

# Patients' Health Information Practices and Perceptions of Provider Knowledge in the Case of the Newly Discovered Alpha-gal Food Allergy

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## Abstract

**Background:** Alpha-gal food allergy is a life-threatening, newly discovered condition with limited presence in authoritative information sources. Sufferers seeking diagnosis are likely to encounter clinicians unfamiliar with the condition. **Objective:** To understand information practices of individuals diagnosed with alpha-gal allergy, how they obtained diagnosis, and their perceptions of health-care providers' awareness of the condition. **Methods:** Semistructured interviews with open- and closed-ended questions were completed with a chronological systematic sample of 28 adults (11% of alpha-gal clinic patients at the time) diagnosed with alpha-gal allergy and treated at University of North Carolina Allergy and Immunology Clinic. **Results:** The majority of patients determined they had alpha-gal allergy through nontraditional health information channels. Three-quarters of patients rated their primary care provider as having little to no knowledge. In 25 specialists' encounters, 23 were rated as having little to no knowledge. **Conclusion:** With new conditions, information is often available through informal networks before appearing in the vetted medical literature. In this study, social connections were the primary pathway to successful diagnosis. Health practitioners need to develop mechanisms to understand that process.

## Keywords

clinician–patient relationship, health literacy, medical decision-making, patient engagement, patient perspectives/narratives, patient satisfaction, physician engagement

## Introduction

Health-care providers (HCPs) have long been considered the authoritative source of health-related knowledge and the most informed participant in the patient–provider relationship (1). With increasing access to information resources, this dynamic is changing. Patients are discussing health information acquired on their own with providers to make diagnosis and treatment decisions (2). One in 3 adults in the United States has gone online to diagnose a condition, and of those, approximately half consulted a HCP about their findings (3).

Information is important for guiding patient behavior and for increasing capacity to cope with anxiety and uncertainty (4). Clear information sharing has been linked to positive health outcomes including reduction of psychological distress and enhanced symptom resolution (5,6). Now patients are increasingly seeking out information on their own (7); in some cases, improved outcomes have been linked with

patients' taking the initiative to obtain their own information (8,9), and patients who take an active role can have lower medical costs (10).

Health-care providers have reacted in varying ways to this phenomenon. Providers' concerns include accuracy of Internet-obtained health information and the ability of patients to interpret information, possibly resulting in inappropriate self-diagnosis (11,12). Some providers have noted benefits of Internet-informed patients, including raising

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patients' baseline knowledge, making clinical decision-making with patients easier (13).

There is very little research on this information-gathering process or on the accuracy of patient self-diagnosis (14). Common conditions (eg, urinary tract infections in the United States and malaria in Malawi) are more likely to be correctly self-diagnosed (15,16). Yet with other conditions (scabies, pregnancy, and vaginal candidiasis), patient misdiagnosis can be common (17–21). In most health-care encounters, diagnosis starts with a patient presenting with a key symptom (22). When symptoms don't follow established patterns or expectations, diagnosis can be delayed with concomitant personal and health-care costs. More research is needed that addresses patients' use of information, particularly in the case of newly discovered conditions.

### *Newly Recognized Food Allergy: Alpha-gal*

The alpha-gal allergy is a newly discovered condition that provides diagnostic challenges (23,24). This novel, severe food allergy to mammalian meat has a highly unusual presentation; unlike most food allergies, there is a delayed reaction between ingestion and symptom onset, usually 3 to 6 hours postconsumption (25). The link between exposure to the putative causative agent (tick bite) and immune response (ranging from hives and/or gastrointestinal distress to anaphylaxis) can persist for years. According to one gastroenterologist, "it violates all the rules (23)." A blood test that confirms diagnosis has been available for the past 6 years; reports of alpha-gal cases are on the rise in the United States and Europe (24,26,27).

In extreme cases, the alpha-gal allergy can cause a life-threatening allergic reaction (28). A prospective study of 70 patients with idiopathic anaphylaxis found 9% of patients tested positively for alpha-gal (29). Patients report allergic reactions with repeated emergency room visits, late at night, or in the early hours of the morning (23). Thus, some patients who might not otherwise engage in health information seeking are highly motivated to discover the cause of their illness.

A newly discovered condition can result in a high volume of information available, but not necessarily in the vetted medical literature, and not always authoritative. There can be consequences for patient information seeking, patient-provider interaction, and health service utilization. The aim of this study was to investigate how patients with this emerging condition discovered and acted on information. To do so, 28 semistructured interviews were conducted with patients having the alpha-gal allergy.

## **Methods**

Participants included patients being actively treated for the alpha-gal allergy at the University of North Carolina (UNC) Allergy and Immunology Clinic. This patient pool consisted of approximately 250 individuals in late 2015 through early

2016. The sample size ( $n = 36$ ) was calculated to detect factors with a 50% prevalence and precision of  $\pm 15\%$ . The sample was systematically selected based on date of patients' first clinic visit. Every seventh individual was invited to participate, via mail. The first mailing yielded 20 participants. A second mailing was sent to 16 individuals and yielded 8 more. In 2016, 28 individuals of the 36 sought completed semistructured interviews.

Interviews were conducted by the primary researcher and her research assistant in private meeting rooms at the local public library and averaged 50 minutes in length. The same interview guide, crafted by the researcher and pretested with 2 individuals diagnosed with the alpha-gal allergy, was used in each case. Questions focused on information seeking and sharing and diagnostic path, and included a scale to rate patients' perception of their HCP's knowledge with regard to existence of the allergy. The interview guide is included as Appendix A. Informed consent was obtained; all agreed to being audio-recorded, and all received compensation of a \$100 gift card for their time and travel. The research protocol was approved by the institutional review board of UNC (15-2747; January 6, 2016).

During the interview, the patients were asked to rate a variety of health-care professionals on a scale of 1 (no knowledge) to 5 (excellent knowledge) with regard to clinicians' knowledge of the alpha-gal allergy. This was the interviewee's subjective report without prompting to what level of knowledge would be considered a specific score. Patients who did not know or did not reply were not included in the "average" value for that category of clinician.

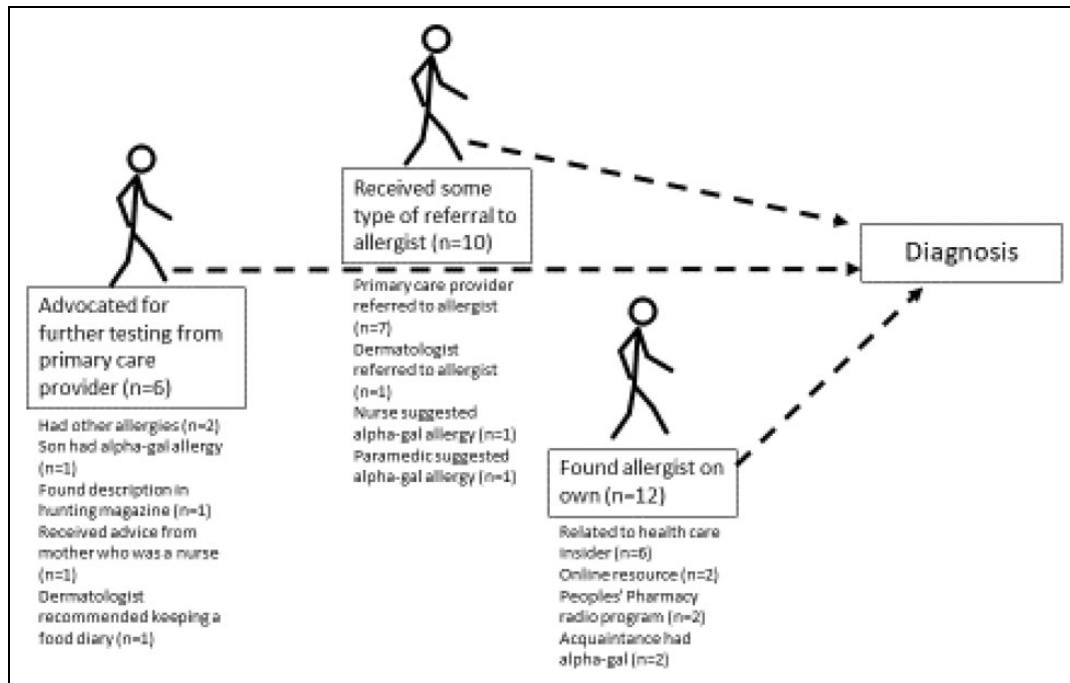
## **Results**

### *Study Population*

Fourteen females and 14 males ( $n = 28$ ) completed interviews in spring 2016, which comprised 11% of the UNC Allergy and Immunology Clinic's alpha-gal allergy diagnosed patient population at the time and 77% of the 36 total patients initially sought. The average age of participants was 56 years (range: 32–81 years); none were African-American or Hispanic. Four (14%) participants had not completed college, 8 (28%) had an undergraduate degree, and 16 (57%) had completed some graduate school or possessed a graduate degree. The length of time between first appearance of symptoms and diagnosis averaged 5.25 years; 71% characterized their first symptoms as severe.

### *Health-Care Encounters*

Encounters with primary care providers that resulted in a diagnosis or referral that led to diagnosis were reported to have occurred in 7 of 27 visits. For the 19 outpatient clinic visits reported, none resulted in a diagnosis or referral that led to diagnosis. In 29 emergency room visits and 2 urgent care clinic visits, one encounter resulted in a diagnosis. In that case, the emergency medical technician transporting the



**Figure 1.** Patients' referral path to allergist and diagnosis.

patient suggested their anaphylaxis may be related to the alpha-gal allergy, so the patient later sought out an allergist. Twelve of 28 patients found the food allergist specializing in alpha-gal on their own. Of those 12, 6 had a close personal relationship or friendship with a medical professional outside of their health-care system with whom they discussed their symptoms, 1 discovered the condition through searching Google, 1 had a wife who used to Google to diagnose, 2 heard about the allergy from the People's Pharmacy radio program, 1 had a relative with the condition, and 1 had a neighbor with the condition.

One patient reported "It was pretty scary, I was popping Benadryl all the time until my girlfriend told me about alpha-gal, she saved my life." Some patients related allergic episodes prior to diagnosis where they took Benadryl or used an epi-pen, then drove to the emergency room, and waited outside for symptoms to improve. Ten of 28 received referrals or were formally diagnosed during a health-care visit. The other 6 patients suspected a food allergy and successfully advocated for further testing. Of those 6, 2 had other allergies, 1 had a mother who was a nurse, 1 had been keeping a food diary upon her dermatologist's advice, 1 had a son with the alpha-gal allergy, and 1 discovered the allergy in a hunting magazine, after 3 visits to the emergency room where no diagnosis or referral took place. Figure 1 represents the variety of patients' paths that ultimately led to the allergist for diagnosis of alpha-gal allergy.

Sixty-eight percent (n = 19) of patients were diagnosed in 2 or less years after first experiencing symptoms. Every one of those individuals had one or more of the following characteristics: they knew someone with the alpha-gal

**Table 1.** Patients' Rating of HCP Knowledge of Alpha-gal Allergy.<sup>a</sup>

Patient Rating Response	1	2	3	4	5	N/A	Average
General physician	16	5	2	0	2	3	1.7
Other specialist	21	2	0	0	2	10	1.4
Emergency room	13	2	0	0	1	12	1.4
Allergist	5	1	3	1	15	3	3.8

Abbreviation: HCP, health-care provider, N/A, not applicable.

<sup>a</sup>Scale of 1 to 5, with 1 = no knowledge.

allergy, they were either HCPs or had close personal relationships with HCPs (spouse or parent of HCP), and/or they had prior experience with severe allergies. Further details of diagnosis and health-care encounters have been reported elsewhere (23).

### Interaction With HCPs

During interviews, patients were presented with a chart listing different types of HCPs they may have encountered and asked: "On a scale of 1 to 5, with 1 being no knowledge at all, how knowledgeable would you say the following people were about alpha-gal when you first started noticing symptoms?" Table 1 demonstrates responses to that question.

The general physician category referred to the patients' primary care provider. Twenty-one of 28 patients rated this category as having very little or no knowledge of the alpha-gal allergy. For those patients who reported symptoms to their primary care providers prediagnosis, typical comments

included “They had no idea what was wrong”; “I had to tell him a lot of information”; and “I lost hope in the doctors.” Another commented, “My GP is a very good doctor, so it was surprising they didn’t know.” Two rated this HCP in the middle range at 3. Two patients rated this HCP with a 5; in one case, the general physician explained he recognized the symptoms because the nurse in his office had the condition, and in the other, the alpha-gal sensitization test was done in response to the symptoms the patient described. Three did not visit their general physician during the prediagnosis phase and went directly to the allergist, and so rated this category as not applicable (N/A).

Other specialists included a variety of providers and fell into 2 types of encounters, visits during the search for diagnosis and sharing knowledge of their condition after being diagnosed. Seven individuals described visits to specialists for diagnosis and rated the knowledge of specialists with a 1 (no knowledge); these specialties included dermatologist (3 individuals), gastroenterologist (2 individuals) naturopath physician, and physician specializing in Lyme. An eighth individual described a particularly difficult diagnostic path, with repeated anaphylactic episodes and hospitalizations: “9 months and 9 doctors without a diagnosis.”

The rating of 2 was assigned by 2 individuals, both of these were encounters that were prediagnosis, 1 with a dermatologist and 1 with a gastroenterologist. For the ratings of 5, one was during prediagnosis to a dermatologist, although the visit did not result in a diagnosis of alpha-gal allergy: “she told me to keep a food diary,” which eventually led to diagnosis of alpha-gal allergy. The other 5 rating was post-diagnosis, where the patient reported the condition during a visit to an otolaryngologist. There were 7 participants who reported informing a specialist after their diagnosis, 6 rated these encounters with a 1.

The category “allergist” was also included in the rating chart. A majority of participants had only interacted with the allergist specializing in the condition at the UNC allergy clinic; thus, 15 of 28 rated this category with a 5, and one rated a 4, all specifying the allergist who diagnosed the condition. Two participants rated allergist with a 3, based on the fact of overall information that’s available, “the test isn’t sensitive enough for the allergist to be completely knowledgeable.” The other 3 rating was someone who had gone to another allergist for a wasp sting: “he hadn’t looked at my chart, and asked ‘Why do you think you have alpha-gal?’ when I mentioned it, and he had diagnosed it!” The 2 rating was also based on the information available to the clinic allergist, not on her knowledge or understanding of the condition. Five had visited a different allergist prior to confirmed diagnosis and gave a rating of 1. Three chose N/A because they had only visited the allergist at the clinic and interpreted the question as describing additional allergists prior to visiting the UNC clinic.

## Information Sharing Practices

For the question, “Do you do anything to increase awareness of alpha-gal in general?,” 11 of 28 participants answered positively. For those 11, most activities fell in the categories of in-person and word of mouth. Examples included: “tell people”; “all the time conversationally”; “told all my providers at my visits”; “told my friends at work”; “talked with people at the Farmer’s Market who sell beef”; “I have the bacon conversation.” One participant commented that she’d like to “learn Facebook, and then I could use that.” Another said she did use Facebook to share information about her condition but discontinued because “it got too stressful.” Another patient described a Facebook group she created for alpha-gal allergy sufferers but explained the site is not moderated, so there are people who “make really wacky statements . . . they’re spreading fear.” Two individuals specified they were not social media users. Another individual made print information packets from information she gleaned on the Internet and distributed to local emergency responders, HCPs, and pharmacists.

Of the participants who answered negatively (they didn’t actively try to increase awareness), one reflected on the question and responded with “I told my primary care provider and cardiologist through emails, and I talk with people, but other than that, I don’t increase awareness formally.” Another respondent reported: “I did share information, but I’m more reserved now . . . I suffered from depression because of alpha-gal, I don’t want it to control my life.” One participant stated she did share her condition on Facebook and found other friends with the condition. She didn’t consider this in the category of increasing awareness because it wasn’t in her terms, a “formal” effort.

Participants were also asked the open-ended question: “Who do you think needs to know about alpha-gal?” The “general public” or “everybody” was mentioned by 9 respondents, with comments such as: “It demands a wide audience.” Restaurants were mentioned by 8 of the interviewees. One commented they were the most important need, because “Restaurants are most likely to cause inadvertent exposure.” Six respondents mentioned primary care providers and 6 mentioned emergency room personnel as needing to know about the allergy. The response to this question was directly correlated with individuals’ experiences. For example, the respondents who answered emergency room personnel had experienced at least one emergency room visit that did not result in diagnosis or referral that led to a diagnosis. When asked if the diagnosis had led to behavior change beyond eliminating meat and meat products from their diets, one participant reported she now reads the obituaries to see if anyone has died of anaphylaxis. Another said during his quest for diagnosis he started praying more.

## Discussion

It is not surprising when patients were asked to rate HCPs’ knowledge of alpha-gal allergy, the majority of responses for

allergist were high, given the population sample was recruited from the allergy clinic. In terms of information seeking in this patient population, participants did not describe a linear pattern of diagnosis, one that started with recognition of symptoms resulting in a primary care provider visit where testing or referral to an allergist took place. In fact, very few respondents described this pattern; each path was unique. Rather than directly addressing questions on health information-seeking behaviors, patients were more interested in discussing the extreme frustration they encountered during the diagnostic process and sharing the distress they felt at what they characterized as disbelief and dismissive behavior that occurred during many health-care encounters.

Increased access to health information is changing how patients discover and share with newly recognized diseases. Motivated patients are looking beyond primary care providers when searching for a diagnosis. Although it is unrealistic and likely unfair to expect every HCP to keep abreast of every new condition, at minimum, we can expect them to engage with patients with an open mind. Follow-up research could include examination of clinical records to determine whether there are commonalities in cases where primary care visits yielded a diagnosis, such as symptoms that are markers (eg, many patients reported itching started on their hands and extreme hives progressed from there; idiopathic anaphylaxis) that trigger testing or routine screening for alpha-gal sensitivity.

As new conditions emerge, there is need for more responsive, timely mechanisms of information sharing among providers than traditional medical literature channels. In this study, social connections, mainly among highly educated people, were the primary pathway to successful diagnosis. The health community needs to develop mechanisms to expand that guiding process and diffuse information about emergent conditions quickly and efficaciously to practitioner bodies. With newly recognized diseases, patients may experience a frustrating, difficult, and time-consuming path to diagnosis. Information on the new condition is often available to patients through informal networks before it makes its way into the medical literature; thus, they may be better informed about the condition than their HCP. If a patient presents with idiopathic anaphylaxis and/or repeated emergency room visits, especially during the night, testing for alpha-gal sensitivity should be considered.

### Limitations

Limitations of the study include self-reported data, which may be subject to recall bias and possible survivor, selection, and referral bias in those who agreed to be interviewed. Testing for alpha-gal sensitization has only been available for 6 years, so confirmed clinical diagnosis is relatively new.

### Conclusion

Health information exchange has historically been a one-way process, with HCPs playing the role of information

dispensary, and the patient for the most part, in the role of passive recipient. A phenomenal increase in information access, in conjunction with more individuals taking responsibility for their health care, is leading to major changes in the traditional patient-provider communication and information-sharing paradigm. In our study, the majority of patients determined they had alpha-gal allergy through nontraditional health information channels, and 75% rated primary care providers as having little to no knowledge of the alpha-gal allergy. Because the medical educational process takes time to incorporate new diagnostic and treatment procedures with newly discovered conditions, it is extremely important to attend to patients' accounts of their experiences.

## Appendix A

### Interview Guide for Alpha-gal Allergy Patients

Thanks for agreeing to discuss your experience with alpha-gal.

- 1) How long have you had the condition?
- 2) What were your initial symptoms?
  - a. Would you rate your initial symptoms as mild, moderate, or severe?
  - b. Why would you describe it that way?
- 3) Did you connect them to a food allergy?
  - a. Having eaten (mammalian) meat?
- 4) Did you look for information about what was happening (your condition) before going to a health-care provider?
  - a. If yes—what kind of information and where/what resources did you use?
    - i. Internet, social media, family, work, other network, etc.
  - b. Was one of those the best resource?
    - i. If yes—which one and why was it the best?
    - ii. Did it enable you to connect what was happening to a food allergy?
      1. More specifically, did you understand the allergy was to (mammalian) meat?
  - c. Did you find any information that wasn't helpful?
    - i. Eg, Led you to think you had a condition that wasn't Alpha-gal?
      1. That delayed your visit to your doctor and/or diagnosis.
- 5) How and when did you decide to see a health-care provider?
  - a. Eg, after 1 episode, 2, etc.
  - b. After finding information on the condition.

- i. What information
  - ii. Where did you find it
- 6) When and from whom did you first receive a formal diagnosis of Alpha-gal allergy?
- 7) Did you suspect you had the Alpha-gal allergy specifically (or the condition that makes you allergic to meat after a tick bite) before receiving a diagnosis of it from a health-care provider?
- a. If yes, how did you describe the condition as such to your health-care provider?
    - i. Specific wording if possible
  - b. When you described the condition, how did your health-care provider respond?
    - i. Were they already aware of the condition in general?
    - ii. Did you feel like you had to teach them about the condition?
- 8) When you described or shared your Alpha-gal symptoms with your health-care provider, what did they tell you?
- a. Did they ask you for more information?
    - i. Eg, Did they ask you to keep a diary of when symptoms occur?
    - ii. Did they ask if you were possibly exposed to a tick bite?
- 9) Did your provider refer you to:
- a. An allergist or specialist
  - b. Information on the condition
  - c. Other resources
- 10) Did you find these sources satisfactory?
- a. Why or why not?
- 11) Do you feel that you have received the information you need to manage your Alpha-gal allergy?
- 12) On a scale of 1-5, with 1 being the little to no impact, how would you rate the impact of your Alpha-gal diagnosis on your lifestyle in the following areas?
- 13) Do you continue to look for information about Alpha-gal?
- a. If so where, what resource, whom do you ask?
  - b. If not, why?

Ability to do my job	1	2	3	4	5	NA
Family life	1	2	3	4	5	NA
Social life	1	2	3	4	5	NA
Hobbies	1	2	3	4	5	NA
Travel	1	2	3	4	5	NA
Eating away from home	1	2	3	4	5	NA
Eating at home	1	2	3	4	5	NA
Religious life	1	2	3	4	5	NA
Physical fitness	1	2	3	4	5	NA

- 14) On a scale of 1 to 5, with 1 being no knowledge at all, how knowledgeable would you say the following people were about Alpha-gal when you first started noticing your symptoms?

General physician	1	2	3	4	5	N/A
Allergist/immunologist	1	2	3	4	5	NA
Insurance	1	2	3	4	5	NA
Other specialists	1	2	3	4	5	NA
Emergency care providers	1	2	3	4	5	NA
Restaurants	1	2	3	4	5	NA
Friends & family	1	2	3	4	5	NA

- 15) Have you shared the knowledge of your condition with other people?
- a. If so, whom? (family, friends, social media contacts, etc)
  - b. If so, how? (in person, social media, etc)
- 16) Do you do anything to increase awareness of Alpha-gal in general?
- a. If yes, what?
- 17) Who do you think needs to know about Alpha-gal?
- a. Eg, HCPs, restaurants
- 18) Have you ever been unable to find something out about your Alpha-gal allergy?
- a. What was it?
  - b. Where did you look for it?
- 19) Do you still have questions about Alpha-gal?
- a. If yes, what are they?

Depending on question, refer to Dr Jerath’s web site for more resources.

<https://www.med.unc.edu/tarc/research/jerath-team/jerath-research>

Do they use insect repellent (or any changed behaviors due to diagnosis)?

What was geographic location when they were bitten (if known)?

Birth year:

Occupation:

Education level:


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