ABSTRACT

Title of Dissertation: PARENTAL HEALTH LITERACY, EMPOWERMENT, AND ADVOCACY IN THE CONTEXT OF FOOD ALLERGIES MANAGEMENT IN SCHOOLS

Laura Warnock Koo, Doctor of Philosophy, 2021

Dissertation directed by: Research Professor Alice M. Horowitz, Department of Behavioral and Community Health and Endowed Professor and Director, Horowitz Center for Health Literacy, Cynthia Baur

Background: Health literacy, empowerment, and advocacy may be important for parents when they communicate with schools related management of their child's food allergies. Understanding prevention and emergency management of life-threatening food allergies may require high levels of health literacy and may be overwhelming to parents. Yet, parents are often the drivers of school food allergy safety practices. Mixed evidence supports the relationships among communicative health literacy, critical health literacy, and empowerment in chronic disease management.

Objective: This cross-sectional study examines the relationships among parental health literacy, particularly communicative and critical health literacy; empowerment; and advocacy in the context of food allergies management in elementary schools.

Methods: Parents of children with food allergies were recruited through food allergy organizations to complete an anonymous 20-minute online survey. Measurements of parental health literacy, empowerment, and advocacy were adapted from validated scales or the literature and refined through pre-testing and pilot-testing.

Results: Participants (N=313) were predominantly white, college-educated mothers with moderately high food allergy knowledge, health literacy, and empowerment. Their children were allergic to an average of three food allergens and nearly half had asthma. Parents who scored at the highest levels on measures of communicative health literacy, critical health literacy, and empowerment engaged in advocacy behaviors perceived to be more effective than parents who scored at the lowest levels. However, this statistical difference may not represent a clinically significant difference. Communicative and critical health literacy were not more strongly associated with advocacy than functional health literacy. Empowerment and quality of the parents' relationship with the school were the strongest predictors of the parents' perceived effectiveness of advocacy efforts. The relationship between parental health literacy and advocacy was mediated by empowerment with a moderate effect size, but reverse causality between health literacy and empowerment could not be completely ruled out.

Conclusions: Parental health literacy may impact the effectiveness of advocacy efforts for safe food allergies practices in schools, with parental empowerment possibly mediating the relationship between health literacy and advocacy. Longitudinal studies with diverse samples should verify findings. Health professionals should encourage parents to build good relationships with school personnel and help to empower families when educating them about food allergies management.

PARENTAL HEALTH LITERACY, EMPOWERMENT, AND ADVOCACY IN THE CONTEXT OF FOOD ALLERGIES MANAGEMENT IN SCHOOLS

by

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List of Abbreviations

CDC – Centers for Disease Control and Prevention

eHeals – eHealth Literacy Scale

FAQOL-PB – Food allergy quality of life – parental burden (modified)

FARE – Food Allergy Research and Education

FCCHLS – Functional, Communicative, and Critical Health Literacy Scale

FDA – Food and Drug Administration

HL – Health literacy

NASEM - National Academies of Sciences, Engineering, and Medicine

NVS – Newest Vital Sign (a measure of health literacy)

Chapter 1. Introduction

Section 1. Statement of the Problem

Food allergies are associated with severe allergic reactions that can be life-threatening. The elementary school setting may increase the risks of severity or fatality associated with food-induced anaphylaxis due to potential for delays in recognition of anaphylaxis or delays in administration of life-saving epinephrine (Bock et al., 2007; Greenhawt & Weiss, 2012; Nowak-Wegrzyn & Conover-Walker, 2001; Sicherer et al., 2001; Szychlinski et al., 2015; Warren et al., 2018). The large quantity of complex recommendations to prevent exposure to food allergens and to identify and respond to life-threatening anaphylaxis may be overwhelming for parents. Parents may need high levels of health literacy and empowerment to understand and advocate for many everyday food allergy practices recommended by complex school guidelines (Centers for Disease Control and Prevention, 2013) to ensure their child's safety at school. Yet, with the challenge of limited comprehension of recommended school guidelines, parents are often the initial drivers who request implementing food allergy safety practices in schools (Lawlis et al., 2017). Growing evidence points to health disparities in food allergy-related anaphylaxis, emergency department visits, and emergency healthcare costs among minority or low-income children compared to white and high-income children (Bilaver et al., 2016; Gupta et al., 2011, 2014; Mahdavinia et al., 2017; National Academies of Sciences, Engineering, and Medicine, 2017; Shah et al., 2014). This study examines how parental health literacy and empowerment impact parental advocacy behaviors for food allergy safety practices to be enacted in elementary schools.

Health literacy, empowerment, and advocacy are interrelated concepts that may be associated with health behaviors and health outcomes (Nutbeam, 2000). Personal health literacy is the degree to which individuals have the capacity to obtain, communicate, appraise, and understand health information and services to make informed and shared health decisions for themselves and others (an adapted definition) (Edwards et al., 2012; Pleasant et al., 2016; Santana et al., 2021; Smith et al., 2013; United States Congress, 2010; von Wagner et al., 2009). Health literacy is composed of functional, communicative (interactive), and critical health literacy skills (Nutbeam, 2000, 2008). It is more than basic literacy skills, encompassing higher cognitive skills such as social and analytical skills (Nutbeam, 2000; Sorensen et al., 2012; von Wagner et al., 2009).

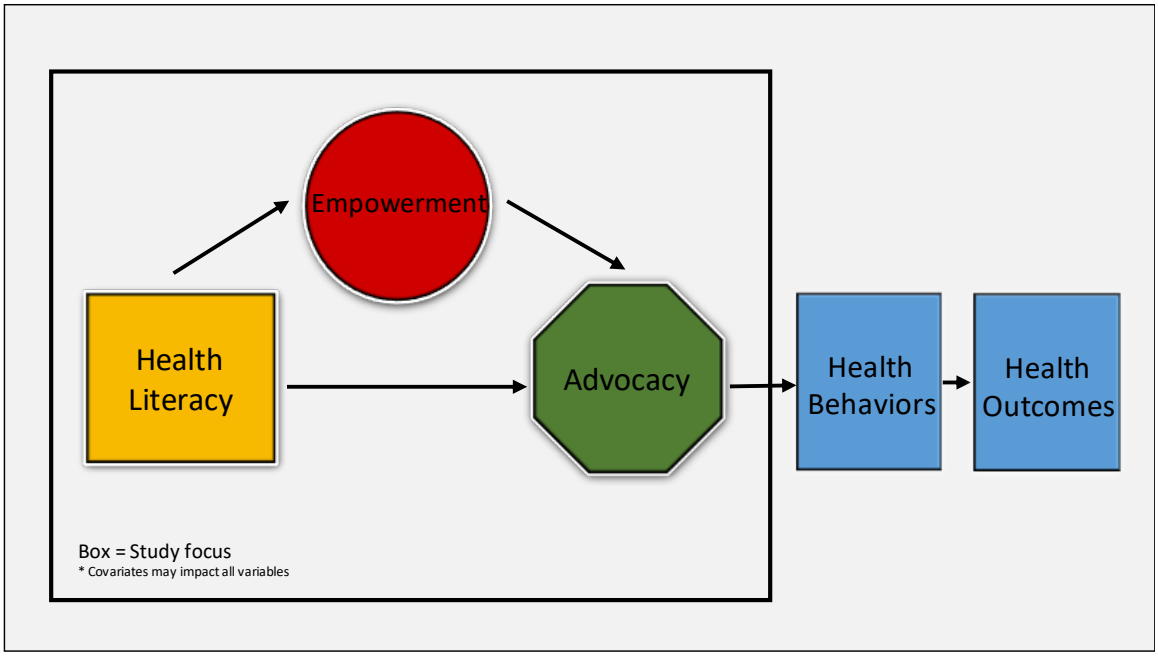
A challenge with Nutbeam's conceptualization of health literacy is that critical health literacy seems conflated with empowerment and advocacy, but Nutbeam also theorizes that critical health literacy *leads to* empowerment (Chinn, 2011; Ishikawa, Nomura, et al., 2008; Ishikawa, Takeuchi, et al., 2008; Nutbeam, 2000, 2008, 2009; Sykes et al., 2013). In Nutbeam's health promotion model, empowerment leads to social action on the social determinants of health to influence health outcomes (Nutbeam, 2000). Some researchers argue that critical health literacy is conceptually distinct from both empowerment and from advocacy (Chinn, 2011; Chinn & McCarthy, 2013; R.-H. Wang et al., 2016). Some evidence suggests that communicative and critical health literacy may be more strongly associated with chronic disease management behaviors and health outcomes than functional health literacy, especially in adult diabetes self-care (Heijmans et al., 2015; Lai et al., 2013; Thompson, 2016). More evidence is needed in chronic conditions other than diabetes, and particularly related to the influence of

parental health literacy on the management of conditions during childhood, such as food allergies. Evidence related to the relationships among health literacy, empowerment, and health outcomes is mixed (Crondahl & Eklund Karlsson, 2016).

This cross-sectional study of parents of children with food allergies examines the relationships among functional health literacy, communicative health literacy, critical health literacy, empowerment, and advocacy. An online survey of parents of children with life-threatening food allergies was conducted during the winter of 2021 to learn how these concepts are interrelated within the context of food allergies management in elementary school.

Figure 1

Conceptual Framework



The results of this study create a foundation for research about health literacy, empowerment, and advocacy in other chronic disease management contexts, such as the management of childhood asthma, obesity, or diabetes. This study provides insight to

inform the development of interventions to decrease food allergy-related health disparities.

Section 2. Research Question and Hypotheses

2.1. Research question

The context of elementary school requires that parents entrust the care of their child with life-threatening food allergies to other adults, school staff members. Given the complexity and quantity of recommendations for managing food allergies, parents may need high levels of health literacy and empowerment to understand and advocate for best practices to ensure the safety of their child at school. Therefore, because the context of food allergies management in elementary school demands the high-level use of health literacy skills and sense of empowerment for parents to engage in advocacy behaviors, the situational circumstance is ideal for studying the relationships among functional health literacy, communicative health literacy, critical health literacy, empowerment, and advocacy. The guiding research question is: *Do parents who score at the highest levels on measures of communicative health literacy, critical health literacy, and empowerment engage in more effective advocacy behaviors for food allergy safety practices than parents who score at the lowest levels?* The parental advocacy behaviors of interest are related to safe food allergy management practices in their child's elementary school.

2.2. Hypotheses

H1. Parents who score at the highest levels on a measure of communicative health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels of communicative health literacy.

H2. Parents who score at the highest levels on a measure of critical health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels of critical health literacy.

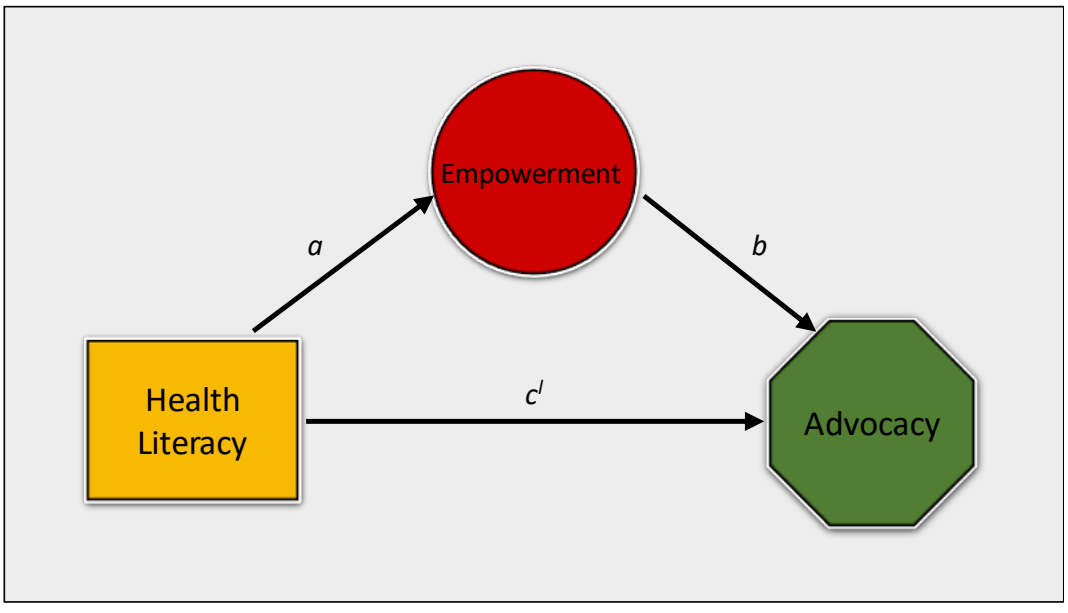
H3. Communicative and critical health literacy are more strongly associated with more effective advocacy behaviors than functional health literacy.

H4. Parents who score at the highest levels on a measure of empowerment engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels of empowerment.

H5. The relationship between parental health literacy and advocacy is mediated by empowerment (Figure 2).

Figure 2

Hypothesis 5. The Relationship between Parental Health Literacy and Advocacy is Mediated by Empowerment.



Section 3. Justification for the Problem

3.1. Significance of Health Literacy

Low health literacy, compared to adequate health literacy, contributes to health disparities, such as poorer health outcomes of chronic diseases and higher mortality rates (Berkman et al., 2011; Chinn & McCarthy, 2013; Neter & Brainin, 2019; World Health Organization, 2016b). Low health literacy is associated with higher healthcare utilization and costs related to more emergency department admissions and hospitalizations compared to adequate health literacy (Berkman et al., 2011; DeWalt et al., 2007; Griffey et al., 2014; Nielsen-Bohlman et al., 2004). Parents with low health literacy demonstrate health behaviors that are less beneficial to their child's health compared with parents with higher health literacy, such methods of dosing liquid medications or managing asthma (DeWalt et al., 2007; DeWalt & Hink, 2009; Yin et al., 2007). In adults with diabetes in four countries, higher communicative and critical health literacy, but not functional health literacy, is associated with better diabetes self-management behaviors, better control, and lower rates of diabetes complications (Ishikawa, Takeuchi, et al., 2008; Lai et al., 2013; Thompson, 2016; R.-H. Wang et al., 2016). Higher communicative and critical health literacy are associated with better self-management of a variety of other chronic diseases (cardiovascular diseases, lung diseases, musculoskeletal diseases, and others) (Heijmans et al., 2015) and anti-hypertension medication adherence (Qiu et al., 2020). Improving health literacy is a recognized national and international public health priority to help improve health promotion and health outcomes (Nielsen-Bohlman et al., 2004; Office of Disease Prevention & Health Promotion, 2020; Office of Disease Prevention and Health Promotion, 2010; United States Congress, 2010).

3.2. Gaps in the Literature

Three gaps in the literature are identified: the infrequent use of multidimensional measurements of health literacy, insufficient evidence about the relationship between health literacy and empowerment, and mixed evidence related to health literacy and health behaviors or outcomes. First, systematic reviews demonstrate that most studies of health literacy and health behaviors or outcomes utilize measurements of functional health literacy without measurements of communicative or critical health literacy, or other dimensions of health literacy (Al Sayah et al., 2013; Berkman et al., 2011; DeWalt & Hink, 2009). While fundamental literacy skills may be a proxy for measuring the broader concept of health literacy, the measurements of functional health literacy do not align with a full conceptualization or definition of health literacy. Therefore a proxy literacy measure may only provide a partial picture of the impact of health literacy. Furthermore, when critical health literacy is measured, it must be distinct from the concepts of empowerment and advocacy. This study of parents and food allergies uses an adapted version of the Functional, Communicative, and Critical Health Literacy Scale (Ishikawa, Takeuchi, et al., 2008) modified for a predominantly American sample of parents of elementary school children with food allergies.

Secondly, the nexus of health literacy and empowerment as theoretically proposed by Nutbeam (2000) has insufficient empirical support for either a mediating or a moderating relationship of these concepts in their associations to health outcomes (Crondahl & Eklund Karlsson, 2016; Mogford et al., 2011; Porr et al., 2006; Schulz & Nakamoto, 2013; Sykes et al., 2013). Limited and mixed evidence suggests that empowerment mediates the relationship between health literacy and chronic disease

management health behaviors (Sak et al., 2017; Schulz et al., 2017; Shin & Lee, 2018). One of the dimensions of psychological empowerment captures the concept of self-efficacy. Limited evidence suggests that self-efficacy is associated with health literacy and chronic disease health behavioral outcomes (Fransen et al., 2012; Mackey et al., 2016). This study of parents and food allergies attempts to increase understanding of the close, yet distinct, concepts of critical health literacy, empowerment, and advocacy. Parental advocacy for safe food allergy practices at school is considered an intermediate health behavior that may influence the health behaviors of school staff and students. This study of parents and food allergies explores how parental empowerment mediates the relationship between parental health literacy and parental advocacy.

Lastly, mixed evidence or insufficient evidence supports the connection between health literacy and health behaviors for management of many chronic diseases (Al Sayah et al., 2013; Berkman et al., 2011; DeWalt & Hink, 2009; Easton et al., 2010; Mackey et al., 2016; Neter & Brainin, 2019). Self-reported measures of communicative and critical health literacy demonstrate associations with better self-management behaviors in diabetes (Ishikawa, Takeuchi, et al., 2008; Lai et al., 2013; R.-H. Wang et al., 2016), in hypertension (Qiu et al., 2020), and in other chronic conditions (Heijmans et al., 2015). Mixed results demonstrate an unclear relationship between critical health literacy, as measured by judgment skills, and chronic disease health behaviors in asthma, sleep disorders, and hypertension (Dubowicz & Schulz, 2014; Londoño & Schulz, 2015; Náfrádi et al., 2016). Limited evidence supports associations between multidimensional measurements of health literacy (that include higher-level cognitive skill measures) and association with diabetes self-care behaviors (RobatSarpooshi et al., 2020; Schinckus et

al., 2018) and heart failure self-care behaviors (Erünal & Mert, 2020). In a systematic review specific to parental health literacy and child health, low parental health literacy was associated with less beneficial health behaviors and poorer child health outcomes, but evidence was mixed related to healthcare utilization for the child (DeWalt & Hink, 2009). The results of this study of parents and food allergies help to provide an understanding of the associations among parental functional, communicative, and critical health literacy; empowerment; and advocacy within the context of food allergy management in elementary schools.

Section 4. Definitions of Key Terminology

Parents – primary caregivers for children; parents may be guardians, mothers, fathers, other family members, or significant others who primarily take care of the well-being of a child. **Parental** (adjective) – refers to these individual primary caregivers.

Context of food allergies management in elementary schools – the collective culture of many interpersonal, socioeconomic, environmental, and institutional factors that influence individual and group behaviors to prevent exposure to food allergens and to be prepared for a food allergy emergency in primary education settings (Centers for Disease Control and Prevention, 2013; Egan & Sicherer, 2016; Gupta et al., 2014; Kao et al., 2018; Sandra et al., 2015).

Parental health literacy (within the context of food allergies management in the elementary school) - the degree to which individual parents have the capacity to obtain, communicate, appraise, and understand health information and services to make informed and shared health decisions for their child with food allergies (an adapted definition) (Edwards et al., 2012; Pleasant et al., 2016; Smith et al., 2013; United States Congress,

2010; von Wagner et al., 2009). It consists of functional health literacy skills (reading, writing, numeracy); communicative health literacy (speaking, listening, interpersonal skills); and critical health literacy (synthesis and appraisal of health information for situational application), adapted from Nutbeam's dimensions of health literacy (Ishikawa, Takeuchi, et al., 2008; Nutbeam, 2000, 2008).

Parental empowerment (within the context of food allergies management in the elementary school) - the psychological empowerment of individual parents involving the intrinsic motivation through which they gain greater control over decisions and actions affecting the health and well-being of their child (adapted definition) (Division of Health Promotion, Education, and Communications, 1998). Parental empowerment gives parents the authority and responsibility for making decisions for the well-being of their child (Schulz & Nakamoto, 2013). In this context where parents rely on other adult caregivers for the well-being of their child, parental empowerment is composed of three components: meaning (relevance), competence (self-efficacy), and impact (locus of causality) (Schulz & Nakamoto, 2013; Spreitzer, 1995a, 1995b; Thomas & Velthouse, 1990).

Parental advocacy (within the context of food allergies management in the elementary school) – the wide array of communicative behaviors that individual parents do to request systematic change and to facilitate systems' support for environmental and social conditions conducive to the safety, well-being, and full participation of their child with food allergies in all school activities (an adapted definition) (Boshoff et al., 2016; Division of Health Promotion, Education, and Communications, 1998; Nachshen et al., 2001; Ryan & Cole, 2009; A. Trainor, 2010). It has three components: educating others,

requesting safety practices, and communicating with school staff (an adapted definition) (Boshoff et al., 2016; Burke et al., 2018; Centers for Disease Control and Prevention, 2013; Nachshen et al., 2001; P. Wright & Wright, 2006).

Chapter 2. Review of the Literature

This study focuses on the dimensions of parental functional, communicative, and critical health literacy in the context of food allergies management in the elementary school. The next sections provide overviews of common conceptualizations and measurements of health literacy, empowerment, and advocacy. This chapter describes key issues in the scholarly debate about how critical health literacy is similar and different from the concepts of empowerment and advocacy. Mixed evidence supports higher communicative and critical health literacy as more influential than functional health literacy in chronic disease management(Heijmans et al., 2015; Ishikawa, Takeuchi, et al., 2008; Lai et al., 2013; Thompson, 2016; R.-H. Wang et al., 2016). Limited and mixed evidence supports empowerment as a mediator between health literacy and disease self-management health behaviors (Sak et al., 2017, 2017; Shin & Lee, 2018). Lastly, the discussion of food allergies demonstrates how the complexity of food allergies management in schools may demand that parents have high health literacy skills and feel highly empowered to effectively advocate for their child's food allergy safety. Parental advocacy for safe food allergies management in schools may include: requesting implementation of numerous prevention strategies, clarifying how to detect early anaphylaxis (severe allergic reaction), and promoting rapid, appropriate treatment of anaphylaxis. The review of the literature reveals questions of: (a) whether higher levels of communicative health literacy, critical health literacy, and empowerment are associated with higher perceived effectiveness of parental advocacy efforts for safe food allergies management in schools (b) whether communicative and critical health literacy are more strongly associated with more effective advocacy behaviors than functional health

literacy and (c) whether the relationship between health literacy and advocacy is mediated by empowerment.

Section 1. Health Literacy

1.1. Conceptualization of Health Literacy

Health literacy is recognized as a trait of individuals, groups, healthcare organizations, communities, and nations; and therefore may be measured accordingly (Batterham et al., 2016; Santana et al., 2021; Sorensen et al., 2012). The focus of this study of parents and food allergies is on individual-level health literacy, empowerment and advocacy. Nutbeam (2000, 2008) proposes organizing individual (or personal) health literacy into three dimensions: functional, interactive (or communicative), and critical health literacy. These dimensions of personal health literacy include: capacity for conceptual and cultural knowledge, understanding, reading and writing skills, numeric skills, navigational skills, listening and speaking skills, and analysis skills, among others (Nielsen-Bohlman et al., 2004; Nouri & Rudd, 2015; Roter et al., 2009; Sorensen et al., 2012). The updated definition of health literacy in *Healthy People 2030* acknowledges the context of health communication as a two-way process between individuals and healthcare organizations by providing separate definitions of personal health literacy and organizational health literacy (Office of Disease Prevention & Health Promotion, 2020; Santana et al., 2021).

For this study of parents and food allergies, the operational definition of parental health literacy is the degree to which individual parents have the capacity to obtain, communicate, appraise, and understand health information and services to make informed and shared health decisions for their children (an adapted definition) (Edwards et al.,

2012; Pleasant et al., 2016; Santana et al., 2021; Smith et al., 2013; von Wagner et al., 2009). One side of the interactive equation related to shared decision-making about food allergy management in the school is captured with the perspective of the parent. The operational definition (Table 1) includes health decisions that are informed and *shared,* meaning that patient's health decisions are informed by a patient's personal research, preferences related to life circumstances, and shared with their clinician who provides individually-tailored recommendations (Edwards et al., 2012; Pleasant et al., 2016; Smith et al., 2013; von Wagner et al., 2009). In this way, health literacy extends beyond the clinical encounter into the individual's health-information gathering, communications, and critical decisions related to the day-to-day management of health, such as those behaviors related to the school environment (Edwards et al., 2012; Pleasant et al., 2016; Smith et al., 2013; von Wagner et al., 2009).

Table 1

Operational Definitions: Health Literacy

Term	Definition
Parental Health Literacy	The degree to which individual parents have the capacity to obtain, communicate, appraise, and understand health information and services to make informed and shared health decisions for their children[a]
Functional Health Literacy	Basic reading, writing, numeracy, and navigational skills to function effectively in everyday life to manage health[b]
Communicative Health Literacy	Speaking, listening, more cognitively and socially advanced skills than functional health literacy for interaction to gather health information to make decisions[b]
Critical Health Literacy	Synthesis and appraisal of health information for application to health decisions in situational circumstances[b]

[a]Edwards et al., 2012; Pleasant et al., 2016; Santana et al., 2021; Smith et al., 2013; von Wagner et al., 2009. [b]Ishikawa, Takeuchi, et al., 2008; Nutbeam, 2000, 2008

Dimensions of Health Literacy. According to Nutbeam (2000, 2008) the three progressive dimensions of health literacy that build on each other from a foundation of basic literacy skills are: functional health literacy, interactive (or communicative) health literacy, and critical health literacy. Nutbeam (2000, 2008) and the World Health Organization (1998) conceptualized that health literacy extends beyond basic reading and navigational skills to include communicative health literacy and critical health literacy.

Functional Health Literacy. Functional health literacy is the basic reading, writing, numeracy, and navigational skills to function effectively in everyday life to manage health (Nutbeam, 2000, 2008). Functioning effectively means being able to understand and increase knowledge of the health condition and associated care. It includes abilities to read prescription and hospital discharge instructions for self-care.

Communicative (or interactive) health literacy. Communicative health literacy is a more cognitively and socially advanced skill for listening and speaking. The purpose is to gather health information, similar to the concept of oral-aural literacy to understand health information in a conversation to make decisions (Nouri & Rudd, 2015; Nutbeam, 2008). It includes dimensions of: technical term use, complexity of general language, and structural characteristics of the dialogue (such as pacing, density, and interactivity) (Roter et al., 2009). Yet, even beyond the capacity of individual listening and speaking, Rudd (2105) has argued that communicative health literacy involves two-way communication between senders and receivers of information.

This two-way communication means that healthcare organizations and healthcare professionals must provide clear and accurate health information in ways that the public

can access, understand, provide feedback, and ask for clarification as needed (Rudd, 2013, 2015). *The National Action Plan to Improve Health Literacy, Healthy People 2030,* and the World Health Organization have endorsed this perspective (Office of Disease Prevention & Health Promotion, 2020; Office of Disease Prevention and Health Promotion, 2010; World Health Organization, 2016a). When conceptualized as a modifiable aspect of healthcare delivery, organizational communicative health literacy may improve patient understanding, satisfaction, and intentions to adhere to health regimens (Duggan, 2006; Frosch & Elwyn, 2014; Koh et al., 2013).

Critical health literacy. Critical health literacy, as described by Nutbeam (2000, 2008) involves: critically appraising health information, understanding the social determinants of health, and understanding how to change public policy to influence community empowerment. As such, critical health literacy includes the capacity to assert and enact decisions that empower people to address the social, economic, and environmental determinants of health (World Health Organization, 2016a, 2016b).

Some debate in the literature exists about whether the concepts of critical health literacy and empowerment are the same, different, or conceptually overlapping (Chinn, 2011; Chinn & McCarthy, 2013; Crondahl & Eklund Karlsson, 2016; Nutbeam, 2000, 2008; Schulz & Nakamoto, 2013; Sykes et al., 2013). The Integrative Framework for Health Literacy (Batterham et al., 2016) includes two axes that intercept at the concept of self-management: the y-axis, where health literacy ranges from an individual to a community focus; and the x-axis, where empowerment ranges from compliance to empowerment. Furthermore, the concepts of critical health literacy and advocacy appear to overlap as well. The latter two components of Nutbeam's critical health literacy

conceptualization (understanding social determinants of health and how to change public policy) overlap with constructs of parental empowerment and advocacy in this study related to food allergies management in schools (Batterham et al., 2016; Chinn, 2011; Ishikawa, Nomura, et al., 2008; Ishikawa, Takeuchi, et al., 2008; Nutbeam, 2000, 2008; Sykes et al., 2013).

The operational definition of parental critical health literacy is the synthesis and appraisal of health information for application to health decisions in situational circumstances. Critical health literacy is defined and credited to Nutbeam's conceptualization as "more advanced skills for critically analyzing information and using information to exert greater control over life events and situations" (Heijmans et al., 2015; Ishikawa, Takeuchi, et al., 2008).

Health Literacy as Context-specific and Content-specific. Some scholars propose that health literacy is applied to a particular health condition in a particular context (Nutbeam, 2009; Paasche-Orlow & Wolf, 2007). Although some conceptual models acknowledge the importance of the context of health communication, few health literacy definitions have included two-way communication processes, health system complexities, and contextual demands (Parker & Ratzan, 2010; Pleasant et al., 2016; Rudd et al., 2012; Rudd, 2015). Healthy People 2030 changed to a two-pronged definition of health literacy that includes personal and organizational health literacy definitions which help acknowledge the context of two way-communication (Office of Disease Prevention & Health Promotion, 2020; Santana et al., 2021).

The context of communication includes social and environmental determinants, situational determinants, and personal determinants (Sorensen et al., 2012). For example,

societal and environmental determinants in the context of parental communication related to food allergies management in schools could include: the local community's attitudes toward dietary issues, type of setting (rural, suburban, urban), local economics related to particular foods, and geographical access to an allergist. The situational determinants could include: the staff's openness to dialogue about current practices, food allergy management policies, the presence of a full-time registered nurse in the school, and the quick availability of epinephrine in case of anaphylaxis. The personal determinants in the communication context could include: educational level, income level, occupation, social support to manage food allergies, and outcome expectancy if their child were to accidentally eat an allergen. These contextual factors would influence communication about informed and shared decisions with school staff related to food allergies management in the school.

The concept of health literacy as content-specific is related to various conceptualizations of health literacy in relationship to knowledge about a particular disease or condition. Frameworks conceptualizing health literacy include knowledge in three ways: as an antecedent to health literacy, as a component of health literacy, or as a consequence of health literacy (Baker, 2006; Lee et al., 2004; Nutbeam, 2000; Paasche-Orlow & Wolf, 2007; Sorensen et al., 2012; Squiers et al., 2012; von Wagner et al., 2009). Prior general background knowledge is considered an antecedent and a dimension of health literacy. Background knowledge includes: vocabulary; conceptual understanding about health, health care, risks, benefits, and probabilities; and cultural knowledge (Baker, 2006; Freedman et al., 2009; Nielsen-Bohlman et al., 2004; Squiers et al., 2012; von Wagner et al., 2009). Sorensen et. al (2012) describe health literacy as a

process that produces knowledge and skills to manage health, with knowledge as a dimension of health literacy within the process. Health-related knowledge not only informs the capacity to appraise and understand health information and but it also is a consequence of health literacy within that process (Sorensen et al., 2012).

Squiers et al. (2012) describes knowledge within a feedback loop of health literacy that is both an antecedence of health literacy and a consequence of it related to comprehension and acceptance of health information. Yet, specific health-related knowledge seems intertwined with capacity to appraise and understand health information, but it is also seen as an outcome of health literacy (Baker, 2006; Nutbeam, 2000; Paasche-Orlow & Wolf, 2007; Pleasant et al., 2016; Sorensen et al., 2012; von Wagner et al., 2009). Disease-specific knowledge is envisioned as a consequence of health literacy, often as an intermediate factor or mediating factor between health literacy and health outcomes (Baker, 2006; Lee et al., 2004; Paasche-Orlow & Wolf, 2007; von Wagner et al., 2009). Nutbeam (2000) describes health literacy as a skill and describes knowledge as part of that skill. Nutbeam further specifies that disease-specific knowledge is an outcome of functional health literacy. Then, Nutbeam (2000) states that the capacity to act on the knowledge is an outcome of communicative (or interactive) health literacy. In this study, food allergy-specific knowledge is conceptually separate from parental health literacy, as supported by frameworks with feedback loops of disease-specific knowledge as an intermediate outcome of health literacy that influences health outcomes and then loops to further act as on antecedent to further health literacy (Baker, 2006; Lee et al., 2004; Nutbeam, 2000; Paasche-Orlow & Wolf, 2007; Sorensen et al., 2012; Squiers et al., 2012; von Wagner et al., 2009).

1.2. Measurement of Health Literacy

Measurements of health literacy have predominantly quantified functional health literacy as a proxy for the whole concept of health literacy (Berkman et al., 2011; Pleasant et al., 2018; Sørensen et al., 2013; van der Heide et al., 2018). Some multidimensional measurements of health literacy have gained usage with increased demonstration of their validity and reliability.

Measurement of Functional Health Literacy. Functional health literacy was initially measured by direct testing of an individual's literacy skills, such as reading, vocabulary comprehension, or numeracy skills. Commonly-used early measurements include the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) (Agency for Healthcare Research and Quality (AHRQ), 2019; Altin et al., 2014). A brief self-report questionnaire regarding difficulties with reading or completing medical paperwork, originally designed for clinical practice and not for research, is another frequently-used health literacy screening tool (Chew et al., 2008). The Newest Vital Sign (NVS) measures numeracy and reading comprehension through testing application of understanding of a food label (Weiss et al., 2005). In families of food-allergic individuals, the NVS may not create a wide distribution of health literacy scores because of highly-developed food label reading skills in this population (Ditzler & Greenhawt, 2016; Weiss et al., 2005). In a study of over 1500 caregivers of children with food allergies, measurement of health literacy with the NVS and eHeals (a measure of internet health literacy) did not correlate well, possibly due to the sample's familiarity with reading food labels and overall high literacy level (Ditzler & Greenhawt, 2016).

Multidimensional Measurements of Health Literacy. Several multidimensional self-report health literacy scales have been developed to assess various dimensions of health literacy derived from theoretical frameworks of health literacy. Examples include: the Health Literacy Questionnaire (HLQ) (Osborne et al., 2013); the European Health Literacy Survey (HLS-EU) (Sørensen et al., 2013); and the Calgary Charter on Health Literacy Scale (Pleasant et al., 2018). These instruments do not specify subscales of functional, communicative, and critical health literacy, and thus were not selected for this study of parents and food allergies.

Measurements of Communicative and Critical Health Literacy. Individual-level communicative and critical health literacy have been measured with direct testing and self-report measures. Two self-report measurements that are short enough to include in a brief online questionnaire include a portion of the Health Literacy Skills Instrument (HLSI) and judgment skills. A few items in the HLSI (McCormack et al., 2010) test listening skills, a component of communicative health literacy. Yet, the HLSI does not include the reciprocal assessment of speaking or expression of thoughts, nor an assessment of critical health literacy skills. Items in judgement skills test complex cognitive abilities to apply content- and context-specific knowledge to scenario questions that ask the reader to choose a correct action (Dubowicz & Schulz, 2014; Londoño & Schulz, 2015; Náfrádi et al., 2016). Judgment skills are strongly correlated with positive self-management outcomes in hypertension, asthma, and sleep disorders (Dubowicz & Schulz, 2014; Londoño & Schulz, 2015; Náfrádi et al., 2016). Judgment skills seem to have been considered both a measurement of critical health literacy and a measurement of a separate construct (Dubowicz & Schulz, 2014; Londoño & Schulz, 2015; Náfrádi et

al., 2016) possibly because controversy exists about whether disease-specific knowledge is a health literacy component, antecedent or outcome of health literacy (Baker, 2006; Nutbeam, 2000; Paasche-Orlow & Wolf, 2007; Pleasant et al., 2016; Sorensen et al., 2012; von Wagner et al., 2009),

Two self-report measures of individual-level communicative and critical health literacy are: the Functional, Communicative, and Critical Health Literacy Scale (FCCHLS) (Ishikawa, Takeuchi, et al., 2008) and the All Aspects of Health Literacy Scale (AAHLS) (Chinn & McCarthy, 2013). AAHLS is a self-report scale that measures critical health literacy with an expanded definition, including understanding social determinants of health and how to influence public policy to improve the health of a community. According to factor analysis, the scale contains functional, communicative, and critical health literacy plus a fourth subscale of empowerment (Chinn & McCarthy, 2013). Therefore, AAHLS is not an appropriate measurement tool for this study of parents and food allergies due to the presence of the subconstruct of empowerment within the health literacy measurement scale.

The FCCHLS measures critical health literacy as an analysis of information for exerting greater control over life situations specific to diabetes management with three health literacy subscales (Ishikawa, Takeuchi, et al., 2008). It does not contain items pertaining to empowerment or advocacy. The FCCHLS (Ishikawa, Takeuchi, et al., 2008) is a 14-item scale with five functional health literacy items; five communicative health literacy items and four critical health literacy items. It was originally intended to assess the level of health literacy of Japanese adults with diabetes. Original response options were on a 4-point scale from never (1) to often (4), with reverse scoring for the five

negatively worded functional health literacy items. The scores for the total scale and the three subscales were calculated as means, with theoretical ranges from 1 to 4 (Ishikawa, Takeuchi, et al., 2008). Median score cut-off was used to form "high" and "low" health literacy groups in a later study, but the cut-off point was not intended to be a clinical screening tool for low health literacy (Ishikawa, Nomura, et al., 2008; Lai et al., 2013).

The FCCHLS as a whole has good validity and overall internal consistency (Cronbach's alpha >0.70) in samples of adults with diabetes in several languages, including English (Lai et al., 2013; Thompson, 2016; Zegers et al., 2020), Dutch (Heijmans et al., 2015; van der Vaart et al., 2012), French (Ousseine et al., 2018), German (Dwinger et al., 2015), Japanese (Ishikawa, Takeuchi, et al., 2008), Norwegian (Finbråten et al., 2018), and Swedish (Wångdahl & Mårtensson, 2014, 2015; Wangmar et al., 2018). The subscales of functional, communicative, and critical health literacy have good internal consistency in English, Dutch, and French (Heijmans et al., 2015; Lai et al., 2013; Ousseine et al., 2018; Zegers et al., 2020). Finbraten et al. (2018) found that a 12-item FCCHL scale, with 2 items deleted from the functional health literacy subscale, improved the reliability of the functional health literacy scale, yet raised some concerns about conceptual balance for the overall scale (Finbråten et al., 2018). Finbraten, et al. (2018) recommended deletion of one functional health literacy item about print being too small, and Ousseine et al.'s (2018) finding of lack of variability in this item supports its deletion.

Factor analyses of the FCCHLS have shown good model fit for the three health literacy subscales in English, Japanese, Dutch, French, and Norwegian (Finbråten et al., 2018; Heijmans et al., 2015; Ishikawa, Takeuchi, et al., 2008; Ousseine et al., 2018;

Zegers et al., 2020). Swedish and German versions have shown better fit for two subscales (functional health literacy and a combined subscale of communicative and critical health literacy) (Dwinger et al., 2015; Wangmar et al., 2018). Of note, the Norwegian FCCHLS demonstrated good model fit for three subscales using multidimensional Rasche modeling, considered to be an advantageous analytical approach over other factor analysis methods (Finbråten et al., 2018).

Response options for the FCCHLS items vary in translated versions from four to five options. Response optional also vary in content, including '*frequency* of performed skills being difficult' to *'difficulty level* of skills' (Heijmans et al., 2015; van der Vaart et al., 2012). With a 4-point response options, Heijmans et al. (2015) found a ceiling effect in the functional and communicative health literacy subscales, but not in the critical health literacy subscale. In a Swedish version, response options were on 5-point scale from 'strongly disagree' to 'strongly agree' with the task being very difficult without ceiling effect reported (Wangmar et al., 2018). This study of parents and food allergies uses an adapted FCCHLS for parents of children with food allergies, with five response options of perceived difficulty of tasks ranging from 'very difficult' (1) to 'very easy' (5). Higher versus lower levels of communicative and critical health literacy will be compared in association with higher perceived effectiveness of parental advocacy efforts for food allergy safety practices in schools.

1.3. Evidence about Communicative and Critical Health Literacy related to Chronic Disease Management

Low health literacy, predominantly measured as low functional health literacy, contributes to health disparities in many areas, including health outcomes of chronic

disease management (Berkman et al., 2011; Chinn & McCarthy, 2013; World Health Organization, 2016b). Some evidence suggests that critical health literacy appears to be more influential in adults' chronic disease self-management than functional health literacy is (Chinn, 2011; Ishikawa, Takeuchi, et al., 2008; Lai et al., 2013; Thompson, 2016; R.-H. Wang et al., 2016). In one study of Japanese office workers (Ishikawa, Nomura, et al., 2008), higher levels of communicative and critical health literacy, compared to lower levels, were associated with more regular eating, regular exercise patterns, less smoking, and better job stress coping. In the Netherlands, better self-management behaviors of a variety of chronic diseases (cardiovascular disease, lung diseases, musculoskeletal disease, diabetes, and others) were more strongly correlated with communicative and critical health literacy, and less strongly correlated with functional health literacy (Heijmans et al., 2015). In adults with diabetes, higher communicative and critical health literacy, but not functional health literacy, was associated with better diabetes self-management behaviors, better control, and lower rates of diabetes complications (Ishikawa, Takeuchi, et al., 2008; Lai et al., 2013). This study of parents and food allergies examines two of these issues related to the dimensions of health literacy: (a) how higher versus lower levels of parental communicative and critical health literacy are associated with parental advocacy for chronic disease management, specifically that of food allergies in elementary schools and (b) how critical health literacy and communicative health literacy, compared to functional health literacy, are associated with parental advocacy for food allergies management in schools.

Section 2. Empowerment

2.1. Conceptualization of Empowerment

Parental empowerment within the context of food allergies management in the elementary school is the psychological empowerment of individual parents involving intrinsic motivation through which they gain greater control over decisions and actions affecting the health and well-being of their child (adapted definition) (Division of Health Promotion, Education, and Communications, 1998). Psychological empowerment is an individual-level cognitive process in which people are motivated and able to make changes in their personal behavior, social situations, environments, and organizations to gain mastery over their lives (Schulz & Nakamoto, 2013; Thomas & Velthouse, 1990; Zimmerman et al., 1992). Empowerment in relationship to health is the process by which people gain more control over decisions and actions that affect their health (Division of Health Promotion, Education, and Communications, 1998). Individual-level empowerment greatly influences the organizational and community levels of empowerment in Zimmerman's model of empowerment (Zimmerman & Warschausky, 1998). Similarly, Nutbeam's conceptualization of health literacy envisions the goal of critical health literacy as leading to individual-level empowerment and community-level empowerment (Nutbeam, 2000). As a social or relational concept that applies to communications, empowerment encompasses issues of power, equity, and problem-solving skills (Schulz & Nakamoto, 2013).

Psychological empowerment is a multidimensional construct (Thomas & Velthouse, 1990; Zimmerman & Warschausky, 1998). The intrapersonal component of psychological empowerment contains four constructs: meaning (relevance), competence

(self-efficacy), self-determination (choice), and impact (locus of causality) (Eisman et al., 2016; Schulz & Nakamoto, 2013; Spreitzer, 1995a, 1995b; Thomas & Velthouse, 1990; Zimmerman, 1995; Zimmerman & Warschausky, 1998). The form of psychological empowerment can change across people (populations), across contexts (situations or tasks), and across time (Thomas & Velthouse, 1990; Zimmerman, 1995). Changes across time include not only societal and historical changes, but also intrapersonal developmental changes in the empowerment growth of a person into a role (Gibson, 1991; Thomas & Velthouse, 1990). Measuring parental empowerment in this cross-sectional survey of parents about food allergies captures one developmental stage in the empowerment process.

Nutbeam (2000, 2008) proposes that health literacy leads to personal and community empowerment, which leads to social action for health. Psychological empowerment is often considered to be a factor in the design of health education interventions, yet it is often not specifically measured as an intermediate outcome (Payrovee et al., 2014; Schulz & Nakamoto, 2013). Empowerment and critical health literacy, as defined by Nutbeam, seem to overlap conceptually (Chinn, 2011; Sykes et al., 2013). Inherent within Nutbeam's definition of critical health literacy is the concept of broader public health awareness, which may spur change in societal structures that impact health in areas such as education, income, racism, and discrimination (Nutbeam, 2008; Sykes et al., 2013; World Health Organization, 2016a). Likewise, empowerment education, also called popular education or Freirian education, incorporates the idea of understanding social actions to decrease health inequities related to the social, economic, and political determinants of health (Porr et al., 2006; Wiggins, 2012). This concept of

empowerment education is conflated with critical health literacy, yet also found to be distinct from critical health literacy by some scholars (Chinn, 2011; Chinn & McCarthy, 2013; Porr et al., 2006).

In contrast to Nutbeam's conceptualization that health literacy leads to empowerment, Schultz and Nakamoto (2013) argue that mismatches in health literacy and psychological empowerment can exist. For example, low health literacy may occur with high empowerment (as evidenced by the anti-vaccination movement), or high health literacy may occur with low empowerment (as evidenced by highly dependent patients). Furthermore, they theorize that even though the concepts are interrelated, health literacy and empowerment may moderate each other when influencing health behavior and health outcomes (Schulz & Nakamoto, 2013). Health literacy provides the capacity to gain knowledge and understanding to approach a health condition, but psychological empowerment provides the intrinsic motivation, authority, and responsibility to address the health issue (Schulz & Nakamoto, 2013; Sykes et al., 2013). Evidence is mixed about whether empowerment mediates the relationship between health literacy and chronic disease management health behaviors as conceptualized by Nutbeam (Sak et al., 2017; Schulz et al., 2017; Shin & Lee, 2018). This study of parents and food allergies examines if empowerment mediates the relationship between parental health literacy and the intermediate health behavior of advocacy for food allergy management practices at school.

Psychological Empowerment, Patient Activation, and Patient Empowerment. Psychological empowerment is distinct, but closely related to concepts of patient activation and patient empowerment. Patient activation is the "knowledge, skills,

confidence, and behaviors needed for managing one's health or chronic condition", or their willingness to manage their health and health care (Hibbard et al., 2005). Patient activation can be viewed as a sub-construct within a broad concept of self-efficacy to manage one's own health and health care, including the empowerment and motivation to do so (Gwynn et al., 2016; Salgado et al., 2017). A widely used measure of patient activation is the Patient Activation Measurement (PAM) in adults related to their self-care (Hibbard et al., 2005; Smith et al., 2013). Mixed results have demonstrated some correlations between patient activation and health literacy in studies of a few chronic diseases, medication side effect management, hospital admissions, and patient-provider communications (Couture et al., 2018; Eneanya et al., 2016; Fulton, 2015; Gwynn et al., 2016; Henselmans et al., 2015; Hickman et al., 2016; Salgado et al., 2017; Sheikh et al., 2016). Adapted from the adult self-care measure of the PAM, the parent-patient activation measure (P-PAM) was developed to measure a parent's knowledge, skills, and confidence in managing their child's health and health care (DeCamp et al., 2016). The P-PAM performance was assessed in parents of well children, with few children coping with chronic health conditions (DeCamp et al., 2016). The usefulness of the P-PAM is unknown for measuring parent activation related to management of a child's chronic health condition.

Secondly, patient empowerment is a process that enables people with health conditions to increase control over their health self-improvement, limiting benefit to the individual (Schulz & Nakamoto, 2013). It is often measured as the patient's participation in the decision-making process for his/her health or health care during an encounter with a health care professional (Schulz & Nakamoto, 2013). Psychological empowerment is a

more comprehensive concept, encompasses a larger scope of influence to impact lives beyond the health care encounter, and beyond personal challenges to manage health encountered with families and institutions, that may impact communities' health (Zimmerman & Warschausky, 1998). In this study of parents and food allergies, parental empowerment is a type of psychological empowerment that extends influence over a child's food allergies management into the school environment.

2.2. Measurement of Empowerment

Measures that were considered to adapt to a food-allergy-specific health empowerment scale for this study include: the Consumer Health Activation Index (CHAI); the Adapted Food Allergy-specific Family Empowerment Scale, and the Health Empowerment Scale. The Consumer Health Activation Index (CHAI) measures patient engagement in five domains: knowledge, self-efficacy, motivation/beliefs, actions, and internal locus of control (Wolf et al., 2018). The CHAI is a generic measurement of patient engagement in self-care during interaction with the health care system, but that does not align well with the operational definition of parental empowerment that extends influence beyond the healthcare encounter.

The Adapted Food Allergy-specific Family Empowerment Scale (Warren et al., 2015) is an expert-selected subset of 16 items from the 34 items of the Family Empowerment Scale (Koren et al., 1992). The Family Empowerment Scale was originally designed from a conceptual model of three expressions of empowerment (attitudes, knowledge, behaviors) and three levels of empowerment (family, service system, and community/political) (Koren et al., 1992). It was originally tested in families of children with mental health disorders and disabilities (Koren et al., 1992). Warren et

al. (2015) reported good internal consistency (Cronbach's alpha=0.96) Positive aspects of the scale are that some items are food-allergy specific and easy to read. However, the underlying subdimensions of the Adapted Food Allergy-specific Family Empowerment Scale are unknown.

The Health Empowerment Scale is a four-dimensional scale based on a well-founded conceptual framework of psychological empowerment originating from the works of Thomas and Velthouse (1990) and Zimmerman (Eisman et al., 2016; Peterson et al., 2006; Zimmerman, 1995, 1995, 2000; Zimmerman et al., 1992; Zimmerman & Warschausky, 1998). Building on their work, Spreitzer (1995a, 1995b) developed the Psychological Empowerment Questionnaire with four dimensions of empowerment: meaningfulness, competence, self-determination, and impact. Then, from Spreitzer's scale, the Health Empowerment Scale, a health-specific 12-item scale, was adapted to specific health contexts (Camerini et al., 2012; Londoño & Schulz, 2015; Náfrádi et al., 2016, 2018). It has been used to measure health-specific empowerment with 5 or 7-point Likert response options, in the contexts of self-management of: asthma, hypertension medication use, fibromyalgia, and perceived health status (Camerini et al., 2012; Londoño & Schulz, 2015; Náfrádi et al., 2016, 2018).

The Psychological Empowerment Questionnaire, the basis from which the Health Empowerment Scale was created, demonstrated excellent fit for the four dimensions according to confirmatory factor analysis (Spreitzer, 1995b). The overall empowerment construct had a Cronbach's alpha of 0.72, and each of the 4 dimensions had a Cronbach's alpha greater than 0.80 using 7-point response options. Convergent validity, divergent validity and test/re-test validity for the scale were good (Spreitzer, 1995b). The English

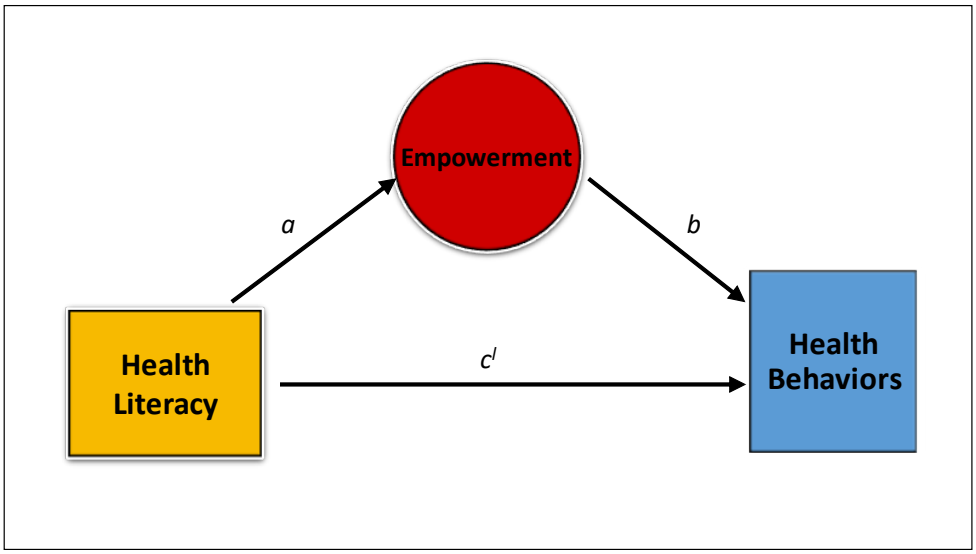
version of the Health Empowerment Scale with 5-point Likert response options and asthma-specific items was confirmed to have the intended four dimensions by factor analysis (Londoño & Schulz, 2015). For the measurement of parental empowerment in this study of parents and food allergies, Health Empowerment Scale items for asthma were adapted for parents of children with food allergies, pre-tested, and pilot tested (Camerini et al., 2012; Londoño & Schulz, 2015; Náfrádi et al., 2016, 2018). Some ideas for wording specific to food allergies came from the Food Allergy-specific Family Empowerment Scale.

2.3. Evidence about Relationships among Empowerment, Health Literacy, and Chronic Disease Management

Limited and mixed evidence supports a mediating role or a moderating role of empowerment on the relationship between health literacy and intermediate health outcomes of chronic disease self-care health behaviors (Figure 3). Several health literacy conceptual frameworks recognize motivational elements, such as empowerment or self-efficacy, as important factors on the pathway between health literacy and health behaviors or health outcomes (Batterham et al., 2016; Nutbeam, 2000, 2008; Paasche-Orlow & Wolf, 2007; Sorensen et al., 2012; von Wagner et al., 2009).

Figure 3

Two Proposed Relationships among Health Literacy, Empowerment, and Health Behaviors from the Literature



		Psychological Empowerment	
		Low	*High*
Health Literacy	*High*	Needlessly Dependent Patient	Effective Self-Manager
	Low	High-needs Patient	Dangerous Self-Manager

→ **Health Behaviors**

a. Mediation (above): Empowerment mediates the pathway from health literacy to health behaviors.
b. Moderation (below): Proposed by the Health Empowerment Model: Empowerment moderates the relationship between health literacy and health behaviors. Health literacy moderates the relationship between empowerment and health behavior (Schultz & Nakamoto, 2013).

Mixed and limited evidence supports a mediating relationship of empowerment on the pathway between health literacy and chronic disease self-care behaviors (Figure 3a) (Sak et al., 2017; Schulz et al., 2017; Shin & Lee, 2018). In one study, the indirect

pathway from health literacy through the mediator empowerment was significant for diabetes self-care behaviors of diet and exercise but not significant for diabetic foot care and blood glucose monitoring behaviors (Shin & Lee, 2018). In another study, the indirect pathway from health literacy through information-seeking and gains in empowerment significantly predicted general practitioner (primary care) utilization (Schulz et al., 2017). A reverse mediation pathway, with health literacy mediating the relationship between empowerment and medical decision-making in older adults was supported in a third study (Sak et al., 2017).

Secondly, limited and partial evidence supports a moderating role of empowerment in the relationship between health literacy and health behaviors as proposed by the Health Empowerment Model. The Health Empowerment Model proposes an interaction in which empowerment moderates the relationship between health literacy and health behaviors, and health literacy moderates the relationship between empowerment and health behaviors (Figure 3b) (Schulz & Nakamoto, 2013). Studies in Taiwan, Italy, Switzerland, and Hungary have demonstrated limited and partial support for the Health Empowerment Model related to outcomes in diabetes, asthma, fibromyalgia, perceived health status, and hypertension medication adherence (Camerini et al., 2012; Londoño & Schulz, 2015; Náfrádi et al., 2016, 2018; R.-H. Wang et al., 2016). For example, empowerment appears helpful for diabetes self-management behaviors in patients with high communicative and critical health literacy, but not useful in patients with low communicative and critical health literacy (R.-H. Wang et al., 2016). The Health Empowerment Model was not supported in a study of the relationships among health literacy and empowerment related to medical decision-making behavior of

older adults (Sak et al., 2017). Meaningfulness appears to be the predominant dimension of empowerment associated with health outcomes and with moderating health literacy (Camerini et al., 2012; Náfrádi et al., 2016, 2018). These studies measured health literacy with a variety of methods; some used a functional health literacy measurement as a proxy for health literacy measurement, which is one explanation for the mixed results.

This study of parents and food allergies examines two issues related to empowerment: (a) whether higher versus lower parental empowerment is associated with more effective parental advocacy for food allergies safety in schools and (b) whether parental empowerment plays a mediating role in the relationship between parental health literacy and advocacy. Predictors of greater empowerment for mothers and fathers of children with food allergies include: support from family or friends, having resources needed to care for the child, lower food allergy severity, and non-Hispanic white race/ethnicity (Warren et al., 2015). Interestingly, mothers, compared to fathers, report greater empowerment regardless of food allergy severity, type, or comorbidities (Warren et al., 2015). Thus, for this study of parents and food allergies, important covariates potentially related to parental empowerment include parental role (mother, father, other), race/ethnicity, support group participation, and food allergy severity.

Section 3. Advocacy

3.1. Conceptualization of Advocacy

Parental advocacy is defined as the wide array of communicative behaviors that individual parents do to request systematic change and to facilitate systems' support for environmental and social conditions conducive to the safety, well-being, and full participation of their child (an adapted definition) (Boshoff et al., 2016; Division of

Health Promotion, Education, and Communications, 1998; Nachshen et al., 2001; Ryan & Cole, 2009; A. Trainor, 2010). In the context of food allergies management in schools, parental advocacy actions are constructive contributions to problem-solving for their own children that include: educating others about food allergies; requesting safety practices; and communicating with school personnel to promote the child's safety and well-being (Boshoff et al., 2016; Burke et al., 2018; Burke & Goldman, 2015; Centers for Disease Control and Prevention, 2013; Food Allergy Research and Education, 2018a; Nachshen et al., 2001). Parental advocates in public schools have two major goals related to their child's school: (1) to make sure that the school provides a free appropriate public education that meets the child's unique needs and (2) to develop or maintain good relationships with school personnel (Office for Civil Rights, 2018b; P. Wright & Wright, 2006).

Effective parental advocates need to learn not only about management of their child's condition, but also about key decision-makers and relevant organizational policies or legislation pertaining to health and educational services (Burke, Goldman, et al., 2016; Burke et al., 2018; Burke & Sandman, 2017; S. R. Cohen, 2013; A. Trainor, 2010). For example, parents need to know that Section 504 of the *Rehabilitation Act of 1973* requires that schools make a "reasonable accommodation" to provide a free and appropriate public education to students with disabilities, including those with life-threatening food allergies (Office for Civil Rights, 2018b). Parents' reports of the success of their advocacy efforts in achieving their desired results in schools are the essence of the effectiveness of their advocacy efforts (A. C. Wright & Taylor, 2014). In this study of parents and food allergies, the perceived effectiveness of parental advocacy efforts for

safe food allergy practices is measured as the participants' reports of degrees of success of their advocacy efforts.

Major Tasks of Parental Advocacy. For the purposes of this study, parental advocacy in the context of food allergy management in elementary school is defined as the wide array of behaviors that parents do to facilitate the safety, well-being, and full participation of their child with food allergies in all school activities. The three major tasks in parental advocacy delineated in this study are: educating others, requesting safety practices, and communicating with school staff (Burke et al., 2018; Nachshen et al., 2001; P. Wright & Wright, 2006). In a qualitative study of school staff and parents of children with special communication needs, Burke et al. (2018) characterized parental advocacy actions with these main tasks: acquiring and sharing knowledge about a child's condition; providing supporting materials or resources (including professionals, therapists, special education teachers, or lawyers); communicating with the school; and making service or accommodation requests. In the context of food allergies management in schools, parents may commonly educate others about the following topics: child-specific allergens; allergen avoidance methods (handwashing, food label reading, avoiding cross-contact with allergens, etc.); signs and symptoms of severe allergic reactions, administration of epinephrine auto-injector; and the potential life-threatening consequences of allergen exposures (NASEM, 2017).

Parental advocates invest their time and energy, with perseverance, into advocating for interventions to benefit their children, according to a meta-synthesis of advocacy studies for children with autism spectrum disorder (Boshoff et al., 2016). Parental advocacy for children with autism spectrum disorders involves "vigilant

parenting" that is a life-long challenge, working to create a better future for their children and other children (Boshoff et al., 2016). Certainly "vigilant parenting" could be a common descriptor of the protective parenting behaviors to restrict a child's environment against food allergen exposure (Bacal & Nadeau, 2013; Dahlquist et al., 2015; Shaker et al., 2017). Additional parental advocacy activities related to schools include: preparing agendas for meetings with administrators, teachers, nurses, cafeteria supervisors, or bus drivers; following-up meetings with written summaries; and developing solutions acceptable to all parties (Boshoff et al., 2016; Burke, Goldman, et al., 2016; Burke et al., 2018; Centers for Disease Control and Prevention, 2013; Food Allergy Research and Education, 2018a; National Academies of Sciences, Engineering, and Medicine, 2017; Ryan & Cole, 2009; P. Wright & Wright, 2006). Items in the advocacy scale for this study of parents and food allergies incorporate assessment of the participants' perceived effectiveness of many of the above listed advocacy activities.

Cause Advocacy. The distinction between advocate and activist is sometimes blurred. Activities ranging from advocacy for an individual child to activism for the good of a population of children were described as on a continuum from 'case advocate' to 'activist' among mothers of children with autism spectrum disorders (Ryan & Cole, 2009; A. Trainor, 2010). Likewise, an advocacy continuum could exist for parents of children with food allergies. An activist is an individual who takes a leadership role in a campaigning organization, and spends substantial amounts of time and energy on promoting a cause, an activity called 'cause advocacy' (Food Allergy Research and Education, 2018a; Ryan & Cole, 2009; A. Trainor, 2010). 'Activism' or 'cause advocacy' may include supporting state and federal legislative efforts, updating regulations, and

promoting institutional policies for the safety and well-being of individuals with food allergies (FARE, 2018a). In a meta-synthesis of qualitative studies about parental advocacy for children with autism spectrum disorders, the theme of personal and societal benefits of advocacy was salient (Boshoff et al., 2016). In this study of parents and food allergies, 'cause advocacy' is framed as a covariate and as an individual-level outcome of parental health literacy. In the context of food allergies, cause advocacy tasks may consist of: attending or speaking at public meetings, spurring public awareness, posting to social media about food allergy policy issues, participating in a food allergy group's efforts toward local or national-level social change, contacting a decision-maker or legislator about policies, and more (Burke & Sandman, 2017; FARE, 2018a).

The Challenging Nature of Advocacy. In a meta-synthesis of qualitative studies about parental advocacy for children with autism spectrum disorders, the challenging nature of parental advocacy was a major theme (Boshoff et al., 2016). Advocacy may be associated with increased parental stress, particularly when it results in delayed outcomes or no outcomes for the child (Malec et al., 2010). Some parents view advocacy for their child to obtain services as an unwanted necessity (Nachshen et al., 2001). Parents of children with autism often feel isolated from a "normal" way of life, but also feel supported by a strong social network. Likewise, parents of children with food allergies, or children themselves often feel isolated from others, but may find solace in support groups (Bacal & Nadeau, 2013; Bollinger et al., 2006). Advocacy includes the tension of balancing the child's needs and parents' multiple responsibilities. Parental dvocacy brings personal benefits, such as sense of altruism and emotional support, yet requires large investments of time, energy, and perseverance (Boshoff et al., 2016). In addition,

advocacy has been identified as an active parental coping strategy for dealing with multiple negative emotions, or for confronting maladaptive coping to search for solutions and hope (Boshoff et al., 2016; Ewles et al., 2014). Thus, an important co-variate in this study of parents and food allergies that captures the emotional challenges is measured by the 'food allergy quality of life - parental burden' described later.

3.2. Measurement of Advocacy

Measurement of Parental Advocacy. Existing measurements of parental advocacy for educational services often pertain to the activities of parents or educational advocates for children with intellectual disabilities, developmental disabilities, autism spectrum disorder, or deafness/hard of hearing (Burke, Goldman, et al., 2016; Cawthon & Caemmerer, 2014; Malec et al., 2010; Nachshen et al., 2001). These scales measure participants' perspectives (such as comfort, confidence, or effectiveness), frequency of advocacy activities, and numbers of services received. Concepts in these parental advocacy measures may be applied to the context of parental advocacy for food allergies management in schools. Some self-administered survey measures of parental advocacy drew concepts from the early work of Naschen et al.'s (2001) semi-structured interview questionnaire about the nature of parental advocacy activities for developmental disabilities, called the Parental Advocacy Scale. The 26 interview items formed a scale with five dimensions of advocacy: frequency and variety of advocacy actions; focus of advocacy (from efforts for one child to international-level efforts); number of organizational memberships; activity level within organizations; and centrality of advocacy role in life (Nachshen et al., 2001).

Based on concepts from the Parental Advocacy Scale, Burke et al. (Burke, Goldman, et al., 2016) created a 10-item advocacy skill self-reported measurement focused on advocacy for an individual child, intended to capture the perspectives of parents and special education advocates about how well they perform advocacy skills. These parental advocacy skills encompass activities such as asserting oneself at meetings, communicating effectively with the school, and collaborating with the school. Their measure has five response options about perceived quality (from 'not at all' to 'excellent') and a Cronbach's alpha of .87 (Burke, Goldman, et al., 2016). A second self-administered questionnaire, The Parent Perceptions of the Individual Education Program (IEP) Process Scale (Cawthon & Caemmerer, 2014) contains twelve items for parents of children who are deaf or hard of hearing to describe their comfort, confidence, understanding, or other aspects of their involvement with the IEP process for their child. Items have five response options about frequency of their positive quality perceptions ranging from never to always. Reliability is good (Cronbach's alpha=.92). A third measurement, a multidimension assessment of the effectiveness of an advocacy training program creates an index to evaluate of the effectiveness of advocacy efforts as a sum number of services received as supplementary or related to special education received (Burke, Magaña, et al., 2016). For this study of parents and food allergies, concepts from the first two scales that elicited participants' perceptions about the effectiveness of advocacy activities were particularly relevant for adaptation and creation of the parental advocacy scale.

Measurement of Cause Advocacy. Malec et al. (2010) developed the 14-item self-report Advocacy Action Scale based on concepts from the interview questionnaire by

Nachshen et al. (2001) to assess the frequency of cause advocacy (activist) activities for people with brain injuries. Items include activities such as speaking at a public rally, contacting a legislative representative, or fundraising (Pearson r =.77). The single item, "Overall, how much time are you involved in the types of advocacy activities described above?" demonstrated good correlation with the entire scale as a single indicator (Malec et al., 2010). Burke and Sandman (2017) created an 8-item legislative advocacy activities scale for parents of students with disabilities with dichotomous (yes/no) response options. The responses then linked items for further elaboration on the numbers of people reached with each activity (Burke & Sandman, 2017). Salient cause advocacy actions of parents are: communications to spur systemic change and secure services for others, such as raising awareness, making phone calls, writing letters or emails, participating in meetings, communicating with decision-makers, and publicizing change efforts (Boshoff et al., 2016; Burke et al., 2018; Burke & Sandman, 2017; Ewles et al., 2014; Malec et al., 2010; Nachshen et al., 2001; A. C. Wright & Taylor, 2014). Many of these activities may require high levels of health literacy and empowerment to accomplish.

Measurement related to School Policies about Food Allergies. Two self-administered surveys, one for nurses and one for administrators, regarding school policies and practices related to food allergies provided concepts specific to the context of school food allergies management for creation of this study's parental advocacy measure (Eldredge et al., 2014; Kao et al., 2018). Both surveys aimed to assess the current status of food allergies policies and status of their implementation (Eldredge et al., 2014; Kao et al., 2018). For this study of parents and food allergies, salient food allergy management policies or practices included assessing: epinephrine availability, staff training, cleansing

surfaces, and food allergies management related to special events (Eldredge et al., 2014; Kao et al., 2018).

3.3. Evidence about Predictors of Parental Advocacy Behaviors

Parents of higher socioeconomic status, higher educational status, and cultural congruence with providers are more successful in advocating and obtaining services for their children than parents who have barriers such as language, culture, financial constraints, or work schedule constraints (Boshoff et al., 2016; Burke et al., 2018). Parents with greater economic capital also use a greater variety of cultural and social capital to find resources, gain support, and leverage advocacy actions (A. Trainor, 2010). Good quality relationships between parents and school staff may be associated with less frequent advocacy actions in the school (Burke et al., 2018). Four types of parent advocates identified in a qualitative study were: intuitive advocates, disability experts, strategists, and agents of systemic change (A. Trainor, 2010). Those who used an intuitive approach were knowledgeable about activities that did and did not work for their child, and less knowledgeable about legislation or regulations than those who used other approaches. Not surprisingly, parents acting as intuitive advocates were not involved in cause advocacy efforts (Trainor, 2010*).*

Limited evidence suggests that parents with more knowledge about special education processes and greater self-efficacy enhances parental advocacy efforts (S. R. Cohen, 2013). A pilot advocacy training program for Latinx families of children with autism spectrum disorders demonstrated increased parental empowerment and increased special education knowledge after the training (Burke, Magaña, et al., 2016). Thus, a

higher level of parental empowerment may be an important influence on the perceived effectiveness of parental advocacy for food allergies management in schools.

Section 4. Food Allergies

4.1. Introduction

The next section discusses childhood food allergies in terms of prevalence, morbidity, mortality, and burden to families to provide background on why food allergies are an important issue related to individual health behaviors, school-based health management, and parental health literacy, empowerment, and advocacy skills. Next, the subsequent sections describe the complexities of food allergies management in school: from preventing allergen exposure, to recognizing anaphylaxis, to treating an allergic reaction. Parents navigate these complexities daily for the safety and well-being of their child. Allergen exposure can occur through multiple avenues, so there are numerous recommendations for prevention from handwashing and sanitizing surfaces, to reading food labels for allergen terminology, to using non-food ingredients for crafts and celebrations at school (Boyce et al., 2010; Centers for Disease Control and Prevention, 2013; Muraro et al., 2014; National Academies of Sciences, Engineering, and Medicine, 2017; Sampson et al., 2014). Having ready access to epinephrine as the first-line treatment of a severe allergic reaction is a high priority at all times and in all environments of the school (P. Lieberman et al., 2015; Muraro et al., 2014; National Academies of Sciences, Engineering, and Medicine, 2017). The health literacy level of parents may impact their understanding of food allergy management recommendations. Parents may feel an extra urgency to assure adequate safety precautions for their child in school because some risk factors for severe food-allergic reactions or fatalities may be

present in schools but absent when under the parents' direct supervision of the child (Greenhawt & Weiss, 2012; Kao et al., 2018; Nowak-Wegrzyn & Conover-Walker, 2001; Sicherer et al., 2001; Szychlinski et al., 2015). This unique context of food allergies management in elementary schools provides understanding for the selection of covariates. This study of parents and food allergies aims to examine how high levels of communicative health literacy, critical health literacy, and empowerment may help parents to advocate successfully for school practices to manage food allergies.

4.2. Definition of Food Allergies

Food allergies are reproducible adverse health effects that occur due to an immunological response upon exposure to a given food ingredient. Typical reactions include manifestations of the skin, such as hives and angioedema; airway and lungs, such as coughing and wheezing; gastrointestinal system, such as abdominal pain and vomiting, and cardiovascular system, such as hypotension and syncope. Reactions can be mild to severe, leading to anaphylaxis and death (Boyce et al., 2010; Muraro et al., 2014; National Academies of Sciences, Engineering, and Medicine, 2017). A severe food-allergic reaction is defined as any report of anaphylaxis, low blood pressure, difficulty breathing, or wheezing, as well as the triple combination of: vomiting, angioedema, and coughing (Bock et al., 2007; Boyce et al., 2010). A mild or moderate food-allergic reaction typically is limited to one body system, such as: (a) angioedema limited to the lips eyes, or face; or (b) coughing or oropharyngeal irritation; or (c) hives, pruritis, flushing, eczema; or (d) vomiting (Gupta et al., 2011).

Types of Food Allergies. Food allergies are IgE-mediated or non-IgE-mediated immune responses to food. Generally, IgE-mediated reactions to food have a rapid onset

involving multiple organ systems and can lead to anaphylaxis; non-IgE mediated reactions may involve a delayed reaction mainly involving the skin and gastrointestinal tract (Pałgan et al., 2018). An example of non-IgE-mediated food allergy that does not lead to anaphylaxis is eosinophilic esophagitis, characterized by gastrointestinal symptoms (Muraro et al., 2014). Two subtypes of IgE-mediated food allergies include: (1) food-dependent, exercise-induced anaphylaxis, in which anaphylaxis occurs after exercising within two hours of eating an allergen; and (2) pollen-associated oral allergy syndrome, in which hives, swelling, itching, or tingling are limited to the mouth area and resolve quickly (National Academies of Sciences, Engineering, and Medicine, 2017; Sampson et al., 2014). In contrast, food intolerances are adverse reactions to foods that are not immune-mediated, such as lactose intolerance, which arises from a metabolic pathway (NASEM, 2017).

More than 170 foods can cause food allergies, but more than 90% of food allergies in the United States are associated with eight major allergens: peanut, milk, egg, tree nuts, crustacean shellfish, fish, wheat, and soy (Warren et al., 2018). In the USA, the most prevalent food allergens in children are: peanut, milk, shellfish, and tree nuts, with about 40% of food-allergic children who are allergic to multiple food allergens (Gupta et al., 2018; Warren et al., 2018). Sesame seeds and mustard seeds are two other common food allergens not yet labeled as food allergens in the United States, but prioritized as food allergens in the European Union and Canada (Gupta et al., 2018; National Academies of Sciences, Engineering, and Medicine, 2017; Sharma et al., 2019).

4.3. Prevalence of Food Allergies in Children

In children younger than 18 years old in the United States, overall prevalence of food allergy to any type of food is approximately 8% (range 3 – 12%) (Boyce et al., 2010; Gupta et al., 2014, 2018). The incidence and prevalence of food allergies has risen over the past 10 to 20 years (Boyce, et al., 2010; Gupta et al.; 2018; NASEM, 2017). Generally, food allergies appear to be equally prevalent among boys and girls (Gupta et al., 2011, 2018; Miller et al., 2016). The highest prevalence of food allergies is among children ages three to five years old compared to all other age groups from infancy through 18 years (Boyce et al., 2010; Gupta et al., 2014; 2018; NASEM, 2017).

Prevalence differs by age groups because some children may outgrow some food allergies. Children are more likely to outgrow milk, egg, and wheat allergies than other foods (Dahdah et al., 2018). Approximately 80% of children with milk or egg allergy are expected to outgrow the allergy and to tolerate eating milk or eggs by school age (Boyce et al., 2010; Pecora, Valluzzi, et al., 2018). Only 20% of children are expected to outgrow and to tolerate eating peanuts and tree nuts by school age (Pecora, Valluzzi, et al., 2018). An estimated 88% of schools in the US have one or more children with food allergies (O'Toole et al., 2007).

Challenges with Food Allergy Prevalence Estimates. Food allergy prevalence surveys have many challenges related to varying definitions of food allergy, diagnostic methodologies, selection bias, nonparticipation bias, timing related to children outgrowing some food allergies, geographical region, and statistical methods (Gupta et al., 2018; Miller et al., 2016; National Academies of Sciences, Engineering, and Medicine, 2017). Prevalence by parental report is about 12%, higher than 3%, estimated

by medical diagnosis with food challenge or symptoms plus sensitization testing (Boyce et al., 2010; Gupta et al., 2014, 2018). The time, expense, high-risk, and ethical problems associated with diagnosis by oral food challenge precludes large-scale prevalence studies with oral food challenge, especially for peanut allergen that causes more fatal anaphylactic reactions (NASEM, 2017). Therefore, acceptable forms for reporting in studies include: parental report or self-report with specific definitions, such as food allergy report with convincing symptoms (such as hives, trouble breathing, gastrointestinal upset, or anaphylaxis), or convincing symptoms plus physician-diagnosed food allergy using clinical markers, such as serum IgE, skin prick test, or oral food challenge (Gupta et al., 2011, 2018; Warren et al., 2015). Parental report related to a specific definition of food allergies with medical terminology of food allergies may represent a health literacy challenge or may represent challenges with differential access to health care.

4.4. Incidence of Food-induced Allergic Reactions and Mortality

Approximately 16 to 18% of children diagnosed with food allergies have a reaction to a food allergen while in school (Nowak-Wegrzyn & Conover-Walker, 2001; Sicherer et al., 2001). About 20 to 25% of the allergic reactions that occur in schools are due to previously unknown allergens and/or children previously undiagnosed with food allergies ((McIntyre et al., 2005; Szychlinski et al., 2015). According to a systematic review of reported rates of allergic reactions in schools (Waserman et al., 2021), a median of 1.3 (range 1 to 11) allergic reactions occur per year at each average school with 350 students. The incidence of anaphylaxis in schools or childcare centers is estimated to be a median of 1 case in every 15 average schools (range 2 to 34 schools)

per year (Waserman et al., 2021). Suspected or reported cases of anaphylaxis occur in about 10-11% of schools in the United States (Waserman et al., 2021).

Asthma is the single most important risk factor associated with increased severity of allergic reactions (Bock et al., 2007; Boyce et al., 2010). One-third of children with food allergies have asthma (Gupta et al., 2018). Allergy to peanut or tree nut, or multiple IgE-mediated food allergies are associated with increased risk of severe allergic reaction (Gupta et al., 2011; P. Lieberman et al., 2015). Furthermore, ingestion of the allergen on an empty stomach or exercise within two hours of ingestion is associated with increased severity of anaphylaxis (P. Lieberman et al., 2015). Some evidence suggests that the severity of food allergies is greater among boys than girls (Gupta et al., 2011, 2018). The odds of a severe allergy versus a mild/moderate allergy rise with each older childhood age group from infancy to adolescence (Gupta et al., 2011, 2018).

Mortality rate due to food-induced anaphylaxis in the United States is estimated to be 0.04 cases per million population per year (Pouessel et al., 2018). Fatalities among food-allergic children are estimated to be 3.25 per one million children with food allergies ages 0 to 19 years per year, or less than one per 100,000 food allergic-children, which is lower than fatality rate due to any type of accidental death in children (NASEM, 2017; Umasunthar, et al., 2013). Fatal food anaphylaxis occurs most often in teens and young adults out of all age groups (Turner et al., 2017). Fatalities due to food-induced anaphylaxis in school-age children are rare, yet reliable statistical data is lacking due inaccuracies in coding of food-induced anaphylactic deaths (Umasunthar et al., 2013). Parents may overestimate fatality risk (Boyle et al., 2017; Hanna et al., 2016), which is a critical health literacy issue. Parental overestimation of fatality risk may impact parental

empowerment and may impact parental advocacy efforts for food allergy management strategies in schools.

Risk factors associated with Fatalities due to Food-induced Anaphylaxis. Major risk factors for fatalities due to food-induced anaphylaxis are asthma and allergies to peanuts or tree nuts. Other significant risk factors for fatalities include: a reaction outside of the home; nonadherence to food allergen avoidance; a delay in recognition of anaphylaxis or epinephrine administration; and lack of access to epinephrine (including nonadherence to carrying epinephrine auto-injectors) (Bock et al., 2007; Boyce et al., 2010; Greenhawt & Weiss, 2012; Herbert et al., 2016; P. Lieberman et al., 2015; National Academies of Sciences, Engineering, and Medicine, 2017; Warren et al., 2018). Many of these risk factors are more likely in the elementary school setting. According to a national survey, about one-third of children under age 18 carry epinephrine on their person (Warren et al., 2018). Barriers to epinephrine-carriage and allergen avoidance include: feeling stigmatized or different; teasing or bullying; needing to plan ahead; forgetting; over-confidence in allergen avoidance; inconvenience; and fashion compromise (Herbert et al., 2016). Factors that help facilitate avoiding food allergens and carrying epinephrine include: understanding the consequences of eating an allergen without access to epinephrine; parental support; and peer support (Herbert et al., 2016). Understanding barriers and facilitators may have parental health literacy and empowerment implications that influence parental advocacy efforts for food allergy management in schools.

4.5. Racial/ethnic and Socioeconomic Disparities in Food Allergies

Evidence suggests higher odds of food allergy prevalence among African American than among non-Hispanic white children (Gupta et al., 2011, 2014, 2018;

Mahdavinia et al., 2017; National Academies of Sciences, Engineering, and Medicine, 2017; Warren et al., 2021). This food allergy prevalence disparity is consistent with trends in racial disparities that exist for the prevalence of asthma and atopic dermatitis (Gupta et al., 2018; Warren et al., 2021). In a national study of 40,000 children, African American and Asian children had higher prevalence of convincing histories of food allergies than white children, but they had lower odds of physician-diagnosed food allergies (Gupta et al., 2011). Hispanic children may have a lower prevalence of food allergies compared to non-Hispanic children, but data is limited due to reporting methods (Gupta et al., 2011; Miller et al., 2016).

Racial and income disparities may exist related to food allergy severity. Children in the lowest household income group had higher odds of severe food allergy compared to mild-to-moderate food allergy (Gupta et al., 2018). In a large cohort study, African American children with food allergies, compared to white children with food allergies, had higher odds of asthma, the largest risk factor for fatality in food-induced anaphylaxis (Mahdavinia et al., 2017). African American and Hispanic children, compared to white children, had higher rates of food allergy-related anaphylaxis and emergency department visits and shorter durations of follow-up with allergists (Mahdavinia et al., 2017). Moreover, they had proportionately greater numbers of allergies to less common allergens, such as corn, fish, soy, and wheat, which could put them at higher risk for adverse events (Mahdavinia et al., 2017).

Some studies have demonstrated higher prevalence of food allergies in higher income versus lower income populations, but they also bring up the question about potential differential access to diagnosis (Gupta et al., 2011; NASEM, 2017). Yet, in one

study, children with public health insurance were 79% more likely to have a food allergy diagnosis compared to children with private insurance (Miller et al., 2016). Urban and suburban areas, compared to rural areas, may have higher prevalence of food allergies, but studies are inconsistent and may reflect sociodemographic factors such as income and access to care (Gupta et al., 2011; National Academies of Sciences, Engineering, and Medicine, 2017; Szychlinski et al., 2015). These socioeconomic challenges may be compounded because low income is associated with limited or insufficient health literacy and poorer health outcomes (Cabellos-García et al., 2018; Eneanya et al., 2016; Kutner et al., 2006; Schaffler et al., 2018).

4.6. Risk Factors in Schools for Food-induced Anaphylaxis Fatalities

Food-allergic reactions that occur in schools may have associated factors that increase the likelihood of severity or fatality. According to a survey of parents about allergic reactions that occurred in schools, about one-third of food-induced allergic reactions in school were severe, involving more than one organ system (Nowak-Wegrzyn & Conover-Walker, 2001). The most identified causative foods were milk, peanut, and egg (Nowak-Wegrzyn & Conover-Walker, 2001). In a separate survey about peanut or tree nut reactions that occurred in schools, 60% of reactions occurred from ingestion of cookies, baked goods or candies; 24% occurred from contact or suspected ingestion; and 16% occurred from inhalation or other means (Sicherer et al., 2001).

The adult in school who responds first to allergic reactions varies, as the reaction location also varies. Allergic reactions occur most often in classrooms, then in less often in playgrounds and cafeterias (Greenhawt & Weiss, 2012; Sicherer et al., 2001). According to a survey of parents, the first adult to become aware of a nut-induced allergic

reaction was the teacher 59% of the time and the parent at pick-up 32% of the time. A cafeteria worker, bus driver, or school nurse was the first to notice during the remaining occurrences (Sicherer et al., 2001). In a survey of Illinois school nurses about response actions to anaphylaxis, the nurse gave epinephrine for 76% of the occurrences and other personnel gave it for 24% of the occurrences (Szychlinski et al., 2015). Even though nurses were present in one school less than 50% of the time, the nurses in that study administered 76% of the epinephrine doses in reported cases (Szychlinski et al., 2015). Parents' health literacy and awareness related to the potential for an allergic reaction to be detected first by non-clinician in the school may impact parental empowerment and advocacy actions with the school.

4.7. Burden of Food Allergies

In the United States, food allergies cost families an annual estimated $24.8 billion (NASEM, 2017). However, estimates vary. According to a MEPS dataset analysis, estimated additional annual medical expenditure for elementary school-aged children with food allergies was about $2,400 per year, which was comparable to annual medical expenditures for children without food allergies (Miller et al., 2016). According to a cross-sectional survey of 1643 caregivers, children with food allergies in the lowest socioeconomic stratum incurred 2.5 times the cost of emergency department visits and hospitalizations compared to children in the highest socioeconomic stratum (Bilaver et al., 2016). The cost of one box of two epinephrine auto-injectors in the Mid-Atlantic region in 2018 ranged from $110 to $600 (FARE, 2018a; pharmacist, Safeway Pharmacy, personal communication, 6/12/2018; pharmacist, CVS Pharmacy, personal communication, 6/12/2018). The minimal annual expense of the auto-injectors alone per

child could be up to $1800 to allow for storage at home, at school, at childcare, and self-carriage, depending on insurance coverage. These cost estimates do not include the additional expense of purchasing specialty foods that do not include specific allergens.

Attendance at school or childcare can be impacted by food allergies. In a small survey of parents of children with food allergies, 34% of parents reported that food allergies had a significant impact on their child's school attendance and 64% reported that it had a significant impact on day care/after-care attendance or selection (Bollinger et al., 2006). Ten percent of those parents reported that they did not send their child to school or chose to homeschool due to food allergies (Bollinger et al., 2006).

Parental Quality of Life related to Food Allergies. Having food allergies is associated with low health-related quality of life and high anxiety (Boyce et al., 2010; J. A. Lieberman & Sicherer, 2011). Health-related quality of life in the context of food allergies describes the impact that food restrictions and food allergy precautions have on everyday life, social situations, and emotional well-being (DunnGalvin et al., 2017). Food allergies impact parents' stress related lower food allergy self-efficacy for safe food preparation to participate in food-related social activities outside the home or at school (Bacal & Nadeau, 2013; Bollinger et al., 2006; Ditzler & Greenhawt, 2016; Hoehn et al., 2017). High parental anxiety may be associated with lower food allergy response capabilities, such as difficulty integrating food allergy management in to daily family life and worry about an allergic reaction in a community setting outside the home (Aika et al., 2017; Bock et al., 2007; Boyce et al., 2010; Klinnert et al., 2015). Parental fear of allergen exposure outside of the home negatively impacts food allergy-related quality of life of mothers more than fathers, regardless of allergen severity, type, comorbidities, or

mothers' higher levels of empowerment (Warren et al., 2015). Overestimation of fatality risk, which is considered a health literacy and empowerment concern, contributes to decreased quality of life and increased anxiety in caregivers of children with food allergies (Boyle et al., 2017; Hanna et al., 2016).

Lower food allergy-related quality of life is associated with many factors, including some with implications for parental health literacy, empowerment, and advocacy in the school setting. Among families with food allergies, lower quality of life is associated with increasing child age from preschool to upper elementary school, higher vigilance, more severe allergic reactions, and carrying epinephrine auto-injectors (Bacal & Nadeau, 2013; DunnGalvin et al., 2017; Shaker et al., 2017; Warren et al., 2015, 2018). At the time of entry into kindergarten, parental apprehension increases due to the transition from a smaller setting of preschool or childcare to a larger school with less vigilance, greater potential for exposure to allergens, and potentially slower access to epinephrine (Boyce et al., 2010; Sanagavarapu, 2017). Lower caregiver food allergy-related quality of life is associated with membership in food allergy advocacy groups compared to non-membership, caring for multiple children with food allergies, milk or egg food allergies, and their child's experience of bullying (Aika et al., 2017; Ditzler & Greenhawt, 2016; Shemesh et al., 2013; Warren et al., 2015). Lower caregiver quality of life is associated with higher trust in online information (Ditzler & Greenhawt, 2016). Trust in online information may have implications for communicative health literacy, critical health literacy, and parental empowerment.

4.8. Treatment of Food Allergies

Treatment of food allergies involves strict avoidance of food allergens and prompt recognition and treatment of allergic reactions. The first-line treatment for a severe allergic reaction is injection of epinephrine (or adrenaline). A promising preventive strategy under research involves changing the immune response to allergens, called immunotherapy, but there is no cure for food allergies.

Allergen avoidance. The first-line treatment for food allergies is strict allergen avoidance (Boyce et al., 2010; Muraro et al., 2014; Sampson et al., 2014). This decreases and eliminates most symptoms of food allergies. Food allergies to a specific food often require avoiding similar foods because of the potential for cross-reactivity. For example, allergy to one tree nut, such as cashew, may be associated with allergy to another tree nut, such as pistachio (Sampson et al., 2014). Vigilance to avoid allergens is required every time that food is eaten in every environment, including, but not limited to homes of friends or family members, childcare centers, and school cafeterias and classrooms. Highly empowered parents may insist on greater vigilance by other caregivers outside the home.

Strict allergen avoidance is a health literacy challenge for parents, caregivers, and children with food allergies due to three major reasons: cross-contact with food allergens, unknown hidden ingredients, and challenges with food label reading. Cross-contact occurs when a “safe” food expected to not contain an allergen is contaminated with the allergen. For example, a jar of jelly that comes into contact with a knife with peanut butter on it or frying oil for potatoes that has shellfish particles due to previous use (NASEM, 2017). Standard cleaning procedures using soap and water remove allergenic

proteins from cooking and eating surfaces (CDC, 2013; NASEM, 2017). Alcohol-based hand sanitizers do not remove an allergen adequately, but handwashing with soap and water removes allergenic proteins to protect against unintentional ingestion (CDC, 2013; NASEM, 2017). Hidden ingredients may occur in prepared foods when a food contains an unexpected allergen. Examples include peanut powder in chili and casein (an allergenic protein in milk) in "nondairy" popsicles.

For school staff to detect and avoid hidden ingredients, higher levels of parental functional, communicative, and critical health literacy and empowerment may be necessary to accomplish good communication with school staff about identifying ingredients and preparing safe foods. Reading food labels is challenging because it involves looking for uncommon allergenic protein names or scientific terms in ingredient lists, a high-level functional health literacy skill. The eight major allergens that the food manufacturers in the United States must identify in an ingredient list are: milk, egg, wheat, soy, peanuts, tree nuts, fish, and crustacean shellfish, according to the *Food Allergen Labeling and Consumer Protection Act of 2004* (NASEM, 2017). Unfortunately, U.S. manufacturers use some unregulated precautionary statements such as, "may contain" or "made in a facility with" that do not clearly convey risk to the consumer (NASEM, 2017). These unregulated statements are crucial communicative and critical health literacy challenges.

Immunotherapy. The goal of food immunotherapy is to alter the body's immune response to an allergen to allow desensitization or tolerance to a small ingested amount of an allergen (Loh & Tang, 2018; Pecora, Valluzzi, et al., 2018). Immunotherapy involves exposure to minute and incrementally larger quantities of an allergen via oral, sublingual,

or epicutaneous routes, but the treatment involves overall increased risk of anaphylaxis (Dahdah et al., 2018; Pecora, Mennini, et al., 2018). Oral immunotherapy (OIT), compared to sublingual immunotherapy (SLIT), appears to have greater efficacy but more severe adverse reactions, including anaphylaxis (Chu et al., 2019; Dahdah et al., 2018; Muraro et al., 2018; Pecora, Mennini, et al., 2018). Understanding the increased risk of anaphylaxis during immunotherapy may require higher parental health literacy and empowerment to advocate for increased vigilance by school staff to detect anaphylaxis while at school.

Treatment of Anaphylaxis or Severe Allergic Reactions. Experts recommend a written action plan to recognize and treat allergic reactions as a first step in preventing fatalities or complications (Sampson et al., 2014). The written plan should include symptoms to recognize an allergic reaction, medication administration instructions, and other emergency actions.

Recognizing Anaphylaxis. Recognizing anaphylaxis or a severe allergic reaction with potential to become anaphylaxis is a difficult diagnostic presentation, even for trained healthcare professionals (Desjardins et al., 2013; Morawetz et al., 2014; J. Wang et al., 2014). Food-induced anaphylaxis may occur from minutes to several hours after exposure to an allergen. Ingestion, not casual exposure through skin or inhalation, is the most common route of exposure leading to anaphylaxis, even in highly-sensitive peanut-allergic individuals (Sampson et al., 2014). Anaphylaxis may manifest differently in different individuals. It includes more than one organ system, progresses rapidly, and becomes fatal without swift and aggressive interventions. Common symptoms of anaphylaxis may include some of the following after exposure to an allergen: respiratory

compromise (dyspnea or wheezing), decreased blood pressure, hives, flushing, or pruritus, swollen lips or tongue, or persistent abdominal cramping or vomiting (Boyce et al., 2010; P. Lieberman et al., 2015). In food-induced anaphylaxis, most patients have skin or mucous membrane manifestations, (such as hives, itching, flushing or angioedema) but an alarming 10% to 20% of cases do not have any cutaneous symptoms (Boyce et al., 2010; NASEM, 2017). Respiratory symptoms (such as wheezing, difficulty breathing, itchy throat, or cough) occur in up to 70% of food-induced anaphylaxis cases and cardiovascular symptoms (such as hypotension, tachycardia, or syncope) occur in up to 35% of cases (Boyce et al., 2010). Thus, because of the complexity and variety of presentations of anaphylaxis, even parents with high health literacy may have difficulty understanding how it could present in their child and have difficulty feeling empowered to communicate that to school staff in advocacy efforts.

First-line Treatment: Epinephrine for anaphylaxis. Intramuscular epinephrine is the first-line treatment for anaphylaxis or severe allergic reaction. Epinephrine is preferred because anaphylaxis can be unpredictable and other agents do no act quickly enough to avert cardiorespiratory decline (Boyce et al., 2010; P. Lieberman et al., 2015; Muraro et al., 2014; National Academies of Sciences, Engineering, and Medicine, 2017). Immediately after injection of epinephrine, responders should call for emergency medical response (to 911) for transport to the nearest emergency facility. Five minutes after the first dose of epinephrine, a second dose of epinephrine should be given if symptoms persist (Boyce et al., 2010). Delays of 30 to 60 minutes from the onset of symptoms to epinephrine administration are associated with higher rates of fatalities from anaphylaxis

(Boyce et al., 2010). Epinephrine should be always quickly available to children with food allergies, in all settings, including schools.

Section 5. Implementation of Food Allergy Management Guidelines in Schools

Parents may start to learn about food allergy management recommendations for schools by reading a consumer-friendly education or support group website, such as one by Food Allergy Research and Education (FARE), www.foodallergy.org, by Food Allergy & Anaphylaxis Connection Team (FAACT), www.foodallergyawareness.org, or Kids with Food Allergies (KFA), www.kidswithfoodallergies.org. Within about three clicks, they could link to a list of at least 10 priority action items for schools and the CDC (2013) *Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs*, a 103-page document written for school administrators and staff, not for parents. Other peer-reviewed food allergy school management guidelines are written for clinicians, education administrators, or policy makers (Sampson et al., 2014; Sicherer et al., 2010; Waserman et al., 2021). The writing in these documents is dense and contains numerous recommendations, which are health literacy concerns for parents.

The CDC, the National Association of School Nurses, and national food allergy organizations have provided supplemental tip sheets about school food allergy management guidelines, many with 10 or more recommendations per sheet (Centers for Disease Control and Prevention, 2018; Food Allergy & Anaphylaxis Connection Team, 2021; Food Allergy Research and Education, 2014a, 2014b; Kids with Food Allergies, 2020; National Association of School Nurses et al., 2014). The large number of recommendations per tip sheet are not readily prioritized, another health literacy concern.

Many parents may be challenged to understand the breadth and depth of these recommended school guidelines because they are very comprehensive and complex. Yet, even with the health literacy challenge of understanding these recommendations, in states requiring that schools have anaphylaxis and allergy management guidelines, principals reported that parents were the primary drivers of school guideline development and implementation (Lawlis et al., 2017).

5.1. CDC's Voluntary Guidelines for Managing Food Allergies in Schools

The goal of the CDC (2013) guidelines is to shift focus onto the prevention of food-induced allergic reactions through systematic planning. The guidelines are voluntary for adoption by schools and early childcare programs, recognizing that schools must follow state and local laws. The guidelines organize recommendations into five priority topics for each school's food allergy management prevention plan (CDC, 2013):

- Individualized daily management plans
- Preparation for food allergy emergencies
- Professional development about food allergies for school personnel
- Education about food allergies for students and families
- Safe and healthy environment

The last major priority topic, "Safe and healthy environment", provides 38 practical strategies called practice recommendations, which are fundamental for daily school safety routines (CDC, 2013, pages 41-43). Parents would consider implementing these practice recommendations in schools very important. Examples of practice recommendations include: encouraging handwashing with soap and water to remove allergen residues, creating allergen-safe zones and food-free zones, cleaning and

sanitizing equipment, as well as practicing emergency drills for anaphylaxis response (Appendix A). However, the 38 practice recommendations are not prioritized, except by repetition of the recommendation to have rapid access to epinephrine in every location or event. Thus, parents or school staff may selectively pick only a few practice recommendations to implement. This could lead to incomplete or unsafe implementation of food allergies management in schools. Therefore, understanding the quantity and complexity of the practice recommendations is a pertinent health literacy issue for the context of this study of parental advocacy for food allergies management in schools.

Role of School Nurses in Implementing the CDC Voluntary Guidelines. The CDC guidelines (2013) recommend that nurses take the lead in planning and coordinating implementation of the food allergy management guidelines in schools. However, nationwide, a little less than 82% of public schools have a part-time or full-time nurse and 18% of schools have no nurse on site (Willgerodt et al., 2018). School nurses work in two or more schools, with an average of three schools per nurse, meaning that nurses are not on-site all the time in one location (Willgerodt et al., 2018). Private schools have proportionately fewer nurses than public schools, with 6% to 35% of them having a full- or part-time nurse (Eldredge et al., 2014; Willgerodt et al., 2018). Furthermore, the odds of having epinephrine available in school are more than two times higher if a school nurse is working full-time compared to part-time (Kao et al., 2018).

5.2. Individualized versus Universal Emergency Plans in Schools

The guidelines recommend individualized student food allergy prevention plans and emergency plans. Yet, the guidelines also acknowledge that for non-clinicians, having one coordinated approach to emergency management of any severe allergic

reaction would be more helpful than a variety of different individualized emergency plans (CDC, 2013). It seems that the guidelines' recommendation for individualized management plans may contradict the guidelines' acknowledgement that a universal emergency management plan would be best for non-clinicians. Yet, several national guidelines recommend that every child in a school or childcare setting should have an individualized written emergency action plan for an allergic reaction signed by a physician or healthcare provider (Boyce et al., 2010; CDC, 2013; Muraro et al., 2014; NASEM, 2017).

Individualized Daily Management Plans. The daily management of food allergies for children includes: (a) individualized written plans and (b) developmentally appropriate child self-management. First, written plans may include one or more of the following: Emergency Care Plan, a doctor's statement about food allergy disability for school food service accommodations, medication forms, Individualized Health Plan, Section 504 Plan, or Individualized Education Program (IEP) (CDC, 2013). Second, CDC (2013) recommends that the school staff should help the student to learn to self-manage their own food allergies as developmentally appropriate, such as: learning to read food labels, recognize symptoms of an allergic reaction, report a reaction to an adult, and self-administer epinephrine. The guidelines encourage students to wear medical alert bracelets, yet do not require them, recognizing that the bracelet may increase stigma (CDC, 2013). The guidelines encourage schools to allow students to self-carry epinephrine auto-injectors to activities at school and during transportation to and from school (CDC, 2013).

Implementation of Individualized Emergency Care Plans and Health Plans. A study examining data from a Chicago Public Schools database demonstrated that about half (50.9%) of students with physician-diagnosed food allergies had an individualized health management plan in school (Gupta et al., 2014). Additionally, lower percentages of low-income and minority race students had individualized health emergency plans compared to higher income or white students (Gupta et al., 2014). In a 2010-2011 survey of parochial schools in Wisconsin, 56% of the schools required an individual food allergy emergency plan (Eldredge et al., 2014). Schools that had *universal* food allergy policies or guidelines were 3.5 times more likely to require a *student-specific* written action plan than schools without universal policies (Eldredge et al., 2014). After Illinois state enactment of food allergy guidelines, rural schools versus suburban or urban schools were less likely to have written universal school emergency plans (Szychlinski et al., 2015). When a school does not have a universal food allergy plan, a parents may be confronted with empowerment challenges to advocate for an individualized emergency plan.

Student-specific 504 Plans. The Office for Civil Rights [OCR], U.S. Department of Education considers life-threatening food allergies a hidden disability. Public schools are required to provide students with disabilities a free and appropriate public education without discrimination under *Section 504 of the Rehabilitation Act of 1973* and the *Americans with Disabilities Amendments Act of 2008* (Office for Civil Rights, 2018a, 2018b). Food allergies are a recognized disability because during episodes of anaphylaxis or severe allergic reaction, major bodily functions or major life activities, such as breathing, are disrupted (Office for Civil Rights, 2018a, 2018b). The episodic nature of

allergic reactions and chronicity of food allergies meets the expanded definition of disability under the amendment (Office for Civil Rights, 2018a).

The purpose of the written 504 accommodation plan is to provide equal opportunity for the student to participate safely and equally along with other students in all aspects of the school activities (Office for Civil Rights, 2018b). The 504 plan may have components in it such as an Individual Health Plan, or a written emergency plan (Food Allergy Research and Education, 2018b). In the Chicago Public Schools, 51% of students with food allergies had a 504 plan compared to 2.7% of all students in that school system (Gupta et al., 2014). Students with asthma and food allergies had increased odds of having a 504 plan compared to those with food allergies without asthma (Gupta et al., 2014). Misconceptions about food allergies as hidden disabilities may be common (My Kids Food Allergies, 2017) and may represent health literacy barriers to empowering parents to request accommodations for food allergies under *Section 504*.

5.3. Preparation for Food Allergy Emergencies in Schools

The CDC voluntary guidelines (2013) recommend comprehensive school emergency planning for food allergies, in ways similar to "all hazards" plans for other emergencies or natural disasters to include: prevention, preparedness, response, and recovery from emergency. The guidelines recommend creating plans for staff to review for expired medications, require staff to carry epinephrine auto-injectors during field trips, and delineate staff member responsibilities during an emergency (CDC, 2013). This type of emergency planning goes beyond the individual-level plans to institution-level procedures, communication methods, and staff training (CDC, 2103). For example, it is a school-level responsibility to store epinephrine auto-injectors in a quickly accessible, yet

secure, manner. However, many state or local policies require medications in schools to be stored under lock and key. The school staff's decision regarding storage should include building-level factors such as the building layout, movement of a child within the building, availability of communication systems, availability of a nurse, responsibilities of a teacher, and preferences of a parent (CDC, 2013). Given multiple factors considered for epinephrine storage in a local school, parental advocacy for quick access to epinephrine could be impacted by parental communicative and critical literacy skills.

Undesignated Epinephrine Availability in Schools. In an effort to increase access to life-saving epinephrine, the federal government enacted the *School Access to Emergency Epinephrine Act* in 2013, creating financial incentives for states to pass legislation requiring schools to stock emergency epinephrine not designated to a specific patient (Food Allergy Research and Education, 2016). Now, all U.S. states have legislation or guidelines allowing or permitting undesignated (or stock) storage of epinephrine auto-injectors in schools and other public facilities. But only a dozen states *require* stock epinephrine in schools (FARE, 2016). In a probability-based sample representing adults nationwide, 52% percent of parents of children with food allergies reported that their child's school had stock epinephrine available, and 50% strongly agreed that stock epinephrine auto-injector would be available for immediate use for their child (Warren et al., 2018). In a 2016 national survey of school nurses, more than 80% reported their school had a stock epinephrine policy (Kao et al., 2018). Financial cost was identified most frequently as the major barrier to implementation of stock epinephrine policies in that study (Kao et al., 2018). Furthermore, the likelihood of stocking undesignated epinephrine is higher in schools with the following: a full-time versus part-

time school nurse, if a severe allergic reaction had occurred during the past year, and in urban or suburban schools versus rural schools (Kao et al., 2018; Szychlinski et al., 2015). These studies did not assess the impact of parental advocacy on the availability of stock epinephrine in schools.

Anaphylaxis Response Drills in Schools. Drills to practice how to respond to a food allergy emergency are another important component of emergency preparedness (CDC, 2013), yet many schools may not perform these drills. In Illinois, two years after implementation of state guidelines that recommended annual anaphylaxis response drills, less than 7% of schools surveyed had conducted anaphylaxis emergency drills (Szychlinski et al., 2015). The most commonly reported barriers to conducting anaphylaxis emergency drills were: the *recommended* versus *mandated* status of the drill recommendation, lack of administrator request for the drills, lack of nurse confidence to conduct anaphylaxis drills, and inadequate time (Szychlinski et al., 2015).

Professional Development about Food Allergies in Schools. The CDC voluntary guidelines (2013) recommend that a health care professional provide school staff with comprehensive training about preventing allergen exposure, signs and symptoms of anaphylaxis, how to administer epinephrine auto-injectors, how to meet the emotional needs of students with food allergies, potential impacts on learning, and knowledge of pertinent legislation. In a 2016 national survey of school nurses, ninety-seven percent (97%) reported their schools had policies about anaphylaxis training for staff (Kao et al., 2018). In Illinois, two years after implementation of state guidelines requiring biannual general food allergy training for school staff, almost 80% of school nurses reported that they had provided training and 54% of health aids had provided

training (Szychlinski et al., 2015). In the same survey, nurses identified the school buses and playgrounds as the most concerning areas where they lacked confidence that staff would know how to respond to a severe allergic reaction (Szychlinski et al., 2015). While progress appears to have been made with school staff food allergies training, this is still a health literacy concern for school staff. Parental understanding of the school's training program and their trust that school staff are well-prepared to keep their child safe may influence their feelings of empowerment and their advocacy efforts to communicate with the school about food allergies management.

Education about Food Allergies for Students and Families. Integrating food allergies content into the curriculum across areas of health sciences or character development is recommended (CDC, 2013). Educating students and family members should go beyond physical signs and symptoms of anaphylaxis and food allergy precautions to include acceptance of differences, respect, and prevention of bullying and isolation (CDC, 2013). Infusing this content into the elementary school curricula and family educational outreach programs is a public health literacy recommendation from the guidelines that may influence local parental health literacy and empowerment.

5.4. Safe and Healthy Environment

Thirty-eight practice recommendations for creating a safe school environment involve comprehensive plans organized around five school locations and events, from cafeterias, to playgrounds, classrooms, buses and field trips (Appendix A; CDC 2013). For example, CDC recommends that schools develop and follow guidelines about food handling to prevent cross-contact of allergens by cleaning and sanitizing surfaces and equipment with all-purpose cleaners. Reading food labels for allergens is an essential

practice recommendation. Another sample recommendation is handwashing with soap and water because it removes allergen residue that alcohol-based hand-sanitizer does not (CDC, 2013). Close supervision of students during meals and snacks may help to discourage food sharing and monitor for allergic reactions. School staff should ensure psychosocial safety in the form of respecting one another and discouraging teasing (CDC, 2013). CDC recommends creating allergen-safe zones, sometimes referred to as "peanut-free" tables, or food-free zones in libraries, buses, or classrooms. Policies should include communication with outside organizations that use the school building to request their compliance with cleaning and allergen-safe zones (CDC, 2013). The myriad and complexity of food allergy practice recommendations creates a health literacy concern for all involved because of the difficulty of understanding, prioritizing, and implementing all recommendations. Two practices, labeling of food items and allergen-safe zones, are discussed below related to their challenges associated with health literacy.

Labeling of Food Items in Schools. Reading and understanding ingredients in food labels should be an integral component of food allergy management (CDC, 2013). It may be a major challenge beyond functional health literacy skills to a challenge for communicative and critical health literacy skills. For example, the same food product from the same manufacturer can change ingredients so the food label must be inspected for allergens with every purchase and every meal preparation (CDC, 2013). Elementary school cafeterias must follow the latest federal Food Code adopted by their state for food labels. The *2013 Food Code* requires that a person-in-charge be on-site and knowledgeable about: major food allergens, identification and labeling of major food allergens, and cross-contact prevention methods during preparation and service

(NASEM, 2017). Unfortunately, most states have not yet adopted the *2013 Food Code* and label laws do not require including some known allergens, such mustard and sesame (NASEM, 2017). Moreover, states may delay for several years before adopting the *FASTER Act* that was passed in April 2021, which recognizes sesame as the ninth major allergen in the United States and requires sesame labeling starting in 2023 (U.S. Food and Drug Administration, 2021). Thus, parental communicative and critical health literacy may be essential to analyzing local school food labeling and interpreting practices.

In 2016, an alarmingly low 30% of schools in the United States had policies about labeling of food items sold in the cafeteria (Kao et al, 2018). Parental report of "lack of school support" was associated with non-adherence to dietary restrictions in children with eosinophilic esophagitis (Henry et al., 2012). Parents with higher communicative and critical health literacy may capture actual food allergen labeling practices in a local school better than those with low health literacy. Parents with higher income may be more likely to pack allergen-safe foods in their child's lunches rather than risk ingestion of unknown or unlabeled ingredients from the school cafeteria. Parents with lower incomes who rely on school food services may need to feel empowered to engage their communicative and critical health literacy skills to advocate for school cafeteria food labeling for allergens.

Implementation of Allergen-safe Zones in Schools. Designation of allergen-safe zones in schools may be a parental health literacy challenge with mixed evidence related to child health and well-begin benefit. In a 2016 survey of school nurses in the United States, more than 60% of schools had policies about designated lunch areas and food guidelines for classrooms (Kao et al., 2018). Massachusetts public schools with

peanut-free tables had lower rates of epinephrine administration for peanut or tree nut exposure compared to schools without peanut-free tables (Bartnikas et al., 2017). Other peanut-restricting policies, such as self-designation of "peanut-free classrooms", self-designation of "peanut-free schools", not serving peanuts at school, or not allowing peanuts brought from home did not impact epinephrine administration for allergic reactions to nuts (Bartnikas et al., 2017). Yet, it is possible that "allergen-free" schools or zones may potentially decrease vigilance for food-induced allergic reactions (Waserman et al., 2021). Recent international guidelines suggest conditional recommendations against allergen-free zones in schools based on a very low certainty of evidence (Waserman et al., 2021).

Understanding use of terms such as "allergen-safe" is a parental health literacy challenge because it does not mean devoid of all allergens, but it means as safe as possible to avoid the allergens. Terms such as "peanut free" and "peanut aware" may be misleading. In one study, two schools self-designated as "peanut free" allowed peanuts to be brought from home, which is self-contradictory (Bartnikas et al., 2017). Likewise, in a qualitative study, parents pointed out the contradiction in which some schools that claimed to be "peanut-aware" hosted events including peanut-containing items in crafts or on lists of "acceptable" snacks (such as "granola") (Anastos, 2007). Even with high health literacy, the inconsistent use of terms such as "allergen-free", "allergen-aware", or "allergen-safe" would contribute to difficulty for parents to understand the food allergy practices of a local school. It may require tenacity in conversations with a school for a parent to understand the school's food allergy practices, thus there is a need to study how

empowerment, communicative health literacy, and critical health literacy are associated with parental food allergy advocacy behaviors in schools.

Section 6. Summary

The complexity of all there is to know about food allergies management could be overwhelming to a parent. It may require a high level of health literacy to understand preventive and emergency management policies for schools, interpret food ingredient labels, and understand the nuances of potentially misleading terms about allergen-safe zones. Mothers of children with food allergies express the need for two-way communication with schools about food allergy management issues, such as "how" and "who" carries out procedures in a policy (Sanagavarapu, 2017). Mothers want to know about storage and access to epinephrine, staff preparedness, safe food alternatives, and food allergy management during special events (Sanagavarapu, 2017). This communication may involve parental empowerment to engage communicative and critical health literacy skills, beyond their use of functional health literacy skills, to advocate for their child's food allergy safety. This study aims to assess how these parent-school communications to advocate for food allergy safety practices could be impacted by the health literacy and empowerment of parents. There is a gap in understanding the relationships among functional, communicative, and critical health literacy; empowerment; and advocacy in chronic disease management, particularly related to food allergy management.

The context of food allergies management in elementary school points to several important school practices and considerations for this survey of parents. Although it is a health literacy challenge to prioritize multiple recommendations, parents may advocate

for many of the following key practices: quick access to epinephrine in all locations, routinely reading food ingredient labels for allergens; handwashing with soap and water; allergen-safe zones; recognizing early signs of anaphylaxis; and responding quickly to anaphylaxis by administering epinephrine. Essential considerations associated with parents that arise from this context include: educational level (or income); food allergy quality of life; quality of the relationship with the school; support group participation; cause advocacy participation; and role of the parent (mother, father, other). Essential child-related factors supported by the literature include: food allergy severity; co-morbid diagnosis of asthma; participation in immunotherapy; and participation in a 504 plan. School-related issues of importance are: school requirement for written emergency plans, school setting (rural versus suburban or urban), and full-time presence of a school nurse. This study seeks to understand the relationships among the health literacy of parents, their empowerment to manage food allergies, and their advocacy behaviors with school staff to facilitate preventive and emergency management of food allergies in elementary schools.

Chapter 3. Methods

Section 1. Overview of Methodology

The purpose of this study was to examine the relationships among parental functional, communicative, and critical health literacy; empowerment; and advocacy in the context of food allergies management in school. The review of the literature revealed questions of: (a) whether higher levels of communicative health literacy, critical health literacy, and empowerment are associated with higher perceived effectiveness of parental advocacy efforts for safe food allergies management in schools (b) whether communicative and critical health literacy are more strongly associated with more effective advocacy behaviors than functional health literacy and (c) whether the relationship between parental health literacy and advocacy is mediated by empowerment. This cross-sectional study addressed these questions through analysis of relationships among constructs from data collected in a web-based survey of parents of school-aged children with life-threatening food allergies. This chapter describes the conceptual framework, target population, pilot study, and changes that were made because of the pilot study. Then, the methodology details the main study recruitment, measures, data collection procedures, data analysis procedures, and ethical considerations.

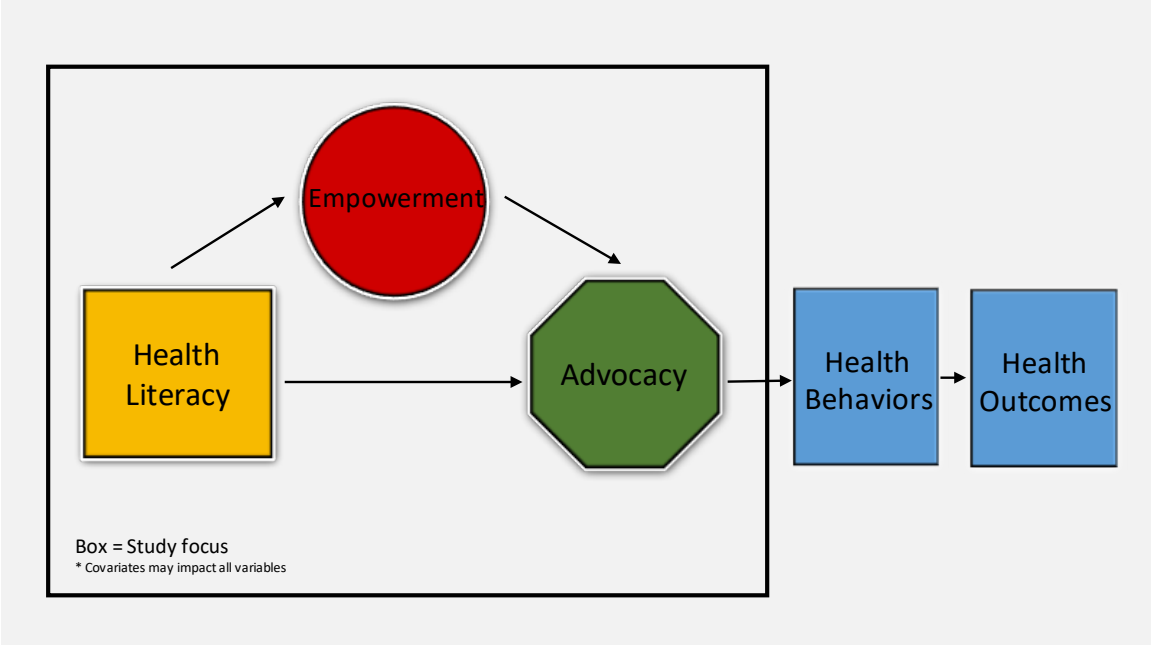
Section 2. Conceptual Framework

The conceptual framework for this study originated from the need to understand the closely-related concepts of critical health literacy, empowerment, and advocacy. This study did not test a full theory, but rather explored the associations among the constructs of health literacy, empowerment, and advocacy. The conceptual framework represents the hypothesized relationships among the three main variables, with the motivational

component of empowerment in the pathway between health literacy and the intermediate health behavior of advocacy, which in turn leads to health behaviors and health outcomes (Batterham et al., 2016; Nutbeam, 2000, 2008; Paasche-Orlow & Wolf, 2007; Schulz et al., 2017; Shin & Lee, 2018; Sorensen et al., 2012; von Wagner et al., 2009). The focus of this study of parents and food allergies was on the associations among parental health literacy, empowerment, and advocacy, as depicted in the box (Figure 4).

Figure 4

Conceptual Framework



In the conceptual framework, parental health literacy leads to parental empowerment, which leads to parental advocacy (Nutbeam, 2000, 2008). Parental health literacy is the degree to which individual parents have the capacity to obtain, communicate, appraise, and understand health information and services to make informed and shared health decisions for their child (an adapted definition) (Edwards et al., 2012; Pleasant et al., 2016; Smith et al., 2013; United States Congress, 2010; von Wagner et al.,

2009). Parental empowerment is the psychological empowerment of individual parents involving the intrinsic motivation through which they gain greater control over decisions and actions affecting the health and well-being of their child (adapted definition) (Division of Health Promotion, Education, and Communications, 1998). Parental advocacy, in the study context of food allergies management in elementary schools, is the wide array of communicative behaviors that individual parents do to request systematic change and to facilitate systems' support for environmental and social conditions conducive to the safety, well-being, and full participation of their child with food allergies in all school activities (an adapted definition) (Boshoff et al., 2016; Division of Health Promotion, Education, and Communications, 1998; Nachshen et al., 2001; A. Trainor, 2010).

On the right-hand side of the conceptual framework, moving beyond the study box, parental advocacy then influences the performance of health behaviors, or food allergy management behaviors, of staff and students at the school. Lastly, the food allergy management behaviors, such as allergen avoidance practices and emergency preparedness activities, impact food allergy-related health outcomes, such as allergic reactions and fatalities due to food-induced anaphylaxis. Due to logistical limitations, the portion of the conceptual framework indicating the school-based health behaviors and health outcomes was not directly assessed with this parental questionnaire but could be examined in future studies. The context of food allergy management in schools is described as the collective culture of many interpersonal, socioeconomic, environmental, and institutional factors that influence individual and group behaviors to prevent exposure to food allergens and to be prepared for a food allergy emergency in primary

education settings (Centers for Disease Control and Prevention, 2013; Egan & Sicherer, 2016; Gupta et al., 2014; Kao et al., 2018; Sandra et al., 2015).

As revealed in the review of the literature, covariates considered important included: parental education level, food allergy support group participation, child's food allergy disease severity, asthma, community setting (rural, urban or suburban), parental food allergy-related quality of life, quality of the parent's relationship with the school, role of parent (mother, father, or other), child age, presence of a full-time school nurse, and school requirement of an emergency action plan.

Section 3. Participants

Inclusion and exclusion criteria for participants in the pilot study and the main study were the same except previous participation in the pilot study or main study were exclusion criteria for the main study.

Inclusion criteria: The sample inclusion criteria included: age greater than or equal to 18 years old; being the parent, guardian, or caregiver of at least one child with healthcare provider-confirmed diagnosis of life-threatening food allergies; the child had to have attended an elementary school (kindergarten through 6th grade) in the United States at any time during the past 12 months; able to read/write English; and had internet access for web-based survey completion with a computer or mobile device.

Exclusion criteria: The exclusion criteria were previous participation in the main study or the pilot study.

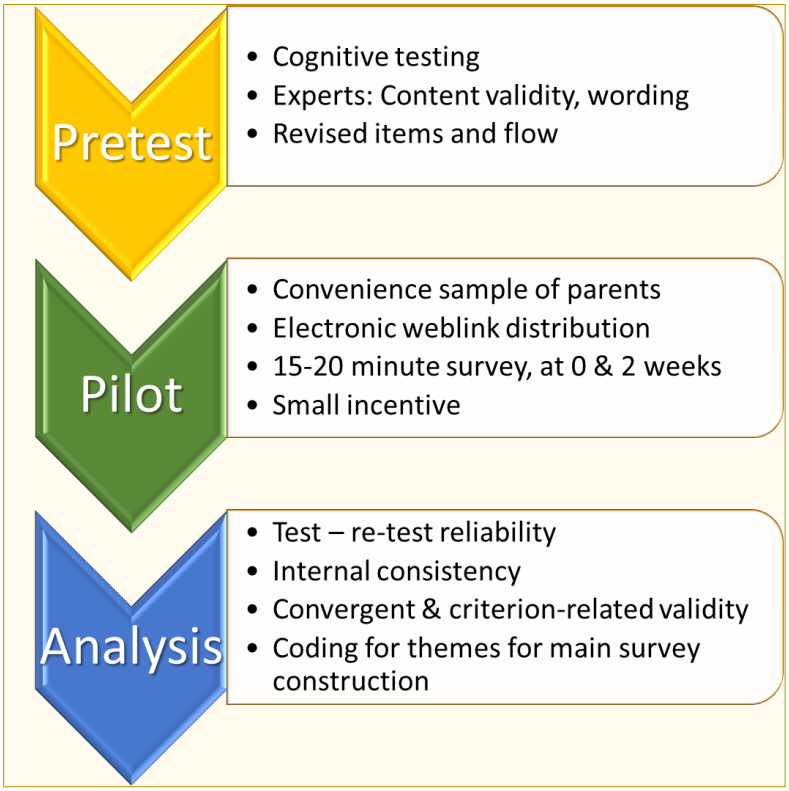
Section 4. Pilot Study

Before the main study, pre-testing of measures and pilot testing of the web-based survey were conducted to examine the feasibility, reliability and preliminary validity of

the web-based survey with measures of parental health literacy, parental empowerment and parental advocacy adapted to the context of food allergies management in elementary schools (Figure 5) (Koo, 2020).

Figure 5

Overview of Pre-testing, Pilot-testing, and Data Analysis for Refinement of Measures



4.1. Pilot Study Measures

Validated and reliable health literacy and empowerment scales were adapted for parental perspectives on child food allergy management in elementary school. The advocacy measure was developed from the literature. Pre-testing, or cognitive testing, with experts helped inform revision of items and helped to assess content validity of measures. Pilot testing was performed to assess measures' convergent validity, criterion-

related validity, test-re-test reliability, and internal consistency. Results of the pilot testing led to further refinement of items and scales.

Parental Health Literacy. The parental health literacy measure was adapted from Ishikawa et al.'s (2008) Functional, Communicative, and Critical Health Literacy Scale (FCCHLS). Permission to adapt and use the FCCHLS was obtained from Dr. Ishikawa. The adapted FCCHLS consisted of three subscales of four items each: functional, communicative, and critical health literacy. All items used similar and consistent stems of "How difficult is it for you to …. ?" (Heijmans et al., 2015) with five response options, from very difficult (1) to very easy (5) (Wangmar et al., 2018) (Appendix B). The mean (sum of items divided by the number of items) was used as the score for each subscale and the total health literacy scale. The theoretical range for scores was from 1 to 5, with a higher mean indicating higher health literacy.

Twelve items from the FCCHLS were adapted from the context of diabetes self-care to the context of parental care of the child with food allergies. As recommended due to low item variability and decreased subscale reliability (Finbråten et al., 2018; Ousseine et al., 2018), the functional health literacy subscale did not include one item about print being too small. A second item, "understand the obtained information" from the communicative health literacy subscale that had the lowest standardized factor loading and highest error variance in Heijmans et al.'s (2015) study was not included.

Response options for this FCCHLS adaptation for parental food allergy management were on a 5-point Likert scale to decrease the likelihood of a ceiling effect in the sample, to anchor both ends uniformly, to allow a neutral opinion option, and to optimize the scale for statistical analysis purposes (Chyung et al., 2017). It further

decreased overall respondent burden in the whole questionnaire by maintaining a consistent number of five response options across all items for all major variable scales.

Parental Empowerment. The parental empowerment measure was adapted for parents' perspectives on management of a child's food allergies in schools predominantly from the Health Empowerment Scale (Camerini et al., 2012; Londoño & Schulz, 2015; Náfrádi et al., 2016, 2018) with some wording of items similar to the Food Allergy-specific Empowerment Scale (Warren, et al., 2015). For the pilot study, it consisted of 12 items in four subscales: meaning (relevance), competence (self-efficacy), impact (locus of control), and self-determination (choice) with five response options (from strongly disagree to strongly agree) using a slide ruler smiley face. The parental empowerment score was the mean of all items, with a theoretical range from 1 to 5, with a higher score indicating greater empowerment.

Parental Advocacy. The parental advocacy measure was developed from the literature (Boshoff et al., 2016; Burke, Goldman, et al., 2016; Burke & Goldman, 2015; Cawthon & Caemmerer, 2014; Ryan & Cole, 2009; A. Trainor, 2010; A. C. Wright & Taylor, 2014; P. Wright & Wright, 2006). For the pilot study, it consisted of 14 items in four subscales: educating others, requesting safety practices, communicating with the school, and cause advocacy. Five response options ranged from 'not successful' (1) to 'completely successful'(5) and the option, 'didn't do' was available for all items. The parental advocacy score was the mean of all items with a theoretical range from 1 to 5, with higher scores indicating greater perceived effectiveness of parental advocacy behaviors.

Items for the parental advocacy scale were created to include major ideas from the literature (Boshoff et al., 2016; Burke et al., 2018; Burke & Sandman, 2017; Centers for Disease Control and Prevention, 2013; Ewles et al., 2014; Goldman et al., 2017; Malec et al., 2010; Nachshen et al., 2001; P. Wright & Wright, 2006). In particular, two parental advocacy scales related to parent-school communications and Individualized Education Plan (IEP) meetings for students with disabilities provided ideas for multiple aspects of parental advocacy specific to a child at school: items about self-confidence with communications, perceptions of meeting effectiveness, comfort with advocacy efforts, and more (Burke, Goldman, et al., 2016; Cawthon & Caemmerer, 2014). Ideas for items in the 'cause advocacy' subscale came from: a scale assessing advocacy efforts related to individuals with brain injuries (Malec et al., 2010); a scale assessing frequency and reach of parental legislative advocacy for children with disabilities (Burke & Sandman, 2017); and from the interview guide about parental advocacy by Nachshen, et al. (2001).

Specific to food allergies, salient ideas for items were collected from a survey of school nurses about school food allergy policies and practices (Kao et al., 2018) and the CDC guidelines for food allergies management in school (CDC, 2013). Response options were assessed as perceived effectiveness because it is the essence of whether or not the parents think their efforts were successful at obtaining their desired result (A. C. Wright & Taylor, 2014). Items were refined in an iterative process during cognitive interviewing as described below.

eHealth Literacy Scale (eHEALS). The eHEALS is a health literacy scale intended to measure consumers' perceived skills in using and critically appraising electronic health information (Norman & Skinner, 2006). The eHEALS consists of 8

items with five response options (strongly disagree to strongly agree). It has good internal consistency (alpha >0.87), good test-retest stability, and has been validated in younger and older English-speaking adults (Chung & Nahm, 2015; Norman & Skinner, 2006). Convergent validity of the parental health literacy measure (adapted FCCHLS) was assessed through correlation with eHEALS.

Attitude of Control and Competence Subscale of the Psychological Empowerment Scale (PES). The PES is designed to assess the psychological empowerment parents of children with disabilities (Akey et al., 2000). The Attitude subscale is designed to assess the intrapersonal dimension of empowerment and consists of 8 items with five response options ranging from strongly disagree to strongly agree. It has good internal consistency (alpha >0.90) and good convergent and discriminant validity (Akey et al., 2000). Convergent validity of the parental empowerment measure (adapted Health Empowerment Scale) was assessed through correlation with this Attitude subscale of the PES.

Food Allergy Independent Measure (FAIM). The FAIM is intended to be a short and independent measure of food allergy-related quality of life with two dimensions: perceived allergy severity and outcome expectancy for oneself (child, adolescent, or adult) (Klinnert et al., 2015; Van Der Velde et al., 2009). The six-item measure demonstrated good reliability (ICC > 0.70) in Dutch and correlated with a longer measure of food allergy-associated perceived quality of life (Van Der Velde et al., 2009). For use as a covariate in this pilot study, FAIM items were adapted for parents' perceptions of their child's perceived food allergies severity and expectancy outcomes for care of their child in the school setting.

Covariates included in the pilot study are described below under Measures for the main study.

4.2. Pre-Testing

Cognitive Interviewing and Content Validity Assessment Procedures. Cognitive interviewing, refinement of survey items, and content validity assessment were conducted with six experts in health literacy, empowerment, advocacy, or food allergy. Experts in health literacy, empowerment, advocacy, or food allergies were asked to attend individual "think aloud" sessions during which they read survey items that comprised the three main variables of health literacy, empowerment, and advocacy. As they read survey items, experts described aloud what they understood each item to mean. When an item was unclear or required clarification, dialogue ensued about the intended meaning and alternate phrasing options. Next, each expert independently rated the relevance of each item to the operational definitions of the construct on a four-point rating scale, from 1 (not relevant) to 4 (very relevant) (Soeken, 2005). A round of cognitive interviews consisted of two independent interviews. The content validity index was calculated for each round of cognitive interviews by dividing the number of times an item was ranked as 3 (quite relevant) or 4 (very relevant) by two (the number of experts per round), with an acceptable threshold set at 0.90 (Park & Park, 2013; Soeken, 2005). The predetermined procedure was to discard or modify any item that was rated as 1 (not relevant) or 2 (somewhat relevant) by the two experts each round. Item revisions were performed in an iterative manner after every round of two cognitive interviewing sessions. Table 2 describes selected types of measurement validity.

Table 2

*Characteristics of Selected Types of Measurement Validity**

Term	Definition	Pre-Test or Pilot Study Method
Measurement Validity	The extent to which a measurement tool achieves the purpose for which it was intended in measuring a concept	Content validity and construct validity (see below)
Content Validity	The extent to which operationalization of a construct, or the content of the measure, covers the relevant content domains of the concept	Cognitive interviewing about items in main variables; Content Validity Index (a measure of experts' ratings of an item's relevance to operational definition of the variable)
Construct Validity	The extent to which the conclusion that operationalization of the construct is truthful and that the tool measures what it is expected to measure	Convergent validity and criterion-related validity (Future studies could assess discriminant validity, item analysis, factor analysis, and differentiation by known groups)
Convergent Validity	A subtype of construct validity; the extent to which a measure is similar to another expected operationalization, e.g. how well a scale correlates to another scale known to measure a similar construct	Correlations of: adapted FCCHLS with eHeals; adapted Health Empowerment Scale with attitude subscale of Psychological Empowerment Scale
Criterion-related Validity	A subtype of construct validity; the extent to which a measure is correlated to another independent measure as expected based on theory. Two types include concurrent validity and predictive validity.	Correlations of: functional health literacy with educational level; and subscales of Parental Advocacy scale with each other

*Sources (Boateng et al., 2018; Jordan et al., 2011; Soeken, 2005; Trochim, 2005)

Results of Cognitive Interviewing and Content Validity Assessment. Three rounds of cognitive interviews (a total of six sessions) were conducted, with each cognitive interview ranging in duration from 45 minutes to 1 hour 20 minutes. The

survey items went through three iterative revisions. Wording revisions occurred for 11 of 38 items until relatively few new insights emerged (Boateng et al., 2018). No items were rated as 1 (not relevant) or 2 (somewhat relevant) during the three rounds. In other words, the content validity index (CVI) for two experts on each revised version was 1.0, indicating that both experts provided a rating of 3 (quite relevant) or 4 (very relevant) for all items related to their operational definitions (Soeken, 2005). The results of this cognitive testing provided a preliminary measure of good content validity (Soeken, 2005).

Spontaneous conversations during the cognitive interviewing process provided additional recommendations for survey flow and covariates. In two measures, this resulted in altering the order of items to create more logical flow. The experts provided recommendations to consider additional covariates, such as a 504 plan, participation in allergen immunotherapy, and parents' education in a health-related field.

4.3. Pilot Study Procedures

Participant Recruitment. IRB-approval was obtained before recruitment for the pilot study. A convenience sample of parents was recruited from a closed, private food allergy social media group and two small email listservs to complete an anonymous web-based survey twice, separated by two weeks. Electronic ads with an anonymous survey weblink were posted or emailed every four to 10 days up to a maximum of four times per group. A small participant incentive was offered for completion of the same survey, two weeks apart, upon completion of the second survey. Offering a participant incentive is beneficial with electronic distribution of an anonymous survey weblink because it may increase response rates, yet it also increases the risk of multiple submissions, participant

misrepresentation, or falsification of responses (Bauermeister et al., 2012; Kramer et al., 2014; Pedersen & Kurz, 2016; Teitcher et al., 2015). To prevent inclusion of low data quality in the analysis due to this risk, several design strategies, software strategies, and data analysis strategies were incorporated.

Survey Flow. First, the anonymous survey weblink was distributed only to the targeted population through closed private electronic avenues, not through public forums (Kramer et al., 2014). When potential participants clicked the anonymous survey weblink, they reviewed the consent form. After agreeing to participate, they responded to screening items for participant inclusion. If they met inclusion criteria, they passed to an internet software screener (CAPTCHA) to prevent survey-completion programs (known as "bots") from responding to the survey (Kramer et al., 2014; Teitcher et al., 2015). They were informed that they were asked to complete the same survey twice, separated by two weeks, and asked to provide an email to receive a link to the second survey. Participants' anonymity remained protected because internet IP addresses were not collected and email addresses were collected in a separate Qualtrics survey if they chose to provide it to participate a second time and receive the participant incentive (Bauermeister et al., 2012; Teitcher et al., 2015). All data was stored in password-protected databases on a secured, password-protected computer.

The survey format was optimized for mobile devices with three to four items per page. The pilot survey contained several multiple-choice items, several 5-point rating scale items, two multiple response items, and four open-ended items. To minimize missing data, reminder requests (not requirements) to complete or skip an item prompted participants brfore progressing to the next page. To access the second survey, participants

entered the survey through their Qualtrics-generated anonymized individual weblink received via email and then provided their participant identification number and child's age, which were verified as anonymously linked data items from the first survey (Kramer et al., 2014).

Participant Incentive. Upon completion of the second survey, the first 30 participants to complete the second survey had the option to provide an email to receive a participant incentive, a $20 Amazon.com Gift Card. Participant name and email contact information were collected in a separate Qualtrics survey and maintained in a separate, password-protected database on a secured, password-protected computer. Participant incentives were distributed two to three weeks after completion of the second survey. This allowed for manual checks for duplicate emails and manual set-up for electronic distribution of incentives (Teitcher et al., 2015).

Process Evaluation. Manual data monitoring occurred at least once every eight to twelve hours while the first and second pilot surveys were live. Data monitoring reviewed all responses for suspicious patterns, such as an individual with the same responses for all items, a large pattern of reported allergens inconsistent with the typical pattern in the literature, or a pattern of multiple responses completed in a less than realistic timeframe (Bauermeister et al., 2012; Kramer et al., 2014). Speeding, or fast completion time, has been demonstrated to be the most helpful to identify meaningless data in web-based surveys (Jones et al., 2015; Leiner, 2019). The protocol included temporary closure of the survey for further evaluation if a pattern of multiple suspicious responses was detected.

Lastly, data analytic strategies for exclusion of highly suspicious responses were pre-set before data collection and analysis (Bauermeister et al., 2012; Jones et al., 2015;

Kramer et al., 2014). Responses that progressed through less than 50% of the questionnaire were excluded from data analysis. Analysis checked for illogic responses to pairs of items plus survey completion within an unrealistic timeframe (Bauermeister et al., 2012; Kramer et al., 2014; Teitcher et al., 2015). Jones et al. (2015) and Leiner (2019) recommend reviewing multiple indicators to improve identification of poor data quality without potentially excluding legitimate responses. The following quality control criteria were pre-set for exclusion of highly suspicious low-quality responses that progressed more than 50% through the questionnaire:

- survey completion (100%) in less than 306 seconds (5 minutes 6 seconds) plus any one of the following logic errors:
    a) child's age at diagnosis greater than current age
    b) number of severe allergic reactions in past 12 month greater than number of lifetime allergic reactions, or
    c) food allergy knowledge score (combined from 4 items) less than 3/8.

Data Analysis. Good item test-retest reliability used two criteria for evaluation: (1) nonsignificance of paired samples t-tests and (2) significant correlations. For paired samples t-tests, acceptable criteria was set at no significance with $p>.05$ (Chung & Nahm, 2015) or for the non-parametric equivalent Wilcoxon signed-rank tests (Field, 2013b). Acceptable criteria for correlations was $r>.40$, $p<.05$ (Boateng et al., 2018). To assess scales' internal consistency, Cronbach's alpha coefficient with more than 0.70 was the threshold for acceptable reliability, and more than 0.80 was designated as good reliability (Boateng et al., 2018). Convergent validity was tested with correlations to available

validated scales, providing an indicator of construct validity (Boateng et al., 2018). Criterion-related validity was tested with correlations among variables that theoretically were expected to correlate (Boateng et al., 2018).

Qualitative data was coded for themes using a focused ethnography approach (Wall, 2015). The focused ethnography approach seeks to understand three main concepts: (1) ideas, beliefs and values (2) knowledge, skills and activities, and (3) power and control (Wall, 2015). Pilot data were coded based on the guiding question, "What are the personal characteristics and best practices of parents who advocate for food allergy management in elementary school that would inform main survey construction?"

4.4. Pilot Study Results

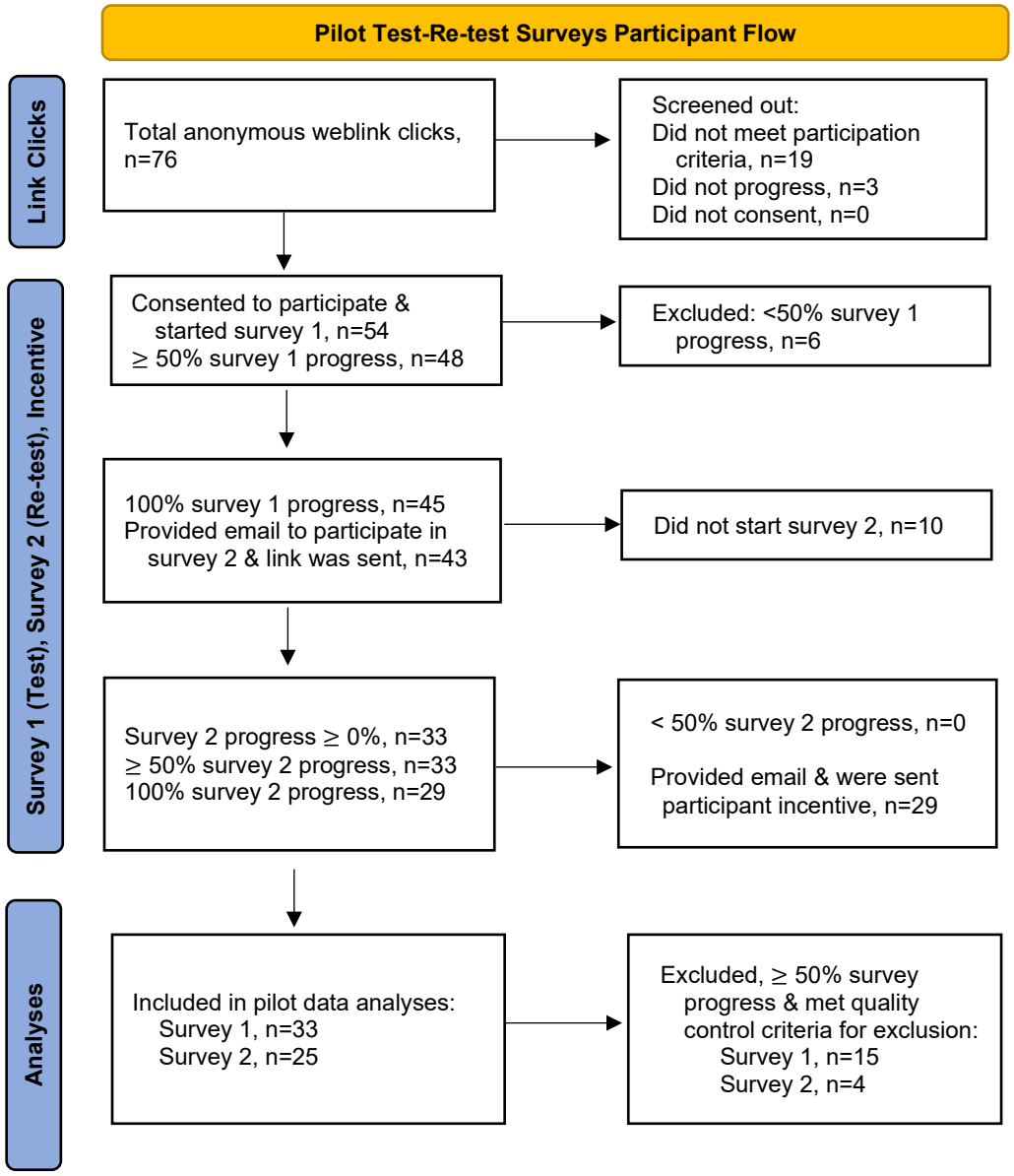
Pilot Study Participant Demographics. Participants were predominantly white (67%), college-educated (85%) mothers (94%, N=33, Survey 1, week 0). They were caregivers of children, ages 5 to 13 (average age 7.6 years). Participants' children had allergies to a median of two allergens (range 1 to 9), with the most commonly reported allergens of peanut and tree nut, followed by milk, egg, and others. Two-thirds of respondents reported that their school community was suburban and 80% of respondents reported that their schools had a school nurse.

Feasibility. Electronic recruitment methods in May 2020 yielded 54/76 participants who met inclusion criteria and consented to participate after clicking on the anonymous survey weblink (Figure 6). Most responses to electronic ads occurred within 24 hours, with median completion time of 20 minutes (range 9 to 43 minutes). Forty-three participants in the first pilot survey (Survey 1, week 0) provided an email to participate in the re-test survey (Survey 2, week 2). Respondent data was analyzed for

exclusion of highly suspicious, low-quality responses and 15/48 responses (31%) were excluded from Survey 1. Four out of 29 responses (14%) were excluded from Survey 2. The resulting pilot sample consisted of 33 participants on the first survey and 25 on re-test. There were no missing data (0%) for the items that comprised the three major variables, and minimal (1 to 2) missing responses on two covariate items in both surveys. More than 85% of respondents substantially answered four out of four short-answer essay items on test and re-test surveys. Unsolicited and freely provided participant feedback reported that the slide-ruler smiley faces for some items were difficult to work and that they preferred the multiple choice 5-option responses over the smiley faces.

Figure 6

Pilot Test/Re-test Surveys Flow, Incentive Participation, and Inclusion in Analyses



Note: Quality control criteria for exclusion from analyses: Progressed through survey in less than 306 seconds plus committed any one of the following logic errors: a) child's age at diagnosis > current age, b) number of severe allergic reactions in past 12 months > number of lifetime allergic reactions, or c) food allergy knowledge score < 3/8.

Descriptive Statistics of Main Variables. No items nor the scales themselves within the parental health literacy and parental empowerment variables met criteria for ceiling effects (more than 15% of sample's scale scores in extreme highest or lowest; or more than 95% of sample responses at extreme for each item). Yet, some moderate concern for a narrow range of variability was noted in the parental empowerment scale (mean 4.33, range 2.58 – 5.00, SD .55). The parental health literacy scale demonstrated the largest range of variability (mean 3.68, range 1.75 – 5.00, SD 0.83) among the three main variables. Four items that comprised the cause advocacy subscale of the parental advocacy scale demonstrated ceiling effects at the low extreme, with about 60% of responses reporting "didn't do". Overall, the parental advocacy scale demonstrated a moderately large range of variability (mean 3.84, range 1.8 – 5.00, SD .84).

Reliability. Good item test-retest reliability was pre-defined as: no significance ($p>.05$) for paired samples t-test or for the non-parametric equivalent Wilcoxon signed-rank tests (Chung & Nahm, 2015; Field, 2013b) and correlations with $r>.40$, $p<.05$ (Boateng et al., 2018). Good test-retest reliability was found for 12/12 parental health literacy items, 5/12 parental empowerment items, and 9/14 parental advocacy items. Of note, all three items comprising the parental empowerment subscale of 'self-determination' had poor test-retest reliability. Additionally, test-retest reliability sensitivity for items comprising the 'cause advocacy' subscale was limited due to those items' ceiling effects at the low extreme. Good test-retest reliability was evident for 5/6 items in the FAIM covariate measure.

Another measure of reliability, called internal consistency, was pre-defined by Cronbach's alpha coefficient more than 0.70 as acceptable reliability, and by more than

0.80 as good reliability (Boateng et al., 2018). The three main variable scales had good internal consistency, with Cronbach's alpha ranging from .88 to .95.

Convergent Validity. The parental health literacy scale correlated moderately well with the eHeals scale ($r=.65$, $p<.001$, $N=33$). The parental empowerment scale correlated strongly with the Attitude subscale of the Psychological Empowerment Scale ($r=.74$, $p<.001$, $N=33$). An external validated scale for convergent validity testing was not available for the parental advocacy scale so criterion-related validity was examined.

Criterion-related Validity. In the parental advocacy scale, the child advocacy subscales of 'communicate with school', 'educate others', and 'request safety practices' demonstrated strong correlations with each other ($r>.74$, $p<.001$, Table 3). The 'cause advocacy' subscale did not correlate with 'communicate with school' and 'request safety practices' subscales ($p>.05$) but did correlate moderately well with the 'educate others' subscale. The 'cause advocacy' subscale did not correlate with 'advocacy for whom', 'time spent advocating', nor 'support group participation' ($p>.05$) as expected (Malec et al., 2010). The functional health literacy subscale did not correlate with educational level ($p>.05$), possibly due to the high educational attainment of the sample (Chou et al., 2020).

Table 3

Correlations among Pilot Subscales of Parental Advocacy Measure (N=25)

Subscale	Communicate with School	Educate Others	Request Safety Practices	Cause Advocacy
Communicate with School	-			
Educate Others	**.86****	-		
Request Safety Practices	**.80****	**.75****	-	
Cause Advocacy	.46	**.60***	.45	-

Themes. Qualitative analysis of essay items revealed a major theme of parents experiencing a negative emotional impact of advocating for food allergy safety at schools. Participants described how challenging, frustrating, or difficult their experiences were in advocating for their child's food allergy safety at school. A second theme that emerged was the advocacy strategy of teaching their child to self-advocate to prevent allergen exposure or teaching their child to identify symptoms of an allergic reaction to ask for help.

4.5. Changes Made as a Result of the Pilot Study

Recruitment and Survey Flow. Overall, recruitment methods and survey flow demonstrated good feasibility but there was concern that approximately one-third of pilot participant responses (15/48) to the first survey were excluded due to meeting data quality criteria for exclusion. Therefore, to further prevent participant misrepresentation by limiting access to the web-based survey, main study recruitment ads posted to closed, private social media groups did not provide an anonymous survey weblink but instead provided a study email and phone number to request an survey weblink (Bauermeister et al., 2012; Kramer et al., 2014; Teitcher et al., 2015). Added to the recruitment ads was a statement to not share or post the ad outside of the private group, but instead to direct interested individuals to contact the study email or phone number. Furthermore, an attention tester item was added as an additional indicator for analysis of pre-set criteria of multiple indicators of data quality ("Paying attention: please mark the third option") (Jones et al., 2015; Leiner, 2019).

Secondly, because most participants responded within 24 hours after recruitment ads were posted or emailed, the main study timeframe for recruitment ad postings was shortened to a minimum of two days between posts. Thirdly, concern that the pilot sample lacked racial and educational diversity created intentional efforts in the main study to include recruitment strategies targeting non-white and low-income parents or caregivers through food allergy organizations serving these communities.

Measures.

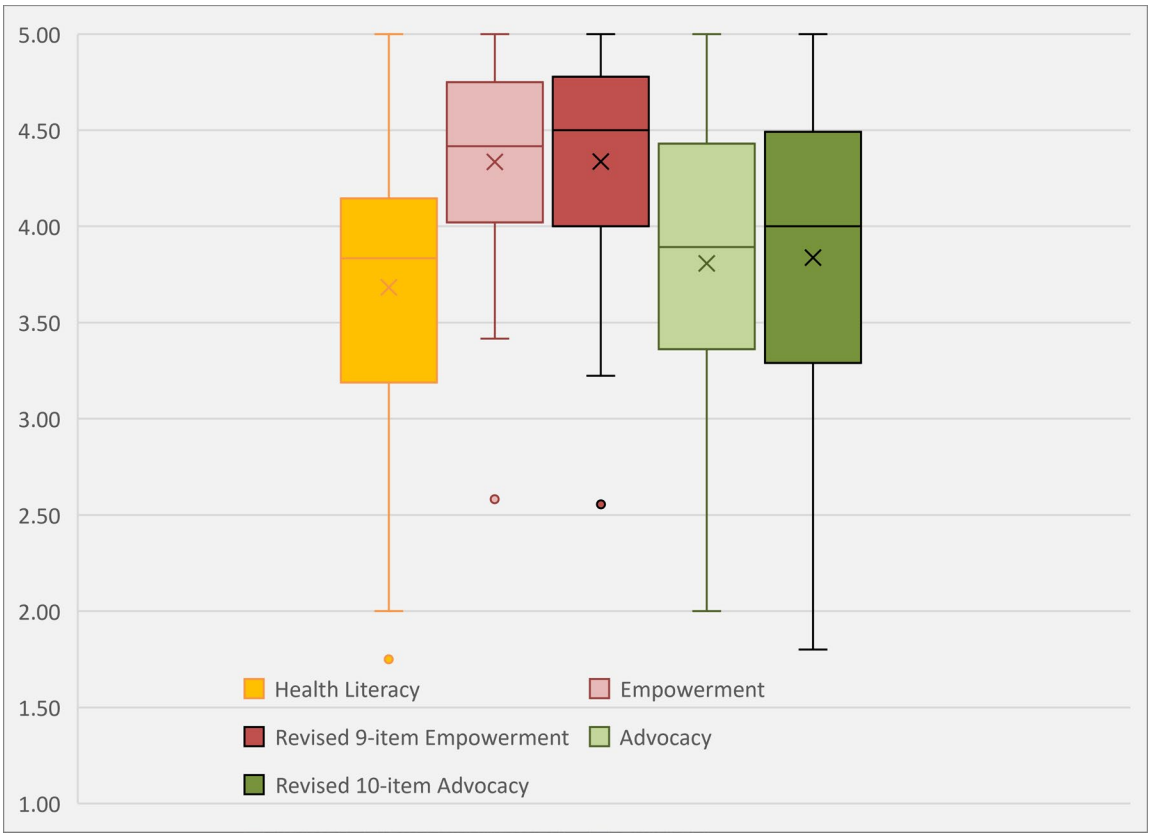
Parental Health Literacy. The parental health literacy measure demonstrated good test-retest reliability for all items, good internal consistency, and moderately good convergent validity. So, all items were retained with a minor wording tweak of two items to specify communicating with healthcare professionals (Nouri & Rudd, 2015; Roter et al., 2009; Santana et al., 2021).

Parental Empowerment. The parental empowerment scale had three items in the 'self-determination' subscale with poor test-retest reliability that were discarded. The test-retest result and qualitative responses highlighted the idea that the construct underlying the 'self-determination' subscale was not well-suited to the context in which parents must rely on school staff or their own child instead of being self-reliant. Because it did not make sense for this context, the 'self-determination' subscale was discarded. The resulting revised 9-item parental empowerment scale had a very similar mean and range as the original 12-item scale (Figure 7). Cronbach's alpha for the revised 9-item parental empowerment scale decreased mildly but remained good (alpha = .82, Table 4). The revised parental empowerment scale correlated strongly with the Attitude subscale of the Psychological Empowerment Scale, with the same r-coefficient value as the original

12-item parental empowerment scale (r=.74, p<.001, N=33). Four other items, at least one in each of the other subscales, demonstrated inadequate test-retest reliability. They were revised for improved clarity of wording for the main study. Response options were changed from the 5-option slide-ruler smiley face to 5-option multiple choice format to improve ease of use.

Figure 7

Ranges, Quartiles, Medians, and Means of Pilot Scales and Revised Scales (N=33)



Parental Advocacy. The parental advocacy scale demonstrated good criterion-related validity for the three child-focused subscales. However, the four items in the 'cause advocacy' subscale did not demonstrate adequate test-retest reliability and demonstrated a ceiling effect at the lower extreme "didn't do". Furthermore, the 'cause

advocacy' subscale did not correlate with two of the three other subscales nor with other expected criterion-related validity items. Because of these results and because the subconstruct of cause advocacy (or activism) is conceptually considered to be either blurred or at the far end of the parental advocacy continuum (Ryan & Cole, 2009; A. Trainor, 2010), the 'cause advocacy' subscale was removed from the parental advocacy scale. Cronbach's alpha of the revised parental advocacy scale improved with deletion of the 'cause advocacy' subscale (alpha=.90). Then, 'cause advocacy' with the four items was treated as a covariate in the main study. One additional scale item with inadequate test-retest reliability contained two ideas and was therefore was separated into two items. Finally, because of a qualitative theme that emerged, two items about educating their child to prevent allergen exposure and to recognize an allergic reaction were added to the parental advocacy subscale 'educating others'.

Covariates. To address the predominant theme from the qualitative responses of the negative emotional impact of advocating for safe food allergy practices in school, the FAIM measure was evaluated for capturing these emotions. Even though the FAIM was a short 6-item measure intended to capture similar concepts and had good test-retest reliability for 5/6 items, the qualitative data showed many comments about the emotional impact that respondents felt a need to share in open-ended questions possibly because prior items had not adequately provided opportunity to describe their emotional burden. Therefore, instead of using the FAIM, permission to adapt and use the food allergy quality of life – parental burden (B. L. Cohen et al., 2004) in the main study was obtained to measure the emotional impact covariate (Boshoff et al., 2016; Ewles et al., 2014). Other covariates were not changed.

Table 4

Characteristics of Scales and Revised Scales in Pilot Testing (N=33)*

Scale	Mean (Range)	SD	Cronbach's alpha	Items with good test-retest reliability (N=25)	Revision Plan
Parental Health Literacy	3.68 (1.75-5.00)	.83	.95	12/12	Tweak wording of 2 items
Parental Empowerment (4 subscales)	4.33 (2.58-5.00)	.55	.89	5/12	Discard 3-item self-determination subscale (not well-suited to context)
Revised Parental Empowerment (3 subscales; no self-determination subscale)	4.34 (2.56-5.00)	.58	.82	5/9	Revise 4 items; Chang all items from smiley face slide ruler to multiple choice
Parental Advocacy (4 subscales)	3.80 (2.00-5.00)	.76	.88 *(N=9)	9/14	Remove 4-item cause advocacy subscale (poor correlation with subscales). Use it as a co-variate
Revised Parental Advocacy (3 subscales; no cause advocacy subscale)	3.84 (1.80-5.00)	.84	.90 *(N=14)	9/10	Split 1 item into 2 items. Add other 2 items per qualitative data themes

* N varies for advocacy scales due to listwise deletion for those who reported "didn't do" for some items.

Section 5. Main Study Measures

5.1 Outcome Variable: Parental advocacy

For the main study, the outcome variable of parental advocacy, or 'perceived effectiveness of advocacy efforts', was measured with a scale that was comprised of three

subscales: educating others, requesting safety practices, and communicating with school staff (Boshoff et al., 2016; Burke et al., 2018; Cawthon & Caemmerer, 2014; Kao et al., 2018; Ryan & Cole, 2009; A. Trainor, 2010; A. C. Wright & Taylor, 2014; P. Wright & Wright, 2006). The parental advocacy scale consisted of 13 items with the stem, "During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?". Items that followed were specific food allergy safety practices, for example: requesting quick access to epinephrine, allergy-friendly seating, precautions for field trips, meetings with school staff, or teaching the child to manage food allergies. Response options assessed the perceived effectiveness of advocacy efforts on a 5-point scale ranging from Not successful (1) to Completely Successful (5) (Appendix C). Scores for the scale were calculated as means, with a theoretical range from 1 to 5, with 5 indicating greater perceived effectiveness of advocacy efforts.

5.2. Predictor Variable: Parental health literacy

For the main study, 12 items from Ishikawa, et al.'s (2008) Functional, Communicative, and Critical Health Literacy Scale were adapted from the context of diabetes self-care to the context of parental care of the child with food allergies with Dr. Ishiwaka's permission. Items were pre-tested and pilot-tested as described above. The adapted FCCHLS, called the parental health literacy scale, consisted of three subscales of four items each: functional, communicative, and critical health literacy. The stems for all items began, "How difficult is it for you to …. ?" with five response options, from very difficult (1) to very easy (5). The scores for each subscale and the parental health literacy scale were calculated as means, theoretically ranging from 1 to 5, with a higher mean

indicating higher health literacy. The cut-points for highest and lowest scorers for communicative health literacy and critical health literacy were determined based on the distribution, median, mean and receiver operator characteristics, as described below in data analysis.

5.3. Predictor Variable: Parental empowerment

For the main study, the parental empowerment measure was composed of 9 items in three subscales after refinement from pre-testing and pilot-testing described above. The parental empowerment scale was adapted from the Health Empowerment Scale which has been used in contexts of asthma, hypertension, and fibromyalgia self-management (Camerini et al., 2012; Londoño & Schulz, 2015; Náfrádi et al., 2016). It was adapted for the context of parental food allergies management with some ideas for item wording from the Adapted Food Allergy-specific Family Empowerment Scale (Warren et al., 2015). The three subscales of the parental empowerment scale for the context of food allergies management in schools were: meaning (relevance), competence (self-efficacy), and impact (locus of control). Parental empowerment items were phrased as statements regarding the participant's perceived confidence, perceived importance of, or perceived control over managing their child's food allergies. Response options were on a five-point Likert scale from Strongly disagree (1) to Strongly agree (5). Scores were calculated as means, with a theoretical range from 1 to 5, with higher scores indicating higher levels of empowerment. The cut-points for highest and lowest parental empowerment scorers were determined based on the distribution, median, mean and receiver operator characteristics, as described below in data analysis.

5.4. Covariates

Participant Sociodemographic Characteristics. The following sociodemographic characteristics of the participants were included: education, race, ethnicity, health-related education, caregiver role (mother, father, other), number of children with food allergies for whom the participant is a primary caregiver, and age of the youngest child in elementary school with life-threatening food allergies. Race and ethnicity had "prefer not to answer" as a response option.

Characteristic of Participant's Youngest Child with Food Allergies in Elementary School.

Food allergens. The ten most common food allergens (components or ingredients) that cause allergic reactions in children were listed for participants to select all that applied to their youngest child in elementary school with food allergies: milk, egg, peanuts, tree nuts, shellfish, wheat, soy, fin fish, sesame, and mustard (Gupta et al., 2011, 2018; National Academies of Sciences, Engineering, and Medicine, 2017; Sharma et al., 2019).

Severity of Food Allergies. A food allergies disease severity index score was calculated from the following items, based on ideas from Warren et al. (2018):

- Concurrent diagnosis of asthma (weighted)
- Number of years since first diagnosed with food allergy (reverse scored),
- Number of food allergens,
- Number of times an allergic reaction to food required epinephrine or treatment by an emergency medical team in the past 12 months

- Number of times an allergic reaction required epinephrine or treatment by an emergency medical team in child's lifetime

Additional covariates that described the child were: participation in allergen immunotherapy (yes, no, prefer not to answer) and has a 504 plan (yes, no, prefer not to answer).

School Characteristics. Characteristics of the school that were covariate items included: community setting (city, rural, suburban, don't know), presence of a registered nurse (none, part-time, full-time, don't know), and the school's requirement of an emergency care plan (yes, no, don't know) (Eldredge et al., 2014; Gupta et al., 2014; Kao et al., 2018).

Additional Covariates.

Food Allergy Knowledge Score. A 4-item food allergy knowledge score was developed from food allergy knowledge items for parents and clinicians, and from concepts in national food allergy guidelines (Centers for Disease Control and Prevention, 2013; Gupta et al., 2009, 2010; National Academies of Sciences, Engineering, and Medicine, 2017; J. Wang et al., 2014). Two items were knowledge items with five response options (from strongly disagree to strongly agree), with two points awarded for the strongly worded correct answer and one point awarded for the less-strongly worded correct answer. The third and fourth items were knowledge application items in the form of multiple-choice response options to food allergy scenarios. Two points were awarded for the one correct option in each item. The knowledge score was calculated by summing item scores, with a theoretical range from 0 to 8, with higher scores indicating more food allergy knowledge. Pilot-testing results demonstrated that 24 out of 25 respondents

answered one item correctly related to a scenario requiring emergency treatment for a severe allergic reaction or anaphylaxis with epinephrine and calling 911, as expected of the knowledge base of the target population (Kramer et al., 2014).

Cause Advocacy. The 4-item cause advocacy scale asked participants how successful they thought their advocacy efforts were at helping all people with food allergies. Activities included working with groups, raising or donating money, posting information, or contacting decision-makers. Items were based predominantly on items by Malec, Brown, and Moessner (2010) with some ideas from Nachshen, et al. (2001) and Burke and Sandman (2017). They were refined through pre-testing and pilot-testing as described previously. The response options assessed perceived effectiveness of advocacy actions on a 5-point scale, from Not successful (1) to Completely successful (5). The mean of the scale was used as the score, with a higher score indicating higher perceived effectiveness of cause advocacy efforts.

Food Allergy Quality of Life – Parental Burden (FAQOL-PB) (modified). The FAQOL-PB is a scale that measures food allergy-related quality of life, including issues impacting family and social activities, meals, childcare, health, and emotional well-being. It has 17 items. It showed good internal consistency (Cronbach's alpha = .95) and ability to discriminate disease severity (B. L. Cohen et al., 2004). Permission to adapt the FAQOL-PB from seven to five response options was obtained from the current owner, Food Allergy Research and Education.

Perceived Quality of Parent-School Relationship. The quality of the parent-school relationship was assessed with "How would you rate your relationship with the school?" and five-point response options from Poor (1) to Excellent (5). The perceived

quality of the parent-school relationship was influential in studies about parental advocacy behaviors in schools for children with disabilities (Burke et al., 2018; Malec et al., 2010).

Support group participation. Support group participation was assessed with "Over the past 12 months, how much did you participate in a food allergy support group?" with five response options from 'None, I did not participate' (1) to 'Very frequently, I performed a leadership role in the group' (5). Participation in food allergy advocacy groups was associated with worse FAQOL-PB scores (Ditzler & Greenhawt, 2016). Having more social support and an older child were associated with less parental monitoring in children's food allergies and more efforts for children to self-manage their food allergies (Williams & Hankey, 2016).

Section 6. Main Study Recruitment

Participants were recruited through multiple methods: through ads distributed by email or posted electronically through closed food allergy social media support groups, food allergy organizations, a food bank, and a patient registry. Due to low prevalence in the general population, this sampling design targeted parents or caregivers dealing with food allergies. Methods were limited to non-in-person recruitment strategies due to limitations related to the COVID-19 pandemic. Food allergy organizations distributed or allowed posting of electronic recruitment ads via the following methods: emailed ad invitations, emailed newsletter ads, posts in closed private social media groups, a blogpost, and a print magazine ad. Ads were posted or emailed every two to fourteen days, depending on the organizations' permissions.

Section 7. Main Study Procedures

7.1. Main Survey Flow

When a potential participant responded to a private recruitment ad sent via a private listserv email, they clicked on an anonymous survey weblink to start the survey eligibility screening items. When a potential participant responded to a public recruitment ad posted to a closed social media food allergy support group, food allergy website, or group electronic newsletter, they emailed or called the study contact provided on the ad to provide an email for receipt of a survey weblink. In response to the email request, the potential participant received an individual weblink emailed from Qualtrics, the survey host online platform. If the participant had not responded to the individual survey weblink after 48 hours, a reminder email with the individual weblink was sent from Qualtrics. The data was anonymized from individual survey weblinks so it could not be associated with an individual's email.

When potential participants clicked on the survey through either the anonymous weblink or the individual weblink, the first few screening items of the survey determined eligibility to participate in the survey. If not eligible, the potential participant viewed words thanking them for their willingness to volunteer and they exited the survey. Eligible participants responded to an item generated by an internet software screener (CAPTCHA) to prevent automatic survey-completion programs (known as "bots") from responding to the survey (Kramer et al., 2014; Teitcher et al., 2015). Then, participants went to the consent form. If they chose to participate, they clicked to start the survey. Participants' anonymity remained protected because internet IP addresses were not collected; email addresses for the optional participant incentive were collected in a

separate survey; and data from individual weblinks was anonymized (Bauermeister et al., 2012; Teitcher et al., 2015). Anonymized data was stored in a secure, password-protected database on a secure, password-protected computer.

The survey format was optimized for mobile devices with three to four items per page. The main survey contained several multiple-choice items, several 5-point rating scale items, two multiple response items, and four open-ended items. The three main variables of parental health literacy, empowerment, and advocacy were measured through scales comprised of several 5-point rating scale items. Covariates included: the child's food allergy severity, elementary school characteristics, parental food allergy-related quality of life, and participant demographics. Open-ended items inquired about the participant's experiences with advocating for food allergy management in the school and their perceived parental characteristics. To limit missing data, reminder requests (not requirements) to complete or skip an item prompted participants upon progressing to the next page.

7.2. Participant Incentive

Upon completion of the survey, the first 300 respondents had the option to provide a name and email to receive the participant incentive, a $15 Amazon.com Gift Card. Participant name and email contact information were collected in a separate Qualtrics survey and maintained in a separate, password-protected database on a secured, password-protected computer. Participant incentives were distributed two to three weeks after participation to allow time for manual verification of non-duplicate emails and manual set-up for electronic distribution (Teitcher et al., 2015).

7.3. Process Evaluation

Manual data monitoring occurred at least once every five to eleven hours while the main survey was live. Data monitoring reviewed responses for suspicious patterns or a pattern of multiple responses completed in a less than realistic timeframe as justified above in pilot study procedures (Bauermeister et al., 2012; Jones et al., 2015; Kramer et al., 2014; Leiner, 2019). (Jones et al., 2015; Leiner, 2019). The protocol included temporary closure of the survey for further evaluation if a pattern of multiple suspicious responses was detected.

Lastly, data analytic strategies for exclusion of highly suspicious responses were pre-set before data collection and analysis (Bauermeister et al., 2012; Jones et al., 2015; Kramer et al., 2014). Responses that progressed through less than 50% of the questionnaire were excluded from analysis. Quality control criteria for exclusion of highly suspicious responses from analyses of those that progressed more than 50% through the questionnaire included:

1) Progressed through 93% of survey (all items before 4 short essay items) in less than 308 seconds (5 minutes 8 seconds), or
2) Progressed through 93% of survey in less than 365 seconds (6 minutes 5 seconds) plus committed any one of the following logic errors:
    a) incorrect attention tester response
    b) child's current age less than 4 years old
    c) child's age at diagnosis greater than current age
    d) number of severe allergic reactions in past 12 month greater than number of lifetime allergic reactions, or

e) food allergy knowledge score less than 3/8 or:

3) Progressed through >50% of survey and provided incorrect attention tester response plus committed any of one of the following logic errors:

a) child's current age less than 4 years old
b) child's age at diagnosis greater than current age
c) number of severe allergic reactions in past 12 month greater than number of lifetime allergic reactions, or
d) food allergy knowledge score less than 3/8

The attention tester item was located at 53% progress through the survey and stated, "Paying attention. If you are reading this, please mark the third option".

Section 8. Main Study Data Analysis Methods

Statistical analyses were conducted by using SPSS v. 27 in three steps: descriptive statistics, bivariate analyses, and general linear model analyses. Descriptive measures examined all variables for their distributions, measures of central tendency, missing data, and outliers (Field, 2013a; Thompson, 2016). To attempt to limit missing data, reminder requests to complete incomplete items popped-up with each survey page completion (after about every 3 to 4 items). If variables had been found to have more than 5% missing data at random, then multiple imputations would have been performed for all variables (Meyers et al., 2012). Means of subscales and scales were used as scores for the main variables, another method to compensate for potential missing data. Testing for ceiling effects was performed for the three main variables and the subscales of functional health literacy, communicative health literacy, and critical health literacy. Pre-determined criteria of a ceiling effect was: if more than 15% of the sample scores were in the extreme

highest (5) or lowest level (1) for a scale (or health literacy subscale), or if more than 95% of the sample scores were at the extreme highest or lowest level for one item (Heijmans et al., 2015; Ousseine et al., 2018; Terwee et al., 2007).

The associations among parental health literacy, parental empowerment, and parental advocacy were examined with bivariate and general linear model analyses. Bivariate associations were assessed with correlations (continuous variables), Chi-square (categorical variables), or independent t-tests (to test the difference between means of main variables between groups). General linear model analyses were conducted with ANCOVA and regression analyses because parametric tests may be used to analyze Likert scale responses (Sullivan & Artino, 2013). After testing for a significant relationship between health literacy and advocacy, a mediation analysis of the mediating role of empowerment on the relationship between health literacy and advocacy was conducted using the PROCESS Macro for SPSS. For all analysis, statistical significance was set to an alpha less than .05.

8.1. Determining Cut-Points for Highest and Lowest Scorers

Creation of dichotomous variables for communicative health literacy, critical health literacy, and parental empowerment were required for Hypotheses 1, 2, and 4 to compare the highest and lowest scorers in those variables. To accommodate different distributions for each variable, the cut-points for highest and lowest scorers were determined for each separate variable. First, the variable distributions, mean and medians were observed, and a preliminary cut-point was selected between the mean and the median in natural step change among scores. Next, the Receiver Operating Characteristics (ROC) table and curve were examined.

The ROC is a graph depicting the relationship between sensitivity and specificity for one variable to predict a dichotomous outcome of another variable (Habibzadeh et al., 2016). Because of established correlations between communicative health literacy and critical health literacy (Finbråten et al., 2018; Heijmans et al., 2015; Ousseine et al., 2018; Zegers et al., 2020), these variables were used to predict one another in the ROC. The ROC table and curve were examined to determine the optimal cut-point for higher and lower scorers by maximizing sensitivity and specificity. An optimal cut-point would have sensitivity and specificity that are equal to one another and greater than 70% (with an area under the curve (AUC) greater than 0.7), depicted by the point in the curve closest to the upper left-hand corner (Chou et al., 2020; Habibzadeh et al., 2016).

The following process was used for any variable, such as parental empowerment, which had a probability distribution that was much narrower than a normal probability distribution and the area under the curve (AUC) was less than 0.7. A small (10-15%) middle portion of the data responses close to the mean and median were discarded to create clear separation between highest and lowest scorers. These cut-points around the mean and median were optimized according to how they were distributed in a stepwise pattern of values along the curve.

8.2. Analysis Plan for Each Hypothesis

The following describes the statistical analysis plan for each hypothesis.

H1. Parents who score at the highest levels on a measure of communicative health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels. Bivariate analyses were conducted with an independent sample t-test (dependent variable: parental advocacy; independent

variable: highest communicative health literacy scorers versus lowest communicative health literacy scorers). General linear model analysis was conducted with ANCOVA (dependent variable: parental advocacy; independent variable: dichotomous communicative health literacy). The following significant continuous covariates from the bivariate analyses were tested for inclusion in the ANCOVA: 'quality of relationship with school', 'perceived effectiveness of cause advocacy efforts' [cause advocacy], 'food allergy quality of life – parental burden (modified)', and their interaction terms (between the independent variable and each covariate). The following categorical covariates were tested for inclusion to see whether they met the ANCOVA assumption of a linear relationship at each level of the independent variable: school community setting, asthma, and 'school requires an emergency action form'.

Before the analysis, examination to meet the assumptions of the ANCOVA were reviewed, such as independence of observations (of residuals, using Durbin-Watson statistic), homoscedasticity (Levene's test), significant outliers (scatterplot), approximately normally distributed residuals (Shapiro-Wilk test), and homogeneity of regression slopes (scatterplot). Bootstrapping of confidence intervals with a Bonferroni correction for the estimated means (adjusted for the covariates) were used to decrease bias in the ANCOVA if a t-test revealed an association between the dependent variable and any covariate.

H2. Parents who score at the highest levels on a measure of critical health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels. T-test and ANCOVA were conducted as described in H1

(dependent variable: parental advocacy), except that the independent variable was dichotomous critical health literacy.

H3. Communicative and critical health literacy are more strongly associated with more effective advocacy behaviors than functional health literacy. Bivariate analyses were conducted with each of the parental health literacy subscale scores and with the parental advocacy score. Also, bivariate analysis were conducted between potential covariates and parental advocacy. A linear regression (dependent variable: parental advocacy; independent variables: functional health literacy, communicative health literacy, and critical health literacy) assessed for the strength of the relationships simultaneously with independent variables and covariates in the model. Covariates included: empowerment, quality of relationship with school, cause advocacy, asthma, school community setting, and food allergy quality of life - parental burden (modified). The values of the standardized beta coefficients determined the magnitude of importance of each parameter in the regression model while holding all the other parameters constant (Field, 2013c). Therefore, if the standardized beta coefficient values of communicative health literacy and critical health literacy were larger than the standardized beta coefficient of functional health literacy in the model, then the hypothesis would have been accepted.

Before the analysis, assessment of meeting the assumptions of the linear regression analysis was conducted, including: an approximately normally distributed dependent variable (histogram), no multicollinearity (using correlation coefficients and Tolerance/VIF), independence of observations (Durbin-Watson statistic), linear relationship between dependent variable and independent variable (scatterplot),

homoscedasticity (scatterplot of regression line), significant outliers (scatterplot), and approximately normally distributed residuals (Shapiro-Wilk test). If the data had failed to meet the assumptions of the regression, then data would have been transformed.

H4. Parents who score at the highest levels on a measure of empowerment engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels. T-test and ANCOVA were conducted as described in H1 and H2, except that the independent variable was dichotomous parental empowerment.

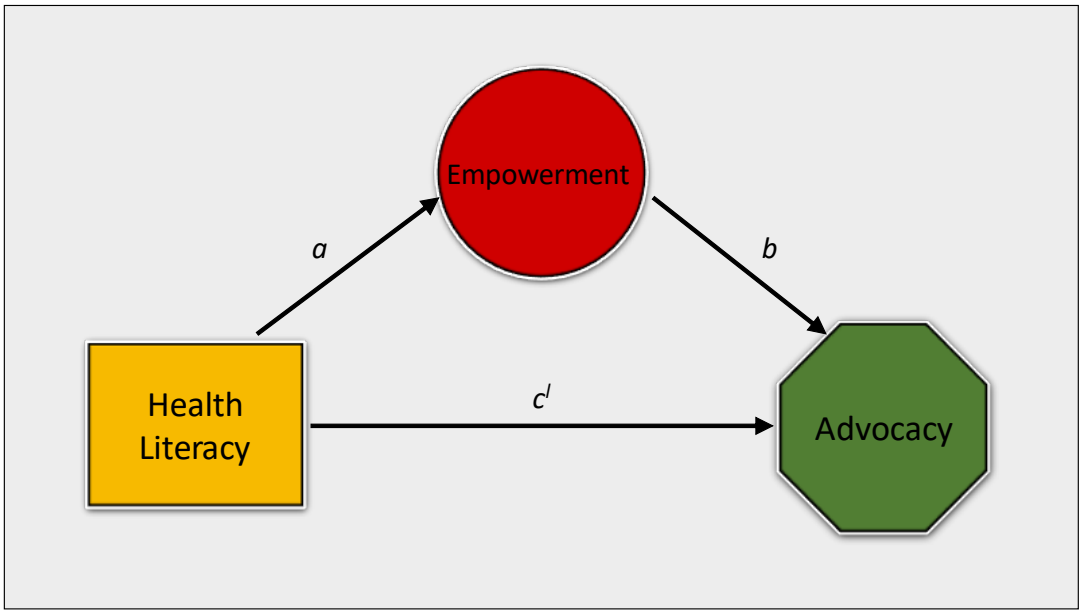
H5. The relationship between parental health literacy and advocacy is mediated by parental empowerment. A mediation analysis of a series of multiple regressions was conducted as depicted below (Figure 8): First, testing for a relationship between parental health literacy (predictor variable) and parental advocacy (outcome variable) was conducted. Next, the model estimation of all of the relationships was conducted using PROCESS for SPSS (Hayes, 2018; Hayes & Rockwood, 2017) with outcome variable: parental advocacy; predictor variable: parental health literacy; and mediator: parental empowerment.

PROCESS is a custom dialog box for SPSS that decreases the manual work of performing mediation analysis in SPSS. It estimates the indirect effect size of the indirect relationship between the predictor variable and the outcome variable through the mediator variable by bootstrapping to generate a confidence interval around the indirect effect size (Field, 2013d). The advantage of using PROCESS is that it employs the Lambert mediation model instead of the Baron and Kenny mediation analysis with Sobel test. Therefore, it can assess partial mediation rather than

requiring complete mediation, as is required by the Sobel test (Field, 2013d). If the confidence interval of the indirect effect does not include zero, then mediation is occurring (Field, 2013d). The size of the indirect effect is expressed as kappa-squared, with a small indirect effect of .01, a medium indirect effect of .09, and a large indirect effect of .25 (Field, 2013d). The final mediation model can then provide the direction and magnitude of the direct relationships between the variables (quantified as the regression coefficients with p-values) and the indirect effect (regression coefficient with bootstrapped confidence interval).

Figure 8

Hypothesis 5. The Relationship between Parental Health Literacy and Advocacy is Mediated by Empowerment



Before the analysis, the assumptions of the mediation analysis were tested, by first assessing the standard assumptions of a linear regression analysis (linearity, independence of errors, homoscedasticity and normality of errors) (Field, 2013c).

Next, assessing for reverse causality was warranted because it cannot be ruled out through temporal relationships due to the cross-sectional nature of the survey data (Fairchild & McDaniel, 2017). Conducting mediation analysis with cross-sectional data cannot demonstrate causation or directionality through observation of a series of correlation coefficients (Fairchild & McDaniel, 2017). Thus, the mediation directionality was assessed by interchanging the outcome variable and the mediator variable to assess for a similar correlation coefficients (b and c^1) in the mediation analysis. If these correlation coefficients were similar, then reverse causality could not be ruled out (Kenny, 2018). Furthermore, because health literacy may play a mediating role in the relationship between empowerment and actual involvement in the last medical treatment decision of adults (Sak et al., 2017), a reverse pathway mediation analysis exchanging the predictor variable and mediator variable was conducted to compare the magnitude of the indirect effects of the mediators in both models. If the indirect effects of the mediators in both models were similar, then reverse causality could not be ruled out.

8.3. Power Analysis

For a single mediator model with an estimated medium indirect effect size, a minimum sample size of 405 was required to achieve adequate statistical power for a mediation analysis using the joint significance test (Fritz & Mackinnon, 2007). Without an accurate *a priori* estimate of the potential indirect effect size in the proposed mediation based on the literature (Hayes, 2018), setting a minimum sample size goal 5% higher was reasonable. Thus, the target minimum sample size was 425 completed surveys

with a minimum recruitment of 475 participants to account for an estimated 10% partial survey completions.

Sample size estimates for statistical analyses in the other hypotheses required smaller sample sizes. *A priori* sample size analysis was performed with G*Power 3.1.9.4 to achieve 80% power with a 2-sided Type 1 error rate of 5% for the following statistical tests. Assuming a moderate effect size (0.3) for an independent t-test, the study would require at least 41 participants in the lowest and highest categories of independent variables (parental health literacy and parental empowerment) for a total of at least 82 participants (Mayr, S. et al., 2007). Assuming a moderate effect size (f^2=0.15) for multiple linear regression with 13 predictors (two variables, an interaction term, and 10 covariates), a sample size of 68 would be required (Faul et al., 2009). Lastly, assuming a moderate effect size (0.25) for ANCOVA, with two groups for comparison and 4 covariates (df=4), a sample size of 196 would be required.

Section 9. Ethical Considerations

For the pilot study and the main study, Institution Review Board (IRB) approval for human subjects work was obtained first from the University of Maryland College Park (UMD), and then from the University of Maryland Baltimore (UMB). For each study, UMD IRB was considered as the primary IRB, and the UMB IRB was considered as the secondary one. Lastly, several food allergy organizations, including the Food Allergy Research and Education Patient Registry, reviewed an abstract of the study aims, methodology, and questionnaire to approve of dissemination of the survey weblink through their organizations. Plans to report study findings back to potential participants

from food allergy organizations were included in discussions with many food allergy organizations because reporting back to the participating communities is important.

Survey participants were assured that confidentiality would be maintained through recruitment ads and the consent form process. The results were reported in aggregate form to avoid identification of any individual. Participant identifiers, such as names and emails, were stored separately and securely in a password-protected database different than the anonymized survey database. Survey responses from individual survey weblinks were anonymized so there was no link to their email address. Computers storing the databases are also password-protected.

Overall, potential risks of the study were considered minimal likelihood and minimal risk. The psychological risk of triggering anxiety related to questions about parental health literacy, empowerment, advocacy, food allergies, school communications, and demographics was considered minimal likelihood and minimal risk. The consent webpage included a statement that the participant may withdraw at any time. For the unlikely event that answering items triggered some feelings of anxiety in a participant, the consent form and the last survey webpage provided a Crisis Text Line to reach a trained crisis counselor (Crisis Text Line, 2019). Overall risks were minimized through the consent process, data protection measures, and provision of the crisis line.

Chapter 4. Results

Section 1. Introduction

The primary aim of the cross-sectional survey research was to determine whether parents of children with food allergies who score at the highest levels on measures of communicative health literacy, critical health literacy, and parental empowerment engage in more effective advocacy behaviors than parents who score at the lowest levels. The parental advocacy behaviors of interest were for safe food allergy management practices in their child's elementary school. The outcome variable, parental advocacy, or 'perceived effectiveness of advocacy efforts', was operationalized as a 13-item scale of the participants' reported success of several communicative behaviors to request support for school environmental and social conditions conducive to the safety, well-being, and full participation of their child with food allergies in all school activities. A total of 313 participants' responses to the online survey met inclusion criteria for data analysis. Descriptive statistics, bivariate analyses, and general linear model analyses were conducted for the following hypotheses:

H1. Parents who score at the highest levels on a measure of communicative health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels of communicative health literacy.

H2. Parents who score at the highest levels on a measure of critical health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels of critical health literacy.

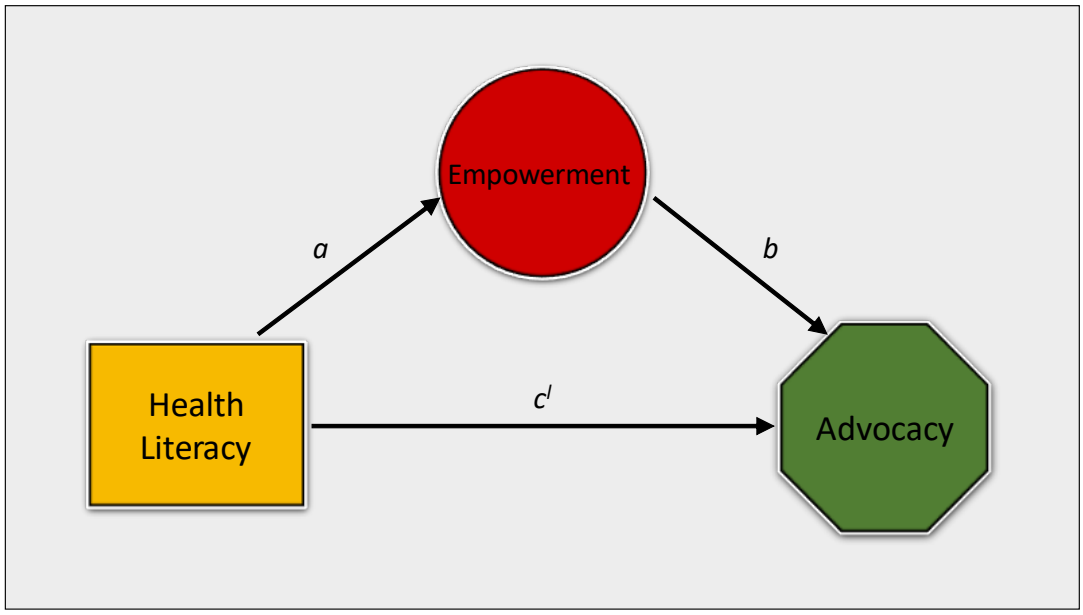
H3. Communicative and critical health literacy are more strongly associated with more effective advocacy behaviors than functional health literacy.

H4. Parents who score at the highest levels on a measure of empowerment engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels of empowerment.

H5. The relationship between parental health literacy and advocacy is mediated by empowerment (Figure 9).

Figure 9

Hypothesis 5. The Relationship between Parental Health Literacy and Advocacy Is Mediated by Empowerment



1.1. Recruitment and Participant Flow

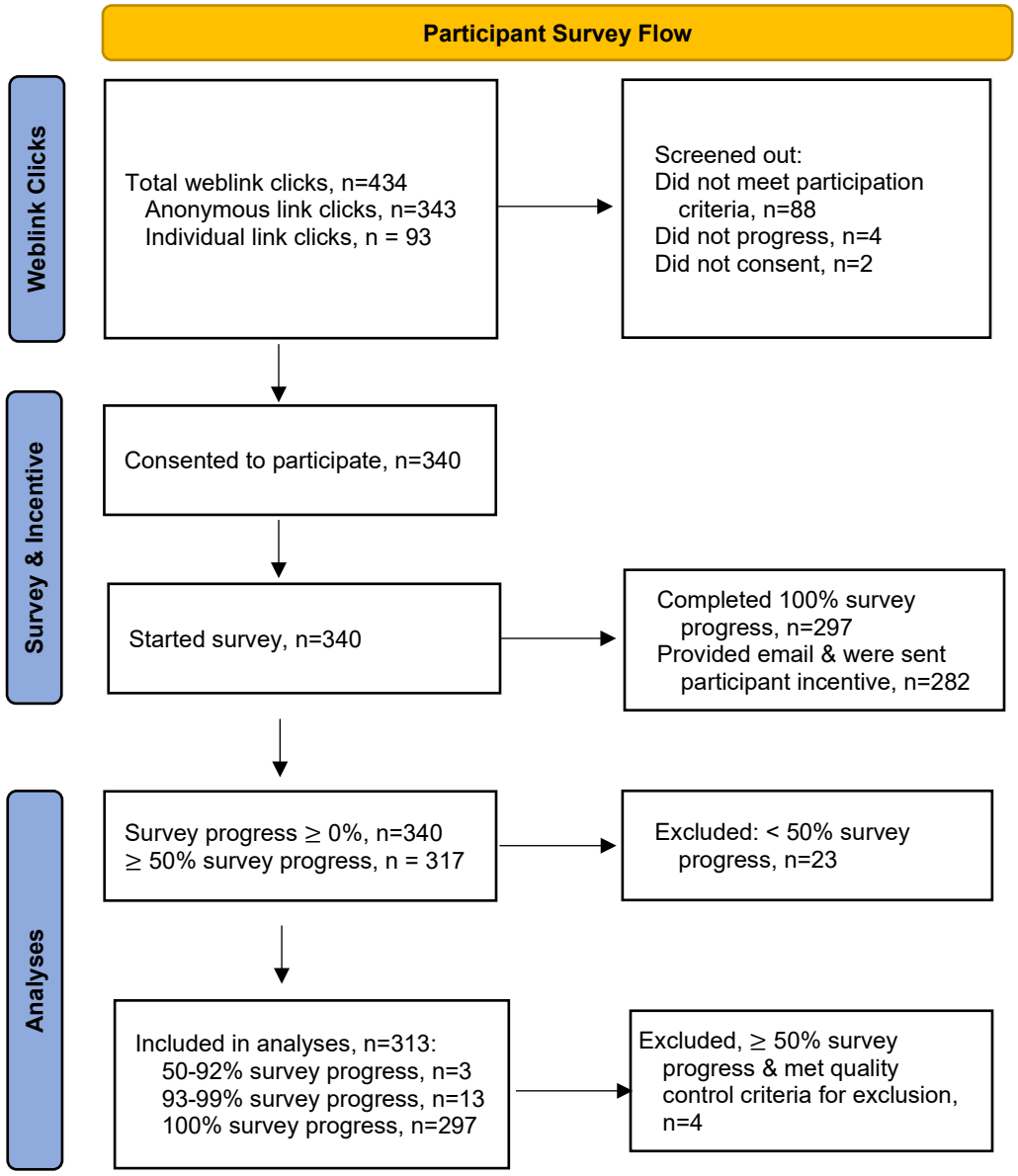
Electronic recruitment ads began in late November 2020. The first survey response occurred in early December 2020 and the last response occurred in late February 2021. Twenty-seven food allergy organizations distributed or allowed posting of recruitment ads via emailed ad invitations, emailed newsletter ads, posts in closed, private social media groups, a blogpost, and a print magazine ad (Appendices D and E). The organizations included several food allergy support groups, several food allergy

blogs/websites, a food allergy patient registry for those willing to participate in research, a food allergy research program, and a food allergy-friendly food bank. Some organizations distributed research recruitment ads using two methods. Research recruitment ads were posted or emailed once every two to fourteen days, depending on the organization's permission. The estimated number of persons who viewed a research survey recruitment ad is 8,200. This estimate is based on statistics from a few social media groups and a few email listserv owners from the same list of food allergy organizations. These statistics described their general viewership, email open rates, and group memberships (a pooled estimate of 21.8% of an estimated total combined groups' reach to 37,600 individuals). It is possible that the actual number of ad viewers was much lower because the same individuals may have potentially received communications from several food allergy organizations therefore a reliable response rate cannot be estimated.

Four hundred and thirty-four (434) individual clicks occurred on the survey weblink. Of those, 343 came from the anonymous survey weblink sent via emailed ad invitations and 93 came from individual survey weblinks sent to individual emails per their requests to participate in response to viewing an ad (93/105, 88.6%) (Figure 10). Eighty-eight (88) individuals who clicked on a survey weblink were screened out and did not meet participation criteria. Three hundred forty (340) consented to participate in the survey.

Figure 10

Participant Survey Flow, Incentive Participation, and Inclusion in Analyses



Note: Quality control criteria for exclusion from analyses: Progressed through 93% of survey (all items before 4 short essay items) in less than 308 seconds; or progressed through 93% of survey in less than 365 second plus committed any one of the following logic errors: a) incorrect attention tester response, b) child's current age < 4 years, c) child's age at diagnosis > current age, d) number of severe allergic reactions in past 12 month > number of lifetime allergic reactions, or e) food allergy knowledge score < 3/8; or progressed through >50% of the survey and provided incorrect attention tester response plus committed any one of the logic errors b) through e) above.

1.2. Missing Data

Of the 340 individuals who consented to participate in the survey, 313 (92%) completed 50% or more of the survey and met quality assurance criteria for inclusion in analyses (Figure 10). Median response duration for participants included in analyses was 20 minutes 36 seconds (mean duration 23.5 minutes, range 5.6 to 56.6 minutes).

Twenty-three responses that progressed through less than 50% of the survey were excluded. Four responses (4/317, 1.3%) that progressed through 50% or more of the survey were excluded because they met quality control exclusion criteria. Quality control criteria for exclusion from analyses included:

1) Progressed through 93% of survey (all items before 4 short essay items) in less than 308 seconds (5 minutes 8 seconds) or
2) Progressed through 93% of survey (the point before short-answer essay responses) in less than 365 seconds (6 minutes 5 seconds) plus committed any one of the following logic errors:
    a) incorrect attention tester response
    b) child's current age less than 4 years old
    c) child's age at diagnosis greater than current age
    d) number of severe allergic reactions in past 12 month greater than number of lifetime allergic reactions, or
    e) food allergy knowledge score less than 3/8 or:
3) Progressed through >50% of survey and provided incorrect attention tester response plus committed any of one of the following logic errors:
    a) child's current age less than 4 years old

b) child's age at diagnosis greater than current age

c) number of severe allergic reactions in past 12 month greater than number of lifetime allergic reactions, or

d) food allergy knowledge score less than 3/8.

The attention tester item was located at 53% progress through the survey and stated, "Paying attention. If you are reading this, please mark the third option". More than 97% (n=305/313, 97.4%) correctly answered the attention tester. Of the eight incorrect attention tester responses (2.6%), none met minimal criteria for exclusion. This was acceptable because average attention is more typical for respondents than extreme attentiveness (Leiner, 2019). The final sample number for analyses was 313 participant responses (92% of those who consented).

Table 5

Missing Data in Items that Composed the Three Major Variables

Scale	Number of items in scale	Number of items in scale with 0 missing responses	Number of items in scale with 1 missing response	Number of items in scale with >1 missing response
Parental Health Literacy	12	11	1	0
Parental Empowerment	9	8	1	0
Parental Advocacy	13	11	2	0
Total	34	30	4	0

Note: N = 313

Missing data for the 34 items in the three major variables was extremely minimal (Table 5). Of the 34 items, four (4) items had 1 missing response (N=1/313, 0.3% per item). The extremely low proportion of missing data was attributed to the use of "pop-up reminders" in Qualtrics survey flow.

Table 6

Re-coded Items from "Didn't do" to Missing for Parental Advocacy Scale Creation

Item: *Stem: During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?* *Your advocacy effort*:	N reported perceived effectiveness of advocacy behavior	N re-coded from "didn't do" to missing (%)
Teaching your child about ways to prevent allergic reactions to foods	308	5 (1.5%)
Teaching your child how to identify a severe allergic reaction to food	304	9 (2.9%)
Requesting quick access to epinephrine in all locations and buses	267	46 (14.7%)
Requesting precautions for field trips or special events	258	55 (17.5%)
Teaching staff about ways to prevent allergic reactions to foods	247	66 (21.1%)
Teaching staff about how to respond to a food allergy emergency	232	81 (25.9%)
Scheduling meetings to discuss food allergy management	232	81 (25.9%)
Requesting handwashing with soap and water before and after handling food	221	92 (29.4%)
Teaching staff about how to identify a severe allergic reaction to food	218	95 (30.4%)
Requesting allergy-friendly seating	217	96 (30.7%)
Discussing food allergy management with staff at unscheduled times	204	109 (34.8%)
Giving staff resources about food allergies management	202	111 (35.5%)
Following-up meetings with key points in emails or letters	201	112 (35.7%)

Note: N = 313

The parental advocacy variable was calculated as the mean of the items that described the perceived effectiveness of each advocacy behavior. Therefore, the response "didn't do" was re-coded to missing for calculation of the mean of the items to create the 'perceived effectiveness of advocacy efforts' scale (parental advocacy scale). For this

scale, the re-coded missing response item values ranged from a low of about 2% for two items to a high of approximately 35% for three items (Table 6).

The 4-item cause advocacy scale covariate was constructed in a similar manner. Individual responses for "didn't do" ranged from 40% to 64% on the items. Collectively, about 80% percent of participants (n=255, 81.5%) reported the effectiveness of at least one cause advocacy activity on the four-item cause advocacy scale, and about 20% of participants reported that they did not perform any of the cause advocacy activities in the past year.

1.3. Statistical Power Achieved

With the main study sample size of 313, adequate statistical power (0.8) was achieved for all hypotheses. For Hypotheses 1 through 4, the largest *a priori* sample size estimated goal of 196 responses required for ANCOVA analyses was achieved. After performing Hypothesis 5 mediation analysis, adequate power (0.8) was determined to have been achieved by using the tables by Fritz and MacKinnon (2007) and examining the achieved calculated mediation effect sizes and the known sample size (n=313).

Section 2. Results

2.1. Participant Demographics

The 313 survey participants were predominantly non-Hispanic, white mothers with a Bachelor's degree or higher level of education (Table 7). More than one-quarter (28.5%) of participants reported education in a health-related field. More than three-quarters of participants (77.2%) were primary caregivers for one child with food allergies and 20.2% were primary caregivers for two children with food allergies (Table 8). Participants' food allergy knowledge scores were moderately high (median 6, range 0 to

8 on a 4-item measure) (Figure 11). The sample had a moderately low level of reported parental food allergy quality of life (mean 3.35, theoretical range 1 to 5, with low scores meaning higher quality of life and high scores meaning lower quality of life).

Food allergy cause advocacy participation was relatively high, with about 30% of participants reporting efforts to benefit their child and other people in the community, state, or nation and 30% reporting efforts for their child and other students in the school or district. Participants perceived their food allergy cause efforts to be moderately effective (median 3.25, range: 1 [not successful] to 5 [completely successful]). More than 60% reported that they spent less than 4 hours weekly on advocacy efforts. Almost one-third (30.9%) of respondents reported that they did not participate in food allergy support groups and nearly 60% of respondents reported participating rarely or often in support groups. Few participated “frequently, actively volunteering” or “very frequently, performing a leadership role” (Figure 12).

Table 7

Sociodemographic Characteristics of Participants

Characteristic	Frequency	Percentage
Primary role as caregiver for child with food allergies		
Father	10	3.2
Mother	301	96.8
Other (guardian, grandparent, etc.)	0	0
Highest level of education completed		
Elementary school or primary school	1	0.3
High school or GED	15	4.8
Associate degree	25	8.0
Bachelor's degree	106	34.1
Any graduate degree	164	52.7
Health-related education		
No	211	71.5
Yes	84	28.5
Hispanic or Latino		
No	282	90.7
Yes	24	7.7
Prefer not to answer	5	1.6
Race		
American Indian or Alaska Native	1	0.3
Asian	20	6.4
Black or African American	5	1.6
Native Hawaiian or Other Pacific Islander	0	0
White	264	84.9
Two or more races	7	2.3
Other	4	1.3
Prefer not to answer	10	3.2

Table 8

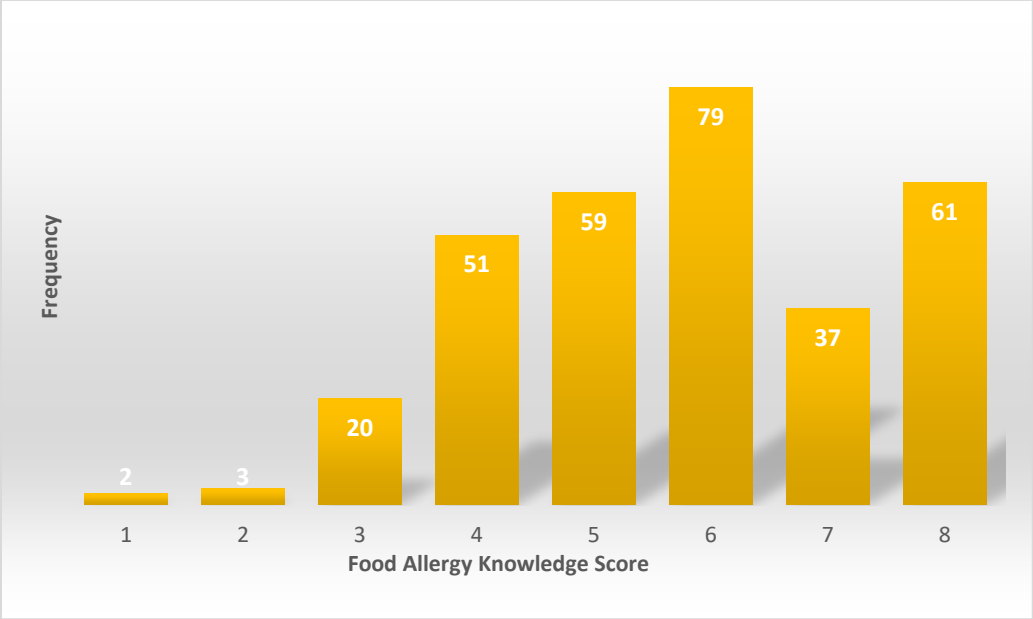
Characteristics of Participants related to Food Allergies

Characteristic	Mean	SD	Median	Range
Food Allergy Knowledge Score (N=312)	5.73	1.60	6.00	1 – 8
Food Allergy Quality of Life (N=311)	3.35	0.85	3.35	1.18 - 5
Cause Advocacy (N=255)	3.31	0.93	3.25	1.00 - 5

Characteristic	Frequency (N=313)	%
Primary caregiver for x number of children with food allergies		
1	240	77.2
2	63	20.3
3	8	2.6
4 or more	0	0
Met with school staff to discuss food allergy management in the past 12 months		
No	43	13.7
Yes	266	85.0
Don't remember	4	1.3
Who benefits from food allergy advocacy efforts		
No one	79	25.3
My child with food allergies	40	12.8
My child with food allergies and other students at school	76	24.4
My child with food allergies and others in the school district	25	8.0
My child with food allergies and other people in the community, state, or nation	92	29.5
Time spent in food allergy advocacy efforts		
None at all	98	31.4
Less than 4 hours per week	188	60.3
4 to 8 hours per week	19	6.1
More than 8 hours per week	7	2.2

Figure 11

Frequency of Participants' Food Allergy Knowledge Scores (N=312 responses)



Note: Possible range 0 (lowest) – 8 (highest)

Figure 12

Frequency of Participants' Reported Food Allergy Support Group Participation (N=312)

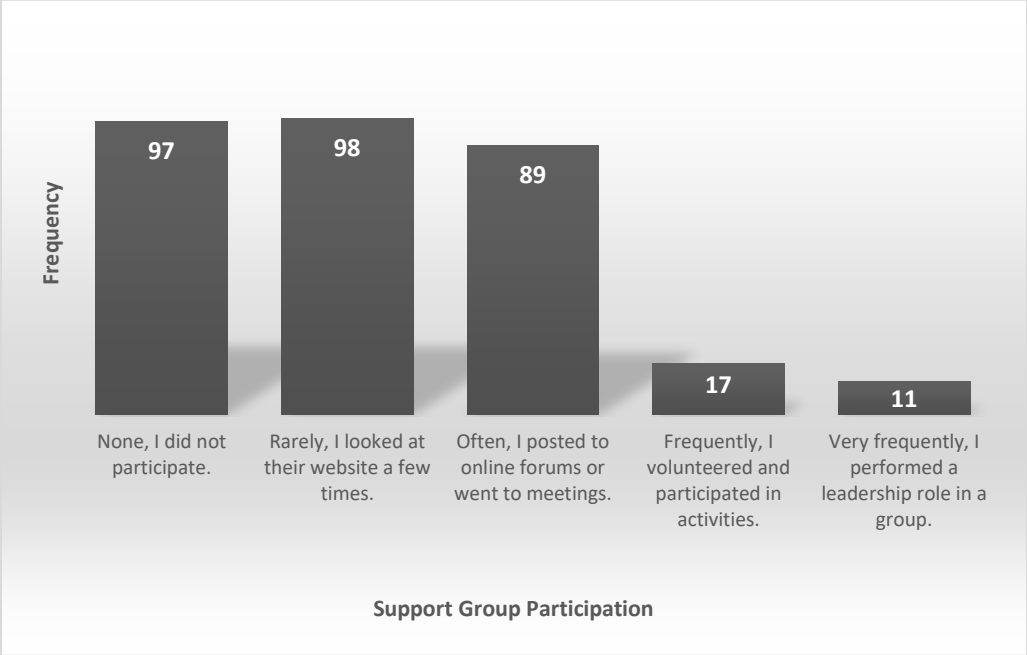


Table 9

Characteristics of Participant's Youngest Child with Food Allergies in Elementary School

Characteristic	Mean	Standard Deviation	Median	Range
Current age in years (N = 310)	8.43	2.26	8.50	4 - 13
Age in years at first diagnosis (N=310)	1.24	1.67	1	0 - 10
Current number of food allergens (N=311)	3.50	2.68	3	1 - 19
Food allergy severity index score (N=313)	4.95	3.40	5	0.5 - 16

Characteristic	Frequency (N=311)	Percentage
Asthma		
Yes	148	48.4
No	158	50.5
Don't know	0	0
504 Plan		
Yes	120	38.5
No	186	59.6
Prefer not to answer	6	1.9
Currently receiving food allergen immunotherapy		
Yes	49	15.7
No	260	83.3
Prefer not to answer	3	1.0

The average age of participants' youngest child with food allergies in elementary school was eight years old, with a range from four to thirteen years old (Table 9). Each one-year age group was substantially represented from five years old to 12 years old (Figure 13). The average age at initial diagnosis of food allergies was about 15 months old. About eighty percent (80.4%) of participants reported two or more current food allergens for their child and about 20% reported their child was allergic to one allergen (median: 3 allergens, range 1 – 19 allergens). Of the top ten food allergens, the most frequently reported food allergens, in descending order, were: tree nut, peanut, egg, milk, and sesame (Figure 14). The number of "other" allergens were the third most frequently

reported, nearly as high as peanuts and tree nuts. The "other" allergens most reported were beans in the legume family, such as chickpeas (garbanzo beans), green peas, green beans, lentils, navy beans, and white beans. The legume family is the same family to which peanuts belong. Almost 50% (48.4%) of participants reported that their child has asthma, a significant predictor for increased risk of fatality in food-induced anaphylaxis. Almost 18% reported that their child had one or more severe allergic reactions to food treated with epinephrine or by an emergency medical team in the past 12 months (Figure 15). Approximately two-thirds (68.7%) of participants reported that their child had one or more severe allergic reactions in their lifetime. Almost forty percent (38.5%) of participants reported that their child had a 504 plan at school related to food allergies.

Figure 13

Frequency of Participants' Youngest Child's Age Reported in Years (N=310)

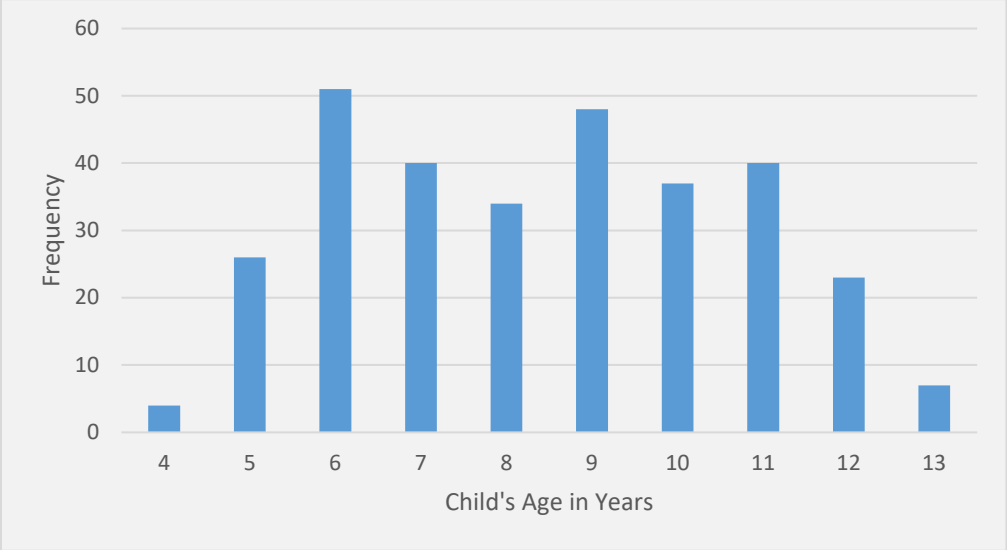
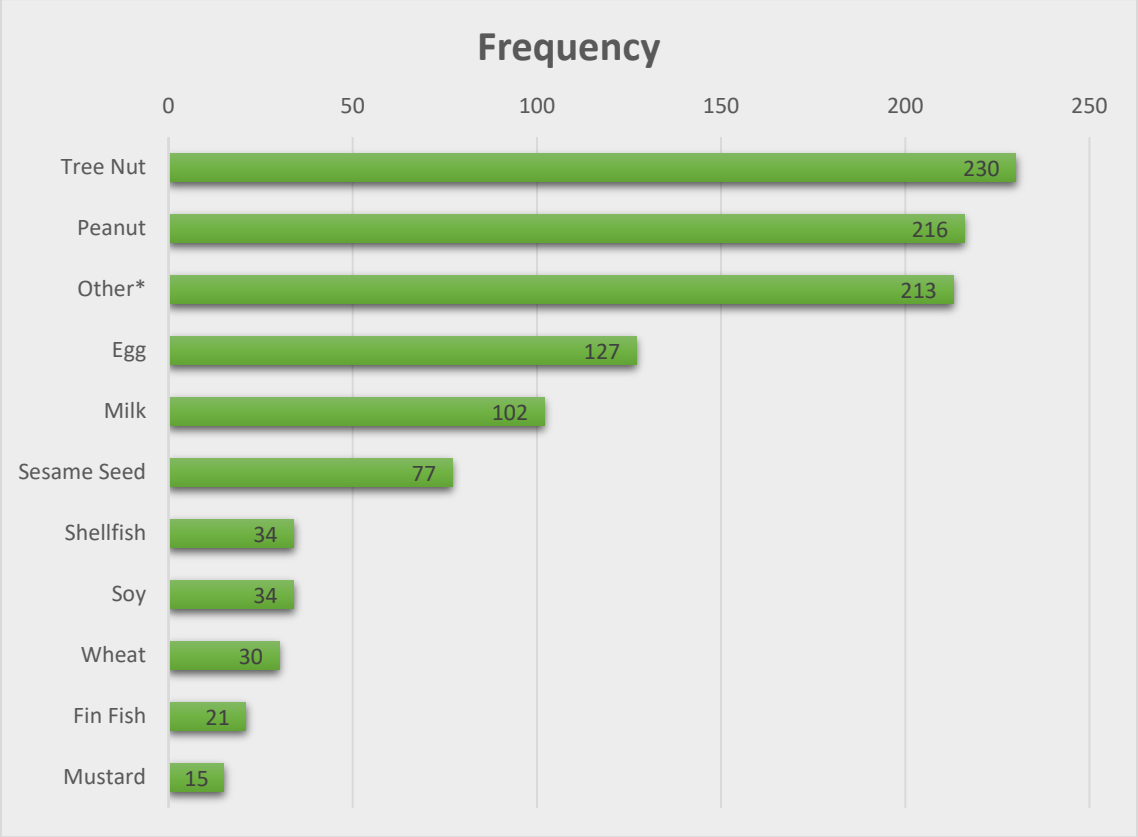


Figure 14

Frequency of Participants' Youngest Child's Reported Food Allergens in Study Sample

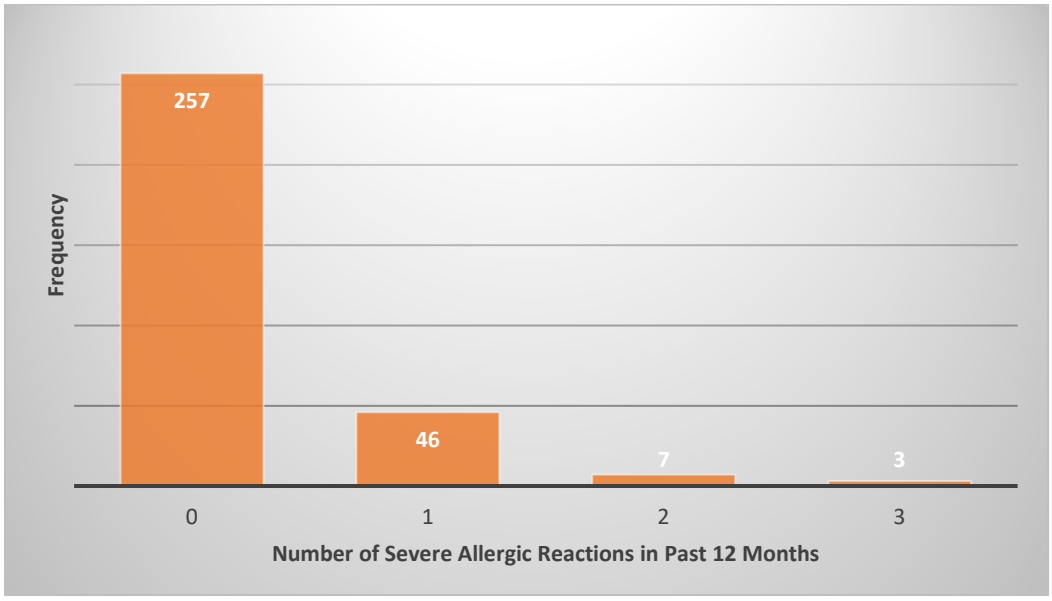


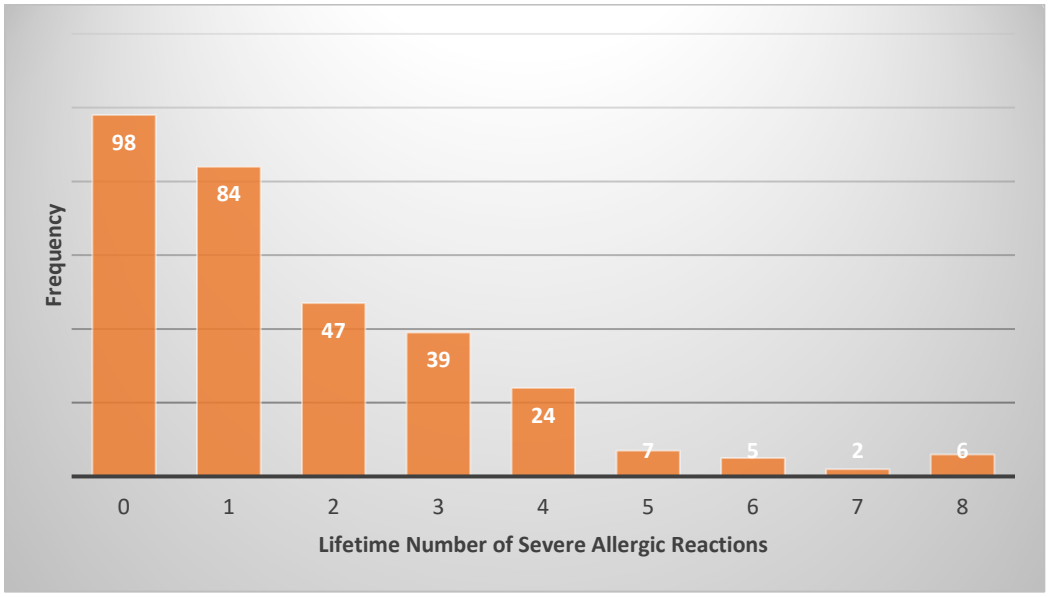
Note: Participants could select more than one response.

*Other allergens reported by participants included: apple, avocado, banana, barley, beans, beef, broccoli, buckwheat, cantaloupe, carrot, cauliflower, celery, chia seed, chicken, chickpea (garbanzo bean), cinnamon, cocoa, coconut, corn, cucumber, date, eggplant, fig, flax seed, "fresh produce", garlic, gluten, grape, green bean, kiwi, legumes, lentils, lima bean, melon, millet, navy beans, nectarine, oat, oral allergy syndrome: birch pollen-associated fruits/vegetables, orange, peach, peas, pineapple, pitted fruits, pomegranate, poppy seed, pork, pumpkin seed, quinoa, red lentil, rice, rye, sorghum, spelt, strawberry, seeds, sunflower seed, sweet potato, tomato, watercress, watermelon, white beans, and zucchini.

Figure 15

Participants' Reported Number of their Child's Severe Allergic Reactions in the Past 12 Months and Lifetime (N=313)*





Note: *Severe allergic reactions were defined as "How many times was your child treated for a severe allergic reaction to food with epinephrine or by an emergency medical team?"

Note. 8 = 8 or more reactions

The food allergy severity index score was composed of a sum of weighted scores for: asthma, number of food allergens, reverse-scored number of years since food allergy diagnosis, number of severe allergic reactions in the past 12 months, and number of severe lifetime allergic reactions. The median food allergy severity index score was 5 (range 0.5 – 16, with low scores indicating lower severity and high scores indicating higher severity. The distribution of the food allergy index severity scores was bimodal, accounting for approximately half of the participants with and without asthma, including a long tail of high scores related to a small proportion of participants with numerous allergens.

Eighty-five percent of participants reported that they had met with school staff to discuss food allergy management in the past 12 months. Over seventy percent (71.8%) reported their relationship with the school was above average or excellent (Figure 16). The three most common reasons that participants reported that they did not meet with the school in the past 12 months were: “I met with school staff in the past and there was nothing new to discuss”; “School staff already know how to prevent exposure and respond to a food allergy emergency effectively”; and other individualized reasons (Figure 17).

Figure 16

Frequency of Participants' Reported Quality of their Relationship with the School (N=313)

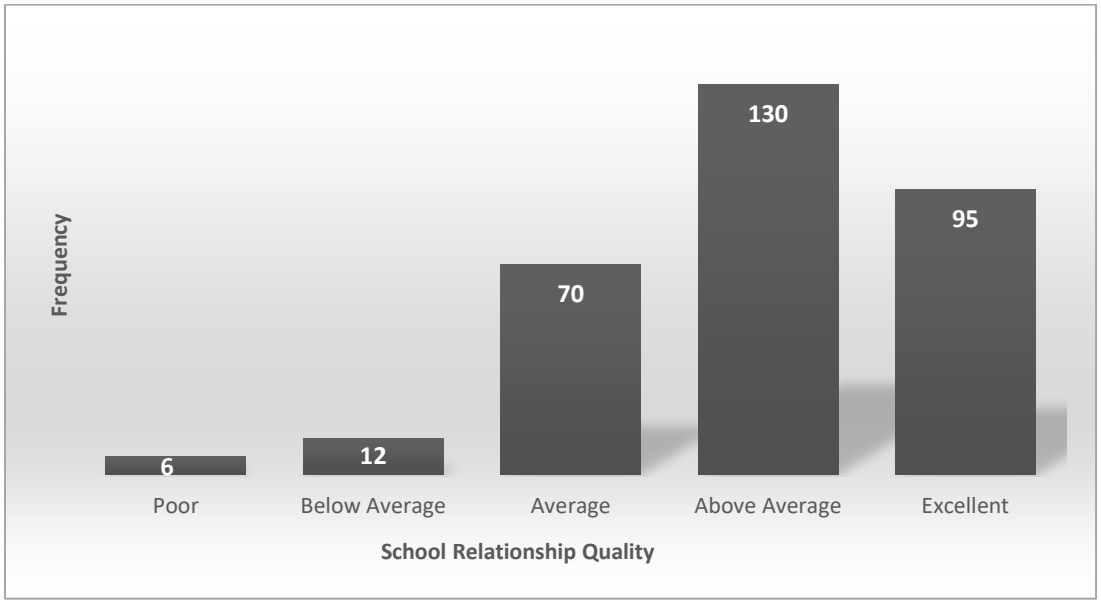
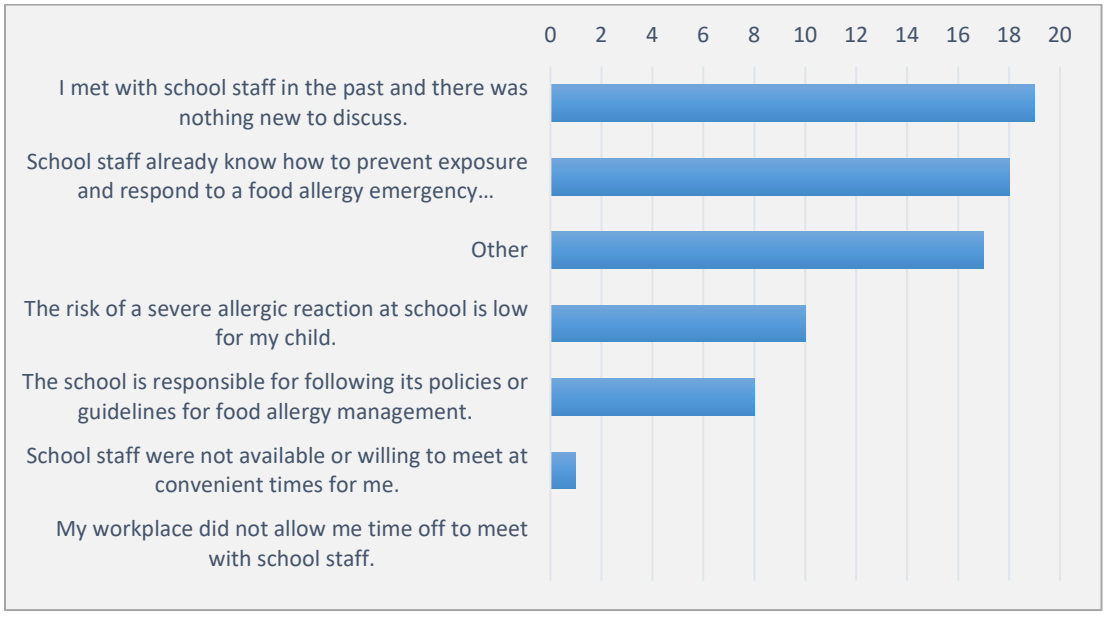


Figure 17

Reported Reasons that Participants Did Not Meet with School in Past 12 Months (N=43)



Note: Participants could select more than one response.

Approximately two-thirds (67%) of schools were in suburban communities; about one-quarter were in city communities (24%) (Figure 18). Nearly ninety percent of elementary schools required an emergency action plan and 84% had a school nurse (Table 10). A registered nurse fulfilled the school nurse role in 55% of the schools with a nurse, but 30% of the participants did not know the credentials of the school nurse (Figure 19). Of those reporting a registered nurse was the school nurse, a little more than 70% of participants reported that the registered nurse was present in the building full-time (on-site for a full school day, 5 days per week).

Figure 18

Participant's Reported School Community Setting (N=312)

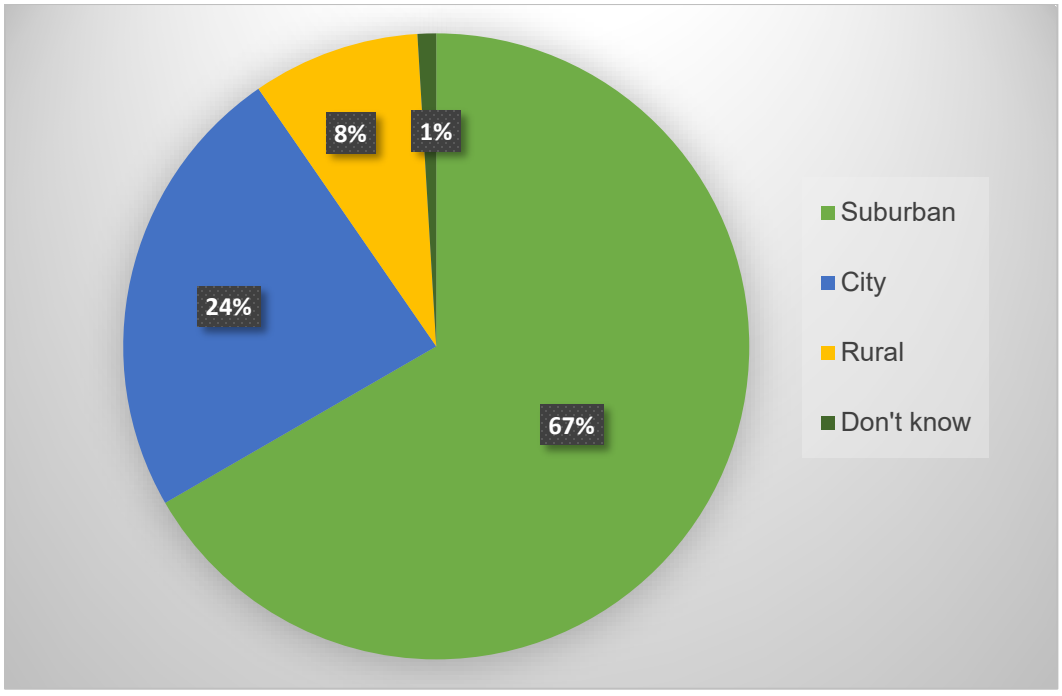


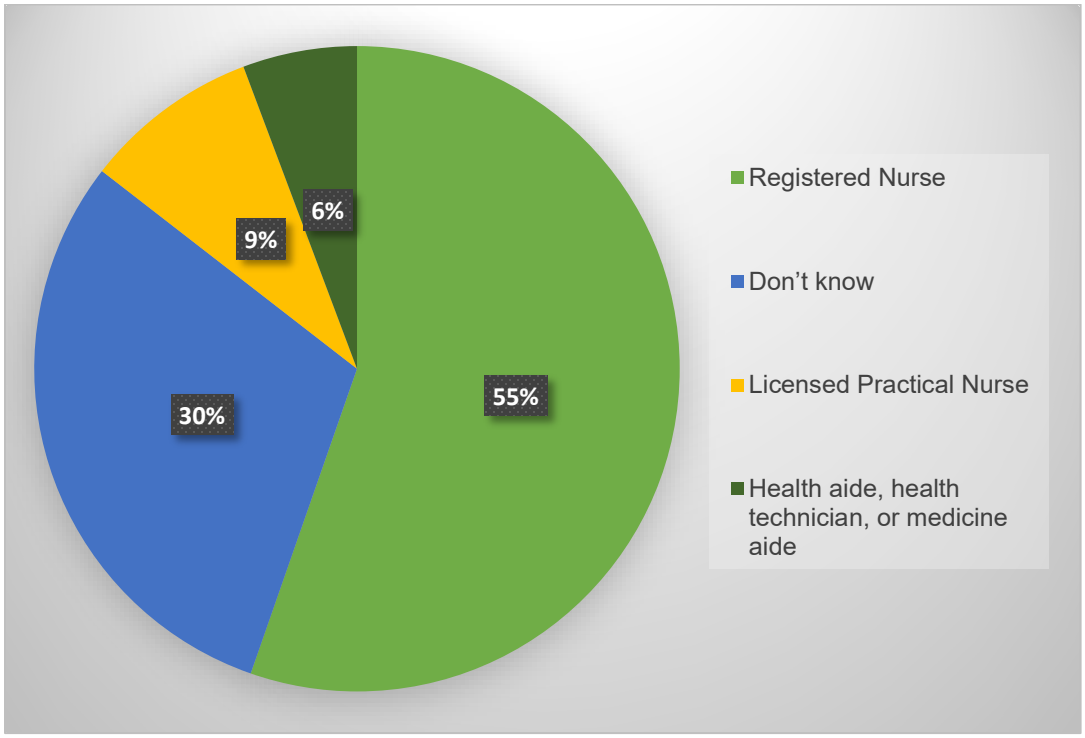
Table 10

Participant's Report of School Characteristics

Characteristic	Frequency	Percentage
Requires an Emergency Action Plan (N=312)		
No	16	5.1
Yes	279	89.4
Don't know	17	5.4
Has a school nurse (N=312)		
No	47	15.1
Yes	262	84.0
Don't know	3	1.0
Registered Nurse presence in school building (n=145)		
Part-time	39	26.9
Full-time	104	71.7
Don't know	2	1.4

Figure 19

Participants' Report of School Nurse Credentials (N=262)

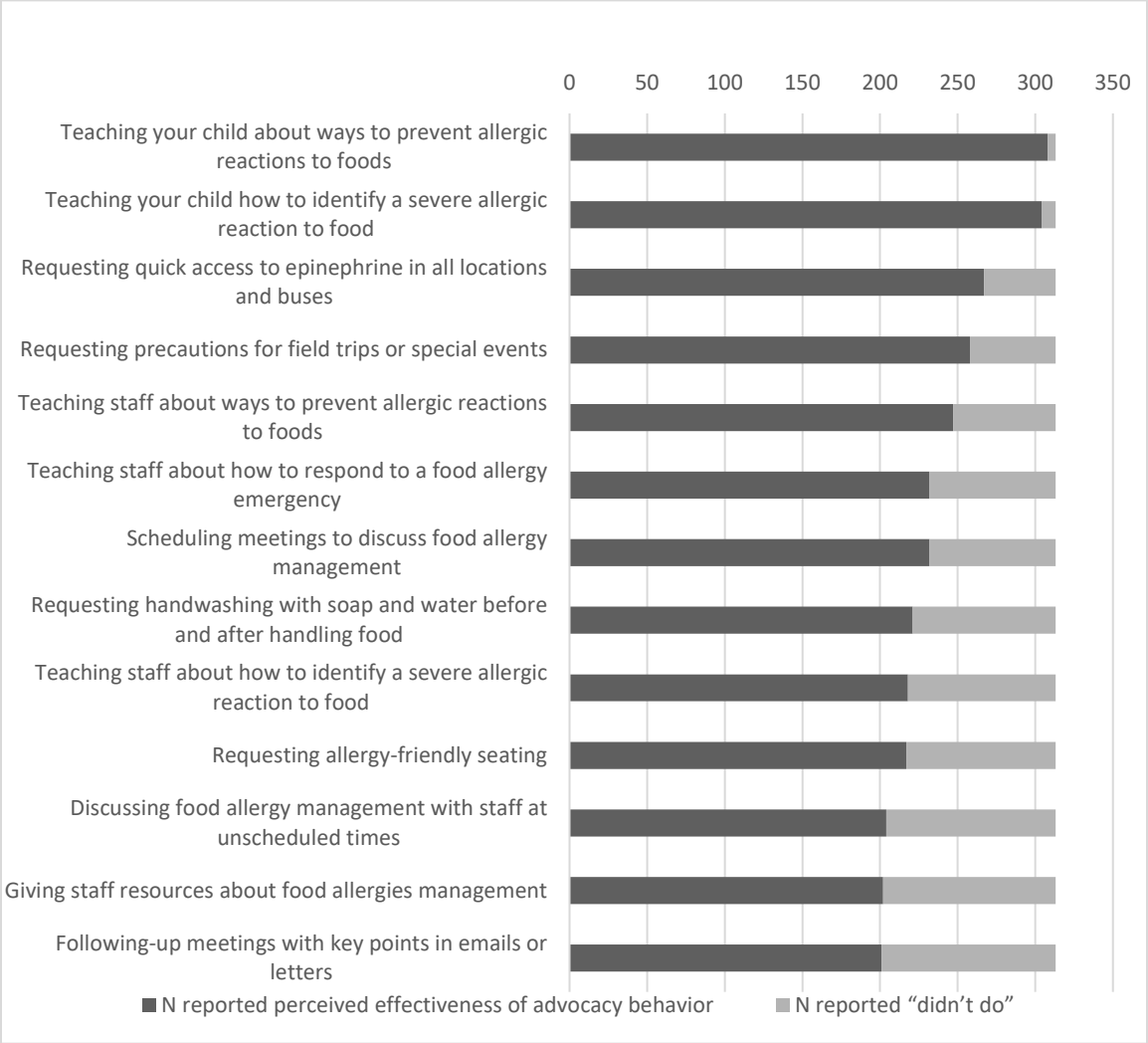


2.2. Descriptive Statistics

The outcome variable of 'perceived effectiveness of advocacy efforts' was composed of 13 parental advocacy behavior items that started with the stem, "During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?". The two most commonly reported parental advocacy behaviors items were about teaching their child to manage food allergies (Figure 20). More than 97% of participants reported their perceived effectiveness of advocacy efforts of "teaching their child ways to prevent allergic reactions to foods" and of "teaching their child how to identify a severe allergic reaction to food" (98.4% and 97.1% respectively). In comparison, approximately 75% of participants reported their perceived effectiveness of their advocacy efforts of "teaching staff about ways to prevent allergic reactions to foods" and "teaching staff about how to respond to a food allergy emergency". Approximately 85% of participants reported their perceived effectiveness of advocacy efforts of requesting quick access to epinephrine and special precautions for field trips or special events (85.3% and 82.5%, respectively). Approximately 65% of participants reported they "didn't do" the following advocacy behaviors: "discussing food allergy management with staff at unscheduled times" (65.2%), "giving staff resources about food allergies management" (64.5%), and "following-up meetings with key points in emails or letters" (64.3%).

Figure 20

Reported Parental Advocacy Items as Any Level of Perceived Effectiveness versus "Didn't do" (N=313)



The outcome variable of 'perceived effectiveness of advocacy efforts' (parental advocacy) was created by re-coding the value of "didn't do" into missing for each advocacy behavior item and then creating a mean (average) score of the 13 items. Parental advocacy behaviors that were not performed in the past 12 months (reported as "didn't do") for a given individual participant were therefore not included in the

'perceived effectiveness of advocacy efforts' scale score. Of note, as a check for partial criterion-related validity of the items, the *sum* of the thirteen parental advocacy items coded *dichotomously* as "didn't do" versus "did do" demonstrated a small and significant correlation with time spent on advocacy efforts (Kendall's tau rank correlation =.19, $p<.001$).

The major variables had distributions that were skewed slightly to the right, at the higher levels of the scales (means ranging from 3.52 to 4.23, with possible ranges from 1 to 5; Table 11 and Figure 21). Testing for ceiling effects was performed by reviewing the proportion of responses at the extreme highest (5) and lowest (1) scores for all items that comprised the three major variables, the three major variables scales, and three health literacy subscales. All major variables had less than 15% of scores in the highest or lowest extremes. A high ceiling effect was found for the functional health literacy subscale (n=49/313, 15.7% at highest score of 5). No items were found to have more than 95% of the scores at the extreme highest or lowest scores. The scales and subscales had adequate internal reliability with Cronbach's alpha ranging from .77 to .93.

Table 11

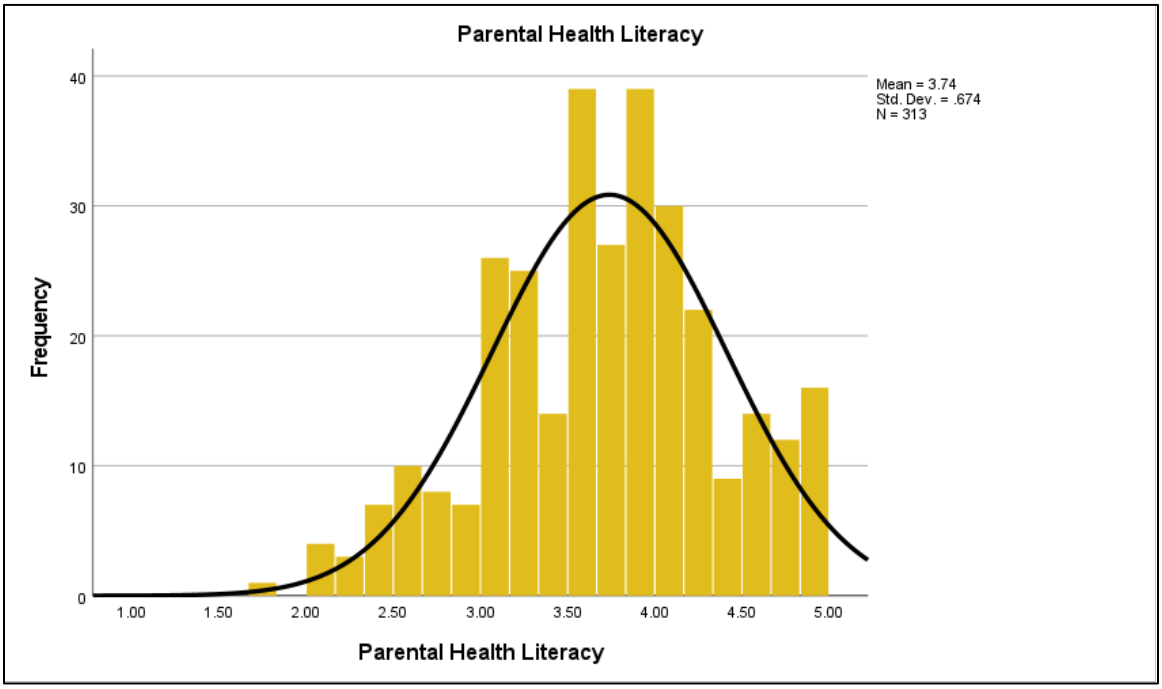
Properties of Major Variable Scales and Health Literacy Subscales

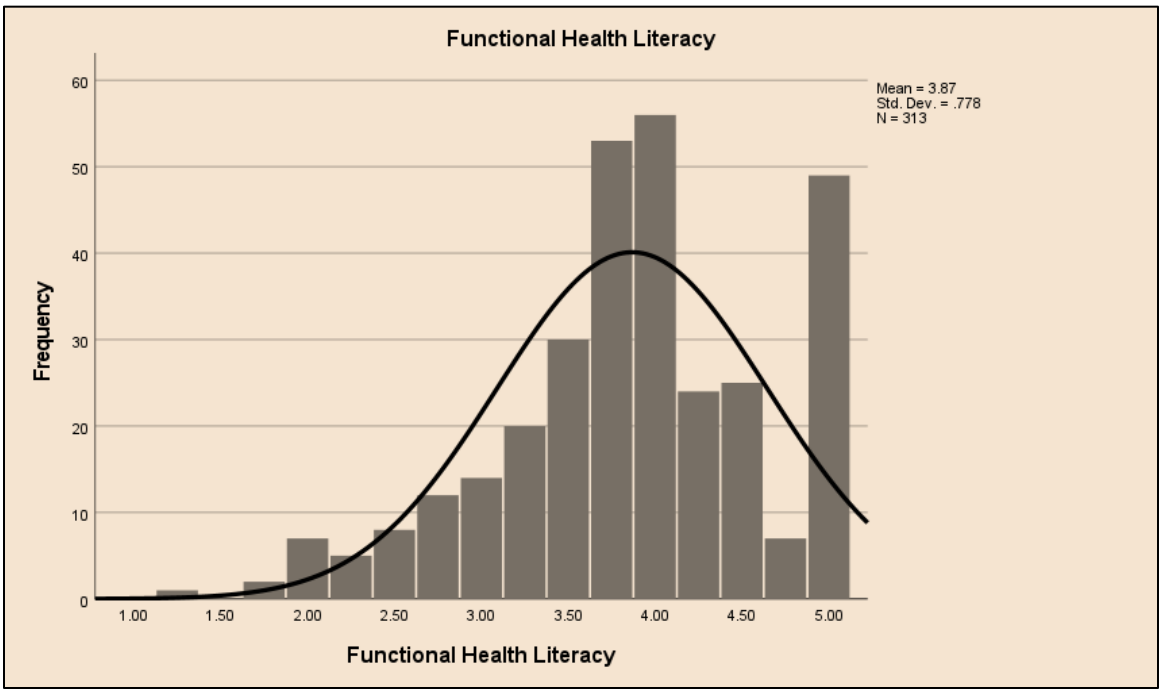
Scale	Mean	SD	Median	Range	Cronbach's alpha
Parental Health Literacy (HL)	3.74	0.67	3.83	1.83 – 5.00	.92
Functional HL	3.87	0.78	4.00	1.25 – 5.00	.85
Communicative HL	3.83	0.72	4.00	1.50 – 5.00	.81
Critical HL	3.52	0.86	3.75	1.00 – 5.00	.91
Parental Empowerment	4.23	0.47	4.22	1.00 – 5.00	.77
Parental Advocacy	3.86	0.73	3.91	1.33 – 5.00	.93

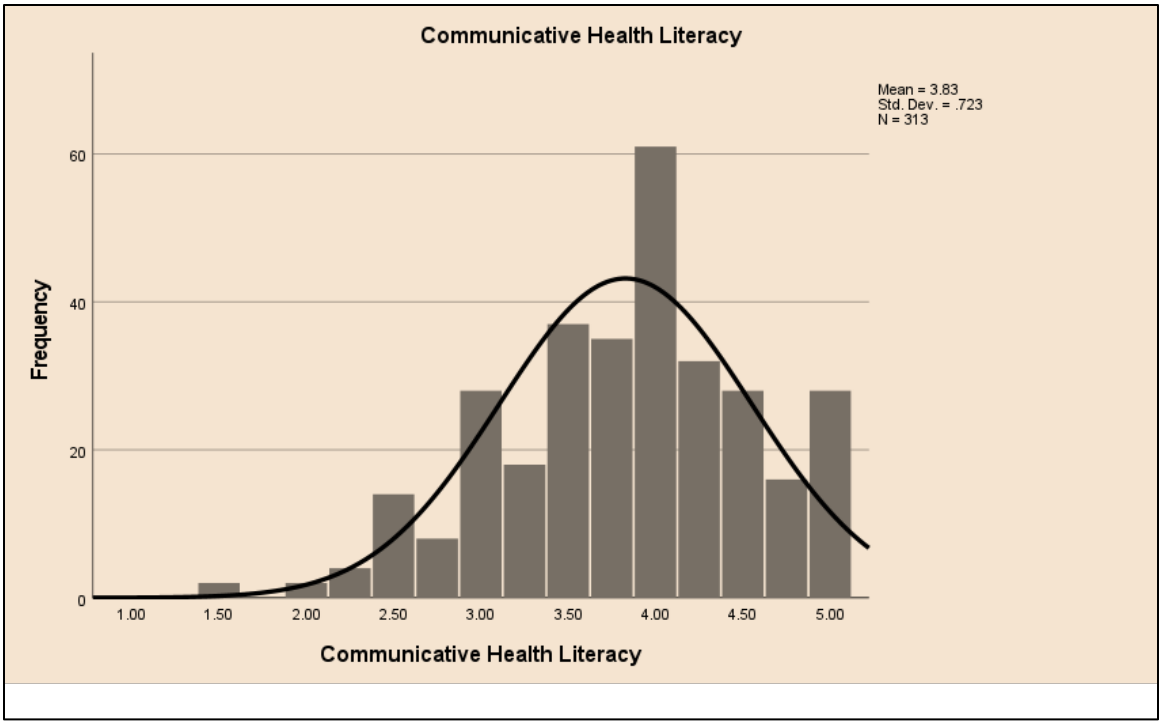
Note: N=313. Possible ranges for all scales: 1.00 – 5.00

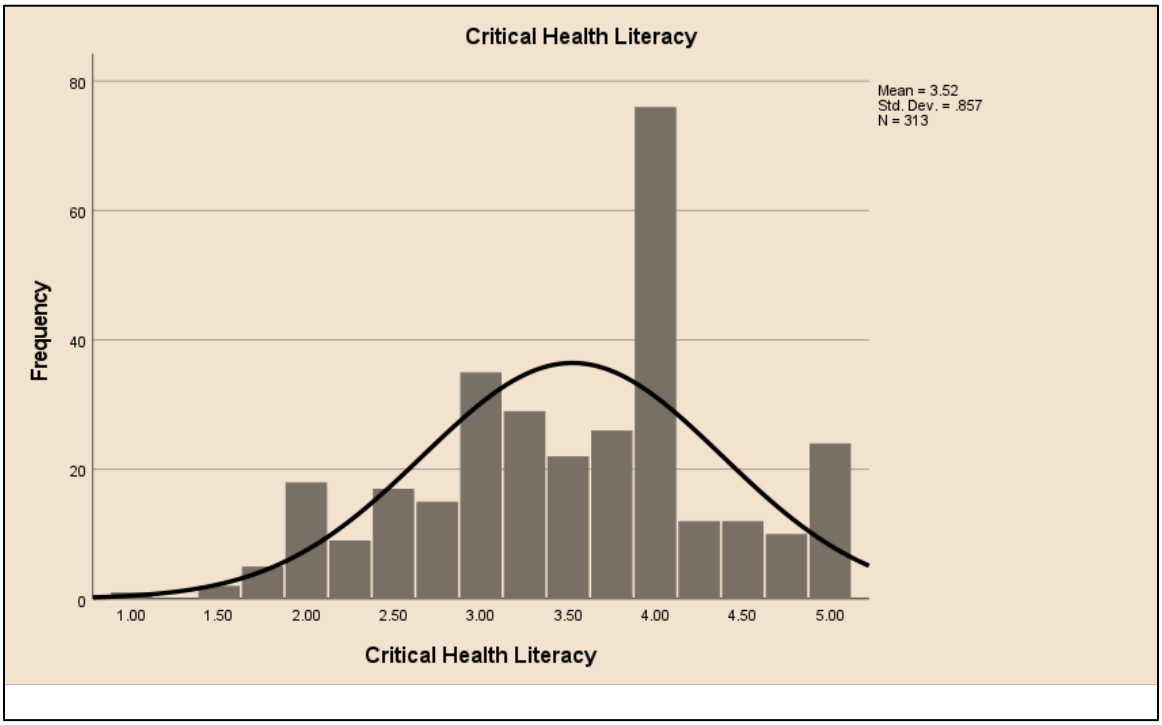
Figure 21

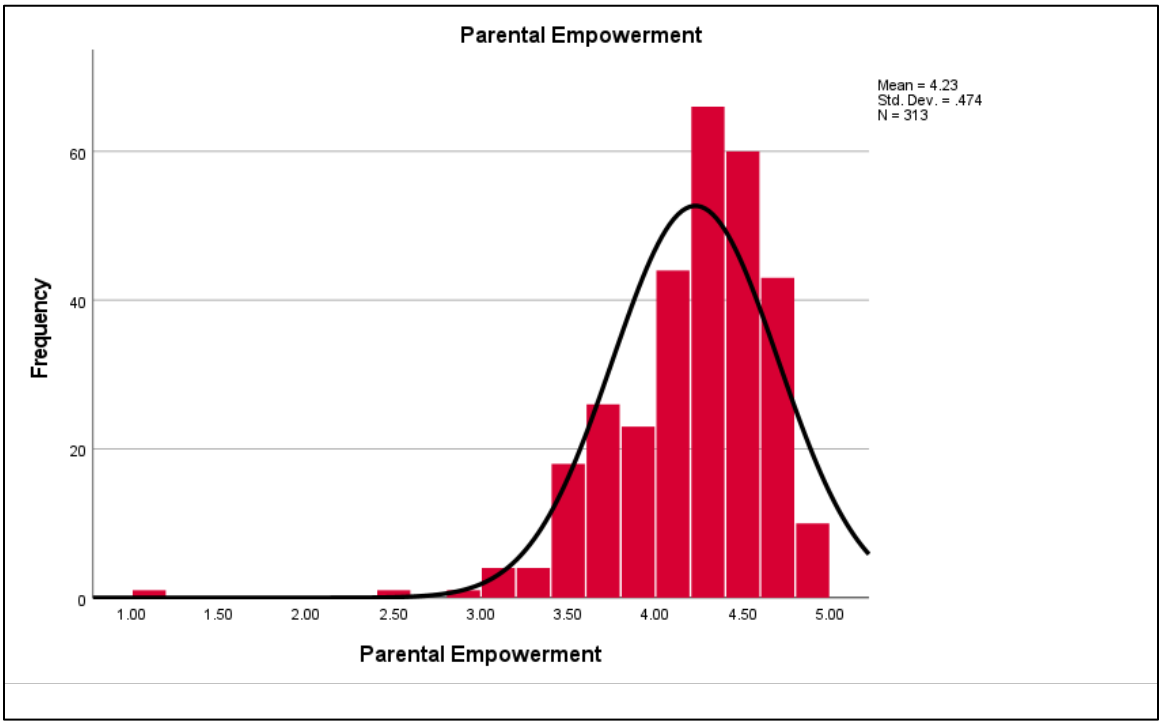
Distributions of Major Variables

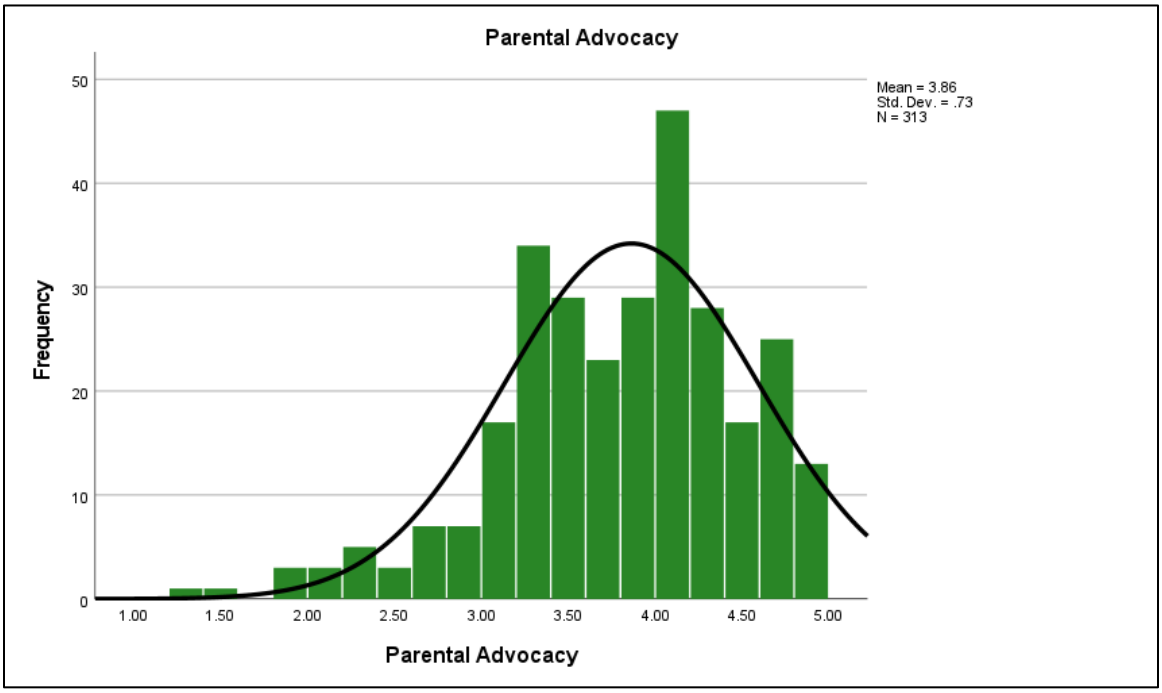





Communicative Health Literacy
Mean = 3.83
Std. Dev. = .723
N = 313
Frequency
60
40
20
0
1.00
1.50
2.00
2.50
3.00
3.50
4.00
4.50
5.00
Communicative Health Literacy


Critical Health Literacy
Mean = 3.52
Std. Dev. = .857
N = 313
Frequency
80
60
40
20
0
1.00
1.50
2.00
2.50
3.00
3.50
4.00
4.50
5.00
Critical Health Literacy

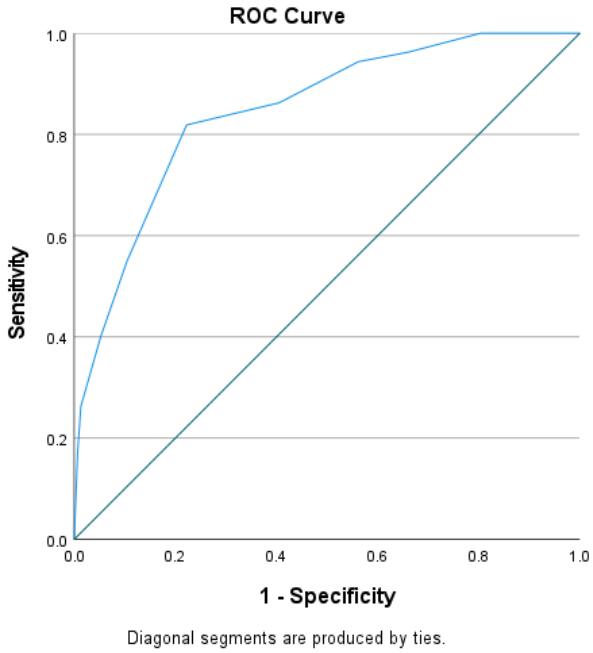

Parental Empowerment
Mean = 4.23
Std. Dev. = .474
N = 313
Frequency
60
40
20
0
1.00
1.50
2.00
2.50
3.00
3.50
4.00
4.50
5.00
Parental Empowerment


Parental Advocacy
Mean = 3.86
Std. Dev. = .73
N = 313
Frequency
50
40
30
20
10
0
1.00
1.50
2.00
2.50
3.00
3.50
4.00
4.50
5.00
Parental Advocacy

Determining Cut-Points for Highest and Lowest Scorers. Three dichotomous variables - communicative health literacy, critical health literacy, and parental empowerment - were required for Hypotheses 1, 2, and 4. To select their cut-points, the means, medians, distribution, and Receiver Operating Characteristic Curves of each variable were examined. Based on the communicative health literacy score between the mean (3.83) and median (4.00) of the distribution, the high communicative health literacy scores were defined at an initial cut-point of 3.875 and above. The low scores were defined as 3.874 and below. Because of established correlations between communicative and critical health literacy (Finbråten et al., 2018; Heijmans et al., 2015; Ousseine et al., 2018; Zegers et al., 2020) and because communicative health literacy and critical health literacy correlate strongly with each other in this sample, ($r=.70$, $p<.001$) the Receiver Operating Characteristic (ROC) Curves in relation to one another were examined to finalize the cut-point. The ROC is a graph depicting the relationship between sensitivity and specificity for one variable to predict a dichotomous outcome of another variable (Habibzadeh et al., 2016). An optimal cut-point would have sensitivity and specificity that are equal to one another and greater than 70%, with an area under the curve (AUC) greater than 0.7, depicted by the point in the curve closest to the upper left-hand corner (Chou et al., 2020; Habibzadeh et al., 2016). A cut-point communicative health literacy score of 3.875 had 81.9% sensitivity and 77.8% specificity to distinguish between high and low communicative health literacy in this sample. The area under the curve (AUC) was 0.846 ($SE = .022$, $p<.001$) (Figure 22). The resultant dichotomous communicative health literacy variable with a cut-point of 3.875 was used as the independent variable for Hypothesis 1 analysis.

Figure 22

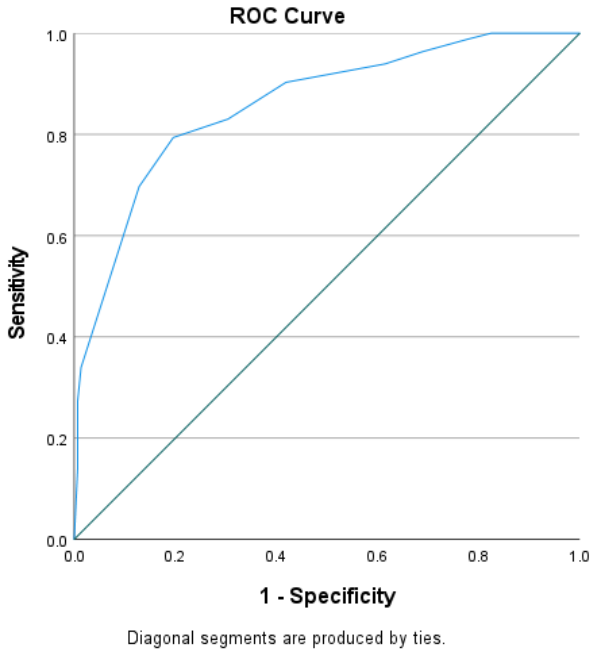
Receiver Operating Characteristic Curve for Communicative Health Literacy on Critical Health Literacy



Likewise, based on the critical health literacy score between the mean (3.52) and median (3.75) of the distribution, the initial high critical health literacy scores were defined at the cut-point of 3.625 and above. The low scores were defined as 3.624 and below. Then, analysis of the Receiver Operating Characteristic (ROC) Curve of critical health literacy in relation to communicative health literacy identified the optimal cut-point. A cut-point critical health literacy score of 3.625 had 79.4% sensitivity and 80.4% specificity to distinguish between high and low critical health literacy in this sample. The area under the curve (AUC) was 0.859 (SE 0.021, $p<.001$) (Figure 23). The resultant dichotomous critical health literacy variable with cut-point of 3.625 was used as the independent variable for Hypothesis 2 analysis.

Figure 23

Receiver Operating Characteristic Curve for Critical Health Literacy on Communicative Health Literacy

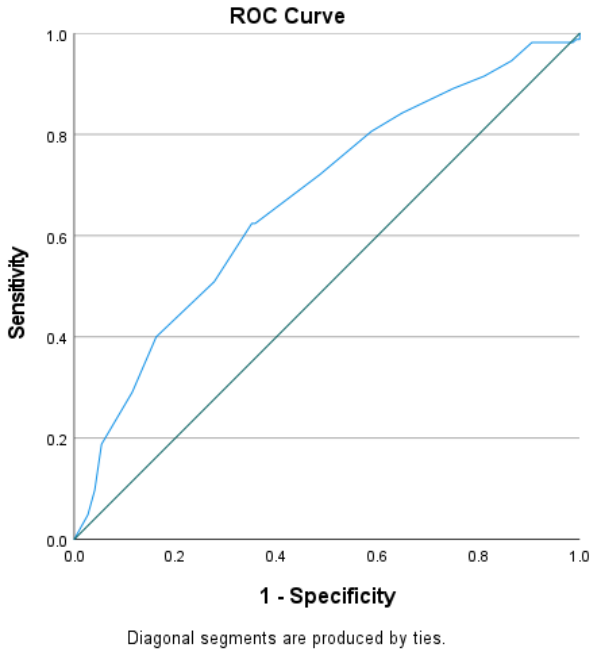


Based on the parental empowerment score between the mean (4.228) and median (4.222) of the distribution, the initial high parental empowerment scores were defined at the cut-point of 4.225 and above. The low scores were defined as 4.224 and below. Parental empowerment had a small correlation to communicative health literacy (r=.257, p<.001). Analysis of the Receiver Operating Characteristic (ROC) Curve of parental empowerment in relation to communicative health literacy identified a revised optimal cut-point. A cut-point parental empowerment score of 4.236 had 62.4% sensitivity and 64.2% specificity to distinguish between high and low parental empowerment in this sample. The area under the curve (AUC) was 0.672 (SE 0.030, p<.001) (Figure 24). Further refinement of the cut-point occurred because the AUC was less than 0.7 and the

parental empowerment score distribution was narrow, meaning there was very little separation between high and low scorers. Therefore, the middle section of scores around the cut-point was discarded (n=36/313, 11.5% discarded), resulting in the high parental empowerment score re-defined as 4.26 or greater and low scores re-defined as 4.21 or less. The resulting dichotomous parental empowerment variable was used as the independent variable for Hypothesis 4 analysis.

Figure 24

Receiver Operating Characteristic Curve for Parental Empowerment on Communicative Health Literacy



2.3. Interferential Statistics

Bivariate Analyses. Bivariate correlations of the major variables in their continuous forms were assessed before conducting analyses for the hypotheses. Pearson's correlations were significant for all pairings ($p<.001$; Table 12) except for the correlation

between parental empowerment and functional health literacy (p>.05). Correlations of the major variables of parental health literacy, health literacy subscales, parental empowerment with the variable 'perceived effectiveness of advocacy efforts' [parental advocacy] were moderate in effect size (r=.28 to .49, p<.001).

Table 12

Pearson Correlations for Major Variables

Variable	1. Parental Advocacy	2. Parental HL	3. Funct. HL	4. Comm HL	5. Critical HL	6. Parental Empwrmnt
1. Parental Advocacy	-					
2. Parental HL	**.34****	-				
3. Functional HL	**.28****	**.82****	-			
4. Communicative HL	**.30****	**.87****	**.58****	-		
5. Critical HL	**.30****	**.88****	**.54****	**.70****	-	
6. Parental Empowerment	**.49****	**.25****	.11	**.26****	**.27****	-

Note: N = 313. * p<.05 ** p<.001

Bivariate correlations of parental advocacy and covariates were examined next. The 'quality of the relationship with the school' strongly and positively correlated with parental advocacy (r=.63, p<.001; Table 13). The 'perceived effectiveness of cause advocacy efforts' correlated positively and moderately with parental advocacy (r=.27, p<.001). The 'food allergy quality of life – parental burden (modified)' [FAQOL-PB] correlated moderately and negatively with parental advocacy, meaning that lower quality of life (higher FAQOL-PB score) was associated with lower 'perceived effectiveness of advocacy efforts'. Other covariates that were not significantly associated with parental advocacy (p>.05), included food allergy severity index score and food allergy knowledge score, among others. Bivariate correlations using Kendall's tau rank correlation were

non-significant for associations of three dimensions of health literacy with educational attainment and with food allergy knowledge score (p>.05).

Food allergy quality of life – parental burden (modified) [FAQOL-PB] was associated with some covariates. FAQOL-PB had a negative and small correlation with 'quality of the relationship with the school', meaning that lower quality of life (higher FAQOL-PB score) was associated with 'lower perceived effectiveness of advocacy efforts' (r= -.14, P<.05). FAQOL-PB correlated positively with food allergy knowledge score and food allergy severity score, meaning lower quality of life was associated with higher food allergy knowledge and higher food allergy severity (r=.20 and r=.25, p<.001, respectively). These correlations also served as criterion-related validity tests for those covariate scales.

Table 13

Pearson Correlations for Parental Advocacy and Selected Co-Variates

Variable	N	1. Advocacy	2. FA Know-ledge	3. FA Severity	4. Relation-ship Quality	5. FA QOL-PB	6. Cause Advocacy
1. Parental Advocacy	313	-					
2. Food Allergy Knowledge Score	312	.03	-				
3. Food Allergy Severity Index	304	.06	.02	-			
4. Quality of Relationship with School	313	**.63****	.03	-.006	-		
5. Food Allergy Quality of Life – Parental Burden	311	**-.21****	**.20****	**.25****	**-.14***	-	
6. Cause Advocacy	255	**.27****	.06	.009	**.14***	-.02	-

Note: *p<.05 ** p<.001. N=313. No significant bivariate correlations between Advocacy and: education level, child's current age, number of years since diagnosis, total number of allergens, lifetime number of severe allergic reactions, 12-month number of severe allergic reactions, degree of support group participation, number of children with food allergies for whom participant is primary caregiver.

Next, bivariate analyses of t-test results demonstrated significantly different means of parental advocacy scores for lowest versus highest scorers in communicative health literacy, critical health literacy, and parental empowerment ($p<.001$; Table 15). Significant covariate predictors of differences in means of parental advocacy scores included the child has a diagnosis of asthma (yes/no) ($p=.010$) and the school requires an emergency action plan (yes/no) ($p=.004$). Different types of school's community settings were significantly associated with different mean parental advocacy scores ($p=.03$; Table 14). The presence of a school nurse, credentials of the school nurse, primary caregiver role (mother/father), race, and ethnicity were not significantly associated with parental advocacy ($p>.05$). Parental advocacy scores were not correlated with education level, who benefited from advocacy efforts, or time spent in advocacy activities (Kendall's tau rank correlation, $p>.05$).

Table 14

Analysis of Variance of School's Community Setting on Parental Advocacy

	N	Mean	SD	F (2,306)	Sig.
School's Community Setting	308			3.50	**.03**
City	74	3.68	.81		
Rural	27	3.92	.76		
Suburban	208	3.94	.67		

Note: ANOVA results showed no significant difference in the means of advocacy for credentials of school health nurse (Health aide/Licensed Practical Nurse/Registered Nurse).

Table 15

T-Test Results Comparing Values of Variables of Interest on Mean of Parental Advocacy

Variable	N	Mean	SD	t	df	Sig. (2-tailed)
Communicative Health Literacy				-.5.08	311	**<.001**
Lowest scorers	148	3.65	.72			
Highest scorers	165	4.05	.69			
Critical Health Literacy				-.4.45	311	**<.001**
Lowest scorers	153	3.68	.72			
Highest scorers	160	4.04	.70			
Parental Empowerment				-9.21	275	**<.001**
Lowest scorers	122	3.48	.74			
Highest scorers	155	4.21	.58			
Asthma				-2.60	304	**.010**
No	158	3.76	.71			
Yes	148	4.00	.75			
School requires an Emergency Action Plan				-2.88	293	**.004**
No	16	3.36	.79			
Yes	279	3.89	.72			
School has a nurse				-.28	307	.781
No	47	3.85	.72			
Yes	262	3.88	.73			
Parent/caregiver role				.56	309	.575
Mother	301	3.87	.73			
Father	10	3.74	.83			
Race				.36	299	.716
White	264	3.87	.71			
Non-white	37	3.82	.87			
Ethnicity				1.64	304	.103
Non-Hispanic	282	3.89	.72			
Hispanic	24	3.64	.77			

Note: T-test results showed no significant difference in the means of Advocacy for: Registered Nurse time in building (part-time/full-time); child has a 504 Plan (yes/no); child on immunotherapy (yes/no); survey participant with health-related education (yes/no).

Hypothesis 1. Parents who score at the highest levels on a measure of communicative health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels.

An analysis of covariance (ANCOVA) was conducted as a general linear model to compare the mean 'perceived effectiveness of advocacy efforts' [parental advocacy] (dependent variable) for lowest and highest scorers of communicative health literacy (independent variable) while controlling for 'quality of relationship with school' and 'perceived effectiveness of cause advocacy efforts' [cause advocacy]. ANCOVA assumptions of: a linear relationship between the dependent variable and covariates at each level of the independent variable, equal error variances (Levene's test), and normally distributed residuals were met. The following covariates were not included in the final model because they did not meet the assumptions of ANCOVA, or they were not significant in the model ($p>.05$): school community setting, asthma, 'school requires an emergency action form', and 'food allergy quality of life – parental burden (modified)'. Interaction terms (between the independent variable and each covariate) and the dependent variable were not significant ($p>.05$) and therefore not retained in the final model. Because a t-test revealed an association between dichotomous communicative health literacy and cause advocacy (covariate), bootstrapping of confidence intervals with a Bonferroni correction for the estimated means (adjusted for the covariates) were used to decrease bias in the ANCOVA.

Dichotomous communicative health literacy, quality of the relationship with the school, and cause advocacy were significantly related to parental advocacy in the model, $p<.001$ (Table 16). The covariate, quality of relationship with school, was significantly

related to parental advocacy with the largest proportion of the model variance, F(1,254) = 168.79, p<.001, partial η^2=.40. The variable of interest, dichotomous communicative health literacy, had a significant effect on mean parental advocacy scores while controlling for the two covariates, F (1,251) = 20.00, p=<.001, partial η^2=.07. The overall model accounted for 48% of the variance of parental advocacy (F(43, 251) = 76.42, p<.001, r^2=.48, adjusted r^2=.47). Specifically, the parental advocacy mean for the highest communicative health literacy scorers (M= 3.97, 95% CI bootstrapped [3.87, 4.09]) was significantly higher than the parental advocacy mean for the lowest communicative health literacy scorers (M=3.67, 95% CI bootstrapped [3.56, 3.79], p<.001). Therefore, the research hypothesis is accepted. Parents who score at the highest levels on a measure of communicative health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels. Yet, the quality of the relationship with the school accounts for most of the variance in mean parental advocacy scores. Dichotomous communicative health literacy has a small effect size on parental advocacy.

Table 16

ANCOVA for Parental Advocacy with Lowest versus Highest Communicative Health Literacy Scorers

Variable	Mean (95% CI) [a]	F[b]	*p*	Partial η^2
Corrected Model		76.42	<.001	.48
Communicative Health Literacy		20.00	<.001	.07
Lowest scorers	3.67 (3.56, 3.79)			
Highest scorers	3.97 (3.87, 4.09)			
Quality of Relationship with School[c]	3.96	168.79	<.001	.40
Cause Advocacy[c]	3.31	12.15	.001	.05

Note: N=255. [a]95% Confidence Interval bootstrap results based on 1000 bootstrap samples. [b]F statistic: Between-subjects degrees of freedom ranged from 1 to 3; Within-subjects degrees of freedom ranged from 251 to 254. [c]Continuous variable.

Hypothesis 2. Parents who score at the highest levels on a measure of critical health literacy engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels.

ANCOVA was conducted as a general linear model to compare the means of 'perceived effectiveness of advocacy efforts' [parental advocacy] (dependent variable) for lowest versus highest critical health literacy scorers (independent variable) while controlling for 'quality of relationship with school' and 'perceived effectiveness of cause advocacy efforts' [cause advocacy]. Analysis assumptions of a linear relationship between the dependent variable and covariates at each level of the independent variable, equal error variances (Levene's test), and normally distributed residuals were met. The following covariates were not included in the final model because they did not meet the assumptions of ANCOVA, or they were not significant in the model (p>.05): school community setting, asthma, 'school requires an emergency action form', and 'food allergy quality of life – parental burden (modified)'. Interaction terms (between the

independent variable and each covariate) and the dependent variable were not significant ($p>.05$) and therefore not retained in the final model. Because t-tests revealed associations between dichotomous critical health literacy and covariates, bootstrapping of confidence intervals with a Bonferroni correction for the estimated means (adjusted for the covariates) were used to decrease bias in the ANCOVA.

Dichotomous critical health literacy, quality of relationship with school, and cause advocacy were significantly related to parental advocacy in the model, $p<.05$ (Table 17). The covariate, quality of relationship with school, was significantly related to parental advocacy with the largest proportion of the variance in the model, $F(1,254) = 157.93$, $p<.001$, partial $\eta^2=.38$. There was also a significant effect of the variable of interest, dichotomous critical health literacy, on mean parental advocacy scores while controlling for the two covariates, $F(1,246) = 2.53$, $p=.004$, partial $\eta^2=.03$. The overall model accounted for 45% of the variance of parental advocacy (($F(3, 251)= 69.58$, $p<.001$, $r^2=.45$, adjusted $r^2=.45$). Specifically, the parental advocacy mean for the highest critical health literacy scorers ($M= 3.93$, 95% CI bootstrapped [3.82, 4.04]), $p=.004$) was significantly greater than the parental advocacy mean for the lowest critical health literacy scorers ($M=3.73$, 95% CI bootstrapped [3.61, 3.84]). Therefore, the research hypothesis is accepted, with acknowledgment of the moderate effect size on parental advocacy by quality of the relationship with the school and of the small effect size by the variable of interest, dichotomous critical health literacy.

Table 17

ANCOVA for Parental Advocacy with Lowest versus Highest Critical Health Literacy Scorers

Variable	Mean (95% CI) [a]	F	*p*	Partial η^2
Corrected Model		69.58	<.001	.45
Critical Health Literacy		2.53	.004	.03
Lowest scorers	3.73 (3.61, 3.84)			
Highest scorers	3.93 (3.82, 4.04)			
Quality of Relationship with School[c]		157.93	<.001	.38
Cause Advocacy[c]		12.59	<.001	.05

Note: N=255. [a]95% Confidence Interval bootstrap results based on 1000 bootstrap samples. [b]F statistic: Between-subjects degrees of freedom ranged from 1 to 3; Within-subjects degrees of freedom ranged from 251 to 254. [c]Continuous variable.

Hypothesis 3. Communicative and critical health literacy are more strongly associated with more effective advocacy behaviors than functional health literacy.

A multiple linear regression analysis was conducted using the enter method for the dependent variable of 'perceived effectiveness of advocacy efforts' with the following independent variables: communicative health literacy, critical health literacy, functional health literacy; and the following covariates: parental empowerment, quality of relationship with school, cause advocacy, asthma, school community setting, and food allergy quality of life - parental burden (modified). Assumptions of normality and independence of errors for the linear regression were met. Multicollinearity was a low concern (variance inflation factor < 2.5 and tolerance >.04 for each variable).

The overall model significantly explained parental advocacy, F(10, 235) = 32.56, p<.001 (Table 18). The quality of the relationship with the school (*B* = .37, p<.001), parental empowerment (*B* = .55, p<.001), asthma, functional health literacy, and cause advocacy significantly predicted parental advocacy. Communicative health literacy,

critical health literacy, school community setting, and food allergy quality of life – parental burden were not significant (p>.05). The regression model explained 56% of the variance of parental advocacy (R^2=.58, adjusted R^2=.56). Therefore, the research hypothesis is rejected because communicative and critical health literacy were not significant predictors in the model, and did not have large effects on parental advocacy than functional health literacy.

Table 18

Regression Coefficients of Health Literacy Subscales and Co-variates on Parental Advocacy

Variable	*B*	SE	t	p
(Constant)	-.90	.39	-.2.27	**.024**
Communicative Health Literacy	.04	.07	.64	.525
Critical Health Literacy	.01	.01	.08	.934
Functional Health Literacy	.11	.05	2.14	**.034**
Parental Empowerment	.55	.08	6.81	**<.001**
Quality of Relationship with School	.37	.04	10.15	**<.001**
Cause Advocacy	.08	.04	2.43	**.016**
Asthma	.13	.06	2.10	**.037**
School Setting				
Rural	.11	.13	.79	.428
Suburban	.07	.08	.99	.323
City (Reference)	-	-	-	-
Food Allergy Quality of Life – Parental Burden	-.02	.04	-.49	.624

Note: Model summary for dependent variable advocacy: F(10, 235) = 32.56, p<.001

Hypothesis 4. Parents who score at the highest levels on a measure of empowerment engage in advocacy behaviors perceived to be more effective than parents who score at the lowest levels.

ANCOVA was conducted as a general linear model to compare the means of 'perceived effectiveness of advocacy efforts' [parental advocacy] (dependent variable) for lowest versus highest parental empowerment scorers (independent variable) while

controlling for ‘quality of relationship with school’, ‘perceived effectiveness of cause advocacy efforts’ [cause advocacy], and the interaction between dichotomous parental empowerment and ‘quality of relationship with school’. Assumptions of conducting the ANCOVA were met, such as a linear relationship between the dependent variable and covariates at each level of the independent variable, equal error variances (Levene’s test), and normally distributed residuals. The following covariates were not included in the final model because they did not meet the assumptions of ANCOVA, or they were not significant in the model ($p>.05$): school community setting, asthma, ‘school requires an emergency action form’, and ‘food allergy quality of life – parental burden (modified)’. The interaction term between dichotomous parental empowerment and cause advocacy was not significant ($p>.05$) and therefore not retained in the final model. However, the significant interaction term between dichomotous parental empowerment and ‘quality of relationship with school’ was retained in the final model. Because t-tests revealed associations between dichotomous parental empowerment and covariates, bootstrapping of confidence intervals with a Bonferroni correction for the estimated means (adjusted for the covariates) were used to decrease bias in the ANCOVA.

Dichotomous parental empowerment, quality of the relationship with the school, the interaction between dichotomous parental empowerment and quality of relationship with school, and cause advocacy were significantly related to parental advocacy in the model, $p<.05$ (Table 19). The covariate, quality of relationship with school, was significantly related to parental advocacy with the largest proportion of the variance of parental advocacy, $F(1,220) = 118.31$, $p<.001$, partial $\eta^2=.35$. The variable of interest, dichotomous parental empowerment, had a significant and small effect on mean parental

advocacy scores while controlling for the three covariates, F (1,220) = 15.58, p<.001, partial η^2=.07. The interaction between dichotomous parental empowerment and 'quality of relationship with school' contributed a very small positive effect on the model F(1, 220) = 6.71, p=.010, partial η^2=.03. The overall model accounted for 56% of the variance of parental advocacy (F(4, 216) = 67.43, p<.001, r^2=.56, adjusted r^2=.55). Specifically, the parental advocacy mean for the highest parental empowerment scorers (M= 4.08, 95% CI bootstrapped [3.95, 4.19]), p=.001) was significantly greater than the parental advocacy mean for the lowest parental empowerment scorers (M=3.63, 95% CI bootstrapped [3.50, 3.75]). Therefore, the research hypothesis is accepted, with acknowledgment of the moderate effect size on parental advocacy by the quality of the relationship with the school and the small effect size by the variable of interest, dichotomous parental empowerment.

Table 19

ANCOVA for Parental Advocacy with Lowest versus Highest Parental Empowerment Scorers

Variable	Mean (95% CI) [a]	F	*p*	Partial η^2
Corrected Model		67.43	<.001	.56
Parental Empowerment		15.58	<.001	.07
Lowest scorers	3.63 (3.50, 3.75)			
Highest scorers	4.08 (3.95, 4.19)			
Quality of Relationship with School		118.31	<.001	.35
Interaction: Parental Empowerment * Quality of Relationship with School		6.71	.010	.03
Cause Advocacy		6.45	.012	.03

Note: N=221. [a]95% Confidence Interval bootstrap results based on 1000 bootstrap samples. [b]F statistic: Between-subjects degrees of freedom ranges from 1 to 4; Within-subjects degrees of freedom ranges from 216 to 220. [c]Continuous variable.

H5. The relationship between parental health literacy and advocacy is mediated by parental empowerment.

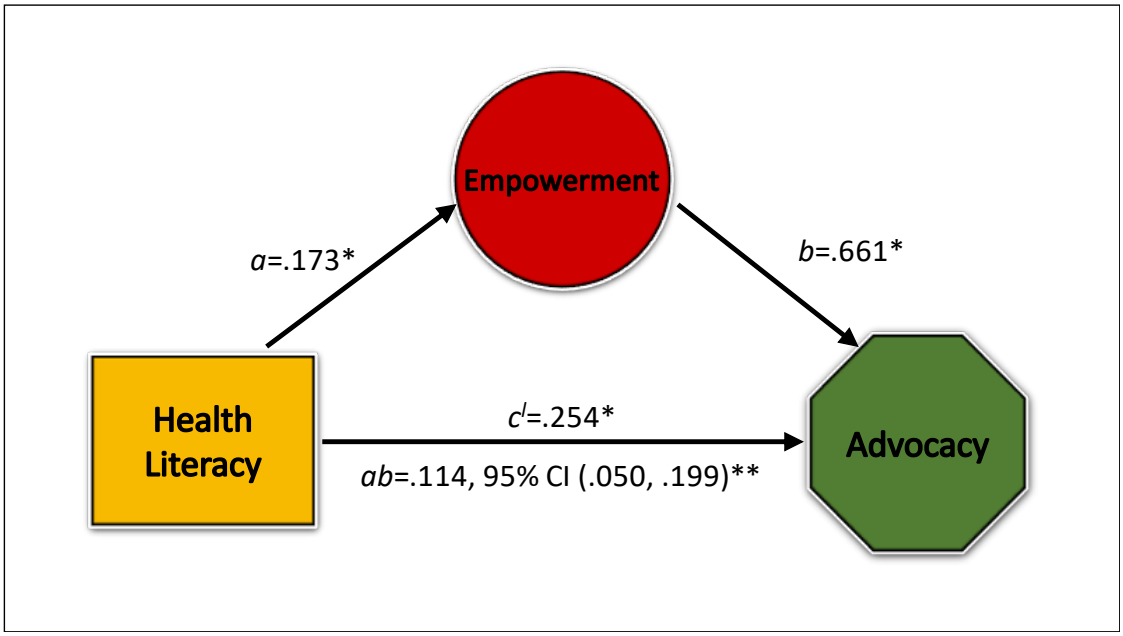
First, the assumptions of conducting a mediation analysis were analyzed. Bivariate analyses were conducted (see above, Table 12) and significant relationships between parental health literacy (predictor), parental empowerment (mediator), and parental advocacy (outcome variable) were confirmed. Next, a linear regression was conducted using enter method with parental advocacy as the dependent variable and with parental health literacy and parental empowerment as the independent variables. The overall model was significant, $F(2, 310) = 62.88$, $p<.001$. Parental health literacy (Std Beta .23, $p<.001$) significantly predicted parental advocacy in that as the parental health literacy score increased by 1, the parental advocacy score increased by .23. Parental empowerment (Std Beta = .43, $p<.001$) significantly predicted parental advocacy, in that as the parental empowerment score increased by 1, the parental advocacy score increased by .43. The model predicted 28% of the variance of perceived effectiveness of advocacy efforts ($R^2=.29$, adjusted $R^2=.28$). The regression met the assumptions of normality, independence of errors, and no multi-collinearity for a mediation analysis. Adequate power at the 0.8 level was achieved for the mediation analysis based on tables by Fritz and Mackinnon (2007) related to effect sizes and the sample size of 313.

A mediation analysis was conducted using the PROCESS macro for SPSS that employs the Lambert mediation model to estimate the indirect relationship between parental health literacy (predictor) and parental advocacy (outcome) through parental empowerment (mediator). As Figure 25 illustrates, the coefficients between parental health literacy and parental empowerment, between parental empowerment and parental

advocacy, and between parental health literacy and parental advocacy were statistically significant (p<.001). The indirect effect of parental health literacy on parental advocacy through the mediator of parental empowerment was positive, moderate size, and significant (*ab* = .114, 95% CI [.050, .199]). The confidence interval for the indirect effect did not include zero and therefore significant mediation occurred, based on 5000 bootstrapped samples. The magnitude of the change from the direct effect of parental health literacy on parental advocacy (c^{l} = .254) to the indirect effect of parental health literacy on parental advocacy through parental empowerment (*ab* =.114) was an approximate decrease by more than 55%, which is a significant change.

Figure 25

Hypothesis 5 Results: The indirect effect of parental health literacy on parental advocacy mediated through parental empowerment



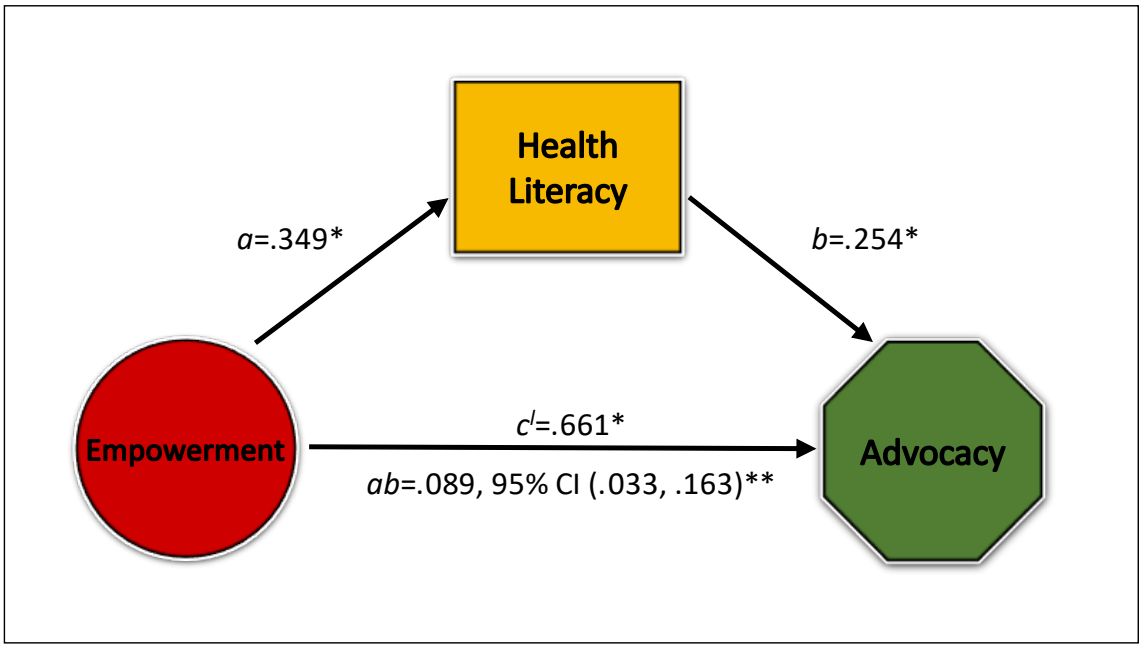
Note: *p<.001. ** 5000 bootstrapped samples.

Reverse causality was ruled out by exchanging the Hypothesis 5 mediator (parental empowerment) and Hypothesis 5 outcome variable (parental advocacy) because the magnitude of the coefficients of *b* and c^{l} pathways were different than the corresponding coefficients in the Hypothesis 5 mediation analysis. In the reversed pathway mediation model, the coefficient of the predictor variable (parental health literacy) on the outcome variable (parental empowerment) was nonsignificant (c^{l}= .063, p=.09). Secondly, the effect size of the mediator (parental advocacy) on the outcome (parental empowerment) is much smaller (*b*=.296, p<.001) than the coefficient *b* in the Hypothesis 5 mediation analysis. Therefore, reverse causality by exchanging parental empowerment and parental advocacy from Hypothesis 5 is ruled out.

However, the reverse causality pathway of exchanging the predictor variable and the mediator cannot be ruled out because the reversed direction indirect effect size of parental empowerment on parental advocacy through the mediator of parental health literacy was similar in magnitude (*ab* = .089, 95% CI [.033, .163]; Figure 26) to the moderate indirect effect size for Hypothesis 5 above. The magnitude of the change from the direct effect of parental empowerment on parental advocacy (c^{1} = .661) to the indirect effect of parental empowerment to parental advocacy mediated through parental health literacy (*ab* = .089) was a large change of more than 85%.

Figure 26

Reversed-Direction Mediation Analysis Results: The indirect effect of parental empowerment on parental advocacy mediated through parental health literacy



Note: *p<.001. ** 5000 bootstrapped samples.

Section 3. Results Summary

These results describe a cross-sectional survey of 313 parents of children with life-threatening food allergies who attended elementary school in-person at some point during the prior 12 months. Data collection occurred during winter 2021. The participants were predominantly white, college-educated mothers with moderately-high levels of food allergies management knowledge. Their children had allergies to an average of three food allergens. Nearly half of their children had asthma. About two-thirds of the children's schools were in suburban communities and nearly 90% of them required food allergy emergency action plans. Most participants reported above average or excellent relationships with their elementary schools.

The sample of participants had moderately high levels of functional, communicative, and critical health literacy. They also had moderately high levels of parental empowerment and perceived effectiveness of their advocacy efforts. The most reported perceived effectiveness of advocacy efforts included teaching their children about food allergies management, requesting quick access to epinephrine at school, and requesting precautions for field trips or special events. Quality of the relationship with the school was highly correlated with parental advocacy. Food allergy quality of life – parental burden was negatively correlated with parental advocacy and with quality of the relationship with the school.

Five hypotheses were tested with inferential statistics. The results demonstrated that parents who scored at the highest levels on measures of communicative health literacy, critical health literacy, and parental empowerment engaged in advocacy behaviors perceived to be more effective than parents who scored at the lowest levels on these respective measures (H1, H2, and H4). However, the quality of the parents' relationship with the school accounted for the majority of the variance of perceived effectiveness of advocacy efforts in these models. Communicative and critical health literacy were not more strongly associated with more effective advocacy behaviors than functional health literacy (H3). Lastly, the relationship between parental health literacy and parental advocacy was mediated by parental empowerment, but reverse causality between the predictor variable and the mediator variable could not be ruled out (H5).

Chapter 5. Discussion

Section 1. Introduction

The results of this study of parents and food allergies are summarized as three main findings. First, and in answer to the research question, the results demonstrate that parents who score at the highest levels of communicative health literacy, critical health literacy, and parental empowerment engaged in more effective advocacy behaviors for safe food allergy management in elementary schools than parents who score at the lowest levels of these measures. Yet, the difference in perceived effectiveness of advocacy efforts for highest versus lowest communicative and critical health literacy scorers may not represent a meaningful difference "in the real world". Second, and contrary to expectation, communicative and critical health literacy, compared to functional health literacy, were not more significantly associated with the perceived effectiveness of advocacy efforts. Parental empowerment and the quality of the relationship with the school were the strongest predictors of the parents' perceived effectiveness of advocacy efforts. Third, and most interestingly, the relationship between parental health literacy and perceived effectiveness of advocacy efforts was mediated by parental empowerment, although reverse causality in terms of exchanging parental health literacy and parental empowerment cannot be ruled out.

Section 2. Discussion of Findings

The research question was, "Do parents who score at the highest levels on measures of communicative health literacy, critical health literacy, and empowerment engage in more effective food allergy management advocacy behaviors than parents who score at the lowest levels?" According to statistical significance of multivariate models,

the answer appears to be, “Yes”. Parents who score at the highest levels on these measures engage in more effective advocacy behaviors than parents who score at the lowest levels. However, the challenge to interpreting these statistical results is whether the difference in mean scores of the parental advocacy measure for the highest and lowest scorers are meaningful “in the real world” for parents, children, and schools related to food allergy management in school.

2.1. Communicative and Critical Health Literacy: Impact on Parental Advocacy

The statistically significant difference in parental advocacy scores for highest versus lowest scorers of communicative and critical health literacy may not imply a clinically substantial increase in the effectiveness of parental advocacy efforts on food allergy management in schools. The newly-created ‘perceived effectiveness of advocacy efforts’ measure requires definition of the threshold for a minimal clinically important difference. Controversy exists in the literature related to statistical inference for minimal clinically important differences on patient-reported outcome measures, yet recommendations related to the standard deviation and confidence intervals may be helpful starting points (Chan, 2013; A. Wright et al., 2012).

First, one recommendation about making statistical inferences is that the difference in means should exceed half of the standard deviation of the outcome variable to be clinically meaningful (A. Wright et al., 2012). The ANCOVA results for the first two hypotheses demonstrate mean differences of 0.30 on the 5-point advocacy scale for highest versus lowest health literacy scorers in both models. These 0.30 differences in the means of parental advocacy for highest and lowest scorers represent less than half of the standard deviation of the mean of the outcome variable, parental advocacy (SD=0.73;

(1/2)SD=0.365). Therefore, according to this recommended criterion, these results may not be relevant in the real world.

Secondly, examination of confidence intervals for the means of an outcome variable for highest versus lowest scorers should demonstrate no overlap to infer a clinically meaningful difference (Chan, 2013). Overlap exists for the bootstrapped 95% confidence intervals around the means of parental advocacy scores for highest versus lowest *critical* health literacy scorers. So, the result for critical health literacy on parental advocacy may not be meaningful in the real world. There is no overlap in the bootstrapped 95% confidence intervals of the parental advocacy means for highest versus lowest *communicative* health literacy scorers. However, the distance between confidence intervals is 0.08, less than a tenth of one point on the five-point parental advocacy scale. This represents an extremely small distance and thus casts doubts that the statistical results represent a true difference clinically. Lastly, communicative and critical health literacy were not significant predictors of parental advocacy in the regression model for Hypothesis 3. Therefore, even though Hypothesis 1 and 2 results are statistically significant, the effects of communicative and critical health literacy on parental advocacy are not clinically meaningful for real world application.

Studies of functional, communicative, and critical health literacy have demonstrated mixed results related to the effect of communicative and critical health literacy on intermediate health behavior outcomes. Some intermediate health behavior outcomes that have been associated with communicative and critical health literacy include: more regular eating and exercise patterns and better coping strategies for job stress (Ishikawa, Nomura, et al., 2008). Other intermediate outcomes associated with

communicative and critical health literacy include: better self-management behaviors in diabetes (Ishikawa, Takeuchi, et al., 2008; Lai et al., 2013; R.-H. Wang et al., 2016), in hypertension (Qiu et al., 2020), and in other chronic conditions (Heijmans et al., 2015). Similarly, multidimensional measurements of health literacy (such as the European Health Literacy Survey Questionnaire and Health Literacy for Iranian Adults) were significantly associated with diabetes self-care behaviors (RobatSarpooshi et al., 2020; Schinckus et al., 2018) and heart failure self-care behaviors (Erünal & Mert, 2020). With a different critical health literacy measure (called judgment skills), critical health literacy was not significantly associated with intermediate health behaviors of asthma self-management (Londoño and Schulz, 2015). Mixed results have demonstrated an unclear relationship between disease-specific judgment skill scores related to performance on scenario-based items and intermediate health outcomes (such as coping with sleep disorders and anti-hypertensive medication adherence) (Dubowicz & Schulz, 2014; Náfrádi et al., 2016). These studies did not specifically describe the threshold for the minimal clinically important difference on their measures of intermediate health behaviors for real-world application. This study of parents and food allergies may be among the first few to examine the associations of parental communicative and critical health literacy related to parental advocacy efforts for food allergies management in schools.

Unexpectedly in this study of parents and food allergies, communicative and critical health literacy were not significant predictors of the intermediate health outcome of perceived effectiveness of advocacy efforts when other variables were in the regression model. The significant independent predictors of parental advocacy included:

functional health literacy, parental empowerment, quality of the relationship with the school, cause advocacy, and a diagnosis of asthma. The significance of examining critical health literacy in relation to empowerment and advocacy is related to Nutbeam's conceptualization of critical health literacy as including, yet increasing, empowerment and advocacy. This study of parents and food allergies measured these concepts as distinct entities to examine their interrelatedness.

One explanation for the current study's results may be because of the overall high levels of parental health literacy and perceived effectiveness of advocacy efforts in the sample. The high levels may not have created enough variability in the independent and dependent variables to demonstrate a substantial difference. In addition, as discussed below, other predictors, such as empowerment and the quality of the relationship with the school, explained more of the variance in the parents' perceived effectiveness of advocacy efforts.

2.2. Functional Health Literacy: Impact on Parental Advocacy

Functional health literacy was a significant predictor with a small effect size on perceived effectiveness of advocacy efforts. However, there was a ceiling effect found in the measure of functional health literacy that is likely explained by the high educational attainment of the predominantly college-educated sample, consistent with other studies as suggested by Chou, et al. (2020). Mixed results have associated functional health literacy with intermediate-level health behavior outcomes in systemic reviews, such as with diabetes self-care behaviors (Al Sayah et al., 2013; Fransen et al., 2012) and oral anticoagulation therapy adherence (Cabellos-García et al., 2018). Specific to food allergies and similar to this study's findings that functional health literacy is an

independent predictor of perceived effectiveness of advocacy efforts, low caregiver functional health literacy and numeracy was associated with incorrect skills in using an epinephrine autoinjector, absence of the epinephrine autoinjector at the visit, and increased number of allergic reactions in the past 12 months (Egan et al., 2019).

Some definitions of health literacy or health literacy frameworks include disease-specific knowledge within the construct of health literacy and others treat disease-specific knowledge as a separate construct in the framework (Lee et al., 2004; Nielsen-Bohlman et al., 2004; Nutbeam, 2000; Paasche-Orlow & Wolf, 2007; Sorensen et al., 2012; Squiers et al., 2012; von Wagner et al., 2009). Sufficient evidence from systematic reviews demonstrates that there is a positive relationship between functional health literacy and disease-specific knowledge in diabetes (Al Sayah et al., 2013) and other chronic conditions in adults (Mackey et al., 2016) and children (DeWalt & Hink, 2009). In this study of parents and food allergies, food allergy knowledge, a four-item disease-specific knowledge assessment that included two scenario-based items, was not significantly associated with any of the three levels of health literacy nor with educational attainment. The lack of correlations was likely because of the ceiling effects on functional health literacy, the high educational attainment, and high food allergy knowledge level in this sample. In a vastly different and low health literate sample, a two-item scenario-based food allergy knowledge measure was associated with functional health literacy (Egan et al., 2019).

2.3. Empowerment: Impact on Parental Advocacy

The difference in means of perceived effectiveness of advocacy efforts for highest versus lowest parental empowerment scorers may be clinically meaningful “in the real

world" of food allergy management in elementary schools for parents, children, and staff. The difference in mean parental advocacy scores for highest versus lowest parental empowerment scorers is 0.45, which is greater than half of the standard deviation of the mean of the outcome variable, parental advocacy (SD=0.73; (1/2)SD=0.365), and thus could be interpreted as a meaningful difference by one criterion (A. Wright et al., 2012). Further support for this conclusion is that the bootstrapped 95% confidence intervals for the estimates of the parental advocacy means of highest versus lowest parental empowerment scorers are clearly distinct and separated by 0.2 points on the five-point parental advocacy scale (Chan, 2013). Lastly, in the regression model to predict parental advocacy, parental empowerment had the largest effect size on parental advocacy out of all the health literacy subscale variables and covariates in the model. These three reasons support the conclusion that the difference in means of parental advocacy for highest versus lowest parental empowerment scorers represent a clinically meaningful difference.

The finding that parental empowerment is significantly associated with the intermediate health outcome of greater perceived effectiveness of advocacy efforts for food allergy management in school is analogous to findings related to the significant impact of psychological empowerment on intermediate health behavior outcomes of asthma self-management (Londoño & Schulz, 2015) and medical decision-making in older adults with sufficient health literacy (Sak et al., 2017). Psychological empowerment was significantly associated with better perceived health status (Náfrádi et al., 2018) and improved health outcomes in fibromyalgia (Camerini et al., 2012), especially among those with sufficient health literacy. Empowerment was also associated with improved glycemic control in diabetes during a two-year prospective study (Long & Gambling,

2012). Because the levels of parental health literacy and empowerment were high in this sample, these findings may represent findings of "effective self-managers", or in this case, effective parental managers of their child's food allergies as described by the Health Empowerment Model (Schulz & Nakamoto, 2013). Furthermore, systematic reviews of health literacy and chronic disease management have found some limited evidence that self-efficacy, a similar concept to the competence dimension of empowerment, is associated with health literacy and chronic disease health behaviors and health outcomes (Fransen et al., 2012; Mackey et al., 2016). However, the current study's result related to empowerment is dissimilar to the result of a study where empowerment was not associated with anti-hypertensive medication nonadherence in adults (Náfrádi et al., 2016). Lastly, the significant interaction term between parental empowerment and quality of the relationship with the school in this study of parents and food allergies is supported by similar findings of a positive correlation between parental empowerment and the family-professional partnership in a study of parental advocacy for special education (Burke et al., 2020).

2.4. Other Predictors of Parental Advocacy

In this study of parents and food allergies, a large proportion of the variance of the parents' perceived effectiveness of advocacy efforts was explained by the parents' perceived quality of their relationship with the school. This is similar to the finding that the parent-professional partnership plays a significant role in intermediate outcomes of parental advocacy for children's special education services (Burke, Lee, et al., 2019; Burke, Rios, et al., 2019; Burke & Hodapp, 2016). Parents of children who advocated for special education services in lower quantities compared to higher quantities had more

positive partnerships with the school and were more satisfied with the services. In addition, those who engaged in the highest amounts of special education advocacy activities reported negative experiences and had less satisfactory partnerships with the school (Burke & Hodapp, 2016). The current study's finding aligns with studies of parents and educators that identify building relationships as foundational to advocacy work (Crawford & Arnold, 2016; A. C. Wright & Taylor, 2014).

In this current study of parents and food allergies, the quality of the parent's relationship with the school was assessed with a single item, "Overall, how would you rate your relationship with the elementary school?" with five response options from poor to excellent. In contrast, the family-professional partnership related to parental advocacy for special education was assessed with a multi-item scale in other studies (Burke, Lee, et al., 2019; Burke, Rios, et al., 2019; Burke & Hodapp, 2016). Of note, it is important to recognize that the quality of a school's response to advocacy efforts and the parents' perceived quality of the relationship with the school are not equivalent to the parent's perception of satisfaction with services (Burke, Rios, et al., 2019) nor the parent's perceived effectiveness of advocacy efforts. This is due to the interactive nature of a parent-school relationship comprised of more than two perspectives. Future studies could assess dyads of parents and schools with a more robust and multi-item measurement of the quality of the parent-school relationship.

The cause advocacy scale, which depicts the perceived effectiveness of food allergy advocacy efforts in public arenas (such as efforts through advocacy groups, fundraising, social media, or political representatives) was a significant covariate associated with the outcome variable of parents' perceived effectiveness of food allergy

advocacy efforts for their child at school. Similar to findings associated with parental special education advocacy, participants perceived advocacy efforts in the micro-advocacy setting of the school to be more effective than the cause advocacy efforts in the macro-advocacy setting of the public arena (A. C. Wright & Taylor, 2014).

The significant covariate of the child's diagnosis of asthma in the regression model may be because asthma is the most important risk factor for fatalities associated with food-induced anaphylaxis (Boyce et al., 2010; P. Lieberman et al., 2015; National Academies of Sciences, Engineering, and Medicine, 2017). This significant covariate of asthma related to parental food allergies advocacy is analogous to factors related to increased severity of disabilities that were associated with increased quantities of parental advocacy activities for special education (Burke & Hodapp, 2016).

Lower parental food allergy quality of life was associated with lower perceived effectiveness of advocacy efforts and poorer quality of relationship with the school in bivariate correlations. This finding corresponds to similar findings among parents who advocate for special education services for their children (Burke, Lee, et al., 2019; Burke, Rios, et al., 2019; Rios et al., 2021; A. C. Wright & Taylor, 2014). In this sample of parents and food allergies, parental food allergy quality of life was fairly low, consistent with findings that lower caregiver food allergy quality of life is associated with higher number of allergens, history of prior anaphylaxis (versus none), type of food allergy, and lower for mothers (than for fathers) (DunnGalvin et al., 2017; Leung et al., 2009; J. A. Lieberman & Sicherer, 2011; Warren et al., 2015). In the current study of parents and food allergies, food allergy quality of life correlated to the measure of food allergy severity as expected (Warren et al., 2015). However, parental food allergy quality of life

was not retained in multivariate analyses because of non-significance in the models. This study is possibly among the first to demonstrate a bivariate correlation between parental food allergy quality of life and an intermediate health behavior outcome, perceived effectiveness of advocacy efforts for food allergy safety in elementary school.

2.5. Empowerment as a Mediator between Health Literacy and Advocacy

Parental empowerment was found to be a mediator in the relationship between parental health literacy and parental advocacy, conceptually an important and unique finding describing the potential interconnectedness of three distinct concepts within Nutbeam's conceptualization of health literacy (Nutbeam, 2000, 2008). Evidence for a mediating relationship between health literacy and empowerment on intermediate health behavior outcomes is sparse and mixed. Analogous to the current study's findings, perceived gains in empowerment from seeking health information on the internet mediated the relationship between a comprehensive measure of health literacy (eHeals) and general practitioner healthcare utilization (Schulz et al., 2017). Mixed findings were reported in a study of diabetes self-care activities in that the indirect effect of health literacy (measured with FCCHLS) through the mediator of empowerment was significant for diet and physical exercise, yet nonsignificant for foot care and blood glucose monitoring (Shin & Lee, 2018). Analogous to the reversed mediation pathway findings in this study of parents and food allergies, functional and navigational health literacy (measured by Chew's 3-item screener) mediated the relationship between empowerment and actual involvement in the last medical treatment decision in older adults (Sak et al., 2017).

The current mediation results may represent only the portion of the population described as “effective self-managers”, or effective managers of their child’s health, in the Health Empowerment Model (Schulz & Nakamoto, 2013). Without adequate representation of individuals with low health literacy or low empowerment, the other groups in the Health Empowerment Model may not be represented and therefore testing for a moderating relationship was not feasible with this sample.

Psychosocial variables, such as empowerment, self-efficacy, and social support, are integrated into some health literacy frameworks as mediators of the relationship between health literacy and health behaviors and/or health outcomes (Baker, 2006; Cudjoe et al., 2020; Paasche-Orlow & Wolf, 2007; Squiers et al., 2012; von Wagner et al., 2009). Evidence for these mediators is also mixed. A systematic review found good support for self-efficacy as a mediator of health literacy and health behavior, although most of these studies were limited to measures of functional health literacy and used cross-section study designs (Cudjoe et al., 2020). Self-efficacy fully mediated the relationship between functional health literacy (as measured by Newest Vital Sign) and intentional medication nonadherence among adults with hypertension (Náfrádi et al., 2016). In one study that employed multiple separate mediation analyses, the ‘acceptance of illness’ mediated many relationships between three dimensions of health literacy and several diabetes self-management behaviors (Qiu et al., 2020). Lastly, and specific to food allergies and a comprehensive measure of health literacy (eHeals), health literacy was associated with food allergy self-efficacy (Ditzler & Greenhawt, 2016) but food allergy management behaviors were not assessed.

Caution is advised in interpretation of the current mediation results as reflecting causality because temporality was not established with this cross-sectional survey. While not demonstrated in the reverse causality mediation analysis in the current sample, it possible that parental advocacy behaviors may have increased empowerment (A. C. Wright & Taylor, 2014) instead of the reverse-direction pathway ending with parental advocacy behaviors. Furthermore, caution with interpretation is advised because the mediation analysis did not control for any covariates.

Section 3. Strengths and Limitations

3.1. Strengths

Strengths of the current study include: adaptation of a validated multidimensional measure of health literacy, creation of a parental advocacy measure of adapted items, pilot testing of measures and methods, and robust statistical methods. These findings are unique in that they are potentially among the first to assess the relationship between parental health literacy and parental advocacy in schools. With advocacy and empowerment uniquely linked to critical health literacy in Nutbeam's (2000, 2008) conceptualization of health literacy, this current work is important in increasing our understanding of the concept of health literacy.

This study includes a disease-specific adaptation of a validated measurement of health literacy, the Functional Communicative and Critical Health Literacy Scale (Ishikawa, Takeuchi, et al., 2008), in contrast to solely measuring health literacy as functional health literacy. Most studies have measured health literacy at the level of functional health literacy according to systematic reviews of health literacy and chronic disease management behaviors (Mackey et al., 2016), chronic disease behavioral risk

factors (Taggart et al., 2012), and pediatric health behaviors and health outcomes (DeWalt & Hink, 2009). Yet many researchers argue that we need to implement more multidimensional assessments of health literacy with an "asset" or public health approach instead of a "risk" or medical model approach (Ishikawa, Takeuchi, et al., 2008; Nutbeam & Lloyd, 2021; Pleasant et al., 2018; Sørensen et al., 2013). Furthermore, few health literacy studies have focused on adult caregivers of children with food allergies (Dilley et al., 2019; Ditzler & Greenhawt, 2016; Egan et al., 2019; Egan & Wang, 2016). Moving the assessment of health literacy outside of the context of the healthcare setting to the context of the community setting has great potential to understand and impact health behaviors (Guzys et al., 2015).

A second strength of this work was the creation of a parental advocacy scale for safe food allergy management practices in schools that builds upon and adapts from work examining parental advocacy related to special education services in schools. While it is a future hope that schools nationwide will implement food allergy management policies and protocols in a standardized manner, it will still be important for parents of some children with rare and severe food allergies to advocate for individualized food allergy safety precautions. So, the newly-developed parental advocacy scale may be instrumental in measuring the effectiveness of these parents' advocacy efforts on health outcomes related to food allergy management in schools.

Another strength of this study is the pre-testing, pilot testing, and iterative revisions of the measures. The parental health literacy and parental empowerment measures were adapted for the specific context of food allergies management, as scholars have argued that measurement of health literacy and empowerment are context-specific

(Gibson, 1991; Nutbeam, 2009; Paasche-Orlow & Wolf, 2007; Sorensen et al., 2012; Thomas & Velthouse, 1990; Zimmerman, 1995). Some items in measures were refined after initial pilot test/re-testing of measures with a convenience sample of the target population. Additionally, the use of "reminder" pop-ups through the online survey demonstrated an effective method to achieve an extremely low amount of missing data while preserving volunteer participants' rights to choose not to answer items.

Lastly, statistical analysis methods were robust. Analyses had adequate power due to the moderately large sample size and the effect sizes of major variables. Use of an optimally chosen cut-point by examining the median, mean, and Receiver Operating Characteristics is a more robust method than simple use of a median cut-point as used for FCCHLS in a previous study (Lai et al., 2013). Bootstrapping of parameter estimates in the ANCOVAs and mediation analyses were used to decrease the bias of confidence intervals for interpretation of results. Statistical inference for "real world" implications were discussed.

3.2. Limitations

Limitations of the present study are related to the cross-sectional design, measurement of constructs, and generalizability of the study sample. The largest limitation of this cross-sectional study is that causality cannot be inferred related to the mediation analysis. Longitudinal studies are required to assess temporal causality of health literacy and empowerment on advocacy. Likewise, the quality of the relationship with the school may not be a predictor of advocacy, but rather a reaction to the school culture and practices (Burke, Lee, et al., 2019; Burke & Hodapp, 2016). Furthermore, some suggest that successful education advocacy actions or family-professional

partnerships may increase empowerment instead of reverse causality (Rios et al., 2021; A. C. Wright & Taylor, 2014).

The measures of the variables in this study of parents and food allergies are all self-reported and therefore may be biased due to inaccurate recall or social desirability bias. No observational data was collected to confirm participants' self-reports. Thus, the inclusion criteria does not include those who, possibly due to barriers in accessing health care, have children with food allergies without a formal healthcare provider-confirmed diagnosis (Boyce et al., 2010; Gupta et al., 2011, 2014; Warren et al., 2015). No data was collected directly from schools about their current culture and food allergy management policies, yet several useful parent-reported descriptors of the schools were included, such as the school's requirement of an emergency action plan and community setting. Future studies should assess for the schools' perspectives and for observable measures in parent-school dyads, such as the presence of stock epinephrine auto-injectors in schools. Pre-hospital treatment with epinephrine is associated with improved health outcomes in children with anaphylaxis (J. L. Trainor et al., 2020). Observing for the presence of stock epinephrine in schools may be a reasonable assessment to accomplish. Other observations in schools could include cafeteria food labeling and staff skills in reading food labels for allergens.

The self-report measurements themselves may have limited validity despite good reliability. The newly-created measurement of perceived effectiveness of advocacy efforts, created from the literature review and from adapted special education advocacy items, should be interpreted cautiously. When other validated parental advocacy measures become available, convergent validity studies in more heterogeneous samples

of parents are warranted. Future studies could also use factor analysis to assess for dimensions of the scale. The cut-points for lowest versus highest scorers on measures of communicative health literacy, critical health literacy, and empowerment in this study do not imply inadequate versus adequate levels of health literacy or empowerment. It is unknown the extent to which thresholds or gradients of health literacy are important to health outcomes (Easton et al., 2010). The covariate, quality of the relationship with the school, was measured with a single item but the construct may have several dimensions worthy of assessment, similar to the measurement of the family-school partnership (Burke, Lee, et al., 2019; Burke, Rios, et al., 2019). Because the questionnaire was intended for parents or caregivers of kindergarteners through 7th graders (6th graders in the previous year), it may have included items that were not specifically relevant to parents on the extremes of the age range due to diversity in children's levels of independence with food allergies self-management. To balance the need to minimize respondent burden yet capture vital covariates, potentially important covariates, such as parental anxiety, child anxiety, or experiencing bullying were not included.

Another limitation of the study is the limited generalizability of the results due to the uniqueness of the study sample. Yet, many demographic characteristics of the participants, their children, and their school settings were described to specifically characterize the sample. Generalizability of results to parents of children with other chronic conditions may be limited because of the focus on parents of children with food allergies. The sample is comprised largely of white, college-educated mothers despite intentional efforts to recruit non-white parents and low-income parents for survey participation. The lack of gender diversity in the sample may overly represent the

mothers' perspectives, yet the true proportion of mothers versus other primary caregivers who advocate for their child's food allergy safety at school is unknown. Because data was collected exclusively online and in English, the sample may not fully represent all parents or caregivers of elementary school-aged children with food allergies. The inclusion criteria of a life-threating food allergy confirmed by a healthcare provider may have excluded some people of lower socioeconomic status who self-diagnose food allergies due to their limited access to formal healthcare services (Boyce et al., 2010; Gupta et al., 2011, 2014, 2018; Warren et al., 2015).

The sample differs somewhat from general prevalence data in the United States related to representation of school-aged children with food allergies. The proportion of children with a reported severe allergic reaction in the past 12 months (18%) is similar to a recent nationally representative sample of parent-reported severe food allergies (19%) (Gupta et al., 2018). However, the current study represents a higher proportion of parents of children with reported lifetime severe food allergy reactions (69% versus 42%) and allergies to two or more allergens (80% versus 40%) compared to a nationally representative sample (Gupta et al., 2018). This sample also over-represents parents of children with food allergies who have a co-morbid diagnosis of asthma and are allergic to "other" allergens and sesame.

Lastly, the sample is subject to historical bias because of the unique time of data collection during some grassroots legislative advocacy efforts before the April 2021 passage of the Food Allergy Safety, Treatment, Education, and Research (FASTER) Act and during the COVID-19 pandemic. The FASTER Act added sesame to the list of allergens that must be labeled in plain language by food manufacturers starting in 2023. It

further required a national public health food allergies report and strategic plan to be presented to the U.S. Congress in 2022 (Food Allergy Research and Education, 2021). The historical context may be one explanation for the high proportion of parents representing children with sesame allergy in the sample. Secondly, regulations related to the COVID-19 pandemic restricted recruitment strategies from using in-person methods. Drawing the sample using solely online recruitment strategies through food allergy organizations and support groups may have increased the likelihood that the sample has lower quality of life and higher anxiety than the general food allergy parent population (Ditzler & Greenhawt, 2016). Furthermore, the COVID-19 pandemic created some unprecedented and stressful circumstances for the target population of parents of young children that may have caused some unusual self-selection bias in survey participation.

Section 4. Implications for Public Health

The mediating effect of parental empowerment on the relationship between parental health literacy and advocacy demonstrated in this study adds to our growing understanding of the complex and multifaceted concept of health literacy. Health literacy is considered a modifiable risk factor of socioeconomic health disparities (Stormacq et al., 2019). Addressing health literacy may mitigate, but does not address, root causes of the social determinants of health related to inequitable distributions and structures of power and wealth in the world (Nutbeam & Lloyd, 2021; Razum et al., 2016; Stormacq et al., 2019). This study of parents and food allergies complements health literacy studies of theoretical frameworks and the interrelatedness of health literacy, psychosocial variables, health behaviors, and health outcomes.

Understanding potential antecedents to health behaviors, such as empowerment and health literacy, may be crucial to design interventions to impact chronic disease management outcomes. For example, a systematic review found that self-management interventions for low-health literate or low-income groups that included bolstering problem-solving skills (considered by some to be a critical health literacy skill) were most effective (Schaffler et al., 2018). Parental empowerment may also be a significant modifiable factor in the parental advocacy process related to educational services, amenable to interventions to improve the health and well-being of schoolchildren with food allergies or other chronic conditions (Burke et al., 2020; Burke, Rios, et al., 2019).

Development and adaptation of the measures in this study for parents or caregivers of children with food allergies may have important implications related to implementing and evaluating food allergy policy changes in schools. To understand phenomena better, we must first be able to describe and measure them. By examining patterns of parental advocacy in schools and school districts, and by assessing school practices related to food allergies, the need for systematic food allergy management policy changes may become clear in the same way that accomplishments have been achieved related to universal special education policies (Burke & Hodapp, 2016). Evolving food allergy management policies may be associated with changes in parental advocacy patterns that could then inform further policy changes, in the same way the data from epidemiological studies informs cycles of food allergy policy changes (Warren et al., 2021). Parental advocacy patterns may also reveal associations related to the quality of the parent-school relationship as an area for intervention to improve the safety and well-being of the child (Burke & Hodapp, 2016).

Section 5. Future Research

First, a complementary qualitative analysis of the responses to four short-answer items from this survey will be forthcoming to describe the best practices and personal characteristics of highly-health literate and highly-empowered parents who advocate for child's food allergy safety at school. This analysis will use a focused ethnography approach to discover themes related beliefs and values; skills and activities; and power and control issues from the participants' responses (Wall, 2015). This analysis could also employ a mixed methods approach to compare and contrast responses of subsets of the sample grouped according to their perceived quality of relationship with the school, their use of a 504 plan, or their cause advocacy participation. A secondary qualitative data analysis could also examine the impact of the COVID-19 pandemic historical context on parental reports of food allergies management in schools.

Longitudinal research studies are needed to determine causality for mediation pathways among health literacy, empowerment and advocacy suggested from the findings of this cross-sectional study. These studies should include participants from diverse educational, socioeconomic, and racial backgrounds. In addition, longitudinal studies could test the mediating effects of other psychosocial variables, such as self-efficacy, related to the effects of health literacy on health behaviors and health outcomes (Cudjoe et al., 2020). Then, assessing for mediating roles of psychosocial variables or controlling for them as covariates or confounders, would increase the robustness of the mediation analysis.

Additionally, future research could examine subscales of health literacy or empowerment or could assess for specific health behaviors. Future studies could test the

three dimensions of health literacy in mediation pathways, as was done in a study of health literacy and diabetes management (Qiu et al., 2020). Broader measurements of health literacy that capture the interactive nature of health literacy instead of a single individual perspective could be particularly helpful (Nouri & Rudd, 2015; van der Heide et al., 2018). Including objective assessments of the match of health literacy skills related to the complexity of information exchanged could capture the two-way communication of health information. Analyses could examine the dimensions of empowerment to assess for the impact of a predominant dimension, such as the dimension of meaningfulness, which was found to impact anti-hypertensive medication nonadherence, fibromyalgia self-care, and perceived health status (Camerini et al., 2012; Náfrádi et al., 2016, 2018). In addition to assessing composite indices of health behaviors, these studies could separately assess specific health behavior outcomes, as was done with several specific diabetes self-care behaviors (Shin & Lee, 2018).

Including measures of other potential predictors of parental advocacy may be helpful in future studies. For example, it may be beneficial to include a multi-dimensional assessment of the quality of the relationship with the school, such as the parent-professional relationship measurement (Burke, Lee, et al., 2019). Similarly, assessing for parental distress could be important because a non-linear relationship between maternal stress and special education advocacy has been observed (Burke & Hodapp, 2016). Finally, further refinement and assessment of the psychometric properties of the newly-created parental advocacy scale should be done. Further determination of the minimal clinically important difference in the advocacy scale could be performed by looking at an

anchoring measure for change in the effectiveness of parental advocacy and comparing it to the mean results of the scale over time (Devji et al., 2020).

Conclusions

This study examined the interrelated concepts of health literacy, empowerment, and advocacy with an online survey of parents of children with severe food allergies. In partial support of Nutbeam's (2000) conceptualization that health literacy leads to empowerment to perform social actions, this study of parents and food allergies found that there is a significant and mediated pathway from health literacy through empowerment to advocacy. In this sample, parental empowerment had a large mediating effect on the relationship between parental health literacy and the perceived effectiveness of advocacy efforts. However, longitudinal research studies using multidimensional measures of health literacy, empowerment, and advocacy should be performed to verify this mediating relationship.

The study results demonstrated that parents with higher self-reported communicative and critical health literacy engaged in more effective parental advocacy efforts compared to parents with lower levels of health literacy, but that difference may not be large enough to be meaningful in daily life. However, higher levels of parental empowerment substantially influenced the perceived effectiveness of advocacy behaviors in large enough ways to be meaningful in the real world. Among highly-educated individuals such as this sample, parental empowerment and the quality of the relationship with the school largely impacted the effectiveness of parental advocacy efforts for safe food allergy management practices in school. Thus, these findings partially support Nutbeam's conceptualization of the importance and interrelatedness of empowerment and

interactive relationships in health education to promote health. Public health practitioners who help families with food allergies management could not only impart food allergy knowledge but also incorporate strategies to increase psychological empowerment, enhance problem-solving skills, and improve the quality of the parent-school relationship. Similar approaches could be used to help improve the management of other childhood conditions at school, such as asthma or diabetes.

Appendix A. Supplemental Information: Food allergies management in schools

Summary of Recommended Practices for Reducing the Risk of Exposure to Food Allergens and Responding to Food Allergies in Schools (CDC, 2013, p. 41-43)

Classroom	**Cafeteria**	**Transportation**	**Events (field trips, celebration, activities before or after school)**	**Physical Education and Recess**
Have quick access to epinephrine	Have quick access to epinephrine	Have quick access to epinephrine	Have quick access to epinephrine	Have quick access to epinephrine
Train staff to respond to food allergy emergency & use epinephrine	Train staff to respond to food allergy emergency & use epinephrine	Train staff to respond to food allergy emergency & use epinephrine	Train staff to respond to food allergy emergency & use epinephrine	Train staff to respond to food allergy emergency & use epinephrine
Wash hands with soap & water before & after handling food	Wash hands with soap & water before & after handling food	Wash hands with soap & water before & after handling food	Wash hands with soap & water before & after handling food	Wash hands with soap & water before & after handling food
Consider allergy-friendly seating	Consider allergy-friendly seating	Do not allow eating on buses except for those with special needs (e.g. diabetes)	Do not exclude children with food allergies from field trips, events, or extracurricular activities	Do not exclude children with food allergies from physical education or recess
Prevent cross-contact of food allergens: lunch or snack storage	Prevent cross contact of food allergens: allergen-safe food preparation; cleanse surfaces with soap & water		Prevent cross contact of food allergens: package meals & snacks appropriately	
Avoid using food allergens in projects, crafts, snacks, celebrations	With parent cooperation, create procedures for identifying children with food allergies (with FERPA privacy protections)		Identify special needs before trips or events; find out if location is safe for children with food allergies	
Offer non-food prizes & gifts	Make reasonable meal accommodations per doctor's dietary orders		Make sure events are consistent with food allergy policies	

Classroom	Cafeteria	Transportation	Events (field trips, celebration, activities before or after school)	Physical Education and Recess
Avoid ordering food from restaurants: allergens may be present but unrecognized	Provide advanced copies of menus to parents for planning			
Help students read food labels to avoid ingesting allergens	Read all food labels and recheck with each purchase for allergens.			
Support parents who provide allergen-safe snacks in case of unexpected circumstances	Be prepared to share food labels & all ingredients in foods served; keep labels for at least 24 hours after servicing; keep contact info for all vendors to request ingredient information			
Inform substitute teachers about children with special needs, including food allergies	Report mistakes (cross-contact mishaps, ingredient list errors) immediately to administrators & parents			

Appendix B. Pilot Study Measures

Pilot Measure: Parental Empowerment Scale

[Subscale: Empowerment Meaning-Relevance]

Slide the bar to indicate how much you disagree or agree with each statement.
If needed, think about situations at school that involve your child with food allergies.

Proactively thinking about my child's food allergies get good results each day.

My effort to take care of my child's food allergies makes a difference in my child's health.

What I do to take care of my child's food allergies is important to their well-being at school.

[Subscale: Empowerment: Self-determination-Choice]

2nd set: Slide the bar. How much do you disagree or agree?

If needed, think about situations at school that involve your child with food allergies.

I can make decisions on my own about my child's needs related to food allergies.

I can act quickly during a food allergy emergency involving my child.

I can choose how to manage my child's food allergies without checking with other people.

[Subscale: Empowerment: Competence-Self-efficacy]

3rd set: Slide the bar. How much do you disagree or agree?

I am prepared to make lifestyle changes in our daily live for my child's food allergies.

I am confident that I can prevent my child from eating a food to which he or she is allergic at school.

I can calmly handle a food allergy emergency involving my child when the school calls.

[Subscale: Empowerment:-Impact-Control]

4th set: Slide the bar. How much do you disagree or agree?

I can make sure that school staff and other caregivers know how to manage my child's food allergies.

I have a lot of control over the management of my child's food allergies.

I like how much I can control the management of my child's food allergies.

Pilot Measure: Parental Health Literacy

[Subscale: Functional Health Literacy]

Answer these questions about how difficult or easy it is for you to do some things.

When you read information from medical offices, pharmacies, or on food labels, how difficult is it for you to ...

Find words of symbols that you know?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Find content that you understand?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Spend enough time to understand information?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Find someone to help you read it, if needed?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

[Subscale: Communicative Health Literacy]

2nd set:

Since your child was diagnosed with food allergies, how difficult is it for you to ...

Collect information from various sources to make health-related decisions?
- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Find information you want to answer your questions?
- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Understand when someone talks about health information related to your child?
- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Share your thoughts or questions about your child's health with someone?
- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

[Subscale: Critical Health Literacy]

3rd set:

Since your child was diagnosed with food allergies, how difficult is it for you to ...

Decide whether health information is applicable to your child's situation?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Judge how much I can trust health information?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Check wither health information is correct?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Compare and contrast information to make health-related decisions?

- Very difficult
- Difficult
- Neutral
- Easy
- Very Easy

Pilot Measure: Parental Advocacy

[Subscale: Requesting Safety Practices]

During the past 12 months, **how successful** were **your advocacy efforts** at helping to keep **your child** with food allergies **safe at elementary school**?

Your advocacy effort:

Requesting allergy-friendly seating
- o Not successful
- o Slightly successful
- o Somewhat successful
- o Very successful
- o Completely successful
- o Didn't do

Requesting handwashing with soap and water before and after handling food
- o Not successful
- o Slightly successful
- o Somewhat successful
- o Very successful
- o Completely successful
- o Didn't do

Requesting quick access to epinephrine in all locations and buses
- o Not successful
- o Slightly successful
- o Somewhat successful
- o Very successful
- o Completely successful
- o Didn't do

Requesting precautions for field trips and special events
- o Not successful
- o Slightly successful
- o Somewhat successful
- o Very successful
- o Completely successful
- o Didn't do

[Subscale: Educating others]
2nd set: During the past 12 months, **how successful** were **your advocacy efforts** at helping to keep **your child** with food allergies **safe at elementary school**?

Your advocacy effort:

Teaching staff about ways to prevent allergic reactions to foods

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Teaching staff about how to identify and respond to a food allergy emergency

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

[Subscale: Communicating with school]

3rd set: During the past 12 months, **how successful** were **your advocacy efforts** at helping to keep **your child** with food allergies **safe at elementary school**?

Your advocacy effort:

Giving staff resources about food allergies management
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Meetings by appointment to discuss food allergy management
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Discussing food allergy management with staff at unscheduled times
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Following-up meeting with key points in emails or letters
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

[Subscale: Cause Advocacy]

During the past 12 months, **how successful** were your advocacy efforts at helping **all people with food allergies**?

Your advocacy effort:

Working with a food allergy support group or advocacy group
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Raising money or donating money to a food allergy group
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Posting information to social media, writing a letter to an editor, or giving a speech
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Calling or emailing decision-makers or political representative
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

[End: Pilot Measures]

Appendix C. Main Study Questionnaire

Food Allergies in Schools Final Survey

Start of Block: Inclusion criteria

Welcome to the Parent Survey: Food Allergies in Schools!

You can use a computer or mobile device. It will take 10 to 20 minutes. Please try to complete it all at one time. If needed, you can pause, and return to the survey on this same device within 2 days to finish. **Let's start with 3 questions to make sure that you can participate in this survey.**

Are you the parent, guardian, or caregiver for at least one child with a diagnosis of life-threatening food allergies that was confirmed by a healthcare provider?

Yes
No

Did your child with food allergies attend elementary school (kindergarten through 6th grade) in the USA, outside of the home, during the past year?

Yes
No

Did you already participate in this survey or the pilot survey?

Yes
No

Browser Meta Info
- Browser
- Version
- Operating System
- Screen Resolution
- Flash Version
- Java Support
- User Agent

Before the survey, please complete this task:
(ReCaptcha task)

End of Block: Inclusion criteria

Start of Block: Informed Consent

Wonderful! You qualify to participate in the survey.

CONSENT TO PARTICIPATE

Project Title	Parent Survey: Food Allergies in Elementary Schools
Purpose of the Study	The purpose of this survey is to examine the relationships among health literacy, empowerment, and advocacy. We invite you to participate in this survey because you are a parent, guardian, or caregiver of a child with life-threatening food allergies who attended elementary school in the United States of America, outside the home, in the past year.
Procedures	You will be asked to complete an online survey that will take 10 to 20 minutes to complete.
Commitment	We ask that you complete the online survey in one sitting, if possible. If not, you may return to the survey on the same device to complete it within 2 days. Please do not complete this survey if you completed the pilot survey. We request that only one adult per family complete the survey.
Potential Risks and Discomforts	There are no physical risks to participating in the survey. You may feel uncomfortable thinking about some questions about food allergies. You may choose not to answer any questions that make you feel uncomfortable. In the unlikely event that you feel anxious related to answering the questions, you may contact the Crisis Text Line by texting HELLO to 741741 to connect with a crisis counselor at any time 24/7 in the United States.
Potential Benefits	There are no direct benefits from participating in this research. We hope that, in the future, other people, may benefit from this study through improved understanding of the issues related to parents' advocacy efforts for food allergies management in schools.
Confidentiality	Any potential loss of confidentiality will be minimized by storing data in password-protected files on secure computers. We will keep your name and email in separate, password-protected files so that they cannot be linked to your survey answers. Only project team members will have access to your name and email. We will destroy all contact information when we no longer need it. If we write a report or make a presentation about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.

Compensation	If you are one of the first 300 participants to complete the survey, you will be offered a $15 Amazon.com Gift Card (Restrictions apply, see Amazon.com/gc-legal). We need only your name and email address to email you the electronic gift card. If fraud or abuse is suspected, you will forfeit any compensation.
Right to Withdraw	Your participation in this research is completely voluntary. You may choose not to take part at all. If you choose to participate, you may stop at any time.
Questions	If you decide to stop taking part in the study, if you have questions, concerns, or complaints related to this project, please contact the investigator: Laura W. Koo, PhD candidate Email: laurakoo@umd.edu Phone: 410-706-3495 or my responsible faculty member, Alice M. Horowitz, PhD Email: ahorowit@umd.edu Phone: 301-405-9797 University of Maryland College Park, School of Public Health
Participant Rights	If you have questions about your rights as a research participant or wish to report a research-related injury, please contact: University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall, College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678 For more information regarding participant rights, please visit: https://research.umd.edu/irb-research-participants This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.
Consent	By clicking "I agree to participate" below, you indicate that: • you are at least 18 years of age; • you have read this consent form • and you voluntarily agree to participate in this survey. *You may print a copy of this consent form for your records now.*

I agree to participate. Start the survey.
I do not agree to participate.

End of Block: Informed Consent

Start of Block: Knowledge Subjective

Click the circle to indicate how much you disagree or agree with each statement. If needed, think about situations at school that involve your child with food allergies.

I know how to prevent exposure to foods that could cause my child to have an allergic reaction.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

I can accurately recognize a food allergy emergency (or severe allergic reaction) in my child.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

End of Block: Knowledge Subjective

Start of Block: Empowerment Competence Self-efficacy

How much you disagree or agree with each statement? If needed, think about situations at school that involve your child with food allergies.

I am prepared to make changes in our daily lifestyle for my child's food allergies.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

I am confident that I can prevent my child from eating a food to which he or she is allergic at school.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

I can calmly handle a food allergy emergency involving my child when the school calls.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

End of Block: Empowerment Competence Self-efficacy

Start of Block: Empowerment Meaning-Relevance

2nd set: How much you disagree or agree with each statement? If needed, think about situations at school that involve your child with food allergies.

Proactively thinking about my child's food allergies get good results each day.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

My effort to take care of my child's food allergies makes a difference in my child's health.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

What I do to take care of my child's food allergies is important to their well-being at school.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

End of Block: Empowerment Meaning-Relevance

Start of Block: Empowerment Impact-Control

3rd set: How much do you disagree or agree?

I can make sure that school staff and other caregivers know how to manage my child's food allergies.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

I have a lot of control over the management of my child's food allergies.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

I like how much I can control the management of my child's food allergies.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

End of Block: Empowerment Impact-Control

Start of Block: Health Literacy Functional

Answer these questions about how difficult or easy it is for you to do some things.

When you read information from medical offices, pharmacies, or on food labels, how difficult is it for you to ...

a. find words or symbols that you know?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

b. find content that you understand?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

c. spend enough time to understand information?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

d. find someone to help you read it, if needed?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

End of Block: Health Literacy Functional

Start of Block: Health Literacy Communicative

2nd set:
Since your child was diagnosed with food allergies, how difficult is it for you to ...

a. collect information from various sources to make health related decisions?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

b. find information you want to answer your questions?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

c. understand when a healthcare professional talks about health information related to your child?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

d. share your thoughts or questions about your child's health with a healthcare professional?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

End of Block: Health Literacy Communicative

Start of Block: Health Literacy Critical

3rd set:
Since your child was diagnosed with food allergies, how difficult is it for you to ...

a. decide whether health information is applicable to your child's situation?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

b. judge how much I can trust health information?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

c. check whether health information is correct?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

---

d. compare and contrast information to make health-related decisions?
- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

End of Block: Health Literacy Critical

Start of Block: School meetings relationship

In the past 12 months, did you meet with elementary school staff to discuss food allergies management?

- Yes
- No
- I don't remember

Overall, how would you rate your relationship with the elementary school?

- Poor
- Below Average
- Average
- Above Average
- Excellent

Display This Question:

If A Meet with school = No

What were the reasons that you did NOT meet with school staff to discuss food allergy management during the past 12 months? (Click all that apply)

- ○ The risk of a severe allergic reaction at school is low for my child.
- ○ School staff already know how to prevent exposure and respond to a food allergy emergency effectively.
- ○ The school is responsible for following its policies or guidelines for food allergy management.
- ○ My workplace did not allow me time off to meet with school staff.
- ○ School staff were not available or willing to meet at convenient times for me.
- ○ I met with school staff in the past and there was nothing new to discuss.
- ○ Other _____

End of Block: School meetings relationship

Start of Block: Advocacy Requesting Safety Practices

You're making good progress! *Your answers help us understand how parents communicate with schools about food allergies.*

During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?

Your advocacy effort:

Requesting allergy-friendly seating
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Requesting handwashing with soap and water before and after handling food
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Requesting quick access to epinephrine in all locations and buses
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Requesting precautions for field trips or special events
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

End of Block: Advocacy Requesting Safety Practices

Start of Block: Advocacy Teaching

During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?

Your advocacy effort:

Teaching staff about ways to prevent allergic reactions to foods
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Teaching staff about how to identify a severe allergic reaction to food
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Teaching staff about how to respond to a food allergy emergency
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?

Your advocacy effort:

Teaching your child about ways to prevent allergic reactions to foods

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Teaching your child how to identify a severe allergic reaction to food

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

End of Block: Advocacy Educating others

Start of Block: Advocacy Communicating with School

2nd set: During the past 12 months, **how successful** were **your advocacy efforts** at helping to keep **your child** with food allergies **safe at elementary school**?

Your advocacy effort:

Giving staff resources about food allergies management
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Scheduling meetings to discuss food allergy management
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Discussing food allergy management with staff at unscheduled times
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

During the past 12 months, how successful were your advocacy efforts at helping to keep your child with food allergies safe at elementary school?

Your advocacy effort:

Following-up meetings with key points in emails or letters
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Paying attention. If you are reading this, please mark the third option.
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

End of Block: Advocacy Communicating with School

Start of Block: Advocacy Cause

During the past 12 months, **how successful** were your advocacy efforts at helping **all people with food allergies**?

Your advocacy effort:

Working with a food allergy support group or advocacy group
- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Raising money or donating money to a food allergy group

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Posting information to social media, writing a letter to an editor, or giving a speech

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

Calling or emailing decision-makers or political representatives

- Not successful
- Slightly successful
- Somewhat successful
- Very successful
- Completely successful
- Didn't do

End of Block: Advocacy Cause

Start of Block: Advocacy quantity focus

Keep going! You're doing fantastic!

Overall, how much time are you involved in the types of advocacy activities described above for your child and other people with food allergies?

- None at all
- Less than 4 hours per week
- 4 to 8 hours per week
- More than 8 hours per week

Who benefits from your advocacy efforts?

- No one. I don't participate in any advocacy efforts.
- My child with food allergies.
- My child with food allergies and other students at the school.
- My child with food allergies and others in the school district.
- My child with food allergies and other people in the community, state, or nation.

Over the past 12 months, how much did you participate in any food allergy support group?

- None, I did not participate.
- Rarely, I looked at their website a few times.
- Often, I posted to online forums or went to meetings.
- Frequently, I volunteered and participated in activities.
- Very frequently, I performed a leadership role in a group.

Save that thought! You'll have a chance to add comments at the end of the survey.

End of Block: Advocacy quantity focus

Start of Block: Knowledge FA Objective

Nicely done! *What you know about food allergies is important.*

How much do you disagree or agree?
A 6-year old student is allergic to milk. The student mistakenly eats with a spoon that touched yogurt. The student is likely to have an allergic reaction.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

On food labels, the statements, "Made in a facility with ... " and "May contain ... " have the same meaning for all food manufacturers.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

A 5-year old student with an egg allergy eats a cookie from the school cafeteria. The student complains of feeling "dizzy" or lightheaded. What is the most likely explanation?

- Being overheated or too warm
- Eating too soon after playing at recess
- Mild allergic reaction
- Severe allergic reaction or anaphylaxis
- Having low blood sugar

A 7-year old student with a peanut allergy mistakenly eats a peanut during recess. Soon, the student does not feel well and asks an adult for help. Now in the health room, the student is struggling to breathe. What is the most appropriate action now?

- Call the student's parent or guardian
- Call a doctor to determine the best treatment
- Give albuterol inhaler (rescue breathing treatment)
- Give diphenhydramine (antihistamine) by mouth
- Give epinephrine injection and then call 911

End of Block: Knowledge FA Objective

Start of Block: Child Demographics: FA

For the next questions, please think about your **youngest** child with food allergies who **attended elementary school last year.**

Now, **how old** is your youngest child with food allergies who attended elementary school last year?

- less than 1 year old
- 1 year old
- 2 years old
- 3 years old
- 4 years old
- 5 years old
- 6 years old
- 7 years old
- 8 years old
- 9 years old
- 10 years old
- 11 years old
- 12 years old
- 13 years old

In the **past 12 months**, how many times was your child treated for a **severe allergic reaction** to food with epinephrine or by an emergency medical team?

- 0 times (never)
- 1 time
- 2 times
- 3 times
- 4 times
- 5 times
- 6 times
- 7 times
- 8 or more times

Does your child have asthma?

- Yes
- No
- I don't know

Click ALL of your child's **current** food allergies.

- ○ Peanut
- ○ Tree nut
- ○ Milk
- ○ Egg
- ○ Shellfish
- ○ Other. List foods: _____
- ○ Fin fish
- ○ Wheat
- ○ Soy
- ○ Mustard
- ○ Sesame seed

End of Block: Child Demographics: FA

Start of Block: More Child FA Demographics

How old was your child when they were **first diagnosed** with food allergies?

- Less than 1 year old
- 1 year old
- 2 years old
- 3 years old
- 4 years old
- 5 years old
- 6 years old
- 7 years old
- 8 years old
- 9 years old
- 10 years old
- 11 years old
- 12 years old
- 13 years old

In your child's **lifetime**, how many times was he or she treated for a **severe allergic reaction** to food with epinephrine or by an emergency medical team?

- 0 times (never)
- 1 time
- 2 times
- 3 times
- 4 times
- 5 times
- 6 times
- 7 times
- 8 or more times

End of Block: More Child FA Demographics

Start of Block: School Covariates

Thanks! Tell us about your child's elementary school. It will help us understand your unique situation.

Does your child's elementary school have a school nurse?

- Yes
- No
- I don't know

Display This Question:

If A School Nurse = Yes

What is the highest licensure level of the nurse working at your child's school?

- Health aide, health technician, or medicine aide
- Licensed Practical Nurse (LPN)
- Registered Nurse (RN)
- I don't know

Display This Question:

If A RN LPN or tech = Registered Nurse (RN)

Does the registered nurse (RN) work full-time or part-time in your child's school building?

- Full-time: in the building for the full day, 5 days per week
- Part-time: in the building for less than the full day, or less than 5 days per week
- I don't know

Does your child's school require that all students with food allergies have an emergency care form completed by the student's healthcare provider?

- Yes
- No
- I don't know

What is the best description of the school's community?

City
Rural
Suburban
I don't know

What is the full name of your child's elementary school and school district?

School names and districts will be kept confidential. We will not publish them. The names will only be used to identify survey responses that may have similar experiences in the same school or district.

Full School Name _____

Full School District Name (County or System Name)

_____

End of Block: School Covariates

Start of Block: More Food Allergy covariates

Does your child have a 504 Plan at school related to food allergies?

Yes
No
I prefer not to answer

Is your child receiving immunotherapy treatment for food allergies (such as oral immunotherapy [OIT], sublingual immunotherapy [SLIT], or subcutaneous immunotherapy [SCIT])?

Yes
No
I prefer not to answer

End of Block: More Food Allergy covariates

Start of Block: FAQOL-PB Quality of Life Parental Burden A

If you and your family were planning a vacation, how much would your choice of vacation be limited by your child's food allergy?

- Not limited
- Slightly limited
- Somewhat limited
- Very limited
- Extremely limited

If you and your family were planning to go to a restaurant, how much would your choice of a restaurant be limited by your child's food allergy?

- Not limited
- Slightly limited
- Somewhat limited
- Very limited
- Extremely limited

If you and your family were planning to participate in social activities with others involving food (e.g. parties, holiday, etc.), how limited would your ability to participate in social activies that involve food be because of your child's food allergy?

- Not limited
- Slightly limited
- Somewhat limited
- Very limited
- Extremely limited

Answer these questions about how troubled you have been by concerns related to your child's food allergies.

How troubled have you been …

a. by your need to spend extra time preparing meals (i.e. label reading, extra time shopping, preparing extra meals, etc.) due to your child's food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

---

b. about your need to take special precautions before going out of the home with your child because of their food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

---

c. by anxiety relating to your child's food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

---

d. that your child may not overcome their food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

2nd set:
How troubled have you been ...

e. by the possibility of, or actually leaving your child in the care of others because of their food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

f. by frustration over other's lack of appreciation for the seriousness of food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

---

g. by sadness regarding the burden your child carries because of their food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

---

h. about your child's attending school, camp, daycare or other group activity with children because of their food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

You're making great progress. Keep going!

3rd set:
How troubled have you been ...
i. by concerns for your child's health because of their food allergy?
Not troubled
Slightly troubled
Somewhat troubled
Very troubled
Extremely troubled

---

j. with worry that you will not be able to help your child if they have an allergic reaction to food?
Not troubled
Slightly troubled
Somewhat troubled
Very troubled
Extremely troubled

---

k. with worry that your child will not have a normal upbringing because of their food allergy?
Not troubled
Slightly troubled
Somewhat troubled
Very troubled
Extremely troubled

4th set:
How troubled have you been ....
l. about concerns for your child's nutrition because of their food allergy?
Not troubled
Slightly troubled
Somewhat troubled
Very troubled
Extremely troubled

---

m. with issues concerning your child being near others while eating because of their food allergy?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

---

n. with being frightened by the thought that your child will have a food allergic reaction?

- Not troubled
- Slightly troubled
- Somewhat troubled
- Very troubled
- Extremely troubled

End of Block: FAQOL-PB Quality of Life Parental Burden A

Start of Block: Parent demographics

Almost done! *Tell us about **you**.*

What is your primary role in caring for your child with food allergies?

- Father
- Mother
- Other (other parent, guardian, primary caregiver, grandparent, etc.)

For how many children with food allergies are you a parent or a primary caregiver?

- 1
- 2
- 3
- 4
- 5 or more

What is the highest level of education that you completed?

- Elementary school or primary school
- High school or GED
- Associate degree
- Bachelor's degree
- Any graduate degree

Display This Question:

If A Education = Associate degree

Or A Education = Bachelor's degree

Or A Education = Any graduate degree

Was your education in a health-related field (nursing, nutrition, public health, medicine, etc.)?

- Yes
- No

Do you consider yourself Hispanic or Latino?

- Yes
- No
- I prefer not to answer

How would you describe your race?

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Two or more races. Describe:

  _____

- Other race. Describe: _____
- I prefer not to answer

End of Block: Parent demographics

Start of Block: Last Comments

Hey, you're doing awesome! Thanks!
Answer the following in your own words. *Please do not use specific names of people.*

Describe a **specific time when you advocated** for your child's safety at school related to food allergies. **Who** did you contact (teacher, nurse, etc.)? **How? Why?** What was the **result**?

_____

_____

_____

_____

_____

How do you advocate for your child's safety related to food allergies at school? **What methods** do you use?

_____

_____

_____

_____

_____

Way to go! Only 3 more questions.
What topics do you discuss most often with school staff related to preventing allergic reactions to foods?

_____

_____

_____

_____

_____

Which **characteristics of yourself** help you to advocate for your child's safety related to food allergies at school? What are **your strengths**?

_____

_____

_____

_____

_____

Last Question! Any additional comments?
What else would you like to tell us about advocating for your child's food allergy safety at school?

_____

_____

_____

_____

_____

End of Block: Last Comments

Start of Block: Survey completion message

Thank you for your time. We will communicate survey results to you through food allergy websites, social media, and professional journals. Look for results where you learned about this survey.

Since you are one of the first 300 people to complete this survey, you will be eligible for a $15 Amazon.com Gift Card*. Your responses are anonymous and kept separately from your name and email. After clicking Submit, you will be directed to enter your name and email. You *must* enter your full name and email to be eligible to receive Amazon.com Gift Card*.

Thank you for your time. Please click the Submit arrow button now.

If you feel anxious, please text HELLO to 741741 to connect to a crisis counselor 24/7.

*Restrictions apply, see Amazon.com/gc-legal

End of Block: Survey completion message

First 300 participants to complete Survey A will be routed to separate Survey B below:

Eligible for gift card - Final Parent Survey Food Allergies in School

Start of Block: Name Email for gift card

Thank you for being one of the first 300 participants to complete the survey! Your answers were recorded.

If you would like to receive a $15 Amazon.com Gift Card*, please enter your name and email.

Your survey answers will not be associated with your name and email. They are anonymous.

- First Name: _____
- Last Name: _____
- Email: _____
- Confirm Email: _____

You will receive an email in 2 - 3 weeks with the Amazon.com Gift Card*. Thank you for your participation.

If you feel anxious, please text HELLO to 741741 to connect to a crisis counselor 24/7.

*Restrictions apply, see Amazon.com/gc-legal

End of Block: Name Email for giftcard

Completion 301 and later participants will be routed to End of Survey below: NOT eligible for gift card.

Thank you for your time! Your responses were recorded.

We are sorry that you are not one of the first 300 participants to complete the survey. You are not eligible to receive a gift card.

We will communicate survey results to you through food allergy websites, social media, and professional journals. Look for results where you learned about this survey.

Your responses are valuable! They will help us learn about how parents communicate with schools related to food allergies. Thanks very much.

If you feel anxious, please text HELLO to 741741 to connect to a crisis counselor 24/7.

Appendix D. Food Allergy Organizations that Helped Distribute Recruitment Ads

Allercuisine

Allergic Child

Allergy Friendly Recipes and Support

Allergy Force: the food allergy management app

Allergy Superheroes

Allergy Support and Recipe Exchange

Disney World with Food Allergies

Feeding Kids with Food Allergies

Food Allergy Ambassadors

Food Allergy Institute

Food Allergy Outcomes in White and African American Racial Differences (FORWARD) newsletter, from Science & Outcomes of Allergy & Asthma Research (SOAAR) Program

Food Allergy Research and Education (FARE) Patient Registry

Food Allergy Support Community

Food and Environmental Allergy Families of Floral Park

Food Equality Initiative

FoodASC: Allergy & Sensitivity Corner

Friends Helping Friends, recognized support group of Food Allergy & Anaphylaxis Connection Team (FAACT)

Kids with Food Allergies

NNMG Food Allergic Families of Maryland

Nut Free Wok: Allergy-friendly Asian Fare

OIT Food Allergy Oral Immunotherapy Treatment Support

Red Sneakers for Oakley: Food allergy awareness

Safe and Included: Food allergy counseling and consulting

Southern California Food Allergy Institute, family support group

The Food Allergy Forum

Thriving with Food Allergies

Tree Nut Allergy Support Group

Appendix E. Recruitment Ads for Main Study: Examples

Recruitment Ads for Closed, Private Social Media Groups

1st Ad, private social media group post

Day 0

Do you have a child with life-threatening food allergies who went to elementary school in the past year? Please complete a 10-20 minute online research survey.

Email FoodAllergiesSurvey@gmail.com to participate. We do not link your name and email to your answers.

Thanks, Laura Koo, food allergy mom and PhD candidate, University of Maryland, College Park

We kindly ask that only one adult per family participate. You are not eligible if you participated in the pilot survey.

*Please do **not** post or share this outside the group.*

Want to share it? Tell others to contact me at FoodAllergiesSurvey@gmail.com or 301-458-6457. *Thank you!*

2nd Ad, private social media group post

Day 2-14

How do you communicate with your child's elementary school related to food allergies? Please answer an anonymous online research survey. It will take 10-20 minutes. Email FoodAllergiesSurvey@gmail.com for your weblink. We do not link your name and email to your answers.

Thanks, Laura Koo, food allergy mom and PhD candidate, University of Maryland, College Park

We kindly ask that only one adult per family participate. You are not eligible if you participated in the pilot survey.

*Please do **not** post or share this outside the group.*

Want to share it? Tell others to contact me at FoodAllergiesSurvey@gmail.com or 301-458-6457. *Thank you!*

Recruitment Ads for Email Listservs

1st email listserv ad
Day 0
Email Subject: Schools and Food Allergies: Parents – Tell us your experiences

Hello,
I'm a food allergy parent like you. I'm studying how parents communicate with schools related to food allergies. Please help me by completing an online research survey.

We do not link your name and email to your answers.
Click here to start the survey: [anonymous survey weblink]

Thank you,
Laura Koo, PhD candidate
University of Maryland, College Park

We kindly ask that only one adult per family participate. You are not eligible if you participated in the pilot survey.

*Please do **not** forward this email or share it on social media.*
If you know someone who may be interested in participating in the survey, please tell them to contact me at FoodAllergiesSurvey@gmail.com *or* 301-458-6457*.*
Thank you!

2nd Email Listserv Ad
Day 2-14

Email Subject: Parent Survey: Food Allergies in Schools

Hello,
How do you communicate with your child's elementary school related to food allergies?
Please answer this online research survey.

We do not link your name and email to your answers.
Click here to start the survey: [anonymous survey weblink]

Thank you,
Laura Koo, PhD candidate
University of Maryland, College Park

We kindly ask that only one adult per family participate. You are not eligible if you participated in the pilot survey.

*Please do **not** forward this email or share it on social media.*
If you know someone who may be interested in participating in the survey, please tell them to contact me at FoodAllergiesSurvey@gmail.com *or* 301-458-6457.
Thank you!

References

Agency for Healthcare Research and Quality (AHRQ). (2019). *Health literacy measurement tools (revised)*. U.S. Department of Health and Human Services. http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy/index.html

Aika, S., Ito, M., & Yamamoto, Y. (2017). Food allergy response capabilities of mothers and related factors. *Nursing & Health Sciences*, *19*(3), 340–350. https://doi.org/10.1111/nhs.12351

Akey, T. M., Marquis, J. G., & Ross, M. E. (2000). Validation of scores on the Psychological Empowerment Scale: A measure of empowerment for parents of children with a disability. *Educational and Psychological Measurement*, *60*(3), 419–438. https://doi.org/10.1177/00131640021970637

Al Sayah, F., Majumdar, S. R., Williams, B., Robertson, S., & Johnson, J. A. (2013). Health literacy and health outcomes in diabetes: A systematic review. *Journal of General Internal Medicine*, *28*(3), 444–452. https://doi.org/10.1007/s11606-012-2241-z

Altin, S. V., Finke, I., Kautz-Freimuth, S., & Stock, S. (2014). The evolution of health literacy assessment tools: A systematic review. *BMC Public Health*, *14*, 1207. https://doi.org/10.1186/1471-2458-14-1207

Anastos, S. L. (2007). *Application of the Transtheoretical Model to aid parents in managing pediatric peanut allergy (UMI Number: 3265872)* [Doctoral Dissertation, Massachusetts School of Professional Psychology]. ProQuest Information and Learning Company.

http://survey.hshsl.umaryland.edu/?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2007-99220-006&site=ehost-live

Bacal, L. R., & Nadeau, K. C. (2013). The impact of food allergies on quality of life. *Pediatric Annals*, *42*(7), 141–145. https://doi.org/10.3928/00904481-20130619-12

Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, *21*(8), 878–883. https://doi.org/10.1111/j.1525-1497.2006.00540.x

Bartnikas, L. M., Huffaker, M. F., Sheehan, W. J., Kanchongkittiphon, W., Petty, C. R., Leibowitz, R., Hauptman, M., Young, M. C., & Phipatanakul, W. (2017). Impact of school peanut-free policies on epinephrine administration. *Journal of Allergy and Clinical Immunology*, *140*(2), 465–473. https://doi.org/10.1016/j.jaci.2017.01.040

Batterham, R. W., Hawkins, M., Collins, P. A., Buchbinder, R., & Osborne, R. H. (2016). Health literacy: Applying current concepts to improve health services and reduce health inequalities. *Public Health*, *132*, 3–12. https://doi.org/10.1016/j.puhe.2016.01.001

Bauermeister, J. A., Pingel, E., Zimmerman, M., Couper, M., Carballo-Diéguez, A., & Strecher, V. J. (2012). Data quality in HIV/AIDS web-based surveys: Handling invalid and suspicious data. *Field Methods*, *24*(3), 272–291. https://doi.org/10.1177/1525822X12443097

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., Holland, A., Brasure, M., Lohr, K. N., Harden, E., Tant, E., Wallace, I., &

Viswanathan, M. (2011). Health literacy interventions and outcomes: An updated systematic review. *Evidence Report/Technology Assessment*, *199*, 1–941.

Bilaver, L. A., Kester, K. M., Smith, B. M., & Gupta, R. S. (2016). Socioeconomic disparities in the economic impact of childhood food allergy. *Pediatrics*, *137*(5), 1–8. https://doi.org/10.1542/peds.2015-3678

Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quiñonez, H. R., & Young, S. L. (2018). Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Frontiers in Public Health*, *6*. https://doi.org/10.3389/fpubh.2018.00149

Bock, S. A., Muñoz-Furlong, A., & Sampson, H. A. (2007). Further fatalities caused by anaphylactic reactions to food, 2001-2006. *Journal of Allergy and Clinical Immunology*, *119*(4), 1016–1018. https://doi.org/10.1016/j.jaci.2006.12.622

Bollinger, M. E., Dahlquist, L. M., Mudd, K., Sonntag, C., Dillinger, L., & McKenna, K. (2006). The impact of food allergy on the daily activities of children and their families. *Annals of Allergy, Asthma & Immunology*, *96*(3), 415–421. https://doi.org/10.1016/S1081-1206(10)60908-8

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: "why and how we advocate": A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, *42*(6), 784–797. https://doi.org/10.1111/cch.12383

Boyce, J. A., Assa'ad, A., W., Burks, A. W., Jones, S. M., Sampson, H. A., Wood, R. A., & et al. (2010). Guidelines for the diagnosis and management of food allergy in the United States: Report of the NIAID-sponsored expert panel. *Journal of*

Allergy and Clinical Immunology, *126*(6, Supplement), S1–S58. https://doi.org/10.1016/j.jaci.2010.10.007

Boyle, R. J., Umasunthar, T., Smith, J. G., Hanna, H., Procktor, A., Phillips, K., Pinto, C., Gore, C., Cox, H. E., Warner, J. O., Vickers, B., & Hodes, M. (2017). A brief psychological intervention for mothers of children with food allergy can change risk perception and reduce anxiety: Outcomes of a randomized controlled trial. *Clinical and Experimental Allergy: Journal of the British Society for Allergy and Clinical Immunology*, *47*(10), 1309–1317. https://doi.org/10.1111/cea.12981

Burke, M. M., & Goldman, S. E. (2015). Identifying the associated factors of mediation and due process in families of students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(5), 1345–1353. https://doi.org/10.1007/s10803-014-2294-4

Burke, M. M., Goldman, S. E., Hart, M. S., & Hodapp, R. M. (2016). Evaluating the efficacy of a special education advocacy training program. *Journal of Policy and Practice in Intellectual Disabilities*, *13*(4), 269–276. https://doi.org/10.1111/jppi.12183

Burke, M. M., & Hodapp, R. M. (2016). The nature, correlates, and conditions of parental advocacy in special education. *Exceptionality*, *24*(3), 137–150. https://doi.org/10.1080/09362835.2015.1064412

Burke, M. M., Lee, C. E., & Rios, K. (2019). A pilot evaluation of an advocacy programme on knowledge, empowerment, family-school partnership and parent well-being. *Journal of Intellectual Disability Research : JIDR*, *63*(8), 969–980. https://doi.org/10.1111/jir.12613

Burke, M. M., Magaña, S., Garcia, M., & Mello, M. P. (2016). Brief Report: The feasibility and effectiveness of an advocacy program for Latino families of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *46*(7), 2532–2538. https://doi.org/10.1007/s10803-016-2765-x

Burke, M. M., Meadan-Kaplansky, H., Patton, K. A., Pearson, J. N., Cummings, K. P., & Lee, C. E. (2018). Advocacy for children with social-communication needs: Perspectives from parents and school professionals. *Journal of Special Education*, *51*(4), 191–200. https://doi.org/10.1177/0022466917716898

Burke, M. M., Rios, K., Garcia, M., & Magaña, S. (2020). Examining differences in empowerment, special education knowledge, and family–school partnerships among Latino and White families of children with autism spectrum disorder. *International Journal of Developmental Disabilities*, *66*(1), 75–81. https://doi.org/10.1080/20473869.2018.1487502

Burke, M. M., Rios, K., & Lee, C. E. (2019). Exploring the special education advocacy process according to families and advocates. *The Journal of Special Education*, *53*(3), 131–141. https://doi.org/10.1177/0022466918810204

Burke, M. M., & Sandman, L. (2017). The effectiveness of a parent legislative advocacy program. *Journal of Policy & Practice in Intellectual Disabilities*, *14*(2), 138–145. https://doi.org/10.1111/jppi.12173

Cabellos-García, A. C., Martínez-Sabater, A., Castro-Sánchez, E., Kangasniemi, M., Juárez-Vela, R., & Gea-Caballero, V. (2018). Relation between health literacy, self-care and adherence to treatment with oral anticoagulants in adults: A

narrative systematic review. *BMC Public Health*, *18*(1), 1157. https://doi.org/10.1186/s12889-018-6070-9

Camerini, L., Schulz, P. J., & Nakamoto, K. (2012). Differential effects of health knowledge and health empowerment over patients' self-management and health outcomes: A cross-sectional evaluation. *Patient Education & Counseling*, *89*(2), 337–344. https://doi.org/10.1016/j.pec.2012.08.005

Cawthon, S. W., & Caemmerer, J. M. (2014). Parents' perspectives on transition and postsecondary outcomes for their children who are deaf or hard of hearing. *American Annals of the Deaf*, *159*(1), 7–21. https://doi.org/10.1353/aad.2014.0013

Centers for Disease Control and Prevention. (2013). *Voluntary guidelines for managing food allergies in schools and early care and education programs*. U.S. Department of Health and Human Services. https://www.cdc.gov/healthyschools/foodallergies/index.htm

Centers for Disease Control and Prevention. (2018, February 14). *Toolkit for managing food allergies in schools*. Healthy Schools: Food Allergies in Schools. U.S. Department of Health and Human Services. https://www.cdc.gov/healthyschools/foodallergies/index.htm

Chan, L. S. (2013). Minimal clinically important difference (MCID)—Adding meaning to statistical inference. *American Journal of Public Health*, *103*(11), e24–e25. https://doi.org/10.2105/AJPH.2013.301580

Chew, L., Griffin, J. P., M., Noorbaloochi, S., Grill, J., Snyder, A., & et al. (2008). Validation of screening questions for limited health literacy in a large VA

outpatient population. *Journal of General Internal Medicine*, *23*(5), 561–566. https://doi.org/10.1007/s11606-008-0520-5

Chinn, D. (2011). Critical health literacy: A review and critical analysis. *Social Science & Medicine*, *73*(1), 60–67. https://doi.org/10.1016/j.socscimed.2011.04.004

Chinn, D., & McCarthy, C. (2013). All Aspects of Health Literacy Scale (AAHLS): Developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings. *Patient Education and Counseling*, *90*(2), 247–253. https://doi.org/10.1016/j.pec.2012.10.019

Chou, H.-L., Lo, Y.-L., Liu, C.-Y., Lin, S.-C., & Chen, Y.-C. (2020). Development and psychometric evaluation of the cancer health literacy scale in newly diagnosed cancer patients. *Cancer Nursing*, *43*(5), E291–E303. https://doi.org/10.1097/NCC.0000000000000711

Chu, D. K., Wood, R. A., French, S., Fiocchi, A., Jordana, M., Waserman, S., Brożek, J. L., & Schünemann, H. J. (2019). Oral immunotherapy for peanut allergy (PACE): A systematic review and meta-analysis of efficacy and safety. *The Lancet*. https://doi.org/10.1016/S0140-6736(19)30420-9

Chung, S.-Y., & Nahm, E.-S. (2015). Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. *CIN: Computers, Informatics, Nursing*, *33*(4), 150–156. https://doi.org/10.1097/CIN.0000000000000146

Chyung, S. Y. Y., Roberts, K., Swanson, I., & Hankinson, A. (2017). Evidence-based survey design: The use of a midpoint on the Likert scale. *Performance Improvement*, *56*(10), 15–23. https://doi.org/10.1002/pfi.21727

Cohen, B. L., Noone, S., Muñoz-Furlong, A., & Sicherer, S. H. (2004). Development of a questionnaire to measure quality of life in families with a child with food allergy. *Journal of Allergy and Clinical Immunology*, *114*(5), 1159–1163. https://doi.org/10.1016/j.jaci.2004.08.007

Cohen, S. R. (2013). Advocacy for the "abandonados": Harnessing cultural beliefs for Latino families and their children with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(1), 71–78. https://doi.org/10.1111/jppi.12021

Couture, É. M., Chouinard, M.-C., Fortin, M., & Hudon, C. (2018). The relationship between health literacy and patient activation among frequent users of healthcare services: A cross-sectional study. *BMC Family Practice*, *19*(1), 38–38. https://doi.org/10.1186/s12875-018-0724-7

Crawford, E. R., & Arnold, N. W. (2016). Exploring the meaning and paths of advocacy for undocumented students' access to education. *Journal of Latinos and Education*, *15*(3), 197–213.

Crisis Text Line. (2019). *Text CONNECT to 741741*. https://www.crisistextline.org/textline

Crondahl, K., & Eklund Karlsson, L. (2016). The nexus between health literacy and empowerment: A scoping review. *SAGE Open*, *6*(2). https://doi.org/10.1177/2158244016646410

Cudjoe, J., Delva, S., Cajita, M., & Han, H.-R. (2020). Empirically tested health literacy frameworks. *HLRP: Health Literacy Research and Practice*, *4*(1), e22–e44. https://doi.org/10.3928/24748307-20191025-01

Dahdah, L., Pecora, V., Riccardi, C., Fierro, V., Valluzzi, R., & Mennini, M. (2018). How to predict and improve prognosis of food allergy. *Current Opinion in Allergy & Clinical Immunology*, *18*(3), 228–233. https://doi.org/10.1097/ACI.0000000000000446

Dahlquist, L. M., Power, T. G., Hahn, A. L., Hoehn, J. L., Thompson, C. C., Herbert, L. J., Law, E. F., & Bollinger, M. E. (2015). Parenting and independent problem-solving in preschool children with food allergy. *Journal of Pediatric Psychology*, *40*(1), 96–108.

DeCamp, L. R., Leifheit, K., Shah, H., Valenzuela-Araujo, D., Sloand, E., Polk, S., & Cheng, T. L. (2016). Cross-cultural validation of the parent-patient activation measure in low income Spanish- and English-speaking parents. *Patient Education and Counseling*, *99*(12), 2055–2062. https://doi.org/10.1016/j.pec.2016.07.003

Desjardins, M., Clarke, A., Alizadehfar, R., Grenier, D., Eisman, H., Carr, S., Vander Leek, T. K., Teperman, L., Higgins, N., Joseph, L., Shand, G., & Ben-Shoshan, M. (2013). Canadian allergists' and nonallergists' perception of epinephrine use and vaccination of persons with egg allergy. *The Journal of Allergy and Clinical Immunology: In Practice*, *1*(3), 289–294. https://doi.org/10.1016/j.jaip.2013.03.006

Devji, T., Carrasco-Labra, A., Qasim, A., Phillips, M., Johnston, B. C., Devasenapathy, N., Zeraatkar, D., Bhatt, M., Jin, X., Brignardello-Petersen, R., Urquhart, O., Foroutan, F., Schandelmaier, S., Pardo-Hernandez, H., Vernooij, R. W., Huang, H., Rizwan, Y., Siemieniuk, R., Lytvyn, L., … Guyatt, G. H. (2020). Evaluating the credibility of anchor-based estimates of minimal important differences for

patient reported outcomes: Instrument development and reliability study. *BMJ*, *369*, m1714. https://doi.org/10.1136/bmj.m1714

DeWalt, D. A., Dilling, M. H., Rosenthal, M. S., & Pignone, M. P. (2007). Low parental literacy associated with worse asthma care measures in children. *Ambulatory Pediatrics : The Official Journal of the Ambulatory Pediatric Association*, *7*(1), 25–31. https://doi.org/10.1016/j.ambp.2006.10.001

DeWalt, D. A., & Hink, A. (2009). Health literacy and child health outcomes: A systematic review of the literature. *Pediatrics*, *124*(Supplement 3), S265–S274. https://doi.org/10.1542/peds.2009-1162B

Dilley, M. A., Rettiganti, M., Christie, L., O'Brien, E., Patterson, M., Weeks, C., Aronson, J., Scurlock, A. M., Perry, T. T., Pesek, R. D., Bell, M. C., Kennedy, J. L., Chandler, P., Magee, J., Simmons, L., Chervinskiy, S. K., Casey, P., & Jones, S. M. (2019). Impact of food allergy on food insecurity and health literacy in a tertiary care pediatric allergy population. *Pediatric Allergy and Immunology : Official Publication of the European Society of Pediatric Allergy and Immunology*, *30*(3), 363–369. https://doi.org/10.1111/pai.13019

Ditzler, N., & Greenhawt, M. (2016). Influence of health literacy and trust in online information on food allergy quality of life and self-efficacy. *Annals Of Allergy, Asthma & Immunology: Official Publication Of The American College Of Allergy, Asthma, & Immunology*, *117*(3), 258-263.e1. https://doi.org/10.1016/j.anai.2016.07.011

Division of Health Promotion, Education, and Communications. (1998). *Health promotion glossary*. WHO.

Dubowicz, A., & Schulz, J. P. (2014). Functional validity of a judgment skills measure within the concept of health literacy for sleeping disorder patients. *International Journal of Environmental Research and Public Health*, *11*(10). https://doi.org/10.3390/ijerph111010868

Duggan, A. (2006). Understanding interpersonal communication processes across health contexts: Advances in the last decade and challenges for the next decade. *Journal of Health Communication*, *11*(1), 93–108. https://doi.org/10.1080/10810730500461125

DunnGalvin, A., Koman, E., Raver, E., Frome, H., Adams, M., Keena, A., Hourihane, J. O., Gallagher, P. L., Flokstra-de Blok, B., Dubois, A., Pyrz, K., Bindslev-Jensen, C., Stensgaard, A., Boyle, R., Vickers, B., Smith, J., Thisanayagam, U., & Greenhawt, M. (2017). An examination of the Food Allergy Quality of Life Questionnaire performance in a countrywide American sample of children: Cross-cultural differences in age and impact in the United States and Europe. *The Journal Of Allergy And Clinical Immunology.In Practice*, *5*(2), 363-368.e2. https://doi.org/10.1016/j.jaip.2016.09.049

Dwinger, S., Kriston, L., Härter, M., & Dirmaier, J. (2015). Translation and validation of a multidimensional instrument to assess health literacy. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, *18*(6), 2776–2786. https://doi.org/10.1111/hex.12252

Easton, P., Entwistle, V. A., & Williams, B. (2010). Health in the "hidden population" of people with low literacy. A systematic review of the literature. *BMC Public Health*, *10*, 459. https://doi.org/10.1186/1471-2458-10-459

Edwards, M., Wood, F., Davies, M., & Edwards, A. (2012). The development of health literacy in patients with a long-term health condition: The health literacy pathway model. *BMC Public Health*, *12*, 130. https://doi.org/10.1186/1471-2458-12-130

Egan, M., & Sicherer, S. (2016). Doctor, my child is bullied: Food allergy management in schools. *Current Opinion In Allergy And Clinical Immunology*, *16*(3), 291–296. https://doi.org/10.1097/ACI.0000000000000269

Egan, M., & Wang, J. (2016). Correct use of epinephrine autoinjectors in relation to health literacy in patients with food allergies. *Journal of Allergy and Clinical Immunology*, *137*(2), AB51. https://doi.org/10.1016/j.jaci.2015.12.168

Egan, M., Yin, H. S., Greenhawt, M., & Wang, J. (2019). Low caregiver health literacy among pediatric food-allergic patients is associated with poorer food allergy management knowledge. *The Journal of Allergy and Clinical Immunology: In Practice*, *7*(2), 655–658. https://doi.org/10.1016/j.jaip.2018.05.021

Eisman, A. B., Zimmerman, M. A., Kruger, D., Reischl, T. M., Miller, A. L., Franzen, S. P., & Morrel-Samuels, S. (2016). Psychological empowerment among urban youth: Measurement model and associations with youth outcomes. *American Journal of Community Psychology*, *58*(3–4), 410–421. https://doi.org/10.1002/ajcp.12094

Eldredge, C., Patterson, L., White, B., & Schellhase, K. (2014). Assessing the readiness of a school system to adopt food allergy management guidelines. *Wisconsin Medical Journal*, *113*(4), 155–161.

Eneanya, N. D., Winter, M., Cabral, H., Waite, K., Henault, L., Bickmore, T., Hanchate, A., Wolf, M., & Paasche-Orlow, M. (2016). Health literacy and education as

mediators of racial disparities in patient activation within an elderly patient cohort. *Journal of Health Care for the Poor & Underserved*, *27*(3), 1427–1440.

Erünal, M., & Mert, H. (2020). Does health literacy affect self-care in patients with heart failure? *The Journal for Nurse Practitioners*, *16*(9), 699–702. https://doi.org/10.1016/j.nurpra.2020.07.016

Ewles, G., Clifford, T., & Minnes, P. (2014). Predictors of advocacy in parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, *20*(1), 73–82.

Fairchild, A. J., & McDaniel, H. L. (2017). Best (but oft-forgotten) practices: Mediation analysis. *The American Journal of Clinical Nutrition*, *105*(6), 1259–1271. https://doi.org/10.3945/ajcn.117.152546

Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, *41*(4), 1149–1160. https://doi.org/10.3758/BRM.41.4.1149

Field, A. (2013a). Chapter 5: The beast of bias. In *Discovering Statistics Using IBM SPSS Statistics, 4th Ed.* Sage Publishing.

Field, A. (2013b). Chapter 6: Non-parametric models. In *Discovering Statistics Using IBM SPSS Statistics, 4th Ed.* Sage Publishing.

Field, A. (2013c). Chapter 8: Regression. In *Discovering Statistics Using IBM SPSS Statistics, 4th Ed.* Sage Publishing.

Field, A. (2013d). Chapter 10: Moderation, mediation and more regression. In *Discovering Statistics Using IBM SPSS Statistics, 4th Ed.* Sage Publishing.

Finbråten, H. S., Guttersrud, Ø., Nordström, G., Pettersen, K. S., Trollvik, A., Wilde-Larsson, B., Finbråten, H. S., Guttersrud, Ø., Nordström, G., Pettersen, K. S., Trollvik, A., & Wilde-Larsson, B. (2018). Validating the Functional, Communicative, and Critical Health Literacy Scale using Rasch modeling and confirmatory factor analysis. *Journal of Nursing Measurement*, *26*(2), 341–363. https://doi.org/10.1891/1061-3749.26.2.341

Food Allergy & Anaphylaxis Connection Team. (2021). *Education: Parents planning for school: For parents*. FAACT. https://www.foodallergyawareness.org/education/parents-planning-for-school/

Food Allergy Research and Education. (2014a). *Keeping children with food allergies safe at school*. FARE. www.foodallergy.org

Food Allergy Research and Education. (2014b). *Reducing the risk of exposure to food allergens: Recommendations from the Centers for Disease Control and Prevention*. FARE. www.foodallergy.org

Food Allergy Research and Education. (2016). *Epinephrine at school: School access to epinephrine map*. FARE. https://www.foodallergy.org/life-food-allergies/epinephrine/epinephrine-school

Food Allergy Research and Education. (2018a). *Advocacy resources*. FARE. https://www.foodallergy.org/education-awareness/advocacy-resources

Food Allergy Research and Education. (2018b). *Section 504 and written management plans*. FARE. https://www.foodallergy.org/education-awareness/advocacy-resources/section-504-and-written-management-plans

Food Allergy Research and Education. (2021). *How FARE advocates helped pass the FASTER Act*. FARE: Resources. https://www.foodallergy.org/resources/how-fare-advocates-helped-pass-faster-act

Fransen, M. P., von Wagner, C., & Essink-Bot, M.-L. (2012). Diabetes self-management in patients with low health literacy: Ordering findings from literature in a health literacy framework. *Patient Education and Counseling*, *88*(1), 44–53. https://doi.org/10.1016/j.pec.2011.11.015

Freedman, D. A., Bess, K. D., Tucker, H. A., Boyd, D. L., Tuchman, A. M., & Wallston, K. A. (2009). Public health literacy defined. *American Journal of Preventive Medicine*, *36*(5), 446–451. https://doi.org/10.1016/j.amepre.2009.02.001

Fritz, M. S., & Mackinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science*, *18*(3), 233–239. PubMed. https://doi.org/10.1111/j.1467-9280.2007.01882.x

Frosch, D. L., & Elwyn, G. (2014). Don't blame patients, engage them: Transforming health systems to address health literacy. *Journal of Health Communication*, *19*(Journal Article), 10–14. https://doi.org/10.1080/10810730.2014.950548

Fulton, D. S. (2015). *Health status and health literacy in older adults (UMI Number: 3683876)* [Doctoral Dissertation, Texas A & M University]. ProQuest Information & Learning. http://survey.hshsl.umaryland.edu/?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2016-99020-206&site=ehost-live

Gibson, C. H. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing*, *16*(3), 354–361. https://doi.org/10.1111/j.1365-2648.1991.tb01660.x

Goldman, S. E., Burke, M. M., Mason, C. Q., & Hodapp, R. M. (2017). Advocacy Measure. *PsycTESTS*, *Journal Article*. https://doi.org/10.1037/t60083-000

Greenhawt, M. J., & Weiss, C. C. (2012). We must create a national policy to protect and manage food allergic students at school. *Annals of Allergy, Asthma & Immunology*, *109*(5), 292–294. https://doi.org/10.1016/j.anai.2012.08.019

Griffey, R. T., Kennedy, S. K., McGownan, L., Goodman, M., & Kaphingst, K. A. (2014). Is low health literacy associated with increased emergency department utilization and recidivism? *Academic Emergency Medicine: Official Journal of the Society for Academic Emergency Medicine*, *21*(10), 1109–1115. https://doi.org/10.1111/acem.12476

Gupta, R. S., Kim, J. S., Springston, E. E., Pongracic, J. A., Wang, X., & Holl, J. (2009). Development of the Chicago Food Allergy Research Surveys: Assessing knowledge, attitudes, and beliefs of parents, physicians, and the general public. *BMC Health Services Research*, *9*(Journal Article), 142–142. https://doi.org/10.1186/1472-6963-9-142

Gupta, R. S., Rivkina, V., DeSantiago-Cardenas, L., Smith, B., Harvey-Gintoft, B., & Whyte, S. A. (2014). Asthma and food allergy management in Chicago Public Schools. *Pediatrics*, *134*(4), 729.

Gupta, R. S., Springston, E. E., Kim, J. S., Smith, B., Pongracic, J. A., Wang, X., & Holl, J. (2010). Food allergy knowledge, attitudes, and beliefs of primary care physicians. *Pediatrics*, *125*(1), 126–132. https://doi.org/10.1542/peds.2009-1116

Gupta, R. S., Springston, E. E., Warrier, M. R., Smith, B., Kumar, R., Pongracic, J., & Holl, J. L. (2011). The prevalence, severity, and distribution of childhood food

allergy in the United States. *Pediatrics*, *128*(1), e9–e17. https://doi.org/10.1542/peds.2011-0204

Gupta, R. S., Warren, C. M., Smith, B. M., Blumenstock, J. A., Jiang, J., Davis, M. M., & Nadeau, K. C. (2018). The public health impact of parent-reported childhood food allergies in the united states. *Pediatrics*, *142*(6). https://doi.org/10.1542/peds.2018-1235

Guzys, D., Kenny, A., Dickson-Swift, V., & Threlkeld, G. (2015). A critical review of population health literacy assessment. *BMC Public Health*, *15*(Journal Article), 215. https://doi.org/10.1186/s12889-015-1551-6

Gwynn, K. B., Winter, M. R., Cabral, H. J., Wolf, M. S., Hanchate, A. D., Henault, L., Waite, K., Bickmore, T. W., & Paasche-Orlow, M. (2016). Racial disparities in patient activation: Evaluating the mediating role of health literacy with path analyses. *Patient Education and Counseling*, *99*(6), 1033–1037. https://doi.org/10.1016/j.pec.2015.12.020

Habibzadeh, F., Habibzadeh, P., & Yadollahie, M. (2016). On determining the most appropriate test cut-off value: The case of tests with continuous results. *Biochemia Medica*, *26*(3), 297–307. https://doi.org/10.11613/BM.2016.034

Hanna, H. J., Emmanuel, J., Naim, S., Umasunthar, T., & Boyle, R. J. (2016). Community healthcare professionals overestimate the risk of fatal anaphylaxis for food allergic children. *Clinical And Experimental Allergy: Journal Of The British Society For Allergy And Clinical Immunology*, *46*(12), 1588–1595. https://doi.org/10.1111/cea.12846

Hayes, A. F. (2018). *Introduction to Mediation, Moderation, and Conditional Process Analysis: Second Edition: A Regression-Based Approach* (2nd ed.). Guilford Press.

Hayes, A. F., & Rockwood, N. J. (2017). Regression-based statistical mediation and moderation analysis in clinical research: Observations, recommendations, and implementation. *Behaviour Research and Therapy*, *98*, 39–57. https://doi.org/10.1016/j.brat.2016.11.001

Heijmans, M., Waverijn, G., Rademakers, J., van der Vaart, R., & Rijken, M. (2015). Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. *Patient Education and Counseling*, *98*(1), 41–48. https://doi.org/10.1016/j.pec.2014.10.006

Henry, M. L., Atkins, D., Fleischer, D., Pan, Z., Ruybal, J., & Furuta, G. T. (2012). Factors contributing to adherence to dietary treatment of eosinophilic gastrointestinal diseases. *Journal of Pediatric Gastroenterology and Nutrition*, *54*(3), 430–432. https://doi.org/10.1097/MPG.0b013e3182407aee

Henselmans, I., Heijmans, M., Rademakers, J., & van Dulmen, S. (2015). Participation of chronic patients in medical consultations: Patients' perceived efficacy, barriers and interest in support. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy*, *18*(6), 2375–2388. https://doi.org/10.1111/hex.12206

Herbert, L. J., Lin, A., Matsui, E., Wood, R. A., & Sharma, H. (2016). Development of a tool to measure youths' food allergy management facilitators and barriers. *Journal of Pediatric Psychology*, *41*(3), 363–372.

Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the Patient Activation Measure. *Health Services Research*, *40*(6), 1918–1930. https://doi.org/10.1111/j.1475-6773.2005.00438.x

Hickman, R. L. J., Clochesy, J. M., & Alaamri, M. (2016). Validation of an interaction model of health behavior among adults with hypertension. *Western Journal of Nursing Research*, *38*(7), 874–892. https://doi.org/10.1177/0193945916628864

Hoehn, J. L., Dahlquist, L. M., Hahn, A. L., & Bollinger, M. E. (2017). Parents of children with food allergy: Gender differences in perceived impact and perceived food allergy severity. *Journal of Pediatric Psychology*, *42*(2), 186–197.

Ishikawa, H., Nomura, K., Sato, M., & Yano, E. (2008). Developing a measure of communicative and critical health literacy: A pilot study of Japanese office workers. *Health Promotion International*, *23*(3), 269–274. https://doi.org/10.1093/heapro/dan017

Ishikawa, H., Takeuchi, T., & Yano, E. (2008). Measuring functional, communicative, and critical health literacy among diabetic patients. *Diabetes Care*, *31*(5), 874--879. https://doi.org/10.2337/dc07-1932

Jones, M. S., House, L. A., & Gao, Z. (2015). Respondent screening and revealed preference axioms: Testing quarantining methods for enhanced data quality in web panel surveys. *Public Opinion Quarterly*, *79*(3), 687–709. https://doi.org/10.1093/poq/nfv015

Jordan, J. E., Osborne, R. H., & Buchbinder, R. (2011). Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and

psychometric weaknesses. *Journal of Clinical Epidemiology*, *64*(4), 366–379. https://doi.org/10.1016/j.jclinepi.2010.04.005

Kao, L. M., Wang, J., Kagan, O., Russell, A., Mustafa, S. S., Houdek, D., Smith, B., & Gupta, R. (2018). School nurse perspectives on school policies for food allergy and anaphylaxis. *Annals of Allergy, Asthma & Immunology*, *120*(3), 304–309. https://doi.org/10.1016/j.anai.2017.12.019

Kenny, D. A. (2018). *Mediation (David A. Kenny)*. http://davidakenny.net/cm/mediate.htm#SE

Kids with Food Allergies. (2020). *Keeping students with food allergies safe at school*. Kids with Food Allergies, A Division of the Asthma and Allergy Foundation of America. https://www.kidswithfoodallergies.org/planning-for-school.aspx

Klinnert, M. D., McQuaid, E. L., Fedele, D. A., Faino, A., Strand, M., Robinson, J., Atkins, D., Fleischer, D. M., Oâ€™B. Hourihane, J., Cohen, S., & Fransen, H. (2015). Children's food allergies: Development of the Food Allergy Management and Adaptation Scale. *Journal of Pediatric Psychology*, *40*(6), 572–580. https://doi.org/10.1093/jpepsy/jsv009

Koh, H. K., Brach, C., Harris, L. M., & Parchman, M. L. (2013). A proposed "health literate care model" would constitute a systems approach to improving patients' engagement in care. *Health Affairs (Project Hope)*, *32*(2), 357–367. https://doi.org/10.1377/hlthaff.2012.1205

Koo, L. (2020). *Pilot testing a web-based survey to assess parental health literacy, empowerment, and advocacy in the context of food allergy management in*

schools [Virtual poster presentation]. Health Literacy in Action / Health Literacy Annual Research Conference.

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, *37*(4), 305–321. https://doi.org/10.1037/h0079106

Kramer, J., Rubin, A., Coster, W., Helmuth, E., Hermos, J., Rosenbloom, D., Moed, R., Dooley, M., Kao, Y., Liljenquist, K., Brief, D., Enggasser, J., Keane, T., Roy, M., & Lachowicz, M. (2014). Strategies to address participant misrepresentation for eligibility in web-based research. *International Journal of Methods in Psychiatric Research*, *23*(1), 120–129. https://doi.org/10.1002/mpr.1415

Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Health Literacy*. U.S. Department of Education. http://necs.ed.gov

Lai, A. Y., Ishikawa, H., Kiuchi, T., Mooppil, N., & Griva, K. (2013). Communicative and critical health literacy, and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis. *Patient Education and Counseling*, *91*(2), 221–227. https://doi.org/10.1016/j.pec.2012.12.018

Lawlis, T., Bakonyi, S., & Williams, L. T. (2017). Food allergy in schools: The importance of government involvement. *Nutrition & Dietetics: The Journal of the Dietitians Association of Australia*, *74*(1), 82–87. https://doi.org/10.1111/1747-0080.12225

Lee, S.-Y. D., Arozullah, A. M., & Cho, Y. I. (2004). Health literacy, social support, and health: A research agenda. *Social Science & Medicine*, *58*(7), 1309–1321. https://doi.org/10.1016/S0277-9536(03)00329-0

Leiner, D. J. (2019). Too fast, too straight, too weird: Non-reactive indicators for meaningless data in internet surveys. *Survey Research Methods*, *13*(3), 229–248. https://doi.org/10.18148/srm/2019.v13i3.7403

Leung, T. F., Yung, E., Wong, Y. S., Li, C. Y., & Wong, G. W. K. (2009). Quality-of-life assessment in Chinese families with food-allergic children. *Clinical & Experimental Allergy*, *39*(6), 890–896. https://doi.org/10.1111/j.1365-2222.2008.03192.x

Lieberman, J. A., & Sicherer, S. H. (2011). Quality of life in food allergy. *Current Opinion in Allergy and Clinical Immunology*, *11*(3), 236. https://doi.org/10.1097/ACI.0b013e3283464cf0

Lieberman, P., Nicklas, R. A., Randolph, C., Oppenheimer, J., Bernstein, D., Bernstein, J., Ellis, A., Golden, D. B. K., Greenberger, P., Kemp, S., Khan, D., Ledford, D., Lieberman, J., Metcalfe, D., Nowak-Wegrzyn, A., Sicherer, S., Wallace, D., Blessing-Moore, J., Lang, D., … Tilles, S. A. (2015). Anaphylaxis—A practice parameter update 2015. *Annals of Allergy, Asthma & Immunology*, *115*(5), 341–384. https://doi.org/10.1016/j.anai.2015.07.019

Loh, W., & Tang, M. L. K. (2018). Debates in allergy medicine: Oral immunotherapy shortens the duration of milk and egg allergy—The con argument. *World Allergy Organization Journal*, *11*(12). https://doi.org/10.1186/s40413-018-0189-0

Londoño, A. M. M., & Schulz, P. J. (2015). Influences of health literacy, judgment skills, and empowerment on asthma self-management practices. *Patient Education and Counseling*, *98*(7), 908–917. https://doi.org/10.1016/j.pec.2015.03.003

Long, A. F., & Gambling, T. (2012). Enhancing health literacy and behavioural change within a tele-care education and support intervention for people with type 2 diabetes. *Health Expectations*, *15*(3), 267–282. https://doi.org/10.1111/j.1369-7625.2011.00678.x

Mackey, L. M., Doody, C., Werner, E. L., & Fullen, B. (2016). Self-management skills in chronic disease management: What role does health literacy have? *Medical Decision Making*, *36*(6), 741–759. https://doi.org/10.1177/0272989X16638330

Mahdavinia, M., Fox, S. R., Smith, B. M., James, C., Palmisano, E. L., Mohammed, A., Zahid, Z., Assa'ad, A., H., Tobin, M. C., & Gupta, R. S. (2017). Racial differences in food allergy phenotype and health care utilization among US children. *The Journal of Allergy and Clinical Immunology in Practice*, *5*(2), 352-357.e1. https://doi.org/10.1016/j.jaip.2016.10.006

Malec, J. F., Brown, A. W., & Moessner, A. M. (2010). Two new measures for assessing advocacy activities and perceived control after acquired brain injury. *Disability and Rehabilitation*, *32*(1), 33–40. https://doi.org/10.3109/09638280902980936

Mayr, S., Erdfelder, E., Buchner, A., & Faul, F. (2007). A short tutorial of GPower. *Tutorials in Quantitative Methods for Psychology*, *2007*(2), 51–59.

McCormack, L., Bann, C., Squiers, L., Berkman, N. D., Squire, C., Schillinger, D., Ohene-Frempong, J., & Hibbard, J. (2010). Measuring health literacy: A pilot

study of a new skills-based instrument. *Journal of Health Communication*, *15*(sup2), 51–71. https://doi.org/10.1080/10810730.2010.499987

McIntyre, C., Sheetz, A., Carroll, C., & Young, M. (2005). Administration of epinephrine for life-threatening allergic reactions in school settings. *Pediatrics*, *116*(5), 1134–1140.

Meyers, L., Gamst, G., & Guarino, A. (2012). Chapter 3b. Data screening using IBM SPSS. In *Applied Multivariate Research: Design and interpretation* (2nd ed.). Sage.

Miller, G. F., Coffield, E., Leroy, Z., & Wallin, R. (2016). Prevalence and costs of five chronic conditions in children. *The Journal of School Nursing*, *32*(5), 357–364. https://doi.org/10.1177/1059840516641190

Mogford, E., Gould, L., & DeVoght, A. (2011). Teaching critical health literacy in the US as a means to action on the social determinants of health. *Health Promotion International*, *26*(1), 4–13. https://doi.org/10.1093/heapro/daq049

Morawetz, D. Y., Hiscock, H., Allen, K. J., Davies, S., & Danchin, M. (2014). Management of food allergy: A survey of Australian paediatricians. *Journal of Paediatrics and Child Health*, *50*(6), 432–437. https://doi.org/10.1111/jpc.12498

Muraro, A., Roberts, G., Halken, S., Agache, I., Angier, E., Fernandez-Rivas, M., Gerth, van W., Jutel, M., Lau, S., Pajno, G., Pfaar, O., Ryan, D., Sturm, G. J., van Ree, R., Varga, E.-M., Bachert, C., Calderon, M., Canonica, G. W., Durham, S. R., & Malling, H. J. (2018). EAACI guidelines on allergen immunotherapy: Executive statement. *Allergy*, *73*(4), 739–743. https://doi.org/10.1111/all.13420

Muraro, A., Werfel, T., Roberts, G., Roberts, G., Beyer, K., Bindslev-Jensen, C., Cardona, V., Dubois, A., duToit, G., Eigenmann, P., Fernandez, R. M., Halken, S., Hickstein, L., Host, A., Knol, E., Lack, G., Marchisotto, M. J., Niggemann, B., Nwaru, B. I., … Akdis C. A. (2014). EAACI food allergy and anaphylaxis guidelines: Diagnosis and management of food allergy. *Allergy*, *69*(8), 1008–1025. https://doi.org/10.1111/all.12429

My Kids Food Allergies. (2017). *Are Food Allergies a Disability?* My Kids Food Allergies. https://mkfa.info/blog/are-food-allergies-a-disability

Nachshen, J., Anderson, L., & Jamieson, J. (2001). The Parent Advocacy Scale: Measuring advocacy in parents of children with special needs. *Journal on Developmental Disabilities [Le Journal Sur Les Handicaps Du Développement]*, *8*(1), 93–105.

Náfrádi, L., Galimberti, E., Nakamoto, K., & Schulz, P. (2016). Intentional and unintentional medication non-adherence in hypertension: The role of health literacy, empowerment and medication beliefs. *Journal of Public Health Research*, *5*(3), 3/21/18.

Náfrádi, L., Nakamoto, K., Csabai, M., Papp-Zipernovszky, O., & Schulz, P. J. (2018). An empirical test of the Health Empowerment Model: Does patient empowerment moderate the effect of health literacy on health status? *Patient Education and Counseling*, *101*(3), 511–517. https://doi.org/10.1016/j.pec.2017.09.004

National Academies of Sciences, Engineering, and Medicine. (2017). *Finding a path to safety in food allergy: Assessment of the global burden, causes, prevention,*

management, and public policy. The National Academies Press. doi: 10.17226/23658

National Association of School Nurses, Centers for Disease Control and Prevention, Food Allergy Research and Education, & National School Board Association. (2014). *Food Allergy and Anaphylaxis: An NASN Tool Kit. CDC, FARE, NSBA, and NASN, 2014 guidance and resources for food allergy and anaphylaxis management in the school setting including a sample District and Support Policy Checklist*. http://www.nasn.org/ToolsResources/FoodAllergyandAnaphylaxis

Neter, E., & Brainin, E. (2019). Association between health literacy, eHealth literacy, and health outcomes among patients with long-term conditions: A systematic review. *European Psychologist*, *24*(1), 68–81. https://doi.org/10.1027/1016-9040/a000350

Nielsen-Bohlman, L., Panzer, A., & Kindig, D. (2004). *Health Literacy: A Prescription to End Confusion*. The National Academies Press. http://www.nap.edu/catalog/10883.htm

Norman, C. D., & Skinner, H. A. (2006). eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research*, *8*(4), e27. https://doi.org/10.2196/jmir.8.4.e27

Nouri, S. S., & Rudd, R. E. (2015). Health literacy in the "oral exchange": An important element of patient-provider communication. *Patient Education and Counseling*, *98*(5), 565–571. https://doi.org/10.1016/j.pec.2014.12.002

Nowak-Wegrzyn, A., & Conover-Walker, M. (2001). Food-allergic reactions in schools and preschools. *Archives of Pediatrics & Adolescent Medicine*, *155*(7), 790–795.

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st

century. *Health Promotion International*, *15*(3), 259–267. https://doi.org/10.1093/heapro/15.3.259

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, *67*(12), 2072–2078. https://doi.org/10.1016/j.socscimed.2008.09.050

Nutbeam, D. (2009). Defining and measuring health literacy: What can we learn from literacy studies? *International Journal of Public Health*, *54*(5), 303. https://doi.org/10.1007/s00038-009-0050-x

Nutbeam, D., & Lloyd, J. E. (2021). Understanding and responding to health literacy as a social determinant of health. *Annual Review of Public Health*, *42*(1), 159–173. https://doi.org/10.1146/annurev-publhealth-090419-102529

Office for Civil Rights. (2018a). *Questions and answers on the ADA Amendments Act of 2008 for students with disabilities attending public elementary and secondary schools*. U.S. Department of Education. https://www2.ed.gov/about/offices/list/ocr/docs/dcl-504faq-201109.html

Office for Civil Rights. (2018b). *The civil rights of students with hidden disabilities under Section 504 of the Rehabilitation Act of 1973*. U.S. Department of Education. https://www2.ed.gov/about/offices/list/ocr/docs/hq5269.html

Office of Disease Prevention & Health Promotion. (2020). *Health literacy in Healthy People 2030*. U.S. Department of Health and Human Services. https://health.gov/our-work/healthy-people/healthy-people-2030/health-literacy-healthy-people-2030

Office of Disease Prevention and Health Promotion. (2010). *National Action Plan to Improve Health Literacy*. U.S. Department of Health and Human Services.

http://health.gov/communication/HLActionPlan/pdf/Health_Literacy_Action_Plan.pdf

Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, *13*(1), 658. https://doi.org/10.1186/1471-2458-13-658

O'Toole, T. P., Anderson, S., Miller, C., & Guthrie, J. (2007). Nutrition services and foods and beverages available at school: Results from the School Health Policies and Programs Study 2006. *Journal of School Health*, *77*(8), 500–521. https://doi.org/10.1111/j.1746-1561.2007.00232.x

Ousseine, Y. M., Rouquette, A., Bouhnik, A.-D., Rigal, L., Ringa, V., Smith, A., & Mancini, J. (2018). Validation of the French version of the Functional, Communicative and Critical Health Literacy Scale (FCCHL). *Journal of Patient-Reported Outcomes*, *2*. https://doi.org/10.1186/s41687-018-0027-8

Paasche-Orlow, M., & Wolf, M. (2007). The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior*, *31*(Suppl 1), S19--S26.

Pałgan, K., Żbikowska-Gotz, M., & Bartuzi, Z. (2018). Dangerous anaphylactic reaction to mustard. *Archives of Medical Science : AMS*, *14*(2), 477–479. https://doi.org/10.5114/aoms.2016.60580

Park, C., & Park, Y.-H. (2013). Validity and reliability of Korean Version of Health Empowerment Scale (K-HES) for older adults. *Asian Nursing Research*, *7*(3), 142–148. https://doi.org/10.1016/j.anr.2013.07.004

Parker, R., & Ratzan, S. C. (2010). Health literacy: A second decade of distinction for Americans. *Journal of Health Communication*, *15*(Apr Supp 2), 20–33. https://doi.org/10.1080/10810730.2010.501094

Payrovee, Z., Kashaninia, Z., Alireza Mahdaviani, S., & Rezasoltani, P. (2014). Effect of family empowerment on the quality of life of school-aged children with asthma. *Tanaffos*, *13*(1), 35–42.

Pecora, V., Mennini, M., Calandrelli, V., Patriarca, G., Valluzzi, R., & Fierro, V. (2018). How to actively treat food allergy. *Current Opinion in Allergy & Clinical Immunology*, *18*(3), 248–257. https://doi.org/10.1097/ACI.0000000000000450

Pecora, V., Valluzzi, R. L., Mennini, M., Fierro, V., & Dahdah, L. (2018). Debates in allergy medicine: Does oral immunotherapy shorten the duration of milk and egg allergy? The pro argument. *World Allergy Organization Journal*, *11*(1), N.PAG-N.PAG. https://doi.org/10.1186/s40413-018-0191-6

Pedersen, E. R., & Kurz, J. (2016). Using Facebook for health-related research study recruitment and program delivery. *Current Opinion in Psychology*, *9*, 38–43. https://doi.org/10.1016/j.copsyc.2015.09.011

Peterson, N. A., Lowe, J. B., Hughey, J., Reid, R. J., Zimmerman, M. A., & Speer, P. W. (2006). Measuring the intrapersonal component of psychological empowerment: Confirmatory factor analysis of the sociopolitical control scale. *American Journal of Community Psychology*, *38*(3–4), 287–297.

Pleasant, A., Maish, C., O'Leary, C., & Carmona, R. H. (2018). A theory-based self-report measure of health literacy: The Calgary Charter on Health Literacy Scale.

Methodological Innovations, *11*(3), 2059799118814394. https://doi.org/10.1177/2059799118814394

Pleasant, A., Rudd, R. E., O'Leary, C., Paasche-Orlow, M. K., Allen, M. P., Alvarado-Little, W., Myers, L., Parson, K., & Rosen, S. (2016). *Considerations for a new definition of health literacy: Discussion paper*. http://nam.edu/wp-content/uploads/2016/04/Considerations-for-a-New-Definition-of-Health-Literacy.pdf

Porr, C., Drummond, J., & Richter, S. (2006). Health literacy as an empowerment tool for low-income mothers. *Family and Community Health*, *29*(4), 328--335.

Pouessel, G., Turner, P. J., Worm, M., Cardona, V., Deschildre, A., Beaudouin, E., Renaudin, J.-M., Demoly, P., & Tanno, L. K. (2018). Food-induced fatal anaphylaxis: From epidemiological data to general prevention strategies. *Clinical and Experimental Allergy: Journal of the British Society for Allergy and Clinical Immunology*, *48*(12), 1584–1593. https://doi.org/10.1111/cea.13287

Qiu, C., Zhang, X., Zang, X., & Zhao, Y. (2020). Acceptance of illness mediate the effects of health literacy on self-management behaviour. *European Journal of Cardiovascular Nursing*, *19*(5), 411–420. https://doi.org/10.1177/1474515119885240

Razum, O., Weishaar, H., & Schaeffer, D. (2016). Health literacy: Strengthening agency or changing structures? *International Journal of Public Health*, *61*(3), 277–278. https://doi.org/10.1007/s00038-016-0788-x

Rios, K., Burke, M. M., & Aleman-Tovar, J. (2021). A study of the families included in Receiving Better Special Education Services (FIRME) project for Latinx families

of children with autism and developmental disabilities. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04827-3

RobatSarpooshi, D., Mahdizadeh, M., Alizadeh Siuki, H., Haddadi, M., Robatsarpooshi, H., & Peyman, N. (2020). The relationship between health literacy level and self-care behaviors in patients with diabetes. *Patient Related Outcome Measures*, *11*, 129–135. https://doi.org/10.2147/PROM.S243678

Roter, D. L., Erby, L., Larson, S., & Ellington, L. (2009). Oral literacy demand of prenatal genetic counseling dialogue: Predictors of learning. *Bridging the International Divide for Health Literacy Research*, *75*(3), 392–397. https://doi.org/10.1016/j.pec.2009.01.005

Rudd, R. E. (2013). Needed action in health literacy. *Journal of Health Psychology*, *18*(8), 1004–1010. https://doi.org/10.1177/1359105312470128

Rudd, R. E. (2015). The evolving concept of health literacy: New directions for health literacy studies. *Journal of Communication in Healthcare*, *8*(1), 7–9. https://doi.org/10.1179/1753806815Z.000000000105

Rudd, R. E., McCray, A. T., & Nutbeam, D. (2012). Chapter 2 Health literacy and definition of terms. In D. Begoray, D. Gillis, & G. Rowlands (Eds.), *Health Literacy in Context*. Nova Science Publishers, Inc.

Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, *22*(1), 43–53. https://doi.org/10.1111/j.1468-3148.2008.00438.x

Sak, G., Rothenfluh, F., & Schulz, P. J. (2017). Assessing the predictive power of psychological empowerment and health literacy for older patients' participation in health care: A cross-sectional population-based study. *BMC Geriatrics*, *17*(1), 59. https://doi.org/10.1186/s12877-017-0448-x

Salgado, T. M., Mackler, E., Severson, J. A., Lindsay, J., Batra, P., Petersen, L., & Farris, K. B. (2017). The relationship between patient activation, confidence to self-manage side effects, and adherence to oral oncolytics: A pilot study with Michigan oncology practices. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *25*(6), 1797–1807. https://doi.org/10.1007/s00520-017-3584-0

Sampson, H. A., Aceves, S., Bock, S. A., James, J., Jones, S., Lang, D., Nadeau, K., Nowak-Wegrzyn, A., Oppenheimer, J., Perry, T. T., Randolph, C., Sicherer, S. H., Simon, R. A., Vickery, B. P., Wood, R., Bernstein, D., Blessing-Moore, J., Khan, D., Lang, D., … Wood, R. (2014). Food allergy: A practice parameter update-2014. *The Journal of Allergy and Clinical Immunology*, *134*(5), 1016-25.e43. https://doi.org/10.1016/j.jaci.2014.05.013

Sanagavarapu, P. (2017). Experiences and support needs of mothers of children with food allergy during the transition to school. *Early Childhood Education Journal*. https://doi.org/10.1007/s10643-017-0880-8

Sandra, V., Jill, S., Maria, S., Mullins, R. J., & Richard, L. (2015). ASCIA guidelines for prevention of anaphylaxis in schools, pre-schools and childcare: 2015 update. *Journal of Paediatrics and Child Health*, *51*(10), 949–954. https://doi.org/10.1111/jpc.12962

Santana, S., Brach, C., Harris, L., Ochiai, E., Blakey, C., Bevington, F., Kleinman, D., & Pronk, N. (2021). Updating health literacy for Healthy People 2030: Defining its importance for a new decade in public health. *Journal of Public Health Management and Practice*, *Publish Ahead of Print*. https://doi.org/10.1097/PHH.0000000000001324

Schaffler, J., Leung, K., Tremblay, S., Merdsoy, L., Belzile, E., Lambrou, A., & Lambert, S. D. (2018). The effectiveness of self-management interventions for individuals with low health literacy and/or low income: A descriptive systematic review. *Journal of General Internal Medicine*, *33*(4), 510–523. https://doi.org/10.1007/s11606-017-4265-x

Schinckus, L., Dangoisse, F., Van den Broucke, S., & Mikolajczak, M. (2018). When knowing is not enough: Emotional distress and depression reduce the positive effects of health literacy on diabetes self-management. *Patient Education and Counseling*, *101*(2), 324–330. https://doi.org/10.1016/j.pec.2017.08.006

Schulz, P. J., Fitzpatrick, M. A., Hess, A., Sudbury-Riley, L., & Hartung, U. (2017). Effects of eHealth literacy on general practitioner consultations: A mediation analysis. *Journal of Medical Internet Research*, *19*(5). https://doi.org/10.2196/jmir.6317

Schulz, P. J., & Nakamoto, K. (2013). Health literacy and patient empowerment in health communication: The importance of separating conjoined twins. *Patient Education & Counseling*, *90*(1), 4–11. https://doi.org/10.1016/j.pec.2012.09.006

Shah, S. S., Parker, C. L., O'Brian Smith, E., & Davis, C. M. (2014). Disparity in the availability of injectable epinephrine in a large, diverse US school district. *The*

Journal of Allergy and Clinical Immunology: In Practice, *2*(3), 288-293.e1. https://doi.org/10.1016/j.jaip.2013.09.016

Shaker, M. S., Schwartz, J., & Ferguson, M. (2017). An update on the impact of food allergy on anxiety and quality of life. *Current Opinion in Pediatrics*, *29*(4), 497–502. https://doi.org/10.1097/MOP.0000000000000509

Sharma, A., Verma, A. K., Gupta, R. K., Neelabh, & Dwivedi, P. D. (2019). A comprehensive review on mustard-induced allergy and implications for human health. *Clinical Reviews in Allergy & Immunology*, *57*(1), 39–54. https://doi.org/10.1007/s12016-017-8651-2

Sheikh, S., Hendry, P., Kalynych, C., Owensby, B., Johnson, J., Kraemer, D. F., & Carden, D. (2016). Assessing patient activation and health literacy in the ED. *The American Journal of Emergency Medicine*, *34*(1), 93–96. https://doi.org/10.1016/j.ajem.2015.09.045

Shemesh, E., Annunziato, R. A., Ambrose, M. A., Ravid, N. L., Mullarkey, C., Rubes, M., Chuang, K., Sicherer, M., & Sicherer, S. H. (2013). Child and parental reports of bullying in a consecutive sample of children with food allergy. *Pediatrics*, *131*(1), e10. https://doi.org/10.1542/peds.2012-1180

Shin, K. S., & Lee, E.-H. (2018). Relationships of health literacy to self-care behaviors in people with diabetes aged 60 and above: Empowerment as a mediator. *Journal of Advanced Nursing*, *74*(10), 2363–2372. https://doi.org/10.1111/jan.13738

Sicherer, S. H., Furlong, T. J., DeSimone, J., & Sampson, H. A. (2001). The US Peanut and Tree Nut Allergy Registry: Characteristics of reactions in schools and day

care. *The Journal of Pediatrics*, *138*(4), 560–565. https://doi.org/10.1067/mpd.2001.111821

Sicherer, S. H., Mahr, T., & the Section on Allergy and Immunology, American Academy of Pediatrics. (2010). Management of food allergy in the school setting. *Pediatrics*, *126*(6), 1232–1239. https://doi.org/10.1542/peds.2010-2575

Smith, S. G., Curtis, L. M., Wardle, J., von Wagner, C., & Wolf, M. S. (2013). Skill set or mind set? Associations between health literacy, patient activation and health. *PLoS ONE*, *8*(9), e74373. https://doi.org/10.1371/journal.pone.0074373

Soeken, K. (2005). Validity of Measures. In *In Waltz, C., Strickland, O., & Lenz, E. (Eds). Measurement in Nursing and Health Research, 3rd Edition*. Springer Publishing Company.

Sorensen, K., Van den Broucke, S., Fullam, J., Doyle, G., & Pelikan, J. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, *12*(1), 80.

Sørensen, K., Van den Broucke, S., Pelikan, J. M., Fullam, J., Doyle, G., Slonska, Z., Kondilis, B., Stoffels, V., Osborne, R. H., & Brand, H. (2013). Measuring health literacy in populations: Illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q). *BMC Public Health*, *13*(1), 948. https://doi.org/10.1186/1471-2458-13-948

Spreitzer, G. M. (1995a). An empirical test of a comprehensive model of intrapersonal empowerment in the workplace. *American Journal of Community Psychology*, *23*(5), 601–629. https://doi.org/10.1007/BF02506984

Spreitzer, G. M. (1995b). Psychological empowerment in the workplace: Dimensions, measurement, and validation. *The Academy of Management Journal*, *38*(5), 1442–1465. https://doi.org/10.2307/256865

Squiers, L., Peinado, S., Berkman, N., Boudewyns, V., & McCormack, L. (2012). The Health Literacy Skills Framework. *Journal of Health Communication*, *17*(sup3), 30–54. https://doi.org/10.1080/10810730.2012.713442

Stormacq, C., Van den Broucke, S., & Wosinski, J. (2019). Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promotion International*, *34*(5), e1–e17. https://doi.org/10.1093/heapro/day062

Sullivan, G. M., & Artino, A. R. (2013). Analyzing and Interpreting Data From Likert-Type Scales. *Journal of Graduate Medical Education*, *5*(4), 541–542. https://doi.org/10.4300/JGME-5-4-18

Sykes, S., Wills, J., Rowlands, G., & Popple, K. (2013). Understanding critical health literacy: A concept analysis. *BMC Public Health*, *13*(1), 1–10. https://doi.org/10.1186/1471-2458-13-150

Szychlinski, C., Schmeissing, K. A., Fuleihan, Z., Qamar, N., Syed, M., Pongracic, J. A., & Singh, A. M. (2015). Food allergy emergency preparedness in Illinois schools: Rural disparity in guideline implementation. *Journal of Allergy and Clinical Immunology: In Practice*, *3*(5), 805--807. https://doi.org/10.1016/j.jaip.2015.04.017

Taggart, J., Williams, A., Dennis, S., Newall, A., Shortus, T., Zwar, N., Denney-Wilson, E., & Harris, M. F. (2012). A systematic review of interventions in primary care

to improve health literacy for chronic disease behavioral risk factors. *BMC Family Practice*, *13*(1), 49. https://doi.org/10.1186/1471-2296-13-49

Teitcher, J. E. F., Bockting, W. O., Bauermeister, J. A., Hoefer, C. J., Miner, M. H., & Klitzman, R. L. (2015). Detecting, preventing, and responding to "fraudsters" in internet research: Ethics and tradeoffs. *The Journal of Law, Medicine & Ethics : A Journal of the American Society of Law, Medicine & Ethics*, *43*(1), 116–133. https://doi.org/10.1111/jlme.12200

Terwee, C., Bot, S., Boer, M., van der Windt, D., Knol, D., Dekker, J., Bouter, L., & De Vet, H. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology*, *60*, 34–42. https://doi.org/10.1016/j.jclinepi.2006.03.012

Thomas, K. W., & Velthouse, B. A. (1990). Cognitive elements of empowerment: An "interpretive" model of intrinsic task motivation. *The Academy of Management Review*, *15*(4), 666–681. https://doi.org/10.2307/258687

Thompson, J. B. (2016). *Health literacy as a moderator in the relationship between diabetes knowledege and diabetes outcomes (ProQuest number: 10117795)* [Doctoral Dissertation, University of Southern Mississippi]. ProQuest Information & Learning. http://survey.hshsl.umaryland.edu/?url=http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2016-58390-164&site=ehost-live

Trainor, A. (2010). Diverse approaches to parent advocacy during special education home-school interactions: Identification and use of cultural and social capital.

Remedial and Special Education, *31*(1), 34–47. https://doi.org/10.1177/0741932508324401

Trainor, J. L., Pittsenbarger, Z. E., Joshi, D., Adler, M. D., Smith, B., & Gupta, R. S. (2020). Outcomes and factors associated with prehospital treatment of pediatric anaphylaxis. *Pediatric Emergency Care*, *Publish Ahead of Print*. https://doi.org/10.1097/PEC.0000000000002146

Trochim, W. M. K. (2005). Chapter 3: The theory of measurement. In *Research Methods: The Concise Knowledge Base*. Atomic Dog Publishing.

Turner, P. J., Jerschow, E., Umasunthar, T., Lin, R., Campbell, D. E., & Boyle, R. J. (2017). Fatal anaphylaxis: Mortality rate and risk factors. *The Journal of Allergy and Clinical Immunology in Practice*, *5*(5), 1169–1178. https://doi.org/10.1016/j.jaip.2017.06.031

Umasunthar, T., Leonardi-Bee, J., Hodes, M., Turner, P. J., Gore, C., Habibi, P., Warner, J. O., & Boyle, R. J. (2013). Incidence of fatal food anaphylaxis in people with food allergy: A systematic review and meta-analysis. *Clinical and Experimental Allergy: Journal of the British Society for Allergy and Clinical Immunology*, *43*(12), 1333–1341. https://doi.org/10.1111/cea.12211

United States Congress. (2010). *Patient Protection and Affordable Care Act. Title V. Section 5001.* https://www.hhs.gov/sites/default/files/v-healthcare-workforce.pdf

U.S. Food and Drug Administration. (2021). *Food labeling and nutrition: Food allergies*. FDA. https://www.fda.gov/food/food-labeling-nutrition/food-allergies

van der Heide, I., Poureslami, I., Mitic, W., Shum, J., Rootman, I., & FitzGerald, J. M. (2018). Health literacy in chronic disease management: A matter of interaction. *Journal of Clinical Epidemiology*, *102*, 134–138. https://doi.org/10.1016/j.jclinepi.2018.05.010

van der Vaart, R., Drossaert, C. H. C., Taal, E., ten Klooster, P. M., Hilderink-Koertshuis, R. T. E., Klaase, J. M., & van de Laar, M. A. F. J. (2012). Validation of the Dutch Functional, Communicative and Critical Health Literacy Scales. *Patient Education and Counseling*, *89*(1), 82–88. https://doi.org/10.1016/j.pec.2012.07.014

Van Der Velde, J., Flokstra-de Blok, B., Vlieg-Boerstra, B., Oude Elberink, J., DunnGalvin A., O'B. Hourihane, J., Duiverman, E. J., & Dubois, A. E. J. (2009). Development, validity and reliability of the Food Allergy Independent Measure (FAIM). *Allergy*, *65*(5), 630–635. https://doi.org/10.1111/j.1398-9995.2009.02216.x

von Wagner, C., Steptoe, A., Wolf, M. S., & Wardle, J. (2009). Health literacy and health actions: A review and a framework from health psychology. *Health Education & Behavior*, *36*(5), 860–877. https://doi.org/10.1177/1090198108322819

Wall, S. S. (2015). Focused ethnography: A methodological adaptation for social research in emerging contexts. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *16*(1), Article 1. https://doi.org/10.17169/fqs-16.1.2182

Wang, J., Young, M. C., & Nowak-Węgrzyn, A. (2014). International survey of knowledge of food-induced anaphylaxis. *Pediatric Allergy and Immunology:*

Official Publication of the European Society of Pediatric Allergy and Immunology, *25*(7), 644–650. https://doi.org/10.1111/pai.12284

Wang, R.-H., Hsu, H.-C., Lee, Y.-J., Shin, S.-J., Lin, K.-D., & An, L.-W. (2016). Patient empowerment interacts with health literacy to associate with subsequent self-management behaviors in patients with type 2 diabetes: A prospective study in Taiwan. *Patient Education and Counseling*, *99*(10), 1626–1631. https://doi.org/10.1016/j.pec.2016.04.001

Wångdahl, J. M., & Mårtensson, L. I. (2014). The Communicative and Critical Health Literacy Scale – Swedish Version. *Scandinavian Journal of Public Health*, *42*(1), 25–31. https://doi.org/10.1177/1403494813500592

Wångdahl, J. M., & Mårtensson, L. I. (2015). Measuring health literacy—The Swedish Functional Health Literacy scale. *Scandinavian Journal of Caring Sciences*, *29*(1), 165–172. rzh. https://doi.org/10.1111/scs.12125

Wangmar, J., Vogelsang, A.-C. von, Hultcrantz, R., Fritzell, K., Wengström, Y., & Jervaeus, A. (2018). Are anxiety levels associated with the decision to participate in a Swedish colorectal cancer screening programme? A nationwide cross-sectional study. *BMJ Open*, *8*(12), e025109. https://doi.org/10.1136/bmjopen-2018-025109

Warren, C. M., Gupta, R. S., Sohn, M.-W., Oh, E. H., Lal, N., Garfield, C. F., Caruso, D., Wang, X., & Pongracic, J. A. (2015). Differences in empowerment and quality of life among parents of children with food allergy. *Annals of Allergy, Asthma & Immunology*, *114*(2), 117-125.e3. https://doi.org/10.1016/j.anai.2014.10.025

Warren, C. M., Turner, P. J., Chinthrajah, R. S., & Gupta, R. S. (2021). Advancing food allergy through epidemiology: Understanding and addressing disparities in food allergy management and outcomes. *The Journal of Allergy and Clinical Immunology: In Practice*, *9*(1), 110–118. https://doi.org/10.1016/j.jaip.2020.09.064

Warren, C. M., Zaslavsky, J. M., Kan, K., Spergel, J. M., & Gupta, R. S. (2018). Epinephrine auto-injector carriage and use practices among US children, adolescents, and adults. *Annals of Allergy, Asthma & Immunology*, *Journal, Electronic*. https://doi.org/10.1016/j.anai.2018.06.010

Waserman, S., Cruickshank, H., Hildebrand, K. J., Mack, D., Bantock, L., Bingemann, T., Chu, D. K., Cuello-Garcia, C., Ebisawa, M., Fahmy, D., Fleischer, D. M., Galloway, L., Gartrell, G., Greenhawt, M., Hamilton, N., Hourihane, J., Langlois, M., Loh, R., Muraro, A., … Brozek, J. L. (2021). Prevention and management of allergic reactions to food in child care centers and schools: Practice guidelines. *Journal of Allergy and Clinical Immunology*, *147*(5), 1561–1578. https://doi.org/10.1016/j.jaci.2021.01.034

Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., Mockbee, J., & Hale, F. A. (2005). Quick assessment of literacy in primary care: The Newest Vital Sign. *Annals of Family Medicine*, *3*(6), 514–522. https://doi.org/10.1370/afm.405

Wiggins, N. (2012). Popular education for health promotion and community empowerment: A review of the literature. *Health Promotion International*, *27*(3), 356--371. https://doi.org/10.1093/heapro/dar046

Willgerodt, M. A., Brock, D. M., & Maughan, E. D. (2018). Public School Nursing Practice in the United States. *The Journal of School Nursing*, *34*(3), 232–244. https://doi.org/10.1177/1059840517752456

Williams, N. A., & Hankey, M. (2016). Implications of social support and parenting self-efficacy for food allergy-related parenting practices. *Pediatric Allergy, Immunology & Pulmonology*, *29*(2), 74–79. https://doi.org/10.1089/ped.2015.0618

Wolf, M. S., Smith, S. G., Pandit, A. U., Condon, D. M., Curtis, L. M., Griffith, J., O'Conor, R., Rush, S., Bailey, S. C., Kaplan, G., Haufle, V., & Martin, D. (2018). Development and validation of the Consumer Health Activation Index. *Medical Decision Making*, *38*(3), 334–343. https://doi.org/10.1177/0272989X17753392

World Health Organization. (2016a). *Health promotion: Health literacy: The mandate for health literacy*. 9th Global Conference on Health Promotion, Shanghai. http://www.who.int/healthpromotion/conferences/9gchp/health-literacy/en/

World Health Organization. (2016b). *Shanghai declaration on promoting health in the 2030 agenda for sustainable development*. WHO. http://www.who.int/healthpromotion/conferences/9gchp/shanghai-declaration/en/

Wright, A. C., & Taylor, S. (2014). Advocacy by parents of young children with special needs: Activities, processes, and perceived effectiveness. *Journal of Social Service Research*, *40*(5), 591–605. https://doi.org/10.1080/01488376.2014.896850

Wright, A., Hannon, J., Hegedus, E. J., & Kavchak, A. E. (2012). Clinimetrics corner: A closer look at the minimal clinically important difference (MCID). *The Journal of*

Manual & Manipulative Therapy, *20*(3), 160–166. https://doi.org/10.1179/2042618612Y.0000000001

Wright, P., & Wright, P. (2006). *Wrightslaw: From Emotions to Advocacy—The special education survival guide* (2nd ed.). Harbor House Law Press, Inc.

Yin, H. S., Dreyer, B. P., Foltin, G., van Schaick, L., & Mendelsohn, A. L. (2007). Association of low caregiver health literacy with reported use of nonstandardized dosing instruments and lack of knowledge of weight-based dosing. *Ambulatory Pediatrics*, *7*(4), 292–298. https://doi.org/10.1016/j.ambp.2007.04.004

Zegers, C. A., Gonzales, K., Smith, L. M., Pullen, C. H., De Alba, A., & Fiandt, K. (2020). The psychometric testing of the Functional, Communicative, and Critical Health Literacy Tool. *Patient Education and Counseling*, *103*(11), 2347–2352. https://doi.org/10.1016/j.pec.2020.05.019

Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. *American Journal of Community Psychology*, *23*(5), 581–599. https://doi.org/10.1007/BF02506983

Zimmerman, M. A. (2000). Empowerment theory: Psychological, organizational, and community levels of analysis. In J. Rappaport, E. Seidman, J. Rappaport, & E. Seidman (Eds.), *Handbook of community psychology.* (pp. 43–63). Kluwer Academic Publishers. https://doi.org/10.1007/978-1-4615-4193-6_2

Zimmerman, M. A., Israel, B. A., Schulz, A., & Checkoway, B. (1992). Further explorations in empowerment theory: An empirical analysis of psychological empowerment. *American Journal of Community Psychology*, *20*(6), 707--727. https://doi.org/10.1007/BF01312604

Zimmerman, M. A., & Warschausky, S. (1998). Empowerment theory for rehabilitation research: Conceptual and methodological issues. *Rehabilitation Psychology*, *43*(1), 3–16.