat anything. Because I didn’t ... I just didn’t really take it seriously.”
(Female aged 20)*

In addition to reinforcing the carriage of medication, specific information and resources were valued such as the *fact sheets* and *advice on managing interactions with restaurants* and the *opportunity to ask the experts questions*:

“I think they do a very good job with the information side of what is an allergy and what foods and things are like included in the allergy, like the fact sheet” (Male aged 19)

“I think it gives me the knowledge of what I need-should be doing, probably better than the healthcare team that saw me initially. But it is difficult to say because I was such a young age. And then once ... once I was diagnosed I wasn’t really told again by the healthcare team, like what I should be doing. So that was more from the charity side that I got that knowledge” (Male aged 19)

*“They have given me sort of like information stuff of what my allergens can be included in or how to deal with it or recommendations for restaurants or things”
(Female aged 15)*

“One group had run and it was things where there were hidden allergens like all the wheat in hair spray... I was like “Oh God” and it sounds like a lie now when I say it but it was there in black-and-white that I physically hadn’t looked. So it was stuff like that that I have found really helpful because I know without a support group I wouldn’t have found those links.” (Female aged 21)

“They actually recommended that we like spoke to the restaurant beforehand. Or sometimes you can take your own like food. Like I went to Pizza Express once and they ... I took my own pizza base and they were ok with that. I think I got recommended that by the group.” (Female aged 15)

“So if you needed advice you could like talk to one of them or you could write down questions for the next time you meet. And then they will give you a good solution to it”(Female aged 15)

The provision of this information and resources led to *feeling more empowered and in control of their allergies*:

“I like seeing the things that otherwise I might not see. It gives me some form of like a control. You know I am more ... I am in control of this because I have seen that, you know, that one on the hairspray I was (unclear) so I am not going to buy that, so I am in control of that.” (Female aged 21)

“Some people ... like don't let their kids like leave the house, pretty much. That is just ridiculous because you can't really have a life if they are just living in the house permanently. And they can't really grow up or anything. Or learn how to manage on their own, which is what they are going to have to do when they get older.” (Male aged 16).

Other areas which were particularly valued by young people were the *food alerts* and *up-to-date- information* shared and posted via social media outlets:

“Their Facebook page sort of shows you new and interesting articles about how allergies are being handled in different situations or news things on different developments and stuff. So it is like a way to keep up with everything that is happening and how it might affect you and your friends and your family and stuff like that” (Female age 15)

“The texts are really, really helpful because if you have bought something and you think it is fine, I think you are aware that you can't eat it, because otherwise you will have an allergic reaction, if you are not aware of it.” (Female aged 12)

“The main thing is like brands of foods – that is the main thing that I get from these groups anyway. But I have found so many foods I probably wouldn't ... I wouldn't even think about checking or that I wouldn't know that I could have, if it wasn't for these Facebook group.” (Female aged 15)

Workshops and training days were also highly with experienced specialists were highly valued:

“When you go on the workshops they like teach you everything there is to know really about your allergies. Like what actually happens and ... err ... what is the best way to deal with it, and why you should carry medication. And it is not like to ruin your life or anything, it's just because if you don't have your medication and something goes wrong you die. There isn't like a second chance.” (Male aged 16)

“They can correct you if you are wrong about something that you say. And I think it is really good because it is reassuring knowing someone professional is there who knows all about it.” (Female aged 12)

Young people also reported *feeling inspired* and *providing reassurance* by and to other people in the group:

“I found it quite inspiring I think... some of the places she had been to I never thought that I would be able to go to places. Like she was travelling around Asia I think and that is not something that you would imagine you would be able to do with nut allergies.” (Female aged 15)

“I guess you feel like you can give the younger children advice on how to keep themselves safe. And then you can also show the parents and the children that you will grow up and life will be ok.” (Male aged 15)

“There were like five parents of little babies or toddlers who were there and they were really worried. “Oh my son is going to die!”, “What shall I do?”, “What shall I do?” And I think they were really reassured that I was there and I was still alive (chuckle) because they were like really worried. And they were like: “Wait!”, “So you are like living with this”? And I was “Yeah it is not too hard when you know lots about

it". I think they were really, really relieved that there was someone there who like had got through it and it wasn't that hard. (Female aged 12)

Recommendations for improving awareness and uptake of support groups by young people

Despite young people reporting many benefits from being a member of support groups, many were unaware that these groups existed. Young people made several suggestions and recommendations which may *raise awareness, largely by education*:

"I wasn't really aware. Ads online are probably the best – maybe like assemblies in school and stuff." (Male aged 15)

"That video that the Anaphylactic Campaign did about that girl ... and she was at the park and then she kissed a boy and then she like died. That was really like good – that was a really good video. I think maybe like show that in schools and then have like an allergy thing. I don't know, but that would be really good" (Female aged 15)

"The videos and stuff, they were cool because they raise awareness. So I think you just need to educate teenagers more on what allergies are and how they can affect your life. And then they will probably feel more open to talk about it or find other ways to deal with it" (Female aged 15)

The *use of social media* was seen by some as a good way to both raise awareness of support groups in addition to being a *forum for young people to interact with between scheduled group meetings*:

"I think advertising on sort of social media and stuff is a big thing for it because everyone my age and younger is on social media; or for adverts during TV because they watch TV on catch-up on their laptops or whatever" (Female aged 21)

"lot of young people use social media, and that would be a really good way to like talk to other people with allergies on social media like on a regular basis" (Male aged 12)

"Personally I find like the Facebook page is the best, 100%. Because you are not like forced to ... I would think to me going to a support group would be a bit ... I don't know how to put it. Err ... not 'patronising' but (chuckle). But I would feel like that would be too daunting for me to go to a support group and to be asked...This is the first time I have talked about it to someone else." (Female aged 16)

"I think social media. Because everyone seems to be on it these days... Maybe just reach out to the people who have like emails, who are members of the Anaphylaxis Campaign. If they do have kids maybe email them (chuckle) to join or something like that and just to get them involved, because it might actually help ... well they do help quite a lot. So they might be quite happy about that" (Female aged 15)

Although the majority of young people saw social media as beneficial, others felt that young people don't engage in discussions and others *felt more cautious*:

"I am really careful with social media what I do and don't put on, because some people perceive it in a different way to how it was meant to be perceived" (Female aged 21)

"I don't think that social media would be as good for young people because I think ...I couldn't see people commenting and engaging in conversation. But I think the ones where you actually meet face-to-face are really helpful."

"I think going to a physical group would be sort of beneficial. Sometimes on social media things get a bit sort of twisted, so you would be able to get it straight from the person who knows what they are talking about, rather than it twisted down the chain. And then you don't always think to ask certain questions when you are just sat at home. But you can be prompted to ask questions that you think might help you." (Female age 21)

Often assumed to be more anonymous, one young person commented on the fact that she would feel uncomfortable about others seeing which groups she belonged to:

"Maybe something like a Facebook... so that other people wouldn't know, because when you Like a page and it comes up and all your friends can see it. So maybe it would be better if they were a ... you could be part of it without anyone else knowing. (Female aged 15)

"A lot of the time on Facebook people don't really ... I think young people don't particularly want to be seen as part of a support groups." (Female aged 15)

Recommendations for improving support for young people with allergies

There were a number of suggestions which young people thought would improve the support they receive. One common recurrent theme was to *improve the geographic distribution of physical support groups* or have *more virtual interaction between group meetings*:

"To have more like local ones, because several people live in like ... up north, and they have to come down to London and sometimes it is a big journey" (Female aged 15)

"I mean my Mum is always like looking into new support groups and stuff. Because it is something that I probably would like to be in, we are just trying to find the right one at the moment." (Male aged 14)

"In more areas, because there are only a few once a year but they are not in the same place they are in ... all dotted around the country" (Female aged 12)

"I think the Anaphylaxis Campaign does a very good job at what it does. Except I would like their workshops because I thought they helped a lot of people. And they replaced them with the videos which I don't think are as effective." (Male aged 16)

"I think maybe if there could be like video chats. Maybe the Admin could go on and like ... like have video chats with us and like ... for everyone ... instead of like you

having to go and meet up with someone physically, you could have like a group Skype session or something.” (Female aged 20)

Young people also suggested that support groups should *include an element of fun or social outings*, this seemed particularly important for younger aged participants:

“Maybe if they did have like activities – like events or trips. Like instead of being like just focussed about allergies, it could like be a place where all of the young people with allergies could kind of hang-out, a bit like a youth club or something.” (Male aged 14)

“I reckon something like similar to the last one – maybe a bit more fun because that was very informative.” (Female aged 15)

“So maybe a camp or something or outdoor activity: maybe even like a chat for people with allergies.” (Male aged 12)

“Maybe like workshops on Saturdays for children: which is like a club so do like activities like just having fun club where you can get to know each other and make friends. But then you can also like talk to each other about your condition. I think it is quite nice when you know someone else who is there in your situation.” (Female aged 12)

Young people also believed that the *age limits for membership* including social media were *quite restrictive* and believed that age should be a *major consideration for the format of how groups are run*:

“I think a problem that I saw with having an age limit younger than 18 was you have to pay to be a member. And I don’t think it’s so comfortable for people to be charging kids who aren’t earning any money, to be part of a support network like that. So I think the Facebook – I think it needs to be like two separate kind of things” (Male aged 19)

“And I always got really annoyed, because I was like “I really want to go”, “I really want to learn more”, “I want to know more about my condition”... but like they keep rejecting me because I wasn’t old enough. And like, if I was old enough they were like in Manchester – and we weren’t driving four hours to Manchester to go to a support group.” (Female aged 12)

“They should do workshops where it is just adults and children. Because then the adults could talk about stuff that they don’t want to talk about in front of the children. And we can talk about what we don’t want to talk about in front of the adults, and like share stuff in common. Because some of the adults didn’t have allergies, their children did. So I think the children can talk about their allergies and what they have in common, and the adults can talk about what they have in common. Like the struggles that the adults have with children with anaphylaxis.” (Female aged 12)

"I think it was better with the ... just young people: not like parents butting in almost. I think it was better that it was just young people." (Female aged 15)

Young people spoke of the *benefits of being a support group member from an early age or diagnosis* as they felt this improved how they managed their allergies. Conversely, young people also reflected how *difficult later development and diagnosis of allergy* might be as this would lead to *greater adjustment*:

"If you are not sure about anything what to do or you have just got it, or like you have like you have just started senior school and you have got it – because I know that they are like the hardest. Because you have lived all of your life and then you have just got something new and then you don't know what to do." (Female aged 12)

"I have never really known not being a member... So I can't pin point the exact benefits apart from that I just know all about my allergies... Which I assume that if you weren't you probably would know half as much, which means that you wouldn't be as safe." (Male aged 16)

Discussion

Exploring young people's motivations for joining or engaging with allergy support groups revealed rich and diverse views. Young people engaged with a variety of types of support from traditional physical groups to online, social media forums. The most commonly reported reason for young people to engage with support groups was the feelings of inclusivity and reduction in isolation. Group membership also led to young people feeling more confident, empowered and competent in managing their allergies and life more generally. Aspects of support groups which seemed to bring about this increased competence and confidence were the positive reinforcement of positive self-care behaviours, such as carrying medication and managing interactions when outside of the home, in addition to more practical advice on hidden/changed ingredients in the form of food alerts, for example. Young people also seemed to benefit from support groups by both gaining and providing reassurance to other members or parents.

All young people reported some benefits of group membership or engagement but felt that awareness of groups was generally low. Only three young people were recommended allergy charities or support groups by their health care team. Young people made several suggestions as to what might increase awareness, including using existing videos but played to wider/school audiences, as well as advertisements via social media outlets such as facebook, twitter and youtube. It was not surprising that social media was heavily referenced in this population, however young people were keen to maintain physical support groups and did not want these replaced by virtual groups. Some of the older aged young people also discussed concerns regarding the accuracy and quality of information shared via social media. This was further emphasised by how much they valued access to expert advice for medical facts and up-to-date research via the support groups.

Despite the overwhelmingly positive remarks from young people, there were some recommendations for improvements. Geographic location of young person-specific groups was seen as a major barrier for some people to engage more meaningfully. This extended to the social events which were appealing to the younger participants but were largely seen as

South/London-centric. Whilst the majority of young people commented on the fact they liked to be separated from parents during groups, they also appreciated a wide variation in age of children and young people from whom to both give and gain advice to/from. Young people also reported feeling inspired by older children or adults and saw people effectively managing their allergies as role models. Most young people favoured at least four meetings per year with the addition of a forum/online/skype scheduled discussions for the in-between periods. Whilst online/text alerts seemed to be the most appealing form of communicating news, some young people also valued the magazines so that they could show others or use for discussion purposes.

These findings are important for charities and organisations like The Anaphylaxis Campaign in order to tailor the support they provide to better suit the needs of young people with serious allergies. We know from existing research in addition to recent media coverage that this group are particularly at risk. In line with The Anaphylaxis Campaign's mission statement, the support provided is empowering young people to manage their condition, by providing accurate medical facts as well as a reassuring space to share experiences. Young people reported articulately that the awareness and distribution of support groups needs to be increased. Given that almost all participants reported the anticipated psychological benefit of support groups (i.e. feeling less alone and isolated) as the fundamental reason for engaging, this may be an area on which to concentrate future publicity campaigns.

Dissemination

An abstract for this study has been accepted for thematic poster discussion at the European Academy of Allergy & Clinical Immunology (EAACI) annual conference in Helsinki in June 2017 (Session TPS 22 scheduled for Monday 19th June 12.15-13.45). A manuscript is underway which will be sent for peer-review in a suitable allergy journal (i.e. Clinical & Experimental Allergy, Paediatric Allergy & Immunology). I will keep The Anaphylaxis Campaign updated on the progress of the manuscript. I will also write to all of the participants and their parents with a summary of the study's findings.

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Appendix 1 – EAACI accepted abstract

Understanding why young people with severe allergies join support groups.

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Background

In a recent study it was found that young people who were members of an allergy support group were 2.5 times more likely to adhere to good self-care behaviours.

Objectives

The aim of this qualitative study was to explore why young people with severe allergies join support groups, areas they find important and resources offered that influence and promote adherence.

Methods

In-depth, semi-structured, telephone interviews were conducted with young people (aged between 12-21 years old) with severe allergies who belonged to allergy support groups. Interviews were audiotaped, transcribed verbatim and analysed using Burnard's structured approach.

Results

21 young people with food, venom or latex allergies, were recruited from a range of physical and online support groups. Of these, 18 young people joined support groups on recommendation of their parents or self-referral. Some participants highlighted that they previously had "never even realised there were support groups", emphasising that such support for young people is not widely publicised. This lack of awareness caused many young people to experience severe isolation "if I say that I want to go to a sleepover... I can never go because my friend's Mums aren't willing to take that responsibility. So I am left out on most things." Networking appeared to be the most fundamental reason for joining a support group, but young people were also interested in learning more about their allergies and how to manage these effectively. The importance of feeling included and sharing experiences was emphasised by the feelings that support groups brought "unity" and comfort in meeting with those "who understand what you're going through". Confidence was felt to increase after support group involvement and this was highlighted by reported improved self-assurance when using their AIE (auto-injectable epinephrine), the ability to disclose their allergies in restaurants and to others without allergies.

Conclusions

This study highlights the role support groups play in aiding young people to manage their allergies and adhere to positive self-care behaviours. Participants expressed how groups provide positive experiences by reducing their isolation, connecting them with others in similar circumstances and improving their confidence in managing allergies. Young people reported a need for increased awareness of support groups, as well as greater geographical distribution.