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Illness Uncertainty, Ways of Coping, and Psychological Adjustment Among 18--25-Year-Olds with Anaphylactic Food Allergy

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ABSTRACT

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by

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M.S., Walden University

B.A., University of Pittsburgh

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

The prevalence of food allergy is increasing, with adolescents and young adults being the group most likely to die from food-induced anaphylaxis. Behavioral and psychological factors contribute to this risk. This study investigated the relationship between illness uncertainty (as measured by the Mishel Uncertainty in Illness Scale Community Form) and emotion- and problem-focused coping (as measured by the Ways of Coping Scale), to see if they contributed to psychological adjustment (as measured by the Depression Anxiety Stress Scale-21) in this population. A cognitive diathesis-stress model was used to explain individual differences in adjustment. Multiple regression was used to test illness uncertainty and coping as moderators and mediators of psychological adjustment. Participants ($N = 36$) were recruited from Internet support groups and social networking sites; the survey was administered online. Illness uncertainty was predictive of psychological adjustment among the entire sample as well as the portions of the sample with more episodes of anaphylaxis and those with exercise-induced anaphylaxis. Emotion-focused coping was positively and significantly associated with depression, anxiety, and stress. Both emotion- and problem-focused coping were significant and positively related to the increased anxiety associated with the number of episodes. This study contributes to positive social change by helping medical practitioners and families recognize characteristics associated with poorer psychological adjustment. Uncertainty will remain a feature of this illness until a treatment or cure is found, but these results can help individuals, families, and providers understand and mitigate specific aspects of uncertainty.

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Dedication

To everyone who lives with anaphylaxis.

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Chapter 1: Introduction to the Study

Background

Food is necessary to maintain life and health. People's relationships to food help construct their identities (Caplan, 1997), and the cliché that "you are what you eat" signifies more than the substance. Food contributes to cultural identity through dietary rules and practices, operates as a metaphor for love and sensuality, has a symbolic and spiritual role in ceremonies and celebrations, and is a ubiquitous part of social gatherings. For people with severe food allergies, eating the wrong foods can be fatal, and participating in the social norms of food experiences is fraught with danger. An anaphylactic food reaction can result in death from respiratory or cardiac arrest within minutes to hours of eating an allergenic food. There is no cure for food allergy, so avoiding foods that trigger a reaction and being prepared to treat a medical emergency is the basis of disease management (Branum & Lukacs, 2008). Most cases of anaphylaxis from food can be reversed or delayed by an injection of epinephrine (Jowett, 2000; Pumphry, 2000; Sampson et al., 2005). Successful management requires vigilance in questioning the ingredients and handling of foods, since even trace amounts of an allergenic food can trigger an anaphylactic reaction (Leitch, Walker, & Davey, 2005; Simons, 2006). But even when care is taken, accidents occur (Anibarro, Seoane, & Mugica, 2007; Martelli et al., 2008; Munoz-Furlong, 2003).

Because of the important role food has in facilitating social events and establishing identity, vigilance can give way to the need for acceptance by a group. This troubled relationship has the potential to interfere with healthy emotional and social

adjustment (Shaw, 2001). These difficulties are most pronounced in adolescence and young adulthood, as evidenced by this age group's heightened risk for death from food-induced anaphylaxis (Bock, Munoz-Furlong & Sampson, 2007; Munoz-Furlong & Weiss, 2009; Sampson, Mendelson, & Rosen, 1992). Uncertainty regarding how to manage severe food allergies may play a role in coping processes and psychological adjustment.

Food allergy affects 6% of young children and 3-4% of adults in Western countries. The prevalence is increasing, but the reasons are not clear (Sicherer & Sampson, 2009). Moneret-Vautrin (1998) suggests that part of the increase may be due to the increasing use of food proteins (e.g., caseinates, alpha-amylase, lactase) as ingredients in foods. Methods of food preparation may also be implicated. Dry roasting of peanuts is common in the United States but it makes them more allergenic than boiling or frying them. In China, peanuts are consumed at the same per capita rate as in the U.S., but they are predominantly fried or boiled and the rate of allergy is much lower (Vierk, Koehler, Fein, & Street, 2007). Environmental influences thought to contribute to food allergy include the hygiene hypothesis (where the immune system has less experience dealing with bacteria and infections), decreased consumption of omega-3 fatty acids, an increased consumption of omega-6 fatty acids, and reduced dietary antioxidants (Sicherer & Sampson, 2009). Early exposure to food proteins through breast milk (Vadas, Wai, Burks, & Perelman, 2001) and early inclusion of foods is also suspected (Mahoney, Sampson, Sicherer, & Burk, 2006).

The literature shows that uncertainty exists in many areas of food allergy management: knowing the ingredients in food (Anibarro et al., 2007), knowing how to

use epinephrine; recognizing and treating symptoms in a timely way (Kim, Sinacore, & Pongracic, 2005; Lyons & Forde, 2004); inadequate or conflicting medical advice (Akeson, Worth, & Sheikh, 2007). When uncertainty is high, vigilance is an often used coping strategy (Mishel, 1988). When uncertainty is prolonged, vigilance can give way to cognitive exhaustion and learned helplessness (Sedek & Kofta, 1990). Denial and other less adaptive forms of coping may result (Lazarus, 1999; Mishel, 1988). In social situations, uncertainty often appears to be expressed as denial, and risk-taking ensues (Sampson, Munoz-Furlong, & Sicherer, 2006; Sharma et al., 2008), particularly among young adults where the need for acceptance by the peer group is high (Erikson, 1950). Most food allergies are diagnosed in childhood and research on families coping with anaphylaxis in a child shows that families experience high levels of stress, have decreased quality of life (QOL), and higher levels of anxiety (Leung, Yung, Wong, Li, & Wong, 2009; Avery, King, Knight, & Hourihane, 2003; Mandell, Curtis, Gold, & Hardie, 2002; Primeau et al., 2000). Such a family environment may contribute to a developmental vulnerability to adjustment problems (Gibb, & Coles, 2005).

Knowing the ingredients in foods is essential to effective management but requires reading food labels. The Food Allergen Labeling and Consumer Protection Act (2004) made this easier by requiring companies to clearly label foods by their common names (e.g., milk, not casein) for the eight most common food allergens. Many foods change ingredients over time and food labels should be read every time a person eats a food. There are also regular occurrences of mistaken labeling or production errors that result in inaccurate labeling (Food Allergy and Anaphylaxis Network [FAAN], 2009).

Eating at restaurants is especially dangerous because labels typically are not accessible and often wait staff provide false assurances (Furlong, DeSimone, & Sicherer, 2001; Leitch et al., 2005). Many adolescents and young adults do not want to call attention to themselves by doing a thorough investigation nor to interfere with the social norms associated with eating. Thus, they decide to go ahead and take a chance (Sampson et al., 2006). For example, Goldbert (1969) provides the first case series description of anaphylactic reactions to food among individuals who presented to an emergency room for treatment. One case describes a 24-year-old male who ate a shrimp casserole prepared by his girlfriend to avoid insulting her, even though he knew he was allergic to the shrimp. In a focus group discussion with adolescents and young adults, aged 13–21 years (*N*=19), with multiple and severe food allergies, Sharma et al. (2008) reported that half of the participants ate foods that were dangerous and did not always carrying epinephrine . They found that effective management of food allergies was impeded by factors such as feeling different or isolated, lack of food labels, and social embarrassment. Management was facilitated by knowledge of adverse consequences, planning, supportive friends, and social confidence.

Problem Statement

Adolescents and young adults with severe food allergy are confronted with illness-related stressors that could place their psychosocial adjustment at risk. They are the group most likely to die from anaphylactic food reactions (Bock, Munoz-Furlong, & Sampson, 2001; Yunginger et al., 1988). Factors associated with these deaths include the failure to carry and/or use epinephrine, eating away from home (Munoz-Furlong &

Weiss, 2009), and denial of symptoms (Yunginger et al., 1988).

Some research examines risk-taking behaviors among adolescents (Akeson et al., 2007; Sampson et al., 2006; Sharma et al., 2008), but there is very little research into psychological adjustment (Herbert & Dahlquist, 2008) or coping among adolescents and young adults with severe food allergy (Sampson et al.). *Illness uncertainty* is a cognitive variable associated with psychological adjustment and different coping styles (Lazarus & Folkman, 1984; Mishel, 1988). When uncertainty is high, coping resources may be perceived as inadequate, and contribute to adjustment problems (Mullins, Chaney, Pace, & Hartman, 1997). By understanding whether illness uncertainty and ways of coping can predict psychological adjustment among 18–25-year-olds with severe food allergy, better ways to promote more effective self-management may emerge.

Nature of the Study

This correlational study used an Internet-based survey to study 18-25 year olds with anaphylactic food allergies. Regression analysis was conducted to see if measures of illness uncertainty and coping processes predict psychological adjustment. The mediating and moderating effects of illness uncertainty and coping processes were examined.

Research Question and Hypotheses

The moderator hypotheses surround whether, and to what extent, illness uncertainty is predictive in its effect on adjustment by coping. This is done by testing for the direct effects of illness uncertainty on adjustment, the direct effects of coping on adjustment, and the direct effects of illness uncertainty in the presence of the different

coping factors on adjustment factors. Moderators identified in the study were also tested as mediators (Baron, & Kenny, 1986).

H_0^1 : Illness uncertainty, as measured by the Mishel Uncertainty in Illness Scale - Community Form (MUIS-C), has no effect on adjustment as measured by the Depression Anxiety Stress Scale (DASS)-21.

H_a^1 : Illness uncertainty, as measured by the MUIS-C, has an effect on adjustment as measured by the DASS-21.

H_0^2: Coping, as measured by the Ways Of Coping scale (WOC), has no effect on adjustment as measured by the DASS-21.

H_a^2: Coping, as measured by the WOC, has an effect on adjustment as measured by the DASS-21.

H_0^3: Illness uncertainty, as measured by the MUIS-C, in the presence of coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

H_a^3: Illness uncertainty (as measured by the MUIS-C) in the presence of coping (as measured by the WOC) has an effect on adjustment as measured by the DASS-21.

H_0^4: Illness uncertainty (as measured by the MUIS-C) does not mediate the effects of coping (as measured by the WOC) on adjustment (as measured by the DASS-21).

H_a^4: Illness uncertainty (as measured by the MUIS-C mediates the effects of coping (as measured by the WOC) on adjustment (as measured by the DASS-21).

Purpose

The purpose of this study was to determine whether and to what extent, illness uncertainty and coping processes affect psychological adjustment among 18-25-year-olds

with anaphylactic food allergies recruited from Internet support groups and social networking sites.

Theoretical Basis

This study used the cognitive diathesis-stress model to understand how individual differences in vulnerability, appraisal, and coping impact psychological adjustment to illness. This model (Abramson, Metalsky, & Alloy, 1989; Beck, 1987) describes an individual's propensity to negative information processing biases. This bias can contribute to the development of adjustment problems and psychopathology, especially depression and anxiety, when negative life events occur. Vulnerabilities can arise from social, psychological, or biological factors that interact with stress to increase the formation of negative cognitive schema (Burke & Elliott, 1999). Illness uncertainty is a cognitive state and a significant stressor for most people (Mishel, 1988).

The transactional theory of stress and coping describes appraisal processes, which are information-processing variables that provide ongoing feedback on the relationship between the person and environment. Individual appraisal of events determines if they are perceived as neutral, a threat, or a challenge. Options for coping are based on the appraisal and personal resources. Problem-focused coping strategies are generally considered more adaptive, but they too vary based on the nature of the threat or challenge. When coping resources are not sufficient to the task, adjustment problems can develop (Lazarus & Folkman, 1984).

Definition of Terms

Terminology associated with allergy and the immune system is provided along with the psychological constructs used in this study.

Adjustment disorder. Psychological and behavioral reactions to identifiable stressors characterized by anxiety, depression, conduct disorder, and social withdrawal. Reactions can be acute or chronic if the stressor is chronic as in chronic illness (APA, 2000).

Allergen. Any substance that stimulates an abnormal immune response in those who have been previously sensitized (*Taber's Cyclopedic Medical Dictionary*, 2005).

Allergy. An immune system response to a foreign antigen. After the immune system has become sensitized to an antigen, subsequent reactions result in the activation of immune system cells such as mast cells, basophils, and T cells which release inflammatory chemicals that act locally or systemically to create allergic symptoms. Symptoms from reactions can range from annoying to life-threatening (*Taber's Cyclopedic Medical Dictionary*, 2005).

Anaphylaxis. A potentially life threatening systemic allergic reaction with symptoms of itching, swelling, wheezing, hypotension, gastrointestinal distress, and an impending sense of doom. Respiratory collapse can result from laryngeal edema and severe hypotension can progress to cardiac arrest (Simons, 2008). Symptoms may occur immediately or within 2 hours after exposure and may present in different combinations in the same individual in response to the same allergen (Schwartz, 2004). Reactions occur most commonly in response to food, medications, insect stings, and latex, but they may

also be triggered by inhalation exposure to foods, especially fish; food dependent exercise induced (when a food alone doesn't trigger anaphylaxis, but does when exercise occurs within 2-3 hours of eating the food); or idiopathic reasons (FAAN, 2009). It usually responds to emergency treatment with epinephrine and steroids, but some cases will not respond to treatment even when received in a timely manner (Pumphry, 2000).

Antigen. A protein marker on the surface of cells that identify them as self (auto-antigen) or non-self (foreign antigen). Damaged auto-antigens and foreign antigens will stimulate B lymphocytes to produce antibodies that will destroy the cell and stimulate an inflammatory response (*Taber's Cyclopedic Medical Dictionary*, 2005).

Appraisal. The process of evaluating a stimulus as benign, a challenge, or threat. Individual differences in appraising the relation of the self to the environment are based on differences in goals, beliefs, and personal resources, and underlie the flow of emotional states (Lazarus, 1999).

Cognitive diathesis-stress model. An information processing model with social, cognitive, and biological components that interact to increase the formation of negative cognitive schema of the self and the world (Burke & Elliott, 1999). Vulnerabilities result from the experience of life stress and individual difference, and can emanate from childhood experience, parenting style, family relationships, physical disability, or genetic predisposition (Slavik & Croake, 2006).

Chronic illness. An extended illness that is rarely cured and often leads to disability and decreased quality of life (Center for Disease Control and Prevention [CDC]), 2009).

Coping. The range of emotional, cognitive, and behavioral responses, adaptive or not, used to manage stress (Lazarus & Folkman, 1984).

Eosinophilic gastroenteropathies. This describes the infiltation of eosinophils (white blood cells) anywhere along the digestive track from the mouth to the anus. Eosinophilic esophogitis describes infiltration of the esophagus. Symptoms include reflux and regurgitation, difficulty swallowing, epigastral and abdominal pain, and poor eating. Symptoms that arise when lower portions of the digestive system are involved include abdominal pain, bloating, diarrhea, weight loss, and difficulty swallowing. Symptoms are often worsened when allergenic foods are ingested (Liacouras, 2007).

Food allergy. An adverse immune responses to food proteins (Sicherer & Sampson, 2009). This definition distinguishes food allergy from other adverse food reactions such as food intolerance, lactose intolerance, and celiac disease which do not involve an immune response to food (Vierk et al., 2007). Eight foods are responsible for 90% of food allergies: Fish, shellfish, tree nuts, peanuts, milk, egg, wheat, and soy, although any food can be an allergen (Branum, & Lukacs, 2008).

Illness Uncertainty. Illness uncertainty is a cognitive state that occurs when illness related events do not fit into an individual's existing cognitive schema and meaning for the event cannot be established (Mishel, 1988).

Mediators. Variables that can act as independent or dependent variables depending on the focus of the analysis. Mediators help elucidate why effects occur (Baron & Kenny, 1986).

Moderator. A qualitative or quantitative variable that influences the direction

and/or strength of the relationship between independent (predictor) variables and dependent (criterion) variables (Baron & Kenny, 1986).

Psychological Adjustment. The presence or absence of psychological symptoms, disorders, and/or negative mood. Psychological adjustment to chronic illness requires adaptation in many life domains (Stanton, Revenson, & Tennen, 2007).

Stress. A situation appraised as exceeding personal coping resources and endangering personal well being (Lazarus & Folkman, 1984).

Assumptions

This study assumes that there are adjustment problems among individuals with anaphylactic food allergies, and that these problems can be sampled from Internet groups. It is assumed that participants are willing to participate and will tell the truth.

Limitations

This study used a self-selected convenience sample from Internet support groups rather than a random sample. Responses were not representative of the larger group of 18-25-year-olds with food anaphylaxis, and only addressed illness uncertainty, coping, and adjustment based on the identified scales. This study was cross-sectional rather than longitudinal. A longitudinal study could better describe how problems develop in this population, but the time and cost required of such a study are prohibitive. All data are derived from self-report rather than experimental manipulation or external observation.

Scope and Delimitations

This study covers 18-25-year-old self-selected Internet users who visit food allergy support group Web sites and who have experienced food-induced anaphylaxis. It

does not attempt to cover other age groups, people who do not use the Internet, or other people with food allergy who have not experienced anaphylaxis.

Significance

Every year, 150–200 people die in the U.S. from food-induced anaphylaxis (Sampson et al., 2006). There are no data on how many more people suffer lasting injury (Pumphry, 2000). A disproportionate number of the deaths are adolescents and young adults, and among this group, psychological and behavioral factors have been implicated (Bock et al., 2007; Munoz-Furlong, & Weiss, 2009; Sampson et al., 1992; Sharma et al., 2008). Adjustment problems among individuals with severe food allergy are not well understood in the medical community (Warmington, 2005). A body of qualitative research has shown lower QOL among families with food allergic children (Avery et al., 2003; Leung et al., 2009; Masia, Mullen, & Scotti, 1998; Mandell et al., 2002; Primeau et al., 2000). Risk taking and coping have been studied (Bock et al.; Sharma et al.), and Herbert and Dahlquist (2008) identified a history of anaphylaxis, perceived severity of illness, and resulting worry as potential risk factors for psychological distress among food allergic young adults.

This study looked at the joint effect of uncertainty and coping on psychological adjustment. Positive social change may result if these issues are better understood and if health care professionals learn how and when to intervene. This study looked specifically at adjustment problems in this population to help to lay the foundation for understanding these issues and educating these professionals.

Summary

Chapter 1 introduced the topic of severe food allergies and described how vigilance and preparation to manage a medical emergency are the cornerstones of treatment. As adolescents and young adults take on responsibility for managing the disease, the necessity of vigilance seems to give way to needs for social acceptance and uncertainty as to what the risks really are and how to best manage them. Differences in how individuals cope with uncertainty may affect psychological adjustment. The purpose of this correlational design is to examine the predictive value of illness uncertainty and coping processes on psychological adjustment and also to examine the extent that coping processes are mediated by illness uncertainty in their effects on adjustment.

Chapter 2 describes the current understanding of food allergy and the pathophysiology and epidemiology of anaphylaxis. The chapter continues with a review of the literature of the cognitive diathesis-stress model and the role of appraisal in determining stress and coping. Literature on psychological aspects of living with severe food allergies is reviewed and areas where illness uncertainty and coping processes likely affect outcomes are identified. Chapter 2 concludes with a review of research on illness uncertainty, and a review of the issues that people with severe food allergy cope with in managing their illness.

Chapter 3 outlines the methodology of the present study including a description of the instruments used to measure illness uncertainty, coping processes, and psychological adjustment. Information on the analysis used to determine the number of participants, recruiting methods, design, data analysis, and ethical considerations will be included.

Chapter 4 provides the results of the present study and chapter 5 discusses the results and how the findings might be applied.

Chapter 2: Literature Review

Introduction

This chapter examined the scientific literature on food allergy and anaphylaxis. and provided a discussion of the pathophysiology and epidemiology of the condition. Psychological adjustment to chronic illness was also discussed. The psychological and social consequences of living with a severe food allergy were discussed within the framework of the cognitive diathesis-stress model. Illness uncertainty and its effects relative to other illnesses, and coping processes, both adaptive and non-adaptive that arise from uncertainty were also reviewed. Coping processes relative to anaphylaxis and its management issues were put into context.

The literature search for this study was conducted using the Pubmed, Ebsco, Medline, and Sage databases. Literature searches used terms such as *anaphylaxis*, *food allergy*, *food sensitivity*, *quality of life*, *coping*, *anxiety* and *psychosocial*. Web resources such as the *Food Allergy and Anaphylaxis Network*, the *CDC*, and *National Institutes of Health* (NIH) were used.

Food Allergy and Anaphylaxis

Food allergy involves the activation of the immune system in response to food proteins that the body mistakenly identifies as harmful (Sicherer & Sampson, 2009). Symptoms of food allergy can cover a range of severity, from mild itching and upset stomach to anaphylaxis, which can lead to death within minutes to hours of eating a food (Branum & Lukacs, 2008). Chronic conditions such as asthma and eczema are also recognized as food allergic processes and their presence increases the risk of anaphylactic

food reactions (Sicherer & Sampson). Eosinophilic gastroenteropathies are also recognized as food-allergic diseases, where chronic elevations in eosinophils infiltrate tissue anywhere along the gastrointestinal track leading to digestive problems; however, their associated risk for anaphylaxis is not clear (Hong & Vogel, 2009; Liacouras, 2007; Sicherer & Sampson). Food allergy is often attributed to a variety of food problems by the general public, including lactose intolerance, celiac disease, and even mild cases of food poisoning (Vierk et al., 2007). The potentially life-threatening aspect of food allergy is often not well understood by physicians nor the general public (Gupta et al., 2008; Lyons & Forde, 2004; Marklund, Wilde-Larsson, Ahlstedt, & Nordstrom, 2007; Warmington, 2005).

Anaphylaxis is a life-threatening, systemic, allergic reaction. It is characterized by severe hypotension, wheezing, gastrointestinal distress, an impending sense of doom, and upper airway obstruction. Precipitating events include insect stings, foods, drugs, latex, and exercise (Golden, 2004). The onset of symptoms can occur immediately or within 2 hours of exposure to an allergen (Simons, 2008). Inhalation exposure to foods, especially fish, can also trigger anaphylaxis (Anibarro et al., 2007; Munoz-Furlong, 2003). Many cases of exercise-induced anaphylaxis are thought to be triggered by foods which, by themselves, do not activate anaphylaxis, but do so when exercise follows within several hours of eating the offending food (Golden, 2004). Exercise-induced anaphylaxis is rare. Our current understanding of this condition is based on case studies and reviews (Robson-Ansley & Toit, 2010). Food exposure can occur in unexpected

ways and cases of anaphylaxis have resulted from kissing a person or being licked by a dog soon after eating an allergenic food (Munoz-Furlong).

Symptoms of anaphylaxis can present in different combinations, which can complicate recognition of symptoms early in the reaction by both the person experiencing it and physicians treating it (Schwartz, 2004). Since there is no diagnostic test for anaphylaxis, diagnosis depends on clinical recognition (Golden, 2004). Systems commonly involved in anaphylaxis include respiratory, cardiovascular, integument, and gastrointestinal. Differences exist in the medical literature as to whether one or two systems need to be affected to diagnose anaphylaxis. Cardiovascular collapse or acute airway obstruction alone are sufficient to diagnose anaphylaxis, but activation of a cutaneous reaction with symptoms of urticaria (rash and hives) and angioedemia (swelling) would be considered a mild allergic reaction and would need to be accompanied by another symptom (e.g., respiratory, gastrointestinal, cardiovascular) to meet the diagnostic threshold for anaphylaxis (Golden, 2004).

Four patterns of anaphylactic reactions have been identified; immediate, biphasic, protracted, and delayed. Both immediate and biphasic reactions have an immediate component, but biphasic reactions show a recurrence of symptoms, which are usually more severe, occur 2-6 hours after initial onset, and often recur after the situation was thought to be resolved. Approximately 25% of cases of fatal or near fatal anaphylaxis occur in the second phase of a biphasic reaction (Golden, 2004). Protracted anaphylaxis describes a situation where symptoms are resistant to treatment, last from 5-32 hours, and

often involve hypotensive shock and respiratory compromise. Protracted or biphasic reactions occur in 20% of food-induced reactions (Simons, 2008).

There are no effective treatments for food allergy and strict avoidance of allergens and emergency preparedness are the cornerstone of disease management. Emergency treatment of anaphylaxis requires parenteral administration of epinephrine (Branum & Lukacs, 2008). Reactions to food can be immediate or slow. Where onset of symptoms is rapid, cases have been associated with greater severity (Golden, 2004). However other researchers warn of worse reactions to food when the onset and progression of symptoms is slow, particularly when urticaria is not present (Sampson et al., 1992). Administration of epinephrine early in the course of a reaction can mitigate its course and severity (Jowett, 2000). Children who had epinephrine administered early in the course of a reaction were significantly less likely to need repeated doses and were less likely to be hospitalized (Gold, 2003) . But anaphylaxis can be resistant to epinephrine, steroids, and fluid replacement (Simons et al., 2007), and there are some cases where death will result no matter how good the care (Pumphry, 2000).

Allergy testing is done by skin prick tests where the size of the resulting wheal, or prick, is measured and interpreted as positive or negative. Food-specific serum immunoglobulin E (IgE) antibodies are also an indication of allergy, but sensitization can be asymptomatic. For instance, 8.6% of the U.S. population is sensitized to peanuts, but only 0.4% show clinical symptoms. An oral food challenge is the most definitive test, where a suspected food is eaten in a controlled medical environment. Thirteen percent of children with negative skin tests are clinically reactive when given a food challenge

(Roberts, 2005; Sicherer & Bock, 2006). Allergy testing usually shows an association between the strength of an allergic response elicited from testing with subsequent reactions, but testing cannot predict which patients are most likely to react, nor the likely severity of the reaction (Golden, 2004). Most cases of food-induced anaphylaxis occur unpredictably in the community despite preventative efforts (Simons, 2007). The average risk of the recurrence of anaphylaxis from foods is once every two years (Martelli et al., 2008).

Pathophysiology

Food allergy and anaphylaxis are associated with a genetic predisposition that leads to allergen-specific B lymphocytes producing IgE antibodies which bind to high-affinity receptors on mast cells and basophils, although the specific genes involved have not been identified (Sicherer & Sampson, 2009). Activation of these effector cells results in degranulation and the release of inflammatory mediators that elicit a systemic anaphylactic response (Jensen-Jarolim & Untersmayr, 2008). A large number of inflammatory mediators are implicated in anaphylaxis; histamine, heparin tryptase, chymase, and tumor necrosis factor are preformed mediators residing inside mast cells and basophils. Platelet-activating factor, nitric oxide, and leukotrienes are generated within minutes of activation by mast cells and basophils. Interleukin (IL)-4 and IL-5 become active over the course of hours. Platelets, eosinophils, monocytes, endothelial cells, and antigen presenting cells also play a role in generating and maintaining the inflammatory response (Simons, 2007).

Mast cells are most abundant in the cardiovascular, cutaneous, respiratory and gastrointestinal systems, but mast cells in any organ may be involved. Histamine can cause smooth muscle contraction of the bronchia and gastrointestinal track, relax the vascular smooth muscle, and increase the permeability of postcapillary venules (Schwartz, 2004). Histamine is also a potent vasodilator of both arteries and veins, and is released early in the course of an allergic reaction. The resulting increase in venous capacity causes decreased venous return. Hypotension is also associated with nausea, vomiting, dyspnea, diaphoresis, collapse, and unconsciousness. Shock occurs from the convergence of various components of hypovolemia such as capillary fluid leak, vasodilation, reduced cardiac contractility, and bradycardia. Pulmonary vasospasm can also contribute by reducing left ventricular filling (Brown, 2007; Simons, 2007).

Mast cells play a role in both acquired and innate immunity and they play a central role in hypersensitivity reactions. In cases of IgE-mediated anaphylaxis, the specific allergen must be presented to B cells for sensitization to occur. Sensitization occurs during an initial experience with the antigen/allergen, and anaphylaxis is possible with subsequent exposures (Schwartz, 2004). When a systemic reaction occurs on first exposure to a substance, the reaction is called anaphylactoid, since it is not mediated by IgE. Anaphylactoid reactions elicit the same symptoms as anaphylaxis and require the same emergency treatments, but the path of mast cell activation differs (Ring, Brockow, & Behrendt, 2004).

Anaphylactic reactions can elicit different symptoms in response to different doses of an allergen at different points in time. A synergistic effect may occur with

medication, alcohol use, exercise, and infection (Pumphry, 2004). Allergies are more frequent in males under the age of 15, but adolescent girls experience more respiratory allergies, asthma, severe food allergies, and anaphylaxis than males by a 60:40 ratio. Estrogen has receptors on mast cells that mediate the effector phase activation of allergy. The threshold for IgE induced degranulation is down regulated in the presence of estrogen which may account for some of the difference in allergen reactivity (Jensen-Jarolim & Untersmayr, 2008).

Epidemiology

Three million children (3.9%) in the United States had reported food allergy in 2007 (Branum & Lukacs, 2008). This is an 18% increase over the 10-year period from 1997 to 2006 with increases seen among preschool and school age groups. Peanuts, tree nuts, fish, shell fish, milk, eggs, soy, and wheat are responsible for triggering 90% of food allergies. Hospital discharge data shows that hospitalizations that included at least one diagnosis related to food allergy increased more than threefold during this 10-year period with approximately 9,500 cases in 2006. Food allergy is more common in children, especially those under age 5. Frequency among boys and girls is similar. Hispanics had lower rates than non-Hispanic whites or non-Hispanic blacks. Asthma and other allergies occur more often in children with food allergy (29%) than in children without food allergy (12%) and the presence of asthma is a risk factor for anaphylactic reactions. The majority of children outgrow their food allergies, but for many people, food allergy remains a lifelong problem (Branum & Lukacs, 2008).

The epidemiology of anaphylaxis is not conclusive since there is no reporting requirement when episodes occur. In an estimate from published studies (Golden, 2004), 35% of cases of anaphylaxis are caused by food, 20% by drugs, 20% by insect stings, 3% allergen vaccines, 5% exercise, and 20% idiopathic. A substantial amount of exercise-induced anaphylaxis and idiopathic causes are suspected of being food induced (Golden, 2004). An estimated 30,000 episodes of food induced anaphylaxis occur in the U.S. each year and 150 deaths (Lieberman & Anderson, 2007). Peanuts and tree nuts are the most common cause (Bock et al., 2007). Pumphry (2004) reports that patients with cognitive and memory problems resulting from cerebral anoxia during anaphylactic reactions are regularly seen in clinic, but no statistics are available for this outcome. Respiratory arrest occurred in a majority of fatal food anaphylactic cases identified in the United Kingdom (Pumphry, 2000) and nut deaths in the United States (Bock et al., 2007), and there are likely additional cases of death from acute asthma where the food allergy went unrecognized (Pumphry, 2000). There is a widespread belief that the true incidence of food induced anaphylaxis is underreported (Gaeta, Clark, Pelletier, & Camargo, 2006; Kumar, Teuber, & Gershwoin, 2005; Pumphry, 2000; Sampson et al., 1992).

The characteristics of people most at risk for a fatal food induced anaphylactic episode include being a teenager or young adult, not asking what ingredients are in food, not carrying epinephrine, eating away from home, having inadequate information from health care providers, and failure to recognize and treat symptoms when they occur (Munoz-Furlong & Weiss, 2009). The concomitant use of alcohol, denial of symptoms, reliance on oral antihistamines, and adrenal suppression from chronic treatment with

glucocorticoids for asthma have also been associated with fatal reactions (Yunginger et al., 1988).

Psychological Adjustment

Psychological adjustment refers to the presence or absence of psychological symptoms and can have physiological, emotional, behavioral, and cognitive dimensions (de Ridder, Greene, Kuijer, & van Middendorp, 2008). When a person develops a chronic illness, adjustments need to be made to their life circumstances to cope with the demands of the illness. The adjustment process varies with individuals, different diseases processes, and the course of the illness. An individual's response to acute and ongoing stress and the resulting distress accounts for problems in psychological adjustment (Stanton et al., 2007). When stressors are formative, they can increase vulnerability or act as precipitants for adjustment problems (Gibb & Coles, 2005). Adjustment disorders are psychological and behavioral reactions to identifiable stressors. Adjustment problems are associated with changes in social relationships and decreased performance at school or work. When a stressor is chronic, as with a chronic illness, adjustment problems such as anxiety, depression, conduct disturbances, social withdrawal, and physical complaints may become chronic as well (APA, 2000).

The CDC (2009) estimates that 133 million people in the United States have at least one chronic illness. Chronic illness is often accompanied by complex medical treatments, pain, and increasing disability. Most people adapt successfully to chronic illness, but for about 30% of people significant adjustment problems exist (Stanton et al., 2007). While food allergy is a chronic illness, it lacks the characteristics typically

associated with chronic illnesses in that pain, progressive deterioration, and complex medical treatments (CDC, 2009) are not an ongoing part of the clinical picture. When anaphylaxis occurs, it often has an unpredictable and traumatic onset, but with appropriate medical treatment, it is most often reversed (Jowett, 2000), although some reactions will be so severe they will not respond to treatment regardless of how promptly it is administered (Pumphry, 2000). Medical treatment may continue for a few days to a week, but normal life and the appearance of good health resumes (Simons, 2007). The appearance of good health among food allergic people may undermine recognition of the seriousness of the problem they face.

Children with physical disorders and chronic illness are at greater risk for adjustment disorders (Carpentier, Mullins, Wagner, Wolfe-Christensen, & Chaney, 2007; Eiser, 1990; White, 2000). This is attributed to the greater number of stressful situations that children and families with chronic illness face. Risk is greatest among those with central nervous system (CNS) involvement, physical disability, and with a greater threat to life itself. Parental perception of disease severity is more predictive of adjustment problems that physician's perceptions of illness severity, or analysis based on drug use (Eiser, 1990). Adjustment problems are most pronounced when diagnosis is first made and when changes in treatment are implemented. After the child's physical condition stabilizes, adjustment problems are reduced (Gledhill, Rangel, & Garralda, 2000). Families with food allergic children report high levels of stress and anxiety in protecting their children and concern that parental overprotection and social limitations may impact their child's development (Leung et al., 2009; Mandell, Curtis, Gold, & Hardie, 2005;

Sicherer, Furlong, Munoz-Furlong, 2001). Herbert and Dalquist (2008) found that young adults with a perceived history of anaphylaxis had more worry about their illness and rated their parents as more overprotective than food allergic young adults who did not have that history, and had more psychological distress. In a comparison study of families coping with rheumatoid arthritis in a child to food allergies in a child, QOL was more adversely affected in the food allergy group (Primeau et al., 2000). Primeau et al. also compared adults with both conditions and found that family burden was higher in the rheumatoid arthritis group than the food allergy group as adults.

In addition to the normal struggles for identity among adolescents and young adults, those who have to contend with a chronic illness face additional difficulties in that they must also contend with feelings of being different from their peers at a time when peer group identity is most important. Young adults are in a stage of psychosocial transition, developing independence, and making decisions about relationships, work, and school (Erikson, 1950). For young adults with severe food allergy, the desire not to call attention to one's self may facilitate risk taking behaviors (Akeson et al., 2007; Sampson et al., 2006; Sharma et al., 2008). This is likely because of developmental issues such as the need to fit in with a peer group, cognitive immaturity, depression, denial, and personality pathology (Shaw, 2001). When events that have important life outcomes are uncertain and uncontrollable, learned helplessness and depression may result (Seligman, Abramson, Semmel, & von Baeyer, 1979).

Avery et al. (2003) describe similarities between type 1 diabetes and food allergy around the importance of food choices, social restrictions, school issues, the need to carry

and use an injection, and the chronicity of the condition. They compared QOL of 20 children with peanut allergy and 20 children with insulin-dependent type 1 diabetes. Subjects had experienced either an allergic reaction or hypoglycemic event. Hypoglycemia is associated with morbidity and with high anxiety among diabetics. Children with allergy were either very or extremely scared of accidentally eating peanuts and diabetic children were moderately scared or less of experiencing hypoglycemia. Allergic children thought their risk of accidental exposure was greater than diabetic children considered their risk of hypoglycemia, they read food labels more than the diabetic group, and 85% compared to 50% thought they generally had to always be careful about what they ate. Allergic children had higher anxiety about going on vacation, attending birthday parties, and eating in restaurants. Both groups had similar worries about managing the disease at home and in school. The allergic group made neutral and negative comments about people not understanding their allergies, while the diabetic group felt more positive about people. Children with food allergy appear to be aware that their condition may be fatal, but diabetic children may not realize the long term implications of their disease. Managing diabetes is a burden, but disease control is more predictable and based on eating right, exercising, monitoring blood sugar, and taking insulin. Food allergy is unpredictable and when treatment is needed, it is during extreme physical and emotional stress. In a longitudinal study of adolescents with type 1 diabetes, Bryden et al. (2001) interviewed adolescents at 11-18 years of age and again at 20 –28 years of age to examine the clinical and psychological course of diabetes as teenagers enter adulthood. Significant morbidity is found in this age group even with intensive

individualized care. While employment and educational levels were comparable to the general population, regular smoking, excess alcohol consumption, weight gain, and a high rate of complications and adverse events were found. Poor glycemic control in later years was associated with adolescent behavioral problems, but emotional problems such as anxiety and depression were associated with better control. It is suggested that anxiety and depression may motivate people to be more vigilant in managing the illness. Lyons and Forde (2004) found higher anxiety among food allergic young adults was associated with better management.

Cognitive Diathesis-Stress Model of Depression

The cognitive diathesis-stress model of depression provides a structure that accounts for individual differences in vulnerability to stress and ways of coping that can impact psychological adjustment. Cognitive diathesis-stress models are information-processing models that account for individual differences in response to stress based on individual differences in vulnerability. A diathesis is a vulnerability, predisposition, or trait, with social, cognitive, and/or biological origins, that enables a disordered state by increasing the formation of negative cognitive schema. When vulnerabilities are activated, they can lead to the development of maladjustment and can account for differences in individual adaptation to chronic illness (Burke & Elliott, 1999). Regardless of the origin of vulnerabilities, biological or learned, they lie within the person. Cognitive vulnerabilities are thought to develop from dysfunctional learning, but traumatic experiences and interpersonal variables can strengthen them (Ingram & Luxton, 2005). Negative information processing biases contribute to the development of

adjustment problems, especially depression and anxiety, when negative life events occur (Abramson et al., 1989). Since food allergy typically develops in childhood and families report high levels of stress and anxiety in managing it, overprotective parenting, and social restrictions on their children (Akeson et al., 2007; Mandell et al., 2005; Primeau et al., 2000), cognitive vulnerabilities are likely to have a fertile ground to develop in this population.

Stress is a physiological response to stimuli (stressor). When a person encounters a situation that endangers physical or psychological well-being and personal coping abilities are deemed inadequate, the body activates the "fight or flight" response. This was first described by Cannon (1932), where the sympathetic nervous system in concert with the hypothalmic-pituitary-adrenal (HPA) system primes the body to attack, defend, or escape against a perceived threat (Everly & Lating, 2002; Lazarus & Folkman, 1984). Fear and anger are the emotions associated with "fight or flight" (LeDoux, 1996). The interaction of stress and vulnerability influence an individual's coping ability (Lazarus, 1999; Slavik & Croake, 2006). Depression is a form of chronic stress that is characterized by feelings of hopelessness, helplessness, and low self-worth (Ingram & Luxton, 2005). Beck (1987) describes how stable negative views of oneself, the world, and the future, lead to the development of depression. Persistent negative attitudes and beliefs causally affect information processing by creating a self-perpetuating negative self-system. Cognitive distortions impact the way an individual processes information and result in depressogenic schema. The stability and generality of these negative views increase vulnerability.

The experience of stress acts to disrupt individuals' physiology, emotion, and cognition, and interferes with homeostasis and adaptation. Individual difference in appraisal influences how an event is perceived and experienced (Ingram & Luxton, 2005). Vulnerabilities are mitigated by protective factors and enhanced by risks. Risks include a negative attributional style, biological dysfunction, and sociocultural factors such as weak social networks, or personal and role identity issues. Protective factors include having good health, being raised in a loving home, having a social network, and good social skills which can act as a buffer to depression (Schotte, Van Den Bossche, De Doncker, Claes & Cosynes, 2006). Personal coping ability can also mitigate the impact of distress (Slavik & Croake, 2006).

Psychosocial stressors, real, imagined, or anticipated, work through cognitive appraisal mechanisms; it is the process of assigning meaning to events. Appraisal occurs in two stages; primary appraisal is a rapid process that assigns significance to an event with respect to personal well-being and can range from irrelevant to stressful; while secondary appraisal is the process of determining what might be done to cope with stress and how likely that response is to succeed. When an event is appraised as stressful, the potential significance includes harm threat, and challenge. Primary and secondary appraisals provide reciprocal feedback (reappraisals) that shape the level of stress and the emotional reaction associated with it (Lazarus & Folkman, 1984). In order to survive biologically, humans are constantly engaged in appraising the relationship of the self to the environment. Emotions change as they are influenced by appraisal, coping processes, and changes in the relationship; anger can become shame, guilt, sorrow, or forgiveness,

and personal meaning develops through this process (Lazarus, 1991). Emotion is tied to cognitive appraisal and colors cognitive interpretations. Emotion is continually present in consciousness and guides ongoing cognitive processes and the storage and retrieval of memories. Mood is a background emotional state that is influenced by stress in that a general negative mood sets the cognitive frame from which other events are filtered, making it more likely that the negative assessment and negative emotion will continue (Izard, 1993).

Illness Uncertainty

Illness uncertainty is a cognitive state that occurs when illness related events do not fit into an individual's existing cognitive schema and may be relevant to adjustment among people with anaphylactic food allergies. Illness uncertainty explains a person's cognitive processes involved in the construction of meaning for illness-related events. When meaning for an event cannot be established, outcomes cannot be predicted, and effective coping cannot be employed. Uncertainty is viewed negatively by most people and is a source of stress and anxiety (Mishel, 1988). Illness uncertainty appears to be a significant factor in adjustment to a number of chronic medical conditions such as rheumatoid arthritis in children (White, 2000), multiple sclerosis (Mullins et al., 2001), and asthma (Mullins et al., 1997; Van Pelt, Mullins, Carpentier, & Wolf-Christensen, 2006) and diabetes among older adolescents (Hoff, Mullins, Chaney, Hartman & Domek, 2002).

Sources of illness uncertainty include ambiguity about the state of the illness, complexity surrounding treatment, lack of information, and unpredictability regarding the

course of the illness (Mishel, 1984). All of these factors have been identified in people with severe food allergy. Ambiguity around the state of food allergy also exists in medical practice. There are differences in how physicians perceive the prevalence of anaphylaxis in general practice and their willingness to prescribe epinephrine (Gold, 2003; Simons et al., 2007). Some physicians think that epinephrine is over prescribed which ends up frightening patients unnecessarily (Colver & Hourihane, 2006). These conflicting professional views often result in conflicting patient information (Akeson et al., 2007).

Kapoor et al. (2004) studied families ($N = 70$) referred to an allergy clinic in Britain with food allergy. The diagnosis patients entered with was accurate in only 34.5% of cases, with the wrong foods identified, an incomplete list of foods identified, or no food allergens identified. Allergy testing is imprecise and often fails to indicate who has significant allergies, or who is at risk for anaphylaxis (Martelli et al., 2008; Sicherer & Bock, 2006). There are also differences in epinephrine use in emergency treatment, although its use is the standard of care for this problem (Accetta, Chong, & Wolf, 2009; Simons, 2007). There are differences in emergency response treatment too (Gaeta et al., 2006), as not all states allow ambulances to carry epinephrine, and if they do, there may not be a technician responding who is authorized to use it (FAAN, 2009).

Many parents describe not being sure when they should use epinephrine to treat a reaction (Kim et al., 2005; Martelli et al., 2008), young adults may experience this same confusion as evidenced by deaths that occur when epinephrine was present, but unused (Bock et al., 2007). One of the side effects of successful management of food allergy by

parents is that children grow up without a memory of an anaphylactic event and they may come to view food allergy as “no big deal” (p. 1215) which can contribute to an unfounded optimistic bias (Akeson et al., 2007).

Warmington (2005) described living with anaphylaxis as a young adult and the shortcomings of the medical profession. She believes it would be most helpful to discuss how allergens affect her and what to do if she thinks she might have eaten an allergenic food, but is not sure. Studies of adolescents and young adults show a variation in knowledge of the disease and its consequences among those affected (Lyons & Forde, 2005; Sharma et al., 2008). Unpredictability of the course of the illness is seen in the variability of symptom presentation, variation in onset, and variation in duration (Golden, 2004). Synergistic effects from alcohol, exercise, aspirin, and concurrent infection all function to raise uncertainty (Pumphry, 2004). Young adults do not want to call attention to themselves and may go along with friends for meals or dessert (Sampson et al., 2006). Results from a survey of allergic reactions from restaurants and other food vendors showed that dessert foods account for the most reactions due to hidden nuts. Specialized cuisine where ingredients can be hidden in sauces and Asian restaurants where peanuts, fish, and nuts are widely used in cooking are particularly risky (Furlong et al., 2001). If a reaction occurs young people tend to go off by themselves and have been found unconscious in restrooms (Munoz-Furlong, 2003).

Uncertainty is preceded by a cognitive frame for illness related events which consist of symptom pattern, event familiarity, and event congruence (Mishel, 1988). Monitoring the body when symptoms are vague, diffuse, and lacking in salience and

patterns can become a continuous activity. Uncertainty is lessened when symptom patterns can be identified (Mishel & Braden, 1988). Symptom variability is significant in anaphylactic food reactions. Recognizing the symptoms of anaphylaxis is key. Very often people know immediately when they have eaten something they are allergic to because of a metallic taste in their mouths, itching, and a sense of dread (Golden, 2004). Recognizing the beginning of a reaction can also be clouded by variation in symptom presentation and denial as to what is happening. Problems recognizing symptoms can be compounded for people with underlying asthma and eczema for whom wheezing and itching, early signs of an allergic reaction, are a common experience, but often associated with a different health problem. For people using denial as a coping strategy, recognition of symptoms and emergency treatment are likely to be delayed. Variability in symptoms over the course of a reaction can also be problematic, particularly for people who do not know that reactions can be biphasic, where symptoms reemerge after they are thought to be resolved (see pp. 17-18 for full description). If they have used their epinephrine during the first phase and thought they were fine and did not seek emergency treatment, when the second phase starts, they may be without more epinephrine.

An uncertainty experience is neutral until it is appraised, then it becomes a danger or an opportunity. Uncertainty in illness is most often viewed as a significant stressor and people seek ways of reducing uncertainty through coping. If coping processes are effective in reducing danger or maintaining opportunity, then adaptation occurs. When people have difficulty adapting, it is not a reflection on the uncertainty itself, but with the coping processes used to manage it (Mishel, 1988).

Inference and illusion are the two processes involved in the appraisal of uncertain events. Inference evaluates uncertainty based on personality dispositions, past experience, and knowledge, and includes learned resourcefulness, sense of mastery, and locus of control. Illusion operates from the construction of beliefs about the uncertainty and they are usually positive. Illusion, avoidance, and denial may operate to maintain ambiguity which allows for hope (Lazarus, 1983; Mishel, 1988). For allergic individuals, illusion may allow for risk taking to seem less risky, and allow for the fulfillment of competing goals, such as acceptance in social situations.

Coping

Coping consists of behavioral and emotional responses designed to attenuate the stress response and reestablish homeostasis. It is affected by the interaction of stress and vulnerability and changes in the relationship between the two can occur over time. Coping is defined as the ongoing behavioral and cognitive effort applied to the management of demands, both internal and/or external that wear on, or exceed an individual's resources. When ambiguity is high, effective coping is inhibited. It is a dynamic process that interacts with situations, may employ healthy or unhealthy behaviors, and may end up strengthening the original stressor. Coping is viewed both as a process that is related to situational variables, and as a personality trait where individuals have a typical response to stress. Problem-focused coping employs strategies that attempt to change the stressful situation directly and generally reflects the belief that something can be done about a situation. Emotion-focused coping employs methods to deal with the emotions a situation arouses (Lazarus & Folkman, 1984) and activities can range from

prayer and meditation to using drugs. This type of coping is more often used when problems seem beyond personal control, although both types of coping are often used together (Kleinke, 2007). McNulty, Livneh, and Wilson (2004) found that spiritual well-being had a mediating effect on illness uncertainty in psychosocial adaptation among individuals with MS. Responding to stress with impulsive behavior, avoidance, and denial are the least effective ways of coping. Active problem solving and self-reliance are the most adaptive. Psychological stress can result from conflict between personal goals and beliefs, and environmental demands (Lazarus, 1999). In social situations, people with severe food allergy often face ambiguity about the safety of foods in the environment, and competing goals of social acceptance and personal safety which can interfere with effective coping.

Yellowlees and Ruffin (1989) looked at psychological defenses and coping styles used by patients ($N = 25$) who had experienced a life-threatening asthma attack on average 13 months earlier. It was hypothesized that these patients would not have high levels of denial because of the seriousness of their experience. However, the whole group had high levels of denial and anxiety, and denial was higher in those without a psychiatric diagnosis. Denial may be adaptive in that it lets people cope and feel normal. It can also be used against emotions of fear, anxiety, and depression. Asthma carries a constant threat of social stigma, and loss of health and self-esteem. Ten patients received a psychiatric diagnosis at the time of interview; nine were for anxiety disorders, and one for major depressive illness. Those who received a diagnosis had family histories of mental illness, were diagnosed with asthma at a younger age, had more hospital

admissions for asthma before the recent near death episode, and appeared more chronically ill. Lung function studies showed the non-psychiatrically diagnosed group had minimally better lung function and medical severity was not attributed to the psychiatric decompensation. Some patients experienced significant family tensions after discharge as families wanted to protect or overprotect them, when patients wanted to deny the illness, resulting in anxiety and anger on all sides.

Monat, Averil, and Lazarus (1972) describe time frames of uncertainty and their effects on anticipatory stress and coping patterns. Temporal uncertainty refers to not knowing where a harmful event will occur and event uncertainty identifies the place an event is likely to occur, but not when it will occur. Avoidance coping was used most in temporal uncertainty and vigilant examination with increased affective arousal was more characteristic of event uncertainty. Temporal uncertainty factors are relevant to food allergy, such as cases of anaphylaxis through the transfer of a trace of an allergen. The transfer of trace levels of allergens is not expected. Event uncertainty is more certain in that anytime a person is eating, there could be a potential problem. Vigilance is a coping mechanisms used in these situations. When uncertainty is prolonged, people attempt to integrate it into their self-structure so that uncertainty is considered part of the natural rhythm of life. The longer people live with a disease the less uncertainty they tend to experience (Cohen, 1993).

Social support is viewed as a mitigating factor in illness uncertainty (Mishel, 1988) and a coping resource (Lazarus & Folkman, 1984). Treharne, Lyons, Booth, and Kitas (2007) looked at coping resources over one year in patients with rheumatoid

arthritis and found that subjects who reported greater social support from friends and family reported higher baseline life satisfaction and reported less depression at six months. However, this effect was not sustained over one year even though social support remained stable. Additionally, after controlling for baseline anxiety, those patients who reported greater support from health care professionals reported greater anxiety at six months. It is surmised that patients who had more contact with health care professionals experienced increased self monitoring which led to increased anxiety. Qualitative studies of food allergic young adults indicate that they often do not tell people that they are food allergic, but also that it would be helpful if more people were educated as to their needs (Sampson et al., 2006; Sharma et al., 2008).

Research Methodologies

Psychological adjustment in response to chronic illness has been studied across a variety of illnesses that have employed a variety of methodologies including qualitative (Mandell et al., 2005), survey (Lyons & Forde, 2006), factorial (Garnefski & Kraaij, 2009), and longitudinal designs (Bryden et al., 2001). Variables investigated include socioeconomic status, ethnicity, gender, psychological symptomatology, personality (Stanton et al., 2007), risks and protective factors such as social support, (Treharne et al., 2007) spirituality (McNulty et al, 2004), appraisal, attribution (Carpientier et al., 2007) self-efficacy, self-esteem, and coping (Dahlbeck & Lightsey, 2008).

Multiple regression analysis of quantitative data is a correlational statistical technique used when there are multiple independent variables being tested for their predictive effects upon a dependent variable of interest within a particular population

(Licht, 1995). This method of analysis is widely used in the study of people with chronic conditions: The effects of illness uncertainty and attributional style on psychological adjustment has been studied among children with chronic illness (Carpienter et al., 2007), rheumatoid arthritis (White, 2005), and in older adolescents and young adults with asthma (Mullins et al., 1997). Hoff et al. (2002) looked at how perceived control and illness uncertainty contributed to psychological distress among adolescents with type 1 diabetes and Van Pelt et al. (2006) examined the effects of illness uncertainty on self-focus among adolescents and young adults with asthma.

Most studies to date that have looked at psychological adjustment issues among food allergic populations have used qualitative methodology: Masia et al. (1998) provide a case study of a young boy with obsessive-compulsive disorder with contamination fears; a number of studies have employed qualitative interviewing that focus of the experience of being food allergic, its psychosocial impact, and QOL issues (Akeson et al., 2007; Mandell et al., 2002; Mandell et al., 2005); and focus group discussions have been conducted to understand participant knowledge of anaphylaxis among parents of affected children, physicians, and the general public (Gupta et al., 2008), to understand risk taking behaviors among adolescents and young adults (Sharma et al., 2008), to develop surveys related to risk taking (Sampson et al., 2006), and to explore the experience of being food hypersensitive (Marklund et al., 2007). Valuable information has been gained from these studies and this methodology has been useful in developing a deeper understanding of the issues that food allergic people face, but limitations of these

studies are seen in the small sample sizes and selected samples that limit the extent to which results can be generalized.

Summary

Severe food allergies often result in anaphylaxis, which is a medical emergency. Avoidance of allergens and being prepared for an emergency are the cornerstone of treatment for this problem. Adolescents and young adults are the group most likely to die from this problem because they fail to recognize symptoms or are unwilling to alter behaviors so as to adequately mitigate resulting risks. As a result, approximately 150 individuals die each year in the United States from food-induced anaphylactic responses. Young adults seem to struggle with the competing goals of social acceptance in environments where food is present and the need for safety. Psychological adjustment problems can result from illness uncertainty and poor coping abilities.

Chapter 3: Research Method

Introduction

This chapter provides a description of the study design, the sample, instruments used, data analysis procedures, and ethical considerations. Rationale for the selection of this research design is provided, a description of validity and reliability of the instruments, and a preliminary discussion of data analysis used is included.

Research Design and Approach

This quantitative, correlational study sought to examine and predict the relationship between illness uncertainty, ways of coping, and psychological adjustment among young adults with anaphylactic food allergies. Multiple regression analyses were used to explain and understand behavior. The predictor variables, illness uncertainty and coping processes, were examined to determine their utility in understanding the criterion variable, psychological adjustment (Licht, 1995). The moderating and mediating effects of the predictor variables were also examined (Baron & Kenny, 1986). This is an appropriate method for this study because the research aims to examine the combined effects of a number of predictor variables to identify factors that influence psychological adjustment. Qualitative studies have indicated that illness uncertainty, difficulties coping, and adjustment problems exist for some people in this population (Akeson et al., 2007; Lyons & Forde, 2005; Marklund, 2007; Sharma et al., 2008), but the number of subjects studied have been small. Qualitative methodology was not used in this study in order to show effects among a larger population where the results can be generalized more broadly.

Setting and Sample

The original plan for this study required 127 participants between 18 and 25 years of age who had experienced food-induced anaphylaxis. This sample size was based on a power analysis conducted with GPower version 3 (Erdfelder, Faul, & Buchner, 1996). It reflected an alpha level of 0.05, an anticipated effect size of 0.15 (medium), and a power level of 0.8. Difficulties in recruiting participants necessitated changing the sample size to 36, which was acceptable for an alpha level of .8 and a large effect size (Newton & Rudestam, 1999).

Participants were recruited from food (a) allergy support groups that participate on a national list of food allergy support groups (Coss, 2008); (b) others that are present on social networking sites such as Facebook, and Livejournal, and (c) regional and online support groups found through Internet searches. An email was sent to these groups requesting permission to post an announcement about the study on a website, in a newsletter, or chat group (see Appendix A). A number of food allergy groups on Facebook and Livejournal agreed to permit announcements. One of the group administrators also runs a Web site, mallergies.com, which linked the announcement to its Facebook group and Twitter link. The website: learningtoeatallergyfree.com hosted an announcement. The Asthma and Allergy Foundation, New England Chapter, sent an email announcement to 1,000 of its members. Permission was granted by a number of support groups that have regional memberships, including Faces of MI Yahoo group, the Phoenix Allergy Network, MOCHAllergies.org, and Parents of Children Having

Allergies. A student support group at the University of Arizona agreed to announce the study. All correspondence is included in Appendix A.

All of the sites announcing this study were detailed fully in the IRB application. The announcements placed at these sites included a brief description of who was eligible to participate and the type of data to be collected. A link to a web site which asked two questions about eligibility to participate and provided a password and link to the survey when answered correctly. The survey was available via an encrypted Web server and hosted by Survey Monkey. Once a participant entered the survey website, a consent form was presented and agreement was indicated by proceeding to the first page of the survey. Permission for use of the participant's information was requested again upon completion of the survey. Consent could be withdrawn by electing not to submit his/her information to the online directory of participant data. When consent was provided both before and after the survey, participant responses were recorded in the encrypted online directory. No personal, identifying information such as name or address was collected and no identifying information from a participant's computer was tracked. This study was active for 13 weeks to attain the requisite number of subjects.

Instruments

Uncertainty in Illness Scale Community Form

The Uncertainty in Illness Scale Community Form ([MUIS-C)]; Mishel, 1983) is a one-factor, 23-item self-report measure of perceived uncertainty in illness The scale examines the four components of uncertainty in illness; ambiguity, uncertainty, lack of information, and unpredictability. The MUIS-C can be used by individuals with a chronic

illness who are not hospitalized and are probably not receiving medical treatment, or by the family members of people with a chronically illness. Participants are asked to rate items on a five-point scale, ranging from 1 ("*strongly agree*") to 5 ("*strongly disagree*"). Sample items included: "They have not given me a specific diagnosis," and "Because of the unpredictability of my illness, I cannot plan for the future." The MUIS-C yields one composite score with higher scores reflecting greater illness uncertainty. It was originally validated on 20 different diagnostic groups with internal consistency alpha scores ranging from .53 to .92 with the average score being .82 (Mishel, 1997). Permission to use this scale has been received and is included in Appendix B.

Ways of Coping Questionnaire

The Ways of Coping Questionnaire (WOC; Folkman & Lazarus, 1988) identifies thoughts and actions individuals use to cope with a specific stressful encounter. It is a 66 item self-report questionnaire, with a four point Likert scale for indicating the frequency with which they use various strategies presented. Responses are rated 0 ("*Does not apply or not used") to 3 ("Used a great deal"). The* scale yields scores on eight coping factors and the internal consistency measures of Cronbach's coefficient alpha are included: confrontive coping (.70), distancing, (.61), self-controlling (.70), seeking social support (.76), accepting responsibility (.66), escape-avoidance (.72), planful problem solving (.68), and positive reappraisal (.79). The estimates of internal consistency are at the low end of the acceptable range, but the scale was constructed to minimize redundancy within each category and since this scale measures coping as a process, which is by definition variable, estimates of reliability are not considered suitable. Validity for the WOC is

supported by findings that are consistent with theoretical predictions; people use both problem and emotion focused strategies in almost all stressful encounters, coping is a process that varies with individual appraisal of what is at stake (primary appraisal) and perceived situational control (secondary appraisal) (Folkman & Lazarus, 1988).

To respond to the WOC, participants must have a particular stressful situation in mind, but the way an encounter is elicited has not been standardized and can be adapted to fit the needs of a particular study. The time frame for recalling the stressful event is recommended to be one week, but other time frames can be used. In this study, participants were asked to respond to a stressful event related to food allergy that occurred in the past month. This time frame was chosen to ensure that participants had a situation in mind to respond to and they were asked to briefly describe the situation, what was at stake, and what they thought their options for coping were (see Appendix C) before responding to WOC statements. Participants were also asked if they have experienced any major stressful events in the past month unrelated to food allergy and to briefly describe it so that scores from participants who have experienced a traumatic event could be considered for exclusion. Raw scores were summed which indicated a subject's responses to items on a given scale and provided a summary of the different types of coping employed in a particular situation (Folkman & Lazarus, 1988). Permission to use this scale has been received and is included in Appendix D.

Depression Anxiety Stress Scales

The Depression Anxiety Stress Scales ([DASS]; Lovibond & Lovibond, 1995a) consists of three scales: depression (DASS-D), anxiety (DASS-A), and stress (DASS-S),

each containing 14 items that reflect negative emotional symptoms. Subjects are to rate the frequency with which they experienced each symptom during the past week on a 0 ("*did not apply to me at all*") to 3 ("*applied to me very much, or most of the time*") scale. The DASS-D asks questions associated with sadness and worthlessness, the DASS-A includes questions primarily associated with physical arousal, panic, and fear. During development, items that did not discriminate anxiety and depression emerged as a new factor that was subsequently labeled "Stress." These items refer to difficulty relaxing, irritability, and agitation. Subjects rate their experience of each symptom over the past week on a 4-point scale of severity and frequency. This scale was normed on a normal non-clinical sample which reflects the view that emotional disorders exist on a continuum and internal consistency for Depression was 0.91, Anxiety was 0.84, and Stress was 0.90 (Lovibond & Lovibond, 1995a). A study of normal subjects (N =717) that compared the DASS with the Beck Depression Inventory (BDI; Beck, Ward, & Mendelson, 1961) and the Beck Anxiety Inventory (BAI; Beck & Steer, 1990) showed the scales were highly correlated; DASS-A and BAI (r=0.81), and DASS-D and BDI (r=0.74). The lower correlation with the BDI is attributed to the inclusion of items that are not unique to depression such as weight loss, irritability, and somatic preoccupation on the BDI, items that were rejected from the DASS-D scale (Lovibond & Lovibond, 1995b).

A short form of the DASS (DASS-21) was developed with seven items on each scale that were taken from the 42-item DASS and scores on the short form are doubled so that they are comparable to the 42-item DASS. In a study testing the psychometric properties of the DASS-21 using a clinical and control sample, concurrent validity was

established with the BDI and BAI where correlations with depression were high and correlations with anxiety moderate. Cronbach's alphas for the DASS-21 sub-scales were calculated for the entire sample; Depression was .94, Anxiety was .87, and Stress was .91. Advantages of the DASS-21 over the 42-item version include a shorter form, a cleaner factor structure, and smaller correlations between factors (Antony, Beiling, Cox, Enns, & Swinson, 1998). Further study of the DASS-21 in a large (N = 1,794) non-clinical sample from the UK further validated use of this instrument as a reliable measure of depression, anxiety, and stress with Cronbach's alpha at .88, .82, and .90 respectively, and .93 for the entire scale. Combining scores from all three scales can be considered a measure of general psychological distress or negative affect (Henry & Crawford, 2005). The DASS-21 was used in this study. This scale is in the public domain and permission for use is provided on the DASS website which is available in Appendix E.

Data Analysis

Data analysis procedures for this study included basic descriptive procedures (e.g. mean, standard deviation, frequency, percentage) for analysis of continuous data derived from the instruments used in this study and inferential analyses. Frequency and percentage statistics were calculated for the categorical variables which include age, gender, presence of asthma, eczema, or eosinohilic gastroenteropathies, history of anaphylaxis, age of first anaphylactic episode, number of reactions in the last two years, ethnicity, country of residence, and family income (see Appendix F). Descriptive procedures were also applied to subscale scores for the independent and dependent variables.

Inferential statistics including multiple regression, standard error, and zero order correlation were applied to this sample. Multiple regression is used to assess the extent to which a relationship exists among a set of continuous variables. Zero order correlations were done to test categorical variables that may relate to the independent and dependent variables. Variables that were significant were entered as control variables (George & Mallery, 2008). SPSS 16.0 was used to conduct a multiple regression analysis to test the hypothesis. Prior to testing the hypotheses, pretest data analyses of assumptions (e.g. linearity, normality, multicollinearity, homoscedasticity) were conducted to ensure that any statistical threats to validity are properly addressed. Alpha coefficients were calculated for all scales and compared to normative data to test the internal consistency of responses. Tests of mediating and moderating effects were done where appropriate.

Research Questions and Hypothesis

Research Question 1: What is the relationship between the independent variable (IV) illness uncertainty as measured by the MUIS-C and the dependent variable (DV) psychological adjustment as measured by the DASS-21.

H_0^1*:* Illness uncertainty as measured by the MUIS-C has no effect on adjustment as measured by the DASS-21.

H_a^1*:* Illness uncertainty as measured by the MUIS-C has an effect on adjustment as measured by the DASS-21.

Analysis 1: Multiple regression was done to assess if scores on the MUIS-C predict scores on the DASS-21. Demographic and other categorical variables were entered as covariates.

Research Question 2: What is the relationship between the potential moderator variable coping as measured by the WOC and the DV psychological adjustment as measured by the DASS-21.

H_0^2*:* Coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

H_a^2: Coping as measured by the WOC has an effect on adjustment as measured by the DASS-21.

Analysis 2: Multiple regression was done to assess if scores on the WOC moderate scores on the DASS-21. Demographic and other categorical variables were entered as covariates.

Research Question 3: What is the relationship between the predictor variable illness uncertainty as measured by the MUIS-C in the presence of different coping factors as measured by the WOC on the DV psychological adjustment as measured by the DASS-21.

H_0^3: Illness uncertainty as measured by the MUIS-C in the presence of coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

H_a^3: Illness uncertainty as measured by the MUIS-C is moderated in the presence of coping as measured by the WOC and has an effect on adjustment as measured by the DASS-21.

Analysis 3: To determine if coping is a moderator of illness uncertainty the following steps were taken: (a) Regress the DV (DASS-21) on both the IV (MUIS-C) and the potential moderator (WOC); (b) Regress the DV (DASS-21) on the interaction

product of the IV (MUIS-C) and the moderator (WOC). If this interaction is significant, the moderator hypothesis is supported.

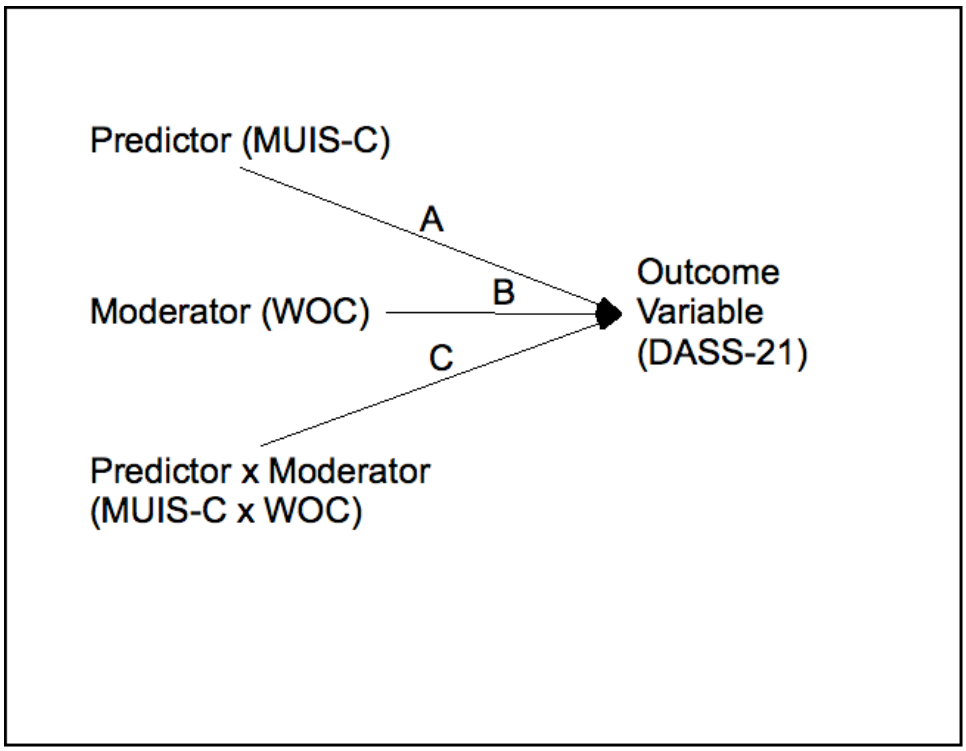

Figure 1. Moderator model.

To the extent that, moderators are identified, their role as mediators was analyzed to determine whether and to what extent, those moderators mediate. According to Baron and Kenny (1986) the following criteria are necessary for mediation: The IV (WOC) must be significantly associated with the DV (DASS-21). The potential mediator (MUIS-C) must be significantly related to the DV (DASS-21). The IV (WOC) must be significantly associated with the potential mediator (MUIS-C). When the potential mediator (MUIS-C) and the IV (WOC) are simultaneously entered into the equation, the mediator contributes independent variance to the DV (DASS-21) and the IV's (WOC) influence on the DV (DASS-21) is significantly reduced.

Research Question 4: If moderators are identified, what is their role in mediating the relationship between the IV's and psychological adjustment?

H_0^4: Illness uncertainty as measured by the MUIS-C does not mediate the effects of coping as measured by the WOC on adjustment as measured by the DASS-21.

H_a^4: Illness uncertainty as measured by the MUIS-C mediates the effects of coping as measured by the WOC on adjustment as measured by the DASS-21.

Analysis 4: To determine if illness uncertainty is a potential mediator of the coping-adjustment relationship, the DV (DASS-21) was first regressed on the IV (WOC). Next, the DV (DASS-21) was regressed on the potential mediator (MUIS-C). The potential mediator (MUIS-C) was regressed on the IV (WOC). The final step involved simultaneously regressing the DV (DASS-21) on both the IV (WOC) and the mediator (MUIS-C).

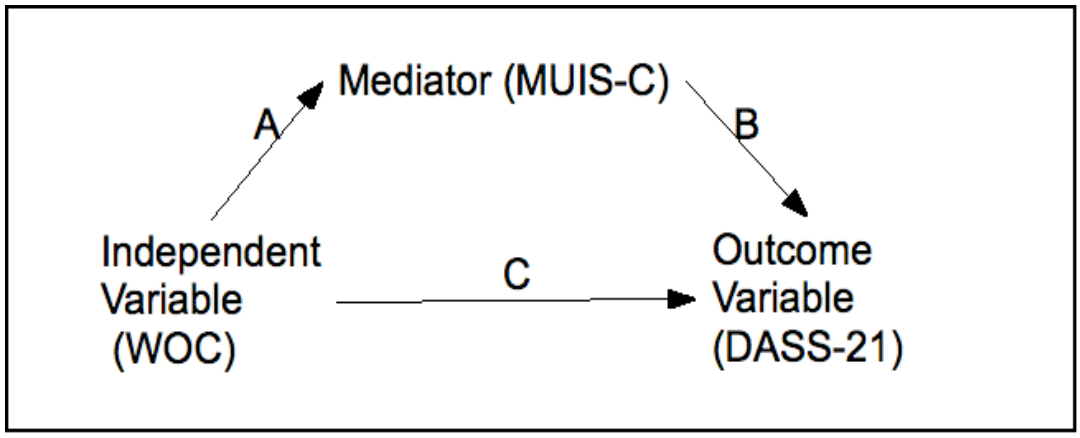

Figure 2. Mediation Model

Ethical Considerations

The ethical standards set by Walden University's Internal Review Board (IRB) application were maintained. Walden University's IRB approval number is 04-29-10-

0005281. Informed consent was provided to all potential participants by providing written information about the procedure for participation in the study and the voluntary nature of the study, risks associated with this study and benefits of participants in the study, and how to contact the researcher and her advisor to answer any questions about the study. The informed consent indicated that all records in this study will remain anonymous. All data collected in this study is stored on a compact disk in a locked safe and will be maintained for 7 years.

Chapter 4: Results

Introduction

Chapter 4 begins with a description of efforts that were made to recruit participants for this study and the changes that were necessary in the original design due to an inadequate number of participants. Results, analysis, and interpretation of the research findings, as they relate to the hypotheses, are provided. They include descriptive statistics for demographic information associated with the sample, descriptive results from the scales, and the reliability coefficients of these scales. Results from the regression models are included along with a summary of results.

Description of Recruitment Procedures and Changes

This study sought a sample of 18-25-year-olds who had a history of anaphylaxis in reaction to food. Participants were recruited through social networking sites on the Internet that focused on food allergy issues, and Internet-based information and support groups. Difficulties were encountered. Efforts were made to find more places to announce the study by contacting the groups that did not respond to the initial request and asking those groups that had previously made an announcement to repeat it.

1. In addition to the contacts described in chapter 3, IRB approval was obtained for additional announcements that were made on the Facebook pages of "Kidswithfoodallergies" and FAAN.
2. The Asthma Allergy Information Association of Canada (AAIA) put an announcement on its web site with other ongoing research projects, and one of the regional support groups associated with this organization sent a direct email announcement to its members.

3. The Allergy and Asthma Foundation's Texas branch announced it on its web site and in its newsletter that was sent directly to members. Additional contacts were made with FAAN, which also agreed to make two different announcements about the study on their Twitter page.
4. Flyers were placed on public bulletin boards at two University of California campuses and at two community colleges in California. However, this approach was discontinued since the survey was hosted online and the online environment is recommended for recruiting when using this method (Teuten, 2010).
5. Announcements were also placed on craigslist in both the Food and Health discussion forums.
6. contacts made with Food Allergy Survivors Together (FAST) which posted an announcement on its web site and send a direct email to their members about the study.
7. Metro DC Food Allergy Support forwarded the study announcement to its Yahoo list.
8. “My” Food Allergy Support Group in Columbus, OH, a Kansas City support group, and another from Charlotte, NC also sent direct emails to their lists.

After attempting to recruit participants for over three months, 64 people began the survey and 36 completed it. Due to the overall low response to the survey and low completion rate of the survey, the analysis plan and the power analysis was changed. The number of IVs was reduced from nine to three by collapsing the eight subscales of the WOC into two scales that support the constructs of Problem-Focused Coping

(Confrontive Coping, Seeking Social Support, Planful Problem Solving) and Emotion-Focused Coping (Distancing, Self-Controlling, Accepting Responsibility, Escape-Avoidance, Positive Reappraisal). Illness uncertainty remained as the third IV. Based on calculations by Newton and Rudestam (1999), a sample size of 36 was acceptable for an alpha level of .8 and a large effect size.

Pre-Analysis Considerations

Before proceeding with the analysis, the surveys were checked for missing data, one participant had 22 blank items out of 66 on the WOC and the mean score from completed surveys was entered for that missing data (George & Mallery, 2008). Two other participants indicated stressful events unrelated to food allergies in the past month. These surveys were included in the analysis because of the limited sample size. The assumptions of normality, linearity, and homoscedasticity necessary for multiple regression analysis were also tested. Visual inspection of scale histograms showed normally distributed data. On the MUIS-C, skewness was 1.22 and kurtosis 2.34. The WOC Problem-Focused and Emotion-Focused scales had skewness of .72 and .81 respectively, and kurtosis of 1.09 and 1.53. All scores for skewness and kurtosis were less than 3, again meeting the normality assumptions required for regression analysis (McNeese, 2010). Linearity was tested by examining Pearson correlation coefficients between the IVs. The Pearson coefficient for the MUIS-C and WOC Problem-Focused was $r(36) = .019$, $p = .911$ and for the MUIS-C and WOC Emotion-Focused was $r(36) = .028$, $p = .871$, indicating that the IVs are not highly intercorrelated and multicolinearity was not present. The IVs and DV were tested for linear correlations as described below.

Scatterplots of the bivariate relationship between each IV and the DV showed random distributions for all of the variables, indicating that the homoscedasticity assumption was met (Tabachnick & Fidell, 1989).

Reliability of the scales was tested and Cronbach's alpha for the MUIS-C was .865, the WOC Problem-Focused scale was .85, and the WOC Emotion-Focused scale .87. Cronbach's alpha for DASS-21 was .904 and the individual subscales were also computed (DASS-D=.93, DASS-A=.858, DASS-S=.887). All are in the acceptable to high range (Cohen & Swerdlik, 2005).

Descriptive Statistics of the Sample

Frequency and percentage statistics were calculated for variables that describe the sample. Thirty-six people completed this survey, 29 (80.6%) female and 7 (19.4%) male. Participants ranged in age from 18–25 years with the average age of 21 years 10 months. All respondents reported a history of anaphylaxis to food that was treated with epinephrine, although one respondent did not affirm this specific history when asked a second time. This survey was included because the responses indicated significant food allergy. The average age that food allergies started was 2.7 years. A history of anaphylaxis where the cause was not identified was reported by 20 (55.5%). The number of anaphylactic reactions reported in the last two years had a broad range with 14 having no reactions, 21 having from 1 and 9 reactions, and 3 reporting 10 or more episodes. The mean number of anaphylactic foods reported was 2.7 (SD = 1.75). A history of exercise-induced anaphylaxis was reported by 8 (22.2 %) people, all female, asthma by 23 (63.8%), eczema by 11 (30.5%), and a diagnosis of eosinophilic gastro-enterophathy by 2

(5.5%). This sample was highly educated with two participants reporting a high school education, 30 had some college or a college degree, and 4 had graduate degrees. Ethnicity was reported as mostly White 32 (85.0%), with 1 (2.7%) Black 1 (2.7%) Asian, and 2 (5.5%) reporting Other. The total household income was reported by 13 (36.1%) as $20,000/year or less, by 5 (13.9%) as $20,000 to 40,000, by 4(11.1%) as $41,000-60,000, by 4(11.1%) as $61,000-80,000, by 3(8.3%) as $81,000-100,000, and by 5(13.9%) as over $100,000. Excluding those not reporting income (n = 34), the average lower bound on income was $22,090. Excluding those not reporting and those reporting more than $100,000/year ($n$ = 29), the average upper bound on income was $38,800. Median income is $20,000 to $40,000. Participant's country of residence included the United Stated (23), Canada (4), United Kingdom (4), Sweden (1), Australia (1) and Nigeria (1). See Table 1 for details.

Table 1

Sociodemographic Data

Characteristic	N	Percent
Age of Participants		
18	2	5.5
19	3	8.3
20	4	11.1
21	8	22.2
22	6	16.7
23	4	11.1

24	4	11.1
25	5	13.9
Gender		
Male	7	19.4
Female	29	80.6
Household income		
$20,000 or less	13	36.1
$20,000-$40,000	5	13.8
41,000-60,000	4	11.1
61,000-80,000	4	11.1
81,000-100,000	3	8.3
> $100,000	5	13.8
Number of anaphylactic reactions last 2 years		
0	14	38.8
1-9	21	58.3
10 or more	3	8.3
Ethnicity		
White	32	84.96
Asian	1	2.7
Black	1	2.7
Other	2	5.5
Country of residence		

United States	23	63.8
Canada	4	11.1
United Kingdom	4	11.1
Sweden	1	2.7
Australia	1	2.7
Nigeria	1	2.7

Health Variables

Anaphylaxis, where cause was not identified	20	55.5
Exercise-induced anaphylaxis	8	22.2
Asthma	23	63.8
Eczema	11	30.5

Descriptive Statistics of Scales

The MUIS-C is a one factor scale with a range of 23 to 115 where higher scores indicate greater uncertainty (Mishel, 1997). The mean score on the MUIS-C was M = 64.97 (N = 36, SD = 14.69), with a range of 46 to 115. This score is comparable to uncertainty data on illness groups such as coronary artery bypass (N = 52, M = 58.8, SD = 9.9), multiple sclerosis (N = 89, M = 65.3, SD = 10.2), *HIV* (N = 24, M = 64.7, SD = 11.5), and renal disease, (N = 71, M = 65.5, SD = 8.6; Mishel, 1997). This is the first

time this scale was used on individuals with food anaphylaxis so a more specific comparison cannot be made.

The mean score for WOC Problem-Focused coping was $M = 16.11$ ($N = 36$, $SD = 10.52$, skewness .72, and kurtosis 1.09). The lowest possible score is 0 and the highest possible score is 54, with higher values indicating increased use of problem-focused coping. The mean score for WOC Emotion-Focused coping was $M = 23.02$ ($N = 36$, $SD = 14.27$, skewness .81, and kurtosis 1.53). The lowest possible score is 0 and the highest possible score is 96 with higher values indicating increased use of Emotion-Focused coping. These scores provide a summary of how often a type of coping was used in a stressful encounter related to the participant's food allergies.

DASS-21 scores range from 0 to 126 with higher values indicating increased levels of depression (DASS-D), anxiety (DASS-A), and stress (DASS-S; Lovibond & Lovibond, 1995a). In this study, the mean total DASS-21 score was $M = 29.67$ ($N = 36$, $SD = 29.34$), sub-scale scores were also calculated: The mean DASS-D score was $M = 7.5$ ($N = 36$, $SD = 10.59$); the DASS-A mean score was $M = 10.39$ ($N = 36$, $SD = 10.60$); and the DASS-S mean score was $M = 11.78$ ($N = 36$, $SD = 10.84$). Each sub-scale has 7 items and varies over the range from 0 to 42 with higher values indicating increased levels of depression, anxiety, and stress respectively. Normal, mild, moderate, severe, and extremely severe scores for depression (0-9, 10-13, 14-20, 21-27, 28+), anxiety (0-7, 8-9, 10-14, 15-19, 20+), and stress (0-14, 15-18, 19-25, 26-33, 34+), indicate the average anxiety score was moderate and all other means as normal (Lovibond & Lovibond, 1995a). Overall, this sample was well adjusted based on results from DASS-21 with

mean depression and stress scores in the normal range and mean anxiety scores in the moderate range.

Inferential Statistics

Five independent sample t-tests were run on categorical variables that described the population with DASS-21 scores to see if they should be included as covariates in the regression analysis. A history of asthma and eczema were not significant, nor was sex. A history of exercise-induced anaphylaxis was significant on the DASS-D scale ($p = .025$). Having a diagnosis of eosinophilia was significant on DASS-S ($p = .0001$) with equal variance not assumed.

One way analysis of variance (ANOVA) tests were conducted on the remaining variables to test for potential effects of population differences on DASS-21 (where the response data was continuous) for possible inclusion as covariates in the regression analysis. The number of episodes of anaphylaxis reported in the last 2 years was significant on DASS-21: $F(6, 29) = 2.457$, $p = .048$ and DASS-A: $F(6,29) = 4.186$, $p = .004$. The numbers of foods participants were anaphylactic to did not reach significance on the DASS-21: $p = .234$. The highest level of education completed was significant on DASS-21: $F(4, 31)$, $p = .003$, but was also significant on the Levene test ($p = .014$), which indicates unequal population variances, and 30 out of 36 (83.3%) were college-level, with only two high school graduates, three masters level students, and one Ph.D. student. This sample is too small for differences in education to be meaningfully interpreted, and was therefore not used as a covariate in the regression analysis (Newton & Rudestam, 1999). Significance was found on ethnicity, but the sample was 89% White,

and included only one Asian, one Black, and two Other. This sample is too small for differences in ethnicity to be meaningful and therefore was not used as a covariate in the regression analysis (Newton & Rudestam, 1999). The variables that were included in the regression analysis include a history of exercise-induced anaphylaxis, having a diagnosis of eosinophillic gastroenteropathy, the number of episodes of anaphylaxis in the last two years, illness uncertainty, and Problem-Focused and Emotion-Focused coping.

Regression Analysis

Multiple regression analysis using the Stepwise procedure was performed to see if varying levels of illness uncertainty as measured by MUIS-C effected a person's psychological adjustment as measured by DASS-21. Illness uncertainty was examined as a potential predictor variable in the relationship to psychological adjustment.

$H_0{}^1$: Illness uncertainty as measured by the MUIS-C has no effect on adjustment as measured by the DASS-21.

$H_a{}^1 1$: Illness uncertainty as measured by the MUIS-C has an effect on adjustment as measured by the DASS-21.

Regression analysis of MUIS-C on DASS-21 accounting for covariates when episodes was removed from the equation was done by entering the MUIS-C Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100) and removing “How many episodes of anaphylaxis have you experienced in the last two years?”, which indicated a main effect $F(1,34) = 8.921$, $p = .005$ of MUIS-C on DASS-21. This accounts for 18.5% of the variance as explained by the adjusted R^2. Regression analysis of MUIS-C on DASS-D accounting for covariates when exercise-induced

anaphylaxis was removed from the equation was done by entering the MUIS-C Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100) and removing "Have you ever had exercise-induced anaphylaxis?", which indicated a main effect $F(1,34) = 8.442$, $p = .006$ of MUIS-C on DASS-D. This accounts for 17.5% of the variance as explained by the adjusted R^2. Regression analysis of MUIS-C on DASS-A accounting for covariates when episodes was removed from the equation was done by entering MUIS-C Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100) and removing "How many episodes of anaphylaxis have you experienced in the last two years?", which indicated a main effect $F(1,34) = 6.564$, $p = .015$ of MUIS-C on DASS-A. This accounts for 13.7% of the variance as explained by adjusted R^2. Regression analysis of MUIS-C on DASS-S accounting for covariates when the diagnosis of eosinophilic gastroenteropathy was removed from the equation by entering MUIS-C Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100) and removing "Have you ever been diagnosed with either eosinophilic esophogitis or eosinophilic gastritis?", which indicated a main effect $F(1,34) = 6.670$, $p = .014$ of MUIS-C on DASS-S. This accounts for 13.9% of the variance as explained by the adjusted R^2. H_0^1 is therefore rejected.

H_0^2: Coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

H_a^2: Coping as measured by the WOC has an effect on adjustment as measured by the DASS-21.

To test H^2, the WOC Problem-Focused and Emotion-Focused scales were entered into the regression equation on DASS-21 by entering Emotion-Focused and Problem-Focused coping and removing the covariate "How many episodes of anaphylaxis have you experienced in the last two years?". Only WOC Emotion-Focused coping showed a moderating effect $F(2,33) = 4.533$, $p = .018$ on DASS-21. This accounts for 16.8% of the variance as explained by the adjusted R^2. Problem-Focused and Emotion-Focused coping scales were entered into the regression equation on DASS-A by entering Emotion-Focused and Problem-Focused coping and removing the covariate "How many episodes of anaphylaxis have you experienced in the last two years?". Both Problem-Focused and Emotion-Focused coping showed a moderating effect $F(2,33) = 5.935$, $p = .006$ on DASS-A. This accounts for 22.0% of the variance as explained by the adjusted R^2. Problem-Focused and Emotion-Focused coping scales were entered into the regression equation on DASS-D by entering Emotion-Focused and Problem-Focused and removing covariate "How many episodes of anaphylaxis have you experienced in the last two years?" and "Have you ever experienced exercise-induced anaphylaxis?". No moderating effect was observed for Problem-Focused or Emotion-Focused coping DASS-D when controlling for either of the covariates. Problem-Focused and Emotion-Focused coping scales were entered into the regression equation on DASS-S by entering Emotion-Focused and Problem-Focused and removing the covariate "How many episodes of anaphylaxis have you experienced in the last two years?". No moderating effect was observed for Problem-Focused or Emotion-Focused coping on DASS-S when controlling for eosinophilic gastroenteropathy.

H_0^2 is therefore rejected for WOC Emotion-Focused coping showing a moderating effect $F(2,33) = 4.533$, $p = .018$ on DASS-21, and for WOC Problem-focused and Emotion-focused coping showing a moderating effect $F(2,23) = 5.935$, $p = .006$ on DASS-A.

H_0^3: Illness uncertainty as measured by the MUIS-C in the presence of coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

H_a^3: Illness uncertainty as measured by the MUIS-C in the presence of coping as measured by the WOC has an effect on adjustment as measured by the DASS-21.

H^3 was tested by additionally regressing the combined effect of MUIS-C x WOC by entering MUIS-C x WOC. This showed a main effect $F(1,34) = 5.450$, $p = .026$ on DASS-21. The H_0^3 is therefore rejected.

H_0^4: Illness uncertainty as measured by the MUIS-C does not mediate the effects of coping as measured by the WOC on adjustment as measured by the DASS-21.

H_a^4: Illness uncertainty as measured by the MUIS-C mediates the effects of coping as measured by the WOC on adjustment as measured by the DASS-21.

To test H^4, WOC Emotion-Focused coping, which was identified as a moderator under H^2, was examined to determine if it is a mediator by entering MUIS-C Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100) and WOC Emotion-Focused Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100). WOC Emotion-Focused coping is not significantly associated with the potential mediator, MUIS-C (adjusted $R^2 = .185$ and .318). Therefore, because the IV (WOC) must be significantly related to the potential mediator (MUIS-C)

as described by Baron and Kenny (1986), WOC Emotion-Focused is not identified as a potential mediator, the criteria for rejecting H_0^4 are not met, and H_0^4 is retained.

Observed Consistencies and Inconsistencies

Normality, linearity, homoscedasticity, and multicolinearity were consistent with valid data for regression analysis. Cronbach's alpha scores for all scales were in the acceptable to high range, indicating that reliability for all scales is good.

This study has participants from six different countries. It is not clear how differences in culture may have affected responses. The small sample size of the study makes it difficult to draw conclusions as to the effect of several variables such as ethnicity, level of education, eosinophilic gastroenteropathy, and sex, even though there is some indication that some of these factors may have an effect.

Summary

This study addressed the following primary research question: To what extent does illness uncertainty and coping processes effect psychological adjustment among 18-25-year-olds with anaphylactic food allergies. This chapter described the difficulties that were encountered recruiting participants for this study and changes that were made in the analyses and power calculation. Reliability coefficients for the scales used and pretest analysis of data were included. Descriptive statistics were provided for the sample and the scales. A description of the data analysis used to determine which variables would be used in the regression equation and the results of the regression analysis were presented and answered the questions posed by the study hypotheses. Results indicated that psychological adjustment was affected by illness uncertainty and H_0^1 was rejected. The

number of episodes of anaphylaxis experienced in the last two years, the presence of exercise-induced anaphylaxis, and the presence of eosinophillic gastroenteropathy had significant effects. Emotion-Focused coping showed a moderating effect on psychological adjustment as measured by the DASS-21 and H_0^2 was rejected. Both Problem-Focused and Emotion-Focused coping showed a moderating effect on anxiety as measured by the DASS-A, when the number of episodes of anaphylaxis experienced in the last two years was removed. The combined effects of illness uncertainty as measured by MUIS-C and coping as measured by WOC showed a significant effect on psychological adjustment as measured by the DASS-21, and H_0^3 was rejected, supporting the moderating hypotheses H_a^3. H_0^4 was accepted indicating that mediation was not present.

Chapter 5 provides a summary of the study and a discussion of the conclusions. Limitations of the study are addressed, implications for positive social change, and recommendations for future research are provided.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction and Overview of the Study

The incidence of food allergy in Western countries is increasing. Anaphylaxis is the most severe manifestation of this illness and it isa life-threatening reaction to food and the most severe manifestation of this illness. There are currently no medical treatments for food allergy. The basis of disease management is avoidance of allergens and being prepared to respond to a medical emergency if anaphylaxis occurs (Branum & Lukacs, 2008). Adolescents and young adults as a group are more likely to die from this condition. Behavioral and psychological factors contribute to this increased risk as they are willing to take risks with the foods they eat, not carry epinephrine (the cornerstone of emergency treatment), and deny the seriousness of the problem (Akeson et al., 2007; Kim et al., 2005; Sharma et al., 2008). Studies have suggested that adjustment problems are likely in this population (Sampson et al., 2006), and that those with a history of anaphylaxis are most affected (Herbert & Dalquest, 2008).

This study sought to investigate cognitive variables of illness uncertainty and ways of coping associated with psychological adjustment among young adults. In particular, it sought to identify the predictive effects of illness uncertainty on psychological adjustment, to identify the moderating effects of coping, to identify moderating effects of uncertainty in combination with coping on psychological adjustment, and to see if uncertainty had a mediating effect on psychological adjustment. In simplest terms, illness uncertainty predicted adjustment; both coping alone and uncertainty in conjunction with coping moderated adjustment, and uncertainty did not have a mediating effect. Detailed results may offer insight into specific aspects of

adjustment which, in turn, may assist in understanding the vulnerabilities and needs of this population.

Interpretation of Findings

As described in chapter 4, the stepwise multiple regression analysis was statistically significant for the first three hypotheses and the null hypotheses were rejected.

H_0^1: Illness uncertainty as measured by the MUIS-C has no effect on adjustment as measured by the DASS-21.

Illness uncertainty is a cognitive variable that describes ambiguity around an illness, treatment complexity, lack of information, and unpredictability as to the course of the illness (Mishel, 1984). For H^1, illness uncertainty showed a predictive effect on psychological adjustment as measured by DASS-21. This means that increased illness uncertainty is associated with increased depression, anxiety, and stress. For the portion of the sample with more episodes of anaphylaxis, illness uncertainty was positively related to DASS-21 and DASS-A. Those who reported a history of exercise-induced anaphylaxis showed a positive relationship on DASS-D in addition to DASS-21. The numerous dimensions of uncertainty around anaphylaxis are discussed in the literature, such as inadequate and conflicting medical advice (Akeson et al., 2007), knowing the ingredients in food (Anibarro et al., 2007), and recognizing and knowing how to treat symptoms when they occur (Kim et al., 2005; Lyons & Forde, 2004). Patients with illnesses characterized by exacerbation and remissions, symptom variability and inconsistency, have greater illness uncertainty (Mishel, 1988). The current study is the first to quantify

illness uncertainty in this population and to relate the finding to psychological adjustment. Twenty-two percent of participants identified a history of exercise-induced anaphylaxis, which is considered a rare syndrome in the scope of anaphylaxis (Robson-Ansley & Toit, 2010). The incidence of increased depression in this group predicted by illness uncertainty appears to be the first indicator of adjustment problems specific to this group. Bryden et al. (2001) associated depression and anxiety with better glycemic control among diabetics, and Lyons and Forde (2004) found that higher anxiety among food allergic young adults was associated with better management. For the portion of the sample with more episodes of anaphylaxis, illness uncertainty was positively related to anxiety. In addition, the entire sample shows a moderate level of anxiety based on DASS-21. This supports the associations between anxiety and better food management noted above since 38.8% of the sample reported zero incidents of anaphylaxis in the last 2 years, but still reported a high level of anxiety.

H_0^2: Coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

Stepwise multiple regression analysis was performed on coping and psychological adjustment. Coping is comprised of an individual's efforts to manage the demands of a situation that are greater than his/her perceived resources. Due to the small sample size, the eight subscales of the WOC had to be collapsed into two broad subscales reflecting Emotion-Focused and Problem-Focused coping. Problem-focused coping is geared toward making direct changes to a situation and emotion-focused strategies are aimed at dealing with the emotions a situation elicits (Lazarus & Folkman, 1984). For H^2,

emotion-focused coping showed a direct effect as a moderator variable and was positively and significantly associated with depression, anxiety, and stress. Anxiety associated with the number of episodes of anaphylaxis experienced in the last two years was positively associated with both problem-focused and emotion-focused coping. Because these scales were collapsed, the extent to which adaptive or maladaptive coping processes are being used cannot be identified. However, emotion-focused coping, which is generally associated with poorer adaptation, (Kleinke, 2007) was used more than problem-focused coping by these respondents. Both types of coping were used more among individuals who had experienced more episodes of anaphylaxis in the last two years. This suggests that these individuals may recognize that they need to find a more effective way of dealing with this problem and that being part of information and support groups that the sample was taken from may help facilitate that. Positive results from the role these support groups play in the lives of people who participate in them may be evidenced by the number of people (n = 14) who reported no episodes of anaphylaxis in the last two years which is the average time frame for recurrence (Martelli et al., 2008).

H_0^3: Illness uncertainty as measured by the MUIS-C in the presence of coping as measured by the WOC has no effect on adjustment as measured by the DASS-21.

For hypothesis H^3, stepwise multiple regression analysis showed that the interaction effect of illness uncertainty and coping on psychological adjustment was significant. According to Barron and Kenny (1986), direct effects on the first two hypotheses are not specifically relevant to the moderator hypotheses. The moderator hypothesis is most clearly interpretable when the null hypotheses are retained for the first

two hypotheses and the null hypothesis for H^3 is rejected (Baron & Kenny, 1984) This was not the outcome of this study. Thus the moderator effect is supported, but not clearly interpretable.

$H_0{}^4$: Illness uncertainty, as measured by the MUIS-C, does not mediate the effects of coping as measured by the WOC on adjustment as measured by the DASS-21.

The criteria for performing additional regression analysis on mediation described in H^4 was not met, and therefore, $H_0{}^4$ was retained.

Theoretical Considerations

The cognitive-diathesis stress model accounts for individual differences in vulnerability based on biological, cognitive, and social factors that can affect individual adaptation to stress (Burke & Elliott, 1999). This study used this model to see if the cognitive variable illness uncertainty had an effect on psychological adjustment. Ways of coping were also examined for their effects on adjustment, both directly and in combination with illness uncertainty. This study indicates that both illness uncertainty and ways of coping are significant factors in adjustment, which is consistent with this theory (Lazarus & Folkman, 1984; Mishel, 1984). Illness uncertainty was predictive among the entire sample as well as the portions of the sample with more episodes of anaphylaxis and those with exercise-induced anaphylaxis. It is logically consistent with this theory that more episodes are resulting from ambiguity associated with the illness uncertainty factors and that exercise-induced anaphylaxis is an uncertain event when anaphylaxis is stimulated by ingesting a food that only causes a reaction in the presence of exercise and likely was consumed safely in the past.

While the average age of onset for food anaphylaxis among these participants was 2.7 years, this was not a significant factor for adjustment in this study. A larger sample may have indicated a developmental vulnerability associated with this population that the theory predicts (Gibb & Coles, 2005). Other variables that were not significant in this study outcome, but are indicated as potentially significant based on the theory include the number of foods one is anaphylactic (Leung et al., 2009) to and other allergic illnesses such as asthma and eczema which are highly comorbid with food induced anaphylaxis (Lieberman & Anderson, 2007) and increase a person's overall illness burden.

Limitations of the Study

The significance of this study is limited by the small sample size that required the statistical power to be decreased and only large effects detected. Illness uncertainty is a relative scale and there are no norms for this group. Ethnicity, level of education, and a history of eosinophilic gastroenteropathy appeared to impact outcomes, but the samples in these categories were too small to be meaningfully interpreted. Women are affected by anaphylaxis to food at a higher rate than men (60% to 40%; Jensen-Jarolim & Untersmayr, 2008), and women accounted for 80.6% of participants, and males accounted for 19.4% of participants. This validates research that shows a greater proportion of women than men seek health information and social support from online support groups (Fallows, 2005). All of the participants who identified a history of exercise-induced anaphylaxis in the present study were women; these individuals also scored higher on uncertainty and psychological adjustment measures than other participants of this study. Further study of how this condition affects both men and

women is indicated and a broader and more representative sample would help to address this limitation. The diversity in country of residence found in participants may also have affected responses based on cultural differences. Without further study these effects cannot be discerned. Participants were self-selected from Internet-based support groups and social networking sites that had a focus on food allergy issues. It is not clear how representative these people are of the larger community of young adults who have a history of food induced anaphylaxis.

Implications for Positive Social Change

This research has identified illness uncertainty as a significant factor in psychological adjustment among young adults with food induced anaphylaxis. The risks of adjustment problems increase for those with repeated episodes of anaphylaxis within a two year time frame and those with exercise-induced anaphylaxis. Patients with these characteristics seeking medical or psychological care should be assessed with the potential for adjustment problems in mind.

While many aspects of illness uncertainty related to food induced anaphylaxis will not be resolved until there is a medical treatment or cure, many aspects of uncertainty such as how to minimize exposure, implement emergency treatment, and help friends understand the nature of the illness may help reduce illness uncertainty and lead to better psychological adjustment. It is also important to emphasize to parents the importance of teaching children to understand and manage their illness rather than doing it for them so that they understand the subtleties of staying safe and that they develop a voice for self-advocacy. Increased attention to these effects may influence a positive

social change by decreasing the incidence of food induced anaphylaxis, its associated medical and health costs, improved psychological adjustment among these patients, and reduced mortality.

Recommendations for Action

To implement this positive social change, it is important to disseminate findings from this study within the medical communities that see food allergic individuals such as pediatricians, family practitioners, and allergists, and to allergic individuals themselves. A summary of these results will be posted to the communities that participated in the study, which will help to increase awareness of these issues and how they may be better addressed. The medical and psychological communities should be educated as to the particular vulnerabilities and needs of this population, and patients, parents, and guardians should be alerted to the presence of these indicators so they can better act to advocate for their well being. Results will also be submitted to peer reviewed publications in the health psychology community.

Recommendations for Further Study

Young adults with food induced anaphylaxis are at risk for adjustment problems and illness uncertainty predicts this risk. Future studies should be undertaken with larger populations to more definitively understand particular dimensions of uncertainty and how they affect this population. Gender differences should also be studied. Coping processes should also be further studied in this population. A study with a larger sample where the coping scale does not have to be collapsed would provide further insight into the processes and contributions to coping embedded in each WOC scale. It may be useful to

understand which situations individuals with food induced anaphylaxis perceive as a threat, challenge, or loss as this may lead to ways to help people reappraise situations and cope more effectively. Locus of control studies may further help elucidate where individuals may be able to cope more effectively. Resiliency should also be examined so that models of successful coping can be shared. Cultural differences, level of education, and socioeconomic status may affect coping and adjustment, and these should be studied in a larger sample.

Conclusion

The results from this study contribute to the literature by providing a quantitative demonstration of the positive relationship among illness uncertainty, ways of coping, and depression, anxiety, and stress. These results are consistent with qualitative research that has indicated uncertainty issues in this population that effect adjustment. Psychological adjustment can be enhanced among young adults with anaphylaxis to food by finding ways to decrease their experience of illness uncertainty.

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Appendix A: Request to Announce Study and Associated Correspondence

Date: February 21, 2010

Dear Food Allergy Support Group,

Re: Food Allergy Research

As a mother of a young adult with anaphlaxis to food, I understand the difficulties in living with this condition. As a doctoral student, I am pursuing my interest in this area by trying to clarify how young adults cope on a day to day basis with the condition. My dissertation topic is "Illness Uncertainty, Ways of Coping, and Psychological Adjustment Among 18 to 25 Year Olds With Anaphylactic Food Allergies."

I am requesting permission to recruit participants for this study from your web site. The surveys used in this study take about 15 minutes to complete and no individually identifying information will be collected. The study will be hosted on Survey Monkey and all information that participants provide will be kept confidential. If you agree to make an announcement about this study, I would like it to read as follows:

"You are invited to take part in a research study of young adults with severe food allergies being conducted by Susan Cohen, a graduate student at Walden University. You are eligible to participate in the study if you are between 18 and 25 years old and have experienced an anaphylactic allergic reaction to food that required treatment with epinephrine (a shot). If you are interested in participating, click here (url will be provided)"

The results of this research will be included in my dissertation and/or may be published in subsequent journals or books. The benefit to participants for being in this study comes from knowing they are helping advance knowledge in the field of food induced anaphylaxis.

If you have any questions about any part of this research please contact me. If you have further questions you may contact my research advisor, Dr. Leann Stadtlander, who is supervising this study at the contact information below.

Please grant permission to host recruiting information in your newsletter, discussion group, or website to help me recruit participants for this research. I appreciate your support and cooperation.

Sincerely,

Susan Cohen, Doctoral Student
Walden University
susan.cohen@waldenu.edu

925-321-3784

Contact Information:
Faculty Advisor:
Leann Stadtlander, Ph.D.
Coordinator, Health Psychology Program
School of Psychology
Walden University
Office: 406-451-6412
leann.stadtlander@waldenu.edu

Current Study Announcement:

You are invited to take part in a research study seeking to understand how young adults with severe food allergies cope with issues surrounding this condition. This research is being conducted by Susan Cohen, a graduate student at Walden University. You are eligible to participate in the study if you are between 18 and 25 years old and have experienced an anaphylactic allergic reaction to food that required treatment with epinephrine (a shot). If you are interested in participating, click here http://calsci.org/Faculty/SusanCohen/FoodAlergySurvey/index.html

Proposed Changes to Study Announcement:

You are invited to take part in a research study seeking to understand how young adults with severe food allergies cope with issues surrounding this condition. This research is being conducted by Susan Cohen, a graduate student at Walden University. You are eligible to participate in the study if you are between 18 and 25 years old and have experienced an anaphylactic allergic reaction to food at some point in your life that required treatment with epinephrine (an injection). If you are interested in participating, click here http://calsci.org/Faculty/SusanCohen/FoodAlergySurvey/index.html

Do you have an **Anaphylactic Food Allergy?**

Be part of an important allergy research study

If you are between **18-25 years of age** and have experienced an anaphylactic reaction to food at some point in your life that required treatment with epinephrine or an Epi-Pen, you are eligible to participate in an online research study (foodallergystudy.com).

The purpose of this 15 to 20 minute study, which consists of several surveys, is to examine how individuals cope with this condition. Benefits include helping others to understand how to deal with severe food allergies.

Research conducted by Susan Cohen, a doctoral student at Walden University.

For more information:

susan.cohen@waldenu.edu

Be part of an important allergy research study

If you are between **18-25 years of age** and have experienced an anaphylactic reaction to food at some point in your life that required treatment with epinephrine or Epi-Pen, you are eligible to participate in an online research study (foodallergystudy.com).

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Research conducted by Susan Cohen, a doctoral student at Walden University.

For more information:

susan.cohen@waldenu.edu

foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu	foodallergystudy.com susan.cohen@waldenu.edu

Advertisement to be posted on craigslist food discussion forum

Be part of an important allergy research study

If you are between **18-25 years of age** and have experienced an anaphylactic reaction to food at some point in your life that required treatment with epinephrine or Epi-Pen, you are eligible to participate in an online research study (http://foodallergystudy.com).

Appendix B: MUIC Permission and Sample Questions

MUIC

Managing Uncertainty In Cancer

SENT Via email 4-15-09 per Merle's Request

Request Form for Adult Uncertainty in Illness Scale (Community Form)

PPUS-FM

PPUS

MUIS-C

MUIS-A

Main Page

I request permission to copy the Adult Uncertainty in Illness Scale (Community Form) for use in my research entitled:

Illness uncertainty, attributional style and psychological adjustment among older adolescents and young adults with severe food allergy.

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study, a printout of the uncertainty data on a 3.5-inch disk containing the data with the data dictionary. The data must contain information on each subject's age, sex, education, and diagnosis, along with data on each subject's response to each item on the *Uncertainty Scale*. This data will be used to establish a normative database for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analysis. Credit will be given to me in any reports referring to my findings.

Susan Cohen

Signature

3-24-09

Date

Positions and full address of Investigator

Susan Cohen
Doctoral Student, Health Psychology
Walden University
572 Leona Dr.
Livermore, CA 94550
susan.cohen@mac.com

Permission is hereby granted to copy the MUIS for use in the research described above.

Merle H. Mishel

Merle H. Mishel

4.15.09

Date

Please send **two signed copies** of this form to Merle H. Mishel, Ph.D., FAAN, School of Nursing, CB#7460 Carrington Hall, University of North Carolina, Chapel Hill, NC, 27599-7460.

MISHEL UNCERTAINTY IN ILLNESS SCALE – COMMUNITY FORM

INSTRUCTIONS:
Please read each statement. Take your time and think about what each statement says. Then place a "X" under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement.

1. **I don't know what is wrong with me.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

2. **I have a lot of questions without answers.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

3. **I am unsure if my illness is getting better or worse.**

Strongly Agree (5)	Agree (4)	Undecided (3)	Disagree (2)	Strongly Disagree (1)
_____	_____	_____	_____	_____

Appendix C: Instructions, Permission, and Sample Questions for Ways of Coping Questionnaire

Take a few moments and think about the most stressful situation you have experienced in relation to your food allergies in the past month. Some types of stressful situations can include but are not limited to going out to eat with people you don't know well, being hungry and not having food available that you know is safe, or having an allergic reaction. By stressful we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you.

Please briefly describe this event. Who was involved? What happened? Why it was stressful? What were the options for coping?

Sample Questions Ways of Coping Questionnaire

0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

1. I just concentrated on what I had to do next – the next step. **0 1 2 3**
2. I tried to analyze the problem in order to understand it better. **0 1 2 3**
3. I turned to work or another activity to take my mind off things..... **0 1 2 3**
4. I felt that time would have made a difference – the only thing was to wait. **0 1 2 3**
5. I bargained or compromised to get something positive from the situation. **0 1 2 3**

Appendix D: Permission to use Ways of Coping Questionnaire

mind garden

www.mindgarden.com

To whom it may concern,

This letter is to grant permission for the above named person to use the following copyright material;

Instrument: ***Ways of Coping Questionnaire***

Authors: ***Susan Folkman, Ph.D. and Richard S. Lazarus, Ph.D.***

Copyright: ***1988 by Consulting Psychologists Press, Inc.***

for his/her thesis research.

Five sample items from this instrument may be reproduced for inclusion in a proposal, thesis, or dissertation.

The entire instrument may not be included or reproduced at any time in any other published material.

Sincerely,

Vicki Jaimez
Mind Garden, Inc.
www.mindgarden.com

Appendix D: Permission to use the DASS:

3. How do I get permission to use the DASS?

The DASS questionnaire is public domain, and so permission is not needed to use it. The DASS questionnaires and scoring key may be downloaded from the DASS website and copied without restriction (go to Download page).

The DASS questionnaires and scoring key may also be distributed, published or made available electronically, with the restrictions that:

a) the scales are not modified,

b) the scales are not sold for profit,

c) the intended audience is researchers or health professionals rather than end users, and

d) reference is included to the DASS website: www.psy.unsw.edu.au/dass/

DASS21

Name: *Date:*

Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

Appendix E: Informed Consent Agreement

Informed Consent Agreement

You are invited to take part in a research study of young adults with severe food allergies being conducted by Susan Cohen, a graduate student at Walden University. You are eligible to participate in the study because you are between 18 and 25 years old and have indicated that you experienced an allergic reaction to food that required treatment with epinephrine (a shot). This form is part of a process called "informed consent" to allow you to understand this study before deciding whether or not to take part.

Background Information:

People with food allergies often worry about what they eat because eating the wrong food can have serious consequences and potentially lead to death. Understanding how people cope with food allergies can help them manage the allergies more effectively. As a person with food allergies, your input is very important because people who live the experience understand the trade-offs in coping better than anyone else. Could you spend 15 to 20 minutes filling out this questionnaire so we may better learn how to help people with this problem? A report of the findings from this study will be posted at a website that will be provided when you complete this form.

Procedures:
If you agree to participate in this study, you will be asked to:

- Provide demographic information.
- Complete a survey that should take 20 to 30 minutes.

Voluntary Nature of the Study:

Your participation in this study is voluntary. If you decide to join the study now, you can still change your mind at any time. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal, although you are encouraged to respond to all questions and all responses are anonymous. There are no risks involved in this study and the benefit comes from adding to the research available to help others with food allergies cope with this problem.

Compensation:

No compensation will be provided to participants.

Confidentiality:

Any information you provide will be anonymous. The researcher will not use your information for any purposes outside of this research project. You will not be asked for your name and personally identifying information will not appear in any reports of the study.

Contacts and Questions:

Questions about the study can be sent to Susan Cohen at susan.cohen@waldenu.edu. or you can call 925-321-3784. Walden University's approval number for this study is 04-29-10-0005281 and it expires on April 28, 2011.

Consent:

Consent to participate in this study is indicated by proceeding to the first page of the survey. Permission for use of your responses will be requested again upon completion of the survey and consent can be withdrawn by electing not to submit your responses to the online survey database.

Appendix F: Demographic Questions

What is your sex?
☐ Male
☐ Female

What is the highest level of education you completed?

☐ Elementary school only
☐ Some high school, but did not finish
☐ Completed high school
☐ Some college, but did not finish
☐ Two-year college degree
☐ Four-year college degree
☐ Some graduate work
☐ Completed Masters or professional degree
☐ Advanced Graduate work or Ph.D.

Have you ever experienced anaphylaxis?

☐ Yes
☐ No

At what age did you first experience anaphylaxis?
☐ Before age one
☐ Age1 to 5
☐ Age 5-12
☐ Age 12-17
☐ After age 17

How many episodes of anaphylaxis have you experienced in the last 2 years?

_____

Check all foods that you are anaphylactic to.
☐ Nuts
☐ Peanuts
☐ Milk
☐ Eggs
☐ Soy
☐ Wheat
☐ Fish
☐ Shellfish
☐ Other _____

Have you ever had exercise-induced anaphylaxis?
☐ Yes
☐ No

Have you had anaphylaxis where the cause wasn't identified?
☐ Yes
☐ No

Do you have asthma?
☐ Yes
☐ No

Do you have eczema?
☐ Yes
☐ No

Have you ever been diagnosed with either eosinophilic eosophogitis or eosinophilic gastritis?
☐ Yes
☐ No

Would you describe yourself as:
☐ American Indian / Native American
☐ Asian
☐ Black / African American
☐ Hispanic / Latino
☐ White / Caucasian
☐ Pacific Islander
☐ Other

In what year were you born?
19__ __

In which country do you live?
_____

What is your total household income?

☐ Less than $20,000
☐ $20,000 to $40.000
☐ $41,000 to $60,000
☐ $61,000 to $80,000
☐ $81,000 to $100,000
☐ Over $100,000

Have you experienced any traumatic event in the last month that was unrelated to your food allergy?

☐ Yes
☐ No

If yes, briefly describe what happened.

Curriculum Vitae

SUSAN COHEN
572 Leona Drive • Livermore, CA 94550 • (925) 454-0170
susan.cohen@waldenu.edu

Holds Masters degree in Psychology, Baccalaureate in English, a professional degree in Nursing, is a Registered Nurse licensed to practice in California, and is a Certified Holistic Stress Management Instructor, a Certified Sexual Assault and Domestic Violence Crisis Counselor, and a Certified Dog Trainer. Experience includes adjunct professor in Criminal Justice teaching courses in psychology and the law and cyberstalking and hate crimes. Currently employed as a Research Associate working in issues related to criminal and civil litigation and digital forensics.

PROFESSIONAL EXPERIENCE

Fred Cohen & Associates 1999 – Present
Research Associate

Responsible for research into psychological issues related to individual and group behaviors. This includes review of historic behaviors of groups and individuals, placing current events and situational information into the historic context, and identifying ranges of potential future behaviors for inclusion in reports and analytical products. Works in association with other researchers focussed on other aspects of the issues to help develop overall work-product, participates in reviews of work-product, and performs individual as well as group research and investigations.

University of New Haven 2000 – 2002
Adjunct Professor

Responsible for developing and delivering courses within a criminal justice program. Developed and delivered a course on cyberstalking and online hate crimes, including research on how the Internet is used to facilitate crime and delivery to in-class Masters of Science students. Delivered a previously developed course on psychology and the law, which covered a range of topics such as eye-witness testimony, theories of crime, and false confessions.

Tri-Valley Haven 1998 – 2000
Advocate and Crisis Counselor

Responsible for taking crisis phone calls, evaluating potential shelter residents, and facilitating resolution of problems through community services. Work with other shelter workers, clients, and potential clients both individually and in small teams; development of ongoing lecture series on health issues, nutrition, childhood education, growth, and development.

Livermore School District 1997 – 1998
Substitute Teacher

Responsible for teaching grades K-12, including all subjects through 6th grade and English and History for all grade levels.

Management Analytics 1987 – 1998
Development Consultant

Designed, reviewed, and edited contracts and proposals, marketing documents, brochures, management reports, and books. Wrote press releases, scheduled talks with various local groups, and worked with local press to enhance awareness of the firm and its areas of expertise. Developed brochures for, and made arrangements to host 1-day short courses.

Massachusetts General Hospital 1985 – 1986
Registered Nurse

Responsible for patient care on a medical cardiac unit, developed patient care plans, taught patients and families about relevant health issues, and provide instruction on procedures and techniques that would be necessary for home care upon discharge from the hospital.

EDUCATION

PhD (in progress) Health Psychology, Walden University 2010 (anticipated)
MS Psychology, Walden University 2000
Professional Nurse, St. Francis Hospital School of Nursing 1984
BA English, University of Pittsburgh 1983

PROFESSIONAL ACTIVITIES

Served as Adjunct Faculty, University of New Haven
Student Affiliate, APA, Health Psychology Division (current)
Member, Association of Pet Dog Trainers