

Life with Nasal Polyps:

The Patient Experience and Opportunities to Improve Care in the U.S.

Chronic rhinosinusitis



With nasal polyps



Asthma and Allergy
Foundation of America

Life with Nasal Polyps: The Patient Experience and Opportunities to Improve Care in the U.S.

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About the Asthma and Allergy Foundation of America (AAFA)

Founded in 1953, AAFA is the oldest and largest nonprofit patient organization dedicated to saving lives and reducing the burden of disease for people with asthma, allergies, and related conditions through research, education, advocacy, and support. AAFA offers extensive support for individuals and families affected by asthma and allergic diseases, such as food allergies and atopic dermatitis (eczema).

Through its online patient support communities, network of regional chapters, and collaborations with community-based groups, AAFA empowers patients and their families by providing practical, evidence-based information and community programs and services. AAFA is the only asthma and allergy patient advocacy group that is certified to meet the standards of excellence set by the National Health Council. AAFA also helps consumers identify products to help them have healthier homes through the **asthma & allergy friendly**® Certification Program. For more information, visit aafa.org.

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The views and opinions expressed in this report are those of the survey respondents and AAFA authors and do not necessarily reflect the policies or positions of other individuals, organizations, or companies.

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Introduction

Nasal polyps are considered a subtype of chronic rhinosinusitis (CRS). CRS is a common condition that affects 5–12% of adults.^{1,2} There are two major types of CRS, characterized by the presence or absence of nasal polyps (NP):

- Chronic rhinosinusitis with nasal polyps (CRSwNP)
- Chronic rhinosinusitis without nasal polyps (CRSsNP)

Around 20–30% people with CRS have nasal polyps (CRSwNP).^{3,4} Nasal polyps are small, non-cancerous growths on the inner lining of the nose or sinus cavities. Nasal polyps are shaped like hanging grapes or teardrops, and they are usually soft and painless.

CRSwNP is associated with type 2 inflammation⁵, which is also linked to asthma, allergic rhinitis (hay fever), atopic dermatitis (eczema), food allergies, eosinophilic esophagitis (EoE). Other common comorbidities include aspirin-exacerbated respiratory disease (AERD), nonsteroidal anti-inflammatory drug-exacerbated respiratory disease (N-ERD), chronic obstructive pulmonary disease (COPD), allergic fungal rhinosinusitis (AFRS), and cystic fibrosis. About half of people with CRSwNP also have asthma, and about 10% of people with CRSwNP have AERD. Due in part to the similarities in symptoms between CRSwNP and conditions like asthma and allergies, diagnosis of nasal polyps can be a lengthy and frustrating process.

The impact of CRSwNP on quality of life can be comparable to other diseases such as COPD, congestive heart failure, and diabetes.⁶ People with nasal polyps experience a significant burden on quality of life due to sleep disturbance, impact on ability to perform daily activities, anxiety, and depression. Decreased quality of life due to CRSwNP is often worse among people with comorbid conditions like asthma and allergic rhinitis.⁷ Despite this, CRSwNP has not received the same national and global recognition and attention as similar conditions.

Standard of care for treating CRSwNP generally includes medications (such as intranasal and systemic corticosteroids) as well as surgery (endoscopic sinus surgery). However, many people with CRSwNP still have uncontrolled disease despite standard of care. For some people, these treatments and surgeries provide short-term relief and can lead to recurrence of nasal polyps as well as the need for additional surgeries.⁸ In recent years, the FDA has approved newer treatment options (biologics) that may help treat the underlying inflammation that causes CRSwNP; however, not all patients may have access to these treatments.

This report looks at insights from patients and caregivers to highlight the current state of CRSwNP care in the United States—including challenges and barriers to timely diagnosis, quality medical care, effective treatments, and access to resources for CRSwNP. These challenges also present opportunities to address the unmet needs and improve future care for people living with CRSwNP in the United States. This report looks in particular at the community served by the Asthma and Allergy Foundation of America (AAFA)—people with comorbid conditions such as asthma and allergic rhinitis—to help guide AAFA’s program development.

Key Findings

Due to the breadth of topics covered by this study, data from the interviews and survey provided a great deal of insights into patient/caregiver experiences, beliefs, and knowledge. Throughout this report, data presented will focus on the following key findings related to: diagnosis, medical care and treatments, disease management, quality of life impact, and resources.

Many patients experience delays in diagnosis for CRSwNP, leading to delayed symptom relief, clinical care, and treatment.

- The majority (53%) of patients said it took more than one year to receive a diagnosis after first experiencing symptoms, including one in eight (12%) who said it took more than ten years to get diagnosed.
- The biggest challenge to getting a diagnosis among this study group was difficulty in distinguishing CRSwNP that it was hard to tell if symptoms were not just bad allergies or asthma.
- Other challenges to diagnosis include not recognizing their symptoms as a sign of a chronic condition, doctor not realizing there was a problem, and having trouble getting the necessary testing for diagnosis. One significant factor that can delay diagnosis is that CRSwNP symptoms mimic those with other conditions like asthma or allergies. Many interview participants reported not knowing they had nasal polyps until seeking medical help for other conditions. 1 in 5 (18%) said they didn't recognize their symptoms as a sign of a chronic condition.

Standard of care is not effective for all patients, and access to newer treatments is challenging for some patients who may benefit.

- The two biggest challenges in long-term management of CRSwNP were reducing or eliminating symptoms (54%) and effectiveness of care and treatment (38%).
- The majority (76%) of patients have used nasal steroids (94%) and oral steroids (76%) at some point for CRSwNP, but some patients reported concerns or challenges with these treatments.
- Among the pharmacological treatments for CRSwNP, patients reported biologics as having the highest utility.
- Efficacy, side effects, and doctor recommendation were reported as the three most important factors for patients when choosing a treatment option.
- Though patient awareness of emerging treatments was low, they are likely to participate in clinical trials if asked.

“CRSwNP” or “Nasal Polyps”?

Historically, chronic rhinosinusitis (CRS) has sometimes been referred to as chronic sinusitis, though CRS terminology is preferred in clinical guidelines, consensus documents, and medical literature. Due to the lack of patient awareness with the term CRS with nasal polyps (CRSwNP) at the time of this study, we simplified our patient-facing research tools to use the term “nasal polyps.” **Throughout this report, we use the terms CRSwNP and “nasal polyps” interchangeably.** More recently, the European Forum for Research and Education in Allergy and Airway Diseases (EUFOREA) convened an expert panel to develop a patient-friendly name for CRSwNP; the final proposed name is Nasal Polyp Syndrome (NPS). Moving forward, AAFA may use the term “Nasal Polyp Syndrome” in our programs and initiatives.



Sinus surgery is effective for some patients, but others experience a recurrence of nasal polyps even after surgery, leading to greater frustration and reduced quality of life.

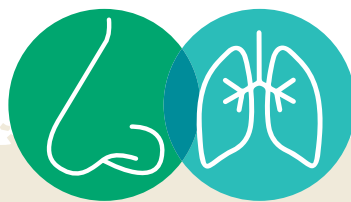
- Most (56%) patients reported having at least one endoscopic surgery to remove nasal polyps, with about three in ten (29%) having more than one surgery.
- Among all treatments for CRSwNP, endoscopic surgery was reported as having the highest utility.
- For some people, recurrence of polyps after surgery led to a significant impact on quality of life.

CRSwNP has a significant impact on quality of life.

- Nearly half (46%) of patients reported that nasal polyps have a significant impact on their ability to get a good night's sleep.
- A third (32%) of patients said nasal polyps have a significant impact on their ability to exercise.
- Mental and emotional impacts are also seen, with about one in four survey respondents saying nasal polyps have a significant impact on their emotional (25%) and mental (23%) health.

Patients and caregivers acknowledge a greater need for support and resources for CRSwNP.

- Patients were dissatisfied with general awareness of nasal polyps (37%) and financial resources to support medical care (37%).
- Patients were divided on their satisfaction with social and emotional support, with about the same number of respondents satisfied with social support (24%) as dissatisfied (28%).
- Two thirds (67%) of patients would like more information about how to manage or reduce symptoms without surgery (67%) as well as treatment options (64%).
- More than half (51%) of patients they would like more basic nasal polyps information such as what they are and what causes them.
- One third of patients would like more information on nasal polyps drug development (35%) and clinical trial opportunities (34%).



Among AAFA's community, many people with CRSwNP have comorbid conditions. The most common comorbid conditions among adult patients in this study were allergic rhinitis (80%) and asthma (70%). One-third (33%) manage food allergy as well. Nearly one in six (15%) respondents reported having "other" comorbid conditions including chronic obstructive pulmonary disease (COPD).

Study Design

Objectives

Beginning in 2022, the Asthma and Allergy Foundation of America (AAFA) conducted a multi-component cross-sectional needs assessment study for chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps). The study aimed to:

- Understand the current state of care for nasal polyps in the U.S.
- Understand the patient journey for nasal polyps
- Identify areas of unmet needs for patients and caregivers

This report uses insights from the needs assessment to identify and provide opportunities for improving nasal polyps care in the United States.

Methodology

This study involved several components. To get an understanding of nasal polyps from the patient and caregiver perspective, AAFA first conducted social listening through its communities and channels. This included insights from peer-to-peer conversations on AAFA and KFA online patient communities, conversations on social media, and incoming requests through AAFA's Support Center and Ask the Allergist service. AAFA used the findings from the social listening analysis to develop a conversation guide for one-on-one semi-structured interviews with patients and caregivers. Interview participants were recruited through a targeted list of nasal polyps patients and caregivers in AAFA's community. Using the findings from the patient and caregiver interviews, AAFA developed a survey tool to collect more information from nasal polyps patients and caregivers. Invitations to complete the survey were sent to AAFA community members, social followers, and email subscribers.



About this Report

This document focuses on select data from the patient and caregiver survey. Throughout this report, most of the graphs represent the aggregated results of N=112 respondents from the survey.

Percentages shown in the graphs have been rounded and may not always equal 100. At times, we have analyzed various subgroups of respondents.

To better capture the patient and caregiver voice directly, we have also included quotes from interview participants as well as open-text responses from survey respondents. Quotes have been edited for length and clarity. Throughout the report, we use the following icons to identify the source of information:

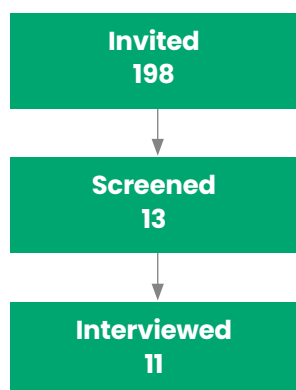


It is important to note that this survey is not representative of the U.S. population or the reported demographics of people with nasal polyps. We acknowledge there may be selection bias in that the members of AAFA's community who responded to the survey may be significantly impacted by nasal polyps or related diseases and therefore may be most motivated to participate. Additional limitations are addressed on page 37.

Study Sample

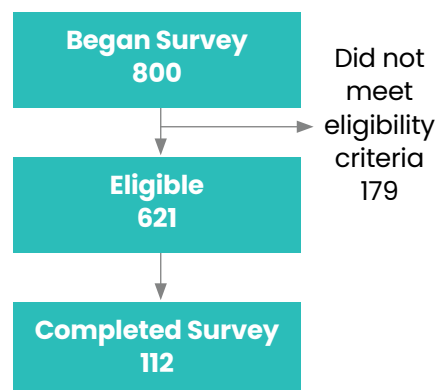
Patient and Caregiver Interviews

AAFA invited 198 candidates to participate in the interviews. After screening 13 respondents, we interviewed 11 patients and caregivers for the study.



Patient and Caregiver Survey

There were 800 people who began the patient and caregiver survey. Based on self-reported diagnoses and location, 621 people qualified and 112 completed the survey.

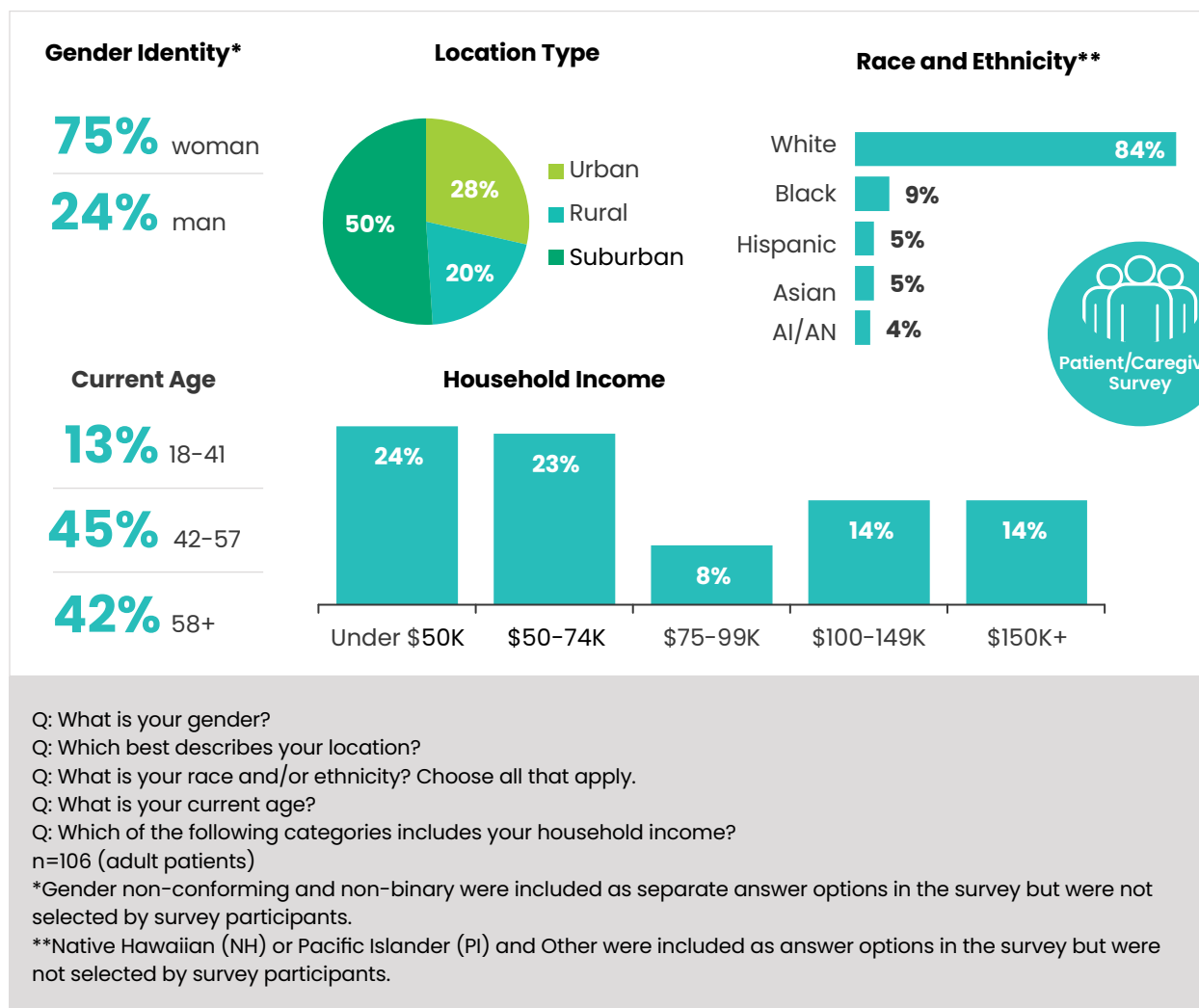


Overview of Respondents

Patient and Caregiver Respondents

A vast majority of adult patient survey respondents self-identified as white and as women. While nasal polyps are reportedly more common in white populations, it is more prevalent in men than women.¹ Half of patients indicated they live in suburban areas, and the majority of patients were between 42–76 years old at the time of the survey. Nearly half (46%) of respondents reported an annual household income of under \$75,000.

Figure 1. Adult Patient Respondent Demographics



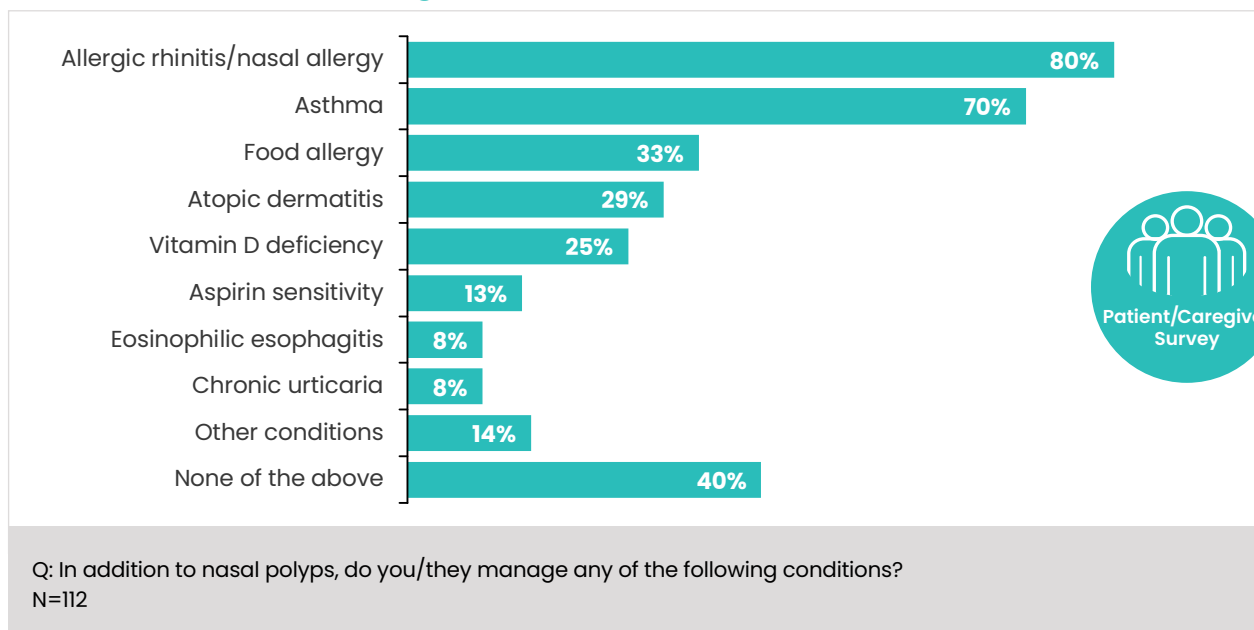
Comorbid Conditions

Many people with chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps) also have other allergic conditions, such as environmental allergies (allergic rhinitis), asthma, and eczema.^{2,3} These related conditions are driven by type 2 inflammatory response. In addition to CRSwNP, allergic diseases caused by type 2 inflammation include:

- **Asthma** – From coughing and wheezing to difficulty breathing, asthma symptoms may impact daily life, especially if it's not controlled. Type 2 inflammation drives both allergic and eosinophilic asthma.
- **Atopic Dermatitis (AD)** – People with AD (a form of eczema), often have frequent dry, scaly skin and red or dark rashes that cause intense itching. Many people are diagnosed with this chronic disease as children and experience unpredictable symptoms into and throughout adulthood.
- **Food Allergies** – Sensitivities to allergens in different foods can cause anaphylaxis, a severe allergic reaction. Symptoms of anaphylaxis can include cause rashes, hives, trouble breathing, wheezing, dizziness, vomiting, diarrhea, and swelling of the lips, tongue, and throat. The most common foods that cause allergic reactions are eggs, milk, peanuts, tree nuts, fish, shellfish, sesame, soy, and wheat.
- **Eosinophilic Esophagitis (EOE)** – EoE is a chronic inflammatory condition of the esophagus (the tube that connects the mouth to the stomach). EoE can make the esophagus narrow, contributing to food impactions and making it difficult and painful to eat.
- **Prurigo Nodularis (PN)** – People with PN have many lumps and bumps that create an intense, persistent itch lasting over six weeks. The stinging, burning, and pain that come with PN worsen get worse with irritation, and can cause people with PN to scratch themselves, leaving their skin damaged and scarred. This can lead to skin infections.

In this study, the most common comorbid conditions among patients were allergic rhinitis (80%) and asthma (70%). One-third (33%) manage food allergy as well. Nearly one in six (15%) respondents reported having “other” comorbid conditions including chronic obstructive pulmonary disease (COPD).

Figure 2. Comorbid Conditions



Because allergic comorbidities are higher in people with CRSwNP than the general population, optimal disease management also includes evaluation and treatment of other type 2 conditions.

Interview Participants

One-on-one, semi-structured interviews were conducted with 11 patients and caregivers managing **chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps)**. All interviewees were adult patients managing nasal polyps. In some cases, family history of nasal polyps was suspected but not confirmed. Interviewees' ages ranged from 20s to 70s. Time since diagnosis ranged from 3 years to over 40 years.



Participants*	
Tom	Adult patient diagnosed with CRSwNP around 3 years ago. Nasal polyps are currently managed through different medications following an unsuccessful surgery.
Mary	Adult patient diagnosed with CRSwNP around 25 years ago. Nasal polyps have been managed over the past 5 years through nasal sprays.
Leo	Adult patient diagnosed with CRSwNP 4 years ago. Has undergone multiple surgeries and treatments, but still has not seen long-term relief
Fiona	Adult patient diagnosed with CRSwNP after dealing with chronic postnasal drip and cough. Doctors did not recommend any treatment, but she uses breathing strips at night.
Tamara	Adult patient diagnosed with CRSwNP at 14 years old. She also has a son who was diagnosed with CRSwNP in his 20s. Her nasal polyps are currently managed through nasal sprays.
Ruth	Adult patient diagnosed with CRSwNP 3 years ago. Nasal polyps have mostly been controlled following surgery, but she started experiencing symptoms again around the time of the interview.
Georgia	Adult patient diagnosed with CRSwNP 7 years ago. Nasal polyps are currently managed through biologics as an add-on after trying prednisone, surgeries, OTC antihistamines, and nasal sprays.
Sam	Adult patient diagnosed with CRSwNP as a teenager. Nasal polyps are currently managed through nasal sprays.
Edward	Adult patient diagnosed with CRSwNP around 10 years ago. Nasal polyps are currently managed through nasal sprays.
Teresa	Adult patient diagnosed with CRSwNP around 3 years ago. Nasal polyps are currently managed through biologic treatment and sinus rinses.
Norah	Adult patient diagnosed with CRSwNP around 13 years ago. Nasal polyps are currently managed through nasal rinses and OTC allergy medicines.

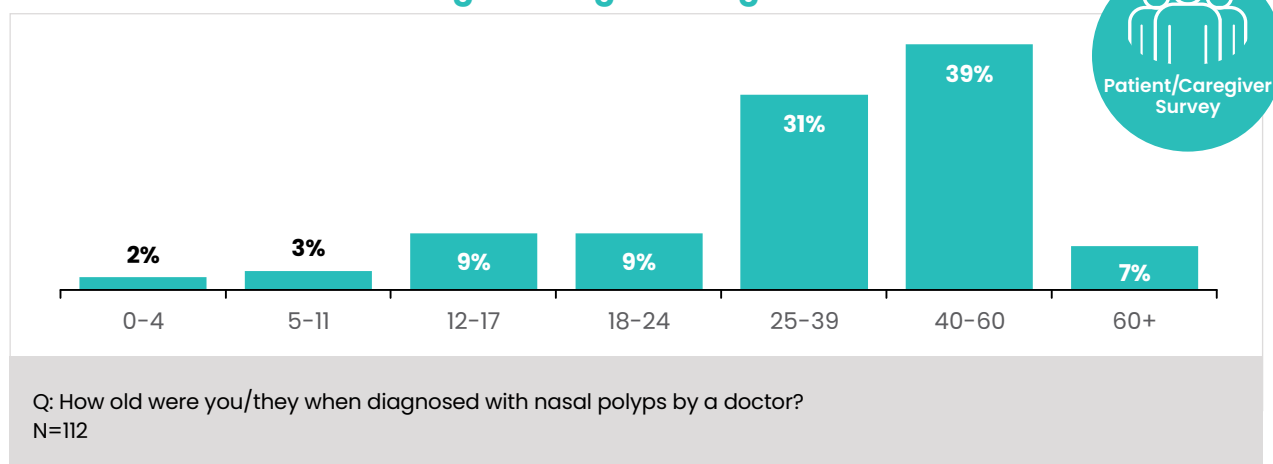
*Pseudonyms have been used

Nasal Polyps Diagnosis

Chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps) is diagnosed through review of symptoms, medical history, and physical examinations. To confirm the diagnosis, two main procedures are used: nasal endoscopy and computed tomography (CT) scan. Nasal endoscopy involves inserting a camera into the nasal passages to directly visualize any polyps or inflammation. A CT scan provides detailed images of the sinuses, which helps assess the extent of sinus disease and confirm the presence of polyps. In some cases, additional tests like smell tests, sinus cultures, or allergy tests may be used to further evaluate the condition and tailor treatment.

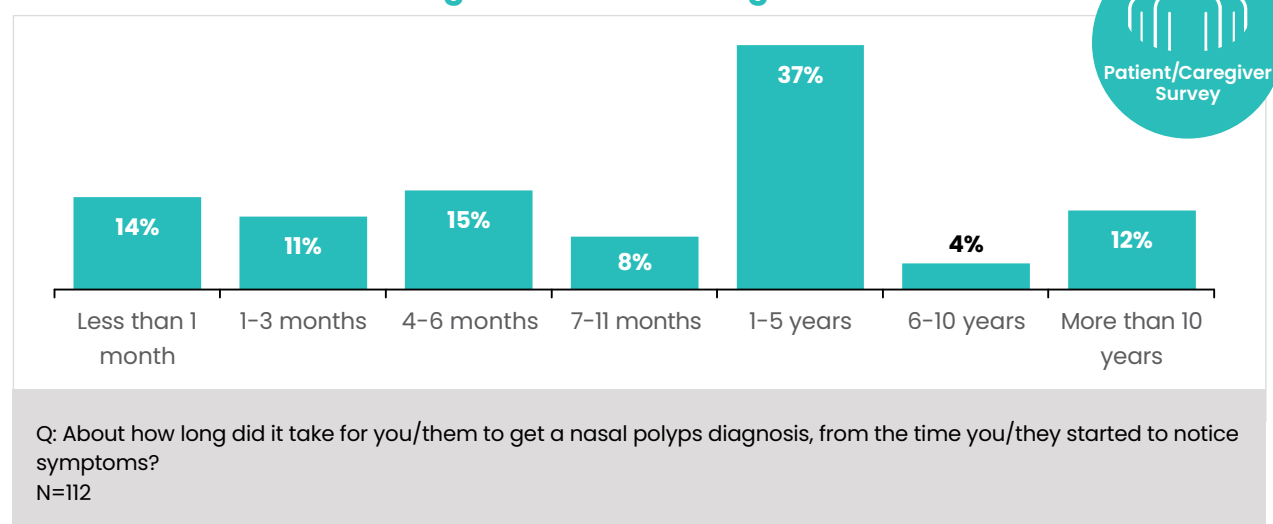
Over three-quarters (78%) of patients/caregivers in this study reported receiving a CRSwNP diagnosis after the age of 25. This tends to mirror the epidemiological distribution of CRSwNP, wherein the average age at diagnosis is 40–60.⁴

Figure 3. Age at Diagnosis



It can take a long time to get a diagnosis of CRSwNP. A majority (52%) of patients and caregivers said it took more than one year to receive a diagnosis after first experiencing symptoms. This includes one in eight (12%) who said it took more than ten years to get diagnosed.

Figure 4. Time to Diagnosis



One significant factor that can delay diagnosis is that CRSwNP symptoms can be similar to those with other conditions like asthma or allergies. Many interview participants reported not knowing they had nasal polyps until seeking medical help for other conditions.

"That's how I found out I had [nasal polyps]. I was being treated for allergic rhinitis and lots of recurring sinus infections, bronchitis, and then the whole shebang of coughing, sneezing some wheezing, stuffiness." – Mary

"For some months I had some nasal congestion issues...I ended up in the hospital and an ENT told me I had a head full of polyps." – Tom

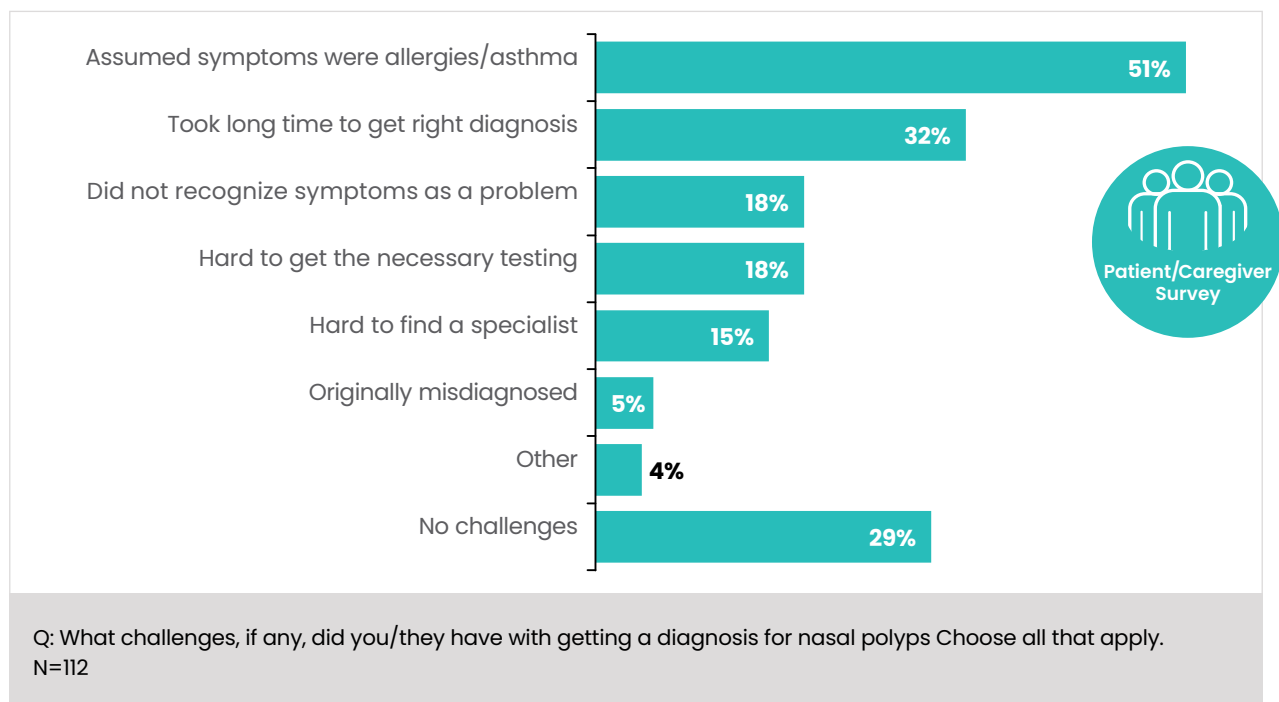
"How would someone know they were developing polyps without seeing an ENT? That seems to be the big mystery to me. [You wouldn't know you have polyps] until they're totally blocking off your nasal passages." – Ruth

"I've had a chronic cough, and they went through everything, and then finally referred me to an allergist. He finally figured out that it was related to my sinuses." – Fiona



These experiences were reflected in the survey results as well, in which most respondents (51%) said that a challenge to getting a diagnosis was that it was hard to tell if symptoms were not just bad allergies or asthma. Some also reported that their doctor(s) did not realize there was a problem, and having challenges getting the necessary testing for diagnosis. These patient-reported challenges highlight educational opportunities for health care providers. Additionally, some patients reported being initially diagnosed with other conditions. Some specified they were initially diagnosed with chronic sinusitis. This highlights an opportunity for patient education on the terminology of rhinosinusitis and sinusitis—as well as their connection with nasal polyps.

Figure 5. Challenges with Diagnosis



Additionally, interview participants reported seeing multiple doctors before getting a diagnosis, including general practitioners, emergency care, allergists/immunologists, and ENTs. In some cases, the long process of seeing multiple doctors made symptoms worse.

"It got to the point where it felt like my head was very cloudy. And every doctor I went to, no one could really give me a diagnosis. I kept going to the ER, they were giving me these injections that would take away inflammation. Then I decided to go to an ENT." – Georgia

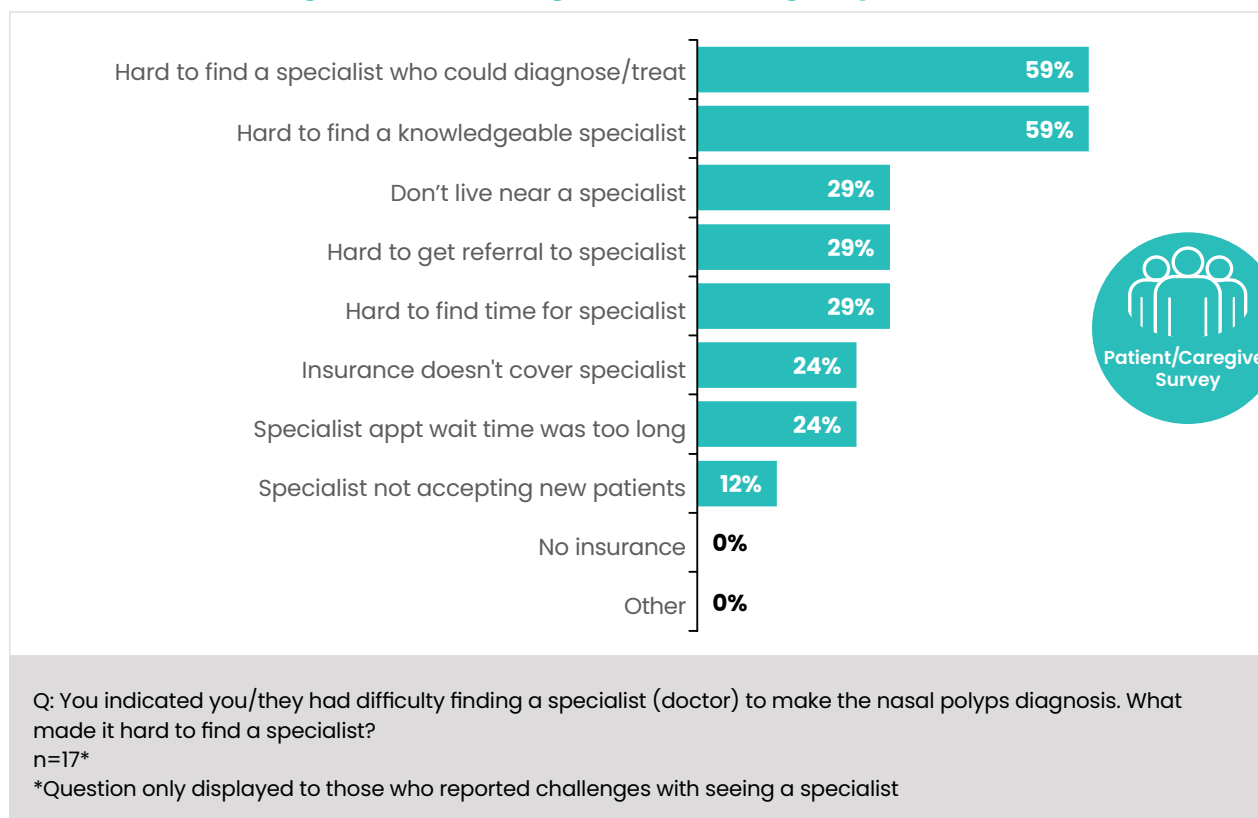
"Every time I moved to a different area...I would flare up again and have to get back on the train of going to the allergy specialist and getting retested for allergies." – Mary

"By the time that they [general practitioner] had referred me to an ENT, they were only doing video visitation. So when I got hospitalized—and the ENT came to visit me in the hospital—I finally got some answers and got some direction as to what to do about it." – Tom



Among those who said they had challenges seeing a specialist, three in five (59%) reported it was hard to find a specialist who could diagnose and treat nasal polyps, and that it was hard to find a specialist who knew about nasal polyps. Three in ten (29%) also reported they don't live near a specialist, it was hard to get a referral to a specialist, and it was hard to find time to see a specialist. These challenges highlight key access issues in the availability of specialists who can diagnose and treat nasal polyps.

Figure 6. Challenges with Seeing a Specialist

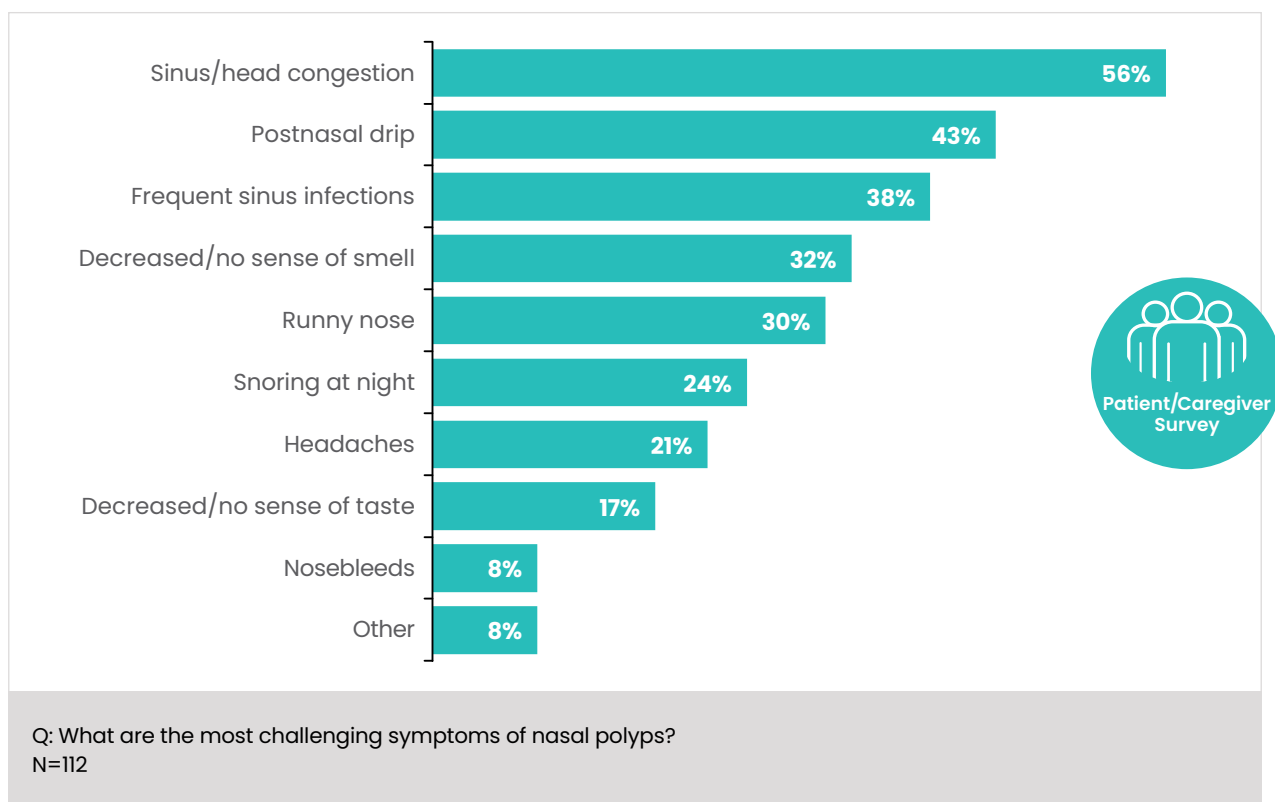


Nasal Polyps Symptoms

Common symptoms of nasal polyps include stuffy nose (congestion), runny nose (rhinorrhea), mucus running down the throat (postnasal drip), loss of taste or smell, facial pain, headache, sinus pressure, and snoring. In some cases, nasal polyps can block nasal passages and sinuses, leading to increased asthma attacks in people with asthma, repeated sinus infections, sleep apnea or other sleep disorders, and difficulty breathing.⁴

Among survey respondents, over half (56%) chose sinus or head congestion as one of the most challenging symptoms they live with. About two in five also mentioned postnasal drip (43%) and frequent sinus infections (38%). One in twelve (8%) listed “other” symptoms as challenging. Other responses included symptoms such as general pain and discomfort, difficulty breathing through the nose, unexpected and unpredictable nasal drainage, and lack of sleep.

Figure 7. Most Challenging Nasal Polyps Symptoms



Challenges with congestion were echoed by interview participants, as were challenges with sinus and respiratory infections. Interview participants also highlighted how chronic symptoms could have dangerous implications.

“It’s pretty severe pain when I get sinus infections because nothing drains... even without a sinus infection, there’s just a lot of nasal discharge just throughout the year that I’m always congested and can’t really breathe through my nose very well.” – Leo

“The congestion bothered him so much that he wasn’t able to breathe correctly...for him, it was something new, and it made it difficult.” – Tamara



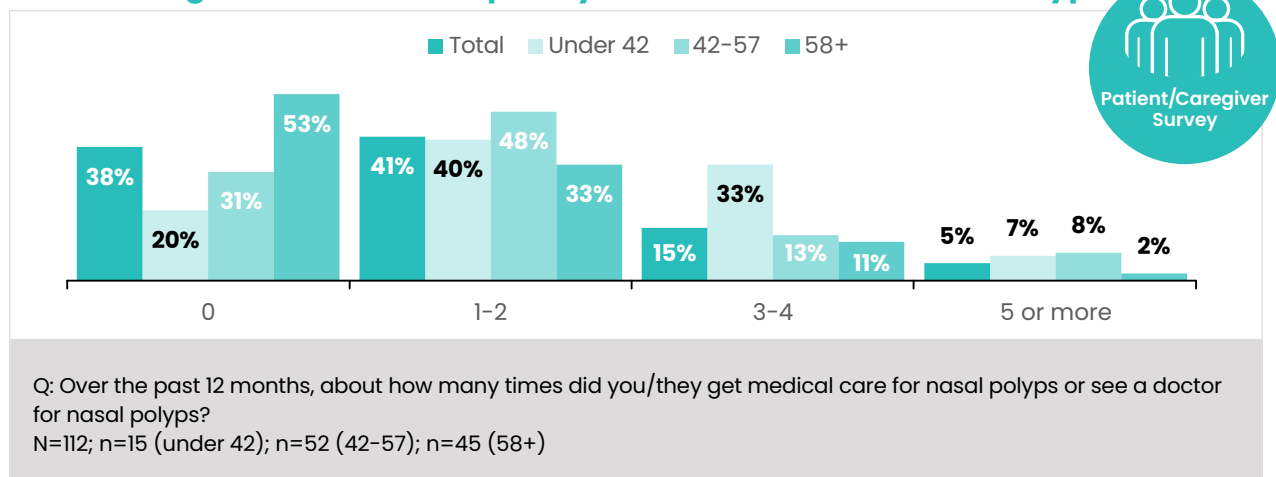
Medical Care and Treatments for Nasal Polyps

Different health care professionals support the diagnosis and ongoing care for chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps). The care team may include:

- Ear, nose, and throat (ENT) specialist
- Allergists/immunologists
- Pulmonologists
- Primary care physicians

About three in five (62%) survey respondents reported seeing a doctor for nasal polyps at least once per year. Respondents under the age of 42 (i.e. Millennial or Gen Z) reported seeing a doctor more often, with about one in three (33%) patients in this age group seeing a doctor for nasal polyps 3–4 times a year. Over half (53%) of patients aged 58 or older (i.e. Baby Boomer or Silent Generation) report seeing a doctor for nasal polyps less than once a year.

Figure 8. Annual Frequency of Doctor Visits for Nasal Polyps



While two-thirds (66%) of survey respondents said they were diagnosed by an ear, nose, and throat (ENT) doctor, and about the same number (64%) say they currently see an ENT for ongoing nasal polyps care, primary care and allergists/immunologists play an important role in nasal polyps management. About one in three respondents say they currently see a primary care/general practice doctor (34%) and/or an allergist/immunologist (31%) for their nasal polyps care.

Figure 9. Doctors Seen for Nasal Polyps Diagnosis and Management

Type of Doctor	Initial Diagnosis	Ongoing Management
Ear, nose, and throat (ENT)	66%	64%
Primary care/general practice	16%	34%
Allergist/immunologist	14%	31%

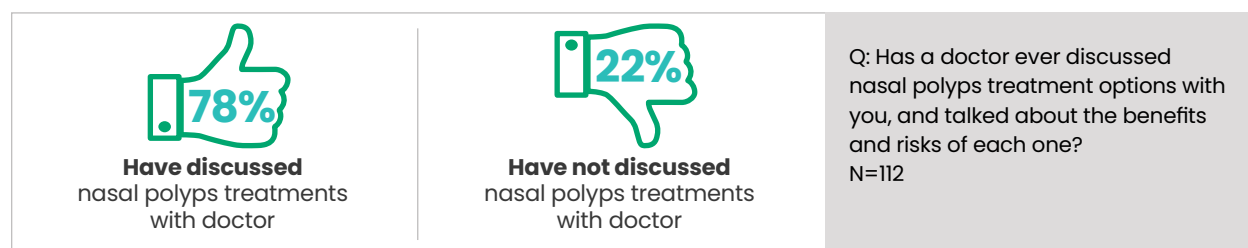
Q: What kind of doctor gave you/them the nasal polyps diagnosis?
Q: Which of the following doctors do you/they see for nasal polyps?
N=112

Chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps) is treated using medications and surgery. CRSwNP treatments can help manage and reduce symptoms associated with the disease. Some treatments also target the underlying inflammation that causes CRSwNP. Current treatment options for nasal polyps include:

- **Intranasal corticosteroids (INCS)** – Intranasal corticosteroids are a commonly used drug treatment for nasal polyps. They can be delivered through nasal sprays or nasal drops. They are made to reduce inflammation in the body and can be used long-term.
- **Saline rinses** – Saline rinses use a saltwater spray or nasal wash to rinse the nasal passages. This can improve mucus flow and remove irritants. Saline rinses can be easily prepared at home using a bottle or syringe, and can be used alone or with other treatments.
- **Oral corticosteroids (OCS)** – Oral corticosteroids are pills taken by the mouth to help reduce inflammation in the sinuses. They may be used if nasal sprays or other treatments are not effective in shrinking or eliminating nasal polyps. Oral corticosteroids are recommended for short-term use only.
- **Biologics** – Biologic medicines target certain cells or proteins to reduce irritation and swelling. They are given by injection or infusion to help target the underlying inflammation causing nasal polyps.
- **Aspirin desensitization** – Aspirin desensitization is a treatment option for people who react badly to aspirin. This treatment involves taking small doses of aspirin over time to help the body get used to it. In some patients, this can decrease the regrowth of nasal polyps and reduce the need for other treatments.
- **Endoscopic sinus surgery (ESS)** – Endoscopic sinus surgery is a surgery in which a surgeon puts a small tube with a lighted lens or tiny camera (endoscope) through the nostrils into the sinuses, then uses small tools to remove the polyps. Long-term medical care and follow-up is needed in most patients who go through surgery.
- **Revision surgery** – Revision surgery happens when an initial surgery didn't relieve symptoms or caused a new problem. With revision surgery, the surgeon removes any obstruction to the sinuses to open them up.

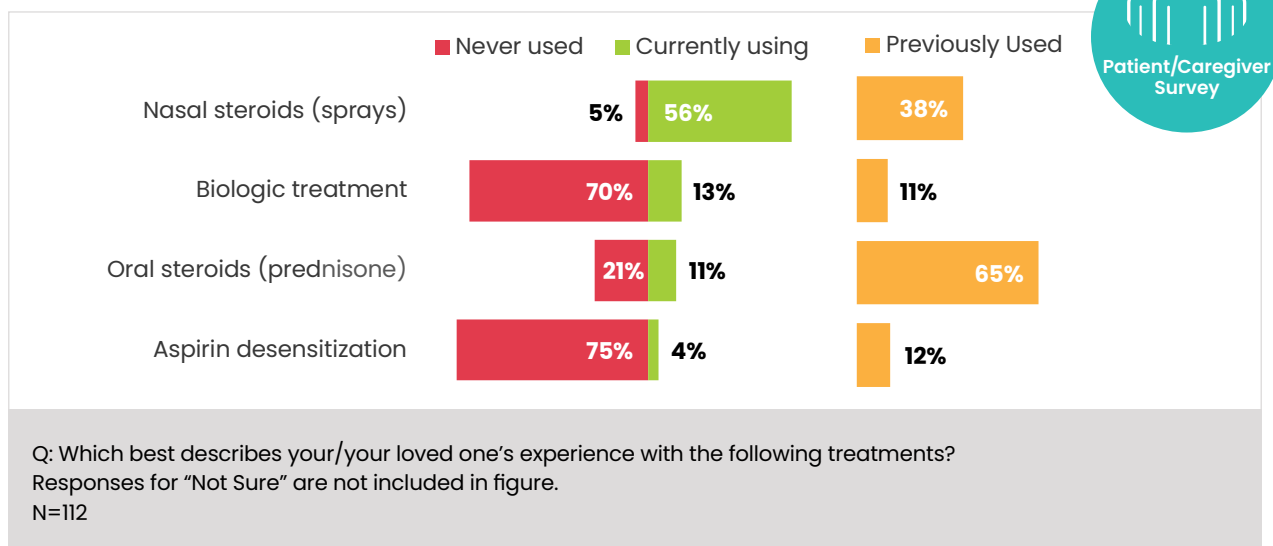
It is important for physicians to work with patients and caregivers to develop and monitor a treatment plan specific to patients' needs. Over three-quarters (78%) of survey respondents indicated that their doctor has discussed nasal polyps treatment options with them and talked about the benefits and risks of each one.

Figure 10. Discussion of Nasal Polyps Treatment Options with Doctor



Most (56%) survey respondents reported currently using nasal steroid sprays to treat nasal polyps symptoms. While few (11%) reported currently using oral steroids to treat their nasal polyps, about two-thirds (65%) said they have used them in the past. Around one in four survey respondents said they have used biologics to treat nasal polyps currently (13%) or in the past (11%).

Figure 11. Experiences with Treatments



Interview participants reported that finding treatments that work effectively and long-term can be a process of trial and error. Many described experiences of treatments not effectively treating symptoms, or working for a while before symptoms or nasal polyps reappear.

"At that point I was still congested, and the congestion would not go away. I took the antibiotics, and they gave me [nasal sprays], but none of it was doing anything."
– Georgia

"I've tried all the other more base level drugs, and then the newer drugs didn't work for me. So it's been almost four years now. The polyps were identified and have been removed twice, but they continue to come back."
– Leo

"It was very frustrating feeling like they'd keep giving me treatments for flus or other things that cause nasal congestion. And those treatments didn't work, so I think 'what's the point of this?'" – Tom

"The last five years, I'd go on a prednisone burst and I'd get my sense of smell back for a while... that would last only a little while, and I'd be going back in [to the doctor]."
– Norah

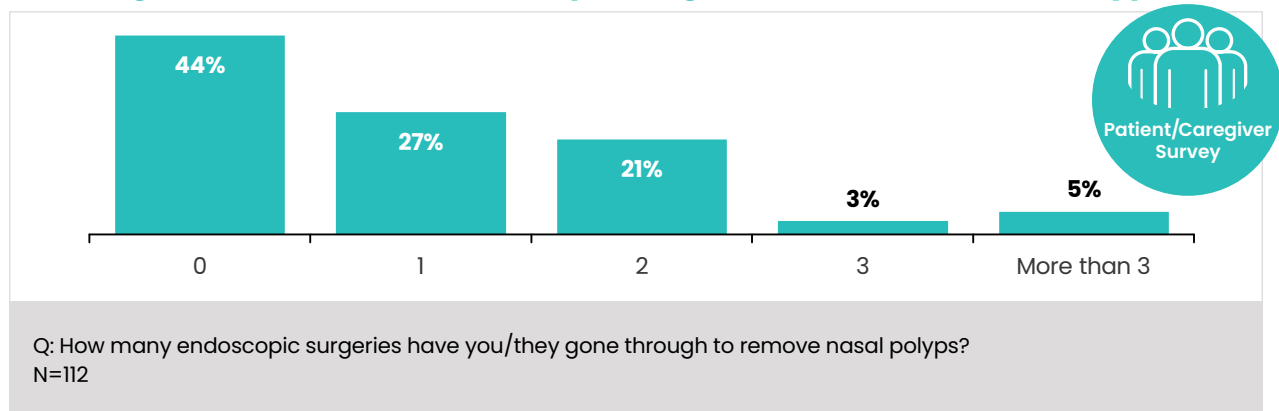
Additionally, effective treatments can also have unexpected and uncomfortable side effects. Interview respondents using nasal sprays discussed how the medicine can be difficult to get into, or stay in, sinus cavities.

"It's not pleasant to be out in public and all of a sudden, all that stuff that you've squirt up your nose [comes out]. It was really hard when I was still working...because I'd bend down to pick up something, and there'd be somebody in the room. And all of a sudden you get this stuff out that you'd put in."
– Norah

"I went out, got [OTC nasal spray]. I squirted it in and it just rolled right out."
– Ruth

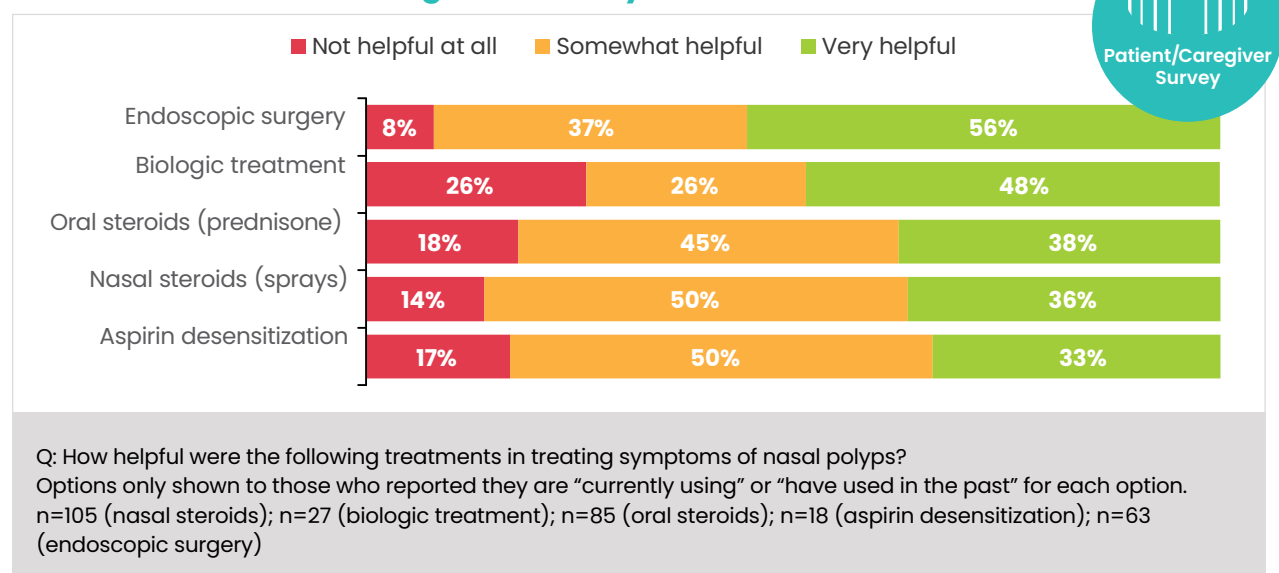
In addition to pharmaceutical treatments, most (56%) survey respondents also reported having at least one endoscopic surgery to remove nasal polyps, with about three in ten (29%) having two or more surgeries.

Figure 12. Number of Endoscopic Surgeries to Remove Nasal Polyps



Among all treatment options, endoscopic surgery was reported to be the most helpful in treating symptoms of nasal polyps among survey respondents who reported having surgery. Though few survey respondents reported taking biologics to treat nasal polyps symptoms, nearly half of respondents who have used them said they were “very helpful” in treating symptoms. Though currently used by most (56%) survey respondents, only about one in three (36%) respondents who use nasal steroids say they are “very helpful” in treating nasal polyps symptoms.

Figure 13. Utility of Treatments



Though endoscopic surgery was indicated by survey respondents as the most effective treatment at addressing nasal polyps symptoms, interview participants described experiences of polyps returning following surgery.

"The success of the surgery lasted probably about a year. After that I started feeling congested. It always starts out with a little bit of congestion. And then from the congestion, you notice your smell starts to deteriorate until you can't smell anymore." – Georgia

"I did a surgery and it just cleared everything out. Then three weeks later after the surgery, on my postop, the polyps were already coming back." – Leo

"My adult son did have surgery maybe six or seven years ago for his polyps. And it worked for a little while, but now they're back." – Tamara

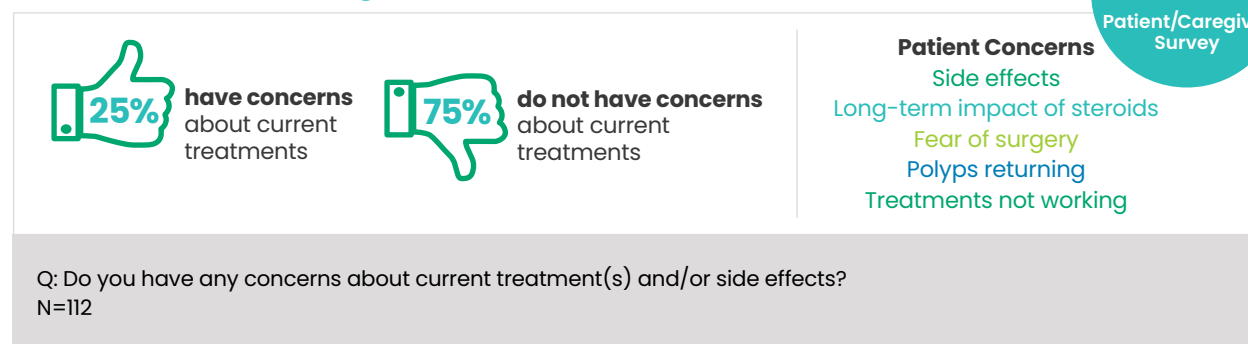
"The sinus surgery helped somewhat, but then they started coming back" – Teresa

"I had surgery to have the polyps removed. They immediately started coming back, I'd say within weeks." – Tom



One in four (25%) survey respondents reported having concerns about current treatments. The most common concerns cited by patients and caregivers included the side effects of treatments, the long-term impacts of steroids, concerns about treatments not working and/or polyps returning, and hesitancy toward getting surgery.

Figure 14. Concerns About Treatments



These concerns were echoed by interview participants, many of whom described difficult side effects of their current treatments, including drowsiness, irritation, and behavioral change.

"With antihistamines, the more you take, the more they just make you sleepy. So you kind of got to balance the treatment with how much do you want to be productive today. Do you want to be awake or do you want to feel better?" – Edward

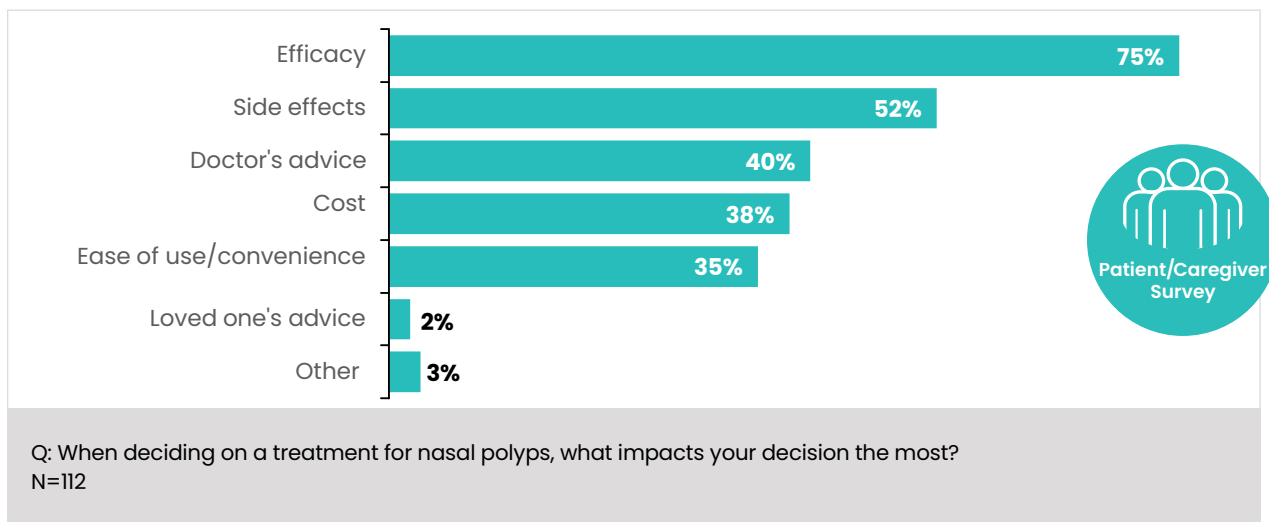
"The medications were not always pleasant to help control everything...it would just make me hyper, I'd be cleaning closets at three in the morning. But in the past probably 15 years, it started to make me very irritable." – Mary

"My allergy doctor was concerned about all the years of taking so much [oral] steroids...he put on my chart that I was never to take any oral steroids ever again." – Mary



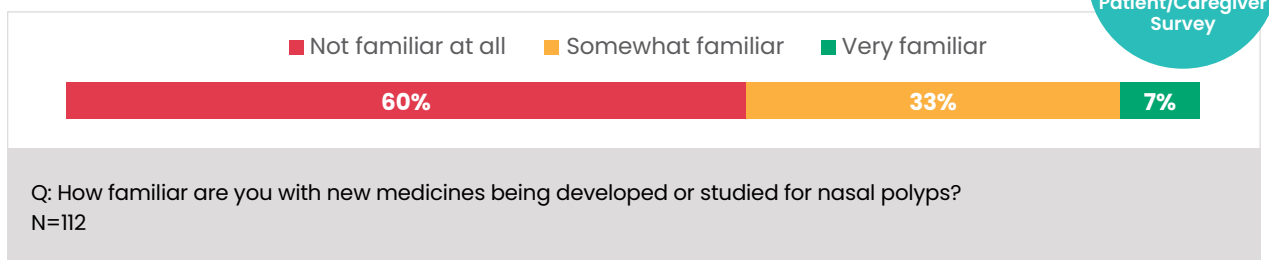
When it comes to making decisions about a treatment path, three in four (75%) survey respondents said efficacy was the most important factor to consider. More than half (52%) also said side effects of treatment were important, and about two in five included their doctor's advice (40%) and cost (38%) as some of the most important factors they consider when deciding on a treatment.

Figure 15. Factors Impacting Treatment Decisions



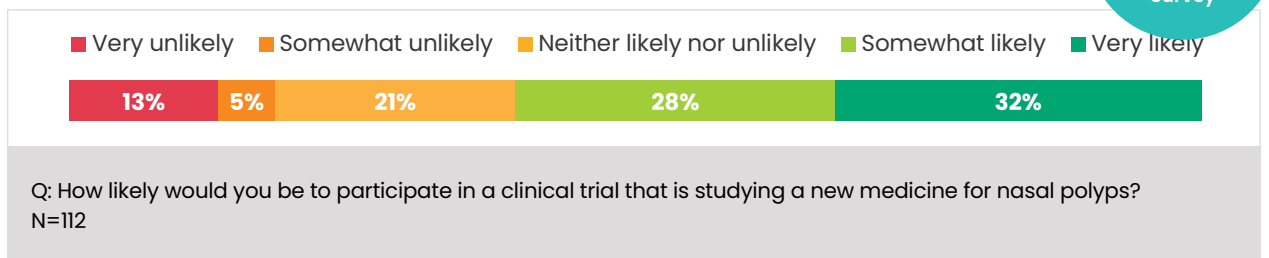
About three in five (60%) survey respondents said they were “not familiar at all” with new medicines being developed or studied for nasal polyps, with one in three (33%) saying they were “somewhat familiar.”

Figure 16. Awareness of Emerging Treatments



Despite low familiarity with emerging treatments, three in five (60%) survey respondents said they would be willing to participate in a clinical trial studying a new medicine for nasal polyps, with one in three saying they would be “very likely” (32%), and about the same number saying they would be “somewhat likely” (28%).

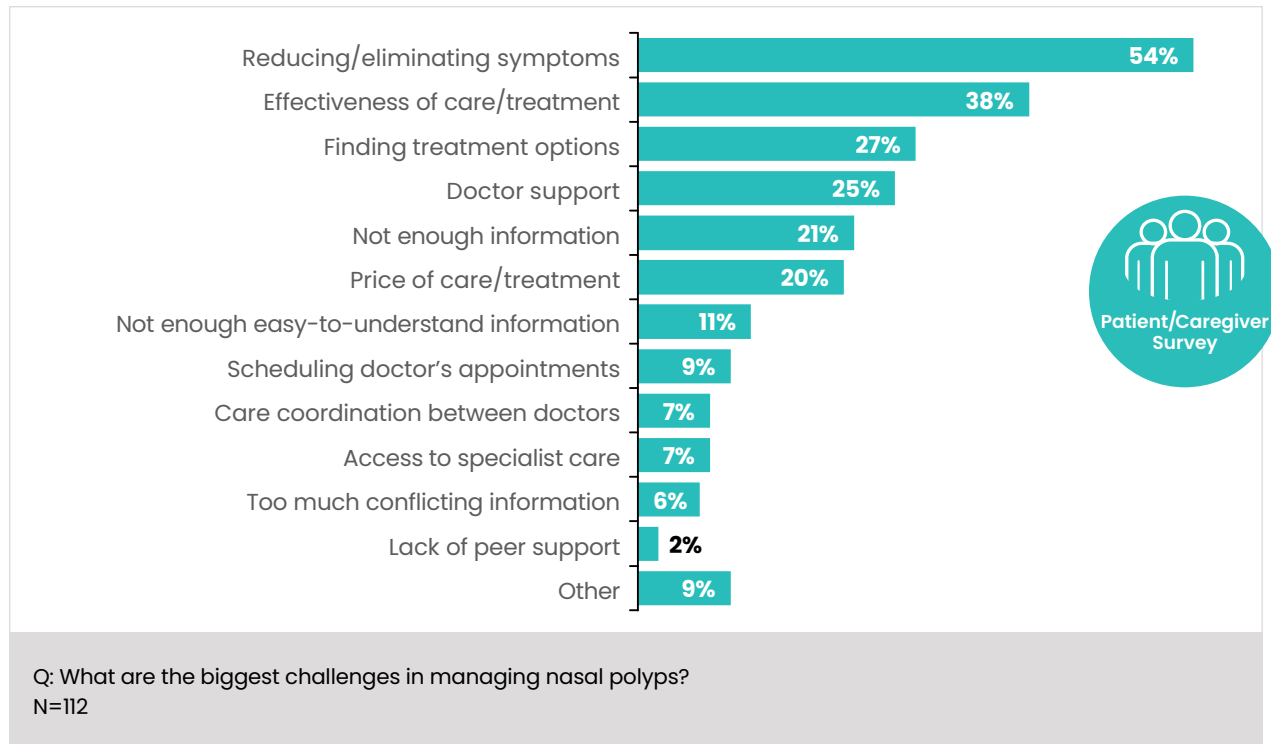
Figure 17. Willingness to Participate in Clinical Trials



Challenges with Managing Nasal Polyps

Even with a diagnosis and treatment plan, people living with chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps) may still go through unexpected challenges in day-to-day management. Over half (54%) of survey respondents said reducing or eliminating symptoms was a significant challenge in managing nasal polyps. About two in five (38%) said effectiveness of care and treatment was one of the biggest challenges.

Figure 18. Challenges with Nasal Polyps Management



One in four (25%) respondents listed doctor support as a challenge to management, and this sentiment was reflected in some patient interviews. Some mentioned doctors downplaying the condition, others expressed frustration at the lack of doctor support in treatment decisions.

"I think the major challenge is that doctors don't take it maybe as seriously as they should. They consider it like a minuscule thing, just an inconvenience and not something that's important, should be addressed, or taken care of. Or like they just want you to try to deal with it on your own instead of offering you any kind of solutions or help to the situation." – Edward

"I didn't get much help from primary care doctors. They said to take [OTC antihistamine] and then come back...It was just always throwing something over-the-counter at it, and not really trying to get to the bottom of what's causing it." – Mary

"I did have another ENT that kind of paired up with [my asthma specialist]. I felt like I was being balanced back and forth between the two. Nobody wanted to make a decision about what to do." – Norah



One in five (20%) survey respondents also listed the price of care as a challenge to managing their nasal polyps. In patient interviews and open-ended survey responses, some described significant challenges with insurance coverage, especially in covering treatments.

"I had to change doctors because of insurance, so I lost my good tie to the good ENT that had diagnosed me." – Norah

"Getting that [biologic] prescription was an incredible odyssey all in itself. Getting it approved and getting the specialty pharmacy to deliver it. And I'd have to call them every couple of weeks to go through this whole rigamarole all over again. It was not fun." – Tom

"I'm in the middle of an appeal process to get the tier lowered on that drug... Otherwise I'm looking at between \$80 and \$120 a month just for the budesonide, because it's a tier four drug under Medicare. They denied it because the FDA doesn't see the need for using it that way. It was not manufactured to be used that way." – Norah

"There's a newer drug but my insurance won't cover it unless I do the awful one [nasal spray] for six weeks first." – Survey respondent



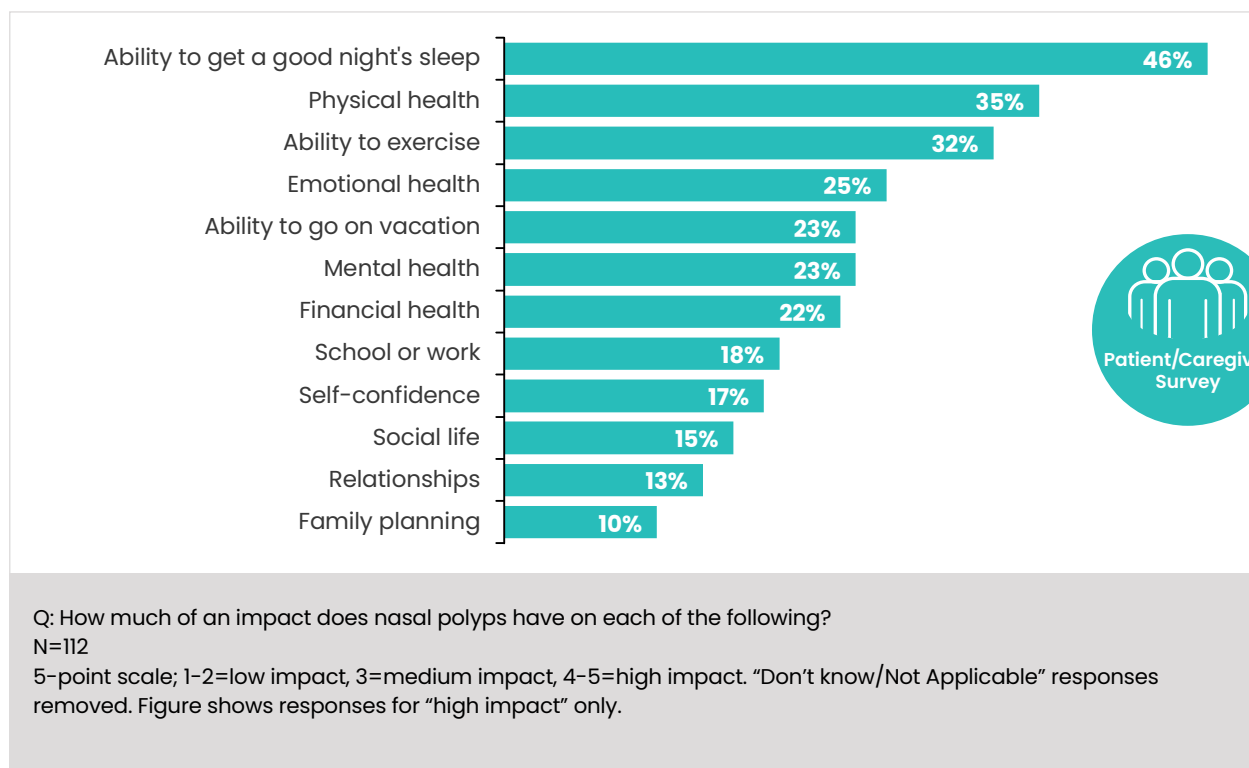
One in ten (9%) survey respondents listed challenges that were outside of the answer options provided. When asked to specify, patients and caregivers reported challenges like feeling there are no more treatment options, the burden of having to keep up with a treatment like a daily nasal spray, and unpleasant experiences with treatments.



Impact of Nasal Polyps

Chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps) can have significant impacts on patients' and caregivers' lives. In this study, in addition to the physical impacts of symptoms like congestion, stuffy and runny nose, and loss of taste or smell, nearly half (46%) of survey respondents said nasal polyps have a significant impact on their ability to get a good night's sleep. About one in three (32%) also said nasal polyps have a significant impact on their ability to exercise. Mental and emotional impacts are also seen, with about one in four survey respondents saying nasal polyps have a significant impact on their emotional (25%) and mental (23%) health.

Figure 19. Impact of Nasal Polyps on Various Aspects of Life



Though less frequently selected by survey respondents, the social and emotional challenges of nasal polyps were apparent in patient interviews. Interviewees described feelings of fear, guilt, social isolation, and sadness when dealing with their symptoms.

"Nasal polyps are so depressing because they'll make you have fear. Because it's like, what if you walk into something you can't smell that could be possibly poisonous to you? They don't have it [classified] as a disability, and I feel like it really is." – Georgia

"They've shown that it can be hereditary. And so I've dealt with the guilt of that, and felt sorry for [my daughter] that she's been through all the testing and allergy shots at a very young age." – Mary

"I had a wonderful three or four months of smelling everything. I was probably a little silly in public, because I'm always saying to my husband, 'Oh, that smells so good.' And food tastes so much better. And I'm starting to struggle with that now, when you eat something and you're thinking, 'Okay, that's supposed to have more of a flavor.' That really has bothered me. It's not fun once you know how good things taste." – Norah

"You have to change plans with friends. If you have a sinus infection and it gets worse and worse. You're constantly altering your life, family events. You just lose your energy, and they get harder to fight." – Teresa

"Sometimes in the back of my head, I can tell that it's affecting me...there's times it gets really frustrating where a person that's seen me play before, a band member or a friend, is like, 'Okay, you okay? You seem a little winded this evening.' And I don't like for anyone to know that." – Sam

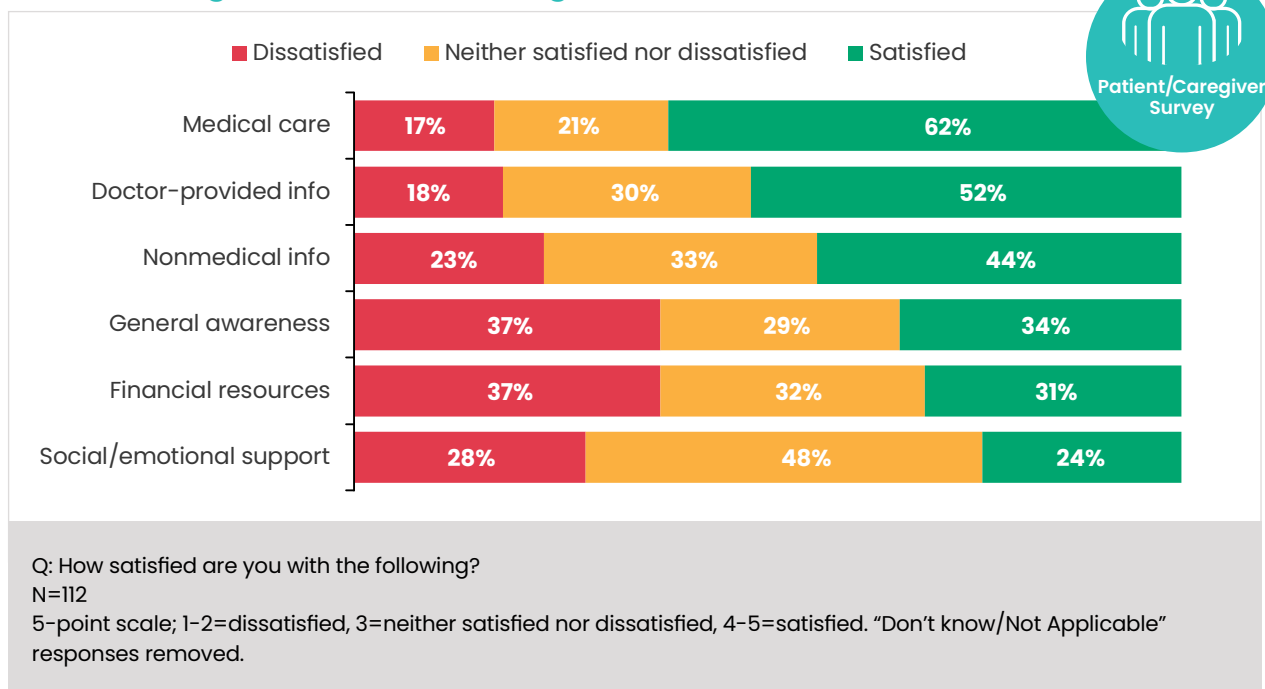


AAFA's online support communities offer patients and caregivers a chance connect with other people who understand what it is like to live with nasal polyps and other allergic conditions. Visit AAFA's community at: aafa.org/join

Resource Needs

Despite challenges identified in chronic rhinosinusitis with nasal polyps (CRSwNP, or nasal polyps) diagnosis and management, most survey respondents reported being satisfied with the medical care they receive for nasal polyps, as well as the education and information about nasal polyps that they receive from their doctor(s). These results highlight the importance of appropriate medical care in nasal polyps management. Areas where patients and caregivers were less satisfied include general awareness of nasal polyps (37% dissatisfied) and financial resources to support medical care (37% dissatisfied).

Figure 20. Patient/Caregiver Satisfaction with Resources



Though patients and caregivers reported high satisfaction with medical care and doctor-provided information in the survey, patient interviews revealed that patients often do their own research to find additional information about nasal polyps following diagnosis.

"I've done a lot of reading online and watching videos and hearing other people's testimonies and stuff...anytime there's anything related to that, I'm curious about it and I'll read it." – Leo

"As years went on and I did start doing some research on my allergies and symptoms and everything online, that helped." – Mary

"Once I became a nurse, I researched it myself. Sometimes you have to do your own research and be your own advocate. So that's pretty much what I did." – Tamara

"Going online and reading about it was helpful. I know I've done that a number of times, including AAFA's website, the Mayo Clinic, whatever I could find online about it." – Teresa

Additionally, survey respondents were divided on their satisfaction with social and emotional support, with about the same number of respondents satisfied with social support (24%) as dissatisfied (28%). These sentiments were reflected in the patient interviews, where participants expressed that it can be difficult for friends and family to understand their condition. However, when it is given, social support from friends, family, and others living with nasal polyps is invaluable.

“They’re looking like, ‘Huh? Polyps? I’ve heard of cancerous polyps, but not nasal polyps.’ And then you got to go through the spiel and be the doctor, and break down things and give people terminologies and stuff, and they’re still lost.” – Georgia

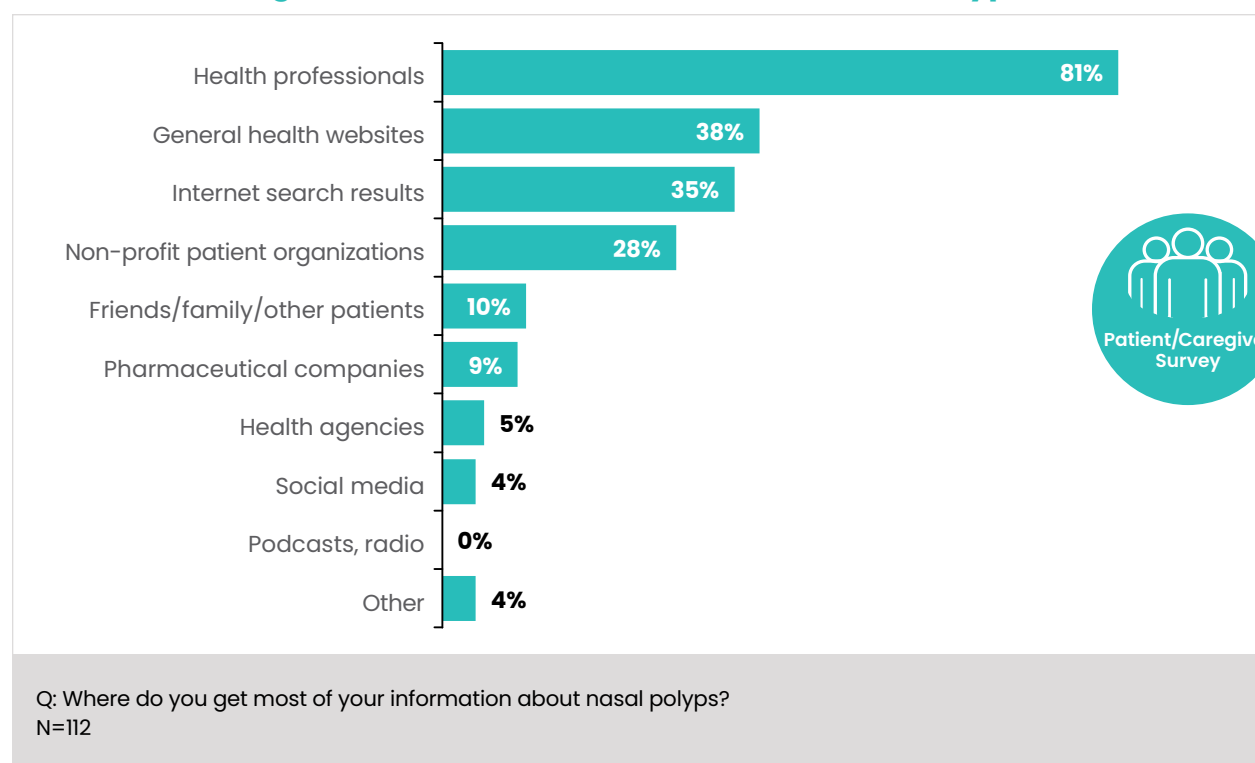
“My parents have been very helpful with all this stuff, and my mom particularly has been involved in doctor’s appointments and stuff. Especially since this started while I was still 17...I have a good support network. So I don’t feel like I’m dealing with it on my own at least.” – Leo

“I was checking with a bank. I got into a conversation with whoever I was talking to and it turned out this person who lived in Colorado or something had polyps, and we were comparing treatments. So that was interesting. I don’t know how we got into that conversation, but we got there. So when you find a compadre, it’s helpful.” – Teresa



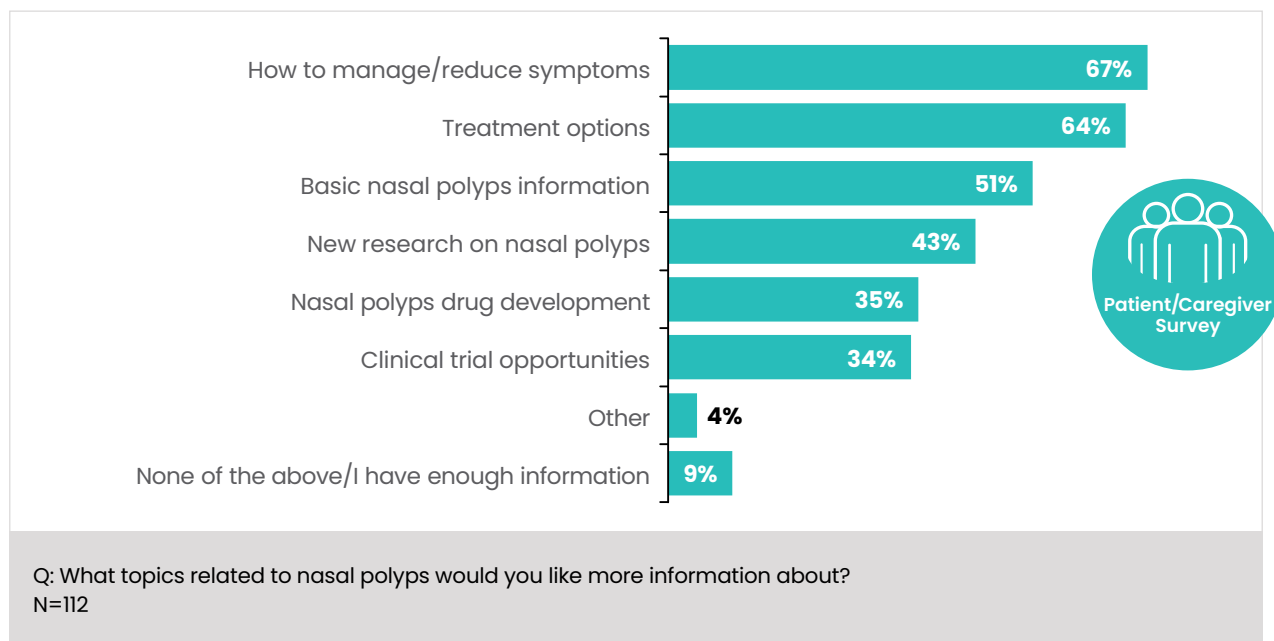
The reliance on health information from health professionals and individual research was evident in survey responses, where four in five (81%) patients and caregivers say they get most of their nasal polyps information from health professionals like their doctor. About two in five said they get most of their information from general health websites (38%) and internet search engine results (35%).

Figure 21. Sources of Information for Nasal Polyps



When it comes to topics of interest, around two thirds of patients and caregivers said they would like more information about how to manage or reduce symptoms without surgery (67%) as well as treatment options (64%). Additionally, more than half (51%) said they would like more basic nasal polyps information such as what they are and what causes them. About one in three survey respondents said they would like more information on nasal polyps drug development (35%) and clinical trial opportunities (34%) Less than one in ten (9%) survey respondents said they don't need any additional information.

Figure 22. Topics of Interest



The most popular topics of interest for survey respondents—management strategies, treatment options, and general nasal polyps information—were also discussed in patient interviews. Interview participants emphasized the value of understanding more about the condition and treatments to be better prepared for self-management and conversations with their doctor(s).

"[Through my research] I was able to understand things to the point where I was better able to ask questions and get the answers that I needed...How things worked, how the different treatments would hopefully lessen the symptoms, outcomes of the different treatments and how the ears and the nose are connected." – Tamara

"I would just love more information, other than what I'm doing, is there anything I can do to keep these from growing back or keep them under control? I guess it would be just more ways of controlling and keeping them from coming back." – Norah

"I am interested in what kind of medications might be prescribed for me when I go back and ask my healthcare provider about this polyp. I know it's in some of the literature that I reviewed a while ago, but I haven't gone back to it." – Fiona



Interview participants also highlighted the need for more information on nasal polyps research and clinical trial opportunities. There is interest in this type of information; however, often patients and caregivers may not know where to find the latest updates.

"I would say providing the most knowledgeable information as it becomes available [is important], pertaining to any research that is being done within science right now. And providing updated research on different medications based on groups of people." – Georgia

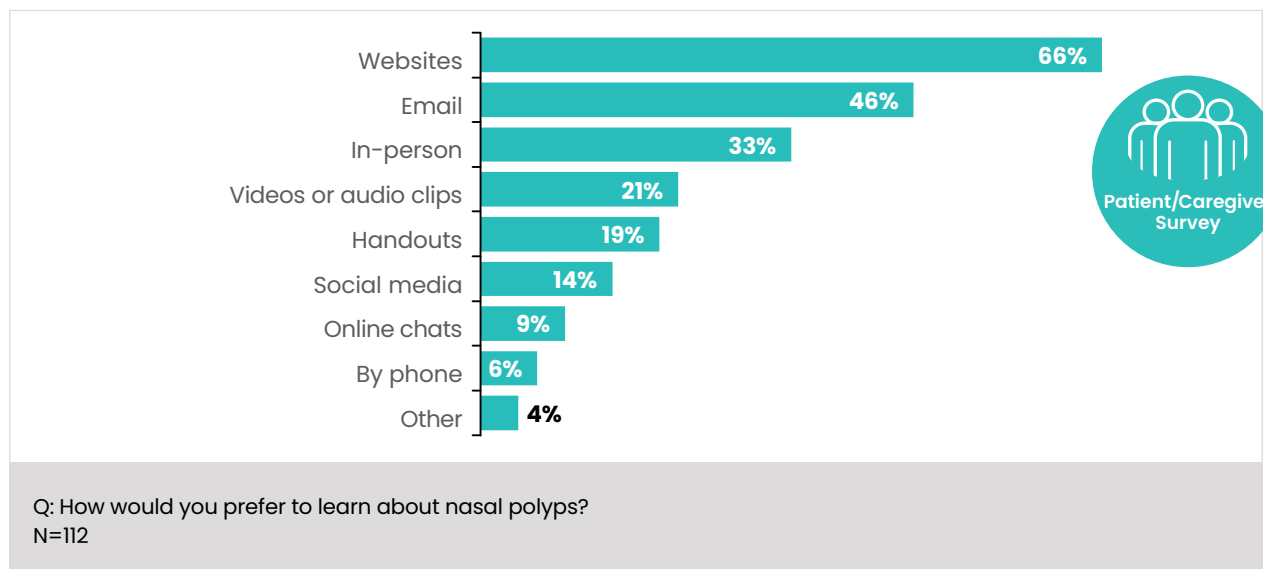
"I'm not really sure how to get involved in clinical trials. Because that is the only step I have left that I haven't tried, and I'm just hoping that I can get involved in some trial with some new drug that works wonders for me." – Leo

"As new research shows more, newer information about allergies and polyps and how to control them, and just even day to day dealing with them [is important]." – Mary



To get the needed information, two-thirds (66%) of survey respondents said they prefer to get nasal polyps information through websites. Nearly half (46%) also indicated they preferred to receive nasal polyps information through email.

Figure 23. Preferred Method of Nasal Polyps Information Communication



Unmet Needs and Opportunities to Improve Care

As the landscape of CRSwNP care in the U.S. continues to evolve, the Asthma and Allergy Foundation of America (AAFA) recognizes the need to better understand current challenges and barriers to timely diagnosis, quality medical care, effective treatments, and access to resources—particularly among AAFA’s patient community of people impacted by comorbid conditions like asthma and allergies.

This report provides an overview of the nasal polyps journey from the patient and caregiver perspective using data gleaned from a multi-component needs assessment study. By analyzing data and common themes from the study, AAFA identified several unmet needs and areas of opportunity for improving CRSwNP care.

In this section, we summarize unmet needs that emerged from the study as well as opportunities for CRSwNP stakeholders to address needs in the following domains:

- Health care provider (HCP) education and clinical care
- Patient education and public awareness
- Treatments and patient-centered research

Unmet Needs in Health Care Provider Education and Clinical Care

Patients and caregivers reported several barriers to accessing optimal care for CRSwNP. The process of diagnosis can be lengthy and frustrating. The majority of patients indicated that it took a year or more for them to receive an accurate diagnosis for CRSwNP after first noticing symptoms (Figure 4).

Some delays were due to limited awareness of CRSwNP among HCPs; leading some patients to report that their HCP did not recognize their symptoms during initial consultations. Many patients reported encountering HCPs who were not knowledgeable in CRSwNP symptoms and diagnosis. Patients reported seeing multiple doctors before getting a diagnosis, including general practitioners, emergency care, allergists/immunologists, and ENTs. In some cases, patients experienced a long period of visiting primary care/generalists before referral to specialists.

Awareness of CRSwNP symptoms—especially in primary care—remains a critical unmet need. HCP education can improve knowledge and awareness of CRSwNP symptoms. This is critical to improving the diagnostic journey for people with nasal polyps.

Opportunity: Build educational programs for health care providers that focus on improving recognition of CRSwNP, especially in people with comorbid conditions that have similar symptoms. Develop educational programs for primary care physicians to promote disease awareness and facilitate referrals to specialists for more timely diagnoses.

Patients cited lack of doctor support as a challenge to diagnosis and diseases management. Some patients felt that their doctors dismissed their symptoms or downplayed their condition. Others expressed frustration at the lack of doctor support in treatment decisions (Figure 18).

In addition to recognizing symptoms, awareness of and alignment with clinical guidelines for CRSwNP can help reduce the barriers to timely and accurate diagnosis. Several expert guidelines are available, including the European Position Paper on Rhinosinusitis and Nasal Polyps (EPOS 2020), International Consensus Statement on Allergy and Rhinology: Rhinosinusitis (ICAR:RS), and guidelines for the medical management of chronic rhinosinusitis with nasal polyps from the AAAAI/ACAAI Joint Task Force on Practice Parameters.

There is a need for physicians to be aware of consensus guidelines—particularly when it comes to supporting treatment decisions for patients with CRSwNP. Treatment algorithms—like EUFOREA’s pocket guide for CRSwNP—can be disseminated to support HCPs in managing treatments.

Opportunity: Increase awareness of current guidelines to support prompt and accurate diagnosis and better long-term management for CRSwNP. Widely disseminate existing tools developed from guidelines (such as referral, diagnostic, and treatment algorithms) to primary and specialty care clinicians, as well as patients.

A multidisciplinary care team is important for effective CRSwNP management; particularly for patients with comorbid type 2 inflammatory conditions. Following diagnosis, ongoing care for CRSwNP may be co-managed by ENTs, allergists, primary care physicians, pulmonologists, and other HCPs.

Two thirds of respondents said they were diagnosed by an ENT doctor and about the same number say they currently see an ENT for ongoing nasal polyps care. However, primary care and allergists/immunologists play an important role in nasal polyps management as well. About one third say they currently see a primary care/general practice doctor and/or an allergist/immunologist for their nasal polyps care (Figure 9).

Opportunity: Develop models of multidisciplinary care teams for both public and private practice settings to help health care providers ensure people with CRSwNP have access to appropriate, comprehensive care. Develop and disseminate referral resources to help improve diagnoses and care coordination.

In addition to a multidisciplinary team of HCPs, the patient is a critical part of the health care team. For optimal patient-centered clinical care, ongoing education for HCPs should incorporate the patient perspective.

Opportunity: Incorporate patient voice and stories into HCP education. Include patient perspectives and experiences through various case studies to help inform HCPs about the struggles people face at different points of their journey and improve patient-provider communication.

Unmet Needs in Patient Education and Public Awareness

To ensure that patients are active participants in their health care, people with CRSwNP need to have access to updated information about seeking appropriate care and taking an active role in determining best treatments to match their needs.

One significant factor that can delay patients in seeking care is that CRSwNP symptoms can mimic those of other conditions like asthma or allergies. Many patients said that a challenge to getting a diagnosis was that it was hard to tell if symptoms were not just bad allergies or asthma (Figure 5). For patients with type 2 inflammatory comorbidities, in particular, many did not receive a diagnosis for nasal polyps until seeking medical help for other conditions.

Following the diagnosis, many patients often do their own research to find additional information about nasal polyps care and treatment options (Figure 20). Conflicting, confusing, and incomplete information about CRSwNP can lead to challenges in managing nasal polyps (Figure 18). Patients indicated a need for resources to better manage/reduce symptoms, treatment options, and basic nasal polyps information (Figure 22). Preferred methods of receiving CRSwNP information for patients/caregivers included digital communications, such as websites, email, and videos, in addition to in-person methods (Figure 23).

Opportunity: Develop and distribute digital patient-facing educational tools, such as webinars and videos. Develop easy-to-understand patient education materials specifically focusing on recognizing symptoms, differentiating with those of other type 2 inflammatory diseases, seeking optimal care, and understanding pharmacological and surgical treatment options.

In addition to patient education materials disseminated directly to patients, there is also a need to develop patient-facing materials for HCPs. The majority of patients say they look to health professionals like their doctor to get information and education about nasal polyps (Figure 21). It is critical for HCPs to have the knowledge and tools to support patient education for CRSwNP at the point of care. In particular, patients requested more patient education on pre-surgery considerations and post-surgery expectations. Patient-facing materials provided to HCPs for use at point of care can help improve patient awareness, ability to self-manage chronic conditions, and patient-provider communications.

Patient education materials should be culturally appropriate and address various patient experiences, such as comorbidities. Patients reported high overlap of allergic comorbidities (Figure 11); materials that consider factors such as comorbid conditions and patient age can support improved self-advocacy for CRSwNP.

Opportunities: Develop and distribute easy-to-understand, culturally relevant patient education materials to health care providers with information about CRSwNP symptoms, management, treatment, and comorbid conditions to share with their patients to promote self-care, health literacy, and shared-decision making.

Additionally, patients reported dissatisfaction with general awareness of CRSwNP (Figure 20), and many spoke about a general lack of acknowledgement about the burden of CRSwNP among the public. Broad awareness and education around CRSwNP signs and symptoms may help undiagnosed patients recognize potential signs of nasal polyps, prompting them to speak with a health care provider. Educational materials that raise awareness about CRSwNP may also help family and friends better understand their loved ones' condition.

Opportunity: Develop and launch public awareness campaigns to teach people common symptoms of CRSwNP to prompt initiation of clinical care. Include messaging for the general public to improve societal understanding of CRSwNP.

Unmet Needs in Treatments and Patient-Centered Research

Patients reported that finding treatments that work effectively and long-term can be a process of trial and error. Many described experiences of treatments not effectively treating symptoms, or working for a while before symptoms or nasal polyps reappear. Most patients reported trying various pharmacological treatments for CRSwNP at some point during their journey (Figure 11). The majority of patients also reported having at least one endoscopic surgery to remove the polyps (Figure 12).

Overall, patients report that most medicines and surgery are at least somewhat helpful, though there are still a number of concerns, including fear of surgery or long-term impact of steroids (Figure 14). Patients and caregivers reported effectiveness of CRSwNP care/treatment as one of the biggest challenges with disease management (Figure 18).

Opportunity: Support ongoing studies to determine which treatments work best for which patients—potentially through development of biomarkers to better predict treatment responders.

In some cases, patients reported frustrations with HCPs who continued to recommend treatment options that were not working for them. Shared decision-making tools can help improve patient/caregiver awareness—as well as HCP awareness— of current treatment options and support patient-centered treatment for CRSwNP.

Opportunity: Develop shared decision-making tools for patients and providers to facilitate discussion about treatment options and determine an appropriate course of therapy that the patient can reasonably access, afford, and adhere to. Patients' lifestyle and treatment preferences need to be considered as this is highly likely to influence adherence to the treatment plan.

As patients continue to search for options that are best for them, it is also critical to develop a tool for measuring CRSwNP control. This is especially important because many patients report use of oral corticosteroids at some point to treat CRSwNP (Figure 11)—which can be a sign of uncontrolled disease. Additionally, about one third of patients who had surgery reported getting additional surgeries—another potential sign of uncontrolled disease.

Opportunity: Develop and validate a control tool for CRSwNP, developed in partnership with patient advocacy organizations and incorporate patient-reported measures to capture outcomes that are most important for patients.

Additionally, it is important for patients to have access to treatments without financial and insurance-related barriers. Patients reported price of care/treatment as one of the biggest challenges in managing CRSwNP (Figure 18) and reported dissatisfaction with financial resources for CRSwNP (Figure 19). Some patients described significant challenges with insurance coverage, especially in covering treatments such as biologics.

Opportunity: Develop and advocate for policies that aim to increase access to new treatments for all patients.

Summary of Unmet Needs and Opportunities

Domains of Unmet Needs	Opportunities
HCP Education and Clinical Care	<ul style="list-style-type: none"> • Build educational programs for health care providers that focus on improving recognition of CRSwNP, especially in people with comorbid conditions that have similar symptoms. Develop educational programs for primary care physicians to promote disease awareness and facilitate referrals to specialists for more timely diagnoses. • Increase awareness of current guidelines to support prompt and accurate diagnosis and better long-term management for CRSwNP. Widely disseminate existing tools developed from guidelines (such as referral, diagnostic, and treatment algorithms) to primary and specialty care clinicians, as well as patients. • Develop models of multidisciplinary care teams for both public and private practice settings to help health care providers ensure people with CRSwNP have access to appropriate, comprehensive care. Develop and disseminate referral resources to help improve diagnoses and care coordination. • Incorporate patient voice and stories into HCP education. Include patient perspectives and experiences through various case studies to help inform HCPs about the struggles people face at different points of their journey and improve patient-provider communication.
Patient Education and Public Awareness	<ul style="list-style-type: none"> • Develop and distribute digital patient-facing educational tools, such as webinars and videos. Develop easy-to-understand patient education materials specifically focusing on recognizing symptoms, differentiating with those of other type 2 inflammatory diseases, seeking optimal care, and understanding pharmacological and surgical treatment options. • Develop and distribute easy-to-understand, culturally relevant patient education materials to health care providers with information about CRSwNP symptoms, management, treatment, and comorbid conditions to share with their patients to promote self-care, health literacy, and shared-decision making. • Develop and launch public awareness campaigns to teach people common symptoms of CRSwNP to prompt initiation of clinical care. Include messaging for the general public to improve societal understanding of CRSwNP.
Treatments and Patient-Centered Research	<ul style="list-style-type: none"> • Support ongoing studies to determine which treatments work best for which patients—potentially through development of biomarkers to better predict treatment responders. • Develop shared decision-making tools for patients and providers to facilitate discussion about treatment options and determine an appropriate course of therapy that the patient can reasonably access, afford, and adhere to. Patients' lifestyle and treatment preferences need to be considered as this is highly likely to influence adherence to the treatment plan. • Develop and validate a control tool for CRSwNP, developed in partnership with patient advocacy organizations and incorporate patient-reported measures to capture outcomes that are most important for patients. • Develop and advocate for policies that aim to increase access to new treatments for all patients.

Limitations

Data presented in this report have limitations that AAFA would like to acknowledge. Patients and caregivers were offered a chance to receive honoraria, which may have contributed to selection bias. Patients and caregivers recruited for the one-on-one interviews and for the patient and caregiver survey were recruited through social media, newsletters, and emails to AAFA community members and followers. Therefore, this study population represents the demographics of AAFA followers, and may not be representative of all those affected by nasal polyps. Members of AAFA's community may also be more impacted by nasal polyps, as those who do not need additional resources for nasal polyps may not join the community. This impacts the generalizability of the results.

Similarly, the demographics of this study population do not reflect the epidemiology of nasal polyps, limiting the generalizability. For example, the participants of this study overwhelmingly self-identified as women. Research shows women are more likely to take online surveys than men, but nevertheless the patient voice of men impacted by nasal polyps is needed in future studies as nasal polyps are more prevalent in men. Respondents of the patient and caregiver survey also largely identified as white. More research is needed to capture the diversity of nasal polyps voices, as existing research has identified key differences in clinical outcomes based on race and ethnicity and therefore different racial and ethnic populations may have different resource needs.

Additionally, while the interviews and survey were open to caregivers of people with nasal polyps, caregiver response rate was low. Research looking at other conditions show distinct experiences and impacts for patients and caregivers.^x Additional research is needed to understand the impacts on caregivers, such as the need to take off time from work to go to medical appointments or care for their loved ones, impacts on caregivers' personal relationships, and financial impacts on the family.

All interview and survey data rely on self-report. While effective in gathering large amounts of patient experience data, self-report is prone to several biases, including social desirability and recall bias. Future research can use multiple data sources, such as medical records or validated instruments, to increase the validity of results. Additionally, reducing the recall period or incorporating methodologies such as diaries can reduce overall recall bias of self-reported data.



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