

Understanding Health Related Challenges in Patients with Alpha-Gal Syndrome

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BACKGROUND

Alpha-gal syndrome (AGS), or alpha-gal allergy, is an immunoglobulin E (IgE) mediated allergy to products containing the sugar molecule, alpha-gal. Alpha-gal (galactose-alpha-1,3-galactose) is present in most mammals (pork, cattle, rabbit, lamb, etc.) and in mammalian products such as gelatin and dairy. Individuals often experience symptoms of AGS after consuming red meat or other alpha-gal-containing products.

Symptoms vary based on the individual and can present as mild, moderate, severe, or life-threatening. Common symptoms include hives, difficulty breathing, indigestion, nausea and diarrhea. Anaphylaxis is also possible.

Typically, AGS is associated with the Lone Star tick, but other etiologies have been suspected. The management of AGS faces numerous unfulfilled needs and disparities, and further investigation is needed to arrive at a universal agreement on the best approach to treating patients with this condition. There are also a limited number of resources for alpha-gal patients and providers to find alpha-gal safe health products.

OBJECTIVE

To assess the medication and health products related challenges for patients with alpha-gal syndrome (AGS). Specifically, experiences regarding 1) allergic reactions 2) difficulty in finding alpha-gal safe products and 3) obtaining accurate information.

METHODS

Retrospectively reviewed anonymous data obtained from a market research survey. Fifteen questions were asked assessing patient experiences around medications and health products. The survey was conducted via social media platforms and word of mouth. Descriptive statistics were used to summarize the data (percent, mean±SD).

RESULTS

Demographics (N=559)	
Mean age (yr)	52.1 ± 10.9
Female (%)	86.8%
Alpha-Gal Diagnosis (%)	100%
Time to Diagnosis (yr)	1.0 ± 6.3

Table 1. Demographics of survey respondents.

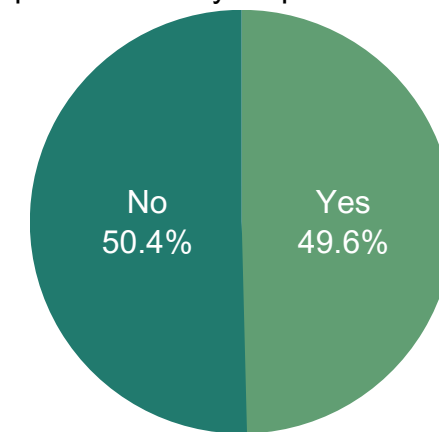


Figure 1. Respondents who reported having an anaphylactic reaction to alpha-gal containing health products.

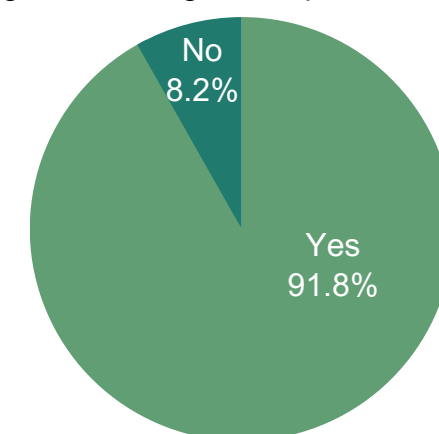


Figure 2. Respondents who reported having to modify their use of medications due to their AGS diagnosis.

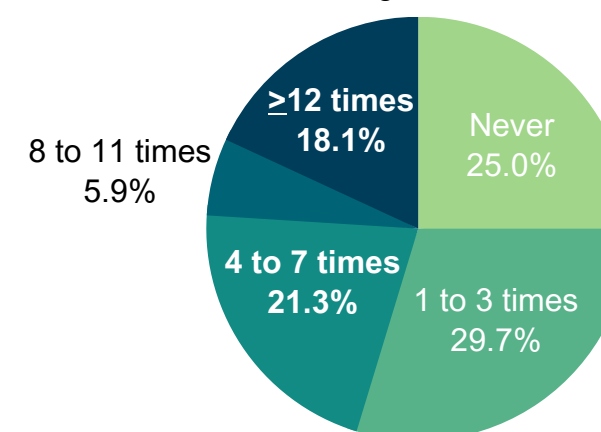


Figure 3. Number of times respondents reported reaching out to drug manufacturers to determine if a product contains animal-derived ingredients.

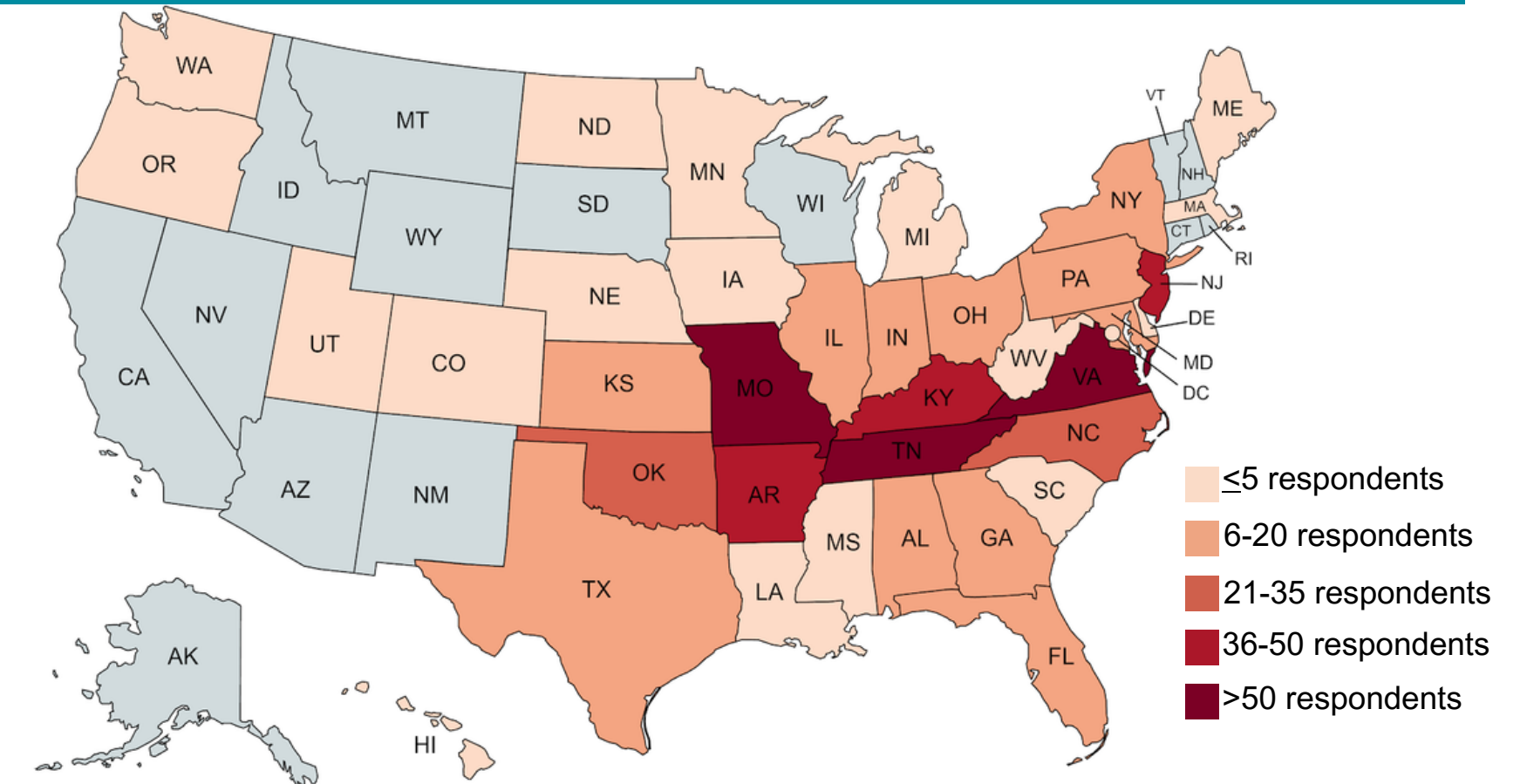


Figure 4. Distribution of respondents who reported having alpha-gal.

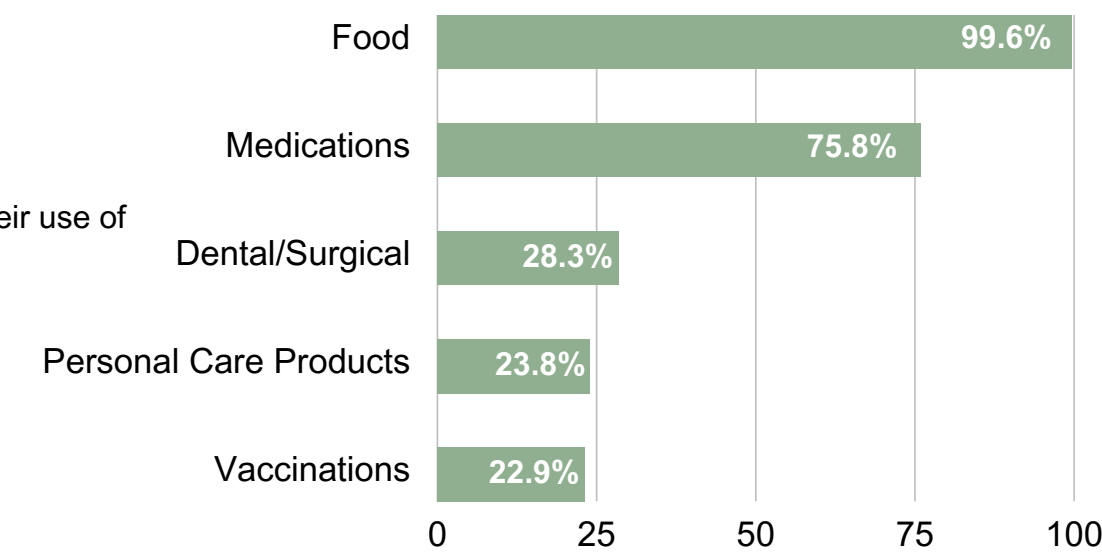


Figure 5. Percentage of respondents who reacted to mammalian-derived ingredients/products.

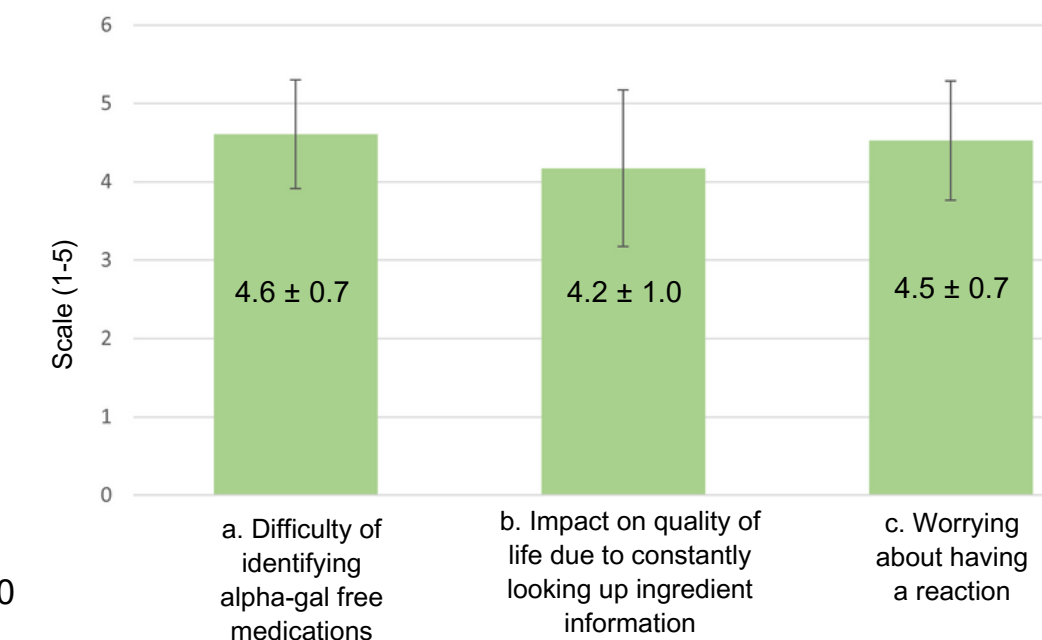


Figure 6. Relationship between alpha-gal allergy and quality of life, with the following scales: a) 1 indicating "very easy" and 5 indicating "extremely difficult," b) 1 indicating "not at all" and 5 indicating "extremely," and c) 1 indicating "not at all" and 5 indicating "extremely."

DISCUSSION

- The American Medical Association Policy H-100.947 advocates for labeling of all animal-derived ingredients and encourages awareness of patient preferences regarding such ingredients in medical products.
- Manufacturers should either independently declare animal-derived ingredients or use external certification platforms.
 - 96.8% of respondents agreed on pharmaceutical companies obtaining independent certification of animal-free products.
 - 50.0% of AGS patients would trust an animal-free certification, while 12.0% and 11.0% would trust drug manufacturers and pharmacists, respectively.
- Further research is necessary to promote the representation of diverse patient populations in medication labeling, including the need to study alpha-gal content in medications that have mammal-derived ingredients, which is currently not well studied, but is nonetheless a significant concern and burden for AGS patients when making medication choices.