2017

Accessibility to Food Intolerance and Food Allergy Resources in McLean County, Illinois: An Interdisciplinary Pilot Study

Raelynn Parmely
Illinois Wesleyan University, rparmely@iwu.edu

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Raelynn Parmely
Illinois Wesleyan University

Honors Committee:
James P. Sikora, Project Advisor
Rebecca Gearhart Mafazy
Deborah Halperin
Mary Ann Bushman

4/24/2017

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ABSTRACT

Food intolerances and food allergies are evolving and diagnoses of such conditions are rapidly increasing. Yet our ancient bodies and social resources are not adapting to this dynamic environment. Accessing healthcare and allergen-free foods is necessary for all people with food allergies and intolerances, but gaps in social resources complicate acquiring these resources, especially for low-income individuals. This interdisciplinary pilot study utilizes a mixed method approach, including sociologically and anthropologically-based surveys and participant observation, respectively, and is guided by the action research approach. Data analysis illustrates major gaps in access to healthcare, specifically to dietitians, and in food acquisition from government agencies and food pantries. All grocery stores included in this study have some amount of allergen-free foods, but knowledge of these products varies drastically. The paper is concluded with a resource-neutral plan of action that aims to enhance the lives of people who suffer from food intolerances in McLean County, Illinois.

ACKNOWLEDGEMENTS

I would first like to thank my entire honor's committee. Each member challenged me as a writer and young researcher in ways that I never would have imagined could be possible. The provided me with constant, patient, guidance and always validated my observations and questions, no matter how crazy I thought they seemed.

I would also like to express my profound love and gratitude of my family, and their limitless encouragement and support. Without them, I would have never attended Illinois Wesleyan University or received my celiac diagnosis, and I would not have developed such a deep-seated passion for food-allergy safety and education.

On August 19th, 2013, coincidentally the day I moved to Illinois Wesleyan University for the first time, I received a call from my doctor letting me know that I was officially diagnosed with celiac disease. I had gone undiagnosed for eighteen years. Celiac disease, although rarely life-threatening, is a serious autoimmune disease (not an allergy) in which the body, particularly the small intestine, attacks itself whenever gluten - wheat, rye, or barley - is ingested. Malabsorption is a common side effect of celiac disease due to the attacks on the digestive system. Celiac disease has no medically-supported cures or treatments, although maintaining a gluten-free lifestyle often works for most Celiac-sufferers.

My experience with Celiac disease and its elusive nature is not an isolated incident. Celiac disease normally falls into one of two categories - classical and nonclassical - depending on the sorts of symptoms displayed. Classical Celiac disease is most commonly associated with signs and symptoms of malabsorption, while the nonclassical form often occurs as many seemingly unrelated symptoms, such as abdominal pain, unexplained infertility, and depression. The Celiac Disease Foundation (CDF) also identifies *silent* or *asymptomatic Celiac disease* as a form with expected intestinal damage, but no typical outward symptoms. Regardless of the form of Celiac disease, the symptoms displayed are often congruent with symptoms of other diseases and disorders, such as Irritable Bowel Syndrome. For this reason, the CDF estimates that 83 percent of Celiac diseases sufferers remain undiagnosed (Celiac Disease Foundation 2016).

Sufferers of food intolerances and food allergies face struggles similar to those I faced when diagnosing their conditions. Many individuals do not know they have one or multiple food intolerances until they have a reaction. A study conducted by Food Allergy Research & Education, Inc. (FARE) found that 20-25 percent of all epinephrine injections administered in schools for food reactions are given to individuals whose intolerance or allergy was unknown at

the time (2016). The unpredictable nature of food allergies results in total costs of preventative and emergency food intolerance treatments of over $24.8 billion annually, or an average of $4,184 per year per family member (FARE 2016). Given the average budget of overall healthcare of $7,690 per year per person (The Organization for Economic Development 2015), coupled with the vastly increased costs of allergen-free foods (Stevens and Rashid 2008), it becomes clear that treating food intolerances and allergies can become a daunting task for individuals and families, especially those in lower income levels.

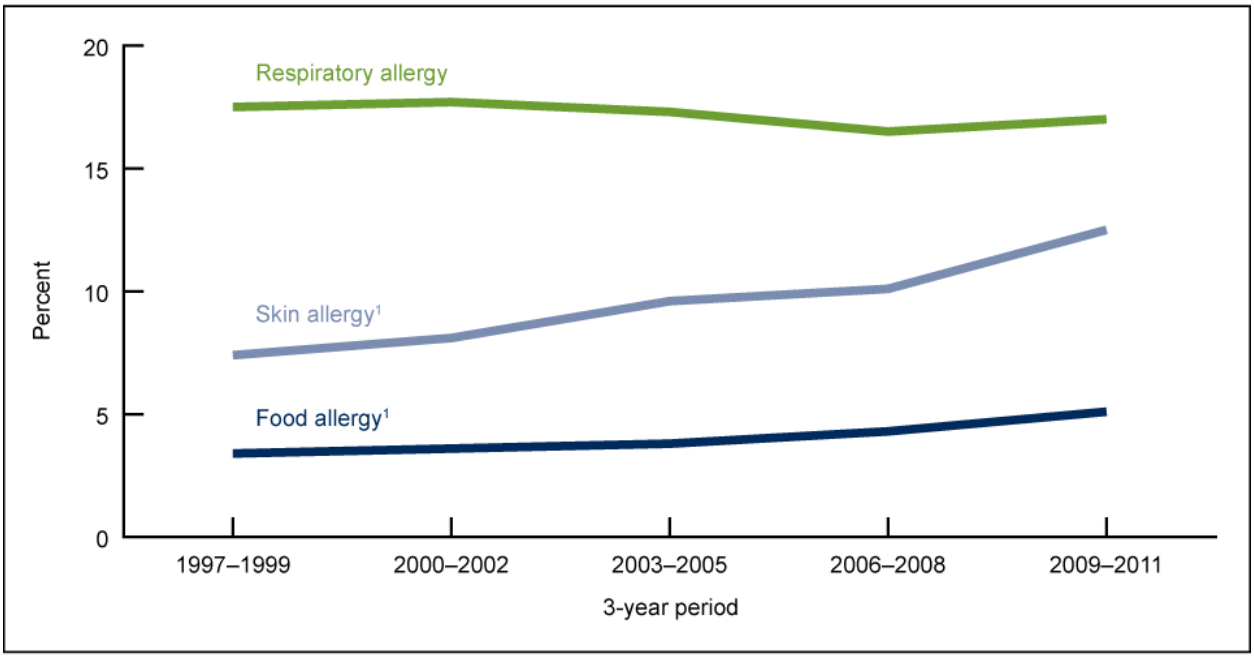
The World Health Organization's (WHO) report on crude birth and death rate indicates that individuals of higher income statuses experience the highest birth rates and lowest death rates across income levels, a fact that can be primarily attributed to increased access to high-quality foods and healthcare (2015). The United States Census Bureau's Selected Economic Characteristics Report approximates the median family income of McLean County residents to be $83,812, within the top 10 percent of all counties in the United States (2013). Given the relatively high-income status of McLean County residents, adapting social resources to accommodate individuals with food allergies and intolerances should already be taking place. However, given the rapidly evolving nature of food intolerances, modifying existing resources and developing new ones is complicated.

THE STATUS OF FOOD ALLERGIES IN THE UNITED STATES

The history of food allergies and a physiological understanding of how we develop food allergies and intolerances remain somewhat of a mystery. Biologists and other medical researchers frequently debate what truly constitutes a food intolerance, especially in cases that do not follow the pattern of 'normal' reactions (Smith 2015). Despite discrepancies in defining food intolerances and food allergies, it is clear that adverse reactions to foods are on the rise. Food

Allergy Research & Education, Inc. (FARE) estimates that there are 15 million people in the United States living with food allergies, consisting of approximately nine million adults and six million children, which equates to 4 percent and 8 percent of the total population, respectively (2016). A long-term study of allergy diagnoses conducted by the Center for Disease Control and Prevention (CDC) in a sampling of hospitals showed an overall increase in the number of food allergy diagnoses from 1997-2011 among children aged 0-17. Notably, the CDC found an increase in the number of food allergy sufferers from 3.4 percent of the population in 1997-1999 to 5.1 percent of the population from 2009-2011, as illustrated in Figure 1 (CDC 2013).

Figure 1. Percentage of children aged 0–17 years with a reported allergic condition in the past 12 months: United States, 1997–2011



[1]Significant increasing linear trend for food and skin allergy from 1997–1999 to 2009–2011.
SOURCE: CDC/NCHS, Health Data Interactive, National Health Interview Survey.

The steady increase of food allergies across populations has resulted in numerous negative implications on individuals' quality of life. Questions about access to safe food and adequate food allergy healthcare are being raised by medical professionals and community activists in an effort to address the growing number of individuals who need specialized care.

The medical community is continuing to develop multiple theories about where food allergies come from, and, ultimately, how we can treat them. No matter how much research is done on the physiological or cultural causes of food allergies, an analysis of the resources available to food allergy and food intolerance sufferers in individual communities is necessary to address the needs of this unique, and growing population.

This pilot study aimed to research the accessibility to healthcare and food for individuals with food allergies in McLean County through an interdisciplinary, multi-method approach. The literature referenced was gathered from multiple disciplines, including, anthropology, sociology, biology, and physiology. The wide-range of consulted literature helps to develop a broad understanding of the complications individuals with food allergies face in accessing allergen-free foods and dietary health education. The action research framework guided the data collection based in sociological and anthropological methods. Sociologically-based quantitative surveys supplied the study with an understanding of how macro-level social institutions such as healthcare, businesses, and social resource organizations affect individuals and families. Qualitative ethnographic participant observation, like that conducted by anthropologists, allowed me to illustrate how individuals with food allergies might interact with larger institutions, in this case, grocery stores.

*Bio**cultural** Evolution of Food Allergies*

The American Anthropological Association (AAA) defines biological anthropology as a subdiscipline dedicated to understanding how humans interact with the environment, the causes of disease and death, and how the human species evolved throughout time. These anthropologists are also concerned with "how biology and culture work together to shape our lives" (AAA *N.d.*), an important consideration when answering questions concerning the rapid rise of food allergies

in the United States. Understanding not only how food intolerances work biologically, but also how culture can both impact our health and also be a response to health changes is crucial to determining where food allergies come from and what steps need to be taken to effectively manage them.

In *Another Person's Poison: A History of Food Allergy* (2015), Matthew Smith traces the medical history of food allergies and food intolerances in the United States, conditions he defines as, "the strangest of all maladies." But what are food allergies and what makes them so strange? Defining food intolerances and allergies is a tricky feat for any medical scientist, because many of the signs and symptoms often overlap (Nordqvist 2016). As Smith notes, if every reactionary symptom was defined as a food allergy, then there would be no differentiation between a mild intolerance or a serious autoimmune condition such as Crohn's Disease (2015:44). In a 1987 study conducted by S. Allen Bock, even a small sample of 17 children demonstrated reactions to foods, ranging from nasal congestion to vomiting and diarrhea (Sicherer 2011:595). Similarly, many medical scientists are divided on how and when humans developed food allergies in the first place, as no concrete history of related conditions exists. When Hippocrates wrote "So the constitutions of these men differ, and the difference lies in the constituent of the body which is hostile to cheese…" (Smith 2015:23), was he possibly citing the cultural definition of a dairy intolerance before it was understood by scientists?

Despite the difficulty in describing a concrete set of definitions for food intolerances and food allergies, several biological and cultural theories have emerged as popular explanations of these "medical maladies." Biologists commonly reference genetics and exposure hypotheses to explain food allergies developed at birth, while environmentalists believe that the increased reliance on genetically modified foods in the United States has left us with foods that our bodies

are unable to adequately process. Additionally, though breastfeeding is considered to be a necessary component of developing the immune systems of infants, women in the United States face stigmas that lead to the unlikelihood of breastfeeding for the recommended amount of time. Understanding the main theories of food intolerances is the first vital step to designing social programs that address the needs of those who suffer from food intolerances.

The first biological theory commonly referenced by medical scientists is that food intolerances are primarily genetic, inheritable conditions. For example, Du Toit, Tsakok, Lack, & Lack note that children have a seven-fold increase in the risk of developing peanut allergies if there is a parent or sibling with the same allergy (2016:999). The hygiene hypothesis is the second common explanation of the origin of food allergies and intolerances. This hypothesis dictates that "a lack of early childhood exposure to infectious agents, symbiotic microorganisms, and parasites increases susceptibility to allergic diseases by suppressing the natural development of the immune system" (du Toit, et al. 2016:998; Gross 2015). Further, du Toit, et al. postulate that exposure to allergens through contact with the skin increases the likelihood that an infant will develop a food allergy, whereas infants who are exposed to allergens through breast milk and other foods are more likely to develop a *tolerance* to that allergen. Additionally, the United States' growing implementation of genetically modified organisms can account for the increased number of allergens in our environment and food supply. Metcalfe (2002:1111) suggests that when genetic material is altered or transferred to other organisms, there is a greater chance that allergenic material is also introduced to otherwise nonallergenic foods.

With these hypotheses in mind, social and cultural explanations emerge that help to better illustrate how food allergies and intolerances evolved into such an overwhelming condition. One of the most expansive theories explaining the rise of food allergies actually begins with a

mother's breast milk. Breast milk is considered to be our best first line of defense against countless pathogens and otherwise foreign substances. Per Brandtzaeg considers breast milk to be an infant's best shot at developing tolerances to common allergens, as he says, "a baby begins to encounter microbes and other foreign substances, collectively called *antigens*, that can stimulate her immune system" (2007:28; Collins 2016). We now live in a culture wherein American women are less likely to breastfeed for the recommended amount of time, approximately 12 months (CDC 2017). Pressures in the workforce to maintain a short maternity leave and social stigma against public breastfeeding often deter American women from continuing to breastfeed as their infants develop. Data collected by the CDC suggests that only 43 percent of American women continue breastfeeding through six months, and only 22 percent through 12 months (Brenner & Buescher 2011:1767). With this in mind, it is reasonable to conclude that the decrease in the amount of time spent breastfeeding may play a key role in the increase of cases of food intolerance and food allergies in the United States.

Knowing where disease comes from helps individuals to access the best treatments possible. Partially due to the ambiguous nature of food intolerances, however, accessibility to allergen-free foods and food intolerance healthcare can be intimidating. How can we develop programs that are well-suited for food intolerances when there are so many variations across the food intolerance experience? The gaps in food accessibility in this country are only heightened for individuals with food allergies, and many healthcare practices are still not well-suited to adapt to the variations among food intolerances. Of the minimal policies in place for the care and management of food allergies, many uncertainties remain concerning the responsibility of businesses and other organizations alike to provide safe, allergen-free foods to their patrons and employees.

Food Allergy Management - Access to Allergen-Free Foods

For many individuals with food intolerances, maintaining an allergen-free lifestyle is often the most logical form of day-to-day management. Eliminating potential contact to allergens, by eating certified allergen-free foods, for example, is the only surefire way to prevent allergic reactions. Unfortunately for many food intolerance sufferers, allergen-free foods can be exorbitantly overpriced. Darmon and Drewnowski have found a strong correlation between cost and diet quality, finding that higher-priced foods are often the healthier foods. As they indicate,

> The argument [is] that food and nutrition play a key part in social inequalities in health, with poor health resulting from buying 'foods richer in energy (high in fat and sugar) to satisfy hunger, which are much cheaper per unit of energy than foods rich in protective nutrients (like fruits and vegetables) (2015:643).

In most cases, allergen-free foods in general cost an average of two to four times the cost of an allergen-containing food item (I have found that a half-loaf of gluten-free sandwich bread, for example, costs at least $6.00). The high costs of these foods does not necessarily mean they are healthy foods. Again, healthy allergen-free foods cost more on average than energy-rich, low-nutrient alternatives. How reasonable then is it for the average citizen to acquire these foods? Given high costs in combination with the overall lack of allergen-free foods, accessing special foods can be particularly challenging for individuals in lower socioeconomic statuses.

In 2013, a student from Lesley University entered into a lawsuit (The United States of America v. Lesley University) with the institution over the university's inadequate number of food selections for students with Celiac disease (Bandini 2015:1577). Under the 2009 amendments to the Americans with Disabilities Act (ADA), which dictates that "people who have more significant or severe reactions are considered to have a disability… which includes individuals with Celiac disease and others who have autoimmune responses to certain foods" (Nienstadt 2016:599), meaning that schools are responsible for complying with the ADA and

providing accommodations for students with those conditions. The student won the case, which has raised questions among other similar institutions about how involved they should become in providing specialized foods for its members, employees, or patrons. While policies exist to protect individuals with severe food intolerances, such as those included under the ADA, they do not help individuals with more mild food intolerances, and they often do not make allergen-free food acquisition easier for populations that need assistance.

Given the rapidly increasing number of cases of food intolerances and allergies (see Figure 1, above), many social service agencies have not yet adapted to assist individuals with food intolerances. While there appears to be little to no difference in the number of food allergy and intolerance diagnoses across socioeconomic levels (Branum, Simon, and Lukacs 2012:45), lower-income individuals have an entirely unique set of struggles in obtaining allergen-free foods. Fuller-Thomson and Redmond's research suggests that approximately only 54 percent of citizens eligible Food Stamp Program (FSP) assistance actually receive the intended benefits (2008:235). Moreover, the FSP does not provide for allergen free foods. Neither Women, Infants, and Children (WIC) nor the Supplemental Nutrition Assistance Program (SNAP) advertises any alterations to food packages, even to those with a diagnosed allergy or intolerance. The fact that these social services have not yet adapted to the increase in food intolerances and allergies is concerning considering the high cost of allergen-free foods. It is highly likely that low-income families are feeling the pressures of trying to put allergen-free meals on the table, with little to no support from the social service programs aimed to assist them.

Grocery stores and supermarkets are often the first source of food acquisition for families across economic levels. The Food Marketing Institute, a group of supermarket researchers and advocates, estimates that consumers take an average number of 1.6 trips to grocery stores

weekly, contributing to yearly supermarket sales near $650 billion dollars a year (2015). Surprisingly, insufficient information is available to understand the experience of grocery store shopping with food allergies or intolerances. Based on the participant-observations I conducted for this research, it appears that many large-name and small stores alike are beginning to stock more allergen-free foods on their shelves. However, there are few studies that analyze whether the food is organized in a unique section of the store or how stores determine what foods to stock in the first place. The lack of unifying policies in supermarkets leads to confusion among many shoppers, especially when there are so many different types of grocery stores. In a survey conducted by Minaker, Elliott, and Clarke, respondents cited feeling unsafe in certain [cheaper] supermarkets, due to perceptions of poor allergen-free food availability and high degrees of cross-contamination (2013:4). While fears of the members of Grossman's study are unlikely to be entirely true, the Food and Drug Administration (FDA) only requires food labels to list any of the top eight allergens – milk, eggs, fish, crustacean shellfish, tree nuts, peanuts, wheat, and soybeans - meaning that many foods with less-common food allergens do not have to be labeled (Grossman, 2015:161). Further studies must be conducted to produce a more comprehensive understanding of the accessibility of allergen-free foods in American grocery stores, including the ease of interpreting labels across social groups.

Healthcare Accessibility

Access to adequate healthcare is also an extremely vital component of diagnosing and treating any food intolerance. Diagnosis alone is a monumental step for many individuals with food intolerances, let alone the life-saving treatments that an allergist or dietitian might provide. Many differences exist between higher-income families and lower-income families when it comes to treating food allergies specifically. Children from low-income families are charged for

almost 250 percent more on hospitalization costs due to food allergies than higher-income children (Bilaver, Kester, Smith, and Gupta 2016:5). This phenomenon can be attributed primarily to the decreased likelihood that a low-income family has access to medical insurance and that they will also be less likely to afford frequent preventative care (Minaker, et al. 2013:4). In a study conducted in a lower income neighborhood in Dayton, Ohio, researchers found several barriers to healthcare among the urban poor population under study, namely, knowledge of services was extremely lacking. Nearly 90 percent of respondents expressing that they did not know there were places in their own community that provided little-to-no cost healthcare (Ahmed, Lemkau, Nealeigh, and Mann 2001:450). When residents have knowledge of healthcare services in their community, they may turn to alternative methods of diagnosis and treatment. Nettleton, Woods, Burrows, and Kerr cited an overall increase in alternative methods of diagnosing and treating food allergies and intolerances over three generations across economic status (2009:652). While alternative medicine is often more affordable than mainstream biomedical practices, it is often seen as ineffective and sometimes dangerous, a consequence that many individuals and families have had to face.

Guidance from dietitians and nutritionists is often a vital element of allergy diagnosis and treatment, outside of other general care. Registered dietitians and nutritionists help to provide "accurate diagnosis, effective medical management, and appropriate support" (Collins 2016:1621). The role of the dietitian outside of diagnosis can be further outlined into five considerations of management and support: dietetic support, label reading, precautionary advisory labels, cross reactivity, and higher-risk situations (Luyt, Ball, Kirk, and Stiefel 2016:289; see Appendix A). Dietitians can also play a key role in creating emergency action plans, working alongside other medical professionals to develop individualized plans for care if

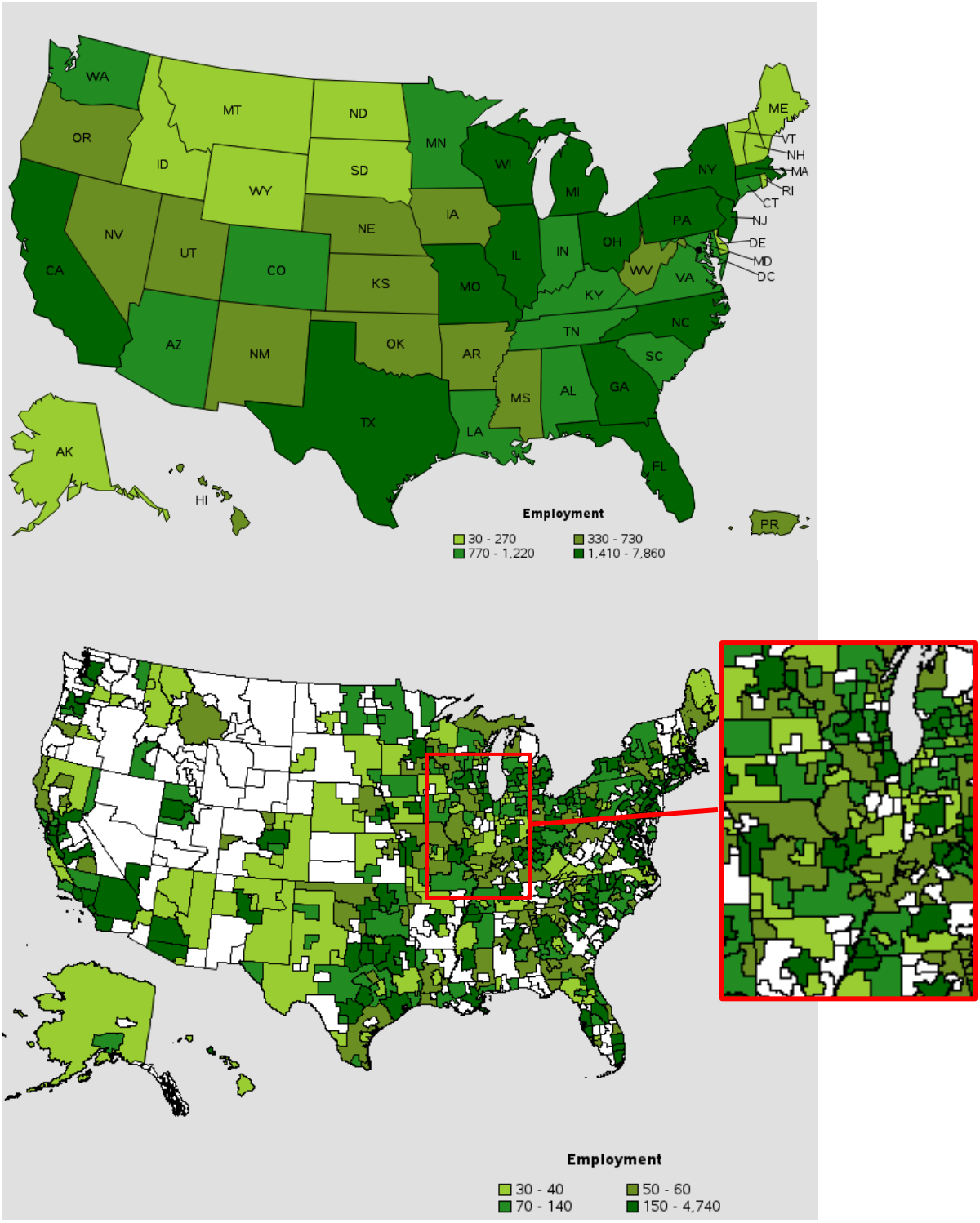
an emergency takes place (Blumenstock, et. al. 2016:319). As seen in Figure 2, the Bureau of Labor Statistics suggests that the employment of full-time dietitians in Central Illinois is low, or at the very least not currently tracked (BLS 2017). For many families, navigating food allergy healthcare is extremely complicated and can be extremely expensive without preventative care or an emergency plan set in place. Without the assistance and guidance of a dietitian or food allergy expert, many individuals have no choice but to rely on emergency care after a potentially fatal reaction has taken place.

Best Practices for Food Allergy Care

Partially due to the rapidly increasing number of food intolerances and allergies, resources for people with these health concerns is not widely available in the United States. Individual hospitals and clinics might have access to food allergy specialists, but they might be too expensive for some individuals, or their opinions on treatment might differ with other allergists. The Celiac Disease Center at the University of Chicago, for example, is home to several gastrointestinal disease experts with notable experience with Celiac Disease and other food intolerances. From my own experience, however, even with insurance, the cost of visiting one of their specialists is a few hundred dollars in addition to the costs of diagnostic testing. Many individuals would never be able to afford the cost of visiting a specialist, and food intolerance specialists rarely make visits to lower-cost healthcare clinics. Visiting a dietitian might be a helpful tool to understanding how to read food labels and know how to maintain an allergen-free household kitchen, but cost is again a likely deterrent from seeking out these services.

Individual grocery stores differ on what allergen-free foods they offer and how they are organized, and finding allergen-free foods can be an intimidating task for even individuals with

Figure 2. Employment of Dietitians by State and by Area. May 2016.



SOURCE: Bureau of Labor Statistics, Occupational Employment Status, Dietitians and Nutritionists.

significant experience of their food intolerance. In the United States, there few food pantries or food banks that advertise distribution of allergen-free foods to lower income populations. Further, there are currently no programs that track where food pantries are located or what they specifically stock. An ideal allergy intolerance program would involve a combination of education and health-related initiatives available for individuals across income levels. If a dietitian or nutritionist was able to donate a few hours to conduct a free workshop for allergy sufferers, many individuals would have a better understanding of what is safe to eat, and possibly help reduce the number of emergency room visits for allergic reactions. Further, individuals who have been educated on how to read food labels improve their chances of enjoying an allergen-free lifestyle.

There are numerous possibilities of how to assist populations with food intolerances and allergies. These best practices will only survive if a clear understanding of the resources already available in a community is developed, so that clear partnerships can result in coordination and collaboration among community members. The research conducted in this study aims to determine the accessibility of healthcare and food for individuals with food intolerances in McLean County, Illinois, and develop a plan of action to efficiently serve the growing population of people with food allergies.

METHODS

This study utilized interdisciplinary methods from anthropology and sociology to collect data. Andrew Johnson's (2005) action research steps served as a guiding tool of the research on accessibility to social resources for individuals with food allergies and intolerances (see Appendix B). The "action research method" follows standard social science research methodologies, but it is unique because of the additional, concluding step of creating a plan of

action after developing conclusions based on the research. An action research framework is therefore particularly useful when analyzing any social phenomena that an individual desires to change or assist in some way. While Johnson is primarily known for his work with action research as it can be applied to the classroom, his steps for action research can be applied to guide inquiries from a wide array of disciplines, including community studies.

To research the accessibility to food acquisition and healthcare resources for individuals with food intolerances, short telephone surveys were conducted with representatives from grocery stores, food pantries, government agencies, and healthcare clinics in McLean County. Phone surveys, based in sociological inquiry, collected quantitative data to determine which organizations have resources for individuals with food intolerances. This sociological data utilized a macro focus, and illustrated some of the effects that society and social institutions have on individuals. Additional participant observation was conducted by the researcher in order to highlight some of the experiences people with food intolerances may face when they are grocery shopping. Anthropological, ethnographic data, such as was collected in the participant observation, provides a micro-level focus of how individuals and communities engage with larger social institutions such as healthcare and food acquisition. As previously mentioned, given the higher than average family income of McLean County residents (United States Census Bureau 2013), a significant number of social resources is expected to be available for individuals with food allergies and intolerances.

Surveys

McLean County, Illinois is home to almost 175,000 people and is composed of individuals across many economic and social identities (United States Census Bureau 2015). Assuming the national statistic that 4 percent of adults and 8 percent of children in the United

States have food allergies and intolerances (FARE 2016), then approximately 3,000 children and 5,500 adults in McLean County suffer from food intolerances. To analyze allergy-friendly food acquisition and healthcare options for residents in the county, I collected quantitative data in the form of phone survey responses from representatives of food banks and food pantries, grocery stores, government agencies, and healthcare practices. All surveys asked similar questions (see Appendix C), aimed at determining whether organizations provided allergen-free foods, food intolerance healthcare, or other food intolerance services. I chose to conduct phone surveys due to my preexisting relationships with many community leaders through my involvement with Illinois Wesleyan University's Action Research Center, allowing me to maintain anonymity and dissuade respondents from altering their responses if they knew about my project. Conducting surveys also allowed for the collection of data from a considerably larger and broader body of respondents, an important consideration when making general statements about multifaceted concepts such as "healthcare" and "food acquisition." Interviews certainly would have provided more in-depth responses, however, I would not have been able to make an accurate conclusion about the resources available in McLean County if I did not survey as many organizations as possible.

A local not-for-profit referral and crisis service, PATH (Providing Access to Help) Crisis Center's website, *www.PathCrisis.org*, contains a database of community social services in McLean County, including family services, food acquisition services, and healthcare services, to name a few. This database includes contact information and short reports on the services provided by each community organization. The initial research sample was chosen from their database, keeping track of the types of services offered and the phone number of each

organization. An initial list of contacts included 18 food pantries, three government agencies, and three healthcare clinics.

Additionally, representatives from area grocery stores were surveyed regarding the allergen-free foods they sold and how they organized the allergen-friendly sections of their store. It was vital to include grocery stores in the survey because they are the primary source of food for most individuals and families. I collected a list of phone numbers from the McLean County Yellow Pages website, and refined my search to grocery stores and supermarkets.[1] The grocery stores chosen chain stores primarily based in the Midwest, although six stores that are either multi-regional or nationwide were also included. To maintain my anonymity as a researcher, I chose to ask questions as though I did not already have some knowledge about the kinds of foods that each store stocked. Store employees were specifically asked if they were aware of whether they stock gluten-free foods and how those foods are organized in the store. I chose to ask about gluten-free foods specifically because of my own experiences in shopping for gluten-free food.

Participant Observation

From my own personal experience, shopping to accommodate a food intolerance can be extremely intimidating. According to the Food Marketing Institute (2015), supermarkets carry an average number of 39,500 items per store. Locating specific items, such as allergen-free foods, can be particularly challenging. I have previous experiences reading food labels, but I still have to consistently have to rely on my own ability to read labels. For individuals who may not have knowledge of how to read food labels, many have to rely on the word of a supermarket employee to direct them to allergen-free foods. To gauge how well employees at McLean County grocery

[1] This research did not collect data from specialty stores such as ethnic food stores or other stores that only specialized in a certain set of items (e.g. liquor stores). Responses from one store that is not yet opened to the public were also not included. The convenience sample excluded responses from stores that did not answer the phone or did not offer individual store phone numbers.

stores might be prepared to assist customers with food allergies, I chose to visit each of the stores included in the surveys (12) and to request help finding gluten-free bread, a logical staple for many individuals with gluten allergies and intolerances. I took note of the times when I entered and exited the store to provide a rough estimate of how long it took an employee to direct me to the requested item. Additionally, I took shorthand field notes to record any pertinent events or opinions related to my request.

Data Analysis

All survey questions and contact information for each unit studied was tracked in four spreadsheets organized by the type of organization (Government Agencies, Grocery Stores, Food Pantries, and Healthcare Organizations). Each organization was only called once, and responses were simultaneously recorded within the same spreadsheet as the phone calls were conducted. Responses were coded within the spreadsheet, and interpreted as pieces of the larger category. Negative responses to phone calls from respondents were noted, but were not given serious further analysis, because one respondent does not represent the mentality of the entire business or organization.

The primary goal of this study was to determine the accessibility of allergen-free food and healthcare resources in McLean County, Illinois. Analysis of responses from the organizations aimed to gauge whether resources existed and how simple they are to attain. The findings are presented by category of organization, and individual responses are given anonymous signifiers (e.g. “a respondent”, “an organization”). Through this analysis, the researcher discovered a surprising number of resources for individuals with food intolerances, however, they also identified significant gaps within individual categories, and overarching gaps related to allergen-free food and healthcare accessibility within the county as a whole.

FINDINGS

The data collected from phone surveys and participant observations suggests communities like McLean County might have ample social resources, but are not ready to fully address the needs of residents with food allergies and intolerances. Namely, current food allergy health education is insufficient and not available for large populations of people who suffer from food intolerances and allergies. This study's findings suggest that while most healthcare and food acquisition organizations have started to explore how to implement allergen-friendly services, many gaps still exist.

Government Agencies and Programs

While seeking assistance from government agencies and programs might seem like an experience to which only low-income people are exposed. Many agencies are well-prepared to provide information about many different services for individuals across income levels. Of the government agencies I surveyed, "access" was split into two categories: access to resources and access to information about those resources. Access to resources from these agencies are contingent on whether the individual meets predetermined criteria, has medical documentation and is willing to make alterations to packages such as replacing peanut butter with more rice or dried beans. This package alteration is can be a problematic solution due the length of time these alternative food items take to prepare. For example, soaking beans and preparing rice takes considerably more time than making a peanut butter sandwich.

Though I expected to receive ample information about social services from the surveys conducted with government agencies and programs, I was not able to access detailed information about offered services over the phone. Each agency that was contacted utilized automated voice answering services, and I was unable to ask direct questions without setting up an appointment or

leaving a message. In one instance, I was prompted to leave a message with questions, but was forewarned that I might not receive a response for 3-5 business days. A low-income person who lives in McLean County, and does not have access to appropriate medical care and food allergy guidance would find it difficult to locate allergen-free food in an efficient manner.

Grocery Stores

All of the twelve grocery stores surveyed were located in either Bloomington or Normal, the largest cities in McLean County. All respondents to the phone surveys identified that they have some amount of gluten-free foods in the store, and knew if there were gluten-free products in the store without having to correspond with another fellow employee. All respondents eagerly inquired if I was looking for a specific item, and if it was something they should go look for. I imitated the role of a community member who was new to the area and looking for a grocery store to accommodate a gluten-free diet. This seemed to encourage respondents to share more information about the amount of gluten-free foods in their store, which ranged from a few items to full or at least partial aisles of food.

Stores vastly ranged in how their gluten-free foods were organized and labeled. All respondents indicated that they had some amount of gluten-free items throughout their store however over half of the stores (58.3 percent or seven out of 12) surveyed also had some sort of organized area for these foods. These specialized areas of the store ranged in size from a small section of an aisle to multiple aisles in a delegated section of the store. One respondent, when prompted to discuss the gluten-free options in the store, additionally shared that the gluten-free foods are also in the same concentrated area as many of the other allergen-free foods. Four respondents (30.0 percent) commented that the store had some sort of health or nutrition aisle where gluten-free products were primarily contained. This choice was particularly intriguing

because not all allergen-free foods are healthy. As a matter of fact, many of the allergen-free foods in these specialized areas are often items that are high in starches and low in essential nutrients (e.g. white bread, cookies, crackers). While further studies would be needed to confirm the nutritional content of allergen-free foods compared to other foods, placing these foods in the "health food" section of the store can be perceived as false advertising.

The supermarkets that did not identify a special section of the store dedicated to allergen-free foods primarily placed responsibility on the consumer to find allergen-free items scattered throughout the store, and to read food labels to ensure they are indeed allergen-free. Only two respondents from supermarkets without a specific allergen-free section (16.7 percent) mentioned having some sort of labels near the price tag with information about what allergens are contained in a product. While these tags appear to be helpful, most only identify one to two allergens within the product. Further, these labels rarely feature information about how the particular allergen came into contact with the food item at hand. For consumers who have severe reactions to even small contacts with their allergen, a tag that suggests that the food does not feature a particular allergen as a main ingredient is not particularly helpful in identifying whether the food is safe to eat. While these tags can still be helpful in many cases, consumers still have to resort to their own abilities to read food labels if they want to ensure they are eating safe food.

Of the supermarkets surveyed, three respondents (25 percent) identified that their store did not have an allergen-free section of their store or special tags to illustrate to customers which foods might be safe to eat. While only three supermarkets might seem like a small number, 25 percent of all supermarkets in McLean County place total responsibility on their customers to find allergen-free foods without any sort of additional assistance. While the Food and Drug Administration suggests that Americans are more likely to read food labels, citing a 10 percent

increase in likelihood to read food labels from 2002 to 2010, only 54 percent of Americans read food labels. While further, updated studies would need to be conducted to determine whether more Americans read food labels today and if food intolerance sufferers are more likely to read food labels, nearly 50 percent of Americans choose not to read food labels for one reason or another (Grossman 2015). In many cases, individuals who do not read food labels either do not have the knowledge to do so or simply do not understand why it is important (see Appendix D). To have 25 percent of a community's grocery stores without any sort of organizational or labeling assistance means that many individuals with food intolerances who shop at those stores do not have a solid understanding of whether the food they are buying is safe for them to eat. In order to bridge this gap, some sort of labeling or organizational system has to be put in place, and employees need to be trained how to assist individuals with food intolerances.

Food Pantries

Surveys were also conducted with 18 food pantries located throughout the county. The majority of these organizations were located in Bloomington and Normal. Similar to the grocery store surveys, I chose to act as though I was in need of services, and asked if they offered gluten-free options. Of the organizations surveyed, I found that six were affiliated with churches (33.3 percent), one was affiliated with veterans' services (5.6 percent), one was associated with women's services (5.6%), and four were not directly affiliated with any other organization (33.3%). Of the 18 food pantries, volunteers at four of the pantries (22.2 percent) "thought" they stocked some amount of gluten-free foods, but were not positive. One participant did believe that gluten-free foods were stocked at the pantry, but only when they were donated, suggesting that there is not a constant supply of these foods. The same respondent did assure me, however, that they would set aside items for clients that had special needs and a positive relationship with the

food pantry. Even so, this unstable supply of gluten-free foods is troubling, because one week a family might be able to eat three meals a day, and the next they might have to search for new ways to put food on the table. Additionally, most of these pantries operate for only a few hours out of the week, making accessing their services complicated.

I also encountered issues contacting these organizations: six of the 18 pantries (33.3%) did not answer the phone call. Given that phones constitute a reliable method of communication, it is troubling that approximately a third of these food pantries were unable to be contacted. Food pantries are a necessary resource for many individuals and families with food insecurity. This data demonstrates that accessing information about the foods available at food pantries in McLean County can be extremely challenging. The consequences of this for people with food allergies and intolerances are additionally disturbing.

Healthcare Organizations

Accessing specialized healthcare is an integral step to diagnosing and managing food intolerances and allergies. All three of the healthcare organizations the researcher surveyed were located in the twin cities of Bloomington and Normal, Illinois. Small, private healthcare practices were located throughout the county, but were not included due to the unlikelihood that many patients in the county are able to access their services. The clinics that were included in the surveys ranged in size, and were the most likely to take new patients or patients from diverse economic backgrounds. Responses collected from these organizations aimed to determine whether the organizations employed a dietitian or food allergy specialist, and how accessible those specialized services are for average patients. Much like with the government agencies and food pantries, access to healthcare was split into accessibility of information and accessibility of resources.

I encountered positive experiences accessing information about dietary services from each of the clinics I surveyed. Larger clinics had easy-to-navigate phone prompts that accurately directed me to the appropriate departments, and I was able to speak to at least one representative from each clinic regardless of size or whether they used an answering service. If a respondent was not able to answer my questions, they transferred my call to someone who could assist me.

Accessing basic information about dietitian employment and services offered was simple. However, I found that only one clinic of the three had a dietitian on staff. The representative from this clinic did not have complete information about whether or not the dietary staff was full-time, or how many individuals comprised the dietary team, but did inform that patients could schedule appointments there or could be referred elsewhere, such as a private clinic. Being referred to dietitians or nutritionists who work at private clinics is particularly alarming since such facilities are rarely accessible to low-income individuals or those without medical insurance.

Participant Observation

In addition to conducting surveys with grocery store representatives, I conducted participant observation in grocery stores as a way to highlight some of the experiences that might occur when shopping for allergen-free food items. Employees were specifically asked where the gluten-free bread was located in the store, because of my own previous knowledge of where gluten-free items were displayed in most stores (primarily in the freezer section). The primary research goals of the participant observation were to determine whether employees could accurately direct an average customer to the gluten-free bread in their store, and how long the stops would take.

All respondents knew that there was gluten-free bread in the store without having to ask for the assistance of another employee or manager. Four respondents (33.3 percent) lead me directly to their gluten-free bread selection, while all other respondents either knew the exact number aisle where it was located or, at the very least, what it was near. Three respondents (25 percent) were not entirely accurate in their directions of where the gluten-free bread was located. In these instances, respondents knew where the gluten-free, dry goods section of the store was, and informed me that that was where their gluten-free bread was also kept. However, in each of these three instances, the employees did not know that many brands of gluten-free bread are kept in the freezer section of the store. In one case, one of the three respondents confidently directed me to the dry goods, gluten-free aisle of the store where no gluten-free bread is actually kept, while he was standing no more than six feet away from a freezer case full of gluten-free breads. This illustrates that while employees might be well-educated about what sorts of products are included in the stores, they might not have a deep understanding of how these foods must be stored.

As a way to further measure employee knowledge of gluten-free products, I loosely kept track of time spent at each grocery store. All but two stops (ten out of 12, 83.3 percent) were less than five minutes long, and the two longest stops were at the largest stores and were mostly spent trying to find someone in the grocery department. The short length of the stops may indicate that employees do have knowledge of gluten-free items in the store. However, “gluten-free” has become a sort of cultural buzzword that most employees have likely heard even before they began working at the store, meaning they could be more comfortable locating those items. Further studies would have to be conducted to determine if grocery store employees were still as

helpful if a customer had a less common dietary restriction, such as to sesame seeds or palm oil, ingredients that do not require overt contents labels.

DISCUSSION

My research relied on collecting data through a convenience sample of institutions that are capable of providing services to people with food allergies. Though community-based research allowed me to explore the accessibility of healthcare and food for individuals with food intolerances, I did encounter some obstacles in my research. To begin with, there was no way to determine the population of individuals who suffer from food allergies in McLean County with total accuracy. Further surveys could be done across the county to determine how many people suffer from food intolerances, but those surveys would have no way to predict how many people do not yet have a diagnosis. Even this gap helps to further confirm the ambiguous nature of food allergies and intolerances – individuals often do not know they have an intolerance until they exhibit physical reactions. I was also unable to evaluate any of the programs that public schools have in place to serve children with food intolerances. At least one elementary school in McLean County operates a sort of food pantry for low-income students to take food home, but it is unclear whether they provide allergen-free options. Further research in McLean County should be conducted to evaluate the role schools play in allergen-free food accessibility. Overall, efforts have been made in the community to address food allergies and intolerances, both hidden and exhibited, but as they continue to rise, further advances will need to be made. By utilizing a community action research model, I have identified gaps in accessibility and have created a plan of action, which aims to help individuals with food intolerances and allergies develop their own sense of autonomy when making healthcare and food acquisition decisions.

Plan of Action

With the academic literature that I consulted and my own data in mind, I have developed a proposed plan of action to address gaps in access to healthcare, education, and allergen-free foods in McLean County. Addressing the gap in accessibility to dietitians and nutritionists in this community is an imperative first step toward better educating individuals with food allergies and intolerances. While our healthcare agencies may not have an overwhelming number of dietitians and nutritionists, efficiently educating individuals with food intolerances is possible with resources already available in McLean County. Partnerships with students enrolled in the Food, Nutrition and Dietetics program at Illinois State University, and community leaders, would be an effective collaboration to host workshops on food allergy treatment and management. These workshops would provide a valuable experience for students at the university, could be held for little to no cost, and would aim to help individuals learn how to read food labels and how to prepare cost-friendly, allergen-free meals. Such workshops could be hosted at varying locations, such as community centers, so individuals across the county would have an opportunity to attend. Such workshops could expand the community's knowledge of food intolerances, how people with food allergies could improve their health, and would enhance the degree of autonomy residents of McLean County would have over their health.

CONCLUSION

Conducting research while utilizing an interdisciplinary approach allowed the research question to be explored from multiple perspectives. A biomedical perspective is necessary to comprehend the physiology, or the signs and symptoms of food intolerances, and is also supported with an anthropological understanding of the evolution of food allergies in humans and how culture impacts the choices individuals make about their health. A sociological

perspective is a vital component of recognizing the role that social institutions, such as government agencies and other social services, play in public health and food allergy management. This combination of perspectives helps to create a more extensive understanding of how the nature of food allergies is changing, and how local governments and social service agencies can adapt policies and programs to better-suit this dynamic community.

This community action research project identified the strengths in accessibility to allergen-free healthcare and food in McLean County, as well as illustrated gaps in the same services. Accessibility to allergen-free food and healthcare can be challenging for individuals from all social backgrounds, and requires rigorous interdisciplinary research to identify common themes among community members and organizations. A complete understanding of the physiology of food allergies and intolerances is only helpful if individuals with those conditions can access the resources necessary to manage them. By employing social science methodologies, I conclude that McLean County has many of the tools necessary to serve its food intolerant population, but that several gaps still exist in accessibility of resources, especially in healthcare and food acquisition for low-income people with food allergies. Further, an anthropological and sociological perspective not only illustrates that our ancient bodies have not evolved to accommodate our rapidly changing diets, but that our social resources have also not yet evolved to adequately serve populations with food allergies and intolerances.

Appendix A - Sample of the types of questions dietitians ask.
(Collins, 2016, p. 1623)

Dietitians play a key role in assisting individual's in ways to care for their food allergies. They can act as a nutrition consultant, or even as the primary physician for food allergy care. Many dietitians are responsible for developing detailed, accurate diagnoses for patients from all backgrounds. This tool outlines many of the diagnostic questions dietitians take into consideration, and illustrates how detail-oriented and comprehensive dietitians can be in their practice – an extremely positive benefit for individuals who think they might have a food allergy.

Category	Items to consider
Symptom and atopic history	• Ask specific questions about symptoms and pattern of appearance by system, including details regarding skin, oropharangeal, gastrointestinal, upper and lower airway, and cardiovascular symptoms. Has anaphylaxis occurred? Do symptoms occur intermittently or continuously?
	• Determine the age, circumstances under which, and location where symptoms first appeared.
	• What were past treatment experiences?
	• Were there any extrinsic factors, such as medications, exercise, or alcohol that might influence reactions?
	• Are there current and/or previous potentially associated conditions (eg, other atopic disease or asthma) in the client? What about other family members? Infertility or pregnancy?
	• Assess anxiety regarding condition.
	• Catalogue current medications or supplements.
Linking foods to symptoms	• Determine what previous food elimination may have been attempted and whether or not it was helpful.
	• Ask about symptoms related to food. Collect a detailed list of potential foods currently being avoided as a means to avoid symptoms.
	• Based on the information collected, determine whether or not the individual is currently on a restricted diet and/or at risk for deficiencies.

Figure 1. Initial questions and information to consider for clients with possible food allergy. Adapted with permission from Skypala and colleagues' Diagnostic Tool for Adults.[18] Note: For interpretation of the questionnaire, Skypala and colleagues provide a detailed chart to interpret symptoms, categorizing them into likely immunoglobulin E–mediated food allergy vs likely non-immunoglobulin E–mediated food allergy or other adverse food reactions. An algorithm for oral allergy syndrome is also provided.

Appendix B - Action Research Steps (Johnson, 2005, p. 49-51)

1. *Identify a problem or research topic*. The first step is to decide what to study. What are you curious about? What piques your interest? Ask a question, identify a problem, or define an area of interest for exploration. Find something that intrigues you, something you would really like to examine in depth.

2. *Set the problem or research topic in a theoretical context.* This means doing a review of the literature. Look in professional journals, books, and web sources to see what others have found out or have to say about your research topic. Relating your research topic to current theories gives you more credibility and provides a theoretical context for your findings. Also, this enables you to link theory and practice by connecting what you find in the literature to what is happening in your classroom.

You might take one of three approaches in doing your literature review. The first approach is to do the review of literature before you begin collecting data. Besides setting your theory in a theoretical context, the literature might also be used to help formulate your question, refine a pedagogical method to be studied, or give you ideas for collecting data. The second approach is to review the literature as you report the data and make your conclusions. The literature is related to each of your concluding points. The third approach is not to do a review of literature at all. Many short action research projects do not include this element.

As you can see, you have a certain amount of freedom in organizing your action research project. The onus is on you, however, to create a credible and coherent report. Linking your study to theories and previous research is one way to do this.

3. *Make a plan for data collection.* In traditional research this is known as methodology. What data are you going to study? How are you going to collect the data? How often will you collect data? Action research is not impressionistic. Nor is it a brochure supporting a particular teaching methodology. Rather, action research is a systematic observation; therefore, data collection must be focused and the elements of data collection must be determined *before* the research begins.

4. *Begin to collect and analyze data*. After you have identified at least two kinds of data, you begin the data collection process. As you collect your data, analyze them by looking for themes, categories, or patterns that emerge. This analysis will influence further data collection by helping you to know what to look for.

5. *If necessary, allow the question or problem to change as you collect data*. Action research is a dynamic, ever-changing process. As a human you cannot help but be influenced by the data you collect. If is very common, therefore, to change a particular teaching strategy, the sources of data, or even the focus of the study as you are collecting data. This is acceptable as long as you let the reader know what you did and why you did it. That is, in writing your report take the reader along with you in all phases of your action research.

6. *Analyze and organize the data*. Hopefully you have been analyzing and organizing the data as you have been collecting them, thus, step 6 should be the final step of an ongoing process. In analyzing your data you need to establish how many total things were recorded, how many categories or kinds of things there are, and how many things are in each category. This is a quick view of analytic induction.

7. *Report the data*. Present the facts or findings. This presentation includes an overview with detailed descriptions and illustrative samples of important events, activities, and responses. Also reported are the number and types of themes, categories, or patterns present in the data. In this section of your report you take the role of a journalist or anthropologist by describing what you saw and providing examples that demonstrate your perceptions.

8. *Make your conclusions and recommendations*. The next step is to interpret the data or tell the reader what they mean. Based on the data, what can you conclude? What do you recommend based on your conclusions? You then answer your research question, provide answers for a problem, or make suggestions based on your new understanding. Also, as stated in step 2, some action researchers do a review of the literature at this point to set their conclusions in a theoretical context.

9. *Create your plan of action.* This is where you put the action in action research. Based on your conclusions and recommendations, what will you do? You create a plan of action. And as you implement your plan of action, you assess what is happening or how effective it is; thus, the action research cycle continues.

Appendix C - Survey Questions

Questions for all food banks/food pantries:

1. Do you have any allergy-friendly food options at your food bank / pantry?
2. Do you have any recommendations where an individual could obtain allergy-friendly foods?

Questions for government agencies:

Representative 1:

1. Are there food packages or coupons for guardians whose child(ren) has a food allergy?

Representative 2:

1. Are you aware of any options in place, such as package increases, for families or individuals who have food allergies?

Representative 3:

1. What services exist in McLean County for low-income individuals with food allergies?

Questions for healthcare clinics:

Healthcare Clinic 1:

1. Do you employ a dietitian or another sort of food nutritionist?

Healthcare Clinic 2:

1. Do your patients have access to food allergy-testing?
2. Do you employ a dietitian or nutritionist?

Healthcare Clinic 3:

1. Do you employ a dietitian or another sort of food nutritionist?

Questions for grocery stores:

1. Do you stock allergen-free foods?
2. Do you have an allergen-free section of your store, or special labels?

Appendix D. Hidden Allergens – Why Reading Food Labels is Complicated (Allergic Living, 2010, http://allergicliving.com/2010/09/01/hidden-allergens/)

This table illustrates the common name of an allergen (sesame), where it can hide in other products, and a sampling of some of its scientific names or derivatives. Sesame is not required to be listed on food labels in the United States, and without guidance from a dietitian or other dietary professional it is nearly impossible to know all of the products sesame can be hiding in, and all of its scientific or uncommon names.

Sesame, Other Seeds:	• baked goods, e.g., breads, cookies, pastries, bagels, buns • Bread crumbs, bread sticks, cereals, crackers, melba toast, muesli • dips, pâtés, spreads, e.g., hummus, chutney • dressings, gravies, marinades, salads, sauces, soups • ethnic foods, e.g., flavored rice, noodles, shish kebabs, stews, stir fry • flavor(ing) • herbs, seasoning, spice • margarine • processed meats, sausages • risotto (rice dish) • sesame oil, sesame salt (gomasio) • snack foods, e.g., bagel/pita chips, candy, granola bars, halvah, pretzels, rice cakes, sesame snap bars • tahini • tempeh • vegetarian burgers • cosmetics and soaps • sauces	• benne/benne seed/benniseed • gingelly/gingelly oil seeds • sesamol/sesamolina • sesamum indicum • sim sim • Tahina • tahini • Til • vegetable oil

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