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"Can't Touch This" Empowering Children with Severe Food Allergy in the Residential Camp Setting

by

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A Project

Submitted in Partial Fulfillment of the Requirements for the Master of Science in Recreation

Department of Recreation, Parks and Leisure Studies

STATE UNIVERSITY OF NEW YORK COLLEGE AT CORTLAND

May 2014

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"Can't Touch This" Empowering Children with Severe Food Allergies in the Residential Camp Setting

Alexsandra Dubin State University of New York at Cortland 2014

The purpose of this project was to create an empowerment program for children with severe food allergy (SFA) in a residential camp setting. Despite recent advancements in research, there is no cure for SFA, thus there is a need for programs to help children manage their allergies and cope with the ramifications of their condition. Quality of life is a major concern for children with SFA, as the constant fear of exposure to an allergen can lead to high levels of anxiety. This is particularly noteworthy because, barring exposure to an allergen, these children are otherwise healthy and symptom free. Empowerment and adventure camp programs provide many outcomes that could greatly benefit children with SFA, but as to date, no such programs targeting children with SFA exist. Research shows that empowerment programs outcomes include improved self-concept and resiliency, better communication skills, feelings of competence and control, feelings of acceptance and an ability to verbalize feelings. Such outcomes could greatly benefit children living with SFA, but programs must be conducted in a safe context. This program was designed to deliver the benefits of an empowerment process program to children with SFA in an environment where they would be safe. The Operations and Safety Plan outlines procedures for the dining hall and mealtime, and forges connections between the dining staff and medical staff for a holistic, multi-faceted approach to safety. It has been shown that residential camp programs can greatly benefit children of all backgrounds and circumstances. A program such as this could lead to an increased number of safe, viable programs that offer camp services and opportunities to children living with SFA.

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Chapter One

Introduction and Statement of the Problem

Introduction

Severe food allergy is a relatively new topic in the body of scientific literature. It is a condition rising in prevalence and severity and has numerous implications for individuals living with food allergies, their families and communities at large (Branum & Lukacs, 2009). Severe food allergy, often referred to as SFA, is a diagnosed medical condition in which an individual's immune system has a reproducible immune response associated with immunological reactivity after exposure to a given food (Burks, Jones, Boyce, Sicherer, Wood, Assa'ad, & Sampson, 2011).

As a severe medical condition, much SFA research has focused on addressing genetics, immunology and ways to manage food allergy (Behrmann, 2010; Monks, Gowland, MacKenzie, Eriewyn-Lajeuneusse, King, Lucas, & Roberts, 2010; Osborne, Koplin, Martin, Gurrin, Thiele, Tang, Ponsony, Dharmage, & Allen, 2010; Sicherer, 2001). This type of research is critical for diagnosing children with SFA and keeping children as safe as possible in school and social settings. However, despite advancements in research, there is no cure for SFA. Thus, there is a need for research on how to help children manage their allergies and cope with the ramifications of their condition.

Cutting edge guidelines for SFA management in schools and other social settings are beginning to focus on encouraging children to be knowledgeable about their allergy and to participate in its management, and to build confidence and positively cope with the

allergy (Behrmann, 2010). These skills are important for children living with SFA as quality of life is negatively affected by chronic conditions. Quality of life is of particular interest for youth living with SFA due to how they compare to other children with chronic conditions. For example, children living with peanut-allergy report statistically significant lower quality of life scores than their peers with insulin dependent diabetes. This was attributed to the fact that although exposure to allergens is sporadic, the anxiety and fear of exposure is always present (Avery, King, Knight & Hourihane, 2003).

Further contributing to the quality of life issues faced by children with SFA is the very fact that they appear to be healthy children. There are no physical attributes that mark these children as ill; therefore, there is not the same level of societal awareness of this disease as there is for many other childhood diseases with expected, observable attributes. This lack of awareness often translates to a lack of consideration of the medical needs of this population. US American culture uses food as a way to develop community, express gratitude and celebrate milestones. This creates ongoing concern for children and families living with SFA because of the constant presence of food at social gatherings (Gaslin & Snoody, 2009).

Self-esteem and self-efficacy are two important attributes for children with SFA, as it is critical for them to feel positively about themselves and feel competent in their own agency. Lightsey, Burke, Ervin, Henderson and Yee (2006) studied the effects of general self-efficacy on self-esteem: they were interested in how individuals' conception of their own competence affected their sense of worth. Their findings indicated that individuals with higher general self-efficacy typically have higher self-esteem, which leads to positive feelings and coping abilities. Coping abilities and feelings of

competence are critical for food allergy management by children themselves, as ultimately this responsibility shifts from parents to children. This has implications for the kinds of programs and policies necessary to facilitate safe allergy management and positive self-concept.

A rich body of literature presents the benefits of adventure and empowerment programs for participants in such programs. Sibthorp, Paisley & Gookin (2007) studied the mechanisms of adventure-based programs to determine how adventure education fosters growth and development in able-bodied participants from various socio-economic backgrounds. They concluded that participants derive the most benefits from programs that empower students to participate in decision-making and take ownership, while also providing opportunities to develop strong relationships between participants and with leaders. Other documented benefits of adventure-based programs include improved self-concept and resiliency (Green, Kleiber & Tarrant, 2000), better communication skills (Shirilla, 2009; Sibthorp, Paisley & Gookin, 2007), feelings of competence, feelings of acceptance (Spencer-Cavaliere & Watkinson, 2010) and a reduction in anxiety levels (Rawson & Barnett, 1993). These findings are important within the scope of this project because anxiety can be a debilitating condition, and children with SFA tend to live with high levels of anxiety.

Though adventure and empowerment programs have not yet been applied to populations of children with SFA, the benefits detailed by the research could be very important to children living with this condition, due to the nature of the challenges they face. Inclusion, acceptance and anxiety are everyday obstacles for children with SFA, and the typical outcomes of adventure programming, such as improved self-esteem, self-

efficacy, communication skills and self-concept help mediate many of these obstacles. The benefits of a camp experience, adventure-based or not, have been found to be reassuring, positive experiences for children living with chronic conditions requiring management. Avery, King, Knight and Hourihane (2003) note the well-established system of camp programs for children with diabetes and suggest such programs could be equally beneficial to children with food allergies. Such programs could facilitate feelings of competence and better control which could help mediate the high levels of fear and anxiety often faced by children with SFA on a daily basis. The benefits derived from such programs could have significant impacts on the health-related and overall quality of life of children with SFA. This project strives to bring safe, monitored empowerment experiences to children with SFA who cannot be served in a typical camp environment in order to offer this population the benefits of an empowerment process program.

Purpose of the Project

The purpose of this project is to design an empowerment program for children with SFA to be implemented in the camp setting. The intention of this program is to increase health related quality of life by facilitating self-efficacy and empowerment of children living with SFA. This will be done via programs that increase feelings of control and competence, while decreasing anxiety. The project will also include the creation of a safety plan to be implemented at a camp in order to safely house and serve children with SFA in the resident camp setting.

Project Objectives

Objectives for the participants

Upon completion of the program, participants will perceive higher health-related quality of life, as demonstrated by the following factors that influence self-efficacy and empowerment and are measured by the Food Allergy Quality of Life Questionnaire Child Form. Upon completing the program, participants will:

Objective 1: Demonstrate feelings of increased control and increased competence in managing their allergy.

Objective 2: Display lower levels of anxiety in daily life and activities.

Objectives for the agency

Upon completion of the program, the agency will:

Objective 1: Have safely housed and fed children with SFA in the resident camp setting.

Objective 2: Demonstrate higher levels of awareness regarding the needs of children with SFA.

Assumptions

It is assumed that all children participating in the program do experience the daily stressors associated with SFA, according to the literature. It is also assumed that

participating children have at least a basic understanding of their condition, even if that understanding is limited to knowing a certain food is strictly off-limits.

Delimitations

The target population for this project is delimited to children ages 8-16 within the setting of a resident camp. All children participating must have at least one severe food allergy, as documented by a medical professional. Pre-test and post-test questionnaires will be administered, using the Food Allergy Quality of Life Questionnaire- Child Form (FAQLQ-CF), to assess program objectives.

Limitations

This project is limited in its ability to be generalized to various settings. In order to function properly, the program requires a resident camp with a sufficient kitchen staff to make preparing meals possible. An additional limitation is the use of the FAQLQ-CF, as it limits the participants to campers who are at least 8 years of age, as the measurement is not valid for younger populations.

Definition of Terms

- 1) Severe Food Allergy (SFA)- a diagnosed medical condition in which an individual's immune system has a reproducible immune response associated with immunological reactivity after exposure to a given food (Burks, et al., 2011). There are two types of food allergy: IgE mediated, which is the production of IgE antibodies to cause a clinical allergic reaction resulting in acute symptoms, and non-IgE mediated, which is a reaction to a food protein resulting in sub-acute and chronic symptoms (Sicherer, 2001).
- 2) Anaphylaxis- a "severe multi-organ reaction associated with IgE mediated hypersensitivity" which can be triggered by minuscule amounts of an allergen (Sicherer, 2001, p. 43).
- 3) Resident Camp- a camp that brings participants to a location for a period of days, providing lodging and meals (Ball & Ball, 2012).
- 4) Adventure/Challenge Course- "a collection of elements [activities or obstacles]... which provides a venue for participants to engage in activities that challenge them physically, socially, emotionally and intellectually." (www.pa.org)
- 5) Health-related quality of life- "the effects of an illness and its consequent therapy on a patient, as perceived by the patient" (Flokstra de Blok, Dubois, Vlieg-

Boerstra, Oude Elberink, Raat, DunnGalvin, Hourihane, Duiverman, p. 238, 2008). In this study, health-related quality of life is defined by participants' scores on the Food Allergy Quality of Life Questionnaire- Child Form (FAQLQ-CF), which measures factors influencing self-efficacy and empowerment: anxiety, competence and feelings of control.

- 6) Empowerment- increasing an individual's capacity to communicate effectively, improve social skills, increase self-efficacy and feel competent in one's own agency. (go.worldbank.org) Perceptions of empowerment are related to the degree to which participants feel responsibility for and ownership of the experience (Sibthorp et al., 2007). In this study, empowerment is measured by the degree to which participants experience increased competence and control, and decreased anxiety, as measured by the FAQLQ-CF.
- 7) Self-Efficacy- an individual's conception of his or her own competence, especially in the face of adversity (Lightsey, et al., 2006). In this study, self-efficacy is measure by the degree to which participants experience increased competence and control, and decreased anxiety, as measured by the FAQLQ-CF.
- 8) Anxiety- "a feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome" (www.oxforddictionaries.com). For children with food allergy, anxiety can unduly restrict daily life further affecting quality of life (Avery, et al. 2003).

- 9) Competence- "the ability [of an individual] to do something successfully or efficiently" (www.oxforddictionary.com). Children with SFA must learn to manage their allergies effectively, as during adolescence the responsibility for their safety begins to transfer from parents to the person with the allergy. This shift can be difficult, as the numbers show: the greatest number of deaths from anaphylaxis due to nut allergies occurs among teenagers and young adults (Monks, et al., 2010).
- 10) Control- "the power to restrain something, especially one's own emotions or actions" (www.oxforddictionaries.com). SFA can be a disempowering condition, as the individual has no way to cure it, and the only treatment is strict avoidance of the allergen (Flokstra de Blok, et al., 2008). This is particularly complicated in a world where food labeling for allergens is loosely regulated and food plays a prominent role in US American culture and daily life.

Chapter 2

Review of the Literature

This chapter reviews literature related to the discussion of severe food allergy, its implications for children living with this condition and possible programs to mediate the implications. Definitions, quality of life, and empowerment are also examined. The following sections are included: (1) introduction; (2) definitions of food allergy and resulting conditions; (3) implications and significance; (4) creating policy for public spaces; (5) current research; (6) empowerment camp programs; (7) summary.

Introduction

Severe food allergy is a relatively new topic in the body of scientific literature. It is a condition that is rising in prevalence and severity and has numerous implications for the individuals living with food allergies, their families and communities at large. The purpose of this project is to examine the barriers faced by people, specifically children, living with severe food allergies in order to create an empowerment program to help mediate the challenges faced daily by this population. Important themes to the discussion are the nature of food allergy, implications of food allergies, quality of life issues, and barriers to empowerment. Also in need of study are the benefits and challenges of conducting research that examines the perspectives of the children living with this condition, rather than the perspective of a proxy, such as their parents, as is often done (van der Velde, Flokstra de Blok, DunnGalvin, Hourihane, Duiverman, & Dubois, 2011).

Definitions of food allergy and resulting conditions

Severe food allergy is a diagnosed medical condition in which an individual's immune system has a reproducible immune response associated with immunological reactivity after exposure to a given food (Burks, A.W., Jones, S.M., Boyce, J.A., Sicherer, S.H., Wood, R.A., Assa'ad, A., & Sampson, H.A., 2011). It is often referred to as SFA, and will typically be referred to as such throughout this paper. There are two types of immunological responses that constitute an allergy; IgE-mediated food allergy and non-IgE-mediated food allergy. An IgE-mediated allergy is one in which upon exposure to a food, T cells instruct B cells to produce food-specific IgE antibodies that attach to tissue mast cells. This is the sensitization stage that occurs upon first exposure. Upon repeated exposure, the IgE antibodies on the mast cells detect the food as a threat and release an allergic mediator such as histamine. This causes a clinical allergic reaction, which is the underlying cause of most acute reactions such as anaphylaxis. Conversely, non-IgE-mediated food allergy is a T cell reaction to the actual food protein, which causes sub-acute and chronic immune responses, such as gastrointestinal distress (Sicherer, 2001). Food allergy should not be confused with food intolerances or food sensitivity in which the adverse reaction to a food is reproducible but nonimmunological, such as an inability to digest lactose (Burks, et al. 2011). In the case of an individual with an IgE-mediated food allergy, a common immunological response, and the most severe food allergen response, is anaphylaxis. The clinical definition of anaphylaxis is a "severe multi-organ reaction associated with IgE-mediated

hypersensitivity" that can be triggered by minuscule amounts of an allergen (Sicherer, p. 43, 2001). This type of allergic reaction is cause for great concern because it can result in death if not treated immediately with epinephrine.

Implications and significance

The significance of this endeavor is derived from two primary sources: issues concerning quality of life and the implications of living with SFA. Quality of life is a concern for all people, as all people deserve to have the highest quality of life possible. However, when dealing with populations that are living with chronic conditions, quality of life becomes a very important issue because chronic conditions can have great negative impacts on quality of life. Quality of life is of particular interest for youth living with SFA because of how they rate in studies when compared to other children with chronic conditions. When comparing children living with peanut-allergy to children living with insulin dependent diabetes, Avery et al. (2003) found that children living with peanut-allergy reported statistically significantly lower quality of life scores than their peers living with insulin dependent diabetes. This was attributed to the fact that although exposure to allergens is sporadic, the anxiety and fear of exposure is always present (Avery et al., 2003). However, other than their food allergies, children with SFA are otherwise healthy. The symptoms of their chronic condition are not a constant presence that diminishes quality of life. Instead it is the worry and fear that symptoms may arise that causes diminished quality of life, especially since these symptoms can be fatal.

This correlation between quality of life score and food allergy versus other chronic diseases was further explored in a study done in the Netherlands comparing Health Related Quality of Life (HRQL) scores for children and adults living with severe food allergy, asthma, irritable bowel syndrome, diabetes mellitus, rheumatoid arthritis and the general population. In this study, it was determined that in all areas, all populations of people with food allergies scored lower than the general population in HRQL scores. In comparison to the other diseases, people with severe food allergies scored significantly lower than people with diabetes mellitus, but higher than people with asthma, irritable bowel syndrome and rheumatoid arthritis. However, researchers noted that the survey groups for the asthma, irritable bowel syndrome and rheumatoid arthritis groups were generally older than the participants in the food allergy group, which may have affected HRQL scores, as older participants tend to perceive lower health-related quality of life in general. An additional potential intervening variable was parental assistance on the health-related questions for children, which could have led to a skewing of results towards the parents' perceptions. One interesting consideration raised by the researchers was the difference in awareness surrounding these diseases, especially the disparity between diabetes awareness and food allergy awareness. While food allergy has greater effects on quality of life than diabetes, much more has been done to further research and awareness of diabetes (Flokstra de Blok, Dubois, Vlieg-Boerstra, Oude Elberink, Raat, DunnGalvin, Hourihane, Duiverman, 2010).

Further contributing to the quality of life issues faced by children with SFA is the very fact that they appear to be healthy children. There are no physical attributes that mark these children as ill; therefore, there is not the same level of societal awareness of

this disease as there is for other childhood diseases with specific attributes. This lack of awareness often translates to a lack of consideration of the medical needs of this population (Gaslin & Snoody, 2009). It is relatively easy to recognize the medical needs of a child with muscular dystrophy who uses a wheelchair for mobility. It is much more difficult to recognize the medical needs of a child who is severely allergic to peanuts who appears perfectly healthy. Additionally, because they look healthy, people who mean well can unknowingly expose children with SFA to potentially fatal allergens. It is standard in US American culture to use food as a medium through which to develop a sense of community and to express feelings such as gratitude or well wishes. Birthdays, baby showers, retirement parties and numerous other occasions are cause for food-centered activities. However, this practice creates ongoing concern for children and families living with SFA because of the constant presence of food at social gatherings (Gaslin & Snoody, 2009).

Creating policy for public spaces

The constant presence of food in everyday activities has far reaching implications for children living with SFA. In school and social settings there are two concerns: safety and inclusion. Safety is a major concern in school and social settings because of the numerous opportunities for unintentional exposure to allergens. Inclusion is a factor when determining what the policy should be and how to implement it. There are many guidelines that exist to aid schools in implementing procedures to ensure the safety of all students (Behrmann, 2010; Burks et al., 2011; Hay, Harper & Moore, 2006) but issues

exist with both the implementation of the guidelines and the nature of the guidelines themselves. School policies are not necessarily compliant with the guidelines due to great levels of variance between individual school's policies and unintentional gaps in policy. Examples could range from not stocking emergency epinephrine, working under the assumption that children carry their own, or having a supply of epinephrine but not having staff that is qualified to administer the drug. In addition, the nature of the guidelines themselves can be an issue as many are inadvertently discriminatory since they cause separation and stigmatization of children with food allergies. Examples of discriminatory policies include having separate lunch lines, lower quality allergen-free food, and allergen free tables that are for use only by children with allergies (Behrmann, 2010).

Observations of such discriminatory policies have led to a push for ethical decision making when writing policy (Behrmann, 2010). These ethical decisions center on confidentiality and anonymity, fair distribution of benefits and burdens, and equal access to opportunities and resources (Behrmann, 2010). Confidentiality and anonymity are crucial because policies that demarcate children with food-allergies as different leave them vulnerable to bullying and stigmatization by their peers. Fair distribution of benefits and burdens applies most directly to food bans, which are often common methods of controlling potential allergen exposure. While they can be useful for pre-schools and other situations where children cannot be expected to distinguish between foods they can and cannot have, they are not highly effective and can be problematic in elementary schools or other similar situations. Food bans may unfairly target certain populations, such as a ban on soy that would be particularly difficult for vegetarians or certain

religious groups. Equal access to opportunities and resources is not only important in the school setting, but is particularly relevant to the scope of this project. In schools, equal access can range from the quality of school lunches provided, to rewards given in class for academic performance, which are sometimes edible (Behrmann, 2010).

These ethical issues have implications not only for the children affected by unethical policies, but also for the people who write policy. Of particular significance is the December 2012 ruling by the Department of Justice that defines SFA as a disability under the Americans with Disabilities Act. A suit was brought forth against Lesley University in regard to unequal access to safe foods for students with SFA and celiac disease who required a meal plan. The ruling ensures equal access to safe, quality food, as well as safe spaces to eat for students with allergies (Department of Justice, 2012). This ruling illustrates how, as the creators of policies that affect the safety and well-being of children in their care, policy makers need to be aware of the ways in which their decisions can impact children positively or negatively. Ways to more equitably and ethically protect all children, those with and without food allergies, must be considered for universal well-being. Policies that can help mediate ethical and safety issues are suggested by numerous authoritative sources. Preventative measures include ageappropriate levels of education on food allergy, high levels of education in kitchen settings on the nature of food allergy and ways to prevent cross contamination, hand washing measures for all people, allergen free tables where any child not consuming a particular allergen can sit, and general "no food sharing" rules. In instances when food distribution is in question separate lunch lines should not be used; instead allergen-free foods should be subtly noted as such and prepackaged separately just like all other food.

Academic rewards or celebrations should focus on non-edible treats, and learning projects must be cautiously planned to exclude materials that contain allergens. In the event of an emergency, all emergency information should be readily available but confidential, epinephrine should be stocked, and a trained person should be present to administer the drug before the person is removed from the presence of the allergen and sent to the hospital (Behrmann, 2010; Burks, et al., 2011; Gaslin & Snoody, 2009; Sicherer, 2001). These guidelines are similar across the various authoritative sources, giving credibility to their efficacy.

Current research

Current research regarding children with SFA is rich in literature addressing genetics, immunology and ways to manage food allergy (Behrmann, 2010; Monks, et al., 2010; Osborne, et al., 2010; Sicherer, 2001). This type of research is critical for diagnosing children with SFA and once diagnosed, keeping children as safe as possible in school and social settings. It is also critical for finding ways to mediate food allergy, and potentially find a cure. However, there is currently no cure for SFA, and thus there is a need for research on how to empower children to manage their allergies and cope with the ramifications of their condition. Empowerment is the process of increasing an individual's capacity to communicate effectively, improve social skills, increase self-efficacy and feel competent in one's own agency (go.worldbank.org). Perceptions of empowerment are related to the degree to which participants feel responsibility for and

ownership of the experience (Sibthorp et al., 2007). When people are empowered, they are more able to address the challenges they face, because they have the skills and confidence to do so.

Coping mechanism studies are necessary as a vehicle for empowerment. Dahlbeck and Lightsey (2008) studied various coping mechanisms implemented by children with disabilities and chronic illnesses in order to identify positive and negative methods of coping. Positive coping techniques are important to identify and encourage because they relate to empowerment by allowing children with disabilities and illnesses to thrive and become well adjusted adults. Positive coping techniques for children include acceptance coping, approach coping, and distance coping. Acceptance coping is characterized by specific efforts to understand the situation and reduce a stressor by "seeking guidance and engaging in problem-solving activities" (Ebata & Moos, 1991; Rudolph, Dennig, & Weisz, 1995, quoted by Dahlbeck & Lightsey, 2008). Approach coping is characterized by the use of strategies to manage stressors or the resulting emotions (Dahlbeck & Lightsey, 2008). Acceptance and approach coping methods could be learning specific ways to decrease stress or reach out to others when confronted with a stressful situation. Finally, distance coping is characterized by "distancing oneself from the disease, chronic illness, problem, or situation to gain understanding, establish meaning, or decrease emotional distress" (Carlick & Biley, 2004, quoted by Dahlbeck & Lightsey, p. 295, 2008). Distance coping methods could be only eating food provided by a parent to avoid having to read labels or ask questions. These strategies empower children to confront their condition and assimilate it on their own terms. Of particular interest is the efficacy of distance coping, as typically ignoring an issue is discouraged

when trying to cope with it. However, for children, this distance can be necessary for acknowledging their chronic condition on their own terms, and thus highlights the importance of policy that does not single children out for their allergies. This school of thought is also apparent, in direct relation to children with SFA, in cutting edge guidelines for the management of SFA in schools and other social and public settings. Encouraging children to be knowledgeable about their allergy and to participate in its management, whatever that may be for a particular individual, builds confidence and is a positive form of coping with the allergy (Behrmann, 2010).

Self-esteem and self-efficacy are two important attributes that can benefit children with SFA in managing severe food allergies, and in navigating life with the condition. Self-esteem is a person's sense of self-worth, and is connected to happiness, health, and well-being. Self-efficacy is one's belief in his or her own ability to cope in the face of adversity (Dahlbeck & Lightsey, 2008). Research on the relationship between self-esteem and self-efficacy could have implications for this population as well. Self-esteem and self-efficacy are two important attributes for children with SFA, as it is critical for their social interaction to feel positively about themselves and feel competent in their own agency. Lightsey et al. (2006) studied the effects of general self-efficacy on self-esteem. They were interested in how individuals' conception of their own competence affected their sense of worth. Their findings indicated that individuals with higher general selfefficacy typically have higher self-esteem, which leads to positive feelings and coping abilities. Positive coping strategies and feelings of competence and empowerment, and the degree to which an individual feels ownership over their experience are critical for the management of food allergies by children themselves, as ultimately this responsibility

shifts from the parents to the child. This has implications for the kinds of programs and policies necessary to facilitate safe allergy management and positive self-concept (Lightsley et al., 2006).

Empowerment and allergy management programs intended for children need to be created with the children to be served in mind. These programs are designed to address the specific issues that can affect quality of life, which is a very subjective experience. This necessitates gathering data from children with SFA themselves, instead of proxies. It has been shown that, once children reach the age of 8, they are capable of accurately reporting their own Health-Related Quality of Life (HRQL). Research comparing responses of parent-proxies and children reported HRQL have revealed discrepancies in reporting. While parents and children tend to score similarly on subjective domains such as symptoms, they tend to differ on socio-emotional domains, as such experiences require first-hand knowledge. Typically, parents reported smaller effects on quality of life than did their children. While this could be attributed to adults' increased capacity to articulate themselves, it could also be attributed to an actual difference in perception and perspective (van der Velde et al., 2011). Whatever the reason for this discrepancy, it indicates a need for gathering data from children themselves. Quality of life is subjective, and thus if children feel their lives are being greatly impacted, that feeling should be acknowledged.

Further evidence supporting the need to conduct research with children subjects, rather than proxies is seen in a study by Spencer-Cavaliere and Watkinson (2010) on inclusion. Inclusion is paramount when dealing with populations with different needs, as inclusion mediates feelings of isolation. In this study, children with disabilities were

interviewed about their experiences in physical education classes to gain insight on the themes that precipitate feelings of inclusion and how it feels to be included. The researchers argued that since inclusion is a subjective experience, it is critical to examine it from the perspective of the child who is "to be included" (Spencer-Cavaliere & Watkinson, 2012, p. 275). Their research found that gaining entry to play, feeling like a legitimate participant, and having friends are the three major themes supporting inclusion, and thus the nature of social interactions and relationships to other children are critical to feeling included for children with disabilities. Additionally it was noted that peer support, social isolation and negative feelings on the part of the child with disabilities negatively affected perceptions of inclusion (Spencer-Cavaliere & Watkinson, 2010). Inclusion is also connected to social capital, which is a person's ability to derive the benefits of belonging to a group by being a full member of the group. This concept of the correlation between social capital and feelings of inclusion was studied in a Midwest residential camp setting in which participants with and without disabilities were interviewed after an experience at an inclusive camp. Reciprocity emerged as a theme relating to social capital and inclusion as it affects interpersonal relationships. The benefits of inclusion for the campers with disabilities were apparent to the campers without disabilities. Conversely, the benefits for the campers without disabilities (i.e. how the campers with disabilities could reciprocate) were less apparent (Devine & Parr, 2008). This indicates that the ability to reciprocate and form social capital is critical to feeling like a true participant, which was already seen to be important for creating feelings of inclusion.

Empowerment programs

A rich body of literature presents the benefits of adventure and empowerment programs for participants in such programs. Sibthorp et al. (2007) studied the mechanisms of adventure-based programs to study how adventure recreation fosters growth and development in various participants without disabilities. They concluded that participants derive the most benefits from programs that empower students to participate in decision-making and take ownership, while also providing opportunities to develop strong relationships between participants and with leaders. It is important to study the adventure mechanisms that lead to successful program outcomes, as programs that provide these mechanisms, even if they do not provide typical adventure activities could be of great value and wider applicability. Many studies have been done on at risk participants, and participants with and without disabilities. The benefits of these programs, as concluded by a variety of studies, include improved self-concept, better communication skills, feelings of competence, feelings of acceptance and an ability to verbalize feelings (Green et al., 2000; Shirilla, 2009; Sibthorp et al., 2007; Spencer-Cavaliere & Watkinson, 2010). Shirilla (2009) collected social skills related data from 4-H Bear Hill summer camp, and found statistically significant increases in social skills and intrapersonal skills after completion of the program. He noted that while adventure programs can improve social skills, especially intrapersonal skills, the issue with the translation of skill sets from the adventure setting to everyday settings remained. One major challenge of adventure programming is equipping participants with the means to apply the skills they learn during the program to their everyday lives. Green et al. 2000,

explored the role of debriefing in assisting with this translation of skill sets, using an "educational processing component" (Green et al., 2000, p. 84). This component consisted of a series of open-ended questions that encouraged the examination of individual and group participation, and allowed participants to analyze their perceptions regarding the activity. Examining an experience in metaphorical terms was deemed particularly important for the translation of a skill set from one setting to another (Green et al., 2000).

Rawson and Barnett (1993) studied the effects of a therapeutic camping program on the anxiety levels of children with various behavioral and emotional issues. Their study used the Revised Children's Manifest Anxiety Scale (RCMAS) to measure the children's anxiety levels before and after a short-term therapeutic camping program. The program was structured to provide "individual learning modules" and "group participation learning modules" to offer children opportunities to succeed on their own and through cooperative action (Rawson & Barnett, p. 25, 1993). The study concluded that, though it is difficult to determine if a reduction of anxiety is a direct result of a therapeutic camping program, anxiety levels are measurable and do decrease during the duration of the program for participants regardless of age or sex. These findings are important within the scope of this project because anxiety can be a debilitating condition, and children with SFA tend to live with high levels of anxiety.

There is a long history of camps that serve children with diabetes that is outlined in a review of literature done by Maslow and Lobato (2009) that could have implications for camps for children with SFA. Diabetes is similar to SFA in that it is a chronic disease that must be constantly monitored for people with the condition to stay healthy. Diabetes

camps have been studied for their efficacy in producing a variety of outcomes to improve the quality of life for children with diabetes. They often educate children about the disease, while also teaching self-management skills such as glucose testing and insulin administration. Psychological benefits of various diabetes camps have been shown to include increased self-concept and self-esteem, greater locus of control, decreased anxiety, and the use of more problem solving based coping mechanisms (Maslow & Lobato, 2009). These outcomes could be of great benefit to children with SFA, who face many similar challenges as children with diabetes.

The American Camp Association undertook a large-scale research project in 2005 called Directions: Youth Development Outcomes of the Camp Experience, in order to study the positive outcomes of camp that are anecdotally believed and accepted. Camp is a unique environment where children are away from home, out of their everyday environment, and around different types of people. Camp is a space where staff works hard to create a positive culture free from negative social pressures. These unique features of camp are often credited for the developmental growth that seems to occur at camp. The study measured ten constructs that were divided into four developmental domains: Positive Identity, Social Skills, Physical and Thinking Skills, and Positive Values and Spirituality. Over 5000 participants responded to the survey, from 80 different camps over the course of two years. In all four domains, statistically significant increases were observed between the pre-camp test, the post-camp test, and the follow-up test (Burkhardt, Henderson, Marsh, Thurber, Scanlin, & Whitaker, 2005).

Despite the wide range of populations studied via adventure and empowerment programs, there is a distinct lack of literature on such programs specifically for children

with SFA. One exception is an article by Gaslin & Snoody (2009) documenting a Center for Courageous Kids (CCK) program that was held at a residential camp for families with children who have SFA. The families and their children were invited for a weekend of respite and safe, fun activities. The article goes into precautions taken to ensure safety for all participants at great length as well as providing some feedback from parents who attended. Most notable are the detailed kitchen safety measures, the creation of a Community Touch Team to reduce the risk of cross contamination in public spaces, and the extensive resources provided to families. The CCK program guide is useful for programmatic details and considerations since not a single child experienced an allergic reaction during the weekend (Gaslin & Snoody, 2009).

Summary

All of the reviewed literature has supported the creation of an empowerment program for children with SFA. The benefits of adventure and empowerment programs have been studied in many populations and are extensive in scope. Though such programs have not been applied to populations of children with SFA, the benefits detailed by the research are programmatic outcomes that could be very important to children living with this condition, due to the nature of the challenges they face. Issues of inclusion, acceptance and anxiety are everyday obstacles for children with SFA, and the typical outcomes of adventure programming, such as improved self-esteem, communication skills and self-concept could help mediate many of these obstacles. The benefits of a camp experience, adventure based or not, have been found to be reassuring,

positive experiences for children living with chronic conditions that require management. Avery et al. (2003) note the well-established system of camp programs for children with diabetes and suggest that such programs could be equally beneficial to children with food allergies.

Though research on coping and its role in positive adjustment has been done in situations involving children with physical disabilities and chronic illnesses, there is no literature examining coping methods employed by children with SFA. This represents a major gap in the literature as the limited research that has been done indicates that children with SFA typically live with a high level of fear and anxiety, thus necessitating positive coping methods in order for them to develop into well-adjusted, healthy adults. Positive coping methods can help decrease anxiety and thus increase quality of life for these children. Education is crucial in working for positive futures for children with SFA, but action is also imperative. The benefits derived from adventure programs, or empowerment processes using adventure mechanisms could have significant impacts on the quality of life of children with SFA. This project will strive to bring safe, monitored empowerment program experiences to children with SFA who cannot be served in a typical camp environment in order to offer this population the benefits of an empowerment process program.

Chapter Three

Methods and Procedures

Introduction

This project outlines a plan to facilitate the empowerment and safe housing of children with SFA at a residential camp. The overall plan consists of two primary components: an Empowerment Program for campers to facilitate perceptions of self-efficacy via increased feelings of control and competence, as well as a Food Service Plan detailing how to provide safe and nutritious meals to children with SFA in the residential camp setting. The Empowerment Program and Food Service Plan are founded on best practices derived from the literature and current inclusive programs. A wide variety of sources were consulted, as there is currently no program in operation that seeks to both bring children with SFA to a residential camp and improve perceptions of empowerment and self-efficacy.

Project Description

Objectives for the participants

Upon completion of the program, participants will perceive higher health-related quality of life, as demonstrated by the following factors that influence self-efficacy and empowerment. Participants will:

- Objective 1: Demonstrate feelings of increased control and increased competence in managing their allergy.
- Objective 2: Display lower levels of anxiety in daily life and activities.

Objectives for the agency

Upon completion of the program, the agency will:

Objective 1: Have safely housed and fed children with SFA in the resident camp setting.

Objective 2: Demonstrate higher levels of awareness regarding the needs of children with SFA.

The Empowerment Program is designed to address the objectives for the participants. Research indicates that programs that enable participants to make decisions and take responsibility tend to lead to increased perception of empowerment (Lightsey et al., 2006). Additionally, programs that facilitate a close rapport between instructors and participants have been found to help improve communication skills (Sibthorp et al., 2007). Thus, this program will encourage participants to be accountable and responsible for decision making, while establishing positive rapport between instructors and participants. By encouraging participants to take responsibility in an environment designed to help them succeed, participants will have opportunities to test their capabilities working with peers, counselors and other adults. Confidence in one's capabilities is crucial to feelings of self-efficacy, which is a major aim of the program (Lightsey et al., 2006). This sense of self confidence and increased self-efficacy can help children with SFA beyond the camp situation, as they transition into adolescence and take on more responsibility for managing their own allergies. This is critical because most fatal allergen exposures occur during adolescence when teens are testing their limits as they become independent (Monks, et al. 2010).

The Food Service Plan details cutting edge guidelines for serving populations with SFA to allow the agency to meet its objectives. Studies show that prevention and

education are key to managing food allergy in public settings. Staff needs to be properly trained and have proper medication (typically epinephrine) on hand in case of exposure. Any individual who is administered epinephrine should be transported to the hospital immediately, even if symptoms appear to subside (Hay et al., 2006). Action plans should be formulated to address how to avoid contact with allergens and what to do in the event that exposure occurs (Food Allergy and Anaphylaxis Network, 2004). Additionally, plans for food service and allergy maintenance must consider ethical ramifications.

Contemporary guidelines are often discriminatory: they often single out children with allergies, or place unfair burden on certain groups by banning a food allergen. Instead, allergy management policies should encourage the empowerment of children to manage their own allergies, with food bans being reserved for settings where children are too young to distinguish foods (Behrmann, 2010).

Target Population

Participants in the program will be children ages 8-16 years who have at least one medically diagnosed severe food allergy. Most camps do not serve children over the age of sixteen, and working with children below the age of eight poses different challenges. Young children cannot always distinguish between safe and unsafe foods, they cannot use the same evaluation forms as children eight years of age or more, and they are not physically capable of the same activities as older children. It is recommended that a group of no more than 20 children participate in the empowerment program to ensure reasonable supervision and contact with staff mentors. The agency will be largely

responsible for recruiting the participants, as they will be attending camp along with campers who do not have SFA.

Procedural Steps for Project Completion

- 1. Utilize best practices to develop a comprehensive and equitable Food Service Plan to be implemented by food service staff, incorporating key components:
- Food acquisition and storage
- Meal preparation
- Serving protocol
- Cleaning protocol
- Hand washing measures
- 2. Consult manuals of adventure challenges, selecting activities that address the following objectives:
- Improving communication skills
- Opportunities for decision making and responsibility
- Forming positive rapport with staff mentors
- Opportunities to be challenged in a supportive environment
- 3. Develop an Empowerment Program, using existing manuals, to compile a curriculum of appropriately focused and challenging activities.

- 4. Develop an educational manual for staff and campers to facilitate understanding of SFA, and encourage safe behaviors such as hand washing.
- 5. Compile a kitchen staff manual containing Food Service Plan and a staff portion of the educational manual on safety.
- 6. Compile staff manual containing Empowerment Program and educational manual.
- Educational manual for staff will contain both the staff portion of the manual, to be completed during staff training, and the camper portion of the manual, to be implemented with campers on the first day of camp.

Needs Assessment

Children with SFA tend to live with high levels of anxiety and lower levels of quality of life (Avery et al., 2003). This can be attributed to the constant fear of exposure to an allergen, as well as the lack of symptomatic indicators of their condition. Severe food allergy as a disease does not have any visible attributes that mark children as ill. Thus, there is a lack of awareness that often endangers children with SFA due to well-meaning individuals who may unknowingly expose children to an allergen (Gaslin & Snoody, 2009). Children who face such challenges daily need to feel confident in their abilities to manage their allergies, as well as feel empowered to speak up for their needs. This is where the need for an empowerment program arises, as there is an extensive body of literature detailing the benefits of empowerment programs. The specific benefits, such

as improved self-concept, better communication skills, feelings of competence, feelings of acceptance and an ability to verbalize feelings could greatly help children with SFA navigate daily life (Green et al., 2000; Shirilla, 2009; Sibthorp et al., 2007; Spencer-Cavaliere & Watkinson, 2010). Such programs have been successfully implemented for children with chronic conditions such as diabetes, and could be equally beneficial to children coping with SFA (Avery et al., 2003).

Role of the Agency

The agency will be responsible for providing the setting in which to implement this program. The setting must include overnight facilities for campers, a medical director willing to collaborate with the dining hall, as well as a sufficiently staffed food service team. The agency will handle all duties regarding staffing for both the empowerment program and dining services. Adequate time for training both staff mentors and kitchen staff must be allocated. Staff mentors will implement the empowerment program, and kitchen staff will prepare and serve meals. Additionally, the agency will be responsible for recruiting participants with SFA, as they will be attending camp concurrently with campers who do not have SFA.

Site Assessment

The main criteria necessary in selecting a site to implement this program is a kitchen and dining hall of appropriate size and staff. The kitchen should be a space large

enough to include separate preparation spaces for certain food, separate sinks for allergen free food preparation, separate sets of pots and pans for certain allergens, and separate storage spaces for certain foods (most notably, allergens that can become airborne). An adequate staff is necessary to have different sous chefs prepare allergen-free dishes while allergen-containing dishes are also being prepared. There should be a food service director/head chef who is knowledgeable regarding food allergies, best practices, sanitation, and nutritional needs of various children with SFA, as well as an allergen manager to act as the liaison between campers, the health center, the kitchen staff and counselors. Additionally, there needs to be a cleaning staff to clean all communal surfaces and clear all individual dishes to prevent cross contamination. Finally, there must be dining facilities of appropriate size or configuration to accommodate groups of campers arranged to prevent cross contamination.

Instrumentation

To evaluate the efficacy of the program, a pre- and post-test questionnaire will be administered to participants in the empowerment program. The instrument will be the self-administered Food Allergy Quality of Life Questionnaire for children (FAQLQ-CF). This instrument was developed by Flokstra de Blok, DunnGalvin, Vlieg-Boestra, Oude Elberink, Duiverman, Hourihane and Dubois (2008). Its purpose is to measure health related quality of life, defined as "the effects of an illness and its consequent therapy on a patient, as perceived by the patient" (Flokstra de Blok, et al., p. 238, 2008). The FAQLQ-CF evaluates anxiety, competence and feelings of control; factors that influence self-

efficacy and empowerment. This instrument has good reliability and internal consistency, with a Cronbach's coefficient of 0.94. Cross-sectional validity was established through comparison of the FAQLQ-CF to the CHQ-CF87, a generic health related quality of life questionnaire that has proven validity in numerous countries and languages (Flokstra de Blok, et al., 2010). The FAQLQ-CF has been found to successfully assess quality of life for children with food allergies, and thus will be used to measure perceptions of quality of life before and after the empowerment program.

Funding Sources

Funding for this program will be obtained largely in the same way in which the existing camp raises funds. Typically this is through fund raising efforts and camper program fees. Due to the nature of this program, and its focus on serving children with SFA, certain organizations and foundations could be approached for donations and grants. One such example is the Celiac Disease Foundation, which currently provides camp scholarships to children with celiac disease through Team Gluten-Free fundraisers (www.celiac.org/tgf). As was noted in the literature, there is currently not a large system of camps for children with SFA, as there is for other diseases such as juvenile diabetes (Avery et al., 2003). In the past few decades, a large system of support for diabetes camp programs has formed via agencies and corporations such as Novo Nordisk (Novo Nordisk Inc., 2013), Camp Angels (www.campangles.com), and the American Diabetes Association (www.diabetes.org). Such a support system could be formed for camps designed for children with SFA through outreach and education.

Evaluation Plan

The evaluation of this program will be twofold, focusing on both the evaluation of the participants, and the evaluation of the supporting residential camp. To evaluate the benefits of an empowerment program for the participants, the FAQLQ-CF will be used as a pre- and post-test to assess any changes in levels of anxiety, feelings of competence and perceptions of control. These three factors are critical in building self-efficacy and empowerment, and thus will assess the effectiveness of the program.

The evaluation of the program for the supporting camp will revolve mainly around the kitchen and dining facilities. An evaluative tool was constructed to analyze the efficacy and ease of the program from the perspective of those working in the dining areas (Appendix G). The evaluations will assess how the agency met its goals of safely housing and feeding children with SFA, as well as raised levels of awareness about SFA. Most important will be a log of any incidents that may occur, either in cross contamination resulting in a reaction in a camper or cross contamination that is identified before meals leave the kitchen (Appendix E). The end of session evaluation will focus on where issues occur, sanitation practices, and the ease or difficulty of meal planning, preparation and serving.

Chapter 4

"Can't Touch This" Program

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Operations and Safety Plan

Kitchen Operations

Hand Washing

- All staff must wash hands for at least 20 seconds, using good hand washing procedures, prior to putting on nitrile or vinyl gloves and preparing food.
- Any staff that switch stations (goes from a nut free to the gluten free stations, for example) must change gloves and wash their hands again between glove changes.
- Good hand washing procedures can be found in Appendix A.

Food Storage

- Department of Health Standards mandate how foods are stored in a refrigerator. These standards greatly assist in preventing cross contamination. One particular consideration is the storage of peanut or other nut butters. If they are kept in the refrigerator, use physical barriers (such as plastic storage containers) to ensure they remain separate from each other, and other foods.
- For non perishables, plastic storage bins should also be used to prevent cross contamination.
 - ex) Putting gluten-free flour in a plastic storage bin, rather than the original bag.

Food Preparation

Work Stations

- At least 4 work stations are necessary to ensure adequate separation of allergens
 - Food containing any/all allergens (a workstation for food <u>not</u> marked "allergen free")
 - 2. Nut free, soy free and fish/shellfish free (peanuts and tree nuts; these foods are most easy to avoid in the cooking stages)
 - 3. Gluten free and dairy free (due to high co-morbidity)
 - 4. "Allergen free" ex. chicken, vegetables, rice (foods not on the Big 8 list)
- Work station should be sanitized after preparing foods, and again before preparing foods, with a bleach and water mixture of 1 tablespoon bleach per gallon of water.

Preparation Utensils

- Each workstation needs utensils, pots and pans that are exclusive to the station.
 Color-coding stations is recommended. Necessary items for each station:
- 1. Cutting board
- 2. Knives
- 3. Mixing spoons
- 4. Spatulas
- 5. Mixing bowls
- 6. Other utensils deemed necessary
- 7. Large pot, small pot
- 8. Large frying pan
- 9. Baking sheets and pans

Cooking

- Splatters and spills can be sources of cross contamination. When cooking allergen containing and allergen free foods at the same time, consider the following:
- 1. Pots that may splatter or boil over should be kept separate
 - e.g. Cook traditional and gluten free pasta at different times; if possible, different stove tops would be ideal.
- 2. When baking, consider oven placement so that spills don't cause cross contamination
 - ex) Place a gluten free cake above a traditional cake in the oven so that spills won't contaminate the gluten free cake with gluten.

Dish Washing

Dishes from different stations should be washed separately, if possible. This
eliminates the risk of cross contamination at this stage, as well as reduces the risk
of the wrong preparation dishes ending up in a work station. If washing dishes
separately is not possible, the use of a bleach water solution after washing is
recommended.

- All dishes should be rinsed before being loaded into the dishwasher to avoid having bits of food stick during the washing process. (Avoiding Crosscontamination in Your Home, Kids with Food Allergies).
- It is recommended that a commercial dishwasher that uses chemical sanitization be employed. This is again to reduce the chances of food sticking during the washing process.

Parent Provisions

Some parents feel more comfortable sending substitutes/additions with which they and their children are familiar. Steps to ensure that the correct provisions are given to the correct child may include:

- 1. A labelled bin for each child with food from home.
- 2. A window where children can go to get their food from home.
 - a. Food that needed preparation should be picked up at the kitchen to prevent confusion at a pick up table.
- A system where children can request a certain food item for a certain meal.
 e.g. Filling out a slip in the morning to request their own veggie burger at dinner instead of those provided by camp.

Dining Hall Operations

Hand Washing

- All campers and staff must wash their hands, using good hand washing procedures, prior to be seated for a meal.
- Good hand washing procedures can be found in Appendix A.

Serving Food

• Recommended buffet style stations:

- Salad bar: most items are allergen free; allergen containing items can be placed in closed, limited serve containers ex) dressing in small nozzled pour containers
- Sandwich station: Traditional bread and GF bread stations needed with distinct toasters (if provided); condiments should be in squeeze bottles or individual packets
- Family style meals are recommended for programmatic reasons of creating trust, community and communication.
- Meals requiring substitutions for allergen reasons must be similar to and of equal quality to allergen containing meals.
- It is recommended that during sessions where campers have severe airborne allergies, the allergen is removed from the menu for the safety and inclusion of all campers, e.g. dining hall should not offer peanut butter during a session where campers have anaphylactic-response airborne peanut allergies

Seating Arrangements

Children with similar allergies can be grouped together ONLY IF they are
integrated into groups with children without allergies
 ex) Three children who need gluten free food can be seated together if it is in a
group with other children who do not need gluten free food

Kitchen Patrol

- Campers with contact allergies should only be on kitchen patrol (a chore rotation
 where children set up, help serve, and clean up the meal) for meal set up to avoid
 contact with allergens.
- Campers with non-contact allergies can be on kitchen patrol for meal set up or clean up: allow campers to self manage, with supervision, by doing tasks they feel safe doing while still participating in the patrol.
 - n.b. This can be a community building exercise if campers can work together to get the job done while keeping everyone safe.

Medical Connections

Camper Advocate- Medical Staff

- It is recommended that camps serving a large number of campers with allergies (more than 15% of the camp population) have a designated Camper Allergy Advocate who works with campers, their families and the medical staff at camp.
- This individual would be responsible for communicating needs and concerns to the medical staff and would work closely with the kitchen staff.
- This connection would be used to articulate and communicate medical needs and
 questions between the medical staff and kitchen staff to reduce the likelihood of
 cross contamination and accidental exposure to allergens.

Emergency Procedures

Food Allergy Action Plan

- All campers with food allergies should have a Food Allergy and Anaphylaxis
 Emergency Care Plan on file (Allergy and Anaphylaxis Network).
- The Food Allergy and Anaphylaxis Emergency Care Plan (FAAECP) form can be found in Appendix B.
- Copies of each FAAECP should be stored in both the Dining Hall and the Health Center and should be reviewed by the Food Service and Health Directors; this is to reduce response time in the event of an emergency.

Emergency Transport

- All directors and unit staff, in addition to the camper's counselor, should be briefed on transport procedures.
- One person (director or unit staff) must ride in the ambulance with a child having an allergic emergency.
- If an EpiPen is given, the empty cartridge must be sent with the child to the hospital.
- EpiPen administration procedures can be found in Appendix C.

If the camp typically provides emergency transport, it should be located within 10 minutes of the nearest hospital to provide transport for allergic emergencies, which can escalate quickly.

Community Touch Team

- A patrol of people, campers or staff, should be assigned to daily Community Touch Team duty.
- This team should sanitize communal surfaces that are frequently touched in and around the dining hall, including:
 - Door handles
 - O Toilet flush mechanisms
 - Sink faucets
 - Countertops
 - Hand rails
 - Chair backs

"Can't Touch This"

An Empowerment Process Program for Children with Severe Food Allergies

Program Activities





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Introduction

This program consists of two segments that may be used together or separately. Activity 1, "Can't Touch This" is an educational program that uses books, hand washing activities and visual demonstrations to teach participants who may or may not have food allergies, about SFA. The following seven activities are team-building exercises aimed at improving participants' abilities to work together, communicate effectively, trust others, problem solve and demonstrate patience. Some activities single participants out for special responsibilities depending on their allergies. This is congruent with the ideas of distance coping and acceptance coping, as it is requires participants to acknowledge the allergy, but also takes it out of a food related context, so there is no actual danger or threat. Participants can process that component of the challenge on their own terms, and in their own way. These activities are part of the empowerment program specifically designed to help children with SFA gain critical skills to help them navigate life with severe allergies.



"Can't Touch This"

Purpose: This short program, comprised of four interactive activities, helps children and adults alike learn about food allergy. The program addresses feelings surrounding having a food allergy, cross contamination and how to keep people with SFA safe.

Directions:

See "Can't Touch This" located in Appendix D

Outcomes: After completing the "Can't Touch This" program, participants will

- 1. Understand the challenges faced by children with SFA.
- 2. Have an awareness of the feelings and emotions evoked by having SFA.
- 3. Understand how cross contamination occurs.
- 4. Know and be able to demonstrate good hand washing procedures.

Resources: References listed in Appendix D

"Can't Touch This"

Food Allergy Awareness Activities



Background on Severe Food Allergy

Food allergy is a severe medical condition in which a person's immune system has an abnormal response to specific food proteins. When an allergen, in this case a food, is ingested, the body produces massive amounts of histamines and other protective chemicals. However, since the perceived toxin is actually benign, the chemicals cause harm. This harm typically affects the respiratory tract, the GI tract, or the skin (Food Allergy Research and Education). In the most severe of cases it leads to anaphylaxis, which is a sudden allergic reaction characterized by tightness of the throat, wheezing, and/or unconsciousness. This reaction can be fatal, which is important to note, as food allergy is the most typical cause of anaphylactic shock (Sicherer, 2001). Swift action is necessary to prevent death in the case of an anaphylactic reaction.

Severe food allergy differs from other life-threatening medical conditions in the manifestation of the symptoms. Children with food allergies are otherwise healthy individuals, barring other medical conditions that may arise in any population, and thus they do not have any particular physical attributes that mark them as ill. This has contributed to the slow pace of recognition, research and accommodations for individuals who are on constant watch for the presence of fatal allergens. Another major difference between severe food allergy and other conditions is the treatment. Treatment for severe food allergy is total avoidance of the allergen. This is a deceptively simple treatment because, although it does not require painful procedures or lengthy hospital stays, it requires constant vigilance, which can lead to constant anxiety (Gaslin & Snoody, 2009).

This constant anxiety due to a sporadic reaction can create a lot of stress for children and families who are living with severe food allergy. Something as seemingly simple as going out to eat can be challenging, frustration and scary. This has many implications for the quality of life of individuals living with food allergy. Food allergy can prevent children from participating in certain activities or from forming the same kind of friendships as their peers. It can cause serious anxiety over engaging in everyday social events and puts significant stress on the family (Gaslin & Snoody, 2009).

Purpose of "Can't Touch This" Program

The purpose of this program is to mediate the issues faced by children living with food allergies by raising awareness among camp staff and campers on the nature of food allergy and the needs of campers with such food allergies. The program seeks to empower camp communities to create an environment that is safe, welcoming and accepting. In addition to the medical challenges faced by children with SFA, there has been a trend of bullying seen where children are taunted with the food to which they are allergic, or even have food thrown at them (Landau, 2013). By participating in this program, you and your campers can learn how to acknowledge and minimize the social effects of food allergy, while interacting with all campers in a positive, natural way. Each activity is specifically designed to raise awareness of a certain issue pertaining to food allergy, and offers opportunities for various modes of learning.

The first activity, reading The BugaBees, is intended to initiate the program with a level of equality. Though some staff and campers may have experience with food allergy, the BugaBees can help create a basis for comprehension for those who do not have any experience. This book also helps shed some light on the perspective of children who actually have these allergies, allowing for a deeper understanding of the issues faced by these campers.

The second activity, the Caravan Walk, is a team building exercise that allows participants to experience the point of view of someone who is empowered, yet responsible for others, and the point of view of some who must rely on others. The people who are sighted, i.e. empowered yet responsible, are like people who care for others with food allergies; they must be constantly vigilant to ensure the safety of their children/campers/friends with allergies. The people who are blindfolded, i.e. reliant upon others, are like children with food allergies; until they are old enough to manage their own allergies, they must rely on others to keep them safe. Even once a child with food allergies becomes an adult, there are still many situations in which that person must rely on others, such as when dining out, visiting friends, or traveling.

The third activity, Painted Hands, is a visual illustration of the way invisible food allergens can travel and spread. It is sometimes difficult to understand the way trace

amounts of food residue can cause such severe allergic reactions, since they cannot be seen. The paint allows everyone involved to see the large effect that the small action of an individual (neglecting to wash your hands) can have. It is particularly relevant in regard to activities that do not involve food because often it is easy to forget that the threat of allergen exposure remains even once your group leaves the kitchen/dining hall/cafeteria.

The fourth and final activity, Hand Washing, is an opportunity for participants to put the knowledge that have gained into practice. By creating a hand-washing poster, staff and campers alike are afforded the opportunity to focus on the aspects of the learning module that they felt were particularly important. The act of writing down a poem or song will encourage people to think about the information in a new and more creative way, hopefully promoting the retention of that new knowledge. The posters will serve as a reminder throughout the camp session of the lessons learned during this program, as well as the importance of hand washing to keep everyone healthy and safe.

For more information on food allergy, guidelines and policies for serving individuals with food allergies, or the personal and social ramifications of food allergies, please see the reference section located at the end of this manual.

Food Allergy Awareness Activities

Activity 1: The Bugabees

Activity 2: The Caravan Walk

Activity 3: Painted Hands

Activity 4: Hand Washing

BugaBees Story

Activity: Read "The BugaBees: Friends with Food Allergies" to the group.

Purpose: To provide an introduction to food allergies through the reader-friendly medium of a children's book. This book will provide information about common food allergies, possible reactions and a positive message about living with food allergies.

Supplies: "The BugaBees: Friends with Food Allergies" by Amy Recob

For Staff: We are going to start this program by reading "The BugaBees: Friend with Food Allergies" by Amy Recob. This is a children's book about living with food allergies that will give us all a similar background from which to continue. This is obviously not a scholarly piece of literature, but it will give us some insight into the symptoms and emotions experienced by children with food allergies.

For Campers: Today we are going to start our adventure by reading "The BugaBees: Friends with Food Allergies." This is a fun story about some buggy friends who have different food allergies. We will learn a little about allergies, and a lot about friendship. Listen carefully, because we're going to talk about the story when we're done.

Debrief: What did we learn? What is the major take-away? (We need to work together to keep each other safe.) What are food allergies? What can we do to help friends with food allergies? Ask campers to discuss how they would feel to be a particular BugaBee. Ask staff to dig deeper and imagine they are a camper with allergies who heard this story. What might you feel? How could this help you relate to your peers? What can we take from the story to help all campers feel welcome and safe?

Caravan Walk

Activity: As a team, the group must work together to go on a walk (pick age and skill appropriate terrain) and navigate around obstacles. The challenge is that for every one person who can see, there will be five people who cannot see. The people who can see must work together to guide the people who can't see.

Purpose: To build teamwork, trust and group cooperation. This activity is also intended to show two different points of view; the view of the person who is responsible for the safety of others, and the view of the person who is hindered in his or her ability to care for him/herself.

Supplies: blindfolds, cones/frisbees/other obstacles (optional)

For Staff: We are going to work together to get our team through this challenge course. The catch is that for every one person who can see, five people cannot. Everyone can speak and use their hands to communicate. The activity will be complete when everyone makes it successfully through the course.

For Campers: We are going to do an activity that is kind of like follow the leader. The difference is that only some people will be able to see, and the rest of you will be asked to close your eyes. You have to talk to each other and guide each other to get everyone through the obstacle course. Remember that we are going to use kind words with all our friends.

Debrief: How did it feel to be able to see? Was it a big responsibility? How did it feel to not be able to see? Did you feel helpless, frustrated, or even scared? How could these feelings happen in other situations (such as being responsible for someone with allergies, or being the person with allergies who needs help)? How do we feel as a group now?

Painted Hands

Activity: Complete an age appropriate, non-food related activity after "eating lunch." In this situation, one person has forgotten to wash his or her hands. The leader will choose this person and put paint on his or her hands. The activity should progress as usual, with the paint spreading onto people, things and places.

Purpose: To visually see how food residues can spread quickly and easily to raise awareness of the importance of good hygiene and hand washing practices. This activity will also illustrate all the "unlikely" places that allergens can linger, driving home the need for compassion and caution.

Supplies: washable paint

For Staff: Imagine we are a group that just finished eating lunch. Everyone remembered to wash his or her hands except "John." We are now leaving the lunch area and are going to build a rope bridge together. [Put paint on John's hands and allow the activity to progress as usual.]

For Campers: Imagine with me that we all just finished lunch and washed our hands on the way to the nature center. Except "Sally" forgot to wash her hands! Oh well, it's not a big deal. Let's still go to the nature center and build a shelter out of sticks. [Put paint on Sally's hands and allow activity to progress as usual.]

Debrief: Ask participants to find all the places where paint ended up and discuss that impact. Were they surprised? How much paint spread? Ask them to imagine that they were allergic to the paint-how would they feel now? What if the paint was invisible, but they were still allergic to it?

Hand Washing

Activity: Create a poster to hang above a hand washing station. The poster should include age appropriate poems, songs or drawings that address some aspect of food allergy that has been covered.

Purpose: Reinforce what has been learned through creative writing and drawing. Also, this activity will result in posters that can be placed at hand washing stations for the duration of the program/session.

Supplies: paper, markers

For Staff: The last activity illustrated how crucial hand washing is to keeping everyone safe at camp. Food residue can spread quickly and is dangerous even on things like benches, handles, and doors. The only way to prevent the spread of allergens through contact is hand washing. This next activity is designed to train us, and our campers, to wash our hands for an adequate amount of time. The activity is to create a poem about hand washing, food allergies, inclusion, or one of the other topics we've covered. The poem should take at least 30 seconds to read (at the rate that a child would read). You will turn this poem into a poster that could be hung above a hand washing station, to encourage people to wash their hands longer than they might otherwise.

For Campers: That last activity was really messy and showed us how important it is to keep our hands clean. If even one person forgets to wash their hands, we could all end up with their germs, peanut butter or anything on us! That's why it's really important to wash our hands long enough to get them really clean. To help us remember to do that, we're going to make a poster to read while we wash our hands. We'll write a little poem or song about something we've learned and draw

pictures for people to look at. That way, we will remember that we need to read all the words and see all the drawings before we're done washing our hands.

Debrief: Have groups present their songs/poems/artwork to the group at large. Ask them to explain why they chose the topic they chose and how their poster will help encourage hand washing. Ask staff to dig deeper and brainstorm other ways to encourage campers to devote adequate time to hand washing.





It's never any fun.

The moment I turn the water on I think "when am I done?"

My hands don't look so germy My fingernails are clean I'm starting to get squirmy I'm done is what I mean!

But here I stand still splashing I must try to stay strong

But wait, the timer's flashing!

Oh. I guess that wasn't long.







Magic Carpet

Purpose: This activity encourages participants to work together, trust each other and practice communication skills in order to succeed.

Materials: one large tarp

Directions:

- 1. Start participants in groups of 10-15. Participants are sailing to the Island of Jelly, over the Sea of Peanut Butter when their boat capsizes.
- 2. Give each team a tarp to lay flat on the ground. This tarp is a bread raft on a sea made of peanut butter.
- 3. Have all members of the team stand on the tarp.
- 4. The object of the activity is for the team to flip the tarp over without any member of the team stepping off the tarp. The only exception is that participants with a gluten allergy can step off once, as their allergy to the raft means they can touch the sea.
- 5. If someone else steps off the tarp, the team must start over.

Modifications: Participants will flip the tarp again. This time, no one can talk, except for people who have a peanut allergy, as they speak the language of the sea.

Outcomes: After completing the Magic Carpet activity, participants will

- 1. Acknowledge and understand the role of cooperation and communication by articulating how cooperation and communication contributed to success.
- 2. Understand the importance of listening skills, and be able to identify good and bad listening habits.
- 3. Have a greater appreciation of the need for trust and be able to explain how trust adds to the activity.

Debriefing Questions (with answer prompts):

- 1. What did we just do?
 - a. flipped a tarp, worked as a team
- 3. Why did we do that?
 - a. to work together, to talk to each other, listen to each other
- 4. How did you feel while we were doing that?
 - a. like people listened to me, like no one worked together, mad
- 5. What helped you succeed? What did not help?
- a. when we worked together, when one person talked at a time, when we trusted others; when people yelled, when one person was bossy
- 6. How else could we use those skills at a restaurant? At a friend's house?
- a. at a restaurant when I have to explain how to keep my food safe, at my friend's house when someone tries to give me food and I can't have it

Resources:

ChallengeTarps Activity Guide, Retrieved from Project Adventure website: https://www.pa.org/webstore/activityguides/

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Activity 3

Giant Skis

Purpose: This activity requires participants to work together and practice effective communication in order to succeed. This activity encourages group cohesion, as the group must act as a single unit to complete the activity.

Materials: one set of Giant Skis (see Resource section for information on purchasing)

Directions:

- 1. Divide participants into groups of 6-8 (depending on the number of "spaces" on the skis) so each person has a space on the skis.
- 2. Have participants stand on the skis and grab the ropes in front of them.
- 3. Direct participants to walk together to the finish line.
- 4. The object of the activity is for the group to walk on the skis to a specified destination.

Modifications: Participants are now crossing an ice cream field on fish sticks. Anyone with a fish allergy must walk on the ice cream, but needs to hold the ropes. Anyone with a dairy allergy must stay on the fish stick skis, but cannot touch the ropes because they touched the ice cream.

Outcomes: After completing the Giant Skis activity, participant will

1. Understand the importance of communication and will articulate how open communication contributed to success.

- 2. Recognize and understand the importance of teamwork by articulating the ways in which the group worked as a unit.
- 3. Acknowledge the role of group cohesion by explaining how it felt to succeed as a team.

Debriefing Questions (with answer prompts)

- 1. How did it feel when you couldn't move the skis? How about when you could?
 - a. frustrating, upsetting, annoying; exciting, like we were a team
- 3. How did you move the skis? What about when some people were on the ground, and others couldn't hold the ropes?
- a. by working together, talking to each other, electing a leader; we had to rely on each other, we had to make a plan for where people should stand
- 4. How did talking to each other help you complete the activity?
- a. people weren't yelling over each other, everyone had a say, we figured out how to all move together, we decided together how we would do it
- 5. How can we use those communication skills in the lunchroom? At a class party?
- a. when people sit too close to me with something I'm allergic to, I can explain why I need space, at a class party I can say what I'm allowed to have or say "no thank you, I can't" when someone offers me something I can't have

Resources:

Skis available for sale at http://www.kit4trainers.co.uk/skis.htm

Skis can also be constructed with two 2x4's between six and eight feet long. Holes should be drilled every 12 in to thread strong rope up through to use as handles. Duct tape can be used as an easy substitute; participants stand on two long strips of tape.

Helium Stick

Purpose: This activity requires participants to work together, yet function as individuals. This activity shows the great impact that the actions of one individual can have, and how that impact is multiplied when more individuals act.

Material: One hula hoop

Directions:

- 1. The instructor will hold the hula hoop, explaining that it is made of helium and so will float away if left alone.
- 2. Have participants stand in a circle with their arms in front of them, one finger from each hand put out to rest the hula hoop upon.
- 3. The goal is to place the hula hoop upon the participants fingers and have them lower it to the ground. If anyone loses contact with the hula hoop at any time it "floats away" and the group must start over.

Modifications: Participants are not allowed to speak. Use a tent pole, instead of a hula hoop, so participants cannot see each other as easily.

Outcomes: After completing the Helium Stick activity participants will

- 1. Show understanding of the effects of their actions by discussing the ways each person could contribute to either the success or failure of the activity.
- 2. Demonstrate knowledge of the ways individuals can function within a group by discussing what they did personally to contribute to the activity.

3. Appreciate the role communication, both verbal and non-verbal, plays in group dynamics by articulating how different styles worked in this activity.

Debrief Questions (with answer prompts):

- 1. Why did the hula hoop float away at first?
- a. everyone was lifting it, we didn't know how to move it together, some people moved faster than others
- 2. How did you keep the hoop from floating away?
- a. we talked to each other, we came up with a plan, we gauged each other's reactions
- 4. What happened if one person wasn't on board?
 - a. the hula hoop didn't lower evenly, we dropped the hoop
- 5. What can we take away from this activity?
- a. its important to listen to each other, everyone's actions have consequences
- 6. Everyone's actions make a difference. How could your actions make a difference when someone doesn't understand your allergy?
- a. I could explain how it could hurt me, I can go away from people who are mean, I can thank friends who try to keep me safe

Activity 5



Worry Hat

Purpose: This activity encourages participants to share something that worries them, to bring the group together over common worries, or the commonality of having worries. It also allows participants to get worries off their minds, and allows fellow participants and instructors to address and potentially help ease those worries.

Materials: One hat, many slips of paper, many pencils or pens

Directions:

- 1. The instructor will hold the hat in front of the group, and explain that it is the worry hat where we put the things that worry us to get them off our minds.
- 2. Every participant will receive a piece of paper and a writing utensil. They will be asked to write down something that worries them: participants are encouraged to write something relating to living with SFA, but it can be anything, and sharing is always challenge by choice.
- 3. Everyone puts their worries into the hat and the instructor shakes them up.
- 4. One by one, participants come forward, select a piece of paper from the hat and read the worry aloud. The participant then explains one way they can understand the worry, or have a similar worry- if they are struggling, instructors may put forward answers. The participant then suggests one way to ease the worry.
- 5. At the very end, the worries are ceremoniously thrown away.

Modifications: With young children, facilitators may wish to read the worries and ask the group of children how they can relate to or understand the worry and make it less concerning.

Outcomes: After completing the Worry Hat participants will

- 1. Demonstrate a better understanding of each other's concerns by explaining how they understand or share those concerns.
- 2. Understand how fears do not need to be barriers by explaining ways to lessen fears.

Debrief Questions (with answer prompts):

- 1. How did it feel to write your worry down? How did it feel to have it read?
 - a. it felt scary, a little embarrassing, it felt ok
- 3. Why did it feel like that?
- a. because it's personal, other people were hearing it, I didn't want people to know it was mine
- 4. How did it feel to hear others talk about how to face your worry?
 - a. it felt good, like I could change it, like I wasn't alone
- 5. What can we take from this activity?
- a. that it's good to share worries, that I can face my fears, that other people are scared of things too

Activity 6

Spider Web





Purpose: This activity requires participants to work together to get everyone through the web. It requires patience, strategy and teamwork. This activity highlights that everyone has strengths that may be different from others.

Materials: 4-6 ropes at least 20 ft. in length, or 8-12 bungee cords at least 10 ft in length, or a Spider Web game frame (see Resources for purchasing information)

Directions:

- 1. The instructor will explain that the group has come across a giant spider web that is the home of a humongous spider that will turn you into a fly if you get stuck. The group cannot go around the web, and so must go through.
- 2. If anyone touches the web, the only way to avoid getting stuck is if everyone starts over. Each space can only be passed through once.
- 3. Participants must figure out how to get everyone through the web without touching it, or going through the same opening twice.
- 4. The instructors will judge if someone touches the web or not.
- 5. Optional accommodation: have one opening touch the ground to accommodate individuals with limited flexibility or mobility.

Modifications: The spider has laid EGGS in some of the openings! Only participants with an egg allergy can use the openings with eggs because they have built up immunity from not eating eggs.

Outcomes: After completing the Spider Web participants will:

- 1. Understand the importance of communication by stating three ways in which communication helped them succeed.
- 2. Acknowledge that everyone has different strengths by explaining how and why certain people went through certain openings.
- 3. Demonstrate a greater understanding of the importance of trust by explaining how it felt to lift people or be lifted.

Debrief Questions (with answer prompts):

- 1. What was the best part of this activity? What was the most challenging?
 - a. when we did it, when I got passed through; when we had to start over,
- 2. How did you work together to succeed?
- a. we passed people through, we encouraged each other, we helped each other balance, we figured out where to have people go through
- 3. How did it feel to work together?
 - a. it felt good, it was hard when people wouldn't listen
- 5. What can we take away from this activity? What did we learn?
- a. you have to work together, it's good to trust people, you have to listen when people are talking
- 6. How did we see people's different strengths? How can we take advantage of our strengths together?
- a. some people fit through different spaces better, some people were better at lifting or spotting, we can work together to keep people safe if some people are better at talking, some are better at being a good friend

Resource:

Project Adventure Store: To purchase web and frame http://www.pa.org/zencart/index.php?main_page=product_info&products_id=294 To see depictions of how to set up the web https://www.pa.org/challenge-courses/course-types-and-elements/low-elements/spiders-web-universal/

Activity 7

Circle Sit

Purpose: This activity requires participants to trust each other completely, as they will be physically supporting each other. They must work as a team and communicate to succeed.

Materials: none

Directions:

- 1. Have participants stand shoulder to shoulder in a circle.
- 2. Have everyone turn in the same direction so they are now looking at someone's back, and are still standing very close. Have participants place their hands on the shoulders of the person in front of them to help with spacing if needed.
- 3. Explain that on the count of 3, everyone will sit down at the same time.

 Everyone ends up supporting the person in front of them on their knees, while sitting on the knees of the person behind them.
- 4. Count to 3, have everyone sit. After a moment, count again and have everyone try to stand up.

Outcomes: After completing the Circle Sit, participants will:

- 1. Demonstrate higher levels of trust within the group by participating fully in the activity.
- 2. Understand the importance of teamwork by explaining three ways the group needed to work together to succeed.

3. Acknowledge the importance of communication by stating three ways in which good communication contributed to the success of the activity.

Debrief Questions (with answer prompts):

- 1. Why did we just do that?
 - a. to get closer, to trust each other, work like a team
- 2. How did it feel?
 - a. scary, cool, I didn't like it at first, awesome
- 3. How did we make it work?
 - a. we talked to each other, we counted down, we trusted each other
- 4. When else might we need to trust people? When do you trust other people to keep you safe?
 - a. in school, on a sports team; when I eat at a restaurant or a friend's house
- 5. When else might we need good communication skills? How do you use communication to keep yourself safe?
 - a. in school, at home; when I tell people how my allergy affects me, when I tell people what I can and cannot have



Activity 8

"Who I Am" T-shirts

Purpose: This activity allows participants the opportunity to reflect, and to creatively express their thoughts and feelings regarding the program, living with allergies, fitting in, or any other related topic.

Materials: 1 T-shirt for every participant, fabric markers, puffy paint, yarn or thread, scrap cardboard

Directions:

- 1. Set up an area for painting where each participant has enough space to lay down his or her T-shirt.
- 2. Give each participant a piece of scrap cardboard to put inside the shirt.
- 3. Explain the activity; that you are painting shirts that show how you feel about having an allergy, fitting in, or anything else that is important to you.
 - a. ex) "I'm just like you"
- 4. Allow participants to decorate their shirts as desired.

Outcomes: After creating "Who I Am" T-shirts, participants will

- 1. Have examined their feelings about camp and having an allergy, and have a creative outlet to express those feelings.
- 2. Have a better understanding of the feelings of their peers.

Time to Talk it Out!

A Guide to Effective Debriefing

What is a debrief?

A debrief is a conversation held between the facilitator and the participants at the end of an activity to analyze the experience. The facilitator poses openended questions that require the participants to reflect upon, and process the activity; their feelings about, role in, and outcomes of the activity (Green et al., p. 84, 2008).

Why do we debrief?

Empowerment programs create great outcomes and strengthen participants' interpersonal and intrapersonal skills. However, research shows that without a process to help with *transference*, programs are of little lasting value: if we don't equip participants with the ability to transfer skills learned during a program to real life situations, then the gains are quickly lost (Green et al., 2008). By debriefing, we can help participants take what they learn during our activities and use it in their everyday lives.

How do we debrief?

There are many different questions that can be used in a debrief, but should all move the conversation towards an understanding of the relevance of the activity. In this context, it is particularly important to help participants understand the ways these activities can help them manage their allergies. Providing participants the opportunity to give feedback on the activity itself is also a valuable part of a debrief.

Questions to get Started

Questions to get feedback

How did we like that activity?

What was too easy? What was too hard?

Can everyone give me a thumb-o-meter¹ on that activity? (Asking participants to give a thumbs up, thumbs down or somewhere in between)

Questions to process the activity

*What did we do?

*Why did we do that?

*How can we use what we learned?

*These three questions make the most basic framework of the overarching structure of a debrief.

How did we use _____ (leadership, teamwork, or another goal) in that activity?

How can we use that skill in school? At home? In other situations?^{2 3}

¹ This is a visual, silent way of providing feedback that works well in practice to efficiently glean opinions.

² Green, Kleiber & Tarrant, 2000, p. 84; emphasizing metaphorical questions helps most with transference, while other questions help most with processing.

³ Dahlbeck & Lightsey, 2008; use of distance coping, and less use of emotion-focused coping is beneficial to the longterm psychological development of youth with chronic illness as it helps reduce the stressors of the illness. These positive coping mechanisms require the ability to recognize strengths and abilities, which can be an outcome of debriefing.

Evaluation Plan

This plan consists of two sections. The first section is the evaluation of the participants: it includes an evaluation tool to gauge the efficacy of the program in terms of increases in quality of life for participants, via pre and posttest opinions of health related quality of life. The second section is the evaluation of the staff: it includes kitchen logs of recorded incidents, as well as open ended questions to gain feedback on the ease or difficulty of operating the kitchen within the prescribed safety protocols.

Section 1

The Food Allergy Quality of Life Questionnaire - Child Form (FAQLQ-CF) questionnaire was specifically developed to evaluate the impact of having a severe food allergy on a child's quality of life (Flokstra de Blok et al., 2008). The researchers recognized the need to evaluate health related quality of life via the perspective of the child with the food allergy, rather than via a parent proxy. The questionnaire is validated for children ages 8-12 and has high internal consistency. There also exists an adolescent form, if the participants trend towards the 13-15 year age range. While it does not discriminate between children who experience anaphylaxis and those who do not, it does discriminate between children with more than two or fewer than two food allergies (Flostra-de Blok, et al., 2008). The full questionnaire can be found in Appendix E.

Section 2

The evaluation of the program from the staff perspective consists of the kitchen log incident reports, as well as staff interviews. The kitchen log template is located in Appendix F. The purpose of the log is to report any incidents of cross contamination. The log further identifies where the contamination occurred and was discovered, in order to help prevent further cases of cross contamination and to recognize cross contamination before dishes leave the kitchen. The staff interview form can be found in Appendix G. The form focuses on the feasibility of implementing necessary safety precautions while running a full service kitchen. It aims to improve the ability of the staff to follow the program and to simplify the implementation.

Chapter 5

Discussion and Conclusions

Severe food allergy (SFA) is a medical condition that is rising in prevalence and severity and has numerous implications for individuals living with food allergies, their families and communities at large. The purpose of this project was to examine the barriers faced by people, specifically children, living with severe food allergies in order to create an empowerment program to help mediate the challenges faced daily by this population. Important themes to the discussion are the nature of food allergy, implications of food allergies, quality of life issues, and barriers to empowerment. In order to empower children living with SFA, a program was created to enable such children to attend resident camp, a context that can facilitate personal growth. The program is multifaceted: it includes an empowerment program guide, an operation and safety plan, and an evaluation tool to gauge the efficacy of the program from both the provider and participant viewpoints. After outlining the project procedures, there will be a discussion of the conclusions and implications of the program, as well as recommendations for future study and the implementation of the program.

Summary of the Procedures and Outcomes

The project consists of three main components: the Empowerment Plan, the Operations and Safety Plan and the Evaluation.

Empowerment Plan

The Empowerment Program is a series of activities aimed towards aiding participants in perceiving higher health related quality of life, as demonstrated by factors that influence self-efficacy and empowerment: increased feelings of control and competence in managing their allergy, and lower levels of anxiety. The first activity is a brief educational program entitled "Can't Touch This." The program uses books, hand washing activities and visual demonstrations to teach participants, those who may or may not have food allergies, about SFA. This is followed by a series of seven team building activities aimed at improving the participants' abilities to work as a team, communicate effectively, trust others, problem solve, and demonstrate patience. Each activity requires the participants to step out of their comfort zones while practicing skills that will help them feel increased levels of control and competence in managing their allergy, and less anxiety in daily life. A key component of this section is the debrief associated with each activity. Debriefing helps participants to transfer skills from one context to another, which is critical for the program to have lasting effects outside of the residential camp experience.

Operations and Safety Plan

The Operations and Safety Plan is directed primarily towards the staff that works at the residential camp. It covers kitchen operations, dining hall operations, and medical connections. The kitchen operations section provides a guide for how to safely store, prepare and serve food to children with, and without, food allergies. The dining hall

section focuses on ways to keep allergens separate and contained during meal time to provide a safe atmosphere for everyone. The medical connections section suggests ways to connect medical staff to the dining process and plans of action in the event of an allergic emergency.

Evaluation Plan

In order to evaluate the efficacy of the program, evaluations were designed for both participants and kitchen staff. To evaluate the program from the perspective of the participants, the Food Allergy Quality of Life Questionnaire- Child Form (FAQLQ-CF) will be given as a pre- and post-test. This test is a valid, self-administered questionnaire that can be used for children ages 8-12 to reliably evaluate health related quality of life, and discriminate between children with and without multiple allergies (Flokstra de Blok, et al., 2008). Data obtained from the questionnaire will be used to analyze changes in participants' perceived quality of life as a result of the program. This in turn, will demonstrate if the program is effectively increasing self-efficacy and empowerment, which influence quality of life.

To evaluate the program from an operations standpoint, two forms of evaluation are necessary. The first is a Kitchen Log Incident Report where staff will record any incidents of cross contamination that occur. The log further identifies where the contamination occurred and was discovered, in order to help prevent further cases of cross contamination and to recognize cross contamination before dishes leave the kitchen. Additionally, there are staff interviews forms to evaluate the feasibility of implementing necessary safety precautions associated with the program, while running a full service

kitchen. These interviews aim to improve the ability of the staff to follow the program and to simplify the implementation of the program.

Conclusions

Based upon the outcomes, and within the limitations of the project, there is a clear need to increase the quality of life for children with SFA, who tend to live with high levels of anxiety. Measures to enable children to self-manage their allergies and positively cope with the ramifications of their allergies are concluded to be critical in achieving this outcome. It was found that encouraging children to be knowledgeable about their allergy, and allowing them to participate in managing their allergy could build confidence and positive coping skills (Behrmann, 2010). Positive coping techniques are closely linked to knowledge about the allergy, as many children require time and space, known as distance coping, to assimilate the allergy on their own terms (Dalhbeck & Lightsey, 2008). It can be concluded that programs designed to serve children with SFA need to offer such opportunities, and that doing so can increase levels of competence and feelings of control. Means of encouraging self-management of allergies are clear: child friendly labeling of foods, seating arrangements designed for an inherent base level of safety, and the collaboration between the medical staff, dining staff and camper via a Camper Allergy Advocate. Providing a safe environment in which to practice selfmanagement of allergies can also assist in reducing anxiety levels in children, who may never have had the opportunity to manage their own allergy.

Facilitating inclusion and acceptance is also concluded to be important in improving quality of life for children with SFA. Having a severe food allergy can be

isolating, and can result in social separation due to the physical inability to participate in certain activities, such as food sharing, accepting food from others at parties or social gatherings, or even being in close contact with individuals who are consuming an allergen. Improving self-esteem, self-concept and communication skills in children with SFA can help mediate these obstacles. The benefits of a camp experience, adventure-based or not, have been found to be positive experiences for children living with chronic conditions, and are used frequently for children with diabetes and other conditions (Avery et al., 2003). Due to similarities in needs and stressors, such programs could be equally beneficial to children with severe food allergies. The use of an empowerment program in the camp setting to purposely target teamwork, communication and issues regarding self-esteem, paired with a safety program, brings these positive programatic outcomes to children with SFA.

Discussion and Implications

This project challenges most popular beliefs of how to serve children with SFA. Cutting edge guidelines are beginning to work towards inclusion, education and equitable service, but most facilities and programs are not operating at that level. Children who have severe food allergies do not need to be kept in a bubble. Anecdotally, it can be helpful to remember that a child with a peanut allergy can eat just as much dirt as a child with no allergy. Guidelines for serving children with severe food allergies tend to trend in one of two directions, sometimes at the same time. They often over-exaggerate the needs of the child, hyper-sterilizing everything with which the child may come into contact, or they downplay the needs of the child, not taking food restrictions seriously, especially

when it comes to label reading. This can manifest as separating a child from others during mealtimes or singling out a child during an activity that involves food. Oftentimes, safety measures fail to include the child in the process of managing the allergy, which ultimately becomes dangerous as the responsibility of managing the allergy transfers to the individual as they reach adolescence. This program strives to include all individuals in every way possible, while making the child an active participant in the allergy management process in order to facilitate feelings of competence.

The impact of this project will hopefully be further inclusion and better understanding of children with SFA. Currently, there are few camps designed specifically to serve children with food allergies, especially in this part of the country. Camps that do serve children with food allergies are often ill equipped to do so, which results in unnecessary separation of a child with a food allergy. An example of this is the fairly common practice of having parents send pre-packaged meals from home with the child for the entire duration of a camp session. In rare instances this can be a necessary step to supplement camp food, but typically serves to draw unnecessary attention to a child, who would be eating something different from everyone else. Mealtime is a programmatic feature of the camp experience: providing a completely different experience to children with and without food allergies does not facilitate inclusion, nor does it provide an equitable camp experience. The intention is that, by creating this program, more children with SFA can go to camp and have a residential camp experience that mirrors the experience of any other child. This will hopefully impact other organizations and encourage them to be more purposeful in the way they include people with SFA in their programs.

Recommendations

For a future project, it would be ideal to conduct a needs assessment survey with a group of children who have SFA, before targeting project objectives. The objectives identified for this project are based off of the current research, but may not accurately reflect what children with SFA self-identify as the most pressing issues. For example, some children feel quite comfortable being vocal about their needs and restrictions, and thus would not benefit as greatly from a program that places great emphasis on developing communication skills as children who do not feel able to express their needs. A needs assessment could also explore what types of accommodations children feel are helpful, necessary and inclusive, versus what accommodations they feel are unnecessary or draw undue attention. When discussing inclusion, it is always best to consult the person to be included when making decisions. This would make an excellent follow-up study to further improve this program.

To best implement the project, it is recommended that there be an appointed head of the project that will oversee its implementation. The program involves a great number of people in a variety of positions at camp; dining services, health services, program staff, and counselors are all involved. This person may or may not play another role in the program, such as the Food Service Director, Health Director, or Camp Director, but should be someone who is familiar with severe food allergy. This individual would most likely serve as the Camper Allergy Advocate, who would help connect parents, campers, the dining staff, and medical staff in order to provide a safe, positive experience, which is ultimately the highest goal.

Appendices

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Appendix A: Poster for hand washing procedures



Appendix B: Food Allergy and Anaphylaxis Emergency Care Plan

Full sized PDF forms may be accessed at: http://www.foodallergy.org/faap

largy to	0.0.8.: PLACE STUDENT'S PICTURE
Asthma: Ves outper For a suspected or active foo	d allergy reaction:
SEVERE SYMPTOMS If checked, give epinephrine immediately if the allergen was definitely eaten, even if there are no symptoms.	NOTE: WHEN IN DOUBT, GIVE EPINEPHRINE. MILD SYMPTOMS If checked, give epinephrine immediately for ANY symptoms if the allergen was likely eater
LUNG Short of breath, wheezing, repetitive cough SKIN SKIN SKIN SKIN SKIN SKIN SKIN SKI	NOSE MOUTH Itchyhurny noso, sneezing Behy mouth SKIN GUT A few hives, mild itch Mild neusealdiscomfort U I. GIVE ANTIHISTAMINES, IF ORDERED BY PHYSICIAN
NOTE: Do not depend on antitistamines or inhales (bronchodilators) to treat a severe reaction. Use Epirephrine. 1. INJECT EPINEPHRINE IMMEDIATELY. 2. Call 911. Request ambulance with epinephrine.	Stay with student; alert emergency contacts. Watch student closely for changes. If symptoms worsen, GIVE EPINEPHRINE.
Consider giving additional medications (following or with the epinophrine): Antihistamine Inhalse (bronchodilator) if asthma Lay the student flat and raise legs. If breathing is difficult or they are veniting, let them sit up or lie on their side. If symptoms do not improve, or symptoms seturn, more does of epinophrine can be given about 5 minutes or more after the last dose. Alter emergency contacts. Transport student to ER even if symptoms resolve. Student should remain in ER for 4+ hours because symptoms may return.	MEDICATIONS/DOSES Epinephrine Brands Epinephrine Dose

Appendix C: EpiPen Administration

The following poster should be displayed prominently in the Dining Hall, Health Center, and with camper's FAAEAP.

Step-by-step instructions should be reviewed with all staff members.



3-step, easy-to-follow instructions⁴

How to use the EpiPen® (epinephrine) Auto-Injector

Prepare the EpiPen or EpiPen Jr® Auto-Injector for injection

- Remove the auto-injector from the clear carrier tube
- Flip open the yellow cap of your EpiPen or the green cap of your EpiPen Jr Auto-Injector carrier tube
- Tip and slide the auto-injector out of the carrier tube
- Grasp the auto-injector in your fist with the orange tip pointing downward
- With your other hand, remove the blue safety release by pulling straight up without bending or twisting it

Never-See-NeedleTM delivers built-in needle protection

- Protects against needle exposure before and after use. The needle comes out of the orange tip
- Never put your thumb, fingers, or hand over the orange tip

Administer the EpiPen or EpiPen Jr Auto-Injector

- Hold the auto-injector with the orange tip near the outer thigh
- Swing and firmly push the orange tip against the outer thigh until it "clicks"
- Keep the auto-injector firmly pushed against the thigh at a 90o angle (perpendicular) to the thigh
- Hold firmly against the thigh for approximately 10 seconds to deliver the drug
- The injection is now complete
- Massage the injection area for 10 seconds

-

⁴ www.epipen.com

Finalize the injection process

- Remove the auto-injector from the thigh (the orange tip will extend to cover the needle)
- Massage the injection area for 10 seconds

Get emergency medical help right away

Appendix D:

References

The following sources are good references if you have further questions about including campers with food allergies and how to best serve their needs:

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Appendix E: Kitchen Log Incident Report

Date	Time	Incident	Location where identified	Staff Signature
7/13	4:55 pm	A traditional pizza was sent to a table with campers who are gluten free without a "not GF" sticker	En route to the table, by a camper who noticed that the crust looked different from the other GF pizzas	AJD

Appendix F: FAQLQ-CF

Appendix A: Food Allergy Quality Of Life Questionnaire - Child Form (8-12 years)

Instructions The questions are about the influence of your food allergy on your quality of life. It is important that you fill out the answers yourself. You may ask your parents for help, but they are not allowed to tell you which answer to give. Answer every question by putting an 'x' in the proper box. You may choose from the following answers. not barely fairly extremely How troublesome do you find it, because of your food allergy, that you . . . must always watch what you eat? 2 can eat fewer things? 3 are limited in buying things you like? have to read labels? П П П П П П have to refuse food when you do things with others? П can less easily stay for a meal with someone? П 7 can taste or try fewer things when eating out? have to tell beforehand about what you are not allowed to eat when eating out? 8 have to check yourself whether you can eat something when eating out? П П П П П П 9 hesitate eating certain foods when you don't know if it is safe? must watch out when touching certain foods? don't get anything when someone is giving treats at school? How troublesome is it, because of your food allergy, . . . П that the ingredients of a food change? that the label states: 'May contain traces of ...'? that you have to explain to people around you that you have a food allergy? П П that people around you forget that you have a food allergy? П П П П П that others can eat the food you are allergic to when you do things with other people? that you don't know how things taste which you can't eat? How frightened are you because of your food allergy . . . of an allergic reaction? of eating the wrong food by accident? to eat something you have never eaten before? Answer the following questions: (How concerned are you that you will never get rid of your food allergy? How disappointed are you when people don't take your food allergy into account? П

24 How disappointed do you feel because you have a food allergy?

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Appendix G: Staff Interview Form

The following survey aims to help improve the Operations and Safety Plan portion of the Can't Touch This program. Please answer each question based on your experience this past season.

Answer the following questions on a scale of 1 to 5; 1 being strongly disagree and 5 being strongly agree.

The Operatio	ns and	Safety	Plan w	as easy	to impl	ement	
Strongly disagree	1	2	3	4	5	Strongly agree	
The Operatio	ns and	Safety	Plan w	as effec	tive at 1	preventing cross contamination	
Strongly disagree	1	2	3	4	5	Strongly agree	
•	-				•	ability to prepare meals on a large so	ale
Strongly disagree	1	2	3	4	5	Strongly agree	
I understand	how to	preven	t cross	contam	ination	in the kitchen	
Strongly disagree	1	2	3	4	5	Strongly agree	
I believe we	should	use this	s progra	am in th	e future	e when serving children with SFA	
Strongly disagree	1	2	3	4	5	Strongly agree	

Please answer the following questions in your own words, based on your experiences this season.

What was the most challenging part of implementing the Operations and Safety Plan?

What safety measures were the easiest to implement?

What aspect of th	e plan do you	ı think most	needs to	be improved?

Was there any part of the Operations and Safety Plan that you did not understand?

How could we simplify the Operations and Safety Plan for future seasons?

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