



Published in final edited form as:

Clin Pediatr (Phila). 2014 July ; 53(8): 758–763. doi:10.1177/0009922814533590.

Using Parental Perceptions of Childhood Allergic Rhinitis to Inform Primary Care Management

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Abstract

Objective—To describe parents' experience with their child's allergic rhinitis (AR) to inform management by the primary care provider (PCP).

Study Design—Two hundred parents with a child 7 to 15 years old with AR symptoms within the past 12-months completed a paper survey.

Results—The child's AR was identified as a significant problem in spring (89.3%), fall (63.4%), summer (50.3%) and winter (21.4%); 51.3% had persistent disease. AR symptoms most commonly interfered with the child's outdoor activities and sleeping, and frequently bothered the parent and other family members. Most parents (88.3%) wanted to know what their child was allergic to and had many concerns about treatment options. 62.9% had sought AR care from the PCP in the past 12 months.

Conclusions—Many families experience significant morbidity from their child's AR and turn to their PCP for help. We identified opportunities for the PCP to reduce AR morbidity.

Keywords

practice-based research network; allergic rhinitis

INTRODUCTION

Allergic rhinitis (AR) is most often cared for in primary care settings, and is one of the top ten reasons for a visit to a primary care pediatrician (PCP).^{1–3} As such, the PCP has the opportunity to impact care. However, there is little information to assist the PCP in optimizing management. Beyond symptom assessment, few studies have assessed the

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Financial Disclosure Statement: The authors declare they have no financial relationships that are broadly relevant to the work.

Potential Conflict of Interest: The authors have no conflicts of interest, real or perceived, including financial, activities, relationships, or affiliations relevant to this article to disclose.

The authors have no financial relationships relevant to this article to disclose.

impact of childhood AR on children and their families. A national telephone survey of 500 families with a child with AR suggested that for many children, the impact of AR on their physical and social health was profound,¹ with important disease manifestations that go beyond the major nasal symptoms of sneezing, rhinorrhea, stuffiness, pruritus and ocular symptoms. These manifestations include a negative impact on the child's social life and school performance, and the overall quality of life not only for the child but the family, as well.^{1,4}

In a recent local survey of over 1,100 parents, 69% identified allergies as a significant health problem for children in our community.⁵ As a first step to identify opportunities for the PCP to work with parents to reduce the impact of AR in a way that is meaningful, we conducted a parent survey to describe the impact of AR on the child and the family and understand current AR management.

METHODS

This parental survey was conducted within the Washington University Pediatric and Adolescent Ambulatory Research Consortium (WU PAARC), a Practice-Based Research Network (PBRN) of community pediatricians. All WU PAARC pediatricians were asked if they would allow a research assistant (RA) in their office for one to two weeks to recruit study subjects in their waiting room. The study was approved by the Washington University Human Research Protection Office with waiver of written consent.

Study Participants and Recruitment

Eligible participants were the parent or legal guardian of a child 5 to 17 years old who the parent reported had nasal allergies, defined as nasal symptoms in the past 12-months including "sneezing, or a runny, or blocked nose when he/she did not have a cold or the flu."^{6,7} This question is adapted from the International Study of Asthma and Allergies in Childhood (ISAAC) and has been widely used in epidemiological studies of AR.⁶ A recent prospective cohort study of 531 children demonstrated this question has 67% sensitivity to identify those with a diagnosis of AR confirmed by assessment by a specialist-physician and skin-testing.⁸ A positive allergy test was not required as this is uncommon in primary care management of childhood AR.⁹ Parents who could not speak English or had previously completed the survey for another child were ineligible. Parents were not approached by the RA in the waiting room if they were immediately called to see the physician, were preoccupied with an administrative task, or if the RA was busy with another parent. If the survey was not completed during the office visit, a stamped addressed envelope was provided to return the completed instrument.

Survey Tool

The survey was developed by the authors, based on the literature, clinical experience and findings from 42 semi-structured parent interviews conducted in four WU PAARC practices. Survey items were refined for clarity after pilot testing. The 50-item survey took approximately ten minutes to complete and had a Flesch-Kincaid reading level of 8.2.

Respondents used categorical scales to indicate the following: how much of a problem allergies were for their child throughout the year (large, medium, small or not a problem); how much allergies affected the child's and family's ability to participate in various activities (a lot, some, a little, not at all). Parents reported their agreement (strongly agree, agree, disagree, strongly disagree) with attitudinal statements about AR and their perception of treatment effectiveness. Responses of "strongly agree" and "agree" were combined and reported as agree. Parents indicated treatments used (current and ever), barriers to use, and the AR care provided by their PCP by selecting items from a list of options. Examples of commonly used medications and environmental control measures were provided in the survey questions. They rated their satisfaction with AR care provided by their PCP choosing from six response options: completely satisfied, couldn't be better; very satisfied; satisfied; dissatisfied; very dissatisfied; and completely dissatisfied, couldn't be worse. Additional questions assessed demographic characteristics.

Similar to the approach used in the revised ARIA (Allergic Rhinitis and its Impact on Asthma) guidelines,¹⁰ a moderate-severe impact subgroup was identified. Children were assigned to this group if the parent reported AR affected or limited the child "a lot" in the past 12-months for at least one of the following six items: daily activities, sleeping, outdoor activities, doing things with the family, doing well at school, and school activities.

Statistical Analysis

Summary statistics are presented as means and standard deviations (SD) or medians and interquartile range (IQR) or range for continuous variables, and percentages for categorical variables. If fewer than 90% of parents responded to a question, the number of respondents is reported. We used the Pearson Chi-square or Fisher's exact test to compare parental responses among groups including the moderate-severe impact groups vs. other children, and between those with AR cared for by the PCP vs. other providers. We also compared use of nasal steroids in younger children and older children (< 7 years old vs. ≥ 7 years old) and cost barriers to medication use for those with and without Medicaid insurance. A probability of $p = 0.05$ (two-tailed) was used to establish statistical significance. All statistical analyses were done using STATA 12.1 (StataCorp, College Station, TX).

RESULTS

Study Population

Fifteen of 34 (44.1%) WU PAARC offices allowed in-office recruitment for the parent survey during the three-month study period (March 3, 2011 to June 10, 2011), a period of time in our community with high tree pollen and the most acute AR symptoms. Participating sites did not differ from non-participating sites for location (most were located in the suburbs) or type of practice (most were group practices). During the times the RA was on-site, 1,152 of 1,288 (89.4%) potential subjects were approached. Of these, 863 were ineligible (most commonly because they did not have a child with AR or the child was < 7 years old or ≥ 18 years old). Thirty-five declined to be screened for eligibility and 260 were eligible by self-report, with 218 of these completing surveys (211 in the office, 7 returned by

mail). Eighteen completed surveys were ineligible (17 ineligible age, 1 no AR) and therefore excluded from the analyses.

Two hundred surveys were included in the analysis (median interviews/office 13, range 3–33). Survey respondents most commonly were the child's parent (89.0% mother, 5.5% father), white (61.5%), from a two-parent family (74.7%), had an Associates degree or higher education (59.1%) and had AR themselves (58.6%); 22.5% used Medicaid insurance for their child. The median age of the child with AR was 10 years (IQR 7.0 to 12.5 years), and 34.2% of children had asthma.

Diagnosis of AR

All subjects reported symptoms compatible with AR in the past 12-months. The parent reported a physician diagnosis of AR for 70.1% (138/197) of children and a diagnostic test for 32.5% (17 blood test, 30 skin test, 18 both tests). Compared to other children, testing was more commonly reported for those children with asthma (47.0% vs. 25.9%, $p=0.004$) and those who had ever received care from a specialist (95.0% vs. 17.7%, $p<0.001$), but did not differ by level of impact of AR (moderate severe 38.8% vs. others 29.6%, $p=0.18$).

Impact of AR

Parents reported their child's AR was a significant (large or medium) problem in spring (89.3%), fall (63.4%), summer (50.3%) and winter (21.4%, 36/168), with 51.3% reporting persistent disease (symptoms rated as at least a small problem in every season). When present, AR symptoms often interfered with the child's activities, most commonly with outdoor activities and sleeping (Table 1). For the 78 (39.0%) children who had missed school because of AR, the median number of days missed/year was 3 (IQ range 2 to 5). Many parents reported they and other family members were bothered by their child's AR (Table 1).

Attitudes Toward AR and AR Treatments

Most (88.3%) parents agreed that knowing exactly what their child was allergic to was important and that AR was a serious problem (68.4%). They found treatment to be expensive (63.4%) and a lot of work (44.6%). Identified barriers to OTC and prescription drug use were similar and included limited duration of effect (OTC, 54.3%; prescription, 29.2%), concern about side effects (35.9%, 34.5%), need for daily medication use (29.3%, 25.6%), and cost (32.3%, 29.2%). Compared with other families, fewer families with Medicaid insurance identified cost as a barrier to using prescription medications (12.8% vs. 33.3%, $p=0.01$).

Care for AR

Overall, 20.5% reported their child had ever seen a specialist for allergy care. In the prior 12-months, AR care was provided by the PCP (62.9%), a specialist (9.1%), or another care provider (5.6%), while 22.3% did not seek AR care.

Regarding current management, parents most commonly reported using environmental control measures (74.6%), OTC allergy medications (78.2%), nasal steroids (43.6%) and

prescribed allergy medications such as leukotriene receptor antagonists (LTRAs) or antihistamines (34.5%). Reported use of nasal steroids did not differ by age group (<7 years old 45.0% vs. 7 years old 43.2%, $p=0.84$). Children with Medicaid were more likely than other children to use nasal steroids (58.5% vs. 38.4%, $p=0.022$) and less likely to use OTC allergy medications (58.5% vs. 83.6%, $p=0.001$). Compared to children cared for by their PCP, those cared for by a specialist more frequently reported current use of prescribed allergy medications (58.6% vs. 38.5%, $p=0.049$) and immunotherapy (20.7% vs. 0, $p<0.001$), with no difference in reported use of OTC medications (72.4% vs. 77.8%, $p=0.53$) or nasal steroids (62.1% vs. 46.7%, $p=0.14$).

Most (79.8%) parents reported they had asked the child's PCP for advice about how to manage the child's AR (16.3% had not asked, 3.9% didn't know), and 53.0% reported they got advice about AR management exclusively from the child's PCP. Additional sources of information about AR management included prior experience (41.0%), friends and relatives (38.5%), the pharmacist (25.5%), and the Internet (22.0%).

Comparison by level of impact of AR

Eighty-seven (43.5%) children were categorized as the moderate-severe impact group. Compared to others, these children were younger (<7 years old, 73.1% vs. 35.9%, $p<0.001$), more likely to have asthma (45.7% vs. 27.4%, $p=0.009$), Medicaid insurance (31.3% vs. 15.7%, $p=0.013$), and to have sought AR care in the prior 12 months (86.9% vs. 70.8%, $p=0.007$) either from their PCP (81.8%) or a specialist (18.1%). For the 124 children seeking AR care from their PCP, parent-reported PCP treatment recommendations and current treatment use essentially did not differ between the moderate-severe impact group and other children (Table 2). Environmental control measures and OTC medications were the most commonly recommended and used AR management strategies. Overall, parents were satisfied with the care provided for AR by the PCP with no difference by impact group (Table 2).

DISCUSSION

The impact of AR was large in this community-based sample of 200 families. AR affected multiple aspects of the child's life and also impacted the parent and other family members. This high level of AR-associated morbidity occurred despite widespread use of environmental control strategies, OTC and prescription medications, and discussion with the PCP regarding AR care.

Parental concerns and experiences with AR management suggest opportunities for the PCP to reduce the considerable impact of AR on the child and family. These include: 1) discussing the role of allergen identification at the time of diagnosis with an initial focus on the timing of symptoms related to well-defined pollen seasons, followed by discussion of allergy testing if needed; 2) using a systematic approach to identify the extent of AR morbidity extending past the clinical manifestations that are the usual therapeutic target;¹ 3) crafting an individualized AR management plan that addresses parental concerns about medications; and 4) facilitating parental adherence to the child's recommended management

plan, for example, by scheduling a follow-up appointment to monitor treatment effectiveness.

Almost all parents stated that knowing what their child was allergic to was important, suggesting that a discussion about allergen identification is important at the time of diagnosis. Allergy testing is not recommended for everyone.⁹ As available treatments have high benefit and low harm,^{9,11} empiric treatment and identification of putative allergens by history is a reasonable approach for the primary care management of children presenting with seasonal nasal symptoms, and a history of specific triggers or a family history of AR,^{9,11} and this strategy occurred frequently in our community. Recommending this approach with a follow-up visit two to four weeks after initiation of a new treatment regimen to assess symptom control¹²⁻¹⁵ and reassess the need for allergen identification may satisfy parents' desire for allergen identification and optimize management. Treatment may need to be stepped up to include more effective treatments such as nasal steroids,^{12,15} and allergy testing may be recommended to inform effective environmental control strategies and immunotherapy.^{9,11} Our findings suggest this more intensive approach to AR management may provide particular benefit for younger children, those with Medicaid insurance, and children with both asthma and AR.

A systematic approach to AR management could be established and supported by the electronic medical record (EMR), for example to establish a registry, standardize the history, schedule follow-up visits, and remind parents to initiate therapy in anticipation of seasonal allergen exposure.¹² A few standardized tools are available to support AR care such as the Rhinitis Control Assessment Tool for those over 12 years old,¹⁶ and a Rhinitis Action Plan¹² (similar to an Asthma Action Plan) to guide treatment. Practitioners could use the questions provided in Table 2 to identify the extent of AR morbidity. Unfortunately, there are no national AR guidelines that are endorsed by the American Academy of Pediatrics (AAP). Guidelines developed by a multidisciplinary joint task force sponsored by the American Academy of Allergy, Asthma & Immunology and the American College of Allergy, Asthma, and Immunology,¹² were published in a subspecialty journal, and few PCPs are familiar with them.¹ Finally, PCPs could advocate for improved and more effective, safe, easy to use treatments and participate in studies to improve the evidence base to support AR treatment.¹⁷

Several study limitations should be noted. The data are self-reported and may not accurately represent AR care provided. Parents identified their child as having nasal allergies with symptoms in the past 12-months and the majority reported a physician diagnosis, but we cannot confirm the diagnosis of AR. The question used to identify those with AR for this study has a sensitivity of 67% for identifying those with a diagnosis confirmed by physician assessment and skin-testing. Although the survey was anonymous to minimize social desirability bias, parents' assessment of satisfaction with PCP care may have been influenced by conducting the survey in the doctor's office. Subjects were recruited in the spring from pediatric practices in the St. Louis metropolitan area and AR may not pose such a significant problem in other communities, possibly limiting generalizability of study findings.

Conclusions

Childhood AR has a large impact on the child and their family and most families seek help from the child's pediatrician. We identified opportunities for the PCP to reduce morbidity from this common disease and suggested strategies that can be used to implement a systematic approach to AR care.

Acknowledgments

The authors thank all the parents who completed the survey and the pediatricians at Affton Medical Center, Blue Fish Pediatrics, The Children's Clinic, Esse Health-Creve Coeur, Esse Health-Florissant, Fenton Pediatrics, Forest Park Pediatrics, Heartland Pediatrics, Johnson Pediatrics, Patients First: Washington, Pediatric Healthcare Unlimited, Southwest Pediatrics, Dr. Robert Strashun Pediatrics, Tots thru Teens Pediatrics, and Way to Grow Pediatrics who allowed us to enroll patients in their offices.

Study data were collected and managed using REDCap electronic data capture tools hosted at Washington University.¹ REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.

Funding Source: This publication was made possible by Grant Number UL1 RR024992 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research. The contents are solely the responsibility of the authors and do not necessarily represent the official view of NCRR or NIH. The sponsors had no involvement in study design or conduct; collection, management, analysis, interpretation of the data; the preparation, review or approval of the manuscript; or the decision to submit the paper for publication.

Abbreviations

AR	Allergic Rhinitis
IQ	Interquartile range
LTRA	Leukotriene receptor antagonists
NIH	National Institutes of Health
OTC	Over-the-counter
PCP	Primary care pediatrician
PBRN	Practice-based research network
RA	Research Assistant
SD	Standard deviation
WU PAARC	Washington University Pediatric and Adolescent Ambulatory Research Consortium

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Table 1

Parents' assessment of the impact of the child's allergic rhinitis (AR) on various activities for the child and the family (N=200).

Activity	Amount child's AR affected or limited child or family for this activity*			
	A lot	Some	A little	None
Impact on the child				
Outdoor activities: organized sports, exercising, or playing with friends ^a	25.3%	39.4%	22.7%	12.6%
Sleeping ^a	22.0%	39.4%	26.3%	12.1%
Daily activities ^a	18.6%	50.8%	22.6%	8.0%
School activities (e.g., recess, field trips) ^a	9.1%	23.1%	29.7%	38.2%
Doing well in school ^a	4.6%	22.2%	25.8%	47.5%
Doing things with the family ^a	4.0%	24.8%	28.8%	42.4%
Impact on the family				
Parent bothered by child's AR	17.7%	39.2%	30.4%	12.7%
Family bothered by child's AR	9.3%	34.5%	30.9%	23.7%
Disrupt parent's sleep	9.1%	33.5%	33.0%	23.9%
Required extra cleaning or housework	23.5%	28.1%	23.5%	25.0%
Family's recreational outdoor activities	12.7%	27.9%	23.9%	35.5%
Disrupt sleep of another family member	4.6%	21.8%	24.9%	43.7%
Reduce visits with family or friends	13.8%	20.9%	13.8%	51.5%

AR: Allergic Rhinitis:

* Percent sum > 100% due to rounding

^a Items used to identify the moderate-severe impact group. The question was phrased as follows: In the past 12 months when your child was bothered by their allergies, how much do you feel their allergies affected or limited what they could do in the following areas?

Table 2

Care for allergic rhinitis provided by the primary care provider (n = 124)

	Moderate-severe impact (N=60)	Other (N=64)	P-value
Interactions with PCP			
Asked if child was bothered by AR	91.3%	88.5%	0.605
Told parent that child had AR	86.2%	79.3%	0.33
Offered diagnostic blood test for AR	32.1%	18.6%	0.096
Offered diagnostic skin prick test for AR	29.8%	21.0%	0.28
Recommended visit to specialist for AR care	28.8%	10.0%	0.009
AR treatments recommended/prescribed			
OTC medications	91.5%	86.0%	0.33
Environmental controls	81.4%	60.0%	0.009
Nasal steroids	62.1%	60.3%	0.84
Allergy medications	61.0%	47.6%	0.14
OTC nasal spray	45.8%	50.0%	0.64
AR treatments using currently			
Environmental controls	79.7%	69.8%	0.21
OTC medications	78.0%	77.8%	0.98
Nasal steroids	49.2%	44.3%	0.59
Allergy medications	45.8%	31.8%	0.11
OTC nasal spray	32.8%	19.1%	0.08
Satisfaction with AR care by PCP			
Completely satisfied	15.5%	26.2%	0.50
Very satisfied	36.2%	27.9%	
Satisfied	37.7%	37.9%	
Dissatisfied/Very dissatisfied	10.3%	8.2%	

PCP: primary care provider; AR: allergic rhinitis; OTC: over-the-counter