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Living with a severe allergy: Lived perspectives from Swedish adolescents and their parents

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ABSTRACT

Background: During adolescence, the young person should gradually develop independence from his or her parents. However, having a chronic disease like a severe allergy may add stress and challenges beyond normal development and involves a struggle between adapting socially, feeling healthy, and managing the disease.

Objective: To describe experiences of living with a severe allergy from the perspective of adolescents and their parents.

Method: A qualitative study with six focus group interviews were performed, two with adolescents and four with their parents (10 adolescents, 10–16 years old and 21 parents). The transcribed data were analyzed using systematic text condensation.

Result: Four themes emerged: *Feeling different* (adolescents and parents), *shift in responsibility* (adolescents and parents), *the importance of parents* (only adolescents) and *the importance of healthcare providers* (only parents). The adolescents relied on their parents, while also taking responsibility for managing their disease. The parents expressed a need to protect their children; but they did not seem to be aware of the responsibility their children took. The parents highlighted the importance of support from healthcare providers but this was not mentioned by the adolescents.

Conclusion: This study showed that both the adolescents and their parents stated that they took responsibility for managing the disease, but in different ways. For healthcare providers, this needs to be taken into account in order to support both adolescents and parents for self-management and shift in responsibilities which begins during adolescents.

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Introduction

More than half of all children have had at least one allergy-related disease during their first 12 years of life (Ballardini et al., 2012; Pols, Bohnen, Nielen, Korevaar, & Bindels, 2017) and co-morbidity is common (Pols et al., 2017). In addition, coexistence of asthma, rhinitis, and eczema in the same individual is increasingly common with age (Ballardini et al., 2012; Ballardini et al., 2015; Gough et al., 2015). Children with several manifestations of allergic diseases in infancy have been shown to have an increased risk for persistent disease up to school age (Goksor, Loid, Alm, Aberg, & Wennergren, 2016). Allergic diseases may debut already in infancy, and may change over time with new and remitting cases throughout childhood (Ballardini et al., 2012; Ballardini et al., 2015; Gough et al., 2015). Since the conditions can

vary and change over time, knowledge about the allergic diseases is vital for those affected and their families (Hoyte, 2017). Having a severe allergy or a family member with a severe allergy often has an impact on everyday life, although the experiences to how much life is affected are expressed differently by parents and affected adolescents (Stensgaard, Bindslev-Jensen, Nielsen, Munch, & DunnGalvin, 2017).

During adolescence, the young person is expected to gradually develop independence from his or her parents and the peer group becomes increasingly important. Having a chronic disease like allergy may add stress and challenges beyond those of normal development and involves a struggle between adapting socially, feeling healthy, and managing the disease (Jonsson et al., 2017; Lagercrantz, Persson, & Kull, 2017).

A major task for healthcare providers working with adolescents is to support the young person, not just the parents, with tools for self-care and preparing for adulthood and adult care (<https://ginasthma.org/>). Adolescence is a time when young people undergo a transfer of care, which ideally should be a well-planned process that addresses the medical, psychosocial, and educational/vocational needs of the adolescent

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(Rosen, Blum, Britto, Sawyer, & Siegel, 2003). However, in a previous study from our group, parents of adolescents with a severe allergy expressed concern about what would happen when their adolescents turned 18 and were transferred from pediatric to primary care (Lagercrantz et al., 2017). Whether or not the adolescents have the same experiences of the transition is less studied and therefore the aim of this study was to describe experiences of living with a severe allergy in the family, from both the adolescent's and their parents' perspective.

Method

Selection and description of participants

Data for this qualitative study were obtained through focus group interviews with adolescents with a severe allergy and their parents. Six focus group interviews (two with adolescents and four with their parents) were conducted at two occasions during spring/autumn in 2016 (Table 1). The adolescents, six boys and four girls, were between 10 and 16 years old, i.e., at the age referred to as adolescence by the WHO https://www.who.int/topics/adolescent_health/en/.

According to parental information, all adolescents had multiple allergic manifestations (i.e., asthma, food allergy, eczema, allergic rhinitis). All adolescents had food allergy and pollen allergy, all but one had asthma, six out of ten were allergic to pets, and three had eczema.

The participants were recruited from a camp for families with children with a severe allergy, organized by the Swedish Asthma and Allergy Association. All participants were native Swedes with no known cultural differences. The use of focus groups was chosen to facilitate interactions among the participants, exploration of their views and opinions on a topic, and provides a deeper insight into the participants' behaviors and motivations (Jayasekara, 2012; Stalmeijer, McNaughton, & Van Mook, 2014).

Data collection

A semi-structured interview guide was used in the discussions, focusing on adolescents' and parents' experiences of living with a severe allergy (Table 2). The principles of focus group interviews were followed with an interaction between the participants as an important part of the data collection (Malterud, 2012a); (Stalmeijer et al., 2014).

All participants were active and contributed in the discussions and the moderator ensured that all participants had a chance to speak. At the beginning of the focus group interviews with the adolescents, the moderator repeated information on the discussion areas before starting the conversation. The focus group interviews with the parents were performed by one of the authors (ÅP or BL), while the focus group interviews with the adolescents were performed by both these authors together. The interviews were between 55 and 75 min long. Parental pairs were separated and placed in different groups, so that they would not affect each other's answers. The interviews were recorded and then transcribed verbatim by two of the authors (ÅP and BL).

Table 1
Focus group participants.

Focus groups with parents of adolescents with a severe allergy				
Group	1	2	3	4
Participants	4	5	6	6
Mothers	2	3	3	4
Fathers	2	2	3	2
Focus groups with adolescents with a severe allergy				
Group	1	2		
Girls	3	1		
Boys	2	4		
Ages (years)	(12, 13, 13, 15, 16)		(10, 11, 11, 12, 15)	

Table 2
The semi-structured interview guide.

Questions	Parents	Adolescents
Introductory question	What is the first thing you think of when you think about your child's allergy?	What is the first thing you think of when you think about your allergy?
Transition issues	How severe allergic disease do you think your child has? How do you think your child perceives his/her illness?	How severe allergic disease do you think you have?
Key issues	Describe how you perceive that your child's everyday life is affected by allergy. Describe how you perceive that your family is affected by your child's allergy. Please describe the support you have received from your healthcare provider. How do you feel that the support you have received/receive on self-care has worked? Could you describe what kind of self-care this was related to?	Describe how you perceive that your daily life is affected by allergy. Describe how you perceive that your family is affected by your allergy. How have things worked in school/leisure activities? Please describe the support/help you have received from your healthcare provider. How do you feel that the support you have received/receive on self-care has worked? Could you describe what kind of self-care this was related to?
End question	Of all the things we have discussed, what's most important to you? The moderator summarized the conversation and asked if it had been perceived correctly. The final question to both parents and adolescents was: Based on this, is there something we should have talked about that we didn't?	Of all the things we have discussed, what's most important to you?

Data analysis

The analysis of the transcribed data was performed based on systematic text condensation (STC) in accordance with Malterud (Table 3) (Malterud, 2012b). The following analysis procedure, consisting of four steps, was used: Step 1, getting an overall impression of the text to find preliminary themes. Step 2, identifying meaning units in the preliminary themes, labelling with codes. Step 3, sorting the codes by meaning and further into subgroups. Lastly, Step 4, summarizing the essence of each code into themes (Malterud, 2012a). During the analysis process, all authors discussed their results jointly until agreement was reached and to ensure that important findings that matched the purpose were not overlooked.

Ethical aspects

The study was approved by the Ethics Committee of the Karolinska Institute, Stockholm, Sweden. The participants were given verbal and written information on how the material would be processed, the aim of the study, and that their participation was voluntary. After this, both the adolescents and the parents gave written consent. In addition, parents also gave written consent that their children could take part in the focus groups.

Results

Four themes emerged in the adolescents' and their parents' experiences of living with a severe allergy. These themes were: *Feeling different* (adolescents and parents), *Shift in responsibilities* (adolescents and parents), *The importance of parents* (only adolescents) and *The importance of healthcare providers* (only parents).

Table 3

The analysis process in STC, step 1–4. Focus group interviews with adolescents with a severe allergy and their parents.

Step 1	Step 2	Step 3	Step 4
Adolescents			
Preliminary themes	Codes	Subgroups	Themes
Embarrassing	Low priority and often didn't fit in. Low status in school class. Teased at school.	Feeling excluded	Feeling different
Limited	Embarrassing to always have to bring medication. Wishing to be like "the others."		
Unsafe routines	An experience that schools had low knowledge of allergy and didn't engage. Unsafe routines at school.	Feeling misunderstood	
Prepared	Preparing for things in order to feel secure. Bringing emergency medication.	Taking responsibility	Shift in responsibilities
Cares a lot	Mom informing school and others in the surroundings. Mom knowing best. One of their parents always having to be present.	Parents always present	The importance of parents
Parents			
Preliminary themes	Codes	Subgroups	Themes
Unfair	Being treated differently. Unlike everyone else.	Focus on the child in a negative way Feeling misunderstood	Feeling different
Anxiety	Poor understanding of how life is affected. Anxiety and sense of insecurity. Poor understanding for their child's needs. Lacking knowledge at school. Lacking routines at school.		
Prepared	A need to constantly protect their child to ensure safety. Always making a risk assessment.	A need of being protective	Shift in responsibilities
Find solutions	Having to be strong and powerful. Stress and pressure.		
Poor understanding	Continuity, high competence and a professional approach. Moved around within healthcare. No one taking responsibility.	Need of help and support	The importance of healthcare providers
Need continuity	Lack of knowledge. Needing support for self-care.		
Unfair care	Difficult to get in touch with healthcare. Parents feeling lonely, vulnerable and needing help from healthcare		

Feeling different (adolescents and parents)

Both the adolescents and their parents expressed that daily life was affected by the disease; a feeling of being different arose. Three subgroups emerged in the category: *feeling excluded* (adolescents), *focus on the child in a negative way* (parents), and *feeling misunderstood* (both adolescents and parents).

Feeling excluded

The adolescents felt different from others in many situations, due to their disease, and expressed a feeling of being excluded. An example of this was that they felt that they had a low priority at school and had a feeling of "not fitting in." A feeling of having "low status" in class was expressed and several adolescents stated that they were teased at school due to their allergic disease. They wanted to be like "the others," those without an allergic disease.

There's a status in our class because they are very high up and I'm, if the class is a little lump, like this, then I and my friends are just outside that lump and that's... (Girl, 10 years)

The adolescents also stated that they felt excluded when they always had to carry an epinephrine auto-injector in case of an emergent allergic reaction.

It's tough because I'm special. I am the one with the bag! (Boy, 14 years).

Focus on the child in a negative way

From the parents perspectives, feeling different meant that they felt that their children were treated differently by people in their

surroundings, both teachers at school, friends, and other parents. They felt that their children were different from other children and that focus on their children was negatively framed.

Our children are always put front and center in a negative way, for example the teachers can say: 'So we must do this because of her.' That is very frustrating. (Mother)

Feeling misunderstood

Feeling different could also appear as a feeling of being misunderstood; this emerged from both the adolescents and the parents. Several of the adolescents felt that school teachers had insufficient knowledge of allergic diseases. Lack of routines at school was mentioned. A problem area that emerged was school meals; adolescents with food allergies expressed that there were difficulties in getting food that they could eat. Sometimes they were served food items that they were allergic to and sometimes the school personnel did not have any food that they could eat.

Yes, and you can't choose either, if you want to go to school or not, you are forced to go to school and then it's not a good environment — it is very strange. (Boy, 15 years)

It is not always I get anything, sometimes I get a banana, when the others eat a cake, and that is not ok. (Girl, 13 years)

The parents felt misunderstood due to a lack of understanding at schools. They said that there was a lack of knowledge and routines at schools, which led to anxiety and a sense of insecurity for the parents.

The parents also felt there was a lack of understanding for their children's needs; for example, their children were excluded from various social events, which made them both sad and angry. The lack of understanding could be due to insufficient knowledge and insecurity among school personnel.

The school has always said that: we do not take responsibility for this. (Father)

Shift in responsibilities (adolescents and parents)

The theme "*shift in responsibilities*" emerged clearly among both the adolescents and the parents and was divided in two subgroups: *taking responsibility* (adolescents) and *a need of being protective* (parents).

Taking responsibility

The adolescents described that they took responsibility for managing their disease. They took responsibility by preparing before visiting friends and going to cafés, for example; they ate at home or brought their own food, so it felt safe and secure. They also brought their emergency medications, even though they felt it was demanding and embarrassing.

I have to take a lot of responsibility myself and I have to think one step further. (Girl, 15 years)

It's a bit of a hassle with the medicine; you always have to bring your bag. (Boy, 13 years)

A need of being protective

The parents expressed that they had to protect their child and a need to prevent severe allergic reactions. The parents mentioned always making a risk assessment, for instance when their child was going to be away from home. Home was regarded as a safe place. The parents stated that as a parent to a child with a severe allergy the parent needed to be strong and powerful, but this meant stress and pressure.

I'm the one holding this jigsaw puzzle together. [(Mother)]

You always have to come along, she can't go with some other family and we come along every time, every time! [(Father)]

The importance of parents (adolescents)

The adolescents emphasized the importance of their parents in several ways. Both parents were important to the adolescents, but the mother was the one keeping tabs on everything. It was the mother who gave information to people who had to know about the child's allergy and treatment for reasons of safety. The adolescents stated that one of their parents had always been present on class trips, sports events or other occasions, for reasons of safety.

Mom knows best, dad knows a bit too, but... (Girl, 12 years).

Our parents, they are involved, engaged, and they want us to be healthy (Boy, 13 years).

The importance of healthcare providers (parents)

Both positive and negative experiences were described in relation to healthcare provider support. Parents with experiences of continuity in healthcare meetings and who felt they were met with a professional

approach were more satisfied with the support from healthcare. Parents felt it was positive when the doctor turned to and interacted with the child during visits. Families that had received various self-care tools, such as written action plans, and had practiced with epinephrine auto-injectors, were more satisfied with care received.

Negative aspects of meetings with healthcare providers included when the families felt they were moved around and no one took full responsibility for managing their child's disease. Several parents stated that there was a lack of knowledge among healthcare providers regarding treatment of allergic diseases. Moreover, support in self-care was lacking. Experiences of difficulties with getting in touch with healthcare providers were expressed. Most of the parents felt lonely and stated they needed help from healthcare providers with information for school personnel, to increase the knowledge about allergic diseases and thereby improve daily lives for children with allergies.

It's a complex world, healthcare; I wish someone could take overall responsibility. [(Father)]

Accessibility at school, no...we need the help of people from healthcare, but now there is no one who can help us. [(Mother)]

Healthcare must be much, much better at supporting those who have problems. [(Father)]

We suggest placing the graphic abstract here.

Discussion

This qualitative study based on focus group interviews with adolescents with a severe allergy and their parents provided important insights into experiences of living with a severe allergy.

The main result showed that both the adolescents and their parents were affected by the child's disease but they expressed this in different ways. The adolescents relied on their parents, while also taking responsibility for managing their disease. The parents expressed a need to protect their children, but did not seem to be aware of the responsibility their children took. The parents also highlighted the importance of support from healthcare providers, but this was not mentioned by the adolescents.

Daily life with a severe allergy

In our study, both the adolescents and the parents mentioned an experience of feeling different and misunderstood in various situations. The parents mainly discussed the anxiety they felt for their children and the problems they experienced with healthcare, while their children discussed their time in school and things that were problems for them in their daily life. The adolescents felt that they were of low priority at school and that they were excluded. Several of them stated they were being teased; reasons for bullying in the present study were related to special treatment in combination with carrying medication. Teasing and bullying of children with allergy have been reported by others (Lieberman, Weiss, Furlong, Sicherer, & Sicherer, 2010). It is known that bullying can contribute to psychological distress and negatively impact on health-related quality of life (Egan & Sicherer, 2016). In the present study the adolescents expressed a wish to be like "the others," those without an allergic disease. Adolescents want to find their own ways of managing their disease and do not want to be identified as a "sick person" (Gallagher, Worth, Cunningham-Burley, & Sheikh, 2012; Roing & Sanner, 2015). Friends can provide support that enables a young person to break free from their parents; peer relationships have been shown as one way to become independent (Roing & Sanner, 2015; Suris, Michaud, & Viner, 2004).

Shift in responsibilities

In the present study, both the adolescents and their parents stated that they took responsibility for managing the diseases, but they seemed not to be aware of each other's attitudes. Similar results were seen in a study regarding experiences of living with type 1 diabetes (Brorsson, Lindholm Olinder, Viklund, Granstrom, & Leksell, 2017).

The parents in our study stated that they felt anxiety related to their children and a need to constantly protect them by making risk assessments. In a study from the US, parents of children with asthma reported a perceived feeling of vulnerability which led them to be increasingly overprotective of their children (Hullmann et al., 2010). However, parental overprotection is an increased and common trend in society today, which may result in young adults having problems with making decisions, developing self-confidence and being independent (Odenweller, Booth-Butterfield, & Weber, 2014).

Factors of importance for care when having a severe allergy

In the present study, the parents talked about the importance of support from healthcare providers to achieve good care for their adolescents. The adolescents themselves did not mention healthcare. This may be due to the fact that the adolescents had not been involved in their own care. It is known that trust, honesty, and speaking in plain language are important for a good therapeutic relationship with adolescents, as well as for continuity (Wilson, 2017). As expected, parents who described continuity in healthcare meetings and had been met with high competence and professional approach of their health care provider were more satisfied with the support.

The parents in the present study stated that knowledge about severe allergy was sometimes inadequate among healthcare providers. Scales et al. describes that establishing adequate knowledge of allergic diseases in healthcare is a challenge, due to the high number of children, adolescents, and adults affected. Today healthcare providers at almost all levels of care need at least basic knowledge of allergic diseases (Scales et al., 2016). A recently published meta-analysis indicated that self-management support about asthma often focuses on medical management and misses the role of social support in the lives of people who have asthma (Eassey et al., 2018). Can only be speculated, but this probably also applies to allergies. Moreover, in a previous study from our research group, it was expressed that healthcare for children with a severe allergy seemed to differ depending on who you met and where in the country you lived (Lagercrantz et al., 2017).

In the present study, the participants stressed that it was important that healthcare providers involve adolescents in care. Adherence has been stated to be best when the healthcare providers and patient work as partners, deciding on management strategies together (Suris et al., 2004). Others have shown that adolescents and their parents constantly struggle for increased independence despite the parents' difficulties in releasing control (Herbert, Shemesh, & Bender, 2016).

Strengths and limitations

Some strengths and weaknesses are worth mentioning in relation to this study. By using a qualitative method, we can reach a holistic understanding of living with a severe allergy, not only knowledge about the diseases as such (Malterud, 2016; Malterud, Hamberg, & Reventlow, 2017). Strength of the present study was the possibility to collect data from both adolescents with a severe allergy and their parents. It is known that parents and children do not always have the same view of the diseases; reports of symptoms and treatment of allergic diseases have been shown to differ (Danell et al., 2013).

The intention with having focus group interviews is to stimulate interactions between participants, to obtain as many opinions and views on the issue as possible (Stalmeijer et al., 2014). However, one risk may be that the participants affected each other's responses. In the

present study we tried to reduce this by separating parental pairs into different groups. The interactions in all focus groups were intense and the participants showed consideration for each other's experiences. In qualitative studies, the number of participants is of minor importance; the information power is more important (Malterud, Siersma, & Guassora, 2015). Information power indicates that the more information the sample holds, relevant for the study at hand, the lower the number of participants needed. In the present study, the participants talked freely about their experiences, which resulted in rich material.

As all studies, ours has some limitations. The fact that the participants had actively sought out and attended the family camp, organized by the Swedish Asthma and Allergy Association may have affected the result. Parents who are involved in a patient association may be more active in obtaining and using information. However, in qualitative research, it is not possible to generalize results; it is the participants' experiences which are the focus (Malterud, 2016).

Conclusion

Based on the participants' experiences, we can learn that living with a severe allergy affected both the adolescents and their parents but in different ways. The adolescents relied heavily on their parents, while also taking responsibility for managing their disease. The parents expressed a need to protect their children, but did not seem to be aware of the responsibility their children took. For healthcare providers, these factors need to be taken into account in order to support both adolescents and parents in the shift of responsibility which begins during adolescence.

Clinical implications

To provide optimal care for adolescents with a severe allergy healthcare providers need to have sufficient competence in allergic diseases. Moreover, healthcare providers need to support and facilitate the shift in responsibilities which begins during adolescence.

To involve the adolescents in their care and provide support to self-management can lead to young people becoming more independent. Parents on their part may need help to become aware of the risk of overprotecting the adolescents.

Author contributions

BL, ÅP, MJ and IK designed the study. BL and ÅP collected the data. The analyses were performed by BL and ÅP under the supervision of MJ and IK. All authors contributed to the interpretation of the data. IK led the drafting of the manuscript, and all authors actively provided detailed feedback on each draft of the manuscript and agreed on the final version.

Declaration of Competing Interest

None.

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