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THE EXPERIENCE OF SEVERE FOOD ALLERGY AT RESIDENTIAL CAMP

A Dissertation
Presented to
the Graduate School of
Clemson University

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy
Parks, Recreation, and Tourism Management

by
Alexandra Dubin
December 2022

Accepted by:
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ABSTRACT

Severe food allergy is an emerging issue in public, educational, and recreational spaces, as the condition rises in prevalence and severity (Capucilli et al., 2019). Nearly all camps serve children with food allergies in some capacity (Schellpfeffer et al., 2020). Research focusing on documenting rates of food allergy, anaphylaxis management, and food allergy management in summer camps has been foundational to ensuring a safe experience for youth attending camp (Gonzalez-Mancebo et al., 2019; Schellpfeffer et al., 2020). Less research, however, has focused on the socio-emotional impacts of attending camp with a food allergy or exploring how children with food allergy experience summer camp (Liebel & Fenton, 2016).

Therefore, the purpose of this study was to understand the experience of summer for children with food allergy using qualitative methods grounded in phenomenology. Four primary themes emerged from the data analysis process: 1) Trust and Transparency, 2) Inclusion is about Connection, and 3) Inclusion and Exclusion Coexist and 4) Parental Influence. The themes identified in this study provide insight into how children with food allergies experience camp and how camp provider accommodations to serve them impact campers' experiences. Generally, campers reported a positive camp experience which was improved by trust in the safety of the food and peer connections that that engendered feelings of inclusion. Campers also expressed a desire for self-care, or managing their allergy, while being included in the traditional camp meal service.

Camp leadership needs to think critically about how they serve the growing population of campers with food allergies, by considering the developmental abilities of

the participants to balance youth needs for autonomy with safety, and to allow campers to practice allergy management in a supportive environment. Camp providers should look to the best practices provided in this manuscript, as well as other guides (i.e., Mudd & Wood, 2011 and Sicherer et al., 2020), to better serve this population of campers.

DEDICATION

This dissertation is dedicated to all the campers with food allergies who so bravely trusted me and worked with me over the years.

For my Girl Scout at Camp Is-Sho-Da, know that you inspired this work and I'm in awe of you. It was an honor to serve you your first safe food away from home.

For my participants, "Luke", "Casey", "Anthony", "Stella", "Lauren", and "Mia", thank you for your candor, honesty, and humor.

You will all do great things. Thriving with a food allergy is just the first of many greats.

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I first want to thank my participants, without whom there would be no dissertation. Thank you to the campers and mothers who shared their stories. Thank you Louise, Chelsea, Laurie, and Lynne for your insights and for recruiting some great kids for this study. The connections that you have with the camp families are so evident in the way they talk about you and about camp.

Next, I'd like to thank the committee, without whom there would be no Dr. Dubin. Barry, you've been there every step of the way as I navigated a qualitative study that called for embeddedness in a setting during a pandemic that required us to go virtual and keep our distance. Your expertise and level-head have helped me keep going even when I didn't know where to go next. Denise, without you I may never have come to Clemson, and you have been a voice of encouragement and reason through all my endeavors here. I would not be who I am today with Finding Your Voice. Nico, your class changed my academic trajectory in all the best ways. You are one of the greatest teachers I've met, and I appreciate the ways in which you made me think more broadly and deeply about qualitative inquiry. Last but not least, thank you Karen. Your knowledge of public health is second only to your empathy for being in academia with a chronic illness, and I appreciate your support and guidance immensely.

Thank you Mom and Melissa for endless phone calls when I was at my lowest lows and for celebrating the highest highs with me. You both made sure that coming home was a break and I have never needed the feeling of home more than during this

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Lastly, thank you Ari for being the best, more grudging, source of emotional support over the past 6 years. Without your cute face, I would have spent much more time inside at the computer and much less time enjoying the beauty Clemson has to offer. You reminded me to take recreation seriously, while also reminding me that sometimes you just need a treat and a nap.

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CHAPTER ONE

INTRODUCTION TO THE EXPERIENCE OF FOOD ALLERGY IN RESIDENTIAL CAMP

Severe Food Allergy (SFA) is a diagnosed medical condition in which an individual's immune system has a reproducible immune response associated with immunological reactivity after exposure to a given food. SFA is an emerging issue in public, educational, and recreational spaces. It is a condition rising in prevalence and severity and has numerous implications for individuals living with food allergies, their families, and communities at large (Branum & Lukacs, 2009; Capucilli et al, 2019). As a severe medical condition, or a medical condition that can be life limiting, research on food allergy has focused on genetics, immunology, and allergy management in schools (Behrmann, 2010; Osborne et al., 2010; Sicherer, 2001). These studies have informed evidence-based practices for diagnosing children with SFA and keeping children as safe as possible in school and out-of-school time (OST) settings. Despite advancements in research in the disciplines of genetics, immunology, immunotherapy, and diagnosis (Kameda et al., 2017; Venter et al., 2018; Wai et al., 2019;), there is no cure for SFA. Thus, children need support to live and thrive with this chronic condition in order to reach adulthood safely and successfully.

Issues Associated with Severe Food Allergy

Managing SFA requires strict avoidance of the food allergen. This can be a difficult task particularly regarding packaged foods due to non-standardized food labelling practices, ambiguous vocabulary used on food labels, and unlikely hidden ingredients. Some allergens are called by many different names, such as milk being labelled as whey or casein, and allergens may be hidden in terms such as "natural flavoring" or "spices" (Sicherer, 2001). Food allergens may also come into contact with otherwise safe foods through cross-contamination, and food

allergens, such as nut oils, may be present in non-food items such as shampoo or body lotion (Sicherer, 2001). Dining out can also pose serious health risks to people with food allergies as servers or cooks may be unaware of ingredients or lack knowledge on best practices such as cross-contamination avoidance (Choi & Rajagopal, 2013). When considering how food allergy impacts the lives of children and families, it is important to understand these barriers to effective allergy management.

Quality of life is a concern for children with SFA and their families, as SFA tends to decrease quality of life for both the child and their family. Parents of children with SFA, particularly mothers, tend to have lower quality of life along with higher levels of anxiety and stress, than parents of children without SFA (King et al., 2009). This discovery has led to studies of the impact of a child's SFA on parents (Cohen et al., 2004; DunnGalvin et al., 2017). Such parent studies are important because they highlight the coping supports parents of children with SFA need (Rouf et al., 2011). Children with food allergies report lower quality of life than both their healthy peers and peers with other chronic conditions (Avery et al., 2003). Common comorbidities (e.g., atopic dermatitis or asthma) account for some of the reduction in children's perception of their general health, but not the high levels of parental stress and worry or disruption to normal family activities (Sicherer et al., 2001). Fear of an allergic reaction is also often compounded by the fear of using an epinephrine autoinjector, as it can be a painful procedure (Chad et al., 2013). Low quality of life scores are therefore attributed to the fact that although exposure to allergens is sporadic, the anxiety and fear of exposure is always present (Avery et al., 2003).

Inclusion, defined as a sense of belonging, acceptance, and value (Stainback & Stainback, 1990), is a major concern for children with SFA because lack of inclusion of children with

special needs can further decrease quality of life by making children feel they do not belong. This conceptualization of inclusion acknowledges that inclusion is a subjective experience that must consider the feelings and experiences of the children who are to be included (Spencer-Cavaliere & Watkinson, 2010). The nature of food allergy often leads to exclusion in school settings where children spend much of their time and are at great risk of allergen exposure and reactions (Behrmann, 2010). Many common strategies for reducing the risk of food allergy reactions in school and childcare settings can be exclusionary or ethically flawed if done improperly. These strategies for safety, while well intended, can often lead to a child being marked as different and leave them vulnerable to bullying. As children age, bullying may manifest as face-to-face verbal or physical abuse or intentional exclusion, as well as online attacks through cyberbullying (Mudd & Wood, 2011).

Camp as a Developmental Setting for Children with SFA

Summer camp is a primary positive youth development setting (Garst et al., 2011). Positive youth development (PYD) settings have key eight features that make them powerful contexts for growth. These features are (1) physical and psychological safety, (2) appropriate structure, (3) supportive relationships, (4) opportunities to belong, (5) positive social norms, (6) support for efficacy and mattering, (7) opportunities for skill building, and (8) integration of family, school, and community efforts (Eccles & Gootman, 2002). For children with food allergies, these PYD setting features can be critical to developing skills to help them cope and thrive with their condition. Camp sessions often foster skill development through activities that include experiential learning, which has been found to be an impactful approach for facilitating new competencies (Wilson et al., 2019). Experiential learning to teach new competencies in the

camp setting has been used for decades for children with diabetes, and similar processes could be used for campers with food allergies (Avery et al., 2003).

The camp experience provides children with a unique developmental context where they can learn and grow (Foster & McCabe, 2015). Camp offers children the opportunity to increase their self-esteem, independence, friendship skills, and more (Thurber et al., 2007; Wilson et al., 2019). Camps are rich environments for learning and skill development in part due to the camp culture, norms, and traditions which form a tight knit community. Camp leaders and staff design and provide experiences to engender feelings of community. These experiences range from group living, to program activities, to rituals such as awards or campfire ceremonies (Foster & McCabe, 2015; Garst et al., 2011).

The positive outcomes associated with summer camp can be particularly beneficial to children with SFA as they may help campers cope with their food allergy and develop skills that may assist in independent allergy management. Such beneficial outcomes include independence and feelings of competence (Hill et al., 2015; Garst et al., 2011), which could help children as they take on a larger responsibility for allergy self-management. Emotional regulation can also be critical as children cope with the fear and anxiety associated with SFA (Avery et al., 2003; Spencer-Cavaliere & Watkinson, 2010). Children with SFA can also be targets of food related bullying, and the camp experience can offer respite from bullying in a positive and cohesive environment (Mudd & Wood, 2011; Wilson et al., 2019). Overnight camps in particular, which prepare and provide the majority of food on site, may be ideal environments for campers to practice allergy management skills such as label reading, asking about ingredients, and carrying epinephrine (Sampson et al., 2006).

Studies exploring food allergy in the camp setting have primarily focused on documentation of food allergy rates and measuring the efficacy of training regarding food allergy and anaphylaxis response (Greenhawt et al., 2010; Schellpfeffer et al., 2017). A small body of research has used quantitative methods to study socio-emotional impacts associated with a camp experience for children with food allergies (Markus, 2017; Shani et al., 2022). There is a large gap in research that explores campers’ experiences with food allergy at camp, particularly studies using qualitative methods to understand how campers’ view their experiences. This dissertation seeks to fill that gap with the use of a phenomenological lens. Phenomenology allows for an understanding of the children’s subjective experiences from their own point of view, and amplifies their voices (Creswell, 2013).

Dissertation Structure

This dissertation is a three-article format. The structure and theoretical framework of each of the three articles is presented in Table 1.

Table 1.
Structure of the Articles

Paper #	Paper Title	Paper Type	Theoretical Frame
Paper 1	Food Allergy and Summer Camp: A Scoping Review	Scoping Review	Scoping Review Process (Arksey & O’Malley, 2005) Person, Concept, Context (Peters et al., 2020)
Paper 2	The Experience of Residential Camp for Children with Severe Food Allergy	Qualitative Research Empirical Study	Phenomenology (Creswell, 2013; Vagel, 2010) Inclusion (Spencer-Cavalier & Watkinson, 2010; Stainback & Stainback, 1990)
Paper 3	Serving Children with Food Allergy at Camp: The Disney Experience	Practitioner-focused Theoretical Paper	Ethical Principles (Behrmann, 2010) Positive Youth Development Setting Attributes (Eccles & Gootman, 2002)

Paper 1

Few studies have offered guidelines for safely serving children with food allergies in the camp setting. Although some literature exists surrounding food allergy at summer camp, it is limited, and is dispersed across disciplines with no previous reviews. Therefore, this dissertation began with a scoping review. Scoping reviews are a useful tool for synthesizing research where limited studies may exist or no previous reviews have been done on a topic (Booth et al., 2016). The scoping review includes research on children with food allergies in summer camp and managing food allergy at summer camp. As the initial review of this topic, there were no specific research questions for this review; instead, there were three primary objectives. The first objective of the scoping review was to examine what had been studied and how, and what evidence that research produced. The second objective was to understand where gaps exist in the research and where additional research is needed. The third objective was to translate this analysis into implications for practice and practitioners.

The results of the scoping review indicated that additional research is needed in all areas of food allergy management in the camp setting, as there is a general lack of literature. In addition, the scoping review identified that nearly all studies have been quantitative, focusing on documenting rates of food allergy in camp, or anaphylaxis training and management. Very few studies focus on the socio-emotional impacts of food allergy. Additional research on the socio-emotional impacts of food allergy in the camp setting are needed, as are qualitative studies focusing on campers' experiences.

Paper 2

The second paper reports the results of the research study associated with this dissertation; a qualitative study based in phenomenology to understand the experience of children with food allergies at residential camp. Particular focus was placed on understanding the

struggles campers face, the impact of various food allergy safety measures, and campers' experience with the concept of inclusion in the camp context.

Data were collected from participants at three camps designated as Tier 1, Tier 2, and Tier 3 camps. The Tier 1 camp is a specialty camp that only serves children with SFA, and their menu excludes all top 9 food allergens. The top 9 food allergens are milk, eggs, peanuts, tree nuts, soy, wheat, shellfish, fish, and sesame (FARE). The Tier 2 camp is a Jewish camp that focuses on healthy eating, which serves kosher food and specializes in serving children with allergies. The Tier 3 camp is a traditional summer camp with no universal accommodations or policies regarding food. Director level and/or healthcare staff from each camp were interviewed about their role in food allergy management at camp, and the camps general food allergy management strategy. Campers were interviewed used a Modified Seidman Approach (Altschuler & Brownlee, 2015) to focus on the phenomenon of experiencing camp with SFA. Mothers provided additional information regarding food allergy diagnosis and management in the home and school environment.

Four primary themes emerged from the data analysis process: 1) Trust and Transparency, 2) Inclusion is about Connection, and 3) Inclusion and Exclusion Coexist and 4) Parental Influence. The themes identified in that study provide insight into how children with food allergies experience camp and how the accommodations put in place to serve them impact their experiences. Generally, campers reported a positive camp experience which was improved by high levels of trust in the safety of the food and connections with peers and staff that engendered feelings of inclusion. The data also suggests that there are effective ways that camps can include children with food allergies, and ways that the camp experience could be modified to better serve this population. In response to these findings, traditional camps may wish to focus on avoiding

cross contamination and having strict labelling practices to better serve campers with allergies to more common, or less easily avoided foods. Specialty food allergy camps and kosher camps are an excellent resource for guidelines and best practices on food separation and the prevention of cross contamination.

Paper 3

Paper three is a practitioner-focused piece centered on serving children with food allergy safely and ethically in the camp setting. The paper is a response to Paper 2, the qualitative study identifying practices in use to successfully serve campers with food allergies. Paper three synthesizes and generates strategies for serving campers with food allergies founded in best practices, research, and the features of positive youth development (PYD) settings. Additionally, the third paper highlights the specific developmental outcomes offered by various camps' allergy management strategies. Outcomes at the Tier 1 camp include opportunity for a unique respite, social acceptance, and the opportunity to learn disease management skills around like others while fostering independence. Outcomes at the Tier 2 camp include opportunities for social comparison, which is a key feature of social identify (Hogg & Ridgeway, 2003). Additionally, campers at the Tier 2 camp can practice allergy management skills, such as label reading, asking about ingredients, carrying epinephrine (Sampson et al., 2006). Outcomes associated with the Tier 3 camp are opportunities to practice disease management and autonomy. Autonomy is fostered through independent disease management and self-advocacy.

Finally, paper three concludes this three-part paper series by identifying and synthesizing strategies for effective food allergy management in the residential camp setting. Strategies for safety must start with the provision of safe food. Label reading is critical to ensure that kitchen staff are aware of what allergens are contained in each food or calling manufacturing companies

to get additional information about the production of the product. Allergen-free food must be prepared without any cross-contamination with allergen-containing food, and food should be labelled in a way that allows campers to make safe food choices. In addition to safe food, camps need to provide a physically and emotionally safe environment through the reduction of accidental exposure to allergens and creation of a supportive environment that is free from bullying and rich in meaningful connections. Finally, the camp must have an effective emergency response plan founded in the standards set by the American Academy of Allergy, Asthma, and Immunology (AAAAI).

In conclusion, this dissertation provides evidence for the need for additional research in the area of food allergy management in summer camp and shares results of an original empirical study exploring the needs and experiences of children with food allergies at residential camp. Based on the study findings, strategies for practitioners are outlined to help any camp provider, regardless of their current level of allergy-accommodation, improve their ability to accommodate food allergies and offer campers a safer camp experience.

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CHAPTER TWO

FOOD ALLERGY AND SUMMER CAMP: A SCOPING REVIEW

Abstract

Every year, summer camps serve children with food allergies. These camps may be specialty camps designed to accommodate children with particular needs, but many are traditional camps serving a wide variety of participants. While there is literature that exists surrounding food allergy at summer camp, but it is limited. Understanding the breadth and depth of this literature is important to direct future research and shape best practices. The purpose of this scoping review was therefore to synthesize the literature regarding food allergy and summer camp. Using two scoping review manuals as guides, as well as contemporary scoping reviews from the field, we systematically retrieved and reviewed the literature from 1950 to the present that encompassed the topics of food allergy and summer camp. We reviewed a final sample of 15 articles to extract topics, methods, sample and setting characteristics, major findings, and implications for future research and practice. Findings are presented as primary themes and additional concerns identified in the literature.

Introduction

Summer camp is a prime youth development context for campers to increase their self-esteem, independence, friendship skills, and more (Wilson et al., 2019). The positive outcomes associated with summer camp can be very powerful, as they are intentionally designed by camp providers (Garst et al., 2011). Summer camps seek to provide these positive youth development experiences to a wide range of campers, including campers of all ages with various disabilities and medical conditions. Campers with disabilities or medical conditions are often served by medical specialty camps, which may be better equipped to handle the specific needs of various populations. Children with food allergies, however, are frequently served by traditional camps, with over 90% of camps accommodating children with food allergies (Redmond et al., 2017; Schellpfeffer et al., 2020).

Research and evidence should be used to establish best practices in a given field. Many fields, however, have historically relied on institutional knowledge and common practices, resulting in a stark difference between best practices as established by the research, and the way things are done in the field. This is known as a research to practice gap. It is important to synthesize the research on topics where a research to practice gap exists in order to understand where gaps may exist both in practice and in available research on a given topic. Scoping reviews are a type of research synthesis determining the coverage of the literature regarding a certain topic, and an overview of the focus within that literature (Munn et al., 2018). Scoping reviews are a useful process for synthesizing research where limited studies may exist or no previous reviews have been done on a topic (Booth et al., 2016). Therefore, a scoping review may be an effective start to the synthesis of literature regarding youth with food allergies and the summer camp experience to inform both future research and practice.

The purpose of this scoping review was to synthesize the literature across multiple disciplines regarding serving youth with food allergies in the summer camp context. This scoping review includes research on children with food allergies in summer camp and managing food allergy at summer camp. The first objective of this scoping review was to examine what had been studied and how, and what evidence that research produced. Objective one is addressed in the findings. The second objective was to understand where gaps exist in the research and where additional research is needed. The third objective was to translate this analysis into implications for practice and practitioners. Objectives two and three are addressed in the discussion section. To accomplish these objectives, the research team analyzed topics, methods, the sample, setting characteristics, limitations, and implications for both research and practice in the reviewed documents and then identified common and missing themes and areas for special consideration.

Methods

In order to conduct this scoping review, we used Arksey and O'Malley's (2005) process for conducting scoping reviews, the Joanna Briggs Institute (JBI; Peters et al., 2020), and the PRISMA-ScR recommendations (Tricco et al., 2018) to guide the review. These process guides provide discreet directions for each step of the review process from topic framing to data presentation. This process was congruent with similar contemporary scoping reviews (Malorni et al., 2022; Warner et al., 2021).

Eligibility Criteria

The eligibility criteria were defined using Peters et al.'s (2020) person, concept, context model. *Person* was any individual attending camp with a food allergy or person working at a camp who may be involved in managing a campers food allergy. Because the focus of the review

is the management of food allergy at camp, the *person* was not a singular individual but instead a range of people who have a food allergy or play a role in food allergy management. The *concept* was food allergy. Literature reviewed centered around managing a food allergy at camp, either as a person with a food allergy or a staff person managing campers' food allergies and serving campers with food allergies. Due to the similarities in managing clinical food allergies and celiac disease, which is not a clinical allergy (Green & Cellier, 2007), this review also includes the management of celiac disease. The *context* was summer camp, and thus literature had to focus specifically on managing food allergy in day and residential summer camp settings, training summer camp staff on food allergy, or children with food allergies at summer camp. This review excluded literature that focused on other out-of-school time contexts that may have implications for summer camp e.g., literature targeting school nurses that may be applicable in certain camp settings.

Literature Included

Food allergy emerged as an area of study in the early 1900's, with 1950 seeing the creation of the gold standard for diagnosis of food allergy; blinded placebo-controlled food trials (Sampson, 1996) therefore, scholarly literature published from 1950 to the present (2022) was considered for review. We included journal articles, theses and dissertations, and refereed conference abstracts. Journal editorials that did not present unique data but rather synthesized a variety of sources were excluded. Finally, documents were included only if they were written in English and available digitally.

Search Strategy

The initial search protocol started with the generation of search terms and databases to search, using the terms selected by Warner et al. (2020) as a guide. This list of terms and

databases was refined with the assistance of a subject area librarian at the Clemson University Library. The resulting list of search terms and database options was reviewed by an expert audit panel comprised of board members and research team members from the Alliance for Camp Health. The final list of search terms and databases was created using the original list and the audit from the expert panel. Using the search terms, a total of seven databases and nine journals were searched for literature, as seen in Table 2.

Table 2.
Search Terms by Stage

Stage	Database or Source	Terms
1	PsychInfo, SocIndex, Health Source: Nursing/Academic, CINHALL, PubMed, Web of Science	“summer camp” OR “summer camps” OR “camper” OR “resident* camp” OR “resident* camps” OR “day camp” OR “day camps” AND “food allergy” OR “food allergic” OR “diet* restriction ” OR “celiac” OR “anaphylaxis”
2	<i>Journal of Allergy and Clinical Immunology/Journal of Allergy and Clinical Immunology in Practice; Annals of Allergy, Asthma & Immunology; Pediatrics; Allergy; Journal of Food Allergy (USA); Journal of School Nursing; Pediatric Allergy and Immunology; Health; Sociology of Health and Illness</i>	Same as Stage 2 terms

Note. We did not include an * after “camp” to avoid capturing campaign

Study Selection

The initial search yielded 93 documents. Removing exact duplicates (n=27) resulted in 66 documents for title and abstract review. The first author reviewed the titles and abstracts of the remaining 66 documents to exclude documents not meeting the inclusion criteria or that met at

least one exclusion criteria (n= 43) leaving 23 documents for further review. Finally, the remaining 23 documents were reviewed in full to determine eligibility, resulting in a final sample of 15 documents for inclusion in the study.

Data Extraction, Validation, and Synthesis

Data extracted from the articles initially consisted of primary topic/focus, method, sample, setting characteristics, results or findings, and suggestions for future research. Authors independently extracted data from a sample of articles (n=6) and compared results to establish consistency and congruence. After comparison, additional data extraction areas were identified resulting in the final data extraction of primary topic/focus, method, sample, setting characteristics, results or findings, limitations, suggestions for practice, and suggestions for future research. Then, as done in other scoping reviews (Povilaitis et al., 2019; Warner et al., 2021), the remaining articles (n= 9) were divided between the authors to extract data independently for the full set of data extraction areas for all articles. An open coding process was then used to identify themes from the primary topic/focus of the articles, resulting in four primary themes: (1) documenting rates of food allergy; (2) food allergy and anaphylaxis management; (3) food allergy and anaphylaxis training; (4) socio-emotional impacts. Frequency of themes was used to determine saliency.

Findings

Scoping Review Standard Analyses

A set of standard scoping review analyses were conducted first to gain an understanding of the breadth and general characteristics of the articles in the data set. Of the 93 documents identified in the initial search, 15 documents (16%) met the inclusion criteria. Manuscripts included in the review were 5 journal abstracts, 9 journal articles, and 1 dissertation. The

majority of the articles were published between 2015 and 2018 (n= 8), with all articles published between 2001 and 2022, despite searching the literature from the years 1950 to the present.

Methodologies

The articles in this review represent a skewed sample of methodologies, with 14 of the articles using quantitative methods, 1 using mixed methods, and no studies using qualitative methods. The most common research design used was a single time survey (n= 8), with other designs including retrospective records review (n= 3), pre-test post-test survey (n= 3), longitudinal survey (n= 1), and phone survey as part of a mixed methods design (n= 1).

Samples

The samples included in the studies varied, as participants were campers with food allergies and those managing food allergies for them. Seven studies sampled minors, who were campers at various summer camps, eight studies sampled adults in care roles for children with allergies, while one study sampled parents of children with food allergies. The articles presented in this review rely heavily on the work of two prolific research teams: The Redmond team, a group from Ohio led by Margaret Redmond, associated with various children's hospitals and Ohio State University (n= 4), and the Schellpfeffer team, a group from Michigan led by Natalie Schellpfeffer, representing hospitals in Ann Arbor, MI (n= 2). With a sample of 15 documents, a sample of 6 stemming from two research teams is a noteworthy proportion (40%).

Themes

Studies focused on 4 primary themes: documenting rates of food allergy (n= 7), food allergy and anaphylaxis management (n= 6), food allergy and anaphylaxis training (n= 6), and socio-emotional impacts (n= 3). Additional concerns spanning across the articles were identified among the literature as emergency action plans, EpiPen usage, and quality of life.

Objective One

The first objective was to summarize the literature published about food allergy and summer camp to understand what knowledge already exists. The findings suggest three dominating themes in the research and one secondary theme. The majority of research has focused on documentation and management of food allergies in the summer camp setting. A small sample of research has explored the socio-emotional impacts of food allergy and the confluence of summer camp with socio-emotional factors. A chart that details all articles included in the review and salient findings can be found in Appendix A.

Theme 1: Documenting Rates of Food Allergy

Nearly half (47%) of the documents focused on documenting rates of food allergy in summer camps. While rates of food allergy are low, between 1.5% and 2.5% for the general camp population (DaVeiga et al., 2005; Schellpfeffer et al., 2017), studies found almost all camps, 94-99% depending on the sample, serve children with food allergies in some capacity (Redmond et al., 2017; Schellpfeffer et al., 2020). The rate of food allergy among campers at camps for children with special needs or medical conditions tends to be higher than the rate at traditional camps, due to the comorbidity of food allergy and other conditions (Redmond et al., 2016a). Medical specialty camps report rates of food allergy in campers around 15%, versus traditional camps with rates between 1.5% and 2.5% (Redmond et al., 2016a; Schellpfeffer et al., 2017).

Theme 2: Allergy and Anaphylaxis Management

There were six studies focusing specifically on allergy or anaphylaxis management in the camp setting. In three studies, researchers found campers with food allergies do not always come to camp with medical plans that follow standards set by the American Academy of Allergy,

Asthma, and Immunology (AAAAI). For example, rates of campers with documented allergies bringing their own self-injectable epinephrine ranged from 32% to 66.5% of campers, despite this being the recommended first line therapy (Greenhawt et al., 2010; Redmond et al., 2016a; Schellpfeffer et al., 2017). Additionally, studies found a large percentage (52.4%) of camps do not require written medical plans (Schellpfeffer et al., 2020) and campers often did not come to camp with written treatment plans from a physician, with one medical specialty camp reporting 0% of participants provided a written treatment plan (Redmond et al., 2016b).

Theme 3: Food Allergy and Anaphylaxis Training

To best serve campers with food allergies, camp staff need to be educated and trained on procedures for providing safe food as well as how to appropriately respond to allergy events. This scoping review identified anywhere between 25% and 45% of non-medical staff caring for children with food allergy had received no training on managing food allergy, even among staff authorized to administer epinephrine (Gonzalez-Mancebo et al., 2019; Redmond et al., 2016b; Redmond et al., 2018; Wahl et al., 2015). When training was provided, staff were able to greatly improve their food allergy knowledge in all studies with areas of focus including proper injection placement, correct treatment sequence, and symptom identification. Thus, the majority of studies called for additional training interventions with larger audiences and expanded topics (Gonzalez-Mancebo et al., 2019; Redmond et al., 2016a; Redmond et al., 2016b; Redmond et al., 2018; Wahl et al., 2015).

Theme 4: Socio-Emotional Impacts

Studies focusing on socio-emotional impacts of camps serving children with food allergies suggest camp experiences are beneficial for the participants. It is important to note these studies used the context of camps designed specifically for children with food allergies, rather

than traditional camps, so the findings may be unique to the medical specialty camp context and not generalizable to a traditional camp context. Knibb and Hourihane (2013) found campers who attended a specialty camp demonstrated statistically significant increased locus of control, decreased anxiety and obsessive-compulsive disorder, and an increase in social quality of life, as demonstrated by being more confident telling their friends about their food allergy. Shani et al. (2022) found campers who attended specialty camp had less anxiety about their disease and more friends than their peers who did not attend camp. Additionally, campers felt less socially restricted and less isolated by their disease after attending camp. Markus (2017) found while children with food allergy have similar levels of self-concept, anxiety, and depression as the published norms, they demonstrate higher levels of anger and disruptive behavior than published norms.

Additional Concerns

Three additional concerns were identified across the literature. First, many articles aimed to improve quality of life, as this can be a concern for people with severe food allergy due to high rates of anxiety and fear (Avery et al., 2003). Secondly, multiple authors (e.g., Redmond et al., 2016a; Schellpfeffer et al., 2020) noted the importance of emergency action plans to safely serve and support children with food allergies. Action plans should be written and individualized for each camper and should include input from a physician. Finally, epinephrine usage was identified as a concern. Many authors identified children with food allergies did not always come to camp with an EpiPen or instructions to use epinephrine as a first line treatment. Additionally, camps are grappling with the feasibility and burden of keeping stock epinephrine on site. These additional concerns are critical when considering the research needed to further the field, as many camps and practitioners do not know to address these concerns. In particular, camps need

know how to implement emergency action plans and what best practices are regarding stock or individual epinephrine on site to safeguard campers with food allergies.

Future Directions Suggested by the Reviewed Studies

For articles offering suggestions for future research (n= 8), most authors recommended measurement improvements and more robust studies. Authors recommended increasing the number of validated measures used, additional collection of survey data, and replication of studies. To add rigor to future studies, authors recommended larger, more representative samples, because many studies featured campers from largely white, middle-class families (e.g., Markus, 2017). Many suggested expanding the area of study to include additional areas of knowledge regarding food allergy management (Gonzalez-Mancebo et al., 2019; Schellpfeffer et al., 2017). Gonzalez-Mancebo et al., 2019 study specifically noted the potential use of the self-efficacy scale to identify areas for future training, while Schellpfeffer et al., 2017 suggested collecting additional survey data to identify knowledge deficits.

The majority of authors (n=12) also included suggestions for practice, with many recommending more trainings and more camp opportunities for children with food allergies. Trainings were recommended for a broader audience of camp staff and on a more regular basis such as annually. Authors (Twarog, 2001; Wahl et al., 2015) also identified a need for additional resources to inform camp staff of food allergy safety procedures and epinephrine usage. Written policies regarding food allergy management and the creation of individualized emergency action plans were also recommended. Studies focusing on socio-emotional outcomes recognized the need for more camp opportunities tailored to children with food allergies and the need for more evidence-based practices to make these camps more effective.

Discussion

To the best of our knowledge, this scoping review represents the first in-depth synthesis of the literature regarding food allergies and the summer camp experience. The study findings suggest a small body of literature exists on food allergies and summer camp, calling for additional research on a variety of topics related to serving children with food allergies at summer camp. In addition, the existing literature on this topic is limited by the lack of experimental design, particularly in studies surrounding training and socio-emotional impacts of food allergy. This lack of literature translates to a lack of resources for establishing best practices to safely serve campers with food allergies.

Objective Two: Implications for Future Research

The body of literature that exists surrounding food allergy and summer camp is extremely limited both in number and in scope. Nearly all existing literature is quantitative, using surveys to understand frequency of allergies, management policies, training, and socio-emotional factors. While this literature is useful in helping to establish best practices, standards of care, and measure training outcomes, it may overlook the experiences children with food allergy have at camps based on various practices implemented. Serving children with food allergies is a unique experience, as is being a child at camp with food allergies. There are many issues for camp leaders to consider in the purchasing, preparing, and serving of safe food, and a mistake at any point in this chain of events can render food dangerous to a child with a food allergy. Qualitative methodologies may be useful to further understand these experiences and phenomena. For example, Dupuis et al. (2020) found via interviews that in the school setting the lack of clear policies on handling allergen containing foods was a major stressor to students with food allergies. Therefore, despite the effort by the school to create policies to facilitate safety, there

was a lack of trust in the efficacy in those policies that burdened both students and their caregivers.

Additionally, a large portion of the existing literature focuses on responding to allergic events or anaphylaxis and being prepared for emergencies. This is a reactive approach to food allergy management, as the only way to avoid a food allergy reaction is to avoid the allergen. Studies that equip staff to avoid allergic reactions more effectively are needed to ensure a safe camp experience for all campers. For example, studies that include parents, such as Greenhawt et al. (2010) can be useful for training staff on how parents avoid reactions at home, to implement similar practices at camp. This focus on avoiding reactions is of particular importance given that nearly all camps serve at least a small portion of children with food allergies, even if they are not camps designed for children with food allergies. Studies exploring the effectiveness of food bans in the camp setting may be helpful. Banning certain allergens is a practice in some camps, but school-related research suggests food bans should only be used in childcare settings caring for very young children who cannot make informed decisions about their food choices and may be prone to putting non-food items in their mouths (Behrmann, 2010; Tsuang & Wang, 2016).

Objective Three: Implications for Practitioners

While some camps may wish to use food bans of the most common allergens, such as a peanut free camp, other strategies to avoid the top allergens, which are extremely common in most camp food, are necessary. These strategies involve training and an understanding of cross contamination, to avoid contact of allergen-free food with allergen-containing food. While a proactive approach to allergy management is recommended, it is also important camps consider policies for food allergy management in line with guidelines from expert bodies, such as the American Academy for Asthma, Allergy, and Immunology (AAAAI). The prevailing guidelines

on anaphylaxis treatment, as per the AAAAI, should include self-injectable epinephrine as a first line therapy, plus an antihistamine as an adjunctive therapy, and immediate medical attention (DaVeiga et al., 2005). Additionally, AAAAI guidelines state that while antihistamines can be used in tandem with epinephrine, antihistamines are not a replacement treatment (Shaker et al., 2020). This review found not all campers with food allergies are coming to camp with epinephrine and that written treatment plans from their doctors may not follow AAAAI guidelines. The American Camp Association does not mention epinephrine in their accreditation standards, except for standard HW.13 Medication Storage and Administration which notes a “limited amount of medication for life-threatening conditions” (p.149, Accreditation process Guide) need not be stored under lock and can instead be carried by the camper or staff person. The American Camp Association should revisit their Health and Wellness standards to better reflect the severity of anaphylaxis and align their standards with AAAAI guidelines. There is precedent for this type of standard as HW.12 requires an Automated External Defibrillator (AED) be available as per authoritative sources such as the American Red Cross and the American Academy of Pediatrics. Authors included in this review (e.g., DaVeiga et al., 2005; Redmond et al., 2016a) encouraged camps to change their policies and procedures to better align with AAAAI guidelines, but such change can be difficult and slow without pressure from an outside entity such as the American Camp Association.

Finally, children with food allergies tend to have lower quality of life than their healthy peers (Sicherer et al., 2001), and therefore as a prime youth development context, summer camps should consider how they can better serve this population. Children with food allergies need opportunities to attend appropriate camps based on their level of autonomy in allergy management. Specialized camps with expertise in managing food allergy may be useful for

helping campers develop the skills needed to independently manage their allergy and make friends with food allergies. Campers also may benefit from a more typical camp experience where they can practice their allergy management skills in a supportive environment as they approach the teenage years when allergy management responsibilities shift to the child from the parents (Mudd & Wood, 2011). This scaffolded process is critical for supporting development through the transitions associated with adolescence as well as preparing children for disease management across their lifespan to maintain safety and quality of life. A challenge for camps in the future is to consider how they are serving children with food allergies and how they can improve their food allergy management strategies to maximize the developmental potential of the camp experience while maintaining the level of safety parents expect.

Limitations

Although the methods used in this review were thorough, it is possible literature was missed that could influence the findings. Future reviews could employ different search terms, search additional databases, or hand search additional journals. A small number of useful articles (e.g., Mudd & Wood, 2011, Sicherer et al., 2020) were not captured by this scoping review due to publication in small, niche journals that were not found during the scoping review process. These journals can be difficult to locate and are not readily available via large databases like SocIndex.

Future reviewers could also include grey literature, or literature that is evidenced based but not published in a peer-reviewed journal. The most notable example is Compass Point, the publication of the Alliance for Camp Health. This literature was omitted from this search due to the format in which Compass Point is currently published, which cannot be searched in any replicable way. Therefore, this literature was not included to maintain the rigorous methodology

required for a scoping review. Compass Point offers articles specifically tailored to the camp healthcare audience on managing food allergies and anaphylaxis from the healthcare perspective, such as responding to anaphylaxis (Gaslin, 2009). This literature could be very impactful and may warrant future study outside of the scoping review process.

Future Research

This scoping review found that most literature focuses on staff training and allergy management, with only three articles studying the socio-emotional impacts of food allergy on children. This suggests a gap in the literature where the processes of management and experience of food allergy should be studied from the perspective of the campers with food allergies. This research should include quantitative studies of subjects such as quality of life, as well as qualitative studies to better understand the experience of campers with food allergy at summer camp. In addition, this research should seek to study more diverse groups to better understand how race, ethnicity, and other factors may influence how children experience food allergies.

In addition, future research should focus on anaphylaxis prevention, as anaphylaxis response is a reactive measure. Camp providers need guidelines and best practices on avoiding food allergen exposure when serving campers with food allergies to avoid anaphylaxis. This will better prepare camps to offer a physically and emotionally safe environment for campers who may already have high levels of anxiety (Avery et al., 2003). Future studies should specifically focus on the efficacy of food bans in preventing food allergen exposure and anaphylaxis. Food bans are typically only suggested for childcare contexts where young children are likely to put non-food items in their mouths (Behrmann, 2010; Tsuang & Wang, 2016). However, food bans may be effective for limited allergens, such as peanuts, which are not a large part of a typical diet. Therefore, research is needed to understand how and if food bans may assist camps in

keeping campers with food allergy safe, or if allergy management should focus more on strict avoidance of cross contamination.

Conclusion

The purpose of this scoping review was to understand the breadth and depth of the knowledge surrounding food allergy and summer camp to provide directions for future research and to inform practice. Findings from this review suggest there is a small amount of literature regarding this topic, with most studies focusing on managing or responding to anaphylaxis in the camp setting. Future studies may wish to focus on the experience of children with food allergy in the camp setting to tailor best practices to meet their needs. Additionally, this review may be of interest to practitioners who wish to improve the camp experience for children with food allergy.

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CHAPTER THREE

THE EXPERIENCE OF RESIDENTIAL SUMMER CAMP FOR CHILDREN WITH SEVERE FOOD ALLERGY

Abstract

Nearly all camps serve children with food allergies in some capacity (Schellpfeffer et al., 2020). Research focusing on documenting rates of food allergy, anaphylaxis management, and food allergy management in summer camps has been foundational to ensuring a safe experience for youth attending camp (Gonzalez-Mancebo et al., 2019; Schellpfeffer et al., 2020). Less research, however, has focused on the socio-emotional impacts of attending camp with a food allergy or exploring how children with food allergies experience summer camp (Liebel & Fenton, 2016). Therefore, the purpose of this study was to understand the experience of summer for children with food allergies using qualitative methods grounded in phenomenology. Four primary themes emerged from the data analysis process: 1) Trust and Transparency, 2) Inclusion is about Connection, and 3) Inclusion and Exclusion Coexist and 4) Parental Influence. The themes identified in this study provide insight into how children with food allergies experience camp and how camp providers can better serve this population.

Introduction

Severe Food Allergy (SFA) is an emerging issue in public, educational, and recreational spaces. It is a condition rising in prevalence and severity and has numerous implications for individuals living with food allergies, their families, and communities at large (Branum & Lukacs, 2009; Capucilli et al, 2019). As a severe medical condition, or a condition that could be life limiting, research on SFA has focused on addressing genetics, immunology, and allergy management in schools (Behrmann, 2010; Osborne et al., 2010; Sicherer, 2001). These studies have informed evidence-based practices for diagnosing children with SFA and keeping children as safe as possible in school and out-of-school settings. Despite advancements in SFA research in the disciplines of genetics, immunology, immunotherapy, and diagnosis (Kameda et al., 2017; Venter et al., 2018; Wai et al., 2019), there is no cure for food allergy. Thus, children need support to live and thrive with this chronic condition to reach adulthood safely and successfully.

The camp experience provides children with a unique developmental context where they can increase their self-esteem, independence, friendship skills, and more (Thurber et al., 2007; Wilson et al., 2019). Camps are rich environments for learning and skill development in part due to the camp culture, norms, and traditions which form a tight knit community. Camp leaders and staff design and provide experiences to engender feelings of community, such as group living, program activities, and rituals such as awards or campfire ceremonies (Foster & McCabe, 2015; Garst et al., 2011). Camp experiences, however, are not always accessible to children with SFA, due to issues with providing safe food, which falls on both parents and program providers. The fear associated with accessing safe food can be extremely stressful for parents of children with SFA, who tend to have high levels of anxiety (King et al., 2009) and can impact their willingness to allow their children to participate in out-of-school time (OST) programs like camp

(Garst et al., 2016). Providing safe food can be particularly difficult for program providers regarding packaged foods due to non-standardized food labelling practices, ambiguous vocabulary used on food labels, and unlikely hidden ingredients (Sicherer, 2001).

Benefits of Summer Camp Experience for Children with SFA

The positive outcomes associated with summer camp can be particularly beneficial to children with SFA. Such outcomes include independence and feelings of competence (Hill et al., 2015; Garst et al., 2011), which could help children as they take on a larger responsibility for allergy self-management. Emotional regulation can also be critical as children cope with the fear and anxiety associated with SFA (Avery et al., 2003; Spencer-Cavaliere & Watkinson, 2010). Children with SFA can also be targets of food related bullying, and the camp experience can offer respite from bullying in a positive and cohesive environment (Mudd & Wood, 2011; Wilson et al., 2019).

During adolescence the primary responsibility for allergy management often shifts to the teenager, rather than parents. Teenagers begin to spend more time with their friends without parental supervision and may take risks to fit in and not attract attention to their needs (Marklund et al., 2007; Mudd & Wood, 2011). Consequently, adolescence is a primary risk factor in death from food-related anaphylaxis (Mudd & Wood, 2011). Youth with SFA need opportunities to learn allergy management skills such as label reading, asking about ingredients, and carrying epinephrine (Sampson et al., 2006). Camps can provide an opportunity for children to practice allergy self-management in a safe and supportive environment (Mudd & Wood, 2011).

Overnight camps may be particularly well suited to offer this critical developmental space due to the extended time away from home. For camps to provide these benefits for children with SFA, it

is critical camp providers are equipped to provide safe experiences where children are not marginalized or ostracized due to their condition.

Issues Associated with Serving Children with SFA in Summer Camp

Anaphylaxis is a potentially fatal reaction, and therefore the majority of literature regarding camps and food allergy is focused on helping camp providers manage anaphylaxis in the camp setting (Mudd & Wood, 2011; Redmond et al., 2016; Authors, 2022) which is needed to keep children safe. The majority of camps (at least 94%) serve children with food allergies, and nearly a quarter (24%) had at least one instance of anaphylaxis requiring epinephrine occur within the past two years (Schellpfeffer et al., 2020). The administration of epinephrine in response to an allergic reaction is a reactive approach to an incident however, and studies suggest to improve practice, camps should implement developmentally appropriate, individualized plans based on the camper needs that allow the camper to make choices regarding food offerings and allergy management (Redmond et al., 2016a; Schellpfeffer et al., 2020). These opportunities to make choices are seen as sources of empowerment to increase youth self-esteem and self-efficacy, while improving quality of life (Leibel & Fenton, 2016).

Inclusion is also an issue that camps need to consider when serving children with food allergies. Inclusion can be understood as a sense of belonging, acceptance, and value (Stainback & Stainback, 1990). When children are excluded from activities or communities due to a medical condition, they do not have the opportunity to experience belonging, acceptance or value, and therefore are not afforded the full opportunity for participation in, or the benefits of, the experience. Many common strategies for reducing the risk of food allergy reactions in school and childcare settings can be exclusionary or ethically flawed if done improperly. These strategies include allergy free tables and food bans that differentiate children with allergies and potentially

make them a target for bullying (Behrmann, 2010; Mudd & Wood, 2011). Thus, camps need policies for allergy management that do not exclude children with food allergies. Additionally, camps need to consider the ramifications of their ability to include children in a camp experience from a more global perspective. Camps are guided by best practices, but also by laws such as the Americans with Disabilities Act. Food allergy is classified as a disability under the American with Disabilities Act (ADA.gov) and as such entitles people with food allergies to accommodations, such as access to safe food, in childcare and recreation spaces like summer camp.

The purpose of this study was to understand the experience of residential camp for children with food allergies. Particular focus was placed on understanding the struggles they face, the impact of various food allergy safety measures, and campers' experience with the concept of inclusion in the camp context. The ultimate aim is to better serve campers with food allergies by improving their camp experience.

Methods

Theoretical Frame

This study utilized a phenomenological lens to understand the experience of children with food allergies attending residential camp. Phenomenology is the study of lived experiences and the way in which the world is presented through experiences (Sokolowski, 2000).

Phenomenology considers the nature of reality to understand how this being in the world intersects with the broader world. In phenomenology, the nature of being and the nature of reality are individual to each participant. The participant's reality with the phenomena is true for that person (Sokolowski, 2000). There is no one objective truth for which a researcher must search. The existence of a different reality for a different participant, even within the same

phenomena, does not negate or impinge upon the validity of the first participant's reality (Creswell, 2013). The phenomenological approach allows for an understanding of the children's subjective experiences from their own point of view (Creswell, 2013).

Ethnography is the study of a culture, or culture-sharing group, to understand the social behaviors of a group and understand the patterns, rituals, and customs that make the occurrence of those behaviors maximally possible (Creswell, 2013). The use of insider's emic perspectives, as well as the researcher's etic perspectives guides the data analysis in the search for patterns guided or informed by the theory which shaped the research. The final product, the ethnography, is a deep understanding of how the culture sharing group functions, and the insider knowledge that is necessary to be a functioning part of the culture sharing group (Creswell, 2013). An ethnographic lens was also used to contextualize the experiences of campers with food allergy to understand how this group functions and the meaning behind actions (Wolcott, 2008). The use of an ethnographic lens within a phenomenological frame helps to better understand the interaction between the subjects and the environment to identify changes that may be necessary within the camp context.

Study Site

Three camps were involved in the study, designated as Tier 1, Tier 2, and Tier 3 camps. The Tier 1 camp is a food allergy specialty camp that only serves children with SFA, and their menu excludes all top 9 food allergens. The top 9 food allergens are milk, eggs, peanuts, tree nuts, soy, wheat, shellfish, fish, and sesame (FARE). The Tier 1 camp is located outside of Portland, OR and primarily serves children from the Pacific Northwest region. Due to the cost of camp, this camp primarily serves camper from families with higher socio-economic means. The Tier 2 camp is a Jewish camp focusing on healthy eating, which serves kosher food and

specializes in serving children with allergies. This camp is located in Western Pennsylvania and primarily serves Jewish campers who live in or around New York City. The Tier 3 camp is a traditional summer camp with no universal accommodations or policies regarding food. This camp is located in Western Pennsylvania and serves a wide range socio-economic backgrounds.

Participants

Staff and camper participants from each camp were recruited via email in cooperation with the administration from the identified camps. Staff members director-level staff or healthcare staff who were involved in food allergy management. Adult staff members signed consent forms for themselves. From each camp, a male and female campers were recruited. The Tier 1 camp was represented by participants who were 12 and 13 years old. The Tier 2 camp had the oldest participants who were 16 and 17 years old. The Tier 3 camp had the younger participants who were 9 and 12 years old. All but one participant family, from the Tier 1 camp, identified as white. The Parents of campers provided consent for themselves and their children, while assent was provided by the campers. This study design was approved by the Clemson Institutional Review Board.

Data Collection

Data collection consisted of an individual recorded Zoom interview with one or two staff members from each camp and interviews with two campers together with their mothers from each camp. Children ranged from age 9 to 16 years and were clinically diagnosed with at least one food allergy or celiac disease. Due to the recruitment issues and similarities in managing clinical food allergies and celiac disease, which is not a clinical allergy (Green & Cellier, 2007), this study also included a participant with celiac disease. Staff were director level or health center employees who played a major role in food allergy management. Camper interviews used

a Modified Seidman Approach (Altschuler & Brownlee, 2015) to focus on the phenomenon of experiencing camp with a food allergy. This approach utilizes a three-part structure: Part 1 is a focused life history regarding the phenomenon, Part 2 is perceptions, insights and experiences with the phenomenon, and Part 3 is reflection on the phenomenon and meanings associated with the phenomenon (Altschuler & Brownlee, 2015). Mothers provided additional information regarding food allergy diagnosis and management in the home and school environments. Staff interviews centered around their role in food allergy management at camp, and the camps general food allergy management strategy.

Data Analysis and Validation

All interviews were video-recorded via Zoom, transcribed verbatim, and analyzed using conventional and directed content analysis of youth interviews (Hsieh & Shannon, 2005). During transcription, all participants were assigned pseudonyms to ensure confidentiality. Themes were generated deductively, based on the research questions, and inductively, emerging from the transcripts, with themes expressing the multiplicities in which a phenomenon exists for participants and present itself to participants (Creswell, 2013; Vagle, 2010). Trustworthiness of data was established with triangulation of youth interviews and staff interviews, and a member-checking procedure where parent-child dyads had the opportunity to review themes and representative quotes and give feedback (Creswell, 2013). Additionally, as is congruent with the phenomenological lens, researcher positionality and reflexivity played a role in data validation.

In phenomenological research the researcher is the primary instrument of data collection and analysis (Creswell, 2013). The primary author developed SFA in her early 20's during her time as a camp staff member. Due to those personal experiences with SFA, and the role in this study as the human instrument, she employed a reflexive technique called bridling, done via

journaling, to address personal bias and experience with the phenomenon under study. Bridling encourages the researcher to slow down and avoid pre-mature declarations. Bridling acknowledges that we cannot eliminate our intentionality towards the world, or our way of being in the world, but that through reflection, we can create the space to understand the phenomenon within our connection to it (Dahlberg, 2006; Vagel 2010).

Findings and Discussion

Youth participants in the study were between the ages of 9 and 16 years at the time of recruitment. There were three female participants (pseudonyms Lauren, Stella, and Mia) and three male participants (pseudonyms Luke, Anthony, and Casey), with one male and female participant from each camp. Participants each had at least one food allergy, with three participants having multiple food allergies.

Four primary themes emerged from the data analysis process: 1) Trust and Transparency, 2) Inclusion is about Connection, and 3) Inclusion and Exclusion Coexist and 4) Parental Influence. The first theme relates to how campers interact with the camp staff and kitchen staff, and the process of building trust with the camper through transparency regarding food preparation. The second theme deals with inclusion at mealtime and inclusion during the camp experience, with opportunities for connection with peers or counselors generating feelings of inclusion. The third theme highlights the tension existing when inclusion requires special accommodations that may mark a child as different, causing exclusion or isolation. The final theme relates to the role of parents in allergy management, and how their role influences how children experience their allergy, as well as how parental attitudes towards the food allergy are sometimes mirrored in their children.

Trust and Transparency

A primary theme present in all the interviews was the idea of trust. Trust encompasses trusting the camp staff to keep campers safe, trusting the kitchen to provide safe food, and trusting others to look out for the food allergic camper. Part of earning or cultivating trust for campers was related to transparency in the kitchen. Campers needed evidence the food was safe in order to start developing trust in the kitchen and camp staff in general. Strategies for providing transparency include lists of allergens contained in each dish, conversations with the kitchen staff preparing the food, and providing labels from food boxes for campers to verify for themselves their allergens are not included in the food. Luke from the Tier 2 camp noted that he felt much safer after volunteering at camp and getting a tour of the kitchen because he was able to see for himself how allergen-free food was prepared in a separate area with separate utensils. The Tier 2 camp chose to provide labels alongside certain allergen free dishes, whereas the Tier 1 camp had a box of labels for every ingredient that came into camp but was rarely consulted as campers had learned the food was safe over the years.

Participants expressed how their camp helped or harmed the cultivation of trust through transparency through the following quotes:

Because they started writing it out like writing out what's in things or like on the allergy table will be a box, like the box of pasta, that they used to make for dinner will be on that table, so they can tell you it doesn't have dairy but that doesn't always make me feel like there's no dairy in it. So I'll look on it and see you know 'oh, okay this this doesn't have milk in it' – Luke

(Having a food allergy was) easy because everything I knew was safe and like at restaurants I'm like scared to eat stuff because also two three years ago, at a restaurant... So, they said it was coconut yogurt but it was actually Greek yogurt, so I had a reaction and then I've been like kind of scared to eat in a restaurant, since then, but then at camp it was easy because I knew everything. – Stella

There was this one time where they didn't label something menu, and it was a fish product so luckily I just know what- I know what these fish products look like. So, it's like fish sticks they look like they look like mozzarella sticks so. You know I just- it was not- it was weird because of the meal that we're having I was like 'would they serve mozzarella

sticks with this?’ So, I just double checked with the counselor like a couple minutes before I was next, and I said, ‘is this fish sticks?’ and they were like ‘yeah, it is’ so they didn’t label that clearly, and I wish they did, but I was just happy that one of my counselors knew before anything happened to me. – Lauren

Campers like Lauren and Luke felt safer when they could verify for themselves that the food was safe. After seeing how the kitchen operated, Luke wanted to see a box label to confirm that the original ingredients were safe, since he trusted the food preparation process. Meanwhile Lauren reported that she needed to constantly make sure the people around her were aware of her allergy so that they could help her avoid incidents where she might mistake an unsafe food like fish sticks for a safe food like mozzarella sticks.

Inclusion is about Connection

Inclusion was a key sensitizing concept in this research, as children with food allergies may be excluded from experiences due to their condition (Behrmann, 2010) and thus themes surrounding inclusion were generated deductively (Creswell, 2003). Campers were questioned about times they felt included or excluded in an effort to understand what facilitates feelings of inclusion. Campers reported feeling included when they were engaged with others in a way that engendered connection. This connection could come from relating to another camper about a shared interest or concern or participating in an activity that brought people together. This connection could center around food allergy and relating to others with similar allergies or medical concerns, or could occur in the broader camp context, centering around working together or engaging in a group activity.

Campers explained these feelings of inclusion below:

So, we know each other pretty well, even though it's like we- we only see each other for a week every year, we know each other pretty well and we have similar interests and that's when that... when you're in like cabin time I feel like most included. – Anthony

We had every week, we would have like a thing, where we would give out bracelets to another camper. So, one person would have a bracelet and they would give it to one person, and that one person would give it to another person and so on, it would go like that so. Everyone was included. Everyone got a bracelet from someone. Everyone says something nice to each other, so it really felt meaningful to everyone, and everyone got a bracelet in the end, and no one was left out. – Lauren

In the Team Leadership Program. We got to work with the younger kids a lot, and when we were like around them, it kind of felt like you know we're all here we're all the same together and they were doing the same stuff we were helping them with stuff. And it's kind of nice to just help other people out. – Luke

Anthony reported that cabin time was his favorite because he had a group of friends he only gets to see at camp. His favorite part of the camp experience, besides nearly unlimited access to safe food, was the opportunity to spend time with his friends and develop those connections. He did not want fancy equipment or novel activities: he wanted quality time with these very special friends who made him feel like a part of a close group.

Inclusion and Exclusion Coexist

This theme that emerged from the data reflects the idea that inclusion and exclusion can coexist, as sometimes including someone in a broader experience means excluding them from smaller pieces of that experience. It may also mean campers need to negotiate experiences to balance safety and maximum inclusion. Campers felt different from others when they had limited food choices, limited time to make food choices, or times when they were not with their friends due to their allergies. This was primarily an issue for campers in the Tier 2 and Tier 3 camps, where not all dishes were safe, but also was experienced by a camper from the Tier 1 camp who was unable to attend another camp with her non-food allergic friends for fear their camp would be unable to safely accommodate her needs.

Campers reflected on times they were included and excluded saying,

I felt like, well, because like, I was eating something different than like everyone in Camp I kind of felt like excluded, but I knew that we were like that, like, no matter what we're kind of still eating the same thing, so kind of like both I would say. – Mia

Well, like we all sat down together at the same table, and we all went up and got like got, got the snack bar together so, yeah I pretty much always included, just like those few times when there weren't safe desserts. – Casey

I told my mom that I was nervous to eat food and then she just like found (this) camp for me. There's this (other) camp called ISTC, and a bunch of my friends are going to go there in the summer, this year, so I want to be with them. – Stella

Mia was in a unique position in that her mother had provided the camp with much of the food she ate throughout her stay. Despite her often eating the same shelf stable foods that were sent for her, which the kitchen prepared, she felt mostly included that they were eating together, and she could have a small selection of foods from the buffet, such as yogurt at the breakfast bar. Mia was the youngest camper and seemed the least concerned about being excluded on occasion, possibly due to a precocious personality and even though she may have been most likely to be excluded since she could not eat a lot of the foods her camp served. Conversely, Stella was able to eat all the food at camp and so she was very included in the dining experiences, but she felt excluded because she could only safely attend this camp. She was excluded from attending a different camp that her friends from home were attending and reported not liking her camp friends as much as her home friends and wishing she could join them.

Parental Support

The final theme that emerged from the data was a result of triangulation between the information provided by and language used by mothers and the thoughts expressed and language used by their children. Many mothers involved in this study were doing an extraordinary amount of work behind the scenes to ensure their child was safe at school, in social situations, and at camp. Many campers, especially younger campers, were not fully aware of the work their

mothers were doing and thus had a skewed perspective of how easy managing their allergy is: it is easy for them because their mother has set them up for success by ensuring there are plans in place for their safety. Stella shared how easy it was to manage her food allergy at school because she always has a food allergy aware friend to sit with at a safe space at a table and mom was shocked to realize Stella had no idea the work that went into that process. Stella's mother had called doctors, talked to the nurse, filed paperwork, and gone through an extensive process to ensure her daughter had a safe lunch experience, and Stella thought it was just the way the school operated.

Some mothers' ways of managing their child's allergy may be maladaptive in the long term, due to overinvolvement. Overparenting, or overinvolvement in parenting activities, tends to be normative in the disability community, where parents need to be more involved with their disabled child than they would be a typically developing child (Gagnon et al., 2020). While this overparenting may help children cope, it has negative impacts on autonomy (Gagnon et al., 2020). The mothers believe they are helping by doing the majority of allergy management for their child, but they are setting their children up for a difficult transition during adolescence when their child begins to spend more time without them (Mudd & Wood, 2011; Sicherer et al., 2020).

Two mothers shared their experiences with food allergy management, where they were doing an extraordinary amount of work that may be classified as overinvolvement, with the following quotes:

We talked with the [school] nurse beforehand, we have an entire basically kind of like a 504. It's called an individualized health plan. You know and that's disseminated to all the teachers. So, you know behind the scenes, like the teachers are making sure her allergens are not in the classroom. And in terms of lunch, you know they make sure that she has her friend in her lunch study, so that she has someone that's familiar with her allergies and comfortable with her allergies. – Stella's Mom

I packed a lot of her foods [for camp]. I so, you know it did come down to what was like shelf stable. So she did have a lot of pastas because I felt like that was shelf stable. Where next year, I think I will get in with the chef and you know freeze meals, things like that too for her and take them down to her. You know they're in the middle of nowhere, so you know, they're kind of restricted. Once they're out of food they're out of food. – Mia's Mom

Additionally, it was apparent that how parents conceptualize or speak about food allergy and food allergy management often becomes how child conceptualizes their allergy or speaks about their allergy. Parents who are very comfortable with allergy management tend to have children who are more comfortable with allergy management, while parents who remain hypervigilant may have children who are hypervigilant.

Mother's perspectives are exemplified below, and also paired with their children's perspectives. Some mothers note how their child has become more proficient at food allergy management, which is reflected in their child's quotes, whereas one mother perseverated on awareness and this idea was also reflect in her child's language:

It's not that difficult to manage. I am also allergic to tree nuts. So, I think that makes it a little bit easier. It's just something that is I mean it's kind of just part of our daily life. It's just how things are. Checking food labels is just part of what we do so it's... not even a thing. We just check food labels, if he is getting a treat at school, he usually texts me a picture of the ingredient panel just to double check, even though he is super vigilant. He is great at identifying with what he can and can't have. – Casey's Mom

Looking at ingredients and everything that we buy. And, like every trip that he goes on, we have to make sure that there's food for him. So, it's still very scary because we have to make sure he takes his Epi Pens and all of that, but he's, he's very much more diligent, now that he's older. He knows more so what he can and can't have so we've kind of stepped back a little bit, but you know we're still involved – Luke's Mom

I kind of know what I can eat at this point. I read ingredients on everything. Look, for the kosher mark. That's about it, I guess. – Luke

From what I understand it's not a severe allergy. I still consume fish. The rest of our family consumes fish. I just don't serve fish to Lauren. We do have EPI pens right in the kitchen. Everyone's trained on how to use them... we always have to make sure that they have a current EPI pen. Um the nurse is aware. That's it. It's documented at school. And

anytime she does attend anything we make it known that she has a fish allergy. – Lauren's Mom

I always had to make sure that I was aware. I would always you know, look at the menu, see what they're serving because I don't want to take any chances of any type of cross contamination or anything or whatever they're serving. So, I always had to keep an eye out and if I didn't know what something was, I would ask one of my like cabin mates or one of my counselors just to make sure that it was either something I could eat or something that I couldn't eat. – Lauren

Casey's mom's experience was unique in that she has the same food allergy as her son, so she found managing his food allergy easy compared to her experiences growing up where tree nuts were everywhere and there was little awareness of nut allergies. She was grateful for the more rigorous and standardized labelling practices that are required now as opposed to when she was new to food allergy. On the other hand, it was apparent how Lauren's mom's stress of dealing with Lauren's fish allergy, a novel concept to her, was impacting mom's stress levels and was influencing the way Lauren thought about her allergy. Mom's hypervigilance and need for control was clear in the way Lauren discussed her allergy and how she always had to make sure everyone was aware so they could help keep her safe.

Implications

The themes identified in this study provide insight into how children with food allergy experience camp and how the accommodations put in place to serve them impact their experiences. Generally, campers reported a positive camp experience which was improved by high levels of trust in the safety of the food and connections with peers and staff that engendered feelings of inclusion. Liebel and Fenton (2016) also found trust was a critical aspect of the camp experience for children with SFA, with children reporting higher levels of trust in accommodating camps with staff that made them feel safe. This study offers examples of

specific actions staff can take to help cultivate feelings of trust and safety, such as providing food labels and allowing campers to see how the kitchen is set up for cross-contamination.

Even when instances of exclusion occurred, such as leaving the dining hall early with a safe treat while the rest of the camp ate a nut-containing dessert, campers reported feeling mostly included because instances of exclusion were brief, and they were never actually alone; they still had food allergic friends with them. Inclusion can be understood as a sense of belonging and acceptance (Stainback & Stainback, 1990), suggesting that while they were being temporarily excluded from a situation, campers still felt generally included because there was still a sense of belonging. Camp friends without food allergies also played a role in facilitating inclusion simply by being accepting and non-judgmental. Luke reported that his friends knew when it was acceptable to joke about food allergy and when a joke would cross a line, and Lauren talked about times her friends supported her in identifying safe or not safe food. Research on inclusion of children with disabilities has noted that inclusion is facilitated when children feel like a legitimate participant and have friends (Spencer-Cavaliere & Watkinson, 2010). Therefore, if camp experiences can provide these key features of legitimate participation, friendship, and a sense of belonging, they may better facilitate inclusion even if there are small parts of camp, such as a dessert or a special snack, that are not safe for campers with food allergies.

Experiences that facilitate feelings of inclusion do not need to be large or time-consuming activities. Mia loved that she could go to the canteen and buy candy like everyone else and felt included because there were safe treats that were “regular” treats. Likewise, Anthony and Casey just wanted to spend time with their friends in their bunk, doing nothing or hanging out. They didn’t want structured programs; they wanted the opportunity to simply be

kids. Luke found connection in helping the younger campers with simple tasks that might be challenging for a seven-year-old but are easy for a teenager.

The themes identified from this study suggest there are effective ways that camps can include children with SFA, and ways the camp experience could be modified to better serve this population. To make camp accessible to children with nut allergies, some camps have used the elimination method used by schools by banning nuts on campus (Mudd & Wood, 2011). While there is a desire by some parents for camps to use an allergen-free model like the Tier 1 camp, it is not feasible for all camps to move to this model, which is extremely costly. For example, the cost of wheat pasta is typically less than \$1/lb. whereas gluten free pasta may be over \$4/lb. Additionally, research shows that there is no significant difference in accidental allergen exposure between schools banning peanuts (the most commonly banned food) and those that do not (Tsuang & Wang, 2016). Researchers therefore suggest food bans should only be used in childcare settings for very young children who cannot make informed decisions about their food choices and may be prone to putting non-food items in their mouths (Behrmann, 2010; Tsuang & Wang, 2016). Traditional camps may wish to focus on avoiding cross contamination and having strict labelling practices to better serve campers with allergies to more common, or less easily avoided foods. Specialty food allergy camps and kosher camps are an excellent resource for guidelines and best practices on food separation and the prevention of cross contamination.

Camp is a unique youth development context that has been used by other populations, such as the diabetes camp community, to produce positive outcomes from children with chronic conditions (McAuliffe-Fogarty et al., 2007; Walker & Pearman, 2009). Avery et al. (2003) noted the well-established system of camp programs for children with diabetes and suggested such programs could be equally beneficial to children with food allergies. Such programs could

facilitate feelings of competence and control which could help mediate the high levels of fear and anxiety often faced by children with SFA on a daily basis (Spencer-Cavaliere & Watkinson, 2010). As seen in this study, campers with food allergies were faced with food-related anxiety at every meal if they were not confident that the camp had a well-rounded, safe meal for them. They were fearful of having reactions if a food was not safe, such as Lauren and her near miss with the fish sticks, and were also stressed by not having enough time to properly weigh their food options.

Adolescence is the most dangerous time for people with food allergies, as primary responsibility for food allergy management shifts from the parent to the child (Mudd & Wood, 2011; Sicherer et al., 2020). Camp leaders need to consider how they can provide an environment where adolescents can practice these critical food allergy management skills and balance the need for safety with autonomy, based on the age, competence, and self-efficacy of the participants. Sicherer et al. (2020) provide a breakdown of challenges to food allergy management across the lifespan. Table 3 builds on Sicherer et al.’s work to include how camp programs can safely accommodate campers or young staff with food allergy across the lifespan while supporting developmental needs.

Table 3.
Food Allergy Support in Camp Across the Lifespan

Age Group	Stakeholder with primary responsibility	Primary challenges	Accommodations	Staff involved
Grade school children	Guardian, camp, patient	Balancing independence with child’s limited ability to self-manage	Camp/parents needs to work together to provide safe food. Staff need to ensure camper is eating safe foods only.	Kitchen staff, healthcare staff, front line staff
Middle school children	Guardian, camp, patient	Balancing independence with	Camp needs to provide safe food.	Kitchen staff, front line staff,

		growing ability to self-manage	Staff need to supervise food choices*.	possibly healthcare staff
High school adolescents	Patient, camp, guardian	Risk-taking behaviors, less supervision causes more reliance on self-management	Camp needs to provide safe food. Campers should be able to select safe food or ask questions to identify safe food*.	Kitchen staff, front line staff to some extent
College aged young adults/staff	Patient, camp	Full dependence on self-management, risk-taking behaviors	Camp needs to provide safe food. Staff know how to identify safe food*.	Kitchen staff

*Labelling dishes with ingredients allows camper/staff with allergies to identify safe food without asking kitchen staff for assistance.

Limitations

The limitations of this study are primarily related to the methodology. This study was a qualitative inquiry founded in phenomenology but cannot be classified as a true phenomenology due to the lack of embeddedness in the research context. Data collection for this study occurred in the summer of 2021, the summer after COVID-19 caused many camps to close and so camps were just starting to resume more typical summer operations with high levels of non-pharmaceutical interventions. This non-traditional camp structure and level of security prevented the researcher from being embedded in a community, which would have allowed for additional layers of data collection and the generation of stronger rapport.

Additionally, due to lasting impacts of the COVID-19 pandemic, camps were operating with fewer campers. Small cohorts of campers meant there were fewer campers available to sample. The original study design called for the recruitment of three campers per camp, but due to a small sample from which to recruit, we were only able to recruit two campers per camp. In addition, there was one camper with celiac disease from the Tier 3 camp who was included as they had very few campers with clinical food allergies in the summer of 2021. Managing celiac disease and food allergy is a very similar process, so the data collected from this participant was

determined to be more valuable than not including them and having an uneven split of participants.

Another COVID-19 related consideration is the impact the pandemic had on typical teenage development. Most of the older campers had not yet had many typical teenage experiences of going to the mall with friends or going out to eat without their parents as they were too young to do so when the pandemic started. Therefore, participating in allergy management at camp was a more novel experience for them than it would be for the teenagers who were involved in studies that occurred prior to the pandemic, such as Mudd & Wood (2011).

Conclusion

Until there is a cure for food allergy, camps will continue to serve campers with a variety of food allergies in their programs. However, there has been a gap in translating the research about food allergy to practice in the camp context. This study highlights how camps have successfully supported campers with food allergies, and areas needing further consideration to best serve this population. By cultivating trust and providing transparency summer camps have an opportunity to not only accommodate children with food allergy by providing safe food, but to contribute positively to their development and provide opportunities to practice autonomy in a safe, supportive environment.

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CHAPTER FOUR

SERVING CHILDREN WITH FOOD ALLERGY AT CAMP: THE DISNEY EXPERIENCE

Abstract

Few studies have offered guidelines for safely serving children with food allergies in the camp setting. The limited research that exists focuses on anaphylaxis response and management, which is critical in the event of a reaction, but is a reactive approach. By studying three camps using different approaches to allergy management, this research identifies effective strategies for safe food service, as well as the outcomes associated with these strategies. This paper offers methods for serving campers with food allergies founded in best practices, research, and the features of positive youth development (PYD) settings. Camps serving children with food allergies should seek to do so in an equitable and safe manner, using strategies that support autonomy and decision-making, to encourage skill development as campers approach the risky teenage years (Marklund et al., 2007; Mudd & Wood, 2011).

Introduction

Every summer, camp programs serve children with food allergies in their typical summer camp programs. Nearly all camp programs, between 94% and 99%, serve children with food allergies in some capacity (Redmond et al., 2017; Schellpfeffer et al., 2020). It is therefore important for camp professionals plan for how they will safely serve this population of campers. While camps should strive for inclusion on principle, as a primary youth development context (Garst et al., 2011), it is of critical importance camps ethically serve campers with food allergy under the Americans with Disabilities Act, which classifies food allergy as a disability as it limits one or more major life functions (Americans with Disabilities Act, 1990).

Few studies have examined children with food allergies in summer camp, and the existing research primarily focuses on anaphylaxis management and response (Mudd & Wood, 2011; Redmond et al., 2016). Therefore, many camps look to literature on managing food allergies in the school setting where more research has focused (Muñoz-Furlong, 2004; Tsuang & Wang, 2016). School setting strategies include allergy free tables, food bans, and handwashing procedures. Camps then adapt these school setting strategies for their unique context, while also referring to the limited set of camp setting allergy management strategies, such as Mudd & Wood (2011). While these strategies may increase child safety, they may also differentiate children with allergies and potentially make them a target for bullying (Behrmann, 2010; Mudd & Wood, 2011). Additionally, certain strategies, such as food bans, may be more appropriate for younger children who cannot make informed decisions about their food choices and may be prone to putting non-food items in their mouths (Behrmann, 2010; Tsuang & Wang, 2016). Older children with food allergies need opportunities to practice allergy management in a safe supportive environment, as adolescence is a primary risk factor in death from food-related

anaphylaxis, as teenagers spend less time with parents and may take risks regarding food (Marklund et al., 2007; Mudd & Wood, 2011).

Positive Youth Development Settings

In this paper, we begin by examining positive youth development. Positive Youth Development settings have eight key identifiable features. These features are (1) physical and psychological safety, (2) appropriate structure, (3) supportive relationships, (4) opportunities to belong, (5) positive social norms, (6) support for efficacy and mattering, (7) opportunities for skill building, and (8) integration of family, school, and community efforts (Eccles & Gootman, 2002). For children with food allergies, these PYD setting features can be critical to developing skills to help them cope and thrive with their condition. Camp sessions often foster skill development through activities that include experiential learning, which has been found to be an impactful approach for facilitating new competencies (Wilson et al., 2019). Experiential learning in the camp setting may be particularly important for children with food allergies who need to develop critical competencies surrounding food allergy management. Experiential learning in the camp setting has been used for decades for children with diabetes to facilitate disease management skills, and similar processes could be used for campers with food allergies (Avery et al., 2003).

Overnight camps in particular, which prepare and provide the majority of food on site, may be ideal environments for campers to practice allergy management skills such as label reading, asking about ingredients, and carrying epinephrine (Sampson et al., 2006). Furthermore, overnight camps serve as a powerful context for youth development due to specific setting characteristics. The camp community often exists in a bubble, and the immersion in camp culture and norms assists in teaching the camp philosophy and goals effectively (Thurber et al., 2007).

Group living is a powerful context for growth, but also an equalizing factor where campers sleep in the same large spaces and eat the same food, without their expensive gadgets and clothing. This context can allow campers to explore their social identity and build social capital (Garst et al., 2011). Furthermore, living in the group setting can help children learn how to make friends and have positive peer relationships (Henderson et al., 2007). The staff are a major part of the safe environment of camp, and their importance cannot be overlooked. Staff play a role in creating and upholding the social norms at camp, which contribute to PYD through the focus on morals, values, service, and other positive attributes (Garst et al., 2011). Additionally, summer camp offers more unstructured time than other out of school time (OST) learning contexts, which allows for the formation of deeper relationships and self-confidence (Garst et al., 2011).

Guidance on allergy management in camps should consider the camper experience and also parental desires, as parents are the primary stakeholders in sending their child to camp (Richmond et al., 2022). Quality of life is a concern for children with severe food allergy (SFA) and their families as well, as SFA tends to decrease quality of life for both the child and their family (Avery et al., 2003). For example, parents of children with food allergies, particularly mothers, tend to have lower quality of life along with higher levels of anxiety and stress, than parents of children without food allergies (King et al., 2009). In order to reduce anxiety, and make parents feel safe in sending their children to camp, it is critical that camps cultivate trust with parent, caregivers, and children, as trust is a critical aspect of the camp experience for all campers (Garst et al., 2020) and especially those with food allergy (Liebel & Fenton, 2016). Parents want the “Disney Experience”: a safe environment, where trustworthy protocols and procedures have been implemented to assure food safety from purchase to plating (Authors, 2022).

Food Allergy Management in Camps

This paper examines food allergy management strategies at three camps implementing different approaches to allergy management to highlight best practices that may be useful for practitioners serving campers with food allergies. Best practices are those defined as strategies encouraging safety, a critical feature, but also autonomy and decision making, which are key skills for campers with food allergies to learn as they approach the dangerous adolescent years (Mudd & Wood, 2011; Sampson et al., 2006). The paper is framed by the features of positive youth development settings, and therefore highlights practices that are in line with the needs of children with food allergies and with the identified features of PYD settings. Because parents are stakeholders in the camp experience, best practices are also those considering the needs of parents, particularly addressing parent anxiety, which tends to be high in parents of children with SFA (King et al., 2009; Liebel & Fenton, 2016),

Current Models

The three camps were ranked from highest level of accommodation to lowest level of accommodation and labelled Tier 1, Tier 2, and Tier 3. The higher-level accommodations tend to be system level, or in place for the camp community as a whole, whereas lower-level accommodations are done on a camper basis, for only the camper needing the accommodation.

Tier 1 Camp

The Tier 1 camp is a food allergy specialty camp near Portland, OR only serving children with food allergies. Their kitchen excludes all top 9 food allergens, and their menu is designed to accommodate over 30 additional allergens reported by participants. The top 9 food allergens are milk, eggs, peanuts, tree nuts, soy, wheat, shellfish, fish, and sesame (FARE). One staff person is responsible for ensuring everyone, campers and staff, is aware of what extra allergens are in the

food and posts a detailed menu with every ingredient in every dish listed. Prior to each meal, this staff member would announce the meal, review the menu items, and highlight the extra allergens in each dish. Due to COVID-19, this camp was using a lunch line style of serving pre-portioned meals, but prior to COVID-19 was known for their buffet where campers could serve themselves.

Tier 2 Camp

The Tier 2 camp is a Jewish camp focusing on healthy eating, which serves kosher food and specializes in serving children with allergies. This camp is located in Eastern Pennsylvania and primarily serves children from in and around New York City. Their kitchen follows strict cross-contamination protocols to keep kosher and to separate allergens, and their dining hall offers an allergen-free table that is free of the top 9 food allergens. There are two kitchens in use for every meal: an allergen containing kitchen and an allergy-free kitchen. Food is served on a lunch line, with campers having the choice of the traditional food line or the allergen-free table. Allergen-free food is cooked and served by a team of staff who are identifiable as the allergy team. This team is available during meals to answer any questions and provide guidance on appropriate food choices.

Tier 3 Camp

The Tier 3 camp is a traditional summer camp with no universal accommodations or policies regarding food. This camp is located in Eastern Pennsylvania but serves a more diverse group from a more rural geographic area. All accommodations are made on an individualized basis via collaboration between the parents, the camp nurse, and the kitchen staff. The nurse is the primary staff member in charge of food allergy management. Some food allergy parents

choose to send supplementary food for their child, which is prepared separately from the main meal, while others request their child eat the main meal in consultation with the nurse.

Outcomes Associated with Current Models

Campers at the Tier 1 camp are offered a unique experience where the environment has been adapted to largely avoid their allergens, providing a unique respite. Summer camp as respite has been studied as providing respite to caregivers as well while campers attend summer camp (Shelton & Witt, 2011) and also as a respite for campers with disabilities, as they are surrounded with similar others in an environment meeting their needs (Devine & Dawson, 2010). Campers at the Tier 1 camp are further offered an opportunity for social acceptance. Social acceptance is defined a supportive environment with like others, which may offer the opportunity for friendship cultivation and social inclusion and has been found to be critical for youth with disabilities (Devine & O'Brien, 2007; Knapp et al., 2015). This model offers campers a rare experience to be part of the majority, similar to how diabetes camps offer children with diabetes a unique opportunity to be surrounded by similar peers. Such experiences with like peers can offer opportunities to learn about disease management and foster independence (Barone et al., 2016).

Campers at the Tier 2 camp are provided an integrated experience where they are cohabitating with campers both with and without food allergies, since the camp serves a much higher percentage of campers with food allergies than a typical camp. This offers opportunities for social comparison, which is a key feature of social identity, in which individuals define themselves in group and intergroup phenomena. The self is defined as an object with the attributes of the group with which the individual identifies (Hogg & Ridgeway, 2003). This process of defining the self in accordance with social categories is called self-categorization, and

this process results in identity formation (Stets & Burke, 2000). The resulting social identity bridges the process between group phenomena and the individual's behavior and can help in the development of the sense of self (Hogg & Ridgeway, 2003). This sense of self is critical as campers begin to negotiate adolescence and the rapid changes occurring throughout that phase, while becoming more independent from their parents. Additionally, campers at the Tier 2 camp are offered opportunities to practice allergy management skills, such as label reading, asking about ingredients, carrying epinephrine (Sampson et al., 2006) and autonomy, which is critical for children with disabilities but may be limited at times due to fear (Gagnon et al., 2020).

Campers at the Tier 3 camp are integrated in a camp setting largely serving children without food allergies. Therefore, they may be at risk of being differentiated due to allergy safety protocols (Behrmann, 2010) but they may also have the greatest opportunity to practice allergy management and autonomy, as there is not a large team of staff responsible for allergy management. Therefore, campers must practice self-advocacy by asking about ingredients (Sampson et al., 2006). The Tier 3 camp also provides opportunities to facilitate trust in staff, which is critical aspect of the camp experiences for children with food allergies (Lieber & Fenton, 2016) due to continuous collaboration with the camp health care staff. Parents and campers develop a close relationship with the health care staff and trust that this person is always available for questions or concerns.

Best Practices for Allergy Management

Inclusion and safety are key features of PYD setting and are primary concerns when designing strategies for food allergy management. Many times, strategies must balance these two potentially conflicting concerns, as common strategies for reducing the risk of food allergy reactions in communal settings can be exclusionary or ethically flawed if done improperly

(Behrmann, 2010). Such strategies are those that mark food allergy children as different, such as an allergen free table for them to sit at, which can make them a target for bullying (Behrmann, 2010; Muñoz-Furlong, 2003). Therefore, it is important food allergy management strategies keep campers safe from the consuming allergen containing food, as well as safe from bullying.

Camps should consider implementing a policy, systems, environment (PSE) lens for the design and implementation of food allergy management strategies, to ensure safety at multiple levels. Policy, systems, environment is a strategy for change that adapts the environment and providing a setting in which individuals can more easily make healthy, appropriate choices for safety (Bunnell et al., 2012). This environment is supported by systems that change rules in the organization and alter infrastructure and policies that mandate or encourage the changes being made (Bunnell et al., 2012). In the camp setting, this might look like policies that require the kitchen accommodate food allergies, with systems that outline cross contamination procedures and safe food acquisition guidelines, and an environment in which safe food is clearly labelled and easily accessible. These PSE-based strategies can be used to facilitate a positive environment to support campers in making safe choices while providing a secure setting.

Therefore, camps must take a multipronged approach to managing food allergies at camp, considering the environment, the food, and the emergency response plan. The following sections details concerns and best practices for managing these areas. These best practices are data informed practices derived from the Tier 1 and Tier 2 camps kitchen manuals, best practices identified in the food allergy literature (Mudd & Wood, 2011; Sicherer 2020), and the features of PYD settings (Eccles & Gootman, 2002).

Providing Safe Food

To provide safe food, camps must start with equipping staff with the knowledge to properly read labels to ensure kitchen staff are aware of what allergens are contained in each food. When labels are insufficient or ambiguous, staff may need to categorize the food as unsafe, or call the manufacturing company to get additional information about the production of the product. Kitchen staff must be educated on cross contamination and how to keep safe food away from allergen containing foods. A system for color coding prep utensils may be useful for ensuring, for example, spoons used to stir peanut butter are never used in peanut-free foods. Food should be labelled in a way allowing campers to make choices about food that is safe for them to consume. For younger campers, this may mean highlighting allergens and having a staff member assist in identifying safe food, whereas for older campers it may be sufficient to write out the ingredients contained in each dish. It is also critical to ensure campers with food allergies still have access to a balanced meal if one dish is not safe for them to consume. Therefore, a staff member in charge of meal planning should ensure all campers can eat a variety of food groups while still avoiding allergens.

Providing campers with enough time to make decisions about safe food is also important. Campers at the Tier 2 camp reported feeling rushed in the food service line and wanted more time to ensure they were making safe food decisions. For camps using a buffet line, staff may wish to print a menu campers can consult before coming to the dining hall, whereas camps serving family style can place a menu on the table so campers can consult the menu while waiting for dishes to arrive. It is also important that campers have access to the kitchen staff who prepared the food, so they can ask them questions directly to avoid miscommunications.

Creating a Safe Environment

A safe environment is one that is both physically and psychologically safe (Eccles & Gootman, 2002). In the food allergy context, a key facet of a safe environment is it is free from accidental exposure to allergens. Most children who are camp aged are able to avoid eating foods that are not safe or putting non-food items in their mouth (Tsuang & Wang, 2016). Camps need a system for scheduled hand washing to ensure campers are not bringing allergens into or outside of the dining hall on their hands. There should also be a system for cleaning frequently touched surfaces that may spread allergens, such as door handles, counters, and serving utensils. Some camps may choose to integrate this step into dining rooms chores campers assist with or may choose to have specific staff assigned this duty. It is important to note that campers with food allergies should not be asked to clean surfaces that may have contact with their allergens. While contact reactions are rare and unlikely to cause significant reactions (Simonte et al., 2003), children with food allergies live with high levels of anxiety about food related reactions (Avery et al., 2003; Rawson & Barnett, 1993), and therefore should not be asked to be in close contact with their allergens.

An emotionally safe environment is equally as important as a physically safe environment (Roth & Brooks-Gunn, 2016). The camp setting is a supportive environment including many traditions that create strong emotional ties to both the camp as a special place and the experiences had at camp (Garst & Whittington, 2020; Wilson et al., 2019). Staff create and uphold camp social norms, which contribute to positive youth outcomes through the focus on morals, values, service, and other positive attributes. This supportive environment may act as a protective factor against bullying, as this intentionally designed community may foster inclusion, or a sense of belonging, acceptance, and value (Stainback & Stainback, 1990), while

close peer relationships and support from friends can be protective factors against bullying (Mudd & Wood, 2011).

Emergency Response Plan

Camps should implement developmentally appropriately, individualized plans for each camper that allows the camper to make choices regarding food offerings and allergy management (Leibel & Fenton, 2016). This individualized health plan is the first step of the emergency response plan, as it seeks to avoid allergic reactions. In the event of an allergic reaction, camps need to ensure their plan meet the standards set by the American Academy of Allergy, Asthma, and Immunology (AAAAI). These standards include steps such as using epinephrine as a first line therapy and seeking immediate medical attention, and only using antihistamines as an adjunctive therapy rather than a replacement for epinephrine (DaVeiga, McColgan & Becker, 2005; Shaker et al., 2020).

Strategies for Safety

Camps can take many steps to better serve campers with food allergies. Some of these steps are useful universal precautions, while others may be necessary only for younger campers or campers with low autonomy. Table 4 offers a visualization of various strategies to safely serve campers with food allergies in a developmentally appropriate manner. These classifications are based on typical developmental abilities, as well as the need to appropriately prepare campers for adolescence before they reach the risk-taking years of later adolescence (Mudd & Wood, 2011; Sampson et al., 2006). The table presents strategies in a time-oriented manner, from when food enters the site to when it is consumed by campers.

Table 4.
Strategies for Food Allergy Safety for Developmental Stages

Strategy	Use for Elementary School campers	Use for Middle School campers	Use for High School campers
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Kitchen has clear knowledge of allergens contained in foods	Always	Always	Always
List of allergens in each dish	Always	Sometimes	Sometimes
List of ingredients in each dish	Sometimes	Sometimes	Always
Staff available to answer questions	Always	Always	Always
Staff supervise food choices	Always	Sometimes	Sometimes
Safe plate made for camper	Sometimes	Sometimes	Never
Self-carried epinephrine	Sometimes	Always	Always
Camper has knowledge of emergency response plan	Sometimes	Always	Always
Camper has ability to recognize allergic reaction	Sometimes	Always	Always

Conclusion

Serving campers with food allergy is a reality for many camps, and camp providers need to ensure they are prepared to safely serve this population. Camps need to ensure they are ready to source, prepare, and serve safe food that is free of allergens, while also providing campers with an equitable experience. This paper suggests strategies for providing campers with food allergies equitable experiences that also support autonomy, decision making, and other PYD outcomes. Summer camps have an opportunity to use their established PYD context to support this vulnerable population of campers with food allergies in a more effective and equitable manner, to improve short-term and long-term outcomes for these campers with food allergies.

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CHAPTER FIVE
CONCLUSIONS AND FUTURE RESEARCH

Introduction

Food allergy in summer camp is an under-researched topic requiring additional study to shape best practices and provide guidance for practitioners. This dissertation started with a scoping review as Paper 1 that identified the need for additional research in the area of food allergy in summer camp, particularly qualitative research that presented the perspectives of children with food allergies. Paper 2 was a qualitative study based in phenomenology to begin filling that gap in the literature. In addition to painting a picture of the experience of residential summer camp with a food allergy, this study identified numerous strategies for safety that were being implemented in camps across the country. Paper 3 then looked at identifying best practices among those strategies for safety using autonomy, safety, and positive youth development setting features as guides.

The next step in this process of making camp a better environment for children with food allergies is broadening application of these strategies to improve health and safety outcomes for campers. These strategies could include, for example, (1) new policy at the national level to change camp programming at the individual camp level, and (2) education that integrates the healthcare and camp communities and (3) a framework to advance advocacy work to improve accommodations for campers with food allergies. The following sections explain how each of these strategies could be implemented within the camp community to address the needs of youth with SFA.

New Policy at the National Level to Change Camp Programming

The American Camp Association (ACA) is the leading authority on summer camp experiences, providing research, education, and training to a wide range of camp professionals in order to offer safe camp experiences to participants and their families (American Camp Association). The ACA offers a national accreditation for camps that promotes health, safety, and risk management and these standards are used as national benchmarks (American Camp Association Accreditation). These standards are published in a resource for camp providers called the *Accreditation Process Guide* (American Camp Association, 2019). Within the *Accreditation Process Guide* (American Camp Association, 2019), the Health and Wellness section focuses on ensuring healthcare at camp follows best practices and prepares providers to offer high quality care.

Currently, the only mention of food allergy related healthcare in the Health and Wellness standards is HW.13 Medication Storage and Administration, which notes that a “limited amount of medication for life-threatening conditions” (American Camp Association, 2019, p. 149) need not be stored under lock and can instead be carried by the camper or staff person. The American Camp Association should revisit their Health and Wellness standards to better reflect the severity of anaphylaxis and align their standards with American Academy of Allergy, Asthma, and Immunology (AAAAI) guidelines. This would include requiring that campers bring their own epinephrine autoinjector device to camp, using epinephrine as a first line therapy for allergic reactions, and using antihistamines as an adjunctive therapy rather than a replacement for epinephrine (Shaker et al., 2020). There is precedent for such standards that reflect leading national organizations guidelines in the *Accreditation Process Guide*, such as Health and Wellness standard 12 (HW.12) which requires that an Automated External Defibrillator (AED)

be available as per authoritative sources such as the American Red Cross and the American Academy of Pediatrics.

As a leading authority in camping, the ACA is the prime voice to make policy-level changes within the camp industry, reflecting the work of the association itself, as well as other intermediaries such as the Alliance for Camp Health (ACH). Working together, ACA and ACH could create policies to impact systems and environments that would promote safety for campers with food allergies. Camps revisit their accreditation status every five years, requiring camps to keep up to date with the standards as they adapt to reflect the changing industry. Therefore, action by ACA and ACH to update the *Accreditation Process Guide* could ensure that all accredited camps are providing safer camp experiences for campers with food allergies in five years or less. While national level policies could help change practices, support and education is needed on the individual level to help campers learn and thrive in these improved camp programs.

Enacting change in the management of a large issue, such as food allergy, requires multiple levels of intervention. Policy, systems, and environment (PSE) is a framework that could give structure to these levels of intervention. PSE is a three-part conceptual framework for change that seeks to adapt the environment and provide a setting in which individuals can more easily make healthy choices (Bunnell et al., 2012). This environment is supported by systems that change rules and infrastructure in the organization or setting and policies that mandate or encourage the changes being made (Bunnell et al., 2012). Within camp settings, most food allergy management accommodations are currently made at the environment level: camps provide special meals or use good cross contamination avoidance procedures to provide safe food. This is also true outside the camp setting where schools offer allergy-free tables or nut-free

classrooms. Little policy exists to ease the struggles associated with food allergy management aside from FDA labels on prepared products (Food and Drug Administration). Action from the American Camp Association in including food allergy management in the accreditation standards, plus education from the Alliance for Camp Health to help camps implement new standards could provide structure to food allergy management plans across camps.

PSE change can happen at local and national levels. On the local level, camps could implement policies that require the kitchen accommodate food allergies, with systems that outline cross contamination procedures and safe food acquisition guidelines, and an environment in which safe food is clearly labelled and easily accessible. At the national level, legislation to improve access to allergen-free food through clearer labelling practices could create systems for manufacturing that limit cross contamination, leading to safer environments as people have increased access to clearly labelled food in their local grocery stores. As food allergy continues to increase in prevalence and severity, such accommodations are necessary to keep people with food allergies safe.

Education to Integrate Healthcare and Camp Communities

As children with food allergies transition to adolescence and ultimately adulthood, the responsibility for food allergy management shifts to them from their parents or caregivers (Mudd & Wood, 2011). Skills such as label reading, asking about ingredients, and using epinephrine are critical skills for safety (Sampson et al., 2006). Problem based learning (PBL) is an educational strategy where learners are taught problem solving by being presented with a specific, realistic problem to solve using their general knowledge of a topic (Mulvaney et al., 2011). Through solving these realistic problems specifically tailored to situations they may encounter, learners are able to increase their decision-making abilities and ability to self-manage issues. PBL has

been used successfully with adolescents with Type-1 Diabetes (Mulvaney et al., 2011), and as well as in more general populations for other chronic conditions such as asthma and arthritis (Williams & Pace, 2009). Learners increase their skills, self-efficacy, and ability to apply factual knowledge (Williams & Pace, 2009). These outcomes and skills are critical for people with food allergies, and therefore PBL may be an excellent approach to build these capacities.

PBL scenarios that depict other teenagers facing these issues in real-world scenarios could help adolescents practice proper food allergy management in safe, hypothetical setting. PBL interventions may not be appropriate for all camp settings, especially those where campers with food allergies are the minority, however PBL interventions may be useful for camps such as the Tier 1 camp where all campers have a diagnosed food allergy. Tier 1 already places emphasis on food allergy management and makes this management part of the daily routine. Therefore, adding in an extra educational intervention may help campers process their food allergies and the ways in which they are already managing their food allergies at home and at camp. Doctors' offices and educational organizations such as Food Allergy Research and Education (FARE) may wish to consider developing PBL modules for patients and families dealing with food allergies. Additionally, ACH may wish to consider how PBL interventions could be used to support camp healthcare staff in serving campers with food allergies and in teaching non-medical staff how to react to food allergy situations. Updates to the *Accreditation Process Guide* and the use of PBL interventions are part of a multi-pronged approach to improving allergy management in camps at a structural and individual level.

A Framework for Advocacy

The International Classification for Functioning, Disability, and Health (ICF) is a framework created by the World Health Organization (WHO) to organize information on

functioning and disability. The ICF “conceptualizes functioning as a dynamic interaction between a person’s health condition, environmental factors, and personal factors” (WHO, 2013). As such, a person experiences functioning in various areas on a sliding scale that are impacted by the health condition itself, the nature of the environment in which the person is operating, and various other factors that are unique to the individual. The ICF is a tool that can be used for evidence-based advocacy as it reaffirms that all categories of rights apply to all people, regardless of their level of functioning in one or many areas (WHO, 2013).

This framework may be helpful to the food allergy community as people with food allergies have limited functioning in the area of eating but did not identify as disabled in the current study. Many families of children with food allergies reported wanted higher levels of inclusion and accommodation: they wanted their child to be able to eat school lunch or attend whatever camp they wished. The campers echoed these sentiments, wishing they could eat food that was not sent from home in a larger range of settings. The Americans with Disabilities Act (ADA) classifies food allergy as a disability as it limits a major life function, but people with food allergies are not likely to invoke the ADA to gain access to the accommodations they seek as they do not classify themselves as disabled and neither do their families (Authors, 2022).

The ICF could be a bridge to help families of children with food allergies see that their child has a functioning limitation that impacts certain areas of their life and that changes to the environment would lessen that limitation. For example, at the Tier 1 camp, children with food allergies contained within the top 9 are essentially free of food related limitations at camp as all the food served is safe for them to eat. While a totally allergen-free environment is unlikely in most contexts, the burden of the functioning limitation would decrease and therefore increase the level of functioning if the environment was better suited to the child with food allergies. If a

child has safe food to eat, the impact of the limitation is lessened as they are able to eat with everyone else. Thus, the ICF could be used as a tool to help families of children with food allergies understand the benefits of invoking the ADA in order to gain access to the accommodations they are looking for, and that they deserve.

Conclusion

Research on SFA examined in this dissertation has numerous programmatic and policy implications and extensions, and a variety of future directions are suggested. There is work to be done in expanding the available research on SFA in summer camps to help researchers, educators, and practitioners identify best-practices and to understand the impacts of various interventions and accommodations on campers' experiences at camp with a food allergy. In addition, education is needed to empower camps to serve campers with food allergy more safely and equitably by encouraging camps to implement safe service policies slowly over time. Finally, advocacy work by industry leaders and intermediaries should push for inclusion so people with food allergies have access to camp settings, which may be done through use of the ICF and ADA. Until a cure is found for food allergy, this work is critical to maintain the health and well-being of people with food allergies.

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APPENDICES

Appendix A. Scoping Review Chart

Authors, Year	Title	Method	Sample	Select Findings	Suggestions for Research	Suggestions for Practice	Limitations
DaVeiga, McColgan & Becker, 2005	Compliance with guidelines for the treatment of accidental ingestion in patients with life-threatening allergies in a camp setting	Retrospective record review	8,526 children avg age of 9 years old in Northeastern US summer camps	1.5% of children had a life-threatening allergy. Only 62% of instructions recommended epinephrine as first-line therapy.	NA	Educational efforts to promote the entire set of guidelines for managing anaphylaxis	NA
Gonzalez-Mancebo et al., 2019	Analysis of the effectiveness of training school personnel in the management of food allergy and anaphylaxis	Pre-and-post test survey (8 questions followed by a clinical case) administered before and after a conference intervention	191 participants (51% dining-room monitors, 24% teachers, 13% cooks, and 12% others) from Allergy unit of University Hospital in Feunlabrada, Spain	43% reported having never received food allergy training. Participants improved their general knowledge and knowledge on anaphylaxis management	Future use of self-efficacy scale by school staff to identify areas for future training.	School and “canteen” staff need training in the management of food allergies	NA
Greenhawt et al., 2010	Food allergy preparedness of summer camps	Web-based 30-question survey	167 parents	78% of campers had action plans and 66% maintained at least 2 epinephrine devices. Peanut and tree nut allergic campers more likely to have multiple epinephrine devices	NA	NA	NA

Authors, Year	Title	Method	Sample	Select Findings	Suggestions for Research	Suggestions for Practice	Limitations
Knibb & Hourihane, 2013	The psychosocial impact of an activity holiday for young children with severe food allergy: a longitudinal study	Longitudinal survey design (pre, post, 3-month, and 6-month data collection points) with 4 measures.	24 children (17 male and 7 female) w/average age of 11.46 years old with clinically confirmed allergy	Significant improvements in social QoL, food allergy specific QoL, total locus of control and internal locus of control score over time	Research needed to evaluate interventions such as the Anaphylaxis Campaign activity holiday.	Future holidays recommended , possibly with follow-up sessions focusing on children and adolescents taking more responsibility for their food allergy.	Small sample size. Uneven gender split. Questionnaires were completed in different settings (at the activity holiday and at home)
Markus, 2017	Battle against food allergy isolation: A quantitative exploration of self-perspective in children with food allergies	Resiliency Scales for Children and Adolescents (RSCA) and Beck Youth Inventories-Second Ed (BYI-2)	70 minors between ages 8 and 18, who had a food allergy and attended Camp Blue Spruce	Significant relationship between Sense of Mastery and Sense of Relatedness, significant differences compared to published norms on anger and disruptive behavior	Survey development to assess emotional reactions to camp with larger studies. Interviews with campers to gain in-depth perspective	NA	Exclusive camp means limited sample (affluent mostly West Coast), sample primarily Caucasian, minor self-report, short camp session
Olympia et al., 2015	Compliance of camps in the US with guidelines for health and safety practices	Cross-sectional web-based survey	2,570 camp administrators (433 completed a questionnaire) from US summer camps	15% never of camps never practice emergency response plan. Medically related camps, ACA-accredited camps, residential camps were more likely to be compliant with guidelines for health and safety practices.	Future studies involving simulated medical emergencies or disaster models in a camp setting needed to determine if compliance affects outcomes such as survival rates and morbidity.	Camps need more robust emergency response plans that are practiced annually	Compliance may have been overestimated due to response bias, non-response, or other sampling effects.

Authors, Year	Title	Method	Sample	Select Findings	Suggestions for Research	Suggestions for Practice	Limitations
Redmond et al., 2016a	Food allergy prevalence and management at an overnight summer camp	Retrospective review of enrollment database; Pre and 30-day post training session survey administered to camp staff measuring food allergy knowledge and comfort	445 campers (209 male and 236 female) w/average age of 12.4 years old from camp for children with special medical needs	15% of campers had at least one food allergy, only 32% of those campers supplied an epinephrine autoinjector. Camp staff who felt very comfortable caring for campers with food allergy increased from 16% to 46%	This study should be replicated in other US camps, including those that are not for children with special medical needs	Food allergy educational sessions should be included in staff training. Summer camps should adopt structured enrollment criteria for all children reporting food allergies	Details regarding camper medical history were unavailable, so parents provided self-report data that could have been influenced by parents' self-report bias, low response rate
Redmond et al., 2017	Understanding anaphylaxis in camps: A study measuring demographics, knowledge, and incidence of allergic reactions	Analysis of de-identified online survey data collected from camps	158 directors and 141 medical personnel, 211 staff from 57 camps	99% of camps reported at least one camper with food allergies; 35% require food allergy action plans; 81% carry stock epinephrine and 34% of staff reported never receiving any food allergy training	NA	Camp personnel need training about treatment of anaphylaxis to properly care for campers with food allergies.	NA
Redmond et al., 2018	Anaphylaxis knowledge in camp personnel	Online survey of camp personnel	Survey data were collected from 158 Camp Directors (CD), 141 Medical Personnel (MP), and 198 Camp Staff (CS).	35% of CD and 34% of CS reported no prior food allergy education. In CS who were authorized to administer epinephrine (40%) 51% reported training in the last 12 months and 14% no prior training.	NA	Focused education should be provided to all summer camp employees at least annually	Limitations include the low response rate for CD compared with MP (6% and 26%), selection bias both in previous training and region of the country

Authors, Year	Title	Method	Sample	Select Findings	Suggestions for Research	Suggestions for Practice	Limitations
Redmond et al., 2016b	Food allergy knowledge among summer camp personnel before and after an evidence-based educational session	Survey data collected following a 1-hour food allergy training	68 campers reported on their food allergy. 43 camp personnel ages 18-24 years old completed the training	Respondents correctly identifying self-injectable epinephrine as first-line anaphylaxis response increased from 88% to 100%. 25% reported no previous training on proper use of epinephrine	NA	Inclusion of educational resources providing basic food allergy management skills targeted at summer camps should be considered a mandatory part of all training	NA
Rimárová et al., 2018	Compliance with gluten-free diet in a selected group of celiac children in the Slovak Republic	Cross-sectional observational anonymous questionnaire, self-administered questionnaire to children and parents	Children with Celiac attending specialized summer camp (223 girls, 102 boys) and their parents	Strict adherence to the GF diet was maintained by 69% of children, less frequent was lower compliance with the diet (31%). Compliance with GF diet was higher among girls vs boys	NA	NA	Bias in selection of the study population as parents whose children attend camp may be more alter to patient's health than non-participating parents.
Schellpfeffer et al., 2017	Food allergy trends and epinephrine autoinjector presence in summer camps	Deidentified EHR data were abstracted from 170 camps	122,424 campers (48% male, 52% female) w/median age of 11 years old	2.5% of campers had documented food allergies. Of these campers, 22% had multiple food allergies. 39.7% of food-allergic children brought an epinephrine autoinjector to camp	Collect additional survey data from camp administration to assess barriers, policies, and knowledge deficits to develop tailored training	NA	Not all camps had food allergy data available. Food allergy prevalence assessment was limited to parent-entered food allergies

Authors, Year	Title	Method	Sample	Select Findings	Suggestions for Research	Suggestions for Practice	Limitations
Schellpfeffer et al., 2020	Camp leadership perspectives on food allergy-related anaphylaxis events and training for camp staff: A national survey of summer camps	20-question web-based survey distributed through an EHR (CampDoc)	559 camp leaders representing 258 available camps	Most camps (94.6%) reported food-allergic children attending their camps. Anaphylaxis treated with epinephrine was reported by 24% of camp leaders within the past 2 years; those leaders were more likely to have staff training session	Conduct a study to determine how stock epinephrine autoinjectors are obtained and paid for by camp leadership. Complete a cost analysis study of stocking epinephrine autoinjectors in summer camps.	Develop educational materials created by key pediatric allergy stakeholders to be used for staff education on anaphylaxis and epinephrine administration training.	Data were collected retrospectively and therefore a recall bias may have influenced data accuracy. Response bias as responding camps may not be entirely representative of the overall camp community.
Shani et al., 2022	The potential benefits of camps for children and adolescents with celiac disease on social support, illness acceptance, and health-related quality of life	Retrospective cross-sectional design among adolescents and emerging adults (ages 14-22) via online survey	165 participants who attended celiac camp in Germany in recent years	Participants who attended at least one camp reported having more friends with Celiac Disease and less anxiety compared with those who did not attend any camp. Campers also had higher average scores of illness acceptance compared with noncampers.	Studies needed to evaluate methods found to be effective in medical specialty camps, such as facilitated discussions aiming to increase self-efficacy and autonomy or educating on the risks of nonadherence.	Healthcare professionals and caregivers should refer young people with CD to take part in recreational activities designed for their needs, with encouragement for CD societies to offer such activities for their members.	Retrospective cross-sectional design prohibits causal inference. Adolescents who are better adapted and are more interested in socializing with similar others may also be those who seek out camps
Twarog, 2001	Food allergy awareness at overnight summer camp	Mailed questionnaire	150 camp directors (40 were completed, all had experience with food-allergic campers)	The most common approach to avoiding exposure was by offering alternative to meals and specific items. Other accommodations included prohibiting food in bunks and prohibiting the sending of food to camp	NA	Additional food allergy awareness training is needed in summer camps.	NA

Authors, Year	Title	Method	Sample	Select Findings	Suggestions for Research	Suggestions for Practice	Limitations
Wahl et al., 2015	The evaluation of a food allergy and epinephrine autoinjector training program for personnel who care for children in schools and community settings	Descriptive, observational mixed method design including written surveys, online surveys, and phone interviews.	4,818 summer camp nurses and school administrators at 247 sites	55% of primary respondents reported prior training on the recognition and prevention of food allergy reactions. Overall, 66% of respondents reported that they were likely or somewhat likely to change the way they managed food allergies	NA	School nurses should be provided with the resources and time to ensure that all staff at facilities that care for children are familiar with existing emergency plans for all of the children under their care.	No control group was used in this study. Possible recall bias. Duplicate survey responses may have been collected from the same person due to the data being collected anonymously.

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