Alpha-gal syndrome: public awareness, lived experiences, and health provider perspectives on plant-based nutrition

by

Judith Sempa

B.S., Makerere University, 2009
M.P.H., Kansas State University, 2016

AN ABSTRACT OF A DISSERTATION

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Department of Food, Nutrition, and Dietetics and Health
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Abstract

There is a global rise in allergic conditions and multimorbidity. Historically, these have been treated as separate clinical entities however, emerging research indicates they share similar immunological roots primarily immune dysregulation. Alpha-gal syndrome (AGS), a tick-borne allergy triggered by lone star tick bites, is increasingly prevalent in the Southern, Eastern and mid-western regions of the United States including Kansas. Simultaneously, 10.2% of adults in Kansas experience multimorbidity (defined as having two or more chronic conditions such as obesity, chronic kidney disease, cardiovascular disease, cancer etc.).

This study explored AGS awareness, distribution, lived experiences and systemic challenges faced by Kansans living with AGS. Using a mixed methods approach, the study included two anonymous surveys targeting Kansas community residents and Extension professionals, as well as in-depth interviews with thirty AGS-affected individuals. Findings revealed that while general awareness of AGS is growing, significant challenges remain related to dietary restrictions and adaptations, psychosocial challenges, financial burdens and gaps in healthcare support. Participants frequently relied on self-management and self-advocacy due to limited health professional knowledge and support, underscoring the need for improved medical education, clearer food labeling, and access to more support and resources.

Our study found that many individuals with AGS adopted plant-based diets (PBDs) as a practical strategy for managing their condition. Emerging evidence indicates that PBDs, rich in antioxidant and anti-inflammatory compounds, can enhance gut health, support immune function, and reduce risk of chronic diseases by mitigating chronic systemic inflammation. Building on this insight, the third phase of the study examined health professionals' readiness to support individuals following PBDs. A narrative review of 27 studies identified key barriers and enablers related to

integration of PBDs in routine patient care which included: time constraints, limited educational resources, insufficient skills, limited interdisciplinary collaboration, and inadequate professional training. The study findings suggest that access to evidence-based research summaries, clear guidelines, ongoing professional development, and other relevant educational resources were crucial for equipping healthcare professionals to support individuals adopting PBDs which would benefit individuals managing AGS as well as those dealing with chronic diseases such as obesity, diabetes and cardiovascular disease.

Overall, this study highlights two seemingly distinct yet interconnected public health challenges: (1) AGS, an emerging allergic condition that has become a leading cause of adult-onset allergies and anaphylaxis in high-prevalence areas; and (2) the critical need to equip healthcare professionals to effectively support individuals adopting a plant-based lifestyle. Given the growing body of evidence linking immune dysregulation to both allergic conditions and chronic disease pathogenesis, better understanding and integration of plant-based nutrition may offer dual benefits in the prevention and management of both.

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Approved by:

Co-Major Professor
Tandalayo Kidd

Approved by:

Co-Major Professor
Priscilla Brenes

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Dedication

This work is dedicated to Hashem- in You there's no darkness, no deceit, no duplicity, no fickleness, nor shadow of turning, and your character never changes.

Chapter 1 - Introduction

The immunological and inflammatory basis of allergic and chronic conditions

Over the past few decades, the global increase in allergic conditions and multimorbidity has emerged as a significant public health concern, with prevalence rates continuing to rise [1,2]. The immune system is designed to differentiate between harmful and harmless substances. However, when this balance is disrupted, it can lead to allergic reactions, which are exaggerated or inappropriate immune responses to typically harmless antigens. Common allergens include pollen, mites, dust, animal dander and certain foods. Immune dysregulation is at the heart of all allergic disorders. Typically, allergens induce immunoglobulin E (IgE)-mediated responses resulting in production of allergen-specific IgE antibodies and sensitization of effector cells. With repeated exposure to allergens, mast cells and basophils are activated, releasing inflammatory mediators such as cytokines and histamine. This triggers allergy symptoms, and when the process persists, may contribute to chronic systemic inflammation [2-6].

As allergic conditions continue to rise globally, multimorbidity has become an increasingly pressing public health concern, especially among aging populations. Multimorbidity refers to the coexistence of two or more chronic conditions such as type 2 diabetes, cardiovascular disease, neurodegenerative disorders and autoimmune disorders. A common underlying factor in many of these conditions is low-grade chronic systemic inflammation [7,8].

Inflammation is a natural process involving activation of both immune and non-immune cells to protect the body from bacteria, toxins, viruses and infections by eliminating pathogens and promoting tissue repair and recovery. Ideally, a normal inflammatory response should be short-lived and resolve once the threat has passed. However, when inflammation becomes persistent, it can disrupt immune tolerance and alter normal cellular physiology ultimately leading to organ

damage and increasing risk of both chronic diseases and allergic conditions [9-12]. When immune homeostasis declines, chronic inflammation, oxidative stress, and cytokine imbalances create an environment conducive to the development and progression of chronic diseases. In turn, these chronic conditions further disrupt immune function creating a cycle that further complicates both prevention and treatment [2, 13, 14].

Historically, allergic disorders and chronic diseases have been treated as separate clinical entities, but research now shows they share a similar immunological root which is immune dysregulation. The principal driver of immune dysregulation is abnormal production of cytokines, with pro-inflammatory signaling affecting multiple organ systems. This cytokine imbalance has been implicated in diseases such as type 2 diabetes, cardiovascular disorders, and neurodegenerative diseases. Additionally, the gut microbiome (a key regulator of immune function) also plays a key role in overall immune function, and microbial imbalance is implicated in systemic inflammation and onset of chronic diseases. Consequently, although allergies and chronic diseases may appear distinct, they often overlap in their underlying immunological and microbial disruptions [2, 14-19].

Diet has emerged as a key modifiable factor in regulating immune function. The typical western or standard American diet (low in fruits, vegetables, legumes and whole grains and rich in processed foods, refined carbohydrates and added sugars, unhealthy fats, high fat dairy, and red meat) has been linked to gut microbiota disruption and chronic systemic inflammation. In contrast, Plant-based diets (PBDs) which emphasize whole vegetables, fruits, whole grains, legumes, nuts, and seeds, offer a wide spectrum of essential nutrients including vitamins C and E, beta-carotene, selenium, and a variety of phytochemicals, such as flavonoids, carotenoids, terpenes, and alkaloids. These nutrients and compounds promote gut health, enhance immune function, and

contribute to the antioxidant and anti-inflammatory properties of PBDs, thereby supporting both immune health and chronic disease prevention through the mitigation of systemic inflammation [10,16, 20, 21].

Alpha-gal Syndrome

Alpha-gal syndrome (AGS) is an emerging tick-borne allergic condition triggered by consumption of mammalian meat or exposure to mammalian-derived products and byproducts. Commonly referred to as "red meat allergy," AGS is caused by an immune response to galactose-alpha-1,3-galactose (alpha-gal), a carbohydrate present in most non-primate mammalian tissues, cells and fluids. When the tick bites, it introduces alpha gal into the blood stream, prompting the immune system to generate immunoglobulin E (IgE) antibodies against it. AGS was first recognized in 2009 following reports of delayed anaphylaxis to red meat and reactions to the cancer drug cetuximab [22- 25].

In the United States, the lone star tick (*Amblyomma Americanum*) is the primary tick species linked to AGS. This tick species is prevalent in the Eastern, Southeastern and central regions of the U.S. (including parts of Kansas) where an estimated 20% of the population is susceptible to the condition [22]. AGS has also been reported globally in the Middle East, South America, Europe, Africa, East and South Asia, Australia and New Zealand, but with different tick species as culprits [26-30].

In Alpha-Gal Syndrome (AGS), allergic reactions are delayed, typically occurring 2 to 6 hours after consuming mammalian meats such as pork, lamb, beef, and organ meats, and certain medications made from mammalian-based ingredients. Reactions may also be triggered by dairy products, gelatin, or even non-mammalian items that contain alpha-gal, such as carrageenan (a seaweed-derived additive). Symptoms can vary from mild manifestations, including hives, skin

rashes, and swelling of the lips, tongue, throat, and eyelids, to more serious effects like wheezing, heartburn, gastrointestinal discomfort (e.g., abdominal pain, nausea, vomiting, and diarrhea), and, in severe cases, anaphylaxis [31-33].

Study Rationale

Historically, allergic disorders and multimorbidity have been treated as separate clinical entities. However, emerging research shows they share similar immunological roots mainly immune dysregulation which is central to both. Diet has also been identified as a key modifiable factor linking allergic conditions and chronic diseases. Alpha-gal syndrome (AGS), a tick-borne allergy triggered by lone star tick bites, highlights this intersection. AGS is increasingly prevalent in the Southern, Eastern and mid-western regions of the United States including Kansas. Despite its growing incidence, public awareness and understanding of AGS remain low, both among the general population and health care professionals. This lack of awareness presents challenges in early recognition, timely diagnosis, and effective long-term management of the condition.

Kansans travel an average of nearly 16 minutes by car to the nearest hospital, compared to 13.3 minutes nationally. Furthermore, 23% of rural Kansans report that accessing good doctors and hospitals is a major problem compared to 18% of those who live in urban areas. For rural Kansans, managing AGS is especially difficult due to limited awareness, restricted access to specialized care and limited access to nutritional resources tailored to AGS management [34].

Dietary management is a key aspect of AGS treatment since the condition requires strict avoidance of all mammalian meat and related products. Research also shows a significant number of individuals diagnosed with AGS are more likely to adopt PBDs. Given the well-established link between diet, immune function, and chronic inflammation, individuals with AGS benefit from adopting PBDs. PBDs are associated with improved immune function and reduced risk of allergic

conditions and chronic diseases. Notably, approximately 10.2% of adults in Kansas experience multimorbidity which is defined as having three or more chronic diseases such as obesity, chronic kidney disease, cardiovascular disease, cancer etc. PBDs not only support overall health but also align with the dietary restrictions imposed by AGS [15,35-36].

Although several scientific and regulatory bodies have consistently endorsed PBDs, knowledge about their safe and practical implementation remains limited in the US [37,38]. This gap is more pronounced in rural parts of Kansas where traditional dietary practices are heavily centered around meat, and cultural and economic reliance on the beef industry present significant barriers to adoption of PBDs even when medically necessary as in the case of AGS. Health professionals are well positioned to provide critical evidence-based education on both AGS and plant-based nutrition. Such education would serve to support AGS management and also contribute to prevention of other diet-related chronic diseases.

The purpose of this study was twofold. First, it investigated awareness, distribution, lived experiences and systemic challenges associated with AGS among rural Kansas residents. This was done using a mixed-methods design comprising of two anonymous surveys and in-depth interviews. Second, the study examined health professionals' readiness to support individuals following PBDs. This was done through a narrative review of existing literature with a focus on identifying key barriers and facilitators related to integration of PBDs in routine patient care.

Theoretical Framework: Social Ecological Model

This study is guided by the Social Ecological Model (SEM) developed by Urie Bronfenbrenner, which provides a comprehensive framework for exploring the complex and dynamic interactions among the **individual**, **interpersonal, institutional, community** and **policy-related** factors that influence human health and disease outcomes [39-41]. Unlike other health

behavior theories such as the **Health Belief model, Theory of Planned Behavior, Social Cognitive Theory, Transtheoretical Model** and **Self-determination Theory**, which primarily focus on individual-level determinants, the SEM emphasizes multi-level interconnected factors influencing behavior change. This broader perspective is especially important when examining a complex, underrecognized condition like AGS that is influenced by multiple interacting factors [42-48].

The **individual** level of the SEM includes personal factors such as awareness and knowledge of AGS, perception of risk, symptom recognition, and dietary adaptation/substitutions. These individual behaviors are in turn influenced by **interpersonal** factors such as support from family, friends and peers. Interpersonal factors may facilitate or hinder effective and safe management of AGS for example emotional support from family members including shared dietary practices would significantly impact adherence to AGS- imposed dietary restrictions and quality of life [39-41]

At the **institutional** level, the readiness and capacity of healthcare systems play a crucial role in the safe and long-term management of AGS. This includes health professionals' knowledge of AGS, diagnostic capabilities, availability of psychosocial support, nutrition education/counseling services, and other clinical resources. Current literature shows that the average timeline for accurate diagnosis of AGS is approximately 5.25 years, highlighting the systemic gaps in healthcare professional awareness and training [49]. Additionally, institutional policies and clinical guidelines can also influence public awareness, recognition, surveillance data and overall quality of care provided to individuals with AGS. For example, AGS is currently a non-notifiable condition which limits case tracking.

The **community** level encompasses broader cultural norms and traditions. Within the rural Kansas context, traditional dietary patterns are centered around meat consumption in addition to the state's economic reliance on the beef industry. This presents challenges to the acceptance and integration of PBDs even in the context of AGS where they are medically required. At this level, public health education campaigns and interventions may need to consider cultural sensitivity and social acceptability [39-41].

The **policy** level of the SEM refers to broad laws, health regulations and institutional policies that may influence access to care and health outcomes. The degree to which AGS is recognized at a national or state level may influence surveillance, reporting, and public health response. For example, AGS is not a nationally notifiable condition, and the state of Kansas does not require healthcare professionals to report AGS cases [50,51]. In addition, health policies may influence recognition of a condition like AGS by insurance companies. Currently some health insurance providers do not recognize it, which means patients have to pay out of pocket for AGS diagnostic tests and treatment. Policies may also influence food labelling regulations, which are important for individuals living with AGS. Mandating clearer labeling of mammalian products and byproducts in food and non-food items would significantly improve safety and quality of life for people living with this condition

Goal and Objectives

This study aims to investigate public awareness, lived experiences and systemic challenges of AGS among Kansas residents, while also assessing the readiness of healthcare professionals to support individuals adopting PBDs as a strategy for management of both AGS and chronic diseases.

Specific Objectives:

1. To assess the general public's and community educators' awareness and knowledge of AGS, as well as its distribution across Kansas.
2. To explore the lived experiences of individuals living with AGS.
3. To explore healthcare professionals' perceptions and readiness to support individuals following a plant-based dietary lifestyle as a strategy for management of diet-related chronic conditions such as AGS and other chronic diseases such as obesity, diabetes, cardiovascular diseases.

Table 1.1 Overview of study chapters

Chapter	Title	Method	Focus	Status
2	Alpha-gal syndrome: public awareness, dietary restrictions, and systemic barriers	Quantitative surveys	AGS awareness in Kansas	Published
3	Living with Alpha-gal Syndrome: exploring lived experiences, dietary transitions, and management strategies	Qualitative interviews based on Phenomenology and Health Belief Model	Lived experiences of people with AGS	Not published
4	Decoding health professionals' attitudes and perceptions towards plant-based nutrition	Narrative review incorporating Theoretical Domains Framework (TDF)	Readiness of Healthcare professionals to support individuals following PBDs	Published

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Chapter 2 - Alpha-gal syndrome: public awareness, dietary restrictions, and systemic barriers

This chapter is based on a manuscript published in the journal of *Nutrients* (2025). The study investigated awareness and understanding of AGS among Kansas residents, focusing on its symptoms, impact, and available management resources.

Citation: Sempa, J., Brenes, P., Tegeler, A., Looper, J., Chao, M., & Park, Y. (2025). Alpha-Gal Syndrome in the Heartland: Dietary Restrictions, Public Awareness, and Systemic Barriers in Rural Kansas. *Nutrients*, *17*(19), 3043. https://doi.org/10.3390/nu17193043

Abstract

Alpha-gal syndrome (AGS) is a tick-borne allergic condition increasingly prevalent in the Southern, Eastern and mid-western regions of the United States including Kansas. This study aims to assess awareness and understanding of AGS among Kansas residents, focusing on its symptoms, impact, and available management resources.

Two anonymous surveys were administered using Qualtrics software, one targeting Kansas Extension professionals and the other directed at Kansas community residents. Participants from both groups demonstrated general awareness of AGS. Beyond the dietary restrictions associated with the condition, individuals with AGS also faced a range of social, financial and health-related challenges. The study revealed critical gaps in healthcare preparedness and support infrastructure for managing AGS in rural Kansas communities.

While awareness of AGS is increasing in Kansas, individuals affected by this condition continue to encounter significant challenges. These are not limited to personal and emotional

hardships but also systemic challenges in healthcare and community support. Study findings highlight a critical gap between growing awareness and implementation of effective action.

Keywords: Alpha-gal syndrome; Tick-borne allergy; Rural healthcare; Dietary restrictions

Background

In Alpha-Gal Syndrome (AGS), allergic reactions are delayed, typically occurring 2 to 6 hours after consuming mammalian meats such as pork, lamb, beef, and organ meats, and certain medications made from mammalian-based ingredients. Reactions may also be triggered by dairy products, gelatin, or even non-mammalian items that contain alpha-gal, such as carrageenan (a seaweed-derived additive). Symptoms can vary from mild manifestations, including hives, skin rashes, and swelling of the lips, tongue, throat, and eyelids, to more serious effects like wheezing, heartburn, gastrointestinal discomfort (e.g., abdominal pain, nausea, vomiting, and diarrhea), and, in severe cases, anaphylaxis [2,3,4]. AGS was first described in 2009 following reports of delayed anaphylaxis to red meat and reactions to the cancer drug cetuximab [5,6,7,8]. AGS has also been reported globally in the Middle East, South America, Europe, Africa, East and South Asia, Australia and New Zealand, but with different tick species as culprits [9,10,11,12,13].

Individuals residing in rural areas like in rural Kansas and those who spend significant time outdoors such as foresters, hunters, hikers, and campers are at greater risk of exposure to ticks and consequently more likely to develop AGS [14]. AGS has been linked to several co-factors that may influence the onset and severity of allergic reactions. These include physical activity, alcohol consumption, and the use of certain medications such as nonsteroidal anti-inflammatory drugs (NSAIDs) among others. These factors can lower the threshold for reactions and exacerbate symptoms following exposure to alpha gal. Although the underlying mechanisms are not fully understood, proposed explanations include enhanced gastrointestinal absorption of the allergen,

potentially due to increased intestinal permeability during exercise and greater blood flow to the gut. Alcohol may intensify symptoms by relaxing tight junctions in the gut epithelium, increasing IgE antibody levels, and promoting histamine release, possibly through lowered pH and increased osmolarity in the gastrointestinal environment [15-19].

AGS has also been linked to certain autoimmune diseases and atherosclerosis; alpha-gal sensitization is thought to correlate with the presence and extent of noncalcified atherosclerotic plaques and obstructive coronary artery disease [20-23]. Between 2011 and 2019, the number of diagnosed AGS cases increased dramatically from 2,330 to over 34,000, underscoring its growing prominence as a public health concern [24]. With the expansion of lone star tick populations, driven by climate change and the rising white-tailed deer population, the incidence of AGS is expected to continue to rise [25,26].

The Kansas population faces unique challenges related to its geographic location, limited specialist access, and limited healthcare communication. This study is the first phase of a larger project aimed at exploring awareness of and resilience to AGS within rural Kansas communities. This particular phase of the study aims to investigate Kansans' awareness and understanding of AGS, its symptoms, and available management resources. It also seeks to examine the geographic distribution of AGS, its impact, and challenges related to long-term symptom management within rural Kansas Communities. By evaluating the accessibility and effectiveness of current educational and informational resources, this study seeks to uncover critical gaps in public health outreach. The findings will inform targeted strategies for prevention, education and ongoing support to empower both healthcare providers and community members to recognize and respond to AGS more effectively.

Materials and Methods

This study follows the STROBE statement guidelines for cross-sectional studies and the CHERRIES checklist for internet E-surveys [35,36]. It involved two anonymous surveys of Kansas Extension professionals and Kansas community residents, administered using Qualtrics software [Qualtrics XM, Provo, UT, USA]. The research received approval from the Institutional Review Board office at Kansas State University (IRB-12256). Participants were notified that their consent was implied upon starting the survey. A $25 gift card was offered as an incentive upon completion of an additional form following the initial survey.

Eligible participants included Kansas Extension professionals and residents of Kansas who were over the age of eighteen. Residency was confirmed by filtering out responses with IP addresses originating outside of Kansas.

Survey Development

Both survey instruments gathered data on participants' age, gender, race, ethnicity, occupation, and county of residence or work. They included both closed and open-ended questions across several topics. These included awareness and knowledge of AGS, whether participants had heard of the condition, were familiar with its symptoms and knew of its link to tick bites. Participants were also asked how many individuals they knew had been affected by AGS in their county. Additional questions explored how AGS impacted affected individuals' diets and daily lives, and public perceptions regarding the availability of AGS information and whether respondents believed more resources were needed.

The community survey instrument also included questions on environmental and behavioral risk factors where respondents were probed about their current occupation, their participation in outdoor activities such as hiking and gardening, and other factors that would

influence their exposure to tick habitats. Both the Kansas Extension professionals' and Kansas community surveys were pilot tested with ten Extension professionals and ten Kansas community members respectively, to improve clarity. The final versions included 20 items each. The Extension survey was open from October 9 to November 9, 2024, while the community survey ran from January 15 to March 25, 2025. Survey invitations for Extension professionals were distributed via email to relevant listservs, Extension newsletters, and during the annual conference. Community survey invitations were shared during listening sessions across Kansas, through local news reports, the Kansas Extension website, and flyers distributed by Family and Consumer Science Extension professionals.

Due to concerns about potential fraud, the initial Kansas community survey was closed after 20 days. A new Kansas community survey was launched with a new weblink and QR code on the 10th of February and closed on the 25th of March. The new survey incorporated enhanced fraud detection measures, including IP address tracking, bot detection, reCAPTCHA, RelevantID, and restrictions on multiple submissions. IP address tracking enabled us to filter out responses from individuals outside the state of Kansas. Bot detection algorithms helped identify and flag automated bot submissions that could skew the data. The inclusion of a reCAPTCHA question at the beginning of the survey ensured that only human respondents participated. RelevantID was used to analyze respondent metadata, allowing us to detect potential instances of multiple submissions from the same individual. Finally, the prevention of multiple submissions feature ensured that each participant could complete the survey only once, safeguarding against duplicate or inflated data [37]. Once a participant commenced the survey, they had 72 hours to complete the questions, and afterwards any partially completed surveys were saved and stored within the survey data.

A total of 555 community surveys were received; of these, 381 were excluded after fraud detection measures listed above. An additional 36 surveys were excluded due to illogical or inconsistent responses (e.g., answers that did not match the survey question). The final sample consisted of 138 community surveys (Figure 1.1).

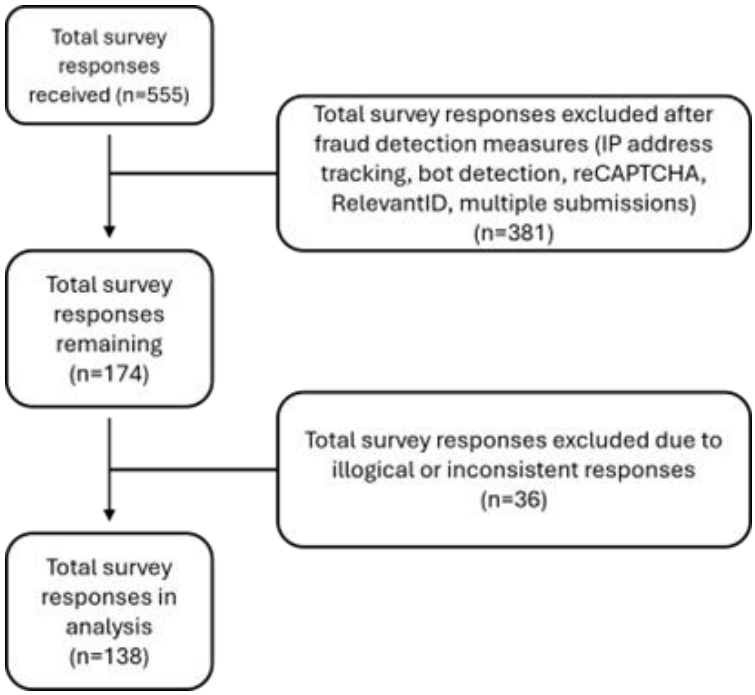

Figure 2.1. Flow diagram of survey response exclusions and final analytic sample.

Data Analysis

The survey responses were exported from Qualtrics (Qualtrics XM, Provo, UT, USA) to Microsoft Excel (2021, Microsoft Corp., Redmond, WA, USA) and subsequently analyzed using SPSS Statistics (version 29.0, IBM, Armonk, NY, USA). Participant demographic characteristics were analyzed descriptively. Age data was collected in categories for consistency with how Extension programs report demographic information to the U.S. Department of Agriculture. As a result, estimated means for age were calculated using weighted average of the midpoints of each

grouped category using the following mid points: 23.5, 38.5, 53.5, and 65.5 for the matching age categories.

Categorical variables are presented as frequency (n) and percentage (%). Binary logistic regression was conducted to examine whether pet ownership, time spent on outdoor activities, age, and gender predicted the likelihood of having AGS. Pet ownership and time spent on outdoor activities were the primary predictors of interest, while age and gender were included as covariates. Age was included as a categorical variable with four levels, with age group 60+ serving as the reference category, while gender was coded as 1=male and 2=female. The dependent variable (self-reported AGS status) was coded as 0 = for individuals who did not have AGS and 1= for those who self-reported having AGS. Odds ratios (ORs) and 95% confidence intervals (CIs) were reported with statistical significance set at $p < 0.05$.

Results

Participant Characteristics

Kansas community participants

The initial and second Kansas community surveys received 178 and 377 responses, respectively, totaling 555 submissions. After eliminating fraudulent submissions, 138 valid responses (25%) remained for analysis. The majority of participants were female (63%), non-Hispanic/Latino (89%), white/Caucasian (90%), and aged 60 years or older (38%) (Table 2.1). Most respondents (42%) were from counties in Eastern Kansas particularly Reno, Wyandotte, Sedgwick and Crawford. Occupation-wise, participants were primarily retired (21%), teachers (8%) and business owners (6%). About 56% reported having AGS. In terms of lifestyle, 79% of participants owned pets, and the majority (33%) spent less than 5 hours per week engaged in outdoor activities, such as gardening and yard work (35%), or adventure and nature exploration,

including hiking, camping, birding, and mountaineering (30%). Unadjusted logistic regression analysis showed that participants with pets had significantly higher odds of having AGS (OR = 3.43, 95% CI (1.42, 8.32), P=0.006), similarly, participants who spent more than ten hours outdoors per week also had increased odds of AGS (OR=2.39, 95% CI (0.97, 5.90), although this association did not reach statistical significance (p=0.060) (table 2.2). After adjusting for age and gender, the association between pet ownership and AGS status remained statistically significant and slightly stronger (OR = 4.04, 95% CI (1.57,10.41), P= 0.004. In contrast, the association between time spent on outdoor activities and AGS status remained non-significant after adjustment (OR = 2.11, 95% CI (0.81, 5.49), P=0.128 (table 2.3).

Table 2.1 Characteristics of Kansas Community participants and Extension Professionals

	Extension professionals (n = 144)	**Community Participants (n =138)**
Characteristic	**n (%)**	**n (%)**
Age		
18-29 years	35 (24)	15 (11)
30-47 years	59 (41)	43 (31)
48-59 years	29 (20)	28 (20)
60+ years	19 (13)	52 (38)
Choose not to provide	2 (1)	-
Estimated mean age	41.5	50.1
Gender		
Female	104 (72)	87 (63)
Male	37 (26)	50 (36)
Choose not to provide	3 (2)	1 (1)
Race		
White or Caucasian	134 (93)	124 (90)
Black or African American	-	9 (7)
American Indian/Alaska Native	2 (1)	2 (1)
Asian	2 (1)	1 (1)
Native Hawaiian/Pacific islander	-	1 (1)
Two or more races	3 (2)	-

Choose not to provide	3 (2)	1 (1)
Ethnicity		
Non-Latino/Hispanic	133 (93)	115 (89)
Latino/Hispanic	4 (3)	6 (5)
Choose not to provide	6 (4)	9 (7)
AGS status		
Currently has AGS	7 (5)	75 (56)
Doesn't have AGS	117 (87)	53 (40)
Doesn't know	10 (8)	6 (5)
Pet ownership		
Has at least one pet	-	105 (79)
Doesn't have pets	-	28 (21)

Note: Percentages are rounded to the nearest whole number and may not total 100% due to rounding. Calculations are based on the number of valid (non-missing) responses. Estimated means for age were calculated using a weighted average of the midpoints of each grouped category (mid points used: 23.5, 38.5, 53.5, 65.5), since age data was collected as categories

Table 2.2: Unadjusted Logistic Regression models predicting likelihood of AGS from pet ownership and time spent outdoors (separate models)

Predictor	**B**	**Wald**	***P***	**OR (Exp (B)**	**95% CI for OR**
Model 1: Pet ownership					
Pet ownership	1.23	7.44	0.006	3.43	(1.42, 8.32)
Model 2: Time outdoors					
Time spent outdoors	0.87	3.54	0.060	2.39	(0.97, 5.90)

Table 2.3: Adjusted Logistic Regression models predicting likelihood of AGS based on pet ownership and time spent outdoors controlling for age and gender

Predictor	**B (Pet Model)**	**OR (95% CI) (Pet Model)**	***P* (Pet Model)**	**B (outdoor Model)**	**OR (95% CI) (Outdoor Model)**	***P* (Outdoor Model)**
Pet ownership	1.40	4.04 (1.57,10.41)	0.004	-	-	-
Time spent Outdoors	-	-	-	0.74	2.11 (0.81, 5.49)	0.128
Age (1)	0.54	1.72 (0.49, 6.05)	0.399	-0.16	0.86 (0.18, 4.11)	0.845
Age (2)	0.51	1.67 (0.44, 6.36)	0.455	-0.26	0.77 (0.14, 4.25)	0.768

Age (3)	0.92	2.50 (0.72, 8.66)	0.147	-0.39	0.67 (0.14, 3.18)	0.618
Gender (1)	-0.73	0.48 (0.22, 1.05)	0.065	-0.67	0.51 (0.19, 1.32)	0.165

Note: pet ownership coded: 1=yes, 0=No; Time spent outdoors coded: 1= >10 hours, 0 = ≤ 10 hours per week; gender coded :1= male, 2=female; age coded: 1= 18-29, 2= 30-47, 3= 48-59 years. OR=odds ratio, CI=confidence interval

Extension professionals

Of the 174 responses received for the Extension professionals' survey, 144 were retained for analysis after excluding incomplete submissions, specifically those in which only the initial characteristic questions were answered. The majority of respondents were female (72%) and non-Hispanic White (93%), with 41% between the ages of 30 and 47 (Table 2.1). About 5% reported having AGS. Most participants reported serving in the Northeastern (28%) and Southeastern (25%) regions of Kansas.

Participants' Knowledge and Awareness of AGS

Kansas community participants

A high percentage of Kansas community participants were familiar with AGS, with 95% aware of the condition, 96% understanding its cause and 88% recognizing its symptoms (Table 2.4). The most reported AGS symptoms were hives (67%) and abdominal pain (67%) followed by diarrhea (64%) and itching (64%). Furthermore, 84% of respondents knew someone diagnosed with AGS within their county, with 32% personally diagnosed and 28% learning about the condition through friends. Participants who self-reported as having AGS were mapped to estimate the geographic distribution of AGS across Kansas counties. Reno and Sedgwick counties seemed to have the highest number of cases (Figure 2.2). A significant proportion (76%) reported not knowing anyone who had recovered from AGS, while 14% knew an individual who had. Most participants (89%) felt there was insufficient public information about AGS treatment and long-term management while 75% expressed interest in receiving AGS information.

Table 2.4: Knowledge and perceptions of Kansas Community participants and Extension Professionals

	Extension professionals (*n* = 144)	**Community Participants (*n* =138)**
Question	n (%)	n (%)
Knowledge of AGS		
Yes	127 (91)	130 (95)
No	13 (9)	7 (5)
Knowledge of AGS cause (tick bite)		
Yes	123 (88)	129 (96)
No	17 (12)	6 (4)
Familiarity with AGS symptoms		
Yes	64 (46)	120 (88)
No	59 (42)	15 (11)
Don't know	17 (12)	1 (1)
Reported known symptoms*		
Abdominal pain	47 (64)	84 (67)
Hives	46 (62)	84 (67)
Diarrhea	45 (61)	80 (64)
Nausea	54 (73)	78 (63)
Vomiting	42 (57)	56 (45)
Heartburn or indigestion	17 (23)	48 (39)
Itching	33 (45)	79 (64)
Swelling of the lips	39 (53)	77 (62)
Shortness of breath	32 (43)	60 (48)
Cough	12 (16)	44 (35)
Wheezing	16 (22)	40 (32)
People you know are diagnosed with AGS		
Knows at least one person	67 (54)	106 (84)
How did you find out they had AGS		
Friends	32 (51)	31 (28)
Respondent has AGS	4 (6)	36 (32)
Family	6 (9)	25 (23)
Programming	8 (13)	-
Word of mouth	6 (10)	-
Church	1 (2)	4(4)
Social media	5 (8)	2 (2)
School	1 (2)	-
Work	-	6 (5)
The person with AGS told them	-	5 (5)
How many people do you know who have recovered from AGS		
None	50 (82)	83 (76)
One person	10 (16)	15 (14)
More than one person	1 (2)	12 (10)
Think that not enough information is available on AGS		
Yes	2 (2)	2 (2)
No	89 (65)	119 (89)
Not sure	45 (33)	13 (10)

Interest in receiving AGS information		
Yes	107 (80)	101 (75)
No	27 (20)	20 (15)
Not sure	-	13 (10)

Note: Percentages are rounded to the nearest whole number and may not total 100% due to rounding. Calculations are based on the number of valid (non-missing) responses. *Participants could select more than one option; therefore, percentages may total more than 100%.

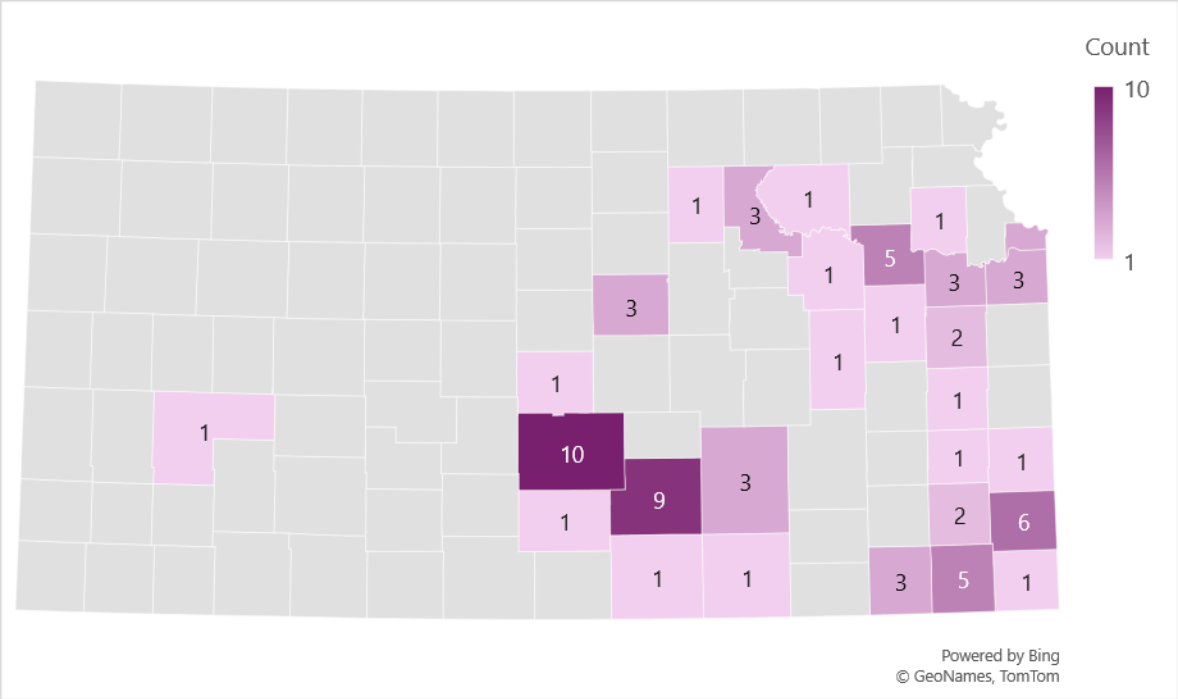

Figure 2.2 Geographic distribution of Community survey participants with self-reported AGS across Kansas counties

Extension professionals

The majority of Extension professionals who participated in the study were familiar with AGS, with 91% reporting awareness of the condition. A significant proportion (88%) correctly identified tick bites as the cause of AGS (Table 2.4). However, only 46% of participants were familiar with the specific symptoms associated with the condition. Among those who were aware of AGS symptoms, the most commonly reported were nausea (73%), abdominal pain (64%), hives (62%), and diarrhea (61%). In terms of community awareness, 54% of participants knew someone

within their county who had been diagnosed with AGS. The majority (51%) had learned about AGS through friends or extension programming activities (13%). Participants' self-reported knowledge of cases of AGS in their respective counties were mapped to estimate the geographic distribution of AGS across Kansas counties. Reno and Neosho seemed to have the highest number of cases (Figure 2.3). The majority (82%) did not know anyone who had recovered from AGS. Most participants (65%) felt there was insufficient information for the public about AGS treatment and management, and only 3% had had their extension offices approached for information pertaining to AGS while 80% expressed interest in attending listening sessions on AGS.

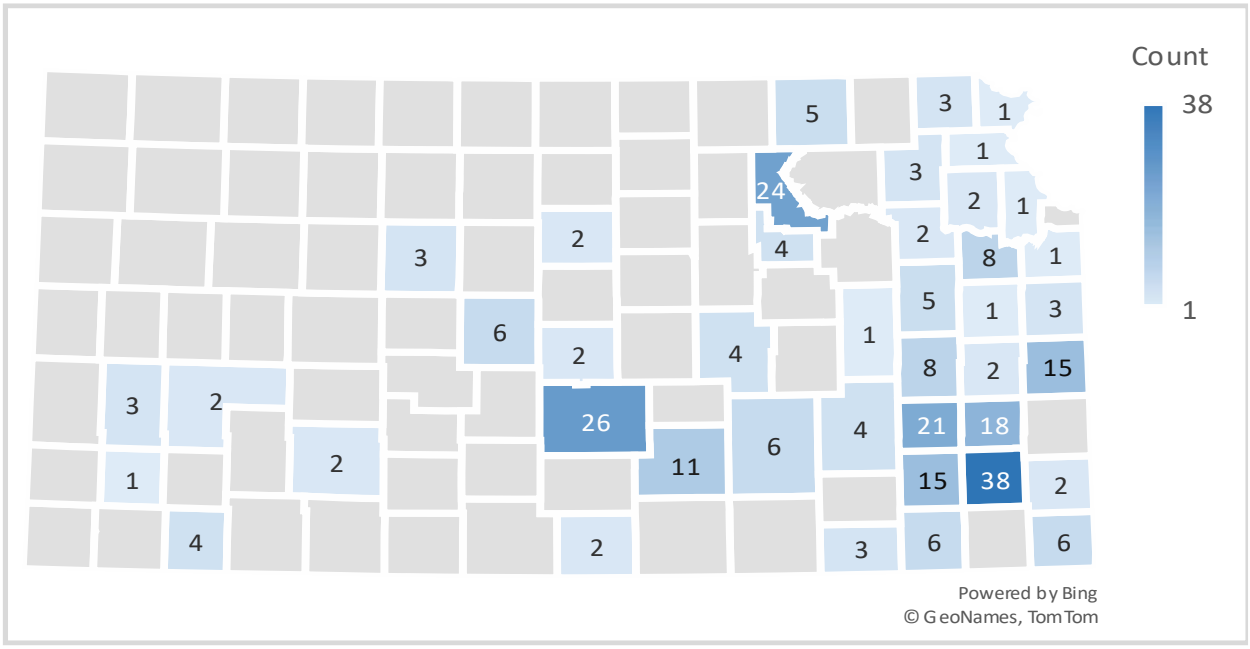

Figure 2.3 Geographic distribution of self-reported knowledge of AGS cases by Extension Professionals across Kansas counties

Participants' perceived impact of AGS on individuals

Dietary Restrictions

Kansas community participants

When asked about their perceptions of how AGS had impacted individuals they knew who had been diagnosed, respondents frequently emphasized the significant lifestyle and dietary challenges associated with the condition. A predominant concern centered on the strict dietary restrictions required to manage AGS, particularly the complete elimination of mammalian meat. Many also reported the necessity of avoiding dairy products and by-products, as well as limiting consumption or use of items containing alpha gal such as gelatin, carrageenan, and other hidden ingredients. In many cases, individuals had to adopt a fully vegan or plant-based diet and routinely scrutinize food labels to avoid inadvertent exposure to mammalian ingredients. One participant described the emotional toll of navigating this unfamiliar dietary landscape: "*This was traumatizing, the first time I went grocery shopping, I sat on the floor in the store and cried because I couldn't find food that I knew would be safe. Eventually I learned and so now I eat mostly chicken and turkey. I use almond milk, plant butter, and check ingredients of everything I buy*," (Table 2.5).

Extension Professionals

Similar to community participants, Extension professionals consistently emphasized the profound impact AGS has on the daily lives of those diagnosed. In particular, they highlighted the significant dietary and lifestyle adjustments required to manage the condition, with the strict dietary restrictions presenting a notable burden. Many individuals shifted to relying on poultry, fish, and vegetarian alternatives as primary sources of protein. Additionally, participants

underscored the constant need for vigilance in avoiding less obvious sources of mammalian by-products such as gelatin, dairy, and certain sugars processed with animal-derived agents like bone char. Most individuals reported depending heavily on home-cooked meals, bringing their own food to social gatherings, and meticulously reading ingredient labels to prevent accidental exposure. One participant described their friends' ordeal as *"I met both individuals at a food preservation program that I did. They were both there because they wanted to learn more about how to preserve their own food because of the amounts of items in other foods that were causing symptoms. One was unable to have sugar due to the bone meal used during the milling process."* Another remarked about an individual they know*, "They are pretty fatigued while they are transitioning to finding foods that they can handle eating. They are finding unique foods that are helping them that weren't on their radar or mine before. They all seem to be very frustrated with having to alter their food habits."*

Health Impact

Kansas community participants

Health-related complications were also noted. Several respondents described adverse reactions to medications containing mammalian-derived components such as gelatin. Some indicated that AGS appeared to exacerbate or trigger additional health conditions and food allergies, such as nut allergies, while others expressed concerns about maintaining adequate nutritional intake given the restricted dietary options. One parent remarked*, "It has definitely been a challenge for my son. He is nine and struggles with not being able to eat what his friends and family do. It's also hard to make sure he is eating enough."* Another participant with AGS reported*, "even with restricting mammalian meat and dairy from my diet, I continue to have*

allergic reactions to other foods and fumes. My doctor suspects that I have Mast Cell Activation syndrome that was brought on from having Alpha Gal syndrome."

Extension Professionals

Extension professionals also reported a range of adverse health complications associated with AGS, many of which significantly affect individuals' quality of life. These included severe allergic reactions such as anaphylaxis, necessitating the regular use of antihistamines, epinephrine, or EpiPens. Respondents noted that individuals with AGS often had to alter medications prescribed for pre-existing conditions, due to the presence of mammalian-derived ingredients. One participant shared, *"They have had to change what medication they take and food they eat."* Another observed, *"They also have to avoid glycerin in pills like Dayquil,"* highlighting the hidden risks in common medications. Beyond physical health, participants also described the toll AGS takes on emotional and mental well-being. Fatigue, chronic stress, and anxiety were commonly reported, stemming from the constant vigilance required to avoid exposure and manage symptoms. Some individuals were described as having lost a significant amount of weight due to the strict dietary limitations and the reduced variety of safe food options.

Social and Financial Impact

Kansas community participants

Social and emotional challenges were also widely reported. Participants highlighted difficulties attending social gatherings, including family events, potlucks, and meals at restaurants where mammalian meat was present or cross-contamination was possible. Many individuals resorted to bringing their own food to such occasions and described experiencing heightened anxiety and emotional distress during meals. One respondent described experiencing *"high anxiety*

over eating at restaurants or any sort of shared meals, frustration over high amounts of hidden mammal byproducts in many foods and people's lack of understanding." The need to request ingredient lists and special accommodations often led to discomfort, and fear of accidental exposure contributed to social withdrawal in some cases. In addition, respondents reported strain on interpersonal relationships due to the increased planning and accommodation required to safely include individuals with AGS in shared meals or events.

Beyond social concerns, participants identified broader lifestyle implications. The need to find suitable alternatives for everyday products containing mammalian-based ingredients such as medications, cosmetics, and personal care items including shampoos and lotions added further complexity to daily life. Financial burden was another recurring theme. Respondents noted increased costs associated with purchasing specialty foods, acquiring separate kitchen appliances and utensils to avoid cross-contamination, and investing in tools such as food-scanning applications, EpiPens, and medications, some of which were not covered by insurance. One respondent succinctly summarized this burden, stating*, "Food is more expensive and harder to find."* Another participant expressed frustration with losing access to medication that had been helpful: *"I was on Dupixent, it helped, but insurance no longer covers it."* One individual reported*, "I purchased entirely new dishes, pots and pans, silverware, etc. for my kitchen to avoid the possibilities of cross-contamination."* Similarly, the importance of readiness for allergic reactions was emphasized by another respondent: *"I always have an EpiPen at home and at work, and I sometimes take it with me if dining somewhere new or travelling."*

Extension Professionals

Similar to community survey participants, Extension professionals reported that individuals living with AGS often turn to home cooking as a primary strategy for managing their

condition. Preparing meals at home allows for greater control over ingredients and reduces the risk of accidental exposure to mammalian products. However, this shift also comes with significant lifestyle challenges. Respondents noted the difficulty individuals face in attending social events, dining out, or participating in communal meals, experiences that are often accompanied by stress, anxiety, and emotional fatigue due to limited safe food and product options. This condition impacts not just individuals, but their families and friends. Participants highlighted how family members and friends often need to adapt their own habits, creating a ripple effect of lifestyle changes. This transition can be particularly difficult for individuals who previously consumed meat regularly, with some respondents describing the emotional strain of giving up familiar and culturally significant foods.

In addition to personal challenges, Extension professionals also noted the financial and professional consequences of AGS for those involved in livestock production, particularly beef producers. Several reported that individuals diagnosed with AGS were forced to modify or completely shift their farming operations to reduce exposure risks. One participant shared, "*One friend raises cattle, they still do, but have added emu to their operation.*" Another wrote, "*As a beef producer, one was devastated*." Others emphasized the broader cultural and economic impact, stating, *"It was hard for everyone I know, especially since beef is such a large part of most Kansas diets*."

Perceived Knowledge gaps and their impact on AGS management

When participants were asked about the adequacy of publicly available information regarding the treatment and management of AGS, the majority expressed dissatisfaction. Respondents consistently reported widespread gaps in awareness not only among the general public but also among healthcare professionals, the restaurant industry, and insurance providers.

These knowledge deficits were seen as significant barriers to timely diagnosis, effective treatment, and daily management of the condition.

A recurrent theme was the difficulty in obtaining a correct diagnosis. Several individuals described delayed or missed diagnoses, sometimes spanning years, which they attributed to limited health care provider knowledge and the tendency to dismiss or minimize patient-reported symptoms. One participant stated, *"There is very little that doctors know about it,*" while another elaborated, "*One of the greatest obstacles I face is that doctors don't believe me when I tell them, they don't understand how to treat me, and many of them seem to lack an understanding of what a mammal is."* Even individuals with a known family history of AGS described delays in obtaining a diagnosis, "*There's so little information that it took nearly 3 years to diagnose me even though a relative had it."*

Participants frequently emphasized the lack of training among healthcare providers and called for more widespread education. This concern extended to access to appropriate diagnostic tests and preventive interventions such as EpiPens. As some noted: "*Doctors need to be educated! There needs to be access to the test!"* and "t*here needs to be more doctor education on this and less shock about it. Easier diagnosis and preventative measures covered like EpiPens."*

Experiences with insurance companies also reflected systemic knowledge gaps. Respondents reported denials of coverage for testing, treatment, and emergency medications due to lack of recognition of AGS as a legitimate medical condition. One participant recounted, "*I have it. Was treated with lots of skepticism after a full anaphylactic emergency room visit. I figured it out and requested the lab for verification and was told insurance probably wouldn't cover it. That changed 3 weeks later when the result came in. Had an EpiPen prescription for those 3 weeks but insurance wouldn't cover it."*

Despite receiving care from allergists, many respondents described treatment plans that were largely limited to basic antihistamines. As one individual reported, "*No, I have not seen any information on how to treat or manage AGS. My allergist only has me taking an allergy pill each day."*

Many individuals reported turning to online sources for information and support. Community-level educational resources were described as nearly nonexistent. *"I do not know of any educational resources in my community. My information is from researching the condition online,"* said one participant. Others highlighted the mixed quality of online information: *"I believe that there is much misinformation mixed with good information on social media sites, but reputable sources lack good information on specific aspects of food manufacturing."*

Participants also noted a lack of social support and general recognition of AGS as a serious, potentially life-threatening condition. "*I wish people accepted allergies as life-threatening conditions,"* one respondent remarked. The lack of awareness in the restaurant industry was also emphasized as a practical concern, with one participant explaining*, "I think more people should be aware, especially in the restaurant industry. We are able to go to a select few due to our own research"*

While most experiences pointed to a general deficit in healthcare preparedness, a few respondents reported isolated positive encounters, such as, "*Many including medical personnel know little about Alpha-gal. I was fortunate with having a nurse practitioner that immediately tested me for tick-related diseases."*

Table 2.5: Illustrative participant quotes related to experiences with AGS

Theme	Representative Quote
Emotional and Psychological impact	"This was traumatizing, the first time I went grocery shopping, I sat on the floor in the store and cried because I couldn't find food that I knew would be safe."
	"They all seem to be very frustrated with having to alter their food habits."
	"High anxiety over eating at restaurants or any sort of shared meals, frustration over high amounts of hidden mammal byproducts in many foods and people's lack of understanding."
Dietary Challenges	"Eventually I learned and so now I eat mostly chicken and turkey. I use almond milk, plant butter, and check ingredients of everything I buy."
	"They are finding unique foods that are helping them that weren't on their radar or mine before."
	"It has definitely been a challenge for my son. He is nine and struggles with not being able to eat what his friends and family do."
Health impact and System barriers	"Even with restricting mammalian meat and dairy from my diet, I continue to have allergic reactions. My doctor suspects that I have Mast Cell Activation syndrome."
	"I was on Dupixent, it helped, but insurance no longer covers it."
	"There is very little that doctors know about it, doctors don't believe me when I tell them, seem to lack an understanding of what a mammal is."
	"Doctors need to be educated! There needs to be access to the test!"
	"No, I have not seen any information on how to treat or manage AGS."
	"I believe that there is much misinformation, but reputable sources lack good information"
	"I was treated with lots of skepticism after a full anaphylactic ER visit"
	"I do not know of any educational resources in my community. My information is from researching the condition online."
Social and Financial impact	"One friend raises cattle; they still do but have added emu to their operation."
	"As a beef producer, one was devastated."
	"It was hard for everyone I know, especially since beef is such a large part of most Kansas diets."
	"Churches need more info on special diets especially alpha gal-friendly diets."
	"I think more people should be aware, especially in the restaurant industry."
	"I purchased entirely new dishes, pots and pans, silverware, etc. for my kitchen to avoid the possibilities of cross-contamination."
	"Food is more expensive and harder to find."

	"I always have an EpiPen at home and at work, but insurance wouldn't cover it."

Discussion

This study aimed to assess public awareness and understanding of Alpha-Gal Syndrome (AGS), including its symptoms and available management resources. Additionally, it examined the distribution of AGS based on self-reports, its impact, and the challenges associated with long-term symptom management in rural communities across Kansas. The study reveals awareness of AGS among both Kansas community members and Extension professionals but also significant dietary, social, financial, and healthcare-related challenges for individuals living with the condition. Moreover, our results highlight critical gaps in healthcare system preparedness, and support infrastructure for managing AGS across rural Kansas communities.

Among both groups of participants, awareness of AGS was significantly high, with over 90% of respondents demonstrating knowledge of the condition and its tick-bone etiology. This may be reflective of the increasing prevalence of AGS in Eastern Kansas and the strong word of mouth communication within communities given 84% of community members reported knowing someone within their county who had been diagnosed. Extension professionals reported slightly lower awareness of symptoms, with only 46% able to accurately identify key symptoms of AGS. This disparity may necessitate further professional development for Extension professionals to support their role as community health educators and communicators.

Geographic distribution data revealed that AGS cases were concentrated in Reno, Neosho, and Sedgwick counties. Notably, both Reno and Neosho counties were also identified by the Kansas Department of Health and Environment (KDHE] as having a high number of suspected cases, exceeding 87 cases per million population annually between 2017 and 2022 [38,].

Thompson et al. [34] further noted that the geographic distribution of AGS mirrors that of ehrlichiosis, a tick-borne illness caused by bacteria Ehrlichia chaffeensis and E. ewingii, which are also transmitted by the lone star tick. This relationship is supported by our findings and is consistent with KDHE data on ehrlichiosis and lone star tick distribution across Kansas [39]. This suggests these areas may warrant targeted public health interventions.

The results suggest that pet ownership is significantly associated with increased odds of AGS, with an unadjusted odds ratio (OR) of 3.43 and an adjusted OR of 4.04 after controlling for age and gender. This increase in OR after adjustment suggests that age and gender had a moderate negative confounding effect on the association, given our sample's demographic imbalance with females comprising 63% and 38% of participants aged 60+. This pattern aligns with findings from Ross et al. (40) who reported higher AGS prevalence among males than females, and an increased likelihood of a positive AGS test increasing age, particularly after age 40. The wide confidence interval reflects limited precision in the effect estimate. This highlights the need for further studies with larger sample sizes to confirm the observed association.

Existing literature on the relationship between pet exposure and AGS remains limited. Mateo-Borrega et al. [41], in a study conducted in Spain, reported a significant correlation between pet exposure and the presence of alpha-gal-specific IgE antibodies, with the association being stronger among individuals exposed to dogs than to cats. Similarly, Chinuki et al. [42] observed that Japanese individuals with red meat allergy were more likely to own dogs. They hypothesized that dogs could act as vectors for tick transmission, potentially introducing ticks to individuals during activities such as walking dogs in grassy areas or petting them after outdoor exposure. In contrast, González et al. [43] found a stronger association between alpha-gal sensitization and cat ownership in both Spanish and Danish cohorts. It has been hypothesized that airborne exposure to

pet dander, particularly from cats, may increase allergic sensitization [44,45]. Despite these associations, the role of pet exposure in AGS development remains inconclusive. In a narrative review, Dr. Commins [46], a leading expert on AGS, argued that pet dander is unlikely to be a significant risk factor for reactive individuals. He emphasized that eating mammalian meat alone was not sufficient to trigger an immune response to alpha-gal, and that other forms of mammalian exposure such as pet dander, have not been conclusively linked to AGS development. Based on this, Commins does not recommend pet removal for AGS patients. Instead, he advises healthcare professionals informing patients that pet dander may contain alpha-gal and recommends washing pets monthly to minimize potential exposure [47].

Participants who spent more than ten hours outdoors per week had higher odds of having AGS, but the odds slightly decreased after adjusting for age and gender from 2.39 to 2.11 and the association remained statistically non-significant. The slight decrease in the OR suggests both gender and age may have had a small confounding effect given our sample composition. Although this association did not reach statistical significance, the observed positive trend suggests a potential dose response relationship. Notably, the wide confidence interval reflects limited precision in the effect estimate which highlights the need for further studies with larger sample sizes to confirm this association. Our research findings are consistent with previous research showing increased participation in outdoor activities is associated with increased tick bites, a key factor in the pathogenesis of AGS [41]. Commins [46] recommends that AGS patients take precautions to prevent tick exposure, as repeat bites may boost alpha-gal-specific IgE antibody levels. Supporting this, Kim et al. [47] found that IgE antibody levels declined among individuals who reduced their exposure to tick bites, although the rate and extent of decline varied. Iweala et al. [48] suggest that this variability may be influenced by factors such as dietary intake of

mammalian meat and co-factors including medications, alcohol, physical activity, and continued tick exposure. Notably, Commins [20] reported that in some cases, alpha-gal-specific IgE levels decreased to a point where patients were able to gradually reintroduce mammalian meat into their diets.

Among both community participants and Extension professionals, the most profound effects of AGS were dietary/nutritional, emotional and social in nature. Respondents described the necessity of making significant dietary changes with a significant number adopting vegetarian or plant-based diets to better manage their symptoms. However, research indicates that many health professionals are not adequately equipped to guide individuals through the complexities of a plant-based lifestyle without compromising essential nutritional and health needs [49]. As with other food allergies, managing AGS presents several challenges. These include the potential for overly restrictive eating patterns, unintentional exposure to allergens through cross-contamination, limited knowledge about which foods to avoid, inadequate allergen labeling on products, difficulties in identifying trigger foods and safe portion sizes. Collectively, these factors can have long-term consequences for an individual's overall health and quality of life [50].

Avoidance diets may lead to nutritional deficiencies if not carefully managed with the support of a dietitian [51,52]. Eliminating red meat requires careful substitution with other protein-rich foods like poultry, fish, legumes, and soy products. Vaz-Rodrigues [53] suggests that individuals diagnosed with AGS should collaborate with a dietitian knowledgeable about the condition to monitor their iron and vitamin B12 levels. The dietitian should also evaluate the need for supplementation, particularly if the individual is allergic to gelatin and milk [28,54]. According to Mofidi [50], individuals with AGS who must eliminate key food groups, such as milk, should find alternative sources of calcium, vitamin D, and B vitamins, with fortified soy milk being a

viable substitute [52]. Education on label reading, allergen identification, and suitable food alternatives remains critical to ensure both safety and nutritional adequacy [55].

The social impact of AGS was well reported with respondents describing the anxiety and emotional exhaustion related to social interactions, fear of accidental exposure and strained interpersonal relationships. Financial strain also emerged as a prominent theme, encompassing the cost of specialty foods, new kitchenware, and uncovered medical expenses such as AGS testing and treatment. For individuals whose livelihood revolved around beef production, AGS not only posed personal health risks but also professional and economic disruption, an angle seldom reported in AGS literature yet vital in agricultural states such as Kansas. Collectively, these accounts illustrate the "invisible burden" of AGS and how it affects the physical health of those diagnosed as well as their emotional resilience, daily routines, and overall quality of life.

Despite high community awareness, participants consistently expressed their frustration with the lack of accessible, reliable information, particularly around treatment, symptom management, and safe food sourcing. A recurring concern was the limited knowledge among healthcare providers. Carpenter and associates [32] found that in a large web-based survey of 1500 health care professionals (including primary care physicians, pediatricians, physician assistants, and nurse practitioners], 42% had never heard of AGS, and among those who had, nearly half (48%) were unaware of the appropriate diagnostic tests. The majority expressed interest in clinical resources including diagnostic and management guidelines. Similar findings have been reported in smaller studies [56,57], reinforcing the urgent need for improved professional education.

Participants also reported delayed diagnoses, disbelief from clinicians, and a lack of individualized care plans, resulting in prolonged suffering, increased healthcare use, and likely underreporting of AGS cases. These findings highlight the critical need for targeted public health

campaigns, ongoing professional development for healthcare and community educators (Extension professionals) and formal recognition of AGS in clinical guidelines and insurance policies. Additionally, there is also a need for community-level education, and standardized protocols for diagnosis and long-term care.

The results of this study can aid in initiating national surveillance efforts for this emerging allergic condition and guide geographically focused outreach to high-risk communities. Whether the increasing numbers of suspected AGS cases reflect increased awareness, increasing emergence, or both remains unclear. However, the responses highlight the urgent need for improved education among healthcare professionals, public awareness campaigns, and the development of accessible, evidence-based resources to support individuals with AGS and their families. Integrating AGS awareness into existing tick-borne disease prevention efforts, especially in counties determined to have high prevalence will facilitate early detection and reduce disease burden. Future research should investigate long-term outcomes for AGS patients, diagnostic barriers in underserved communities, and interventions that address their challenges.

Study Limitations

A significant limitation of this study was the use of electronic surveys which may have introduced sampling bias given only individuals with access to the internet were involved. This study sample may not be representative of the target population. There was a substantial number of fraudulent responses during the data collection phase. While rigorous data cleaning procedures were applied to improve the validity of the dataset, the high volume of unusable responses may reflect vulnerabilities in the survey distribution method, particularly in online environments where open-access links can be exploited by bots or individuals seeking incentives. The exclusion of these responses, although necessary for data integrity, reduced the effective sample size and may

have influenced the demographic balance within the final dataset. Consequently, these factors may limit the generalizability of the findings and underscore the importance of implementing stronger fraud-prevention mechanisms in future studies.

Additionally, self-selection bias is an important consideration, given a significant portion of participants self-reported having AGS, due to the voluntary nature of participation. Individuals affected by AGS may have been motivated to complete the survey, which may have inflated the observed associations. In the absence of confirmed clinical diagnoses, reliance on self-reported symptoms may have led to overestimation of AGS distribution estimates. Furthermore, because age data was collected using grouped categories, estimated means for age were reported rather than the true means. In addition, there was imbalance in the age range distribution across groups. Most Extension professionals were aged 30-47 years, whereas most community participants were 60 years or older. These differences likely reflect the demographic profile of Extension programming, which tends to engage a larger proportion of adults aged 60 and above.

Conclusions

While AGS awareness is growing in Kansas, individuals living with the condition continue to face significant dietary, emotional, financial, and systemic challenges. The data reveals a critical gap between awareness and action, that is between knowing about AGS and being equipped to live with it safely and sustainably. Addressing this gap will require coordinated efforts across public health, medical, agricultural, and educational sectors to ensure that no Kansan navigating AGS is left unsupported.

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Chapter 3 - Living with Alpha-gal Syndrome: exploring lived experiences, dietary transitions, and management strategies

Abstract

Alpha-gal syndrome (AGS) is increasingly prevalent in the Southern, Eastern and mid-western regions of the United States. This qualitative study was the second phase of a larger project focused on increasing AGS awareness and fostering resilience. The study employed both the phenomenological approach and the Health Belief Model to explore the lived experiences of Kansans living with AGS including impact on daily life and coping strategies. Thirty participants recruited through purposive sampling were interviewed using in-depth interviews. Thematic analysis revealed six major themes: exposure risk and context; symptom experience and diagnosis; dietary changes and challenges; navigating food substitutions; social, emotional and daily life impact; and healthcare system and support needs. Participants described their risk and exposures, dietary challenges, gaps in the healthcare system, and psychosocial challenges faced while navigating life with AGS. Many participants relied on self-management and self-advocacy rather than rely on healthcare professionals or the healthcare system. As a result, they recommended improvements in medical education and awareness along with clearer food and drug labeling policies, and expanded support and resources.

Background

Alpha-gal syndrome (AGS) is the leading cause of adult-onset allergies as well as anaphylaxis in regions where the condition is highly prevalent [1,2]. The onset and severity of AGS are influenced by several co-factors including physical exertion, alcohol consumption, and the use of certain medications such as nonsteroidal anti-inflammatory drugs (NSAIDs). These factors can lower the threshold for reactions and exacerbate symptoms following exposure to alpha gal. Although the underlying mechanisms are not fully understood, proposed explanations include enhanced gastrointestinal absorption of the allergen, potentially due to increased intestinal permeability during exercise and greater blood flow to the gut. Alcohol may intensify symptoms by relaxing tight junctions in the gut epithelium, increasing IgE antibody levels, and promoting histamine release, possibly through lowered pH and increased osmolarity in the gastrointestinal environment [3-7].

Management of AGS primarily involves strict avoidance of mammalian meat including beef, pork, venison, bison, buffalo, rabbit, horse, goat, and lamb [6]. Fatty meats are more consistently linked to symptoms and more intense reactions. While cooking does not alter the alpha-gal epitope, it may lessen the severity of reactions likely by reducing the fat content [8,9]. Mammal organ meat such as liver, kidneys, and intestines can trigger reactions and should be avoided as well. In addition, meat broth, fatback or bacon in salads, bouillon, stock and gravy should also be avoided [8,10]. Dairy products also contain small amounts of alpha-gal, especially ice cream and cream cheese which are high in fat [11,12].

Strict avoidance diets may lead to nutritional deficiencies if not carefully managed with the support of a healthcare professional [13,14]. Vaz-Rodrigues [15] suggests that individuals diagnosed with AGS should collaborate with a healthcare professional knowledgeable about the

condition to monitor their iron and vitamin B12 levels. The health care professional should also evaluate the need for supplementation, particularly if the individual is also allergic to gelatin and milk [9,16]. According to Mofidi [13], individuals with AGS who must also eliminate key food groups, such as milk, should find alternative sources of calcium, vitamin D, and B vitamins, with fortified soy milk being a viable substitute.

In adults, the management of anaphylaxis is complicated by the presence of comorbidities such as cardiovascular diseases, and the drugs used to treat them including Beta-blockers and ACE inhibitors. This is underscored by research showing that cardiac mast cells are key components of atherosclerotic plaques [2]. Interestingly, AGS has also been linked to atherosclerosis and certain autoimmune diseases. Sensitization to AGS is thought to correlate with the presence and extent of noncalcified atherosclerotic plaques and obstructive coronary artery disease [17-20].

AGS remains a non-nationally notifiable condition, albeit diagnosed cases surged from 2,330 to over 34,000 between 2011 and 2019, underscoring its growing prominence as a public health concern [21]. With the expansion of lone star tick populations, driven by climate variability and the rising white-tailed deer population, the incidence of AGS is expected to continue to rise [22,23]. Yet despite this growing threat, healthcare providers remain largely unaware of the condition, forcing many patients to seek information from nontraditional sources [24]. This limited health provider knowledge creates significant informational gaps that delay diagnosis and hinder effective AGS management. Kansas, which is located in the midwestern part of the United States, is home to many rural communities with high tick exposure yet the state does not require reporting of AGS cases and the prevalence and impact of AGS remains largely underrecognized. The lack of surveillance obscures the true impact of this condition on affected communities. Understanding the lived experiences and challenges faced by individuals living with this condition is essential for

informing policy makers and developing targeted public health interventions to address this emerging health challenge.

Methodology

Study design and participant recruitment

The purpose of this study was to conduct in-depth interviews with individuals living with AGS in Kansas, to better understand how the condition impacts their daily lives. This qualitative study is the second phase of a larger project focused on raising awareness and fostering resilience to AGS within rural Kansas communities.

Using the phenomenological approach and the Health Belief Model (HBM), this study sought to explore how individuals living with AGS navigate dietary changes and challenges, manage symptoms, cope with social challenges and maintain their overall quality of life. Phenomenology focuses on understanding the shared meaning of lived experiences among individuals facing a common phenomenon, which in this case is living with AGS. It emphasizes how people make sense of their experiences and how these interpretations shape their understanding of themselves and the world around them [25,26,27,28].

The Health Belief model provided a useful theoretical lens through which to examine participants' health decision-making. The HBM helps explain how individuals perceive and respond to health threats such as AGS through its constructs which include perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. Three of these HBM constructs were employed that is **perceived susceptibility** (awareness of tick exposure), **perceived severity** (symptom onset and impact), and **perceived barriers** (challenges in avoiding further tick bites and accessing appropriate healthcare) [29].

In this study, a semi-structured, in-depth interview format was used to explore the lived experiences of people living with AGS to better understand what they go through and how they experience it. This format allowed for consistency across interviews while allowing flexibility to dig deeper into each person's unique experiences and perspectives.

We used purposive sampling with the aim of interviewing at least 29 individuals currently living in Kansas with a diagnosis of AGS. This sample size was based on Galvin's [30] formula, which estimated that 29 interviewees represented a greater than 95% probability of identifying a theme if it is shared by at least 10% of the target population. The final sample size (N=30) proved sufficient as no new sub-themes emerged in later interviews, and key themes were consistently repeated across participants.

Participants were recruited through multiple channels, including previous surveys (that is individuals who had taken part in the first phase of the qualitative study and self-identified as having AGS) and social media platforms such as Facebook. In addition, in-person outreach was done with flyers and fact sheets that described the study and eligibility criteria. Eligible participants were invited to attend a 60–90-minute interview conducted via zoom or phone. With their consent, interviews were audio-recorded to ensure accurate reporting of their responses. As a token of appreciation for their time and contribution, participants were mailed a $50 gift card a few days after completing the interview.

Procedure and materials

The study protocol was reviewed and approved by the Institutional Review Board office at Kansas State University (IRB-12256). Recruitment materials including flyers and fact sheets were designed with the study's email address, allowing prospective participants to contact the

research team directly. Prospective participants were screened for eligibility, and informed consent was obtained through an online survey distributed via Qualtrics (Qualtrics XM, Provo, UT, USA).

Individual interviews were conducted between May and June 2025. A semi-structured interview protocol was developed based on the Health Belief model (HBM) and the phenomenological approach (Table 3.1). The protocol was pretested with ten individuals living with AGS who were not part of the main study, to improve question clarity. The final interview questions were open-ended and based on three constructs of the HBM: perceived susceptibility, perceived severity, and perceived barriers [31].

Table 3.1 Interview protocol

Questions
To explore participant environmental risk/exposure, and onset of AGS:
How long have you lived in your town for? What outdoor activities do you enjoy participating in? Probe: what do you for fun? Do you remember finding a tick on yourself? Can you describe the day/week's events leading up to the discovery of a tick/s? Are you able to give an estimate of the time in between finding the tick and when your symptoms started? Probe: When is the first time you remember being bitten by a tick after working/being outside? How did you first become aware that you might have AGS? Probe: What symptoms or reactions did you experience that led you to suspect Alpha-Gal Syndrome?
To explore dietary habits/ changes and Management strategies:

Can you describe your typical eating habits and diet before you began experiencing Alpha-Gal Syndrome?

Probe: How often did you consume red meat, dairy, or other animal products in your diet before experiencing symptoms of Alpha-Gal Syndrome?

Are there particular foods, medications, cosmetics or products that you used before experiencing AGS that you can no longer use?

Since experiencing AGS, what specific adjustments to your diet have you made?

Probe: Are there any particular foods or alternative protein sources that have helped you maintain a nutritionally balanced eating plan?

Have you found suitable alternatives or substitutes for foods that you can no longer consume? Can you share some examples?

Probe: Which alternative ingredients or products have you discovered that effectively replace red meat/mammalian products in your favorite recipes?

Have you consulted healthcare professionals to help manage your dietary needs with AGS?

Probe: What specific advice or recommendations have healthcare professionals provided to help you manage your AGS and maintain a nutritionally balanced diet?

To explore the social /emotional aspects of living with AGS, and coping strategies:

How do you handle situations such as dining out or attending social gatherings where it may be challenging to avoid foods that may trigger your AGS symptoms?

Probe: What strategies or precautions do you take when eating at restaurants or social events to ensure your meals are free of Alpha-Gal or related allergens?

Have you experienced any emotional or social challenges related to dietary restrictions?

What type of information or resources would be most beneficial and urgent in managing your Alpha-Gal Syndrome?

Probe: Are there particular aspects of Alpha-Gal Syndrome, such as dietary management, symptom monitoring, or treatment options, where you feel more information is needed?

Each interview lasted up to 90 minutes or until all the questions had been addressed. Participant demographic data was collected through the same Qualtrics survey used for screening and consent. Two researchers conducted the interviews via Zoom and phone, following the same protocol developed. All interviews were audio-recorded to ensure accurate reporting of participants' responses. The study is reported in partial accordance with the Consolidated criteria for reporting qualitative research (COREQ) checklist [32].

Coding and analysis

The audio recordings were saved as m4a files for qualitative analysis, and transcriptions were automatically generated via Zoom. Audio recordings were stored securely on password-protected computers with only authorized members of the research team having access to these files. Qualitative data was analyzed using thematic analysis. Transcripts generated were reviewed and manually cleaned to ensure accuracy and completeness before being imported into NVivo (version 15; QSR International, 2025), a qualitative data analysis computer software. NVivo facilitated coding and organization of the data into initial themes. A reflexive thematic analysis approach, developed by Braun and Clarke [33], and interpreted through a phenomenological lens guided the analytical process, which involved six phases: becoming familiar with data, generating initial codes, developing themes, reviewing and refining themes, defining and naming themes, and eventually reporting the findings [33]. Reflexive thematic analysis as described by Byrne [34] was chosen for its flexibility and emphasis on the researcher's active role in identifying and interpreting patterns of meaning across qualitative datasets.

Results

The study involved 30 adult participants (11 men and 19 women), the majority of whom were 48 years or older (70%). Most identified as white (97%) and non-Latino/Hispanic (97%). A significant portion (67%) held a bachelor's or graduate degree, and nearly half (47%) reported a household income of $100,000 or more (Table 2.2). All the respondents resided in the eastern part of Kansas, with more than half (57%) coming from Crawford, Riley, Shawnee, Reno, Johnson, Wilson and Douglas counties. The average duration of residence in participants' current town was 26.7 years (SD= 17.7).

Table 3.2 Demographic **c**haracteristics of study participants

Variable	**Statistic**
N	30
Age (years), n (%)	
18-29	2 (7)
30-47	7 (23)
48-59	11 (37)
60+	10 (33)
Female, *n* (%)	19 (63)
Race *n* (%)	
White	29 (97)
Two or more races	11 (3)
Ethnicity *n* (%)	
Non-Latino/Hispanic	29 (97)
Latino/ Hispanic	1 (3)
Education, *n* (%)	
High school or equivalent	2 (7)
Some degree but no degree	4 (13)
Associate degree	4 (13)
Bachelor's	9 (30)
Graduate degree	11 (37)
Household income n (%)	
Less than $ 20,000	2 (7)
$20,000-39,999	3 (10)
$40,000-59,999	2 (7)
$60,000-79,999	3 (10)
$80,000-99,999	6 (20)

100,000 or more	14 (46)
Length of time spent in current town (years)	
Mean (Standard deviation)	26.7 (17.7)
Minimum, maximum	1, 69

Note: Percentages are rounded to the nearest whole number and may not total 100% due to rounding. Calculations are based on the number of valid (non-missing) responses.

Ninety percent (90%) of the participants had received a formal diagnosis of AGS, though only 30% were currently receiving some form of treatment (Table 3.3). The most commonly reported treatments included Xolair, Benadryl, and acupuncture. Nearly half (47%) had experienced AGS symptoms for more than five years.

Most respondents (80%) reported that AGS had significantly impacted their financial situation: 67% reported increased medical expenses, 80% reported additional costs related to lifestyle changes (such as food and other adjustments), and 30% reported reduced ability to work (Table 3.3).

Only four respondents had other family members also living with AGS, while majority (83%) reported no other family members with the condition (table 3.3). The most commonly reported secondary health challenges were insect allergies (33%) and other food allergies (30%).

Most participants (43%) reported sensitivity to meat, dairy and meat vapors (Table 3.3). Beef was the most frequently cited trigger for allergic reactions followed by pork and game meat. Other non-typical food triggers reported were carrageenan, dietary supplements, black licorice and sugar processed with bone char. Non-food triggers were also commonly reported and included gelatin or glycerin-containing food products, gel-cap medications and various cosmetic products. Other personal care and household products such as shampoos, soaps, toothpaste, laundry detergents, and make-up products were also reported as potential triggers. A majority of

participants (57%) reported experiencing reactions or AGS-related symptoms within 2 to 6 hours of exposure. The most frequently reported symptoms were itching (77%) and hives (73%).

Table 3.3 Summary of participant characteristics

Characteristic	Statistic
	n (%)
Received formal AGS diagnosis	26 (90)
Currently receiving treatment for AGS	9 (30)
Length of time when you have had AGS-related symptoms	
More than 5 years	14 (47)
3-5 years	6 (20)
Financially impacted by AGS (Yes)	24 (80)
Increased medical costs	20 (67)
Additional costs related to lifestyle changes	24 (80)
Reduced ability to work	9 (30)
Other family members with AGS	
Spouse	2 (7)
Siblings	1 (3)
Children	1(3)
None	25 (83)
Other health challenges besides AGS*	
Other food allergies	9 (30)
Pet allergies	7 (23)
Insect allergies	10 (33)
Lactose intolerance	4 (13)
Soy allergies	2 (7)
Autoimmune disorders	4 (13)
Diabetes	3 (10)
Obesity	1 (3)
Cardiovascular disease	2 (7)
Extent of AGS-related sensitivity	
I am not able to eat any meat or dairy products, and cooked meat vapors affect me	13 (43)
I am not able to eat any meat or dairy products	6 (20)
I am not able to eat meat products, but I can eat dairy products	8 (27)
I can endure low levels of meat products	1 (3)
I can endure low levels of dairy products	1 (3)
Onset of AGS symptoms after following meat or dairy consumption	
Less than 1-2 hours	6 (20)
Between 2-6 hours	17 (57)
After 6 hours or more	5 (17)
Most common AGS symptoms*	

Itching	23 (77)
Hives	22 (73)
Abdominal pain	19 (63)
Diarrhea	18 (60)
Top mammalian-based products causing the most sensitivity*	
Beef	27 (90)
Pork	26 (87)
Game meat	20 (67)
Gelatin/glycerin-containing food products	20 (67)
Lard/tallow	20 (67)
Gel-cap medications	18 (60)
Milk	18 (60)

Note: Percentages are rounded to the nearest whole number and may not total 100% due to rounding. Calculations are based on the number of valid (non-missing) responses. *Participants could select more than one option; therefore, percentages may total more than 100%.

From the thematic analysis, six key themes emerged reflecting the lived experiences of people living with AGS: [1] exposure risk and context [2] symptom experience and diagnosis [3] dietary changes and challenges [4] navigating food substitutions [5] social, emotional and daily life impact; and [6] healthcare system and support needs. Each theme was explored in detail with corresponding subthemes, and illustrative participant quotes are provided to highlight key insights (Table 3.4)

Exposure risk and Context

This theme comprised of factors that increase participants' risk of tick exposure including recreational, occupational and community outdoor activities, as well as the context in which these exposures occurred. Recreational activities mentioned included hiking, hunting, fishing, gardening, horseback riding and outdoor sports such as golf and pickleball. Occupational exposures were related to Kansas' strong agricultural presence. Several participants worked in farming and livestock management and therefore spent a significant amount of time outdoors increasing their exposure to tick bites. For instance, one participant shared, "*I live on a farm. We*

are outside all the time, we raise fallow deer, so I have animals brushing up against me all the time that can have ticks on them" (ID 04*).* Another noted, "a *lot of my work also requires me to be outside quite a bit. I'm a field crop entomologist."* (ID 08). Additional occupational activities contributing to exposure included photography and wood working, with one participant explaining, *"I have a photography business, and I like to do photography for fun too. My husband has a woodworking business…" (*ID 03).

Social and community contexts also contributed to elevated risk. Activities connecting local groups such as scouting and future farmers of America (FFA) brought people outdoors. One medical officer described their involvement, "*I do a lot of work for the scouts providing medical services at various camps… Teaching wilderness medicine."* (ID 05). Another participant shared, "*we fish, camp, do 4-H and FFA. Sports. We're outside a lot. We garden and have cows."* (ID 16). Overall, participants daily activities and social engagements often revolved around outdoor environments which increased their potential for tick exposure.

A significant number of respondents distinctly remembered specific tick encounters and were able to estimate the time between tick bite and onset of symptoms. These recollections often involved noticing a tick in an unusual location or specifically identifying the lone star tick. One participant shared their encounter with a lone star tick *"Because I grew up in Northeast Kansas, I distinctly remember pulling a tick off of me and going, that's really strange, why does this tick have a big white dot on it?"* (ID 04). Another shared a recollection related to their job, *"I worked at a grain elevator last summer in Salina. One day specifically, we were cleaning off the railroad tracks getting ready for a train to come in. That was the day I found a tick in my armpit"* (ID 12).

Others could not pinpoint the exact tick bite but noted frequent tick contact, such as one participant who shared, *"I don't remember exactly when I was bitten, but I know I got into a seed*

tick nest. I had like 200 of them on me, probably late April," (ID 09), while another who was also uncertain stated, *"Yes, I've had… lots and lots of tick bites, uh, in my lifetime, and I don't know specifically which one."* (ID 15). Some reported long-term exposure to tick bites as one participant shared, "*I've had numerous ticks my whole life, I mean, even as a child... In the last 20 to 30 years, they're definitely more prevalent."* (ID 23).

Symptom experience and diagnosis

This theme captures accounts of how and when participants first became aware of AGS symptoms and their experiences in seeking AGS diagnosis. For many, symptoms appeared several weeks to a few months after a suspected tick bite. One participant recalled, "*Within a month or so, between realizing I might have been bitten by a tick, and then having those symptoms"* (ID 20), while another shared, *"I think it was a couple months' time. I started getting symptoms in August of 2019, which was severe hives, by November, I was 90% covered in hives"* (ID 04). A few described longer durations before symptom onset, such as, *"I was bitten in April, and I didn't start becoming symptomatic until October."* (ID 05).

For most, the commonest symptoms were related to gastrointestinal issues often occurring shortly after consuming or exposure to mammalian products. Participants described several reactions including diarrhea, nausea, stomach ache, vomiting, and cramping. One shared, *"My son experiences vomiting, diarrhea, stomach ache, and headache within 30 minutes of consuming mammalian products, I have stomach aches and sometimes diarrhea"* (ID 16). Another recounted "d*iarrhea, stomach cramps, pain, sweating, later, I got blisters all throughout my mouth. I started clearing my throat and coughing."* (ID 21). Additional symptoms included itching, hives, rashes, coughing, sweating, difficulty breathing, and in some cases more unusual reactions such as heart palpitations, low blood pressure, joint pain, dizziness, fatigue, anxiety and hypersomnia. One

participant noted, *"I had hives and itching after eating bacon, that was my first-time experiencing hives."* (ID 06), while another shared, "*I had a rash initially. About two weeks later, I experienced nausea, GI symptoms, and cramping."* (ID 02).

Several participants reported experiencing delays in receiving a correct diagnosis, often occurring after being misdiagnosed or being told their symptoms were unrelated. One participant described the prolonged process: "*it took six and a half months to get into a specialist, and when I was actually tested, it came back negative, I hopped around to four or five different specialists... later I was told by my new allergist that the negative test was due to steroid use"* (ID 04). Another described a misdiagnosis: "*When I was nursing, I got a lot of stomach issues, a lot of gas, cramping, and a lot of migraines. They told me it was irritable bowel syndrome. They sent me to different specialists, who ran tests that cost me like $5,000 worth of blood work."* (ID 28). For some the delay was even longer, as one participant shared, *"I Kept getting sick after supper like 4 to 6 hours later, I would wake up violently sick. Well, I couldn't get any air in. I was trying to vomit, and my throat was kind of shutting down, Doctors were telling me I was fine, everything was fine. It took 3 years to get proper diagnosis."* (ID 13).

In several cases, participants themselves or their family members ultimately identified AGS as the possible cause of their symptoms. This self-directed research often played a crucial role in obtaining correct diagnosis. One participant shared, *"every time I ate cheese burgers; I would get sick with migraines and diarrhea. I went to the doctor, and they tested me for Lyme's disease only. she didn't have a clue, so I did my own diagnosis by checking things on the internet."* (ID 29). Others described how spouses or friends helped identify the cause of their suffering: *"My wife just started Googling it, and so the next time we're in the ER, she let the doctors know to check for it."* (ID 13), while another shared, *"a friend saw an article about a tick-related illness and sent*

it to me. I read it and thought this is exactly what I've been experiencing." (ID 02). These narratives highlighted the often delayed and complex road to correct AGS diagnosis underscoring both the variability in symptom presentation and the key role played by patients in the process.

Dietary changes and challenges

This theme encompassed participants' dietary habits before and after AGS diagnosis, and the ongoing challenges of managing mammalian product avoidance while navigating dietary restrictions. Prior to diagnosis, many participants reported a high consumption of mammalian meat and dairy, often tied to farming, hunting, and other Kansas cultural norms. These diets typically included meat and dairy multiple times a day. For example, one respondent shared, *"Typical farmer diet: Meat, potatoes, vegetables, salads, and milk, and cheese. Consumed meat and dairy three times a day."* (ID 11). Another shared, *"I had red meat every meal, three times a day."* (ID 04). Others noted similar habits: "*We raised cows, so lots of beef. My husband worked on a pig farm, so beef and pork were regular staples."* (ID 16), and *"I consumed meat and dairy every day."* (ID 22).

Some participants described moderate or infrequent consumption of meat and dairy which amounted to a couple of times a week rather than daily. One participant shared, *I didn't eat meat every day, but a fair amount of meat. I grew up on a farm and its typical to have a quarter of beef and half of a pig in my freezer, and so I would eat beef and pork probably two to three times a week."* (ID 15). Others reported more infrequent consumption often for health or personal reasons. One said, "*My typical eating habits are mostly vegetarian, So meat was once or twice a month. I'm mostly plant-based diet"* (ID 30), while another shared, *"I've always eaten healthy, we ate a lot of seafood and chicken, and rarely had beef, more fruits and vegetables"* (ID 27).

Following diagnosis all participants reported eliminating mammalian meat from their diet, and many also removed dairy and mammalian byproducts. Several adopted plant-based or some version of vegetarian diets. One participant shared, *"Complete removal of mammalian products, byproducts, Dairy."* (D 04), while another said, *"I avoid all mammalian products. I mainly eat chicken, salmon, shrimp, eggs, and occasionally turkey. I've switched to vegan cheeses and sour cream."* (ID 08). Others described a gradual elimination process, eventually moving toward full plant-based eating: *"I started with removing red meat, then dairy, carrageenan, and sugar filtered through bone char. Eventually, I transitioned to a vegan diet."* (ID 02). Some switched to vegan protein sources and meat alternatives: *"I cut out all mammalian meat and anything with gelatin or dairy. I switched to plant-based protein; I buy vegan versions of a lot of things now."* (ID 17).

In addition to food-related changes, some participants also reported having to deal with non-food exposures to mammalian-based products. These included medications, personal care items, and household products. One participant discovered, "*after symptoms began, I found out I couldn't take medications in gel capsules, like ibuprofen."* (ID 12). Others recounted reactions to everyday products: *"I completely cut out all makeup, lotions, hand soap, I had to be really, really careful about. I moved to ultra-sensitive laundry detergent."* (ID 04). A couple of participants reported heightened sensitivity to airborne exposures including meat fumes and hidden ingredients, "*some reactions happened due to things I didn't realize had mammal in them, such as airborne meat vapors or hidden ingredients."* (ID 03). These accounts revealed the dietary and lifestyle adjustments AGS requires, and the complexity of identifying and navigating avoidance of mammalian products and byproducts in both expected and unexpected sources.

Navigating food substitutions

This theme captured how participants adapted their diets after AGS diagnosis, specifically the strategies they employed to meet their nutritional needs while avoiding mammalian products. Several participants reported experimenting with plant-based or vegetarian diets as a way to feel safe and reduce risk of accidental exposure or cross-contamination. These substitutions included plant-based meat alternatives, dairy-alternatives and ingredient swaps in recipes.

For some participants, these adjustments were successful as one shared, "*I use Beyond Meat for recipes that used to call for ground beef. I also found a vegan cheese coconut milk-based yogurt, Light life brand for hot dogs. It's not exactly the same, but close enough" (ID* 18). Another said, *"black bean burgers, and Don Lee Farms chicken patties, chickpeas and eggs also help, and I eat a lot of protein-rich plant options.* (ID 02). Others mentioned using various combinations of plant-based proteins, nuts and plant-based milk drinks. "*We've tried some plant-based proteins, like chorizo, where plant-based milk drinks, protein drinks. I eat a lot of nuts."* (ID 13).

However, reactions to plant-based alternatives were mixed. Some participants expressed frustration with the taste, texture or cost of plant-based options. As one participant shared, *"I mean black bean burgers were fine. I was extremely disappointed by the taste as well as the price"* (ID 04). Another said, *I have a Vegan butter. Not found a suitable substitute for bacon yet. I make zoodles, Noodles made out of zucchini."* (ID 22). There were also concerns about the highly processed nature of some of the commercial plant-based meat substitutes. "I *have tried Impossible Burger, and it was actually really good. Rebel cheese and Miyoko's mozzarella. Plant-based alternatives are more processed than the real thing."* (ID 14).

Some participants chose not to explore plant-based meat alternatives at all. Instead, they chose familiar protein sources that they could safely consume. As one said, "*I haven't really*

explored many alternatives beyond whey protein, chicken, and fish." (ID 10), Another shared, *"I have been okay with chicken, turkey, fish. I love seafood anyway. I haven't really gone out searching."* (ID 05). Others completely avoided substitutes stating the sensory experience of plan-based substitutes did not come close to the real thing. *"I haven't found anything that replaces a juicy ribeye. I haven't tried Beyond Meat or Impossible Burgers"* (ID 11). Another shared, *"Nothing tastes like real meat. I don't like vegan diets."* (ID 19).

Overall participants' approaches to food substitutions varied from being eager to experiment to complete avoidance. The decision to incorporate substitutions was influenced by not only dietary needs and AGS safety concerns, but also personal preferences, cost, and personal attachments to meat.

Social, Emotional and Daily life impact

This theme highlighted the often-over-looked psychosocial burden of AGS, particularly in the context of social gatherings, dining out and the psychological stress of navigating daily life while avoiding mammalian products and cross contamination. Participants described a wide range of strategies they employed to maintain safety while still trying to engage in social and professional settings that have food involved.

When dining out or attending social events, many respondents took practical steps to reduce their risk of exposure and cross-contamination. These included researching restaurants and their menus ahead of time, calling ahead to ask questions, and clearly communicating their allergy to restaurant staff. "*If I know ahead of time at a restaurant, most of them are online, you can read the menu, and I don't have any trouble speaking… speaking up and asking questions,"* shared one participant (ID 02). Another added, *"I try to look at the restaurant menu ahead of time, and call*

the restaurant and ask questions, and then when I'm at the restaurant, I tell them I have an allergy" (ID 16).

Some participants chose to carry their own food to social events to ensure their safety. One participant noted, "I t*ake my own food"* (ID 05). Other participants opted for menu items they felt confident were safe. "*I get nachos somewhere, I get chicken. I just order stuff that I know I won't have a reaction to"* (ID 27), and another shared *"Whenever I go out to eat, I always try and get something breaded so I try to order something where it's not going to get cross-contaminated with the meat."* (ID 14). Additional precautions included informing wait staff directly or using written cards to explain the allergy. *"Alerting the wait staff to avoid cross-contamination."* (ID 07) and another echoed this, *"I carry little cards with me. When we're eating out, that explain to the wait staff and to the kitchen staff what I have."* (ID 12). Some mentioned always carrying an EpiPen in case of accidental exposure, *"I always have an EpiPen in case something does mess up."* (ID 14).

A significant number of respondents resorted to withdrawing from social events altogether due to fear of exposure or previous negative experiences. "*I avoid new restaurants unless I've verified ingredients,"* (ID 09), and *"I avoid certain restaurants due to past reactions,"* (ID 06). One participant explained, *"I'm not big in social gatherings anyway. I tend to avoid them, or just avoid eating, it's got me depressed. Frustrated"* (ID 15). A couple of others had high sensitivity to airborne vapors which made social events impossible: *"I have not been in a restaurant since I got the allergy, I would love to go in a restaurant, but I have fume reactions"* (ID 19).

The emotional toll of avoiding social gatherings was a recurring theme. Participants reported a range of feelings including fear, anxiety, isolation and grief. "*It's very hard. I've had airborne reactions at basketball games due to concessions. We've stopped eating out for the most part"* (ID 04). Another shared, *"Social gatherings at work are more challenging. I try to avoid*

these gatherings or eat at my desk." (ID 11). The psychological burden was echoed in sentiments such as *"It scares me to eat out, because they don't take it seriously."* (ID 29), and *"definitely, it's isolating."* (ID 10). For some, what used to be an enjoyable activity became a source of stress, *"social dining is stressful, and I no longer enjoy eating out."* (ID 09).

Healthcare system and support needs

This theme captured participants' experiences with the healthcare system both before and after receiving an AGS diagnosis, highlighting significant provider knowledge gaps, barriers to effective health care and lack of support within traditional healthcare channels. Respondents frequently expressed frustration over the lack of or limited awareness and understanding of AGS among healthcare providers, including primary care physicians, specialists and nutrition specialists/dietitians, forcing them to self-educate, self-manage and self-advocate.

Participants consistently reported a lack of awareness and limited knowledge about AGS among both primary healthcare providers and specialists. The absence of knowledge often led to delays in receiving correct diagnosis and in some cases resulted in harmful medical advice. One participant explained, *"I was aware of it because my brother had had it for years, I contacted my doctor and told him what I thought I had. He wasn't familiar, so I did the research."* (ID 06). Others narrated similar experiences: *"Had severe abdominal upset after eating red meat; diarrhea and vomiting. I asked my doctor, and she had no idea in 2021* (ID 30). Some felt it was up to them to educate their health care providers, *"I've dealt with my physician, and she had never heard of it, and I educated her on it. I've had two allergists that I wouldn't give you a nickel for. They were terrible. One told me to go eat a cheeseburger because my numbers were too low, and I didn't have it, and I'd be just fine."* (ID 11). Another participant shared, *"I've had to educate healthcare professionals about AGS, especially about animal-based ingredients in medications like aspirin,*

gel caps, and sedatives." (ID 08). Many expressed a lack of trust in their providers' knowledge and understanding of AGS, "*I haven't received any specific advice or guidance from healthcare professionals"* (ID 10); *"We went to an allergist, but the allergist didn't really seem to understand much about alpha gal; I felt like I knew more after a few weeks of learning about it than the allergist."* (ID 17).

Some reported encountering resistance or misinformation from healthcare providers. One respondent shared, *"I've even had medical professionals try to administer medications with mammal in them during anaphylaxis."* (ID 03). Another described a distressing experience with a surgical team, *"I had to stand my ground with a doctor about not using Pitocin. My surgeon and anesthesiologist collaborated with me to find safe ingredients for a procedure, to verify safe medications."* (ID 21).

As a result of these experiences, many participants turned to alternative sources for guidance and support. Online communities emerged as crucial resources for individuals as one participant shared, "*I've learned more from online communities than from doctors."* (ID 19). *"I rely more on online groups and people going through the same thing than I do on medical advice."* (ID 09). Some took matters into their own hands rather than rely on the healthcare system: *"I now self-manage through online groups and my own research"* (ID 02); "*All my research and management have been self-directed."* (ID 10); and *"Most learning has been through my own research. I advocate for myself because many medical professionals aren't aware of AGS ingredients in medications or products"* (ID 08).

The nutritional implications of AGS were a recurring source of concern among participants, exacerbated by the lack of informed dietary support from nutrition/dietetics professionals. Some struggled to obtain safe supplements as one respondent shared, "*Supplements*

were nearly impossible to find that were safe, because almost all of them came in a gel cap" (ID 04). Another shared about her frustration with a dietitian who lacked basic knowledge about the condition*, "I saw a dietitian at Levine, but she wasn't familiar with AGS, so her advice wasn't very helpful. I try to eat enough calories and carbs but still don't eat much due to fear of reactions,"* (ID 12). Participants expressed a need for practical informed nutrition guidance tailored to AGS-specific dietary restrictions.

Participant Recommendations

Participants proposed several strategies to address the shortcomings of the healthcare system and the broader society in responding to AGS.

The most salient recommendation was for increased healthcare provider education. Many expressed concerns about the fact that AGS remained overlooked in medical training and professional development for healthcare providers. *"Provider education is the most important. People need to be able to get proper medical care without being told outdated or incorrect information."* (ID 03). Another said, *"I think there's a big gap in awareness among medical professionals. It's alarming how many don't know that mammalian ingredients are used in common medications like aspirin, sedatives, and IV solutions"* (ID 08). Another added, *"Healthcare providers need more education. It's not just another allergy, this can be life-threatening."* (ID 05). Many emphasized the need for systemic inclusion of AGS information in hospital systems and medical databases, *"It needs to be on the computer systems in the hospitals. "(*ID 01).

Participants also highlighted the importance of transparency in both food and non-food product labelling. Several pointed out the prevalence of mammalian-derived ingredients that were mislabeled or listed under vague and unclear names in everyday products. *"More transparency in*

food labeling. People don't realize how many ingredients are animal derived." (ID 02). One participant shared an incident: *"I was eating turkey jerky and went into anaphylaxis the next morning. When I called up the supplier who informed me the jerky was produced in the same plant as the beef and pork jerky, and they didn't put it on the packaging."* (ID 14).

Several respondents advocated for government intervention to improve safety and access to AGS information. For instance, *"The USDA should declare beef an allergen, so labeling becomes easier for people with AGS."* (ID 05). Others called for evidence-based resources, "*A list of safe foods and medications would be really helpful."* (ID 09). *"Access to information about how to safely eat, what products are safe, and how to manage airborne reactions is critical."* (ID 03). Some called for further investigation into the long-term impact of AGS, *"I would like more clarity on the long-term effects of AGS, especially non-symptomatic impacts like potential cardiac issues"* (ID 10).

Participants expressed a strong desire for further research, "*More awareness and research, especially with ingredients like "natural flavors," sugars, and animal-derived supplements. I'd like clearer guidelines."* (ID 02*).* There were also concerns about hidden sources of exposure, *"Research of what goes into stuff, stuff that you wouldn't even think that had to have animal product in them. Something as simple as laundry detergent was making me sick for like 3 years and I didn't know"* (ID 13). Others requested for more resources such as AGS-friendly cookbooks, and guidelines for cross-contamination: *"Resources like an alpha-gal cookbook would have been essential, more research done into alpha-gal and Mast Cell Activation System"* (ID 04*);* and *"I wish there was a clearer list of safe and unsafe foods, especially for processed stuff." (ID 19).*

Overall, participants depicted a healthcare system largely unprepared to support individuals suffering from this condition.

Table 3.4 Identified Themes, Subthemes, and representative quotes derived from participant interviews

Theme	Sub-theme	Representative quote
1. Exposure risk and context	1.1 Recreational outdoor activities	"Hiking, going to the lake, playing outdoor sports, lawn work, gardening, and especially golf and pickleball." (ID 02) "Hunting, fishing, anything you can imagine outside, I would love to do. Same, anything outdoors." (ID 12) "I do a lot of hiking, birdwatching, and gardening. I am an outside person. What I do for fun is go outside." (ID 30) "I garden, do outdoor sports, bike, hike. I used to ride horseback. I play pickleball and spend a lot of time outdoors." (ID 18)
	1.2 Work-based outdoor activities	"My husband and I farm and raise livestock. We camp. I garden. Just about anything I want to do, really." (ID 11) "I live on a farm. We are outside all the time, we raise fallow deer, so I have animals brushing up against me all the time that can have ticks on them" (ID 04) "A lot of my work also requires me to be outside quite a bit. I'm a field crop entomologist." (ID 08) "I'm outside a lot due to work, housekeeping. I'm outside all the time." (ID 14) "I live on a horse-breeding farm and show horses" (ID 29)
	1.3 Social/community-based outdoor activities	"Doing stuff with the scouts. I am actually a medical officer. I do a lot of work for the scouts providing medical services at various camps… Teaching wilderness medicine." (ID 05) "We fish, camp, do 4-H and FFA. Sports. We're outside a lot. We garden and have cows." (ID 16) "Gardening, hiking, camping, watching sporting events, spending time with grandkids, going to live music, comedy clubs, the zoo, and with family and friends." (ID 27)
	1.4 Context of exposure	"I remember a particular tick bite when I ended up going to Mayo Clinic, where I was treated in urgent care." (ID 10) "Yes. I got into a seed tick nest. I had around 200 ticks on me while hiking in Lawrence, Kansas." (ID 02)

	"Yes, I do. I distinctly do, because I grew up in Northeast Kansas. And I distinctly remember pulling a tick off of me and going, that's really strange, why does this tick have a big white dot on it?" (ID 04) "I was working in my yard. I came in the house and found a tick between my toes. That was the only tick I had that year, so I'm sure that's where it came from." (ID 06) "I am a videographer, photographer; I was out on a photo shoot of a machine in a field…and I found the tick at about four o'clock when I arrived home because I was going to take a shower. I'd been out in the field." (ID 18) "It was in Fort Leonard Wood in Missouri, so when I got bit, when I pulled the tick off, I put it in a Ziploc bag, and I saw the white dot on the back." (ID 03) "I don't remember exactly when I was bitten, but I know I got into a seed tick nest. I had like 200 of them on me, probably late April." (ID 09) "Yes, I've had… lots and lots of tick bites, uh, in my lifetime, and I don't know specifically which one." (ID 15) "I've had numerous ticks my whole life, I mean, even as a child... In the last 20 to 30 years, they're definitely more prevalent." (ID 23)
	"I worked at a grain elevator last summer in Salina. One day specifically, we were cleaning off the railroad tracks getting ready for a train to come in. That was the day I found a tick in my armpit" (ID 12) "We were mushroom hunting in the middle of summer…" (ID 21) "We were constantly having ticks just playing in the front yard, we live in the middle of a tick haven with deer running on the property" (ID 21)

2. **Symptom experience and Diagnosis**	2.1 Symptom onset	“Within a month or so, between realizing I might have been bitten by a tick, and then having those symptoms” (ID 20) “I was bitten in April, and I didn't start becoming symptomatic until October.” (ID 05) “I’d guess it was maybe two or three weeks between the tick bite and the symptoms.” (ID 06) “It was probably just about a month after that I woke up ill in the middle of the night after eating meatloaf” (ID 07) “I think it was a couple months' time. I started getting symptoms in August of 2019, which was severe hives. By November, I was 90% covered in hives” (ID 04) “It was about two months later when the symptoms really kicked in” (ID 09)
	2.2 Symptoms prompting diagnosis	“I had a rash initially. About two weeks later, I experienced nausea, GI symptoms, and cramping.” (ID 02) “I had Hives and itching after eating bacon, that was my first-time experiencing hives.” (ID 06) “My son experiences vomiting, diarrhea, stomach ache, and headache within 30 minutes of consuming mammalian products, I have stomach aches and sometimes diarrhea” (ID 16) “Diarrhea, stomach cramps, pain, sweating. Later, I got blisters all throughout my mouth. I started clearing my throat and coughing.” (ID 21) “Coughing, diarrhea 24 hours after exposure that lasts for about 3 days.” (ID 11)
	2.3 Delayed/misdiagnosis	“It took six and a half months to get into a specialist, and when I was actually tested, it came back negative, I hopped around to 4 or 5 different specialists... Later I was told by my new allergist that the negative test was due to steroid use” (ID 04) “Kept getting sick after supper like 4 to 6 hours later, I would wake up violently sick. Well, I couldn't get any air in. I was trying to vomit, and my throat was kind of shutting down, Doctors were telling me I was fine, everything was fine. It took 3 years to get proper diagnosis.” (ID 13) “When I was nursing, I got a lot of stomach issues, a lot of gas, cramping, and a lot of migraines. They told me it was irritable bowel syndrome. They sent me to different specialists, who ran tests that cost me like $5,000 worth of blood work.” (ID 28)

	2.4 Patient-led diagnosis	“My wife just started Googling it, and so the next time we're in the ER, she let the doctors know to check for it.” (ID 13) “Every time I ate cheese burgers, I would get sick with migraines and diarrhea. I went to the doctor, and they tested me for Lyme's disease only. she didn't have a clue, so I did my own diagnosis by checking things on the internet.” (ID 29) “A friend saw an article about a tick-related illness and sent it to me. I read it and thought this is exactly what I’ve been experiencing.” (ID 02)
3. **Dietary changes and challenges**	3.1 Pre-diagnosis dietary patterns	“We ate a lot of venison and beef and pork since we have a ranch.” (ID 17) “Consumed meat and dairy every day” (ID 29) “Our family are hunters, so we would eat a lot of venison, we ate a lot of beef” (ID 20) “We raised cows, so lots of beef. My husband worked on a pig farm, so beef and pork were regular staples.” (ID 16) “I consumed meat and dairy every day.” (ID 22) “I ate steak, hamburgers, pork chops, bacon, anything I wanted, all week. I had a steak night every week. I ate red meat regularly.” (ID 12) “I had red meat every meal, three times a day.” (ID 04) “Typical farmer diet: Meat, potatoes, vegetables, salads, and milk, and cheese. Consumed meat and dairy three times a day.” (ID 11)
	3.2 Moderate consumption	“I didn't eat meat every day, but a fair amount of meat. I grew up on a farm and its typical to have a quarter of beef and half of a pig in my freezer, and so I would eat beef and pork probably two to three times a week.” (ID 15) “Maybe once or twice a week we had red meat. Other nights were chicken and fish and salads.” (ID 21) “I consumed beef regularly but less often than chicken or fish, maybe once a week.” (ID 10)

	3.3 Low consumption	“My typical eating habits are mostly vegetarian, So meat was once or twice a month. I'm mostly plant-based diet” (ID 30) “I didn't eat much beef. but I did eat quite a bit of dairy. I had gone on a diet back in 2012, mainly vegetarian anyway” (ID 18) “I've always eaten healthy, we ate a lot of seafood and chicken, and rarely had beef, more fruits and vegetables” (ID 27)
	3.4 post-diagnosis eliminations	“I never had another piece of meat. I'll use ground turkey. I can buy a salmon patty. I can buy frozen chicken patty” (ID 01) “I started with removing red meat, then dairy, carrageenan, and sugar filtered through bone char. Eventually, I transitioned to a vegan diet.” (ID 02) “I eliminated everything from our home because of how sensitive I got. We converted recipes to be safe, I eliminated all mammal products. I stopped eating things like marshmallows, gummy worms, and food with gelatin. I also removed all mammal byproducts from the house because I became very sensitive even airborne exposure could trigger a reaction.” (ID 03) “Complete removal of mammalian products, byproducts, Dairy.” (ID 04) “I avoid all mammalian products. I mainly eat chicken, salmon, shrimp, eggs, and occasionally turkey. I’ve switched to vegan cheeses and sour cream.” (ID 08) “No beef, pork, or mammal-based products. I use dairy alternatives like oat milk and coconut yogurt.” (ID 14) “I'm vegan, but I eat turkey and some fish. Fish has to be wild caught. Farmed fish is fed mammalian byproducts” (ID 16) “I've gone totally, Vegan, except for the chicken and fish, fish and fowl.” (ID 25) “I just don't cook with any meat, cheese or milk anymore. We eat a lot of vegetables” (ID 11) “I cut out all mammalian meat and anything with gelatin or dairy. I switched to plant-based protein; I buy vegan versions of a lot of things now.” (ID 17) “I eat a lot of chicken and rice now. I don’t eat as much or as often. I try to eat enough calories and carbs but still don’t eat much due to fear of reactions.” (ID 12)

		"I've eliminated red meat, since I was already mostly vegetarian, I didn't make any other changes." "Just staying away from ground beef or a hamburger when I go out is basically it" (ID 28)
	3.5 Non-food mammalian exposure	"After symptoms began, I found out I couldn't take medications in gel capsules, like ibuprofen." (ID 12) "Some reactions happened due to things I didn't realize had mammal in them, such as airborne meat vapors or hidden ingredients." (ID 03) "I completely cut out all makeup, lotions, hand soap, I had to be really, really careful about. I moved to ultra-sensitive laundry detergent." (ID 04)
4. **Navigating food substitutions**	4.1 Plant-based alternatives	"We've made a lot of substitutions. My family challenges themselves to convert regular recipes into something I can eat. My son bakes gluten-free, dairy-free apple pie. (ID 03) "I mean like black bean burgers were fine. I was extremely disappointed by the taste as well as the price" (ID 04) "We've tried some plant-based proteins, like chorizo, where plant-based milk drinks, protein drinks. I eat a lot of nuts." (ID 13) "Have tried Impossible Burger, and it was actually really good. Rebel cheese and Miyoko's mozzarella. Plant-based alternatives are more processed than the real thing." (ID 14) "I use Beyond Meat for recipes that used to call for ground beef. I also found a vegan cheese coconut milk-based yogurt, Light life brand for hot dogs. It's not exactly the same, but close enough" (ID 18) "I have a Vegan butter. Not found a suitable substitute for bacon yet. I make zoodles, Noodles made out of zucchini." (ID 22) "My normal plant-based beans, legumes diet keeps me good." (ID 24) "Just adapt your cooking a little bit. I kind of made up a little sandwich spread that's made out of Garbanzos." (ID 01) "Black bean burgers, and Don Lee Farms chicken patties, chickpeas and eggs also help, and I eat a lot of protein-rich plant options. (ID 02)

	4.2 Limited or no substitutions	“I have been okay with chicken, turkey, fish. I love seafood anyway. I haven’t really gone out searching.” (ID 05) “I haven’t really explored many alternatives beyond whey protein, chicken, and fish. “(ID 10) “I haven’t found anything that replaces a juicy ribeye. I haven’t tried Beyond Meat or Impossible Burgers” (ID 11) “Nothing tastes like real meat. I don’t like vegan diets.” (ID 19)
5. **Social, Emotional and daily life impact**	5.1 Dining out strategies	“If I know ahead of time at restaurant, most of them are online, you can read the menu, and I don't have any trouble speaking… speaking up and asking questions” (ID 02) “Take my own food” (ID 05) “I usually don’t eat much when I go out unless I know it’s safe. I’ll eat before or bring something with me” (ID 10) “Alerting the wait staff to avoid cross-contamination.” (ID 07) “I carry little cards with me. When we're eating out, that… that explain to the wait staff and to the kitchen staff what I have.” (ID 12) “Whenever I go out to eat, I always try and get something breaded, so I try to order something where it's not going to get cross-contaminated with the meat.” (ID 14) “I try to look at the restaurant menu ahead of time, and call the restaurant and ask questions, and then when I'm at the restaurant, I tell them I have an allergy” (ID 16) “I get nachos somewhere, I get chicken. I just order stuff that I know I won't have a reaction to” (ID 27) “I always have an EpiPen in case something does mess up.” (ID 14)
	5.2 Social avoidance	“I avoid certain restaurants due to past reactions.” (ID 06) “I avoid new restaurants unless I’ve verified ingredients.” (ID 09) “I'm not big in social gatherings anyway. So, I tend to avoid them, or just avoid eating It's got me depressed. Frustrated” (ID 15) “And I have not been in a restaurant since I got the allergy … I would love to go in a restaurant, but I have fume reactions” (ID 19) “I don't partake in any of the food.” (ID 26)

	5.3 Emotional Impact	“It’s very hard. I’ve had airborne reactions at basketball games due to concessions. We’ve stopped eating out for the most part” (ID 04) “Social gatherings at work are more challenging. I try to avoid these gatherings or eat at my desk.” (ID 11) “It scares me to eat out, because they don't take it seriously.” (ID 29) “There’s frustration around filtered water, sugar, meat vapors” (ID 22) “Definitely. It’s isolating.” (ID 10) “Social dining is stressful, and I no longer enjoy eating out.” (ID 09)
6. **Healthcare system and support needs**	6.1 Health provider knowledge gaps	“I was aware of it because my brother had had it for years, I contacted my doctor and told him what I thought I had. He wasn’t familiar, so I did the research.” (ID 06) “Had severe abdominal upset after eating red meat, diarrhea and vomiting. I asked my doctor, and she had no idea in 2021. Later in 2022, she said let's test for alpha-gal.” (ID 30) “I've dealt with my physician, and she had never heard of it, and I educated her on it. I've had two allergists that I wouldn't give you a nickel for. They were terrible. One told me to go eat a cheeseburger because my numbers were too low, and I didn't have it, and I'd be just fine.” (ID 11) “I’ve even had medical professionals try to administer medications with mammal in them during anaphylaxis.” (ID 03)
		“I saw a few doctors, but none were helpful. They didn’t understand AGS.” (ID 02) “Many providers don’t know anything about AGS. My current provider only knows what I’ve taught him.” (ID 03) “I’ve had to educate healthcare professionals about AGS, especially about animal-based ingredients in medications like aspirin, gel caps, and sedatives.” (ID 08) “Yes, but most doctors don’t really know what to do. I’ve had to teach my doctor a lot about it.” (ID 09) “I haven’t received any specific advice or guidance from healthcare professionals” (ID 10) “she's a good doctor and everything, I just honestly don't think she knew a whole lot about it; didn't even tell me about the soaps, or everyday products. The wife actually just did the whole research and actually told me what I can and can't have.” (ID 13) “We went to an allergist, but the allergist didn't really seem to understand much about alpha gal; I felt like I knew more after a few weeks of learning about it than the allergist.” (ID 17)

		"I've learned more from online communities than from doctors." (ID 19) "I had to stand my ground with a doctor about not using Pitocin. My surgeon and anesthesiologist collaborated with me to find safe ingredients for a procedure, to verify safe medications." (ID 21)
	6.2 Self-management	"I started using MyChart" (ID 01) "I now self-manage through online groups and my own research" (ID 02) "Most learning has been through my own research. I advocate for myself because many medical professionals aren't aware of AGS ingredients in medications or products" (ID 08) "I rely more on online groups and people going through the same thing than I do on medical advice." (ID 09) "All my research and management have been self-directed." (ID 10) "We continue to monitor symptoms and dietary needs, but much of the learning has come from personal research." (ID 16)
	6.3 Gaps in nutrition support	"Supplements were nearly impossible to find that were safe, because almost all of them came in a gel cap" (ID 04) "I saw a dietitian at Levine, but she wasn't familiar with AGS, so her advice wasn't very helpful." (ID 12)
	6.4 Recommendations for improved awareness, labelling and policy	"Provider education is the most important. People need to be able to get proper medical care without being told outdated or incorrect information." (ID 03) "Healthcare providers need more education. It's not just another allergy, this can be life-threatening." (ID 05) "I think there's a big gap in awareness among medical professionals. It's alarming how many don't know that mammalian ingredients are used in common medications like aspirin, sedatives, and IV solutions" (ID 08) "More awareness in the medical community. Sometimes even the doctors don't know what's safe, even nurses, haven't heard of Alpha-gal." (ID 09) "It needs to be on the computer systems in the hospitals. "(ID 01)

	“More transparency in food labeling. People don’t realize how many ingredients are animal derived.” (ID 02) “The USDA should declare beef an allergen, so labeling becomes easier for people with AGS.” (ID 05)
	“More awareness and research, especially with ingredients like “natural flavors,” sugars, and animal-derived supplements. I’d like clearer guidelines.” (ID 02) “Access to information about how to safely eat, what products are safe, and how to manage airborne reactions is critical.” (ID 03) “Resources like an alpha-gal cookbook would have been essential, more research done into if alpha-gal and Mast Cell Activation System” (ID 04) “A list of safe foods and medications would be really helpful.” (ID 09) “I would like more clarity on the long-term effects of AGS, especially non-symptomatic impacts like potential cardiac issues” (ID 10) “I'd like to get rid of it, I'd like information to not have it anymore.” (ID 11) “Research of what goes into stuff, stuff that you wouldn't even think that had to have animal product in them. Something as simple as laundry detergent was making me sick for like 3 years and I didn't know” (ID 13) “All resources e.g., cross-contamination concerns” (ID 15) “Treatment options, even management.” (ID 14) “I wish there was a clearer list of safe and unsafe foods, especially for processed stuff.” (ID 19) “Push for labeling or have accurate numbers of how many people are actually dealing with this” (ID 13) “I was eating turkey jerky and went into anaphylaxis the next morning. When I called up the supplier who informed me the jerky was produced in the same plant as the beef and pork jerky, and they didn't put it on the packaging.” (ID 14) “Maybe getting a push to USDA to actually declare beef as an Allergen.” (ID 03)

Figure 3.1 Word cloud presentation of participant recommendations

Discussion

This study explored the lived experiences of Kansans living with AGS using thematic analysis which yielded six themes: [1] exposure risk and context [2] symptom experience and diagnosis [3] dietary changes and challenges [4] navigating food substitutions [5] social, emotional and daily life impact; and [6] healthcare system and support needs. These themes reflect how AGS affects individuals physically, emotionally, socially, and overall quality of life. While other studies have focused on the pathogenesis and pathophysiology of AGS this study adds depth to the understanding of AGS as a lived condition [6,35,36].

Participants' narratives revealed that geographical location along with both occupational and recreational/social activities, played a significant role in increasing their exposure to ticks as shown by previous studies [37]. Daily life activities including hobbies and economic activities served as routes to tick contact. Most participants resided in rural parts of Kansas and had resigned themselves to regarding tick encounters as normal given how their livelihood and normal life were intertwined with outdoor life.

The main recommendation for AGS prevention is avoiding tick-infested areas [6,38]. Additional recommendations include appropriate clothing and sprays [39]. However, the context of exposure revealed by this study highlights a broader public health issue for rural states like Kansas. That is, states where people's livelihoods and cultural identities are intertwined with outdoor life, and therefore the traditional prevention advice may not be tenable.

Many respondents described the AGS diagnostic journey as long and convoluted, often marked by disbelief, dismissal and lack of awareness among healthcare providers. Participants frequently reported spending months and in some cases, years seeking answers while enduring debilitating symptoms including anaphylaxis which can be life-threatening. Misdiagnoses such as

urticaria and irritable bowel syndrome were also common and have been reported elsewhere [6, 40,41]. Others reported negative AGS test results despite continued symptoms which further prolonged correct AGS diagnosis and treatment.

These findings align with research done by Flaherty and colleagues [42]. They conducted a survey of 28 adults diagnosed with AGS and found that the average time between the onset of symptoms and an accurate diagnosis was approximately 5.25 years. Notably, majority of their study participants as well as those in our study reported identifying AGS through non-traditional means such as online resources and personal research rather than through direct medical channels. This further highlights the vital role patient self-advocacy plays in the diagnostic process for AGS. However, although patient self-advocacy and management is commendable, it does place a significant burden on patients and their families, especially if they are not technologically savvy, have limited access to digital resources or lack the health-literacy skills required to successfully navigate complex medical literature. Dr. Scott Commins, a leading AGS expert, recommends increasing awareness of AGS among healthcare providers as a strategy for improving both AGS diagnosis and management [6].

The most profound impact of AGS for participants were dietary disruptions and adaptations required to safely manage the condition, and this has been reported elsewhere [43]. Majority of study participants described previous ability to regularly consume dairy and meat-rich diets, often multiple times a day. Eating habits were also tied to Kansas' cultural norms and traditions such as farming and hunting. After AGS diagnosis, participants had to eliminate not only mammalian meat but also dairy and several other mammalian byproducts. This painted AGS as not only a medical diagnosis but also as a departure from familiar and long held dietary patterns and traditions. Some participants reported adopting plant-based diets or integrating plant-based meat and dairy

alternatives to avoid cross contamination. These substitutions included commercial plant-based meat products, and dairy free alternatives such as vegan cheeses and butters. However, many expressed frustration and disappointment with the taste, texture, high cost and highly processed nature of these products as has been reported by previous research [44-46]. Others rejected substitutes altogether because they did not match the sensory attributes of meat and dairy products as shown by studies comparing meat and plant-based meat alternatives [47,48].

The variation in adaptation strategies may necessitate dietitians and nutritionists to provide individualized and patient-centered dietary guidance rather than a one-size fits-all approach. The European Academy of allergy and clinical Immunology (EAACI) 2024 recommendations similarly emphasize the importance of personalized management plans for individuals living with allergies in the context of AGS [49, 50]. These findings underscore the importance of access to dietitians and nutritionists who are well-trained in both allergy management and plant-based nutrition, as it relates to AGS.

The complexity of AGS extended beyond food, as participants described reactions to non-food items such as medications, cosmetics, personal care items, and even airborne meat vapors or fumes. These experiences revealed the constant vigilance required to manage AGS safely, moreover many did not have professional support or clear guidance. This heightened state of alertness affected social, emotional and psychological aspects of their lives. Many described feelings of anxiety, frustration, fear, and vigilance in avoiding trace contaminants and less obvious sources of mammalian byproducts. Routine activities such as dining out and family/social gatherings required constant planning, vigilance and explanation, which led to emotional exhaustion and isolation. These findings highlight the significant yet often overlooked psychosocial burden of AGS as highlighted in prior research [43]. Additionally, the broader mental

health ramifications of food allergies have been well documented [51-55] providing context for understanding the emotional challenges faced by individuals living with AGS.

Participants described a wide range of strategies used to mitigate risk when dining out or attending social events which included researching restaurant menus online, calling restaurants ahead of time to clarify ingredients and inform staff of their allergies. The vigilance required reflects the excessive amount of planning required to engage in what would otherwise be routine social experiences. Some had to carry their own food or select particular menu items that were deemed safe while others went as far as carrying EpiPens during such visits as a form of self-protection. Concerns about anxiety when dining out among individuals living with food allergies have been documented elsewhere [56,57]. These concerns are supported by existing research highlighting the heightened risks associated with eating out for individuals with food allergies. For example, Pumphrey [58] reported that out of 200 cases of anaphylactic reactions in the UK, 25% occurred while dining out at restaurants. Similarly, Bock et al. [59] found that 65% of food-induced anaphylaxis incidents took place outside the home.

The 2024 guidelines from the European Academy of allergy and clinical Immunology (EAACI) include psychological support as part of their recommendations for the management of IgE-mediated food allergies [49]. Although AGS is not specifically mentioned in their report, the guidelines acknowledge the emotional and psychological burden associated with managing food allergies and recommend support from trained health care professionals as a way to alleviate distress and anxiety. In cases where psychological care is limited or unavailable, the guidelines suggest that healthcare providers step in to address the psychological impact. They recommend providing resources such as online or in-person support groups, remote consultations with health care providers, and educational materials or counseling sessions.

The healthcare system was another distressing factor as many participants perceived it to be ill-equipped to support individuals with AGS. Most reported widespread lack of provider knowledge regarding diagnosis, treatment and management of AGS. Many gave accounts of receiving misinformation or having their symptoms dismissed by their providers. Consequently, many felt the need to take on the role and burden of educating their healthcare providers, including correcting potentially harmful prescriptions. The lack of AGS awareness and limited knowledge among healthcare professionals has been reported in previous research [60,61].

In a large web-based study conducted by Carpenter and colleagues [12] in 2022, 1500 healthcare professionals were surveyed, including 1000 primary care physicians, 250 pediatricians, and 250 physician assistants and nurse practitioners. The results revealed: 42% of study respondents had never heard of AGS, and another 35% reported limited confidence in their ability to diagnose or manage patients with AGS. Only 5% of study respondents expressed confidence in their ability to diagnose and manage patients with AGS. Among the 58% who were aware of AGS, just 5% had knowledge of its etiology, appropriate testing and patient counseling needs. Nearly half of these providers (48%) did not know the correct AGS diagnostic tests to order for their patients, and one third were unsure how AGS was acquired.

Interestingly, the same study found that pediatricians tended to have higher knowledge scores, while number of years in practice did not significantly impact AGS knowledge. Notably their study also revealed an inverse relationship between provider knowledge of AGS, and the number of AGS cases they reported managing. In other words, the less providers knew about AGS including its etiology, testing and patient counseling, the more patients they claimed to be treating for it. This suggests that some of the healthcare providers may have incorrectly diagnosed AGS possibly based on symptoms or testing alone and consequently were prescribing unnecessary

dietary restrictions. Limited provider knowledge remains a significant barrier contributing to both delayed and missed diagnoses [6].

A direct consequence of limited provider knowledge was patient self-management. Study participants described relying on their own research, online platforms/communities and trial and error to manage their symptoms and avoid risks. Many turned to social media groups, and other online tools and social applications to navigate their condition rather than rely on medical advice. Compounding this problem were the gaps in nutrition and dietary support that many participants encountered. Despite dietary restrictions and adaptations being the hallmark of this condition, many nutrition professionals consulted by participants lacked adequate knowledge of AGS-specific needs or training in plant-based nutrition, a dietary approach adopted by many living with AGS. Several participants reported significant weight loss and upon testing, discovered nutrient deficiencies such as inadequate vitamin B12.

The Academy of Nutrition and Dietetics (the world's largest organization of food and nutrition professionals) has issued a position paper on vegetarian and plant-based diets. They recognize them as healthful and nutritionally adequate for all stages of the lifecycle including pregnancy, lactation, infancy, childhood, adolescence, and for athletes, when appropriately planned [62,63]. However, without careful planning, plant-based diets can increase risk of nutrient deficiencies, either due to insufficient intake or reduced bioavailability [64]. Nutrients of concern often include protein, vitamins, and minerals such as vitamin B12, vitamin D, iron, zinc, calcium, and omega-3 fatty acids. Moreover, plant-based foods such as legumes, nuts, seeds, and grains contain naturally occurring compounds known as anti-nutritional factors. These substances interfere with digestion and nutrient absorption potentially contributing to nutrient malabsorption

(due to phytates, tannins and oxalates), protein and carbohydrate maldigestion, gut dysfunction, inflammation, and even autoimmune responses [65-67].

Notably, the most commonly reported secondary health challenges were insect allergies and other food allergies. This finding aligns with a case-control study done by Taylor and colleagues [68] which reported that individuals living with AGS (cases) often had intrinsic factors that may have contributed to their susceptibility to AGS. Among these were a history of allergies, specifically, childhood insect allergies that took long to heal after being stung or bitten by insects. In addition, cases also tended to experience food allergies (besides red meat) during childhood and for most, these allergic reactions would require medical care in the form of urgent care or hospitalization.

Participants made several recommendations for improved provider education and systemic changes. Several suggested the integration of AGS into hospital electronic databases, and continuing professional development for healthcare professionals including dietitians and nutritionists. Others called for reform in the food industry particularly food labelling and accountability regarding hidden mammalian ingredients. Participants also called for more access to resources to support AGS management in the form of safe food and medication lists, better ingredient labeling laws, guidelines for providers and more investment in AGS research.

This study explores the lived experiences of individuals living with AGS in Kansas, highlighting critical gaps in healthcare provider preparedness, medical and nutritional support and the overall healthcare system. Delayed diagnoses and limited provider knowledge forced patients to self-advocate and rely on their research to safely manage the condition. Beyond the health-related challenges, the study highlighted the psychosocial burden of AGS including anxiety, isolation and the emotional toll of constant vigilance. These findings underscore the urgent need

for increased AGS education and awareness among healthcare professionals including physicians, dietitians and nutrition specialists. Additionally, psychosocial support should also be integrated into patient routine patient care to address the emotional and mental health challenges associated with living with this condition. As AGS becomes more prevalent, more public education, clearer food and drug labeling laws coupled with more focused research and surveillance, and systemic reforms will be needed to ensure people affected by this condition receive appropriate care and support to lead fulfilling lives.

One limitation of this study is reliance on self-reported accounts of AGS without seeking verification through clinical or medical records. This reliance on self-reporting introduces the possibility of misclassification.

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Chapter 4 - Decoding health professionals' attitudes and perceptions towards plant-based nutrition

This chapter is based on a manuscript published in the journal of *Nutrients* (2025). The study investigated healthcare professionals' attitudes and perceptions towards plant-based nutrition.

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Abstract

The ongoing obesity epidemic remains a significant public health challenge in the U.S. Nearly one-third of adults are overweight, and nearly half of the population (42.4%) are obese. These conditions, driven by poor and unsustainable diets, are major risk factors for several chronic diseases, including heart disease, which continues to be the leading cause of death in the country. This review aims to examine existing research on health care professionals' attitudes and perceptions of plant-based nutrition and explore how this knowledge can be utilized to increase health care professional support for people adopting plant-based diets (PBDs) when medically required as in AGS management and as an alternative to the standard American diet. PubMed and Web of Science databases were searched in April 2024. Out of the 151 articles identified, 27 were deemed eligible and included in the narrative review. Nine key themes were identified as major influences on the attitudes and behaviors of health professionals regarding PBDs. These themes were mapped with the domains of the Theoretical Domains Framework (TDF) to stratify key enablers and barriers to implementation of PBDs in routine care for patients. Key barriers to incorporating plant-based nutrition into routine care include time constraints, limited educational resources, insufficient skills, lack of multidisciplinary collaboration, and inadequate professional training. Access to evidence-based research summaries, clear guidelines, ongoing professional development, and other relevant educational resources were identified as facilitators of successfully integrating PBDs into everyday practice.

Keywords: plant-based diets; attitudes; health professionals; obesity

Background

Although obesity has been around for centuries, the obesity epidemic is a new phenomenon that continues to be an issue of public health concern in the US [1]. According to the National Institute of Health (NIH) [2], nearly one in three adults in the US are overweight, and nearly half the population (42.4%) is obese. Children are also grappling with obesity, with close to twenty percent (19.3%) of children aged two to nineteen years having obesity, despite intense focus on reducing childhood obesity [3]. In the last one hundred years, obesity has increased from 3.4% to 35%, a tenfold jump [4]. Overweight and obesity are risk factors for several other chronic diseases including diabetes, high blood pressure, stroke, certain cancers, and heart disease, which is America's number one killer [1,5]. Less commonly discussed but equally important are emerging chronic conditions such as Alpha-gal syndrome (AGS) that can result in long-term dietary restrictions. Both obesity-related and non-obesity related chronic conditions such as AGS have significant health and economic costs. According to the Center for Disease Control and Prevention (CDC), 90% of the country's 4.1 trillion-dollar annual health expenditure is spent on chronic and mental health conditions. Obesity alone costs America's health care system $ 173 billion annually [6].

The etiology of obesity is complex and multifaceted, comprising a complex interplay of genetic, metabolic, behavioral, environmental, and socioeconomic factors among others [7,8]. The World cancer research fund attributes obesity to two broad causes: lack of physical activity, and poor diets characterized by high consumption of processed foods (foods that have been altered from their natural state through various methods to enhance shelf life, flavor, texture, or convenience) and red meat, and very low intake of fruits and vegetables, whole grains and fiber [9]. Poor diets are also inextricably linked to the declining health of the planet by way of

degradation of natural resources, greenhouse gas emissions, and loss of biodiversity [10,11]. There is growing consensus that the standard American diet, which is high in processed foods, refined carbohydrates and added sugars, unhealthy fats, high fat dairy, and red meat, while low in fruits, vegetables, nuts and seeds, and whole grains, is unsustainable for promoting long-term human and planetary health [12,13].

Sustainable diets are defined by the Food and Agricultural Organization (FAO) as diets that promote all dimensions of an individual's health and wellbeing, have low environmental pressure and impact, are accessible, affordable, safe, and equitable, and are culturally acceptable [14]. Plant-based diets (PBDs) are generally defined as diets that maximize consumption of nutrient-dense whole plant foods and minimize intake of processed foods, oils and animal foods (including high-fat dairy products and eggs). In essence, they emphasize the intake of whole: grains, fruits, vegetables, seeds, nuts, beans, lentils, soybeans, and herbs and spices. PBDs support nutrition security and human health and are associated with reduced risk of most of the top ten leading causes of death in America [15-20]. They are similarly associated with reduced greenhouse gas emissions and environmental degradation; have low environmental pressure and impact and consequently promote environmental and ecological health [21-25]. PBDs are also associated with lower body weight and a decline in weight gain [15,26-30].

Current research underscores the benefits of PBDs, and several scientific and regulatory bodies have consistently recommended them. The Academy of Nutrition and Dietetics (the world's largest organization of food and nutrition professionals) has issued a position paper on vegetarian diets. They have been commended as being healthful and nutritionally adequate for all stages of the lifecycle including pregnancy, lactation, infancy, childhood, adolescence, and for athletes, when appropriately planned [31,32]. The American Institute for Cancer Research (AICR) has also

recommended PBDs as being protective against cancer [33]. Additionally, the 2020-2025 *Dietary Guidelines for Americans* like the previous guidelines (2015-2020) continue to recommend and highlight the benefits of plant-based eating patterns [34].

Despite the potential benefits of plant-based nutrition, its adoption in the USA remains low, with less than 10% of Americans following a PBD [35-37]. Encouraging the US population to transition from the standard American diet to adopt more minimally processed PBDs requires involvement of various public health stakeholders who are the gatekeepers of nutrition education. Dietitians and nutritionists are specifically trained in the application of food, nutrition, and dietetics to promote public health and wellbeing. However, studies show that dietetic practitioners have knowledge gaps and low self-efficacy regarding plant-based nutrition and are less likely to recommend PBDs to clients. A study done by Lea and associates [38] reported that although patients were willing to try PBDs in Europe, healthcare providers were less likely to recommend lifestyle modification (including adopting PBDs) as a form of disease management. They cited patients' unwillingness to adopt PBDs and lack of adequate information about plant-based nutrition as their reasons for not recommending plant-based nutrition to their clients. Contrarily, a study done by Morton and colleagues [39] revealed that 55% of patients were more willing to implement a PBD for three weeks if a nutritionist or dietitian recommended it.

The narrative review aims to explore and synthesize existing research on attitudes and perceptions of health professionals (including dietitians, nutritionists, physicians, nurses, and other health care professionals) towards PBDs. It also examines barriers and enablers influencing their incorporation of PBDs in routine patient care.

Plant-Based Diets

Plant-based diets generally emphasize consumption of whole grains, fruits, vegetables, nuts, legumes, and seeds, while minimizing processed foods, oils, and animal products [40,41]. There are several variations of PBDs including: lacto-vegetarian and ovo- vegetarian diets, lacto-ovo vegetarian diets, pesco-vegetarian diets, and vegan diets [11,42]. There are other diets related to PBDs such as the Mediterranean diet, and Dietary Approaches to stop Hypertension (DASH) diet which call for reduced consumption of meat and animal products [43-45]. Table 4.**1** below provides a breakdown of common PBDs.

Table 4.1 Definitions of plant-based diets

Diet	**Definition**
Vegetarian	Includes fruits, vegetables, grains, nuts, seeds, beans, pulses, dairy and/or eggs. Excludes meat and fish, dairy and/or eggs
Lacto-vegetarian	Includes fruits, vegetables, seeds, beans, pulses, grains, nuts, and dairy. Excludes meat, fish and eggs
Ovo-vegetarian	Includes fruits, vegetables, grains, nuts, seeds, beans, pulses and eggs. Excludes meat, fish and dairy
Lacto-ovo vegetarian	Includes fruits, vegetables, grains, nuts, seeds, beans, pulses, and dairy and eggs. Excludes meat and fish
Semi-vegetarian/flexitarian	Includes fruits, vegetables, grains, nuts, seeds, beans, pulses and fish, dairy, eggs and meat (on some but not all days of the week). Excludes restrictions on meat
Pollo vegetarian	Excludes red meats
Pescatarian (pesctarian, pesco-vegetarian, fish-eater	Includes fruits, vegetables, grains, nuts, seeds, beans, pulses and fish, dairy and eggs. Excludes meat
Vegan	Includes fruits, vegetables, grains, nuts, seeds, beans and pulses. Excludes all animal and animal-derived products such as honey etc.

Whole-foods vegan	Mainly whole plant foods (such as fresh fruits, vegetables, nuts, seeds and grains), with limited or no processed foods or products of animal origin. Also known as "Whole-foods plant-based diet"
Mediterranean diet	Moderate meat and dairy and emphasis on selected plant-based foods such as olive oil, olives, nuts and moderate red wine intake
Dietary approaches to stop hypertension (DASH) diet	Encourage fat-free/low-fat dairy instead of full-fat dairy products. Poultry and fish instead of red and processed meats. Limited sugar-sweetened foods and beverages and sodium
Planetary health diet	Moderate seafood, poultry and dairy (if included at all). Limit red meat, processed meat, added sugar, refined grains, starchy vegetables and highly processed foods
Nordic-style diet	Rich in fruits and berries, vegetables, rye, low-fat dairy products and fish. Emphasis on local foods

Role of Plant-Based Diets in reducing risk of Chronic Diseases

Cardiovascular disease

Cardiovascular disease (CVD) is the leading cause of morbidity and mortality and accounts for 32% of all deaths globally [46]. In 2022, 702,880 deaths (1 in 5) in the US were attributable to cardiovascular disease [47]. Cardiovascular disease refers to multiple disorders of the heart and blood vessels which include coronary artery disease, atherosclerosis, cerebrovascular disease, heart failure, congenital heart disease, rheumatic heart disease, peripheral arterial disease, deep vein thrombosis and pulmonary embolism among others. Heart attacks and strokes are typically sudden events, primarily caused by a blockage that disrupts blood flow to the heart and brain respectively. This is most commonly due to a build-up of fatty deposits on the inner walls of the blood vessels supplying these areas. [48,49].

Behavioral and lifestyle risk factors for cardiovascular disease (CVD) include poor dietary habits, lack of physical activity, smoking, and excessive alcohol consumption. These behaviors

often lead to high blood pressure, elevated blood glucose, high blood lipid levels, and obesity. Among these, high body mass index, high fasting plasma glucose and smoking are the leading risk factors for CVD [46,48]. Consequently, dietary intake and nutrition status are crucial in the prevention and management of cardiovascular risk factors. Evidence for the protective effect of PBDs in the prevention and management of cardiovascular disorders is derived from observational studies, prospective cohorts, randomized controlled clinical trials (RCTs), systematic reviews, and meta-analyses, as well as medical case reports [50]. The benefits of PBDs are not just due to the foods avoided but more importantly the food consumed.

Hypertension

Hypertension, also known as high blood pressure, is a significant, consistent, and independent risk factor for cardiovascular disease, heart failure, stroke, and kidney disease. It causes endothelial injury and dysfunction, which leads to atherosclerosis and cardiovascular impairment. As a key driver of CVD development and related mortality, hypertension is a crucial risk factor to manage [48-50]. Hypertension is defined by a systolic blood pressure greater than 120mmHg and a diastolic blood pressure greater than 80mmHg [49]. Observational studies suggest that hypertension is less common among individuals following PBDs than among those following western diets even after adjusting for sex, age, and BMI [51]. A study done by Borgi and colleagues [52] examined data from three prospective cohort studies of non-hypertensive individuals. These were the Nurses' Health study I (62,273 women), the Nurses' Health study II (88,831 women) and the Health Fellowship follow-up study (37,414 men). Their results showed that consumption of red meat and poultry was associated with increased risk of hypertension regardless of whole grain, vegetable, and fruit consumption.

A meta-analysis done by Lopez and associates [53] which included 11 clinical trials, and 983 participants revealed that PBDs reduced both systolic and diastolic blood pressure. Moreover, less restrictive PBDs were more effective than restrictive PBDs. In another meta-analysis involving 7 clinical trials (311 participants) and 32 observational studies (21,604 participants), consumption of vegetarian diets was associated with reduction in mean systolic and diastolic blood pressure compared with consumption of non-vegetarian diets [54]. A systematic review and meta-analysis of 41 RCTs (8416 participants) revealed PBDs (Mediterranean diet, DASH diet, Nordic diet, lacto-ovo vegetarian diet etc.) were associated with lower systolic and diastolic blood pressure. Like the previous meta-analysis, this study's results showed that restrictive PBDs such as the lacto-ovo vegetarian diet were as effective as the other less restrictive diets such as DASH and Nordic diet [55]. Most of these studies show that in addition to PBDs, there are other important factors such as calorie restriction, weight loss, lower dietary sodium, higher potassium and magnesium intake, and regular exercise, which are necessary for effective blood pressure management [51].

Hyperlipidemia

Elevated levels of LDL cholesterol, total cholesterol, and triglycerides in the blood can damage and impair endothelial cells, setting the stage for atherosclerosis [56]. High LDL and total cholesterol levels lead to the accumulation of cholesterol deposits (plaque) on the walls of arteries and other blood vessels, contributing to the hardening of the arteries (atherosclerosis). The gradual accumulation of plaque narrows the arteries, restricting the flow of oxygen-rich blood and increasing the risk of heart attacks and strokes [57]. Research shows individuals following PBDs have lower blood lipids and switching to PBDs may result in significant reduction in both LDL and total cholesterol levels [58-60]. There are several mechanisms by which PBDs are protective

against hyperlipidemia. First, PBDs are low in saturated fats and cholesterol whereas animal-based diets tend to be rich in both [50,51]. Secondly, healthy PBDs are rich in both mono and poly unsaturated fats (from sources like nuts, seeds, and their oils) which have been shown to lower blood cholesterol levels [61]. Third, dietary fiber in plant foods helps lower cholesterol by binding to bile salts and increasing the excretion of cholesterol from the body [50].

Obesity

Excess body weight, particularly abdominal (central) adiposity and related cardiometabolic risk factors such as insulin resistance, hypertension, and hyperlipidemia play a significant role in the development of CVD [50]. Overweight and obesity are defined based on body mass index (BMI) (kg/m^2). Overweight is defined by a BMI between 25-29.9 kg/m^2 and obesity by a BMI greater than 30 kg/m^2 (CDC, n.d.). Generally, individuals following PBDs tend to have lower body weight than those who do not. The weight management benefits of PBDs can be partly attributed to reduced intake of fat, energy, and animal protein, along with increased consumption of fiber, carbohydrates, fruits, whole grains, and vegetables [50]. In addition, PBDs are high in fiber which increases satiety, hence reducing caloric intake. The high fruit and vegetable intake associated with PBDs provides a rich source of inulin-like fructans, which can alter gut microbiota in ways that impact adiposity [50]. Inulin-type fructans have been shown to regulate the secretion of gastrointestinal peptides that play a role in appetite control. This process helps reduce appetite and increase feelings of fullness, ultimately supporting better weight management [62].

There are several observational studies from all over the world which provide supporting evidence that PBDs are associated with lower adiposity [63-70]. Fraser and colleagues [71] studied a subgroup of Black men and women from the Adventist Health Study 2, comparing the

BMIs of vegetarians and nonvegetarians after adjusting for factors such as age, gender, education, and physical activity. Their findings revealed a significant link between vegetarian dietary patterns and lower mean BMI and waist circumference, with nonvegetarians having higher BMI and waist circumference compared to vegetarians [71]. There are several RCTs examining the impact of PBDs on obesity [72-77]. A recent review which included 27 intervention trials (3361 participants), and 6 meta-analyses (9168 participants) reported that PBDs resulted in significant weight loss and improved metabolic outcomes. The study authors further recommended PBDs as a sustainable approach to long-term weight loss and weight loss maintenance [79].

Type 2 diabetes

Type 2 diabetes (T2D) is a chronic condition defined by insufficient insulin production or poor utilization of the insulin produced, leading to elevated blood glucose levels (hyperglycemia) [49]. High blood glucose levels, caused by the body's inability to properly utilize insulin produced by the pancreas, ultimately prevent cells from using the glucose circulating in the bloodstream. Hyperglycemia can result in various complications, including damage to the heart, blood vessels, nerves, kidneys, and eyes. Multiple studies indicate that PBDs may offer protective benefits in preventing T2D [51]. PBDs support weight management as plant-based foods are typically low in energy density and promote fullness and satiety. Studies examining the impact of PBDs on diabetic patients have shown significant improvements in fasting blood sugar and hemoglobin levels, with increased consumption of whole grains, legumes, vegetables, and fruits rich in dietary fiber and phytochemicals. Soluble fiber (oats and legumes) is especially effective in regulating blood sugar responses. Additionally, soluble fiber is fermented by gut bacteria to produce short-chain fatty acids, which help modulate glucose response, insulin signaling, and insulin sensitivity [49,72].

In the Adventist Health Study II, which followed 41,387 participants without diabetes over two years, vegetarians were found to have a significantly lower risk of developing T2D compared to regular meat eaters, even after adjusting for various confounding factors [81]. A study done by Satija and associates [82] followed three prospective cohort studies consisting of 69,949 and 90,239 women from the Nurses' health study and Nurses' health study II respectively, and 40,539 men from the health professional's follow-up study. Their results showed that PBDs that were low in animal foods were associated with 20% reduction in risk of type 2 diabetes. A similar study by Pan and colleagues [83], which included 26,357 men from the Health Professionals Follow-Up Study, along with 48,709 women from the Nurses' Health Study and 74,077 women from Nurses' Health Study II, found that consuming more than 0.5 servings of red meat per day over a four-year period was linked to a 48% higher risk of developing type 2 diabetes. Conversely, reducing red meat consumption by the same amount during the same period was associated with a 14% lower risk of the disease. A systematic review and meta-analysis involving nine RCTs and 664 participants revealed that PBDs significantly improved LDL-cholesterol and lowered fasting blood glucose levels [84].

Inflammation

Inflammation is a natural response that helps the body heal from infections, injuries, or harmful substances. However, chronic inflammation is a risk factor for various conditions, including cardiovascular disease, obesity, type 2 diabetes, cancer, neurodegenerative diseases, alcoholic liver disease, and chronic kidney disease. Research shows that certain nutrients can trigger inflammation, while a diet rich in plant-based foods such as fruits, vegetables, and whole grains, can help reduce postprandial inflammation [50,57]. Oxidative stress, which occurs when there is an imbalance between the production of reactive oxygen species and the body's ability to

neutralize them with antioxidants, can contribute to chronic inflammation, ultimately triggering the onset of many chronic diseases [50, 85, 86]. PBDs being rich in vegetables, fruits, whole grains, legumes, nuts, and seeds, offer a wide array of essential nutrients. These include vitamins C and E, beta-carotene, minerals like selenium, and a variety of phytochemicals, including flavonoids, carotenoids, terpenes, and alkaloids. These nutrients and compounds contribute to the diet's antioxidant and anti-inflammatory properties [87,88].

Research from large prospective studies such as the Nurses' Health study indicates that diets with higher pro-inflammatory potential are associated with increased blood vessel inflammation and increased risk of cardiovascular diseases. However, lowering the inflammatory potential of a diet such as by increasing the intake of antioxidant-rich foods like green leafy and cruciferous vegetables, whole grains, nuts, seeds, berries, citrus fruits, vegetables, and tea, while reducing pro-inflammatory foods like red meat and processed foods may help reduce the risk of cardiovascular disease [87-91]. A systematic review and meta-analysis of 95 prospective studies reported that fruit and vegetable intake was associated with reduced risk of cardiovascular disease, cancer and all-cause mortality [92].

Cancer

Cancer is the second leading cause of death in the United States and accounts for one in six deaths worldwide [93]. Worldwide, the most common cancers in men are lung, prostate, liver, and stomach cancer, while in women, the most prevalent cancers are breast, colorectal, lung, cervical, and thyroid cancer [94]. Cancer is an assortment of many diseases which result from uncontrolled cellular growth. Most cancers result from environmental and lifestyle factors though a small number of cancers are caused by inherited genes. Dietary changes have the potential to influence the epigenetic expression of genes, which could reduce cancer risk, even in those who

are genetically predisposed. Nutrition plays a critical role in regulating key cellular and molecular processes associated with cancer development. Modifiable diet and lifestyle factors that contribute to cancer risk include overweight and obesity, lack of physical activity, high consumption of dairy, red and processed meats, excessive alcohol intake, smoking, and low intake of plant-based foods such as whole grains, fruits, and vegetables [50, 95-97].

Research from observational studies indicates that PBDs have the potential to reduce the risk of common cancers [50,97]. Several prospective cohort studies have provided valuable insights into the link between diet and cancer. One notable example is the Adventist Health Study, which involved 34,192 California seventh-day Adventists. Their study showed colon and prostate cancer incidence was higher among nonvegetarians than among vegetarians; and regular meat consumers had a higher risk of bladder cancer [98]. The second Adventist Health Study involved 73,308 Seventh-day Adventist men and women and compared the relationship between vegetarian dietary patterns and all-cause and cause-specific mortality. The study results indicated vegetarian diets were associated with lower all-cause mortality and with some reductions in cause-specific mortality [66]. A systematic review and meta- analysis involving 7 cohort studies and 124,706 participants reported a 18% lower incidence of cancer among vegetarians than among regular meat consumers [99]. Currently, there are no published randomized controlled trials examining the relationship between PBDs and cancer however there are a couple of ongoing trials [99-103]. However, findings from other studies have been inconsistent, suggesting that factors beyond diet may also influence the relationship between diet and cancer. Additionally, the quality of a plant-based or vegetarian diet plays a significant role in this connection. Research has shown that plant-based diets consisting of unhealthy, highly processed and refined foods and unhealthy fats and added sugars, may increase the risk of certain cancers, such as colorectal cancer [104].

Chronic respiratory disease

Chronic respiratory diseases include chronic obstructive pulmonary disease (COPD), asthma, lung cancer and other lung diseases. COPDs (such as emphysema and chronic bronchitis) are the third leading cause of mortality globally. COPD is a long-term, multifactorial condition that is heavily influenced by genetic, environmental, and behavioral factors, such as poor diet and lack of physical activity, though smoking is the leading cause. Several studies highlight the potential role of plant-based diets (PBDs) and plant foods in reducing the risk of COPD and other lung diseases. The proposed mechanisms for this protective effect include the antioxidant and anti-inflammatory properties of plant foods such as nuts, seeds, legumes, fruits and vegetables [105]. A prospective study by Walda and colleagues (106), which analyzed 20-year COPD mortality data from five cohorts of middle-aged men across three European countries, found that a 100g increase in fruit consumption was linked to a 24% lower risk of COPD mortality after adjusting for factors such as smoking, age, and country. Similarly, a prospective study of 44,335 Swedish men [107] reported a significant inverse relationship between total fruit and vegetable intake and COPD risk, with each additional daily serving of fruits and vegetables reducing the risk by 8%. A Swedish case-control study also found that adherence to a Mediterranean diet was associated with a lower likelihood of developing COPD [108]. A systematic review and meta-analysis, which included 5 prospective cohort studies from the US and Sweden with a total of 289,952 participants, investigated the link between processed red meat consumption and COPD. The findings indicated a positive association, showing that each 50g weekly increase in processed red meat intake was linked to an 8% higher risk of developing COPD [109]. The proposed mechanism linking processed meats to COPD suggests that the nitrite preservatives in these meats may replicate the lung-damaging effects of nitrite by-products found in cigarette smoke [110].

Asthma is a chronic inflammatory condition marked by frequent episodes of airway narrowing and inflammation, leading to symptoms such as wheezing, shortness of breath, and coughing. [111,112]. The first phase of the International Study of Asthma and Allergies in Childhood (ISAAC) examined the prevalence and severity of asthma, rhino conjunctivitis, and eczema across diverse global populations to identify the factors that influence these conditions. The study was done between 1992 and 1997 and involved two groups of children aged 6-7 years and 13-14 years, with 3000 children in each age group. The study revealed that prevalence of these three conditions including asthma was positively associated with trans fatty acids and smoking but inversely associated with plant-based foods [113]. A comparable study involving the same study group found that adolescents living in regions where grains, vegetables, starchy foods, and nuts were commonly consumed were less likely to experience chronic symptoms of wheezing, atopic eczema, and allergic rhino conjunctivitis. [114]. A cross-sectional study of 99,574 women and 56,742 men from India, aged between 20 and 49 years found that individuals who consumed meat daily were more likely to suffer from asthma than those who did not, albeit the association was weak and only accounted for a small proportion of cases [115].

Chronic kidney disease

Chronic kidney disease (CKD) is a condition where the kidneys are damaged and unable to filter blood effectively. As a result, excess fluid and waste build up in the body, potentially leading to health issues like heart disease [116]. According to the CDC [116], about 35.5 million US adults have CKD, and 40% of people with reduced kidney function are not aware of having the condition. In the US, type 2 diabetes and high blood pressure are the leading causes of kidney failure. The heightened risk of cardiovascular disease associated with chronic kidney disease (CKD) stands as the primary driver of morbidity and mortality within the U.S. population,

underscoring the vital role kidneys play in sustaining optimal cardiovascular function. Most CKD cases are linked to nutritional factors and are largely preventable [117,118]. The Nurses' Health study initiated in 1972 had 121, 700 nurses aged between 30 and 55 years, as participants. Lin and colleagues [119] investigated how diet influenced microalbuminuria in people with well-preserved kidney function. Microalbuminuria is the presence of small amounts of albumin protein in the urine, which serves as an early sign of kidney damage. Their study identified three dietary factors animal protein, animal fat, and cholesterol that were associated with declining kidney function. However, no link was found between kidney function decline and plant-based protein or fat from plant sources. An observational study which explored the association between vegetarian diets and chronic kidney disease among 55,113 participants reported that there was a strong reduction in incidence of CKD among vegetarians compared to those who regularly ate meat [120].

Several short-term (less than 8 weeks) randomized clinical trials have demonstrated the benefits of plant protein in reducing CKD [121-123]. Liu and colleagues [124] conducted a longer six-month, double-blind, randomized, placebo-controlled clinical trial involving 270 participants to examine the long-term effects of soy protein on kidney function. They reported that six months of whole soy (plant protein) consumption modestly improved renal function in prehypertensive postmenopausal women with previously impaired kidney function. A recent systematic review [125] of 32 clinical trials examined the effect of plant-based protein on kidney function and chronic kidney disease outcomes in adults with stage 3-5 chronic kidney disease. The findings were inconsistent, with most of the included studies exhibiting poor research methods, leading to unreliable conclusions. As a result, the data synthesis and analysis were primarily based on a smaller subset of five studies that focused on changes in protein source. Of these, only one study reported a decrease in kidney function, while the remaining four showed no change. Further

research in form of randomized controlled trials is required to support evidence from observational studies.

Fatty liver disease

Fatty liver disease ranks among the top ten leading causes of death in the United States, accounting for approximately 4.5 million deaths annually [126]. Nonalcoholic fatty liver disease (NAFLD) is a condition characterized by the abnormal accumulation of fat within the liver in the absence of significant alcohol consumption [127]. NAFLD is the most common cause of fatty liver and is frequently comorbid with a range of metabolic disorders, including metabolic syndrome, obesity, type 2 diabetes, hypertension, hyperglycemia, and atherogenic dyslipidemia, an abnormal lipid profile marked by elevated triglycerides and reduced HDL cholesterol levels [49]. NAFLD is classified into two subtypes: nonalcoholic fatty liver (NAFL) and nonalcoholic steatohepatitis (NASH). Fat accumulation in the liver results from excessive caloric intake and dietary fat consumption. Frequent fast-food consumption including high consumption of meat and sugar-sweetened beverages have been implicated in NAFLD [128].

Adherence to the Mediterranean diet, which is abundant in vegetables, fruits, whole grains, nuts, seeds, and beans, has been linked in some studies to a reduction in the severity of nonalcoholic fatty liver disease (NAFLD) [129]. Ioannou and colleagues [130] analyzed part of the data from the first National Health and Nutrition Examination Survey (NHANES I), which tracked thousands of Americans over more than a decade. Their study included 9,221 adults aged 25-74 who showed no signs of cirrhosis or liver disease at the study's onset or during the first five years of follow-up. After 13.3 years, their findings indicated that a high dietary protein intake was associated with an increased risk of hospitalization or death due to cirrhosis or liver cancer. Conversely, individuals whose diets were rich in carbohydrates exhibited a lower risk after

adjusting for various potential confounders. The study also found that higher cholesterol consumption was linked to an elevated risk. A systematic review and meta-analysis, which included 26 randomized controlled trials and 3,037 participants, investigated the effectiveness and acceptability of a Mediterranean diet and calorie restriction for managing NAFLD. The findings revealed a dose-response relationship between the extent of calorie restriction and improvements in liver function and NAFLD activity. The Mediterranean diet was shown to have beneficial effects even without calorie restriction, suggesting it may improve NAFLD independently of weight loss. However, combining calorie restriction with the Mediterranean diet resulted in both improvements in NAFLD and weight loss [131]. A recent systematic review and meta-analysis of randomized controlled trials assessed the effects of a Mediterranean diet intervention on various markers, including liver enzymes, fibrosis, and intrahepatic fat, in a cohort of NAFLD patients. The analysis found that while the Mediterranean diet appeared to reduce liver stiffness and total cholesterol, its impact on liver enzymes was not statistically significant. These findings suggest that the Mediterranean diet may have the potential to improve key parameters associated with NAFLD severity, such as liver fibrosis and total cholesterol levels [132].

Brain disease

Stroke and Alzheimer's disease are among the most debilitating and fatal neurological disorders [133]. Both rank as leading causes of death in the United States, with stroke accounting for 17.5% of all deaths and remaining the primary cause of long-term disability. In contrast, Alzheimer's disease is the seventh leading cause of death, affecting an estimated 6.9 million Americans over the age of 65 [134]. Majority of strokes are ischemic strokes where blood flow to the brain is cut off depriving it of oxygen and killing the part supplied by the clogged artery. The other type of strokes are the hemorrhagic strokes which are caused when a blood vessel bursts and

bleeds into the brain [134]. Research shows that high fiber intake may reduce the risk of stroke [135]. Unprocessed whole plant foods are rich in fiber and animal foods have none. A systematic review and meta-analysis reported that a seven-gram increase in daily fiber intake was associated with a 7% reduction in risk of stroke [135]. The possible mechanism by which fiber protects against stroke is by regulating cholesterol and blood sugar levels which may reduce plaque in blood vessels [136]. Fiber also helps regulate blood pressure, reducing the risk of hemorrhagic strokes [137].

Theoretical Domains Framework (TDF)

The Theoretical Domains Framework (TDF) was developed for implementation of research to identify influences of health professionals' behavior in relation to implementation of evidence-based recommendations. The TDF integrates 33 theories of behavior and behavior change, and 128 key theoretical constructs related to behavior change into a single framework with 14 theoretical domains, which cover the main factors influencing practitioner clinical behavior and behavior change. The 14 domains include: knowledge (knowledge about a condition or scientific rationale), skills (competence/skill assessment), social/ professional role and identity (influence of societal and professional roles on behavior), beliefs about capabilities (self-efficacy/self-confidence to perform behavior), optimism, beliefs about consequences/anticipated outcomes/attitude, reinforcement, intentions, goals, memory, attention and decision processes, environmental context and resources (environmental constraints), social influences, emotion, and behavioral regulation. [138-141].

Materials and Methods

The methodology outlined by Arskey and O'Malley [142] was used, which includes identifying the research question, finding relevant research studies, study selection, compiling data, summarizing and reporting findings.

Research Question

This review seeks to explore an important research question: what factors serve as enablers and barriers for health care professionals regarding their recommendation of plant-based nutrition to their patients? By examining existing literature, this review will investigate the influences that encourage or hinder health care professionals in promoting plant-based nutrition as part of patient care.

Literature search

The literature search was conducted using the PubMed and Web of Science databases, selected for their extensive coverage of biomedical and clinical research, as well as their robust citation metrics and comprehensive indexing. These were accessed through Kansas State University. The search was done on April 18, 2024. To investigate attitudes and perceptions of health professionals, the search terms used included: [Attitude OR perception OR view OR opinion OR belief OR "Attitude of Health Personnel'] AND [Dietitian OR nutritionist] OR health professional OR Health Personnel] AND [Vegan OR vegetarian OR plant-based diet OR Mediterranean diet] OR DASH diet] OR "dietary approaches to stop hypertension Diet" OR "Plant-Based"]. All research articles published in English with at least one search term from each category were considered, and no filter was applied regarding year of publication.

Eligibility Criteria

Peer-reviewed studies in the English language available in full text were included. The articles included had to be investigating views, opinions, attitudes, or perceptions of health professionals towards any of the plant-based diets/terms used in the search terms. In case of interventions, the evaluation/assessment had to have been done prior to the intervention. Elimination criteria included: articles not written in English, commentaries or reviews, studies where only health professionals following a vegan or plant-based diet were involved, studies where intervention preceded assessment, and studies where subjects were not health professionals.

Data Profiling and Synthesis of Results

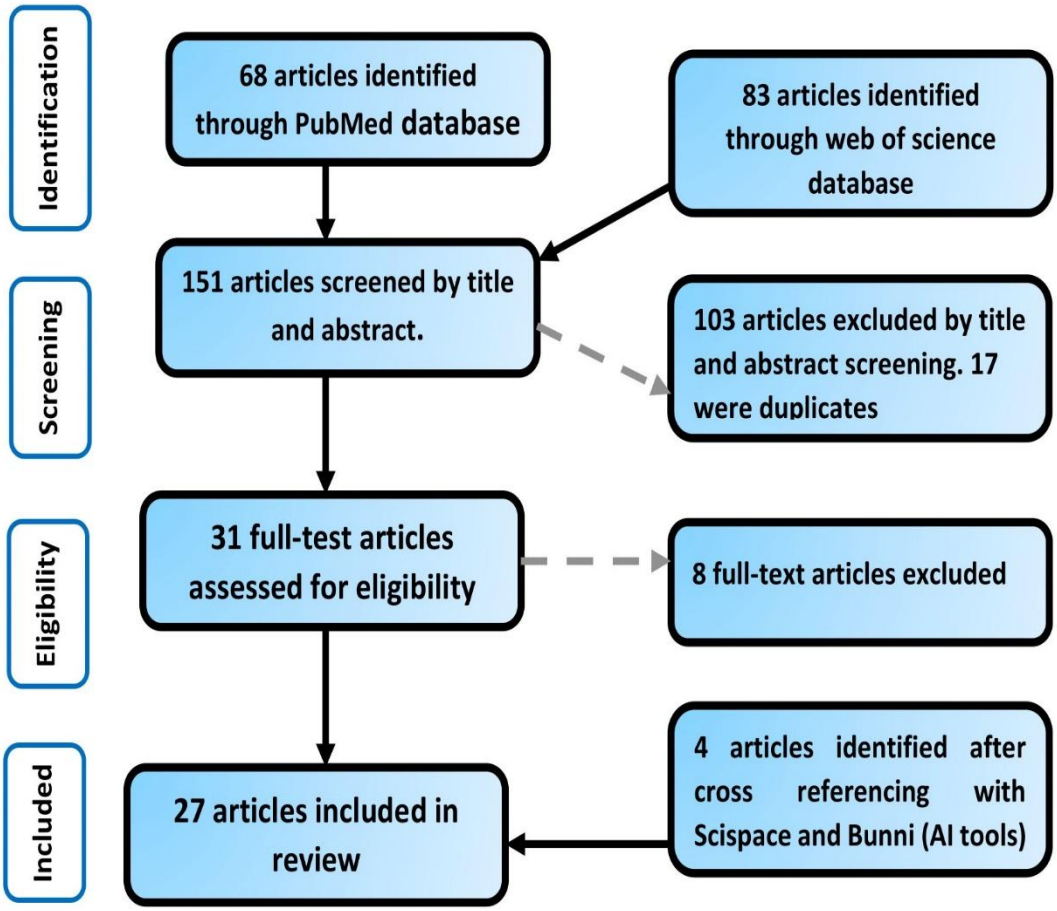
An Excel table was created to extract relevant data from the 27 articles including title, author, year of publication, country of origin, study design, key study objectives, sample size, methodology, and key findings. An inductive qualitative analysis approach was employed using an iterative process of coding and comparison across the 27 studies to identify key themes emerging from the articles which were related to health professionals' attitudes, perceptions, barriers, enablers, and behavioral practices in relation to PBDs. Data from each study was coded and analyzed in Microsoft Excel (2021, Microsoft Corp) for themes using thematic analysis [143]. Descriptive codes that captured key concepts related to the research objectives were created, and these initial codes were then refined and grouped into preliminary factors/themes. A cross-study comparison was conducted to validate and refine these preliminary factors/themes. Codes from individual studies were cross-referenced with those from other studies to identify consistent, overarching patterns.

This iterative process allowed for the synthesis of comprehensive themes reflecting the breadth and depth of findings across the 27 studies. Following the inductive analysis, a deductive approach was used to map and align identified themes with the domains of the Theoretical Domains Framework. Each theme was reviewed and aligned with a relevant TDF domain to stratify barriers and enablers influencing health professionals' attitudes and behavior toward implementing PBDs in routine care for patients.

Article search and selection

The initial search yielded 151 articles. This was narrowed down to 31 articles after title and abstract screening and elimination of 17 duplicate articles. After full article screening, eight articles were further excluded because they did not meet eligibility criteria. Cross referencing Artificial Intelligence (AI) tools, Scispace and Bunni yielded four more articles which brought the total number of articles used for the review to twenty-seven [144,145]. The flow of article selection is depicted in figure 4.1 below.

Figure 4.1 Flow diagram of review selection process from initial search to final number of included studies



Results

General Overview of Included Studies

All the articles were published between 2015 and 2024, except for one article which was published in 1999. Majority [62.9%] were published between 2020 and 2024. Twenty-three of the twenty-seven articles used questionnaires for data collection. Two used interviews exclusively and the other two used both interviews and questionnaires. The articles came from 12 countries, with most (14/27) articles coming from the USA (9/27) and Australia (5/27). Other countries were Canada (2/27), the UK (2/27), Spain (2/27), France (1/27), Peru (1/27), New Zealand (1/27), Israel (1/27), South Africa (1/27), Italy (1/27), and the Netherlands (1/27). Nine studies were conducted with only dietitians or nutritionists [146-154], eight included dietitians/nutritionists and various health professionals, and ten studies were conducted with health professionals not including dietitians or nutritionists. Details of characteristics pertaining to the articles are depicted in **Table 4**.2

General Overview of Health Professionals' Attitudes and Perceptions

Currently, there is a paucity of research investigating attitudes and perceptions of health professionals towards plant-based nutrition. PBDs were perceived favorably by health professionals except in 3 studies [155-157]. Reasons for these negative attitudes include association of PBDs with higher risk of nutrient deficiencies among pregnant women and among children [155,156], health professionals linking PBDs with eating disorders and consequently nutrient deficiencies among youth with eating disorders [157]. Positive attributes associated with PBDs included being healthy [158,159], management of chronic conditions such as chronic kidney disease, type 2 diabetes, and cardiovascular disease (CVD) among others [146, 148, 150, 160],

reducing risk of chronic co-morbidities, weight loss [161], being more environmentally sustainable [162] and others.

Table 4.2 Summary of articles included in the review with key characteristics.

Author, Year	Country	Study Design	Population and sample	Objective	Methodology	Key Findings
Stanford et al., 2022	Australia	Cross-sectional	N=35 renal dietitians completed online surveys, and 11 participated in in-depth interviews	Explore perspectives of renal dietitians regarding PBDs for chronic kidney disease (CKD) management, and evaluate their acceptability of a hypothetical plant-based dietary prescription	Exploratory Mixed methods: Short online questionnaire and in-depth semi-structured interview	Renal Dietitians perceived PBDs as beneficial to patients with CKD
Betz et al., 2022	USA	Cross-sectional	N=382 dietitians (154 physicians, 62 nurse practitioners, 32 fellows, 13 physician assistants, 14 other professionals)	Understand perspectives of nephrology professionals towards use of PBDs for treatment of CKD	Online questionnaire based on previous survey	Nephrology professionals believed PBDs were beneficial in management of CKD, but dietitians were more likely to be aware of the benefits of PBDs than other professionals
Fuller & Hill, 2022	UK	Cross-sectional	N=116 specialist eating disorder professionals, 90 general mental health and 186 other professionals	Investigate attitudes of healthcare professionals towards veganism	Self-reported questionnaire based on General eating habits and ATvegan questionnaires	All had positive views of veganism, but general mental health professionals had more positive attitudes than eating disorder specialists and other professionals

Bettinelli et al., 2019	Italy	Cross-sectional	140 nurses,135 pediatric nurses, 60 midwives, 43 health care support workers, 40 staff nurses	Assess knowledge of healthcare professionals regarding adoption of vegetarian diets from pregnancy through adolescence	Online questionnaire developed for the study and pre-tested	Clinicians had positive view of the Mediterranean diet (MD), though it was not routinely recommended due to limited knowledge, practice skills and training.
Hughes et al., 2014	USA	Cross-sectional	N=136 dietitians of which 124 were registered dietitians	Assess dietitians' perceptions of plant-based protein quality	Online questionnaire developed for the study and pre-tested	Dietitians had a positive attitude towards PBDs but knowledge about plant-based protein quality was limited
Moutou et al., 2021	UK	Cross-sectional	N=12 registered dietitians	Explore dietitians' views about advising on 5 dietary patterns (including MD and DASH diets) deemed effective for management of type 2 diabetes	Semi-structured interviews with short demographic questionnaires developed for the study.	Study participants considered the MD effective, but most had mixed responses about the DASH diet.
Mayr et al., 2022	Australia	Cross-sectional	N=57 clinicians (21 nurses, 19 doctors, 13 dietitians and 4 physiotherapists)	Explore multidisciplinary health care professionals' perspectives on recommending MD to patients with coronary heart disease and type 2 diabetes	Qualitative study with individual semi-structured interviews via telephone or face-to- face	The MD was not routinely recommended, clinicians had limited knowledge and practice skills regarding MD; barriers to recommending the MD were lack of education and training, and

						personal experience/interest
Meulenbroeks et al., 2021	Netherlands	Cross-sectional	N=411 (121 midwives, 179 obstetricians, and 111 dietitians)	Evaluate self-reported knowledge and advice given by Dutch obstetric caregivers and dietitians to pregnant women following PBDs	Online questionnaire developed based on focus group interviews	Both obstetricians and midwives reported limited knowledge about strict PBDs. Only 38.7% of dietitians felt they had enough knowledge to advise pregnant women on strict PBDs. They believed that women following a strict PBD during pregnancy were at a higher risk of nutrient deficiencies.

Mayr et al., 2022	Australia	Cross-sectional	N=14 (7 doctors, 3 nurses, 3 dietitians and 1 exercise physiologist)	Assess multidisciplinary clinicians' perspectives on whether the Mediterranean diet (MD) is recommended in routine management of non-alcoholic liver disease	Semi-structured individual phone and face-to-face interviews	The MD was seen as an evidence-based approach for enhancing diet quality, promoting weight loss, and reducing the risk of chronic co-morbidities. However, some doctors and nurses had limited knowledge of the specific literature supporting the benefits of following a MD.
Hawkins et al., 2019	USA	Cross-sectional	N= 205 nutrition and dietetics program directors	Investigate curricular practices in accredited dietetics programs and assess prevalence and perceived importance of vegetarian and vegan nutrition instruction	Online questionnaire developed for the study and pre-tested	Over 90% of program directors agreed that vegetarian nutrition should be taught, while 87% agreed that vegan nutrition should be taught. Program directors in northeastern programs had higher percentages of agreement than those in southern programs. 51% and 49% of the programs teach

						vegetarian and vegan nutrition, respectively.
Albertelli et al., 2024	France	Cross-sectional	N= 18 (14 dietitians, 3 physicians specialized in nutrition, and 1 psychiatrist)	Investigate healthcare professionals' subjective experience of vegetarianism in patients with eating disorders (ED)	Qualitative study with remotely administered semi- structured interviews via videoconferences and telephone.	Health professionals regarded vegetarianism as a restrictive approach and often linked it to eating disorders in patients. They were strongly opposed to veganism, citing the risk of severe nutritional deficiencies.

Mayr et al., 2020	Australia	Cross-sectional	N=182 dietitians who had practiced with at least one of the relevant chronic disease patient groups.	Evaluate the extent the MD is routinely recommended by dietitians to patients with chronic diseases.	Online questionnaire based on TDF	62%, 46%, and 39% of dietitians strongly agreed that there was enough evidence to support recommending MD to patients with CVD, type 2 diabetes, and non-alcoholic liver disease respectively. 48% strongly agreed that they were knowledgeable about the principles of MD, and 46% were confident in counseling patients about MD.
McHugh et al., 2019	New Zealand	Cross-sectional	N=41 (20 doctors, 13 nurses, 7 pharmacists, and 1 osteopath)	Investigate whether health professionals have sufficient nutrition education for their roles in health education and promotion, and whether their nutrition beliefs were consistent with current literature	Mixed methods including online de novo questionnaire and one focus group	PBDs were generally viewed as beneficial to health but deemed complicated. 43% of participants reported dissatisfaction with the amount of nutritional training received.

Olfert et al., 2020	USA	Descriptive case study	N= 29 health professionals, 15 currently practicing in cohort 1 and 14 aspiring health professionals in cohort 2 from various disciplines	Determine effectiveness of culinary medicine and MD to enhance nutritional knowledge, attitudes and self-efficacy of current and aspiring (student) health professionals	Online questionnaire developed but influenced by evidence-based sources	At baseline, cohort 2 had higher attitude and knowledge scores. There was no significant difference in mean self-efficacy scores or mean MD adherence scores.
Hamiel et al., 2020	Israel	Cross-sectional	N=270 pediatricians, 14.1% were following a vegetarian diet	Assess knowledge and attitudes of pediatricians towards vegetarian diets	Online questionnaire based on Previously validated questionnaire	Pediatricians had knowledge gaps regarding vegetarian nutrition, and most did not have a positive attitude towards vegetarian diets. Knowledge was positively correlated with attitude
Lessem et al., 2020	USA	Experiential education program	N=30 (13 nurse practitioners, 14 registered nurses, and 3 physicians)	Increase knowledge and acceptance of whole-food plant-based [WFPB] diet, and likelihood of counseling patients about the diet among health care workers	Online questionnaires based on previously validated research	Pre-intervention average knowledge scores were 65.4%. Average self-efficacy scores for knowledge and counseling were 2.64 and 2.38 at baseline on a scale of 1 to 4.

Sentenach et al., 2019	Spain	Cross-sectional	N=422 physicians (PREDIMED screener) and N= 212 physicians (knowledge/opinion survey)	Evaluate physicians' knowledge/awareness of and adherence to a MD	Online questionnaire based on PREDIMED MD screener previously used in the PREDIMED study	Most physicians did not adhere to MD but 70% considered themselves knowledgeable about the benefits of the MD, and 60% were willing to recommend it to patients
Estell & Hughes, 2021	Australia	Cross-sectional	N=660 (228 nutrition professionals)	Explore consumer and nutrition professional perceptions and attitudes to plant protein including plant-based meat alternatives	Online questionnaire based on previous research	Over 80% of nutrition professionals agreed that following a PBD promoted good nutrition, and over 70% disagreed that it was hard to meet protein requirements while following a PBD.
Asher et al., 2021	Canada	Cross-sectional	N=403 dietitians	Assess Canadian registered Dietitians' attitudes and behaviors towards the new food guidelines' increased plant-based recommendations	Online questionnaire developed for the study and pre-tested	Over 80% of dietitians considered the food guide's recommendation to choose plant-based protein foods as evidence-based. Most had a positive view of the new guidelines, and 58.7% were more likely to encourage their clients to select plant-based protein options.

Aggarwal et al., 2019	USA	Cross-sectional	N=303 physicians from departments of cardiology and general medicine	Assess nutrition and exercise knowledge and personal health behaviors of physicians	Online questionnaire based on validated surveys	Less than 25% of the physicians in the study followed the facets of MD
Saintila et al., 2021	Peru	Cross-sectional	N=179 registered dietitians (72 vegetarians and 107 non-vegetarians)	Compare level of knowledge of vegetarian and non-vegetarian Peruvian dietitians regarding vegetarianism	Online questionnaire based on the recommendations of the current dietary guidelines	Vegetarian dietitians were more knowledgeable about the risks and benefits associated with vegetarian diets
Janse et al., 2021	South Africa	Cross-sectional	N=101 dietitians (45 government employed and 48 in private practice)	Assess whether dietitians in South Africa would use a whole foods plant-based diet (WFPBD) to address chronic diseases	Online questionnaire based on validated surveys	A significant number of dietitians reported inadequate university training surrounding PBDs, albeit a significant number of them were confident about prescribing PBDs to clients.
Duncan & Bergman, 1999	USA	Cross-sectional	N=183 registered dietitians from Vermont, Nebraska, and Washington	Investigate what registered dietitians know about safety, adequacy, and health benefits of vegetarian diets	paper questionnaire sent by mail	Average knowledge and attitude scores were greater for registered dietitians who were currently or had previously followed a vegetarian diet. Overall knowledge scores varied between states.

Fresan et al., 2023	Spain	Cross-sectional	N=2545 health professionals (550 dietitian-nutritionists, 1139 nurses, 427 physicians and 346 pharmacists, and 83 others)	Assess knowledge and attitudes regarding sustainable diets among health professionals in Spain	Online questionnaire developed for the study	21.5% of respondents had not previously heard about sustainable diets, and 32.4% acknowledged their limited knowledge about the subject. Most when presented with information about sustainable diets considered it important to promote them.
Krause et al., 2019	USA	Cross-sectional	N=64 (12 residents,6 fellows, 46 physician attendings)	Assess medical providers' knowledge of plant-based nutrition and their willingness to recommend it to patients	Online questionnaire developed for the study	33% of respondents were willing to recommend PBDs, while majority (51%) responded with maybe. Only 28% were willing to adopt a PBDs, 25% were willing to try it for 6 months or more.

Lee et al., 2015	Canada	Cross-sectional	N= 98 patients and 25 healthcare providers	Assess awareness, barriers, and promoters of plant-based diet use for management of type 2 diabetes for the development of an educational program	2 sets of questionnaires for patients and health care providers were developed for the study.	72% of health care providers reported knowledge of PBDs for management of type 2 while majority of patients (89%) had not heard of using PBDs to treat/manage type 2 diabetes. Less than 50% of respondents were aware of the benefits of PBDs regarding other chronic conditions.
Harkin et al., 2018	USA	Cross-sectional	N=236 (140 physicians and 96 cardiologists)	Assess basic nutritional knowledge, attitudes, and practices of physicians	Online questionnaire based on validated surveys	Nutrition knowledge was average, with only 13.5% feeling sufficiently trained to discuss nutrition with their patients. Physicians most commonly recommended the MD (55.1%), followed by the DASH diet (38.2%), to their patients.

Factors Influencing Health Professionals' Attitudes and Perceptions Towards Plant-Based Diets

Nine key themes were identified during analysis as determinants influencing health professionals' perceptions (encompassing attitudes, viewpoints, and opinions) and behavioral practices regarding plant-based nutrition. In this study, perceptions refer to the cognitive and affective factors including attitudes (feelings towards PBDs), viewpoints (broader professional perspectives shaped by experience) and opinions (specific beliefs). Behavioral practices refer to clinical actions and routine behaviors related to recommending and prescribing PBDs in patient care. Identified themes were knowledge, education and training, evidence-based guidelines, multidisciplinary collaboration, personal experience and interest, educational resources for both patients and health professionals, lack of time, safety and compliance challenges, and lack of confidence in patient capabilities. These were mapped with TDF domains (based on theoretical relevance and empirical evidence) to stratify enablers and barriers to implementation of PBDs in routine care for patients as shown in Table 4.3. The most salient TDF domains determined to be strongly linked to these themes were environmental context and resources (n=5), skills (n=4), social/professional role and identity (n=3), beliefs about consequences (n=3), and knowledge (n=2) where n refers to the number of key themes coded to a particular domain. Other domains that were identified were optimism, goals, emotion, beliefs about capabilities, and social influences.

Knowledge

Knowledge was identified in 12 of the 27 studies that were analyzed as a key factor that can either enable or act as a barrier for health professionals to implementing and recommending plant-based nutrition. Generally, the majority of health professionals considered their knowledge

about plant-based nutrition insufficient and inadequate [147, 156, 161, 163]. Most lacked knowledge about the definitions of PBDs, the key principles behind them, their benefits for human health, disease management and planetary health, as well as the robust scientific evidence supporting their application through various stages of the lifecycle among others. Health professionals with a history of following PBDs were found to be more knowledgeable about PBDs than their counterparts who had never tried any version of PBDs. High knowledge scores in some studies were found to be positively correlated with positive attitudes towards PBDs [155].

Education and training

Ten of the twenty-seven studies reviewed reported indicated their university and professional education and training had not equipped them with education and skills related to plant-based nutrition and therefore felt less confident about discussing and implementing it in their practice [150, 152, 156, 161, 164, 165]. Harkin and colleagues [166] reported that in a sample of 140 physicians and 96 cardiologists, only 13.5% agreed that their academic training had prepared them to discuss nutrition with their patients. Within this group, 78.4% thought additional training in nutrition would help them provide better clinical care in the prevention of cardiovascular diseases. For many, scientific literature was not the main source of information but rather media, online sources, and social settings. Several studies reported education and training as an enabler for health professionals to discuss and recommend plant-based nutrition with their patients [37, 146, 154, 157, 160,165].

Evidence-based guidelines

A few studies suggested that some health professionals were aware of the scientific research supporting claims about the benefits of plant-based nutrition, particularly in the

prevention and management of chronic diseases [37,148,150]. In other studies, participants were not aware of the scientific evidence backing claims made about the benefits of plant-based nutrition, and as such these health professionals were more reluctant to discuss or recommend plant-based nutrition in their practice [150,161,165]. Some health professionals indicated that having robust evidence-based guidelines/summaries of research findings regarding plant-based nutrition would increase their self-efficacy and enable them to discuss and recommend it to their clients [37, 148, 150, 160, 165]. One of the participants in Lee and colleagues' [37] study is quoted as saying that, "there is a lack of clear clinical practice guidelines and diet-specific educational support."

Multidisciplinary collaboration

In connection with evidence-based guidelines, a few studies also highlighted the need for collaborations across various health/scientific disciplines involved in providing healthcare services relating to diet and nutrition to patients. They opined that having consistent messaging would avoid causing confusion to clients [146, 148, 161, 165]

Personal experience and interest

Health professionals were more inclined to provide regular counseling on plant-based nutrition if they personally adhered to it most of the time or always in contrast to only occasionally or less frequently [150,159]. Studies showed that most participants did not adhere to or have any personal experience with any of the PBDs [37, 154, 159, 167, 168]. Consequently, they perceived them as unrealistic, complicated, difficult to sustain, lacking in variety, not filling, and cost-prohibitive among other reasons. On the other hand, participants who had tried some of the PBDs were found to have more positive attitudes. These were driven by factors such as curiosity,

environmental and ethical concerns, health benefits, and factors related to personal preference regarding taste, cost, and ingredients [152, 158,167].

Educational resources

Several participants indicated that access to opportunities for practical based professional development, such as scientific conferences, continuous training programs and plant-based nutrition-related education resources [150] and tools for both health professionals and their clients, would enhance their ability to deliver improved clinical care to their patients. These would have to be evidence-based, easily accessible and visually appealing, and could be in the form of mobile phone applications with clear and concise messaging, handouts, posters, recipes, cookbooks, menu plans, and food swaps among others [146, 148, 150,162].

Lack of time

Study participants also reported that they were limited by time constraints regarding keeping up with literature and had limited clinician time to discuss and counsel patients on plant-based nutrition [149, 150, 160, 161, 168, 169, 170]. Time constraints were also linked to the inability of patients to adopt PBDs with respect to food preparation because patients tend to prioritize convenience over other factors.

Safety and compliance challenges

Study participants expressed fear around potassium control in patients with chronic kidney disease especially in instances of comorbid conditions such as diabetes and CVD. There were concerns about prescribing dried fruit, nuts, and seeds regarding potassium control and fear of inducing hyperkalemia and/or hyperglycemia [146, 148, 160, 170].

Lack of confidence in patient capabilities

Several health professionals expressed a lack of belief in patients' capabilities to change behavior and improve diet adherence. Some opined PBDs were "not realistic for the patient," and that patients are not interested in plant-based nutrition and have knowledge deficit of diet–disease relationship. They also asserted socioeconomic challenges, culturally diverse backgrounds coupled with long-held unhealthy eating patterns, and heavy reliance on convenience foods, as key challenges to aligning diet education regarding patient adoption of plant-based nutrition [160,165]. In contrast, some expressed support for single nutrient-based advice as more straightforward, with evidence of clearer links to management of specific clinical risk markers [165]. Some patients were reported as unwilling to have appointments with a dietitian [161]. Participants working in private versus public settings were also more likely to strongly agree they were confident to counsel patients on plant-based nutrition [161].

Table 4.3 Identified themes mapped with TDF Domains

Theme	TDF Domains	Enablers	Barriers
Knowledge	-Knowledge -Skills	- Personal experience with PBDs -Knowledge of diet-disease relationship -Adequate knowledge of PBDs and their benefits -Knowledge of scientific rationale for PBDs	-Limited knowledge of basic principles of PBDs to discuss with patients -Lack of knowledge about benefits of PBDs - Limited knowledge and practice skills -Limited knowledge exchange within and across multidisciplinary teams.
Education and training	-Skills -Social/professional role and identity -Environmental context and resources	-Education about PBDs at university level and continuous professional evidence-based training, conferences, etc. -Patient knowledge about PBDs	-Lack of education or training at degree and professional levels -Misinformation from other health professionals and non-peer-reviewed sources such as internet, media

		-Online nutrition education	-Low self-efficacy to discuss PBDs with patients due to inadequate training
Evidence-based guidelines	-Skills -Social/professional role and identity -Beliefs about consequences	-Awareness of peer-reviewed evidence -Awareness of current dietary guidelines in support of PBDs -Access to position papers in support of PBDs from respectable scientific bodies	-Perceived lack of evidence-based properly tested practice guidelines -Lack of access to evidence summaries -Disagreement with available evidence
Multi-disciplinary collaboration	- Social/professional role and identity - Environmental context and resources -Social influences	-Consistent messaging from various health professionals	-Misinformation from other health professionals - Limited knowledge exchange within and across multidisciplinary teams.
Personal experience and interest	-Skills -Beliefs about capabilities - Environmental context and resources	-Health professionals trying out PBDs even if for a limited time, and counseling patients based on evidence and experience	-Lack of health professional/patient personal experience with PBDs - Lack of interest to try PBDs even for a short time. -Providing counseling based on personal biases rather than evidence
Educational resources for both patients and health professionals	-Knowledge - Environmental context and resources	-Availability of educational materials such as meal plans, menu plans, food checklists, recipes, and mobile apps to teach and share with patients - Access to evidence summaries - Access to visually appealing content for patients	-Absence of patient education tools and resources/materials -Low confidence to discuss PBDs with patients -Limited/non-existent practical- based professional development -Access to clinical guidelines related to PBDs.

Lack of time	-Goals -Environmental context and resources	-Access to resources and tools to share with clients to use at home	-Limited time allocated to patients' consultations -Limited time to keep up with peer-reviewed literature -Belief that patients prioritize convenience foods over food preparation due to limited time
Safety and compliance challenges	- Beliefs about consequences -Emotion	- Individual patient counselling -Access to evidence-based clinical guidelines -Having knowledge of PBD benefits	-Fear of inducing comorbidities like hyperkalemia and or hyperglycemia among patients with chronic kidney disease [CKD] -Fear around potassium control among patients with CKD -Deficiency concerns
Lack of confidence in patient capabilities	- Beliefs about consequences -Optimism	-Educating patients about PBD health benefits and key concepts -Individual patient counselling -Inclusion of evidence-based or endorsed patient resources and tools. -Goal setting around changing patient dietary patterns	-Diet presumed unrealistic for patients of low socioeconomic background - PBDs perceived to be incompatible with patient food culture and eating patterns -Patients deemed to have low health literacy/knowledge deficit of diet-disease relationship -Assume patients are unwilling to try PBDs because they are hard/complicated

Subgroup Analysis of Barriers and Enablers by professional category

The studies included in this analysis explored the knowledge, attitudes and perceptions of various health professionals regarding PBDs, however most did not account for the distinct roles, responsibilities and levels of nutrition training across the various professional categories. In response to differences in nutrition training and clinical responsibilities among health

professionals, a subgroup analysis was conducted to identify key barriers and enablers related to PBD recommendations by professional category (physicians/clinicians versus dietitians/nutritionists) (table 4.4).

Table 4.4 Subgroup Analysis of Barriers and Enablers by professional Category

Category	Physicians/Clinicians	Dietitians/Nutritionists
Barriers	Limited nutrition education, training, and practical kills at degree and professional level	Patient resistance/culture
	Time constraints	Limited resources
	Lack of clear clinical practice guidelines and lack of knowledge of guidelines	Time constraints
	Uncertainty about scientific evidence or benefits of PBDs	Lack of patient education and monitoring resources
	Limited resources	
	Perception that diet counseling is not their responsibility	
	Worry about overall health/fear of patient injury/risk of deficiency	
	Limited dietary knowledge exchange within and across multidisciplinary teams	
	Lack of diet-specific educational support	
	Low perceived patient acceptability	
	Low self-efficacy	
	Financial disincentives	
Enablers	Patient interest in PBDs	Professional development
	Evidence-based support for PBD benefits	Patient interest in PBDS
	Professional development	Personal history of following a PBD
	Institutional initiatives promoting preventive care	Knowledge sharing from expert dietitians
	Interest in lifestyle medicine	
	Beliefs about consequences	
	Personal history of following a PBD	

Discussion and Conclusions

This review assessed health professionals' attitudes and perceptions and the key barriers and enablers influencing their integration of PBDs into routine patient care, with the overarching goal of informing strategies to promote wider adoption of plant-based nutrition among Americans. The review revealed that health professionals often felt unprepared and uncertain about including plant-based nutrition in their daily practice. This study identified nine themes that influenced health professionals' attitudes and behaviors/practices regarding plant-based nutrition. By aligning these themes with the domains of the Theoretical Domains Framework (TDF), the study highlighted important enablers and facilitators that could promote behavior change among health professionals, while also highlighting barriers to integration of plant-based nutrition into routine patient counseling.

The most prominent domain highlighted by this study was environmental context and resources. This reveals that whether a health professional's environment or circumstances support or hinder the application of plant-based nutrition in daily practice is a key factor. A systematic review by Boocock and colleagues [171] examining clinicians' perceived barriers and enablers to dietary management of adults with type 2 diabetes, also reported environmental context and resources as the most significant TDF domain in their study. Similarly, a study by Mayr and associates [161] exploring clinician perspectives of barriers and enablers to implementing the Mediterranean dietary pattern in routine care for both coronary heart disease and type 2 diabetes, also reported environmental context and resources to be the dominant domain. In the present study, this domain encompassed education and training, multidisciplinary collaboration, educational resources and lack of time. Misinformation was also identified as a barrier. Limited patient consultation time and educational resources have been recognized in other studies as barriers to health professionals providing nutrition education and integrating evidence-based practices such as plant-based nutrition in routine care [172, 173].

"Skills" was the second most prominent TDF domain. It was related to 4 of the 9 identified influencers of health professionals' behaviors in relation to plant-based nutrition. This domain according to

Atkins and colleagues [141] relates to proficiency acquired through practice, and encompasses skills development, competence, ability, interpersonal skills, practice, and skills' assessment as constructs. Lack of or limited skills was identified in several studies as a barrier to health professionals discussing and recommending plant-based nutrition to patients [150, 165]. Additionally, lack of skills such as meal planning and cooking skills, was also identified as a barrier for patients' adoption of PBDs [37, 146, 151,170]. In the current study, this domain encompassed themes such as knowledge, education and training, and evidence-based guidelines. Access to relevant evidence-based research summaries and guidelines was considered an enabler; however, the lack of time to keep up to date with relevant scientific literature was a barrier. Other studies have also identified time constraints for finding and reviewing scientific information, limited skills in critically analyzing scientific literature, and a lack of research applicable to everyday practice, as key barriers to incorporating plant-based nutrition in routine care [174, 175]. Research shows that improved access to skill-based professional training on PBDs, coupled with consistent integration into university curricula, would enhance health professionals' knowledge, skills, confidence, and self-efficacy in delivering evidence-based nutrition education. Furthermore, these opportunities could be more effectively supported and integrated within existing healthcare frameworks to further strengthen outcomes [171,173, 176-179].

Other significant domains were social/professional role and identity, and beliefs about consequences. The social/professional role and identity domain encompasses aspects like professional identity, role, social identity, professional boundaries, professional confidence, group identity, and leadership. Several studies revealed participants reported inadequate professional training as a barrier to discussing and recommending PBDs to clients. In contrast, professional development opportunities such as scientific conferences, ongoing training programs, and PBD-based educational resources were seen as facilitators for discussing and recommending PBDs during routine practice. A lack of multidisciplinary collaboration where knowledge is exchanged both within and across disciplines, was identified as a barrier and a major source of misinformation when providing nutrition education to clients [37, 156, 154, 160, 161,

157]. Health professionals who were well-informed about evidence-based research and current dietary guidelines were more likely to recommend plant-based nutrition to their clients. This further emphasized the importance of improved access to practice-focused professional development on plant-based nutrition [161,172].

The domain of beliefs about consequences encompasses expectations about outcomes, characteristics of those outcomes, and consequences [139, 141]. Boocock and colleagues [171] suggest that health professionals' beliefs regarding consequences of interventions, such as recommending plant-based nutrition in management of chronic conditions, may lead to reservations about their effectiveness for patients. Mayr and colleagues [161] found that clinicians' lack of optimism and belief in the potential consequences led them to doubt that recommending a Mediterranean dietary pattern (a type of PBD) would improve clinical outcomes for patients with coronary heart disease and type 2 diabetes. This perspective contrasts with the positive findings from an umbrella review of meta-analyses by Dinu and colleagues [180] which included 13 meta-analyses of observational studies and 16 meta-analyses of randomized controlled trials. The review covered a total of 12.8 million subjects and investigated 37 health outcomes including cardiovascular outcomes, cancer outcomes, cognitive disorders and metabolic disorders among others.

Subgroup analysis by professional category (physicians/clinicians versus dietitians/nutritionists) highlighted unique barriers and enablers both groups face in relation to recommending PBDs. Physicians often cited time constraints, limited nutrition education during medical and professional training, and uncertainty regarding the evidence base as key barriers, whereas dietitians and nutritionists more frequently highlighted limited resources and patient resistance. These findings underpin the importance of tailored strategies to address profession-specific needs. For physicians/clinicians, enhancing undergraduate and continuing medical education in nutrition, more specifically evidence-based guidance on PBDs could increase their confidence in prescribing PBDs. For dietitians and nutritionists, efforts may be better focused on improving institutional support, resources, and interdisciplinary collaboration to enhance long-term dietary counseling.

Credible scientific studies demonstrate that adopting a PBD is linked to better health outcomes, reduced body weight, and reduced long-term weight gain, positioning it as a promising strategy in combating the obesity epidemic [39, 181-186]. Additionally, PBDs support the preservation of biodiversity and planetary health [11, 186-189] while also being affordable and culturally acceptable [18]. Recent updates by a limited number of professional societies have begun to reflect the growing evidence base supporting PBDs, however, these updates remain the exception rather than the norm. Consequently, it is understandable that many health professionals may lack adequate training or confidence in recommending PBDs in clinical practice. While the U.S. Dietary Guidelines for 2020–2025 encourage the inclusion of more plant-based foods, they do not fully align with more progressive international frameworks such as the EAT-Lancet commission's planetary health diet or the World Health Organization's recommendations on sustainable healthy diets, which integrate both human health and environmental sustainability [10,34]. This disparity highlights the need to update national and institutional guidelines to reflect current scientific consensus on the benefits of plant-based nutrition.

To increase the adoption of PBDs within the American population, it is crucial to prioritize strategies that support health professionals in counseling on plant-based nutrition while also addressing identified barriers. Health professionals need continuous opportunities to enhance their knowledge and skills through targeted training programs, workshops, and conferences related to PBDs. Multidisciplinary collaboration between dietitians, physicians, nurses, and other health professionals is also crucial for sharing expertise and providing comprehensive care. Access to up-to-date, evidence-based guidelines and resources will further empower health professionals to confidently recommend plant-based nutrition, ensuring that patient care is informed by the latest scientific research [190]. For instance, the American college of lifestyle Medicine (ACLM) provides comprehensive evidence-based clinical practice guidelines and toolkits designed to support prescription of whole-food plant-based diets for chronic disease prevention and management [191]. Kaiser Permanente, one of the largest not-for-profit healthcare providers in the U.S. has published clinical guidelines promoting PBDs for prevention and treatment of chronic diseases [192,

193]. In addition, online platforms such as Nutritionfacts.org, curated by Dr. Michael Greger, and the Physicians Committee for Responsible Medicine offer regularly updated educational materials and clinical support tools for both health professionals and patients [194].

Policy makers should draft policies and update food-based dietary guidelines to align with current scientific literature and prioritize public health concerns such as reduced risk of chronic diseases and premature mortality. This information should be made available to all health professionals involved in nutrition counseling, including physicians, nurses, dietitians, nutritionists, extension agents and others. Policies and guidelines should also be clearly communicated and widely disseminated to the public through popular media channels, ensuring clarity and consistency to avoid confusion and conflicting messages. Since a lack of personal experience with plant-based nutrition principles hindered the ability to recommend them to patients, experiential education, such as culinary nutrition, could be an effective strategy to enhance health professionals' knowledge of plant-based nutrition and boost their self-efficacy, while culinary programs in schools and community centers for both adults and children could also help develop practical cooking skills for PBDs [195-200].

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Chapter 5 - Conclusions and Recommendations for future research

This study's objectives were to investigate public AGS awareness, lived experiences, impact and systemic challenges of living with AGS among Kansas residents, while also assessing the readiness of healthcare professionals to support individuals following PBDs, and integrate plant-based nutrition into routine care and management of both AGS and chronic diseases (multimorbidity).

Research findings indicated a general awareness of AGS among both Kansas community residents and Extension professionals, which may reflect the growing prevalence of the condition, especially in the eastern part of the state. Geographical location along with both occupational and recreational/social activities significantly influenced individuals 'exposure to ticks. Daily life activities including hobbies and economic activities served as routes to tick exposure. Most participants living in rural areas of Kansas had accepted tick encounters as a normal part of life given how their livelihoods and daily routines were intertwined with the outdoors. These findings highlight the need for targeted state surveillance and geographically focused interventions in high-risk counties.

Study results also revealed that both healthcare professionals and the health care system were largely unprepared to adequately support individuals living with AGS. For most AGS patients, the journey to correct diagnosis and effective management was long and arduous, characterized by dismissal and misdiagnosis by healthcare professionals who were unfamiliar with the condition. As a result, many turned to self-management often researching their symptoms on their own without professional support or guidance

These results highlight the urgent need for improved education among healthcare professionals including nutritionists and dietitians, public awareness campaigns, and the

development of accessible, evidence-based resources to support individuals with AGS and their families. Integrating AGS awareness into existing tick-borne disease prevention efforts, especially in counties determined to have high prevalence will also facilitate early detection and reduce disease burden.

Previous studies on AGS have focused on its pathogenesis and pathophysiology, however this study highlighted the psychosocial impact of this condition, a seldom discussed aspect. Participants described increased anxiety, fear, frustration and the constant vigilance required to avoid cross contamination. As a result, many experienced emotional exhaustion and isolation in addition to feeling unsupported by health professionals. To address the nutritional and mental health challenges associated with living with AGS, Psychosocial support and nutrition counseling should be integrated into routine patient care for people living with AGS.

The complexity of AGS extended beyond food, as participants reported allergic reactions to a wide range of non-food products including medications, cosmetics, personal care items, and other household items. This underscores significant policy and regulatory gaps related to clear ingredient labelling and transparency of mammalian-based ingredients in both food and non-food items. The absence of standardized labeling guidelines or accessible information resources forces individuals living with AGS to navigate daily life under the constant burden of hyper-vigilance and anxiety about accidental exposure. This highlights the need for policy reform and consumer protection regulations in addition to development of a reliable information database to support individuals living with AGS.

Study findings revealed that most individuals adopted a plant-based lifestyle following their AGS diagnosis. However, many were forced to navigate this significant dietary transition without the necessary professional support from healthcare professionals such as clinicians,

nutritionists or dietitians, which put them at potential risk of nutrient deficiencies and other health complications. A review of the literature further revealed that many healthcare professionals including physicians, nurses, dietitians and others were not adequately trained or prepared to support patients in adopting and sustaining plant-based dietary patterns. These findings further underscore the need for improved education and training for health care professionals on integrating evidence-based dietary interventions particularly PBDs into management of AGS, as well as in reducing the risk of other chronic conditions such as obesity, diabetes, cardiovascular diseases, autoimmune disorders, and neurodegenerative disorders.

Lastly, study participants proposed several recommendations to improve the diagnosis and safe management of AGS. These include increasing both the general public's and healthcare professionals' awareness of AGS through improved education and training; increased access to nutritional and psychosocial support; policy changes such as stronger food and drug labeling regulations; improved access to resources such as safe food and medication lists, and more focused research and surveillance in addition to broader systemic reforms.

Study limitations

A significant limitation of this study the use of electronic surveys which might have excluded individuals without internet access leading to sampling bias. Additionally, the involvement of extension professionals in dissemination of information about the study may have excluded individuals who do not normally interact with extension professionals leading to selection bias.

In addition, the presence of a substantial number of fraudulent responses during the data collection phase with the electronic surveys was another study limitation. While rigorous data cleaning procedures were applied to improve the validity of the dataset, the high volume of

unusable responses may reflect vulnerabilities in the survey distribution method, particularly in online environments where open-access links can be exploited by bots or individuals seeking incentives. The exclusion of these responses, although necessary for data integrity, reduced the effective sample size and may have influenced the demographic balance within the final dataset. Consequently, these factors may limit the generalizability of the findings and underscore the importance of implementing stronger fraud-prevention mechanisms in future studies.

Additionally, the study relied on self-reported accounts of AGS without seeking verification through clinical or medical records. This reliance on self-reporting introduces the possibility of misclassification.

The predominance of observational studies in the narrative review limits the generalizability of the findings. Although the inclusion of studies from multiple countries and a variety of health professionals provides a more diverse perspective, the overall evidence remains limited by study design.

Recommendations for future research and practice

To the best of our knowledge this study is among the first to investigate the lived experiences, psychosocial impact and systemic challenges faced by individuals living with AGS in a high prevalence region. Existing research has largely focused on the pathogenesis and pathophysiology of AGS, but this research contributes valuable insights into the daily realities and challenges faced by individuals living with this condition.

Future research should consider employing non-monetary incentives to reduce the likelihood of fraudulent responses motivated by financial gain. Additionally, clearly

communicating the study's quality control measures to potential study participants may also deter fraudulent behavior.

In addition, incorporating other methodologies to future studies such as focus group discussions, might enrich understanding by capturing the nuanced experiences of individuals living with AGS.

To overcome limited generalizability due to predominance of observational studies in the narrative review, future studies should aim to incorporate a greater number of studies, including longitudinal studies, to enhance the robustness and applicability of results.

Appendix A - Extension survey questionnaire

Project title: Cultivating Awareness and Resilience Against Alpha-Gal Syndrome (AGS) in Rural Kansas

Purpose of the program: This survey will help gather key information about Alpha-Gal Syndrome, also known as red meat allergy, in the state of Kansas. Participation is voluntary. You can skip any questions that make you uncomfortable, and all information will be kept private. We will separate your name to receive the gift card from your survey responses prior to analyzing the responses. By completing this survey, you will consent to participating in the survey. This survey will take approximately 10 minutes to complete. Any identifiable information will be removed from the survey data before analysis. The remaining data might be used for this current and future research and reporting purposes.

Potential risks: The risks of harm anticipated in the proposed research are not greater, considering

probability and magnitude, than those ordinarily encountered in daily life or during answering a routine questionnaire.

Contact persons: If you wish to discuss aspects of the survey, please contact Michael Chao

(mdchao@ksu.edu) and/or Priscilla Brenes (pbrenes@ksu.edu). If you wish to discuss any aspect of the research with an official of the university, you may contact Lisa Rubin, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224; Brad Woods, Associate Vice President for Research Compliance, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224.

Please complete this survey to help gather information about Alpha-Gal Syndrome, also known as red meat allergy. Participation is voluntary. You can skip any questions that make you uncomfortable, and all information will be kept private. The return of this form will let us know that you consent to participate in this survey. It will take approximately 10 minutes to complete. Thank

you!

Please tell us the last 5 digits of your phone number.

Demographics

Age (please select one)

18-29

30-47

48-59

60+

Choose not to provide

Gender (please select one)

Male

Female

Non-binary

Other

Choose not to provide

Which county/counties do you serve as an Extension agent?

Racial Identity (please select one):

American Indian/Alaska Native

Asian

Black or African American

Native Hawaiian/ Pacific Islander

White or Caucasian

Two or more races

Choose not to provide

Ethnic Identity (please select one)

Latino/Hispanic

Not Latino/Hispanic

Choose not to provide

Have you heard of Alpha-gal syndrome (AGS, red meat allergy, mammalian meat allergy)?

Yes

No

I'm not sure

Are you familiar with the symptoms of AGS?

Yes

No

I don't know

If you answered “yes” to the previous question, please mark the symptoms you are familiar with.

Abdominal Pain

Nausea

Diarrhea

Vomiting

Heartburn/indigestion

Hives

Itching

Swelling of lips, face eyelids, or other associated part of the body

Shortness of breath

Cough

Wheezing

Other (please describe)

Did you know that AGS is related to tick bites?

Yes

No

Can you estimate how many people you know that have either been diagnosed with AGS or think they have AGS in your county/counties? If you serve more than one county, can you tell us the estimate by each county? (If listing multiple counties, please format answer by county, then number. (Ex. Riley, 1; Dickinson, 2; …)

If you know anyone in your county who has AGS, please tell us how you found out about their condition (Ex. Through programming, friends, church group…etc.)? If you know anyone in your county who has AGS, please tell us how has the allergy affected their way of life or eating habits?

If you know anyone in your county who has AGS, please tell us how many of them have recovered from symptoms of AGS?

Do you think there is enough information for the public about ways to treat or manage AGS?

Yes, there is enough

No

I'm not sure

If you answered “yes” and want to tell us more, please use the space below.

Has anyone in your county approached your Extension office for information on AGS?

Yes

No

I'm not sure

If you answered “yes” to question 15, please describe this interaction. What were their questions? What information or resources did you direct them to?

Would you be interested in attending a listening session on AGS?

Yes

No

Do you have AGS?

Yes

No

I don't know

If you had prior knowledge of AGS before this survey, have you felt worried or noticed any changes in your actions because you might get AGS from tick bites?

Always

Sometimes

Never

Do you have any comments or suggestions you would like us to know?

Please fill out our our Gift Card Form to receive a $25 Amazon Gift Card. Your answers will remain anonymous. Yes, I would like to submit my information and receive a gift card (This option will open a new survey) No, I would like to opt out of the gift card.

Appendix B - Community survey questionnaire

Q1 **Project title:** Cultivating Awareness and Resilience Against Alpha-Gal Syndrome (AGS) in Rural Kansas **Purpose of the program:** This survey will help gather key information about Alpha-Gal Syndrome, also known as red meat allergy, in the state of Kansas. Participation is voluntary. You can skip any questions that make you uncomfortable, and all information will be kept private. We will separate your name to receive the gift card from your survey responses prior to analyzing the responses. By completing this survey, you will consent to participating in the survey. This survey will take approximately 10 minutes to complete. Any identifiable information will be removed from the survey data before analysis. The remaining data might be used for this current and future research and reporting purposes. **Potential risks:** The risks of harm anticipated in the proposed research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life or during answering a routine questionnaire. **Contact persons:** If you wish to discuss aspects of the survey, please contact Michael Chao (mdchao@ksu.edu) and/or Priscilla Brenes (pbrenes@ksu.edu). If you wish to discuss any aspect of the research with an official of the university, you may contact Lisa Rubin, Chair, Committee on Research Involving Human Subjects, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224; Brad Woods, Associate Vice President for Research Compliance, 203 Fairchild Hall, Kansas State University, Manhattan, KS 66506, (785) 532-3224.

Q2 Please complete this survey to help gather information about Alpha-Gal Syndrome, also known as red meat allergy. Participation is voluntary. You can skip any questions that make you uncomfortable, and all information will be kept private. The return of this form will let us know that you consent to participate in this survey. It will take approximately 10 minutes to complete. Thank you!

Information: Please tell us the last 5 digits of your phone number.

_____

Q3 Age (please select one)

- ○ 18-29
- ○ 30-47
- ○ 48-59
- ○ 60+
- ○ Choose not to provide

Q5 Gender (please select one)

- ○ Male

- ○ Female
- ○ Non-binary
- ○ Other
- ○ Choose not to provide

Q6 Which city and county do you live in?

_____

Q7 Racial Identity (please select one):

- ○ American Indian/Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Native Hawaiian/ Pacific Islander
- ○ White or Caucasian
- ○ Two or more races
- ○ Choose not to provide

Q8 Ethnic Identity (please select one)

- ○ Latino/Hispanic
- ○ Not Latino/Hispanic
- ○ Choose not to provide

Q4 Have you heard of Alpha-gal syndrome (AGS, red meat allergy, mammalian meat allergy)?

- ○ Yes
- ○ No

○ I'm not sure

Q9 Are you familiar with the symptoms of AGS?

○ Yes

○ No

○ I don't know

Q10 If you answered “yes” to the previous question, please mark the symptoms you are familiar with.

☐ Abdominal Pain

☐ Nausea

☐ Diarrhea

☐ Vomiting

☐ Heartburn/indigestion

☐ Hives

☐ Itching

☐ Swelling of lips, face eyelids, or other associated part of the body

☐ Shortness of breath

☐ Cough

☐ Wheezing

☐ Other (please describe) _____

Q11 Did you know that AGS is related to tick bites?

○ Yes

○ No

Q12 Can you estimate how many people you know that have either been diagnosed with AGS or think they have AGS in your county?

_____

Q13 If you know anyone in your county who has AGS, please tell us how you found out about their condition (Ex. Your relative, friends, church group…etc).

_____

Q14 If you know anyone in your county who has AGS, please tell us how the allergy has affected their way of life or eating habits.

_____

Q15 If you know anyone in your county who has AGS, please tell us how many of them have recovered from symptoms of AGS.

_____

Q16 Do you think there is enough information for the public about ways to treat or manage AGS?

○ Yes, there is enough

○ No

○ I'm not sure

Q17 If you answered “yes” and want to tell us more, please use the space below.

_____

Q18 What is your current occupation? Please provide a brief description.

_____

Q19 What outdoor activities do you participate in (hiking, hunting, gardening, etc)? Please provide an estimate of how many hours per week are spent on these activities.

_____

Q20 Do you have any pets? If yes, please describe the type(s)

_____

Q21 Would you be interested in receiving more educational information about AGS?

- ○ Yes
- ○ No
- ○ I'm not sure

Q22 Do you have AGS?

- ○ Yes
- ○ No
- ○ I don't know

Q23 Please fill out our Gift Card Form to receive a $25 Amazon Gift Card. Your answers will remain anonymous.

- ○ Yes, I would like to submit my information and receive a gift card (This option will open a new survey)
- ○ No, I would like to opt out of the gift card

Appendix C - Interview protocol

Prior to interview:

1. **Send them link to the demographic survey**
2. Send a reminder email or text message at least 5 hours before the interview to
3. inform the interviewee of **recording measures, estimated time requirement, and to confirm time.**
4. Ensure that you are in a quiet environment
5. Have two recording methods for the interview. One will serve as a backup recording.
6. Ensure that all recording devices are adequately charged and operational

Interview Script:

1. Good morning/afternoon/evening!
2. My name is (either J or T), and I am working on this project funded by the K-State Global Food Systems initiative that is investigating the prevalence of Alpha-gal Syndrome in the KS population.
    a. *Brief explanation of who you are related to the project*
3. Working with ……. in the department of Animal Science, ……. in the department of Entomology, and …….. in the department of Nutrition and Dietetics'.
4. Reminder that this will be recorded:
    a. If over phone
        i. Briefly, I want to remind/inform you that this interview will be recorded for audio to ensure that we report your responses as accurately as possible.
    b. If over zoom
        i. Briefly, I want to remind/inform you that this interview will be recorded for audio and video to ensure that we report your responses as accurately as possible.
5. Inform them that if at any point they are uncomfortable with the interview, they are welcome to opt out at any time.
6. Ask them if they have any questions prior to starting the interview
    a. If yes:
        i. Allow them to ask any questions, answer them to the best of your ability.
    b. If no:
        i. Proceed
7. **Ensure that they did fill out the demographics form online. Ask for last 5 digits of their phone number**
    a. If yes:
        i. Proceed
    b. If no:

i. Resend the form and ask them to complete it prior to starting the interview.

Interview questions

1. **How long have you lived in your town?**
2. **What outdoor activities do you enjoy participating in?**
    a. Probe Question
        i. What do you for fun?
3. **Do you remember finding a tick on yourself? Can you describe the day/week's events leading up to the discovery of a tick/s? Are you able to give an estimate of the time in between finding the tick and when your symptoms started?**
    a. Probe questions
        i. When is the first time you remember being bitten by a tick after working/being outside?
4. **How did you first become aware that you might have Alpha-Gal Syndrome?**
    a. Probe questions below if clarification is needed for this discussion
        i. What symptoms or reactions did you experience that led you to suspect Alpha-Gal Syndrome?
        ii. Did you seek medical advice or conduct any research on your own when you first noticed these symptoms? If so, what did you learn?
5. **Can you describe your typical eating habits and diet before you began experiencing Alpha-Gal Syndrome?**
    a. Probe questions below if clarification is needed for this discussion
        i. How often did you consume red meat, dairy, or other animal products in your diet before experiencing symptoms of Alpha-Gal Syndrome?
        ii. Were there any particular meals, foods, medications, or cosmetics that you ate/used before experiencing symptoms of Alpha-Gal Syndrome?
6. **Since experiencing AGS, did you make adjustments to your diet?**
    a. Probe questions below if clarification is needed for this discussion
        i. What specific changes did you make to your diet to avoid AGS symptoms?
        ii. Are there any particular foods or alternative protein sources that have helped you maintain a nutritionally balanced eating plan?
7. **Have you found suitable alternatives or substitutions for foods that you can no longer consume? Can you share some examples?**
    a. Probe questions below if clarification is needed for this discussion
        i. Which alternative ingredients or products have you discovered that effectively replace red meat/mammalian products in your favorite recipes?
        ii. Are there any specific brands or types of substitute foods that you prefer, and how do they compare in taste and nutritional value to the foods you used to eat?

8. **How do you handle situations such as dining out or attending social gatherings where it may be challenging to avoid foods that may trigger your AGS symptoms?**
    a. Probe questions below if clarification is needed for this discussion
        i. What strategies or precautions do you take when eating at restaurants or social events to ensure your meals are free of Alpha-Gal or related allergens?
        ii. Have you encountered any specific challenges or incidents at social gatherings related to your AGS, and how did you manage them?
        iii. Have you experienced any emotional or social challenges related to dietary restrictions?
9. **Have you sought guidance or support from healthcare professionals to manage your dietary needs with AGS?**
    a. Probe questions below if clarification is needed for this discussion
        i. How do you ensure that you get adequate nutrition despite dietary restrictions imposed by AGS?
        ii. What specific advice or recommendations have healthcare professionals provided to help you manage your AGS and maintain a nutritionally balanced diet?
10. **What type of information or resources would be most beneficial and urgent in managing your Alpha-Gal Syndrome?**
    a. Probe questions below if clarification is needed for this discussion
        i. Are there particular aspects of Alpha-Gal Syndrome, such as dietary management, symptom monitoring, or treatment options, where you feel more information is needed?
11. **Is there anything else you would like to tell us about what we have discussed today?**
12. **Would you like us to contact you with updates and additional information about Alpha-Gal as it becomes available?**

Conclude the survey with

"Thank you so much for participating in our interview. We greatly appreciate your responses and experiences. Your responses will be utilized to help us generate a source of information and resources for others who are learning how to navigate life with AGS, are worried they may have AGS, or just want to learn more to support friends or family that may have it. We will be supplying you with a $50 Amazon gift card.

STOP RECORDING AND ASK THEM TO PROVIDE THEIR CONTACT INFO WHERE THE GIFT CARD WILL BE MAILED

You should receive the gift card within the coming weeks. If you have any questions now or in the future regarding this research, feel free to reach out to Judith at j**********, or contact her at 6**********