BALANCING SAFETY AND NORMALCY: A STUDY OF PARENTS' MANAGEMENT OF YOUNG CHILDREN'S SEVERE FOOD ALLERGIES

by

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ABSTRACT

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While severe food allergies have been extensively studied by physicians, sociologists have not yet examined the parental management of children's severe food allergies. In this thesis, I examine how parents negotiate physical, emotional, and social issues that arise in daily life with a severely allergic child. Severe food allergy management is not an easy task given the potentially fatalistic nature of severe food allergies coupled with the inadequate level of social awareness of such allergies. In order to better understand the parental management of food allergies, I interviewed twelve parents of severely food allergic children regarding the various spheres of allergy management including physical, emotional and social management. Through the use of qualitative coding and data analysis, this study, anchored in a grounded theory approach, revealed the emergence of several sociologically relevant phenomena or themes: intensive parenting, collective legitimization and the negotiation of difference. Intensive parenting emerged as an overarching theme in that these parents were very child-centered and emotionally absorbed in the management of their children's allergies. Collective legitimization was also observed as a mechanism of intensive parenting. Parents utilized a variety of strategies, such as creating group cohesion with other parents of children with severe food allergies, in order to legitimize their children’s allergies to themselves and outsiders. Finally, through the negotiation of difference parents worked diligently to offset social stigmas in a world of intensive parenting.

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CHAPTER 1

INTRODUCTION

The purpose of this thesis project is to investigate the dynamics that govern parents' physical, emotional and social management of young children's severe food allergies. More and more Americans, especially toddlers and young children, are being diagnosed with life threatening food allergies to one or more of the eight major food allergens: milk, egg, peanut, tree nut, fish, shellfish, soy, and wheat. Research suggests that food allergies occur in approximately 2% of the U.S. population (Sicherer, et al. 2001, 2003). Approximately half of this percentage is represented by allergies to peanuts with the other half represented by the other seven major food allergens. Although it is rare, a severely food allergic individual can die as a result of a severe allergic reaction also known as anaphylaxis. It is estimated that 100-200 of food allergic individuals, many of which are young children, die each year from allergy induced anaphylaxis. Individuals with severe food allergies should exercise strict avoidance of the allergy-causing food. However, if exposure does occur and results in a severe allergic reaction, the best treatment for anaphylaxis is the prescription drug Epinephrine, also known as "adrenaline," which is the medication of choice for counteracting a severe reaction.

The effective management of a severe food allergy is relatively complex for the parents of allergic individuals. Parents of severely allergic children, especially young children, are faced with the job of balancing safety and normalcy for their child given the often contradictory needs of ensuring a child's physical, emotional, and social health. It is strongly suspected that this balancing act is anything but an easy task given the general public's lack of awareness of the seriousness of severe food allergies coupled with the potentially fatalistic nature of a severe food allergic reaction. The parent is, therefore, responsible for keeping their child safe, while at the same time providing an emotionally and socially healthy environment for the child with little or no support from society including extended family members, teachers, and restaurant personnel to name a few.

Parents' management of severe food allergies tends to fall into three interrelated and overlapping categories: physical, emotional and social management. Examples of physical management include allergen avoidance as well as the administration of life saving medication in the event of a severe allergic reaction. Emotional management includes educating, comforting and listening to one's child regarding their allergy as well as the parent dealing with their own emotions with respect to the allergy. Finally, social management for a parent encompasses communicating their child's allergy and accompanying needs to various groups and individuals in society including, but not limited to, family, friends, schools, and healthcare providers.

The management of a child's severe food allergy can have both negative and positive effects on the parents of severely food allergic children as well as the children themselves. Negative effects can include: stress and anxiety associated with the hyper-vigilant avoidance of severe food allergens as well as a generalized loss of spontaneity within the family of the food allergic child due to the level of anticipation and planning that managing a child's allergy involves. Positive effects can include: a healthier lifestyle as a result of avoiding food allergens, such as dairy products, in the family's diet as well as improved family relations between husband and wife and among siblings.

This is clearly a growing public and societal issue worthy of further sociological exploration. In order to delve deeper into this research topic, an exploratory research study was undertaken. This study utilized sociological qualitative methods via in-depth interviews with twelve parents of severely food allergic children. The data were analyzed utilizing qualitative coding techniques to reveal any trends in parents' management of their children's severe food allergies as well as differences across cases. Study results have revealed several sociological components at play in parents' management of their children's severe food allergies. The ideology of *intensive parenting* has emerged as an overarching frame for understanding parents' management strategies given how child-centered, expert-guided and emotionally absorbing this parental management appears to be. Additionally, in the spirit of intensive parenting these parents struggle with how they, their child and their child's allergy is received by outsiders. As a result, they engage in *collective legitimization* whereby they act as a group with other parents of severely food allergic children as they legitimize the allergy to themselves, other group members and the outside non-allergic world. This does not, however, always result in a positive outcome. The presence of a hierarchy of allergies has surfaced from the data wherein parents of children with different allergies and different allergy severities tend to draw comparisons with each other based on the nature and difficulty of allergy management. Parents struggle for status within their own subgroup as parents of food allergic children. This divisiveness frequently involves negative emotions such as hostility, jealousy and irritation. Finally, and also in the spirit of intensive parenting, these parents engage in a *negotiation of difference* for their children. Parents of food allergic children have to delicately balance how they present their children as different to outsiders due to the food allergy while at the same time work to keep the child from feeling different or treated different due to the food allergy. They accomplish this through various, and at times contradictory, mechanisms including how they choose to communicate their children's special needs to others as well as how they buffer any negative consequences of the allergy such as stigmatization. These sociological concepts aid in understanding how parents of severely food allergic children manage their children's allergies.

In the next chapter I will present a literature review summarizing the prior research focused on food allergies and food allergy management as it applies both directly and indirectly to the research topic. Chapter three focuses on the methodology of this research project including the premise for the study, how participants were selected, specifics of the study's sample, the data measurement and collection processes employed, and the analytic approach utilized in order to draw study conclusions. Chapter four encompasses the findings of the study with subsections on the physical, emotional and social management of parental severe food allergy management. Chapter five is a discussion section for the purposes of summarizing the study's findings as well as recommendations for future research.

CHAPTER 2

LITERATURE REVIEW

The main purpose of this research project is to explore how parents negotiate / manage their children's food allergies. Most food allergy research has been undertaken by medical professionals, such as allergists, who focus on the scientific / medical side of severe food allergies. A reasonable amount of popular press self-help literature has also been published on the research topic which serves to aid the parent of the food allergic child in their quest to understand and manage their child's food allergy. Also from the field of medicine, but from a less scientific viewpoint, work on the public perception of food allergies and the impact of food allergies on allergic individuals' quality of life was also ascertained through the literature review process. From the field of sociology, a small amount of work from the field of sociology of medicine was revealed which directly related to the research topic as well. This work focused on how food allergy management in public settings, such as schools, was viewed from the perspective of the non-allergic population.   Although the aforementioned research does examine various management strategies to a certain extent, it leaves something to be desired in terms of understanding how parents handle the challenges of managing severe food allergies in a world that is not fully accepting of such allergies. Drawing on sociological concepts may provide a view into the underlying dynamics affecting food allergy management -- the social management of food allergies in particular. How parents manage within the home versus outside the home as well as how they legitimize the allergy to themselves and the outside world have yet to be examined.

For the purposes of this study, it is the sociological literature on intensive parenting that provides for the research study's development and focus as well as the interpretation of the data. Intensive parenting can be seen in the data with respect to how this group feels about their children's allergies, how they legitimize the allergy, as well as how they negotiate difference for their children. In this chapter, I review the medical literature including subsections on the prevalence, increased incidence and severity of food allergies, the public education regarding severe food allergies, and the consequences of physical, emotional and social aspects of food allergies. In addition to the medical literature, I will also review the sociological literature on intensive mothering.

2.1 Medical Literature

The majority of the research on severe food allergies is from a medical perspective which emphasizes the definition, prevalence, exposure, avoidance, and treatment of food allergies as well as some parental management techniques. The following subsections will focus on the literature regarding prevalence, increased incidence and severity of food allergies; public education regarding severe food allergies; the parental management of allergies including physical, emotional and social management; and, finally, literature focusing on the quality of life for those affected by severe food allergies.

2.1.1. Prevalence, increased incidence and severity of food allergies

The two common themes that emerge from the medically based literature on food allergies are the prevalence, particularly the increased prevalence, of severe food allergies and the seriousness of food allergies in terms of severity. Although an individual could be allergic to any food, such as fruits, vegetables, and meats, there are eight foods that account for 90% of all food-allergic reactions. These are: milk, egg, peanut, tree nut, fish, shellfish, soy, and wheat with peanuts topping the list of the most deadly severe food allergens. Approximately 2% of the U.S. population is affected by food allergies with roughly half (1%) represented by peanut and or tree nut allergies and the other half (1%) represented by one or more of the other major food allergens.

There appears to be an *increased incidence* of food allergies as well. According to a random digit dial telephone survey, self-reported *peanut allergy* alone has doubled among children from 1997 to 2002, and peanut allergies, tree nut allergies, or both continue to be reported by more than 3 million or approximately 1% of Americans (Sicherer, Munoz-Furlong, and Sampson, 2003). This helps to explain why the majority of the food allergy medical research focuses on peanut allergies coupled with the fact that peanuts allergies claim more lives than any other major food allergen. Rous and Hunt (2004) also find evidence of an increased incidence of food allergies over recent decades. They report peanut sensitization, as measured by a standard positive skin prick test, has increased by 55% while allergic reactions have raised 95% over the last 10 years.

Severe food allergies claim approximately 100-200 American lives every year as a result of a food induced severe allergic reaction resulting in full blown anaphylaxis. Anaphylaxis is a sudden, severe, potentially fatal, systemic allergic reaction that can involve various areas of the body (such as the skin, respiratory tract, gastrointestinal tract, and cardiovascular system). Sicherer et al. (2001) argue that “allergic reactions to peanut and tree nut are frequently severe, often occur on the first known exposure, and can become more severe over time” (128). In sum, food allergies are prevalent, appear to increasing in frequency, and can be severe especially in the case of peanuts.

2.1.2. Public education regarding severe food allergies

Perhaps the most difficult challenge for the parent of a severely food allergic child is gaining cooperation from society at large on behalf of their child. The general perception of food allergies, like other allergies, is that they are merely a nuisance for the afflicted individual. It is difficult for many individuals to believe that otherwise wholesome food could be deadly (Collins, 2000). This misperception promotes an environment in which allergic individuals are at increased risk of potentially fatal exposure.

There is near universal agreement among scholars that improved education on the possible severity of food allergies is necessary (Bock et al., 2001; Eigenmann and Zamora, 2002). The public misperception concerning food allergies is two fold. First, the general public does not fully understand the *potential seriousness* of severe food allergies as previously mentioned. Additionally, in their efforts to socially manage their children's severe allergy, parents are also challenged by issues concerning the self-perception of food allergies when in fact no allergy exits. In terms of public *self-perception*, perceived food allergies are quite high ranging from 13.9% to 16.6% based on a mailed consumer questionnaire. These perceived food allergies typically lack a true medical diagnosis and are quite often not in fact true allergies. Studies using traditional medical standards, such as double-blind placebo-controlled food challenges, suggest that the prevalence of food allergy is about 2%. However, according to Altman and Chiaramonte (1996:1247), "perceived food allergy is widespread and persistent". This is unfortunate given that many individuals that are not truly allergic present themselves as allergic. This can sabotage the efforts of truly allergic individuals. Touting of food allergies on the part of non-allergic individuals tends to create skepticism on the part of the public. It makes it difficult for individuals to take an allergic person's claim of being allergic seriously, which would create a challenge to parents. This can have a backlash effect on truly food allergic individuals and the management effort of their parents.

Although overall public awareness of allergies is relatively lacking, there has been a recent shift towards awareness in certain sectors, such as education. The response to allergy management, however, has been negative by the non-allergic community. In an effort to acknowledge and deal with food allergies, some entities have been seen as over-correcting with respect to food allergy management. Rous and Hunt (2004) examine the world of severe food allergies from the non-allergic community's perspective and educators' management of severe food allergies in particular. They contend that the lines between public and private life have been seriously blurred where teachers are responsibilized for the physical safety of food allergic children. It is understandable that teachers be required to keep their students safe, but the level of effort being demanded in Rous and Hunt's study suggest that bureaucratic policy makers have gone too far and have perhaps overcorrected in their efforts to protect a small minority of children. These consequences exemplify the fact that severe food allergies have far reaching effects -- for the severely food allergic individual and also the individuals that work to keep them safe.

2.1.3. Parental management of allergies: physical, emotional and social

In the quest to manage their child's severe food allergy, it is expected that parents face a whole host of issues and challenges. These can range from preparing safe meals free from potentially fatal allergens to helping their child deal with anxiety relating to issues deriving from the food allergy (e.g. school bullying or feeling ostracized). The parent of a severely food allergic child is charged with several different spheres of responsibility given that their child's physical, emotional, and social health are all affected by their severe food allergy. These parental management strategies, with much overlap, tend to be categorized as physical, emotional and social in nature.

The *physical management* of food allergies affects many spheres of life including how parents take preventative measure to keep their children safe. Bollinger, et al. (2006) found, for example, that "more than 60% of caregivers reported that food allergy significantly affected meal preparation and 49% or more indicated that food allergy affected family social activities. Forty-one percent of parents reported a significant impact on their stress levels and 34% reported that food allergy had an impact on school attendance, with 10% choosing to home school their children because of food allergy" (Bollinger et al., 2006:385-6). The effect that a child's food allergy has on a parent can have far reaching effects extending its grasp to almost all aspects of daily life. A parent cannot just choose to take their child out to lunch, send their child off to school or even leave their child with family or friends without putting a great deal of planning and effort into ensuring their child's safety.

Although the physical management of severe food allergies might seem to be the easiest of the three major management techniques, it might prove to be quite challenging for parents to provide a safe environment for a severely food allergic child. Recent medical research by Kim, Sinacore and Pongracic (2005) suggests, for example, that parents are often reluctant to administer life-saving medication to their children in the event of a severe allergic reaction. Parents' reasons for not administering epinephrine included the fact that Benadryl (an antihistamine) had initially been given in response to symptoms or that the parent did not believe that the reaction was serious enough to elicit the administration of epinephrine (Kim et al., 2005) Many of the parents reporting to be uncomfortable with administering life saving drugs were often concerned that they might not recognize the symptoms of anaphylaxis, fear hurting their child or perhaps forgot how to use life saving medication.

The *emotional management* of severe food allergies also presents many challenges to the parents of allergic children in that many of the emotions parents experience regarding their children's allergy derive from the physical and social management of the allergy. As previously mentioned these three types of management are often interrelated and overlapping. "Management of allergies depends on strict allergen avoidance and emergency preparedness. The demands of allergy management and concerns for the child's safety may place parents at risk of developing emotional distress or difficulties coping" (Lebovidge, et al., 2006:472). To exemplify the potential for this type of emotional distress, popular press work done by Collins finds that parents are faced with issues concerning fear, responsibility and guilt. Specifically, "caring for a food-allergic child often produces deep emotions, including fear" (Collins, 2000:94-95). Responsibility issues also arise in managing a severe food allergy in that the parents and caregivers of food-allergic children bear an unusually high sense of responsibility given that the stakes could not be higher than an innocent child's life (Collins, 2000). Guilt also plays a pivotal role in how parents manage food allergies. It is expected that parents could feel a horrible sense of guilt if they expose a child to the specific allergen or perhaps wait to long to begin treatment in the unfortunate event of a severe allergic reaction. For example, "peanut –allergic patients are affected by a condition which forces them and their families to exercise extreme dietary vigilance and experience constant uncertainty throughout their lives" (Primeau, et al., 2000:1135).

Given the level of public awareness of the severity of food allergies and a backlash against public involvement in the management of food allergies (Rous and Hunt, 2004), parents' *social management* of their child's allergy is a difficult task. "Difficulty in convincing others of the potential seriousness of food allergies is the most common problem experienced by parents" (Collins, 2000:74). The outside world can treat parents of severely food allergic children as neurotic, hypersensitive and "crazy". These types of negative interactions can happen within families, between friends and with individuals at places where allergic children receive education or care giving.

2.1.4. Consequences of physical, emotional and social aspects of food allergies

Given the difficulty managing the physical, emotional and social aspects of food allergies, it is not surprising that there exist many negative consequences. Studies have revealed that siblings and parents of food allergic children had lower levels of what psychosocial researchers refer to as Health Related Quality of Life (HRQL). Specifically, both siblings and parents of a child with food hypersensitivity exhibited lower predicted psychosocial HRQL (Marklund, et al., 2006). HRQL in parents and children affected by severe food allergies has been shown to affect family/social activities such as eating out, social activities, child care, and vacation as well as school, time for meal preparation, health concerns, and emotional issues (Cohen, et al., 2004). In the aforementioned Swedish study done by Marklund, et al., researchers found that "it is rather the risk of food reactions and measures to avoid them that are associated with lower HRQL than the clinical reactivity induced by food intake. Therefore, food hypersensitivity must be considered to have a strong psychosocial impact" (2006:4:48). Additionally, Primeau, et al. (2000) finds that "the parents of peanut-allergic children, compared to the parents of children with rheumatological disease, reported that their children had significantly more disruption in their daily activities. Furthermore, the parents of peanut-allergic children reported more impairment in the familial-social dimension of the IFQ (Impact on Family Questionnaire)" (2000:1135).

Two articles in particular focus on the quality of life of severely allergic individuals as opposed to siblings or parents of the allergic individual. Sicherer, Noone, and Munoz-Furlong find that "childhood food allergy has a significant impact on general health perception, emotional impact on the parent, and limitation of family activities" (2001:443). Additionally, Avery et al. found that "children with peanut allergy are faced with food and social restrictions due to the potentially life-threatening nature of their disease, for which there is no cure or treatment" (2003:378). This study revealed that children with peanut allergy actually reported a lower quality of life (QoL) than children with insulin-dependent diabetes mellitus (IDDM). The "peanut allergic children reported more fear of an adverse event and more anxiety about eating, especially when eating away from home" (Avery, et. al., 2003:378). The anxiety associated with the allergy might be useful in terms of being vigilant about avoiding their food allergen, however, the emotional costs of such anxiety is not clear. The children in the study were particularly concerned about eating in restaurants; however, they did feel safe eating in familiar restaurants if they were carrying their life-saving epinephrine kit. Clearly, food hypersensitivity can have real psychosocial effects on those individuals afflicted with severe food allergies as well as their parents and siblings.

As can be seen from the medical literature, food allergies and some of their effects have been extensively studied, however, the social dynamics concerning how parents communicate and manage their children's allergies to themselves, other parents of food allergic children, and to the outside world are still understudied. The following section on sociological literature will help bridge this gap by demonstrating how the sociological concept of intensive parenting possibly shapes and defines parents' management of their children's severe food allergies.

2.2 Sociological Literature

The parental management of a child's severe food allergy is an intensive pursuit given the already intensive, not to mention potentially fatalistic, nature of severe food allergies. It seems likely that many of the child-centered methods utilized by parents in the management of children's severe food allergies might be very similar to, if not derived from, the methods of intensive parenting. Parents today are far more "intensive" in their parenting style than parents of just one or two centuries ago. There has been a general shift in child rearing where children are now viewed as innocent, priceless and deserving of an almost superior position within the family with their needs coming before their parents. This ideology of intensive parenting, specifically intensive mothering, has been conceptualized and is most notably depicted by sociologist Sharon Hays in her 1996 book The Cultural Contradictions of Motherhood. Hays' model of intensive mothering states that "the methods of appropriate child rearing are *constructed* as child-centered, expert-guided, emotionally absorbing, labor-intensive, and financially expensive" (Hays,1996:8).

According to Hays, "the same society that disseminates an ideology urging mothers to give unselfishly of their time, money, and love on behalf of sacred children simultaneously valorizes a set of ideas that run directly counter to it, one emphasizing impersonal relations between isolated individuals efficiently pursuing their personal profit" (Hays,1996:97). She writes of rational actors where mothers, like fathers, would be expected to maximize one's own needs and put the needs of others after her own. She contends that the current model of intensive mothering, as well as all previous models of mothering, are socially constructed and heavily influenced by the historical context in which they exist. "Each historical period, within any particular geographic region, offers a number of cultural models for appropriate child rearing. Over time, older models are discarded and fade from historical memory, and new models arise in new social contexts" (Hays,1996:21). Over the past one to two centuries, a model of *intensive* mothering has emerged as a result of changing norms in society. She "proposes that in the last

150 years the value attached to children and their care has changed dramatically. Rather than relegating the care of infants and children to governesses, wet nurses, and younger siblings, in earlier centuries, families in the United States have placed increasing value on *mother* care" (Moen and Roehling, 2005:82). In Hays' book, she demonstrates both the variable nature of child-rearing ideas and their increasingly intensive qualities over time starting with the "earliest discovery of childhood innocence in Western Europe, through the religiously grounded model of the American Puritans, the nineteenth-century valorization of mothers, and the turn-of-the-century establishment of expert-guided child rearing, to the dawning of the permissive era" (Hays, 1996:22).

Intensive parenting, as it relates to parents' management of severe food allergies, as well as other sociological concepts have surfaced in the literature review process which might provide a more expansive understanding of parents' management of young children's severe food allergies. These concepts include collective legitimization as a subgroup, self-identity, impression-management, negotiation of difference, and the medicalization of food allergies with intensive parenting emerging as an overarching theme. These additional concepts will be discussed in Chapter 4 as part of the data analysis portion of this paper.

2.2.1. Intensive parenting / mothering

Given the intensive nature of severe food allergies, it had been suspected at the outset of this thesis project that the parents of children with severe food allergies might perhaps be susceptible to intensive parenting or specifically intensive mothering. According to sociologist Sharon Hays, the current notion of motherhood has become a relatively all intensive pursuit. Although the vast majority of sociological research on intensive parenting focuses on intensive *mothering*, it should be noted that fathers, too, can engage in intensive parenting. Mothers and fathers, to varying degrees, hold themselves and are held to intensive parenting standards today. The primacy of motherhood has emerged gradually over the last two hundred years. Today, children come first and mothers come second, third or even last. A divide has erupted between mothers that are seen as putting their children first and those who are seen as not putting their children first. Mothers feel the social pressure to be good mothers which translates in modern times to intensive mothers – those who do truly put their children's needs before their own (both physical and emotional).

In addition to Hays, other social scientists including Garey (1999) and Hattery (2001), agree that intensive mothering is clearly the dominant mothering ideology of today's culture. Cultural sociologist Anita Ilta Garey reveals that working mothers engage in what she calls *weaving* whereby working mothers juggle both the demands of work and home with an emphasis on home. In the intensive mothering spirit, her study shows that working mothers employ a number of tactics which include "doing motherhood" by taking part in public performances as "good mothers" as set forth by the intensive mothering ideology. They also engage in what Garey refers to as *sequencing* by varying their working patterns over the life course depending on factors such as their children's ages, marital situation and financial needs.

Similarly, Angela Hattery (2001) finds that intensive mothering is so pervasive that few mothers are able to operate outside its methods. Hattery (2001) contends that mothers fall into one of four distinct types of mothers: conformists, nonconformists, pragmatists and innovators. Conformists, at one end of the spectrum, fully embrace intensive mothering in that they choose full-time motherhood and believe that mothers should be the sole caregivers for their children. Innovators are more or less intensive mothers, but are open to outside employment and work hard to minimize the amount of time a child needs childcare. Pragmatists engage in a similar mechanism to Garey's *sequencing* in that they make changes in employment and child-care arrangement during their childrearing years. At the other end of the spectrum are nonconformists who believe in individual achievement by working outside the home to earn income and who feel that children benefit from being away from their mothers. Although the nonconformists may not appear to be intensive mothers, in a sense, they still are. They are the primary parent that meets their child's needs. Hattery's work demonstrates that all mothers are subjected to an environment of intensive mothering. Both Garey and Hattery's work draw on Hays (1996) as they reinforce a reality and pervasiveness of intensive mothering. "Efforts to define mothering ideology inevitably return to Hays' (1996) definitive work on intensive mothering as the dominant ideology of our culture" (Johnston and Swanson, 2006).

It also appears that the extent to which intensive parenting / mothering is practiced can be influenced by social class position as well. Research done by Annette Lareau (2002) establishes that social circumstances, such as class, shape how parents transfer advantages to their children. She demonstrates that "parents differ by class in the ways they define their own roles in their children's lives as well as in how they perceive the nature of childhood" (Lareau, 2002:748). Her research reveals that both middle class blacks and whites tend to conform to what Lareau refers to as *"concerted cultivation"* (a.k.a. intensive parenting). "This 'cultivation' approach results in a wider range of experiences for children but also creates a frenetic pace for parents, a cult of individualism within the family, and an emphasis on children's performance" (Lareau, 2002:748). This approach tended to foster a more open relationship between parents and children and focuses on transference of life skills from parents to their children for a brighter future. The working class, on the other hand, tended to emphasize a parenting style commensurate with the accomplishment of *"natural growth"*. In particular, "these parents believe that as long as they provide love, food, and safety, their children will grow and thrive. They do not focus on developing their children's special talents" (Lareau, 2002:749). This group also puts more emphasis on giving children directives as opposed to negotiating with children. Familial social ties are also strong within this social group. It would appear that working class parents are less "intensive" or "concerted" than middle class parents irrespective of race based on this particular study's findings. Garey (1999) and Hattery (2001) also support the idea that the level and nature of intensive mothering is affected by social class. The s*equencing* and *weaving* strategies referred to in their work are both based on the assumption that another source of financial sustenance is available for these mothers to be able to engage in such strategies.

Hays' study looked at mothers from four major social classes and holds the view that irrespective of social class, there is a general shift occurring over time towards a model of intensive parenting. She writes of an unevenness of intensive mothering. "Though working-class women may have knowledge of the cult of the home and the emerging ideology of child rearing that attended it, intensive mothering was not an everyday experience for them, either as women or as members of the community of working poor" (Hays, 1996:39). This affirms the previously mentioned work by Annette Lareau in that although all parents live in a world of emerging intensive parenting. Some are more affected by it than others with social class being a determining factor (i.e.: the middle and upper class appearing more intensive). Although based on a different qualifier, parents of severely food allergic children, too, are also potentially more susceptible or affected by the methods of intensive parenting or concerted cultivation.

Intensive mothering is a socially constructed notion (Hays1996). Nonetheless, it is a reality within current society and mothers within that society are unavoidably affected by its tenants. It is logical to believe that mothers of severely food allergic children are no exception. They perhaps are even at greater risk of practicing this type of mothering given the nature and requirements of managing a severe food allergy especially for a young innocent child. In other words, it is possible that mothers of severely food allergic children will, albeit not necessarily intentionally, adopt an even more intensive mothering view in their attempts to successfully manage their child's food allergy. The way parents of food allergic children collectively legitimize themselves including medicalization of allergies and the methods undertaken to negotiate difference for their children are perhaps highly characteristic of intensive mothering. This is not to say that there is a causal relationship between having a child with a severe food allergy and being an intensive mother, but instead that there is an interaction at play which results in a reinforcement or heightened level of intensive mothering in an already intensive parenting environment. It is not clear as to what degree this might happen. A priori some mothers are going to be more susceptible to practicing intensive mothering than others, but it is possible that the management of food allergies makes these particular mothers much more susceptible. Managing severe food allergies is and of itself an intensive and laborious endeavor. It requires a certain level of vigilance and at times hyper-vigilance in order to keep a severely food allergic child physically safe. There appears to be a correlation between what is required of an intensive mother and what is required of a mother of a severely food allergic child.

2.2.2. Intensive parenting / mothering as it pertains to food allergies

In accordance with intensive mothering guidelines, mothers of severely food allergic children would be doing what is in their children's best interest if they were to become fully immersed in the management of their child's allergy whereby the allergy management becomes at the forefront of childrearing to the point that the child's allergy dictates daily life for the purpose of keeping the child safe. This would, under intensive mothering standards, be seen as the behavior of a good mother. Doing what is in a child's best interest and resulting guilt over not doing what is in a child's best interest are very characteristic of intensive mothering. It is conceivable that mothers of severely food allergic children might blame themselves for their child's allergy either by their own actions or lack thereof. Additionally, intensive mothers focus heavily on the delicate and innocent nature of children allowing mothers of allergic children to dwell on the negative emotional and social ramifications of their child's allergy perhaps more so than is necessary. "The model of intensive mothering tells us that children are innocent and priceless, that their rearing should be carried out primarily by individual mothers and that it should be centered on children's needs, with methods that are informed by experts, labor-intensive, and costly" (Hays, 996:21). All of this can be very emotionally absorbing which Hays speaks of when describing her model of intensive mothering. Successfully managing a severe food allergy, depending on the specific food allergen, can be very time consuming and a job within itself. It is possible that mothers of allergic children feel to a certain extent that managing their child's allergy is in effect a job. Parental gender is also of importance here in that mothers of severely food allergic children are potentially more apt to follow a philosophy of intensive parenting in managing their children's allergies as opposed to fathers of severely food allergic children. However, given that the management of a child's severe food allergy can be such a daunting task and inescapable task for a parent, it is also possible that fathers may become more intensive that they would have otherwise been as a result of the allergy.

It is also possible that, although intensive parenting cannot cause food allergies, the increased prevalence in the *diagnosis* and *misperception* of food allergies is a result of intensive parenting. This would be a result of a joint effort, albeit not intentional, on the part of parents, medical care providers and other sources such as parenting manuals, playgroups or even the internet. For instance, a cautious medical care provider already dealing with an intensive parent, might diagnosis a food allergy as opposed to run the risk of being wrong and potentially be sued for not taking the possible allergy more seriously. Given the litigious nature of medical malpractice this is not inconceivable. Along the same lines, the medicalization of allergies might also be taking place whereby parents are diagnosing their own children as *severely* food allergic. Both of these scenarios could contribute to the increased self-perception and overestimation of food allergies (Altman and Chiaramonte, 1996).

With respect to self-identity, it is suggested by Hays that the intensiveness of motherhood gives mothers meaning and purpose. This is even more likely to be the case for a stay-at-home mother who feels she has to validate her decision to stay home and break free of the frumpy housewife stereotype who might otherwise feel that she has lost her own identity to motherhood. A child's allergy could very well provide a legitimate reason, at least in the mind of the food allergic child's mother, to become intensively involved with the child's life vis-à-vis the food allergy. As Hay makes mention, "part of the reason they feel that they are losing their identity is that they know the outside world does not recognize a mother's work as valuable"

(Hays,1996:137). A mother of an allergic child may find that managing their child's allergy gives them meaning and purpose that is not being derived otherwise. Many mothers, with or without a food allergic child, will find themselves being intensive mothers, but it is possible that the presence of a severe food allergy will perhaps make this currently constructed notion of motherhood all the more likely.

The degree that parents, specifically mothers, of severely food children are affected by the methods of intensive mothering will hopefully be revealed throughout the research project. It is also expected that class will reveal itself as a determinant of the level of intensive parenting exhibited by the parents of this study. As has previously been established, intensive parenting does have gendered and class components. It is important to bear in mind that the level of intensive parenting being undertaken by the parents in this study of primarily middle and middle upper class parents will be affected by class position as Hays (1996) and Lareau (2002) both reveal in their research. It is expected that intensive parenting is most certainly at play and to perhaps to a stronger degree than seen in the general population given the *intensive* nature of severe food allergy management.

CHAPTER 3

METHODOLOGY

3.1 Methodological Approach

3.1.1. The premise for the study

As the mother of a severely food allergic child, I was fascinated by how difficult the task of managing a young child's severe food allergy proved to be. I wondered if other parents struggled with the same challenges and experienced the same range of emotions that I did in my attempts to effectively manage my child's severe peanut allergy. Given my experience as a student of sociology, it was clear to me that in order to look at this from a sociological standpoint, I would have to undertake a study of my own since this particular topic has not been extensively researched within the field of sociology. Although this study is not an ethnography, in many ways it felt so given my position as a mother of a severely food allergic child. Having already done some quantitative research on restaurant workers' awareness of food allergies during my graduate studies, I decided to gain Internal Review Board (IRB) approval (see Appendix A) to undertake an exploratory qualitative study of twelve to fifteen parents on the underlying dynamics which govern parental management of children's severe food allergies with the hope of gaining a better understanding of how other parents managed their children's severe food allergies.

3.1.2. Study participant criteria

In order to qualify for the study, a participant needed to be a parent of a child with either a medically diagnosed severe food allergy or a self-reported severe food allergy. Additionally, the participant's child must be less than thirteen years of age in accordance with the study's focus on parents' management of *young* children's severe food allergies. As children become older, they begin to manage their own allergies with decreasing assistance from their parents and by young adulthood children will ultimately manage their allergies independent of any help from their parents. These were the only qualifying criteria set forth by the study.

3.2 The Sample

Twelve participants were gathered by convenience and snowball sampling methods. Two participants were gained by word of mouth. An additional seven participants were gained by contacting a local food allergy support group. From these seven participants, three additional participants were gained. Each of these three participants were gained as a result of snowball sampling and were spouses of one of the seven support group participants. In all cases, the severely allergic child lived with the parent at the time of the interview.

Of the twelve parents participating in the study, nine were mothers and three were fathers. It is important to note that three married couples participated, therefore, nine households not twelve were interviewed. Husband and wives were, however, interviewed separately. The hope was that this would provide another dimension into married parents' food allergy management. Study results, however, did not reveal that the management for mothers versus fathers was all that different. Gender did not appear to be a strong contributing factor to how one managed a child's allergy, however, some small differences were noted and are mentioned throughout the study's findings.

All three fathers as well as six of the nine mothers were employed outside of the home. Three stay-at-home mothers also participated. Only two of the children of study participants were only children. The other ten participants had more than one child. The children of the study's participants ranged in age from 15 months to 9 years old with allergies to peanuts, tree nuts, eggs, wheat, soy and milk. All of the participants could be categorized as middle to upper middle class. The majority of respondents were formally educated. Specifically, two participants had 1-3 years of college but no degree, six participants had bachelor's degrees and four participants had graduate degrees. All but one participant was married and cohabitating with the allergic child's other parent. The entire sample was Caucasian. The sample ranged in age from 31 to 47.

3.3 Measurement and Data Collection

Given the qualitative and exploratory nature of this research project, in-depth semi-structured interviews were employed in an effort to delve as deeply as possible into this relatively untapped research topic. Participation was completely confidential and voluntary. Study participants were informed that they may opt out of the interview / study at any time without consequence. Each participant signed an Informed Consent Form prior to being interviewed. Study participants were assigned a code number which has been indicated on all research materials pertaining to that specific participant. All interviews were conducted face to face. Each interview was tape recorded and later transcribed into typewritten form. The location of the interviews included the interviewer's home, the interviewee's home, and the interviewee's place of business with all but two of the interviews conducted at the interviewees' homes. Additionally, a demographic face sheet was completed which includes basic demographic information on the study participant, the participant's food allergic child and other family members as well. This was not part of the actual interview process, but instead completed after the interview process. Much of the information obtained on the face sheet was delicate in nature such as age, household income and marital status. It was the intent of the researcher/interviewer to make the interviewee as comfortable as possible and it was thought that asking for the information before the in-depth interview might contribute to the interviewee feeling less comfortable during the interview process. It was important that a rapport be built between the interviewer and the interviewee prior to asking somewhat personal questions of the interviewee.

Each study participant was asked twelve open-ended guiding questions concerning the management of their child's severe food allergy focusing on several dimensions of such management: physical, emotional and social. The interview guide (see Appendix C) was utilized in order to steer the interview and provide as much consistency as possible from one interview to the next. The interview guide started with participants being asked about how and when they came to learn of their child's food allergy. They were additionally asked to tell a story about their child's allergy, report on any additional reactions since the time of initial diagnosis and also explain how they physically manage their child's allergy. These questions helped to establish the nature and extent of the child's allergy. Several additional questions were asked of participants concerning their child's emotional and social responses to the presence of the allergy. The parents, too, were asked about their emotional and social management of the allergy. Parents were also asked to comment on how they viewed the challenges of managing children's food allergies compared to the challenges faced by parents managing other childhood chronic medical conditions such as epilepsy, diabetes, etc. in order to possibly appreciate similarities and differences between subgroups. Finally, participants were asked about how they felt about the future of their child's allergy as well as the future of allergies in general. For instance, participants were asked if they thought their children would outgrow their allergy, how they felt about a cure for food allergies, and how they felt about future allergy testing and vaccines. In the spirit of an open-ended interview, all study participants were given an opportunity at the end of the interview process to add anything to the discussion that had not already been discussed during the interview.

3.4 Analytic Approach and Data Analysis

Given the understudied nature of the research topic, a qualitative research study was employed. The fact that the research topic had not been studied extensively within the field of sociology also validated the type of *exploratory* qualitative research undertaken. "Instead of beginning with a theory, qualitative researchers are more likely to begin with an examination of the empirical world" (Esterberg, 2002:34). This study did not employ already formed hypotheses or hypothesis testing, but instead utilized a grounded theory approach in the hope that a possible theory or theories might surface or emerge from the collected data as the research was conducted and later analyzed (Esterberg, 2002).

Specifically, the measurement of the underlying dynamics governing parents' management of children's severe food allergy was accomplished through qualitative coding methods. In order to analyze the collected research data, several levels of coding were utilized including open coding and focused coding. This dual coding process is truly within the spirit of qualitative analysis and allowed for 1) the noticing of relevant data, 2) examples of that relevant data, and 3) an analysis of such relevant data to reveal similarities, differences, patterns and trends among the data set in order to develop themes and possible theories relating to the research topic (Esterberg, 2002). Similar to Esterberg's two tier qualitative coding, qualitative coding techniques by Anselm Strauss (1987) were also employed including open coding, axial coding and selective coding. *Open coding*, in effect, is an initial or first round of coding whereby the interview is scrutinized very closely sometimes line by line or even word by word in an effort to allow concepts to emerge. *Axial coding*, on the other hand, is focused on intense analysis of one category at a time which can result in cumulative knowledge about relationships between that category and other categories or subcategories (Strauss, 1987). Finally, *selective coding* is the final stage of qualitative coding which involves looking for conditions, consequences, and so forth that relate to the core category or categories discovered through open or axial coding (Strauss, 1987). The use of procedural and analytic memos was also employed (Esterberg, 2002). Procedural memos aided during the data collection and data analysis processes as a way of recalling how data was collected, analyzed and other methods utilized in the research process. Analytic memos were used during the coding process in order to organize relevant data with respect to the emergence of themes and concepts relating to parents' management of children's severe food allergies.

It is also noteworthy to acknowledge that given the small sample size along with the use of convenience / snowball sampling, the results of this study cannot be seen as representative or wholly generalizable. Nevertheless, it will provide much in-depth insight into this sample's experiences and perhaps lay the foundation for future sociological work on this research topic.

CHAPTER 4

STUDY FINDINGS / ANALYSIS OF DATA

4.1 Introduction

From the research, three major conclusions are able to be drawn. Parents of severely food allergic children are clearly engaging in an intensive parenting model as defined by Sharon Hays and other social scientists. The intensive parenting ideology serves as a backdrop for how these parents handle the physical, emotional and social aspects of managing their children's allergies. Through the exploratory interviews, the mechanisms through which parents use intensive mothering became evident. Specifically, parents utilize mechanisms such as collective legitimization, the medicalization of allergies, negotiation of difference strategies and other tactics as ways of managing / handling their children's allergies.

The *physical management* of the children's allergies seemed to be governed by an overall environment of intensive parenting. This included the expert-guided diagnosis of the allergy. Child-centered tactics were employed by parents whereby extraordinary lengths were often taken to keep food allergic children physically safe. Additionally, the way parents felt about physically administering life saving epinephrine was also characteristic of an intensive parenting approach. *Emotional management* was also very child-centered and emotionally absorbing in nature. Parents suffered with guilt, frustration and many other negative emotions as a result of learning of their children's allergies as well as the ongoing management of such allergies. With respect to *social management*, parents had to find ways to exist in a world that does not fully understand and appreciate the seriousness of severe food allergies. Specific mechanisms that allowed parents to manage their children's allergies socially include collective legitimization as a group, a certain level of medicalization of allergies, and negotiation of difference strategies. By engaging in collectively legitimization with other parents of food allergic children, parents were able to legitimate or justify the allergy to themselves, other parents of food allergic children and to outsiders. The medicalization of allergies also appears to be taking place where parents possibly medicalize their child's allergy as more serious than it truly it is in order to illicit cooperation from others in an overall effort to keep their child as safe as possible. Parents also engaged in negotiation of difference strategies for their children which often created a paradox. On the one hand, they had to admit and convey to others the fact that their children were different due to their allergy, but on the other hand worked hard to protect their children from feeling different or being treated differently due to the allergy.

The following four subsections will focus on parents' physical, emotional and social management of their children's food allergies. Again, intensive mothering methods tend to permeate throughout the data, however, other sociological concepts also appear to be at play in parents' physical, emotional and management of their children's allergies. This is especially evident with respect to the social management of food allergies including collective legitimization, medicalization and the negotiation of difference.

4.2 Physical management of children's severe food allergies

4.2.1. Expert-guided diagnosis and support for food allergies

All of the parents in this research study sought out the help of a pediatric allergist or a pediatrician that was well versed in food allergy management. They do not stop there, however, in terms of educating themselves on severe food allergies. Sharon Hays contends that *intensive mothering* is expert-guided in that the intensive mothers tend to employ the use of parenting manuals, such as those written by Benjamin Spock, T. Berry Brazelton and Penelope Leach, which all promote intensive parenting. A similar type of behavior can be appreciated in the actions exhibited by parents of food allergic children. They, too, have gone to great lengths to educate themselves on their child's allergy with the help of physicians as well as online resources, allergy associations such as the Food Allergy and Anaphylaxis Network, and food allergy support groups. A good number of the parents in the study remark that their first step after learning of their child's allergy was to not just seek out the advice of medical professionals, but to do their own research as well. Several study participants remark that doing research was the first and most important thing they could do to keep their children safe. Some parents also did not trust medical professionals. It is possible that the advice given by medical professionals is not seen as intensive enough given the intensive mothering environment in which these participants find themselves.

Several parents shared that it was not their children's doctors they turned to the most, but instead websites, support groups, and organizations devoted to food allergy management. One mother of a severely peanut allergic child admits that although her allergist was helpful, she admits that "I've learned way more on the internet and talking to other moms than from the allergy guy". Another mother felt that her child's doctor was unsympathetic and uneducated about severe food allergies. She explains that "I mean they were so uneducated in terms of what was out there and just kind of left us hanging". These mothers tended to turn to other sources of education, validation and perhaps legitimacy just as Hays' participants turned to the work of Spock, Brazelton and Leach. This creates a contradiction of sorts given that, on the one hand, these parents want medical professionals to acknowledge a child's severe food allergy, but, on the other hand, when the doctor does not tell them what they want to hear they will turn to other sources validation. Intensive parents of today perhaps expect doctors to be intensive in their methods as well. This might, in turn, be a driving force in the intensive parent "medicalizing" the child's allergy as severe without the aid of a physician. Medicalization of allergies will be specifically discussed in Subsection 4.4. Non-intensive mothers of the past would have most likely taken physicians' advice without question. Intensive mothers of today, however, are perhaps more skeptical of physicians' advice and will look to other sources of validation with respect to their children's food allergies. This was certainly the case with several participants in the data set.

4.2.2. Measures taken to ensure physical safety

The degree to which study participants go to ensure their child's physical safety is somewhat variable. At one end of the spectrum there are parents that will allow a child's severe food allergen to be present in the home as well as eaten around the child; at the other end of the spectrum there are parents that have gone to what seems like extraordinary lengths to ensure a safe and allergen free home. From a sociological standpoint, this brings up several concerns. First, are the efforts undertaken by these parents to keep their children safe reasonable given the current recommendations on ensuring physical safety for a severely allergic child? Secondly, what effect do these measures, whether they are of a hyper-vigilant or completely lackadaisical nature, have on the child or the parent in question?

Of the twelve study participants, three have made their homes completely allergen free. Of the remaining nine, one's home was previously allergen free. It should be noted that the decision for these parents of whether or not to make their homes allergen free is determined to a strong degree on the specific allergen affecting their child and the severity of the allergy. For instance, making a home peanut free is a far easier feat than making a home milk, wheat or egg free simply due to higher prevalence of those allergens in everyday foods. Three of the parents in the study with peanut allergic children have made their homes peanut free which according to these participants was relatively easy. Therefore, the decision to remove all peanuts from the home by the three participants with peanut allergic children is viewed much differently than, for example, the extraordinary measures taken by parents of dairy allergic children to remove all dairy from their homes.

The extent that some of the families in this study have gone to in order to make their child's home environment safe clearly stands out in the research data. This is interesting sociologically given that very little or no medical research support such dramatic measures. Casual contact with allergens rarely, if ever, results in significant reactions that would warrant some of the measures undertaken by some of the parents in this study. None of the parents in the study were advised by their medical professionals to make their homes completely allergen free.

The participants that stand out most in the data are the parents of a six year old severely milk allergic child. Upon learning of the child's severe allergy, the family made a decision to go completely dairy-free in their home. This included disposing of any household item that had ever come in contact with dairy products including many kitchen items. The father mentioned that it was very difficult for him to come to terms with the fact that his wife felt that the home needed to be completely dairy-free, but did agree that it had to be done for the physical safety of his child. In his words, "It was me and my wife getting together and saying the only way that we can be completely sure it is safe is to remove all dairy from the house".

The mother of this child was very committed to the fact that she wanted her daughter's home to be the one place where the child could feel completely safe. This mother admits that this behavior is probably "over the top" but she is still convinced that she is doing the right thing by making her home allergen free. She sees herself as obsessive about the physical management and appeared uneasy when she spoke of the extreme measures her and her husband take when they do make an exception and bring a dairy product into the house. On occasion and in an effort to have normalcy, the couple will eat pizza in their home when their allergic child is not present. Specifically, they bring a table from outside into the house and cover it with plastic trash bags. Additionally, the television remote control is placed inside a Ziploc type storage bag as to be protected from any milk products. The father goes in his car to pick up the pizza which he only carries in one hand in an effort not to get any potential allergen in the car where his daughter will later be riding. After they finish eating, the mother reports that she and her husband wash their hands and faces, change their clothes, brush their teeth, vacuum the floors, wipe down the couch and put the table used for eating back outside.

This is a clear cut example of Hays' intensive parenting in terms of intensive parenting being child-centered and emotionally absorbing. It is interesting to see the lengths gone to by this couple to ensure their child's physical safety and emotional mindset of having a safe home environment. It is this same mother that remarks that she has seen a therapist over her emotional difficulty managing her daughter's allergy. She mentioned that she suffers from panic attacks and her therapist helps her manage the allergy constructively as opposed to being highly obsessed with the management of the allergy. These extreme measures lead the mother to believe that she is being a good mother and that her hyper-vigilant behavior is attributed to her quality as a mother. To her this hyper-vigilance creates a safe home environment for the child. She states, "We're over the top on the house because we need to have a safe environment".

Other examples of parents' physical management of their children's allergy that stand out in the data include the lengths that parents go to in order to provide safe food for their children. Almost all parents in the study do not allow their children to buy lunch at school if their children attend school. They comment on the fact that they do not trust the school to keep their children safe, and therefore, will also pack their children's lunches. Many mothers remark that it is very exhausting, but simply easier to be the individual completely responsible for what actually goes into their children's mouths. Two mothers in the study provide all the snacks that are eaten at their children's schools during snack time. In one of the mother's words "It was exhausting to always have to be the person to volunteer to say 'oh, I'll do it with a willing heart I'm thrilled to do it', but really I didn't always want to be the one to volunteer for everything". They explain that this is the only way to be able to be certain that the snacks are safe. One mother notes that this was very emotionally exhausting for her in the early days of her son's peanut allergy. In the event that the allergic child's family wants to go out to eat, more often than not the allergic child's food is brought from home. This brings up the concern over the effect that having to eat something different from the rest of the family might have on the child as well. Although it was noted in this study, this could potentially lead to the child feeling ostracized for being different. It also might contribute to the child being, like the parent, over zealous or anxious about their allergy.

In keeping with the concepts of intensive mothering, the aforementioned measures being undertaken by parents of severely food allergic children certainly seem to suggest that a good amount of intensiveness, as described by Sharon Hays, is being undertaken. This is in no way to suggests that these parents should not be taking measures to keep their children safe, especially when there is the potential for death, but perhaps they are going to extreme measures given the current climate of intensive mothering or parenting that permeates throughout society today. This is even more so considering that these extraordinary measures taken by these parents may perhaps have detrimental emotional and social effects on the food allergic children. It also follows that parents that are too care free also pose a potential physical danger to their child. Managing a childhood severe food allergies obviously requires balancing the child's physical, emotional and social needs. This subsection demonstrates that in their effort to physically protect their children, parents of food allergic children potentially create emotional and social consequences for their children and themselves.

4.2.3. Physical administration of life-saving medication

Epinephrine, the life-saving drug of choice for counteracting a severe allergic reaction, has been shown to be underused by parents of severely food allergic children during a severe allergic reaction (Kim and Pongracic, 2005). This research finds that parents' reasons for not administering epinephrine included the fact that Benadryl (an antihistamine) had initially been given in response to symptoms or that the parent did not believe that the reaction was serious enough to elicit the administration of epinephrine. Additionally, the study revealed that of parents studied that were *uncomfortable* administering epinephrine, 51% are concerned that they will not have the ability to recognize symptoms, 40% fear they would hurt their child, and 36% say they would forget how to administer the medicine and do it incorrectly (Kim and Pongracic, 2005). These results with respect to parents' uneasiness were duplicated to a certain degree in this research study. The administration of life-saving medication, epinephrine in this case, creates a potential conflict of interest in many parents of severely food allergic children. On the one hand, intensive parents would do practically anything to keep their child physically safe and on the other hand they will grapple over the possible negative physical and emotional effects of taking such action. This specific type of behavior was certainly seen in the study's data.

With respect to study participants that felt uneasy about administering epinephrine to their children, the main reasons for their trepidation were fear of physically hurting their child, the concern over psychological / emotional effect of giving the shot and finally the concern over not administering the drug correctly. Interestingly, these feelings were expressed frequently in the exploratory research undertaken here when parents were asked about administering epinephrine. Several mothers mentioned during their interviews that they felt that they should have administered epinephrine for a reaction in the past and did not. They go on explain that they have really beat themselves up and blame themselves for not giving the medicine when they felt that their child probably needed it. Even though one mother's son turned out not have encountered his severe food allergen, the mother was a wreck over an incident in which she thought the child was having a severe allergic reaction and she chose not to give epinephrine. She remarks that she regretted not taking action and really went on to beat herself up over the incident. Another mother is so uncomfortable with administering epinephrine that she has taken her son to the hospital on multiple occasions due to the fact that if he turns out needing epinephrine she will not have to be the one to administer it. She mentions that going to hospital makes sense since it is just two minutes away and that if the hospital was not that close she would, if necessary, give her son the shot. She says, "I'd rather be there if something has to be done”. The hospital being close the family’s home seems to accommodate the mother given her extreme fear of having to administer an epinephrine shot to her son. A mother of a severely dairy allergic child also notes that she felt that she should have administered epinephrine to her daughter during an allergic reaction but was highly conflicted about doing so and ultimately did not give the child the medicine. She went on to explain that she was most worried about the emotional effects it might have had on her daughter. She explains, “I would be more concerned about the emotional side effect on Meredith. That’s why I really wavered that evening – I couldn’t figure out what to do and I did not want to subject her to this if I didn’t have to”. One mother also expressed concern over the safety of the life-saving medication epinephrine. Other parents also commented on the fear of not knowing what the drug would do to their child physically, which they admit probably contributes to their hesitation to administer the medicine. Two fathers also made mention of the fact that they were concerned about the physical effects of the drug and were not as concerned about any psychological / emotional impact the drug might cause. The two men felt that they were primarily concerned about physically protecting their child from not just the allergen, but from the medication as well. Given the safety of epinephrine, it is interesting that parents do not trust that the drug will absolutely not harm their children.

The majority of study participants in this research study felt uneasy about administering epinephrine to their children with only three participants feeling very comfortable. Of course, all the parents admit that they would administer the drug if absolutely necessary. It should be noted that the three parents who did feel comfortable administering the medicine had either witnessed a full blown anaphylactic reaction in their child or had previously administered epinephrine to their child in response to a reaction in their child. Two participants, who are married to each other, both stated that they felt very comfortable administering epinephrine to their severely peanut allergic son. The mother of the child had witnessed her child go into full anaphylactic shock and almost die. At the onset of the reaction, she called 911 and witnessed paramedics administer epinephrine to her son before he was taken to the hospital. As she describes it, having witnessed her son in a life-threatening scenario really made her realize how important the drug is and she would feel no hesitation in giving the shot of medicine to her son in the future if needed because she has seen what can happen. Although this child's father was not present at the time of the life-threatening reaction, he is also very comfortable administering the shot having seen his child after he arrived at the hospital as medical personnel were working on his son. The third participant that was comfortable administering an epinephrine shot was a mother that had at the time of the interview already administered several epinephrine shots to her son for what she felt were severe reactions. As research confirms, "parents who had administered the EpiPen previously had a higher comfort level than parents who had not." (Kim and Pongracic, 2005:164) The fact that these three parents felt comfortable with administering epinephrine does not suggest that they are not intensive in other ways, but that they have been faced with a life and death scenario that has forced the parent to first and foremost physically protect the child. This goes along with a more pre-intensive parenting style where ensuring a child's physical needs alone was equated with adequate parenting with emotional and social concerns being secondary.

4.3 Emotional management of children's severe food allergies

4.3.1. Child-centered guilt as a factor in parental management of severe food allergies

When asked about the initial feelings they experienced after learning of their child's severe food allergy, several, but not all, participants responded that they felt guilty. Parental guilt is a common characteristic of the intensive parenting ideology in that parents feel incredibly responsible for their children and when something goes wrong they tend to blame themselves. "The guilt, the sleepless nights, and the worry about doing it appropriately are common to many mothers. As it turns out, nearly all the issues that they worry about follow directly from the logic of intensive child rearing." (Hays,1996:121) Guilt is a common feeling for parents of allergic children to experience. Although not all participants reported that they felt guilt after learning of their child's allergy, there was a general feeling throughout the interview process that both mothers and fathers held themselves somewhat responsible for their child's allergy. Intensive *mothers,* in particular, have the potential for feeling guilty about their children and worry that the decisions they have made and will make can affect their delicate and innocent children. Mothers of severely allergic children can be seen as being at an even greater risk for feeling guilty due to their child's allergy. Within the intensive mothering framework, ultimate responsibility of children is assumed by mothers – one that supersedes in many ways the responsibility that a father has for a child. This type of parenting style is being undertaken in this subgroup of parents, with an emphasis on mothers, as evidenced by the fact that mothers make mention of being bothered by guilt far more frequently than fathers.

In addition to the aforementioned generalized guilt felt by mothers *and* fathers, several female participants revealed that they were very concerned that their decision to breastfeed or not to breastfeed had perhaps contributed to their child's allergy. One mother felt that her child might possibly be allergic because she *had not* breastfed. She expresses that, "I had read that breastfed babies tend to have less illness, less allergies". On the other hand, several mothers felt that it was the fact that they *had* breastfeed their child that caused the child to be allergic in that somehow their child became allergic to a particular food as a result of being exposed to it through the mother's breast milk. One child's allergy became known as a result of the mother weaning the child from the breast and offering an initial bottle of formula which led to the first severe allergic reaction in the child. She experienced terrible guilt in that she felt that her decision to stop breastfeeding had caused the allergy. She immediately returned to breastfeeding although it was very inconvenient for her at the time due to her work schedule. In discussing the days after she learned of her son's allergy, she states, "I decided I was going to exclusively breast feed again". She felt that her child came first and even though she had wanted to wean him from the breast, she was not willing to do so. This mother felt that there was no substitute for her, or in this case her breast milk, which goes along with Hays' findings which suggest that intensive mothers see themselves as the primary caregiver of their child with no real substitute. "Constant nurture, if that is what the child needs, is therefore the child's right – even if it means the mother must temporarily put her own life on hold." Hays,1996:111) It is interesting from a sociological standpoint that these mothers felt guilty in cases where they chose to breastfeed *and* in cases where they chose not to breastfeed. It is as if they managed to feel guilty one way or the other. They feel guilty in that they grapple over the possibility that they could have perhaps done something to prevent the allergy which has so negatively affected the precious and innocent child's life.

One father remarks that his wife experiences great guilt over their daughter's allergy in that she feels that as a mother she should have known what was going on and gotten help sooner instead of having had a life-threatening reaction happen first. These mothers, in effect, blame themselves in varying ways for the presence of their child's allergy and thereby feel guilty. Would a mother not practicing intensive parenting burden herself in this same way? Mothers perhaps feel that irrespective of how expert-guided, child-centered or emotionally absorbed they become in their food allergic children's lives, that there is still room to improve and be even better mothers.

4.3.2. Other child-centered emotions as factors in parental management of severe food allergies

In addition to guilt, parents of food allergic children also mentioned feeling fearful, overwhelmed, mentally exhausted, and mentally absorbed after learning of their child's allergy. Some parents felt challenged, disappointed, isolated, devastated, and disbelief over the allergy. Interestingly, a few parents even felt relief in that they had finally figured out why their child had been experiencing physical problems and that an allergy was the culprit. These parents felt a sense of validation in that now they could tell others that their child was afflicted by a serious medical condition. Often times, children's ailments associated with the allergy are not well understood and a severe food allergy diagnosis can aid in the validation process for parents. In terms of isolation, many mothers felt isolated, lost and alone in their efforts to manage their children's allergies. This not only occurred in the outside world, but also in their homes. Two mothers in the study commented that their husbands doubted the existence of food allergies and were certainly not supportive of their efforts to manage the allergies. One mother says, "My husband and I weren't on the same page with this so I did feel like I was doing what needed to be done alone as far getting Sean taken care of". Nonetheless, many of the emotions can be seen as reflecting several of the tenants of intensive parenting.

Focusing on the emotionally taxing aspects of managing a severe food allergy, several participants remarked that they experienced fear and felt overwhelmed after learning of their child's allergy. These parents all seem to live with the fear that at any moment their child could die as result of their severe food allergy. This fear tends to permeate throughout their daily lives. Feeling overwhelmed, in particular, was a commonly experienced emotion by participants. As Hays points out, intensive mothering is emotionally exhausting. Many of the mothers in the study stated that they felt overwhelmed and emotionally exhausted as a result of learning of their child's allergy. One mother remarks that once she started doing research she knew it was going to be overwhelming. She later notes that it is a constant challenge taking her son anywhere because of the overwhelming task of getting others to understand how severe her child's allergy is. In describing how she feels about her son's peanut allergy, one mother states that she feels fear, ostracized, mentally exhausted and overwhelmed. She admits that she became mentally exhausted as a result of trying to control her son's food intake.

Several mothers commented during the interview process on how labor-intensive the education process can be in trying to convey to others the seriousness of their child's allergy. These mothers experienced frustration in their attempts to educate others which often times fell on deaf ears. When discussing an accidental exposure at school, one mother passionately reveals that she found herself very frustrated with the school given the fact that she had worked hard to educate them and yet they still exposed her child to the severe food allergen. According to this mother, "I was too emotionally upset about it – I needed to cool off over the weekend". At the point in the interview when parents were asked to tell a story pertaining to their child's allergy, a good number of participants shared a story that involved their child being accidentally exposed after the parent had gone to great lengths to educate others. Many of these parents felt very frustrated and emotionally exhausted given their best efforts to keep their child focused on and safe. This is clearly child-centered and emotionally absorbing behavior which is so characteristic of intensive parenting.

4.4 Social management of children's severe food allergies: Collective Legitimization / Medicalization

From the research data, it can be concluded that one of the ways parents socially manage their children's allergies is by utilizing what Erving Goffman (1922-1982) referred to as impression-management. His first book, Presentation of Self in Everyday Life, gave popular culture the expression *impression-management.* Goffman held the view that individuals in social interactions were engaged in the artful management of what others thought about them (Lemert, 2004:281). Drawing on Goffman's impression-management, sociologists Anne M. Velliquette and Jeff B. Murray, conceptualize the theme of collective legitimization in their work on tattoo artists as a subculture. According to the authors, "a *subculture* is defined as a system of values, attitudes, modes of behavior, and lifestyles of a social group that is distinct from, but related to, the dominant culture of society" (1999:71). Parents of severely food allergic children are, in essence, a subculture or a social group in that they share a sense of common identity and belonging and can interact on a regular basis. A social subculture "signifies a way of life of a group of people" and is "characterized by an interaction, continuity, and outsider and insider definitions of distinctiveness" (Prus 1996:85). Just as tattoo artists attempt to legitimize their profession by taking such steps as providing a clinical atmosphere, becoming certified, showing their work at galleries and even attending national conventions, parents of severely food allergic children engage in similar mechanisms to legitimize their children's allergies. These mechanisms include collective legitimization as a subgroup and the possible medicalization, as depicted by sociologist Peter Conrad, of their children's allergies.

Parents of food allergic children appear to legitimize their children's food allergies by creating group cohesion with other parents of food allergic children through the use of food allergy support groups. Specifically, this type of collective legitimacy serves the purpose of making the allergy real not just to the parents of food allergic children, but to outsiders as well. Severe food allergies are not well understood or accepted by society in general. The difficulties parents encounter in their attempts to communicate their child's needs to others positions these parents to engage in collective legitimization. A similar dynamic is seen among tattoo artists. Just as tattoo artistry was once viewed negatively and associated with lower social class such as thugs and bikers, the existence of severe food allergies has also been viewed negatively. Velliquette and Murray find that tattoo artists attempt to legitimize among themselves as well as to their customers. The fact that these tattoo artists consider themselves *artists* is a possible example of this collective legitimization process given that the general population might not consider tattoo artists in the same category with other types of visual artists such as painters and sculptors. They participate in what Goffman calls *front stage* behavior to their customers and *back stage* behavior among themselves. It is possible that parents of severely food allergic children engage in a similar type of behavior. They must manage within the home (back stage) and with society at large (front stage). Specifically, with respect front stage behavior, parents may feel compelled to impress upon outsiders a certain level of severity of their children's allergies given the inadequate level of social awareness concerning food allergies in hopes that the allergy will be taken at least somewhat seriously. Many individuals do not feel that food allergies are real and do not accept that they can be life threatening. This creates a push effect in parents at the outset in that they know or soon learn that they are going to have to take certain measures to gain what they feel is an adequate level of cooperation from the outside skeptical world. Being part of larger group with other parents of food allergic children can aid in these efforts.

Parents of severely food allergic children, as a subgroup, might also engage in other legitimization strategies in their attempts to convey the seriousness of their child's allergy to outsiders. One of the ways they might accomplish this *legitimization* is to *medicalize* (Conrad, 2005) their child's allergy. This potentially positions the parent to actively seek legitimization from both the medical field and fellow parents of allergic children. The medicalization of allergies might also aid in the friction that has erupted between parents of children with different allergies and allergy severities which was appreciated in this exploratory study. This "hierarchy of allergies" is discussed at length in Subsection 4.4.3. According to sociologist Peter Conrad, medicalization is seen as the process by which health or behavior problems come to be defined and treated as medical issues. "The essence of medicalization became the definitional issue: defining a *problem* in medical terms, usually as an illness or disorder, or using medical intervention to treat it." (Conrad, 2005:3) Medicalization has typically been seen in relation to childhood behavior problems such as Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) as well as in relation to adult behavior problems such as sexual dysfunction (SD) and clinical depression (CD). *Severe* food allergies, of course, do not need to be medicalized given that they are a true medical reality for a certain percentage of the population. It is suspected, however, that many parents have chosen to medicalize their children's *mild* allergies as *severe* allergies in an effort to legitimize the allergy. "Individual's self-medicalization is becoming increasingly common, with patients taking their problems to their physicians and often asking directly for a specific medical solution. A prominent example of this has been the increasing medicalization of unhappiness and expansive treatment with antidepressents." (Conrad, 2005:9) Medicalization might be taking place when parents overplay the seriousness of their child's either mild or possibly even non-existent allergy to the medical community or to the general public. The medical community, specifically physicians, would also play into this medicalization when they prescribe medication to treat a severe allergic reaction for a child who may or may not have a severe food allergy. Given the litigious nature of society with respect to medicine, physicians might rather err on the cautious side in the event that a child's allergy might in fact be or become severe.

Given the public's lack of awareness of the seriousness of severe food allergies coupled with the potential for an innocent child's death, this subgroup will attempt to legitimize itself through these various strategies as well as others. Parents of food allergic children do not exist only in their own world. They are forced to rely on the cooperation of outsiders in their attempt to keep their child safe. The following subsections will demonstrate several instances in which study participants engaged in this type of collective legitimization including the medicalization of food allergies.

4.4.1. Allergy testing as a mechanism for individual legitimacy

All of the children of the parents in the study at some point or another have been allergy tested for the presence of antibodies to specific food proteins. It appears that the parents in the study rely heavily on these tests to legitimize their child's allergy. Within medicine, there is a reasonable amount of debate on the validity of such allergy testing. Skin prick allergy testing is perhaps the most controversial of all. A positive skin prick test does reveal if a person has a histamine release as a result of being exposed to a certain food protein, but such tests are apparently notorious for giving false positives. Even if an individual has a positive skin test, this is not highly reliable in determining the extent of an allergy and certainly not a good indicator of the severity of potential allergic reaction. A few children of parents in the study have only had skin prick tests performed. In the world of food allergies, a clear symptomatic diagnosis is the best indicator of how severe a food allergy truly is. It is when this type of symptomatic diagnosis is coupled with a clinical diagnosis based on blood tests that screen for the presence of antibodies, that a more accurate diagnosis for a severe food allergy can be made.

It is possible that some parents in the study are utilizing inferior allergy testing such as skin prick testing and even blood tests as a means to validate or legitimize their children's allergies to the outside world. This is interesting sociologically in that it allows for the possibility that these parents might be managing allergies needlessly. Obviously, as has been demonstrated thus far, such management is no easy feat and can have negative repercussions on the child, the parents, and others. The possibility that parents might be managing a mild allergy as a severe allergy by medicalizing the seriousness of the allergy brings up several concerns. One possible concern would be whether the parent is aware of the fact that the allergy may not be that serious given that only skin testing had been done on the child. This may offer an explanation as to the underuse of epinephrine by parents beyond those put forth by Kim et al. (2005). If a parent suspects that the allergy is not that serious, it might inhibit that parent from taking action in what appears to be a life threatening situation.

4.4.2. Legitimization via support groups

Not all study participants were in allergy support groups, but seven mothers did acknowledge that they were involved in an allergy support group. Most of the mothers who were in an allergy support group were very involved. Participation in a food allergy support group appears to be gendered. Several of the mothers in the study remarked early on in the interview process that they felt very isolated, alone and lost after learning of their children's allergies. These feelings can very possibly be attributed to the lack of social awareness on food allergies, particularly severe food allergies.

One mother of a fifteen month old child with multiple severe food allergies remarked that she completely lost her social life as a result of her child's allergy. Between her work outside the home and all the efforts she put into making virtually all meals at home, she feels that she lost herself to the allergy. According to her, “Pretty much me and my husband are second and third in this family – I have no social life”. Being in a support group likely gives her a sense of belonging that she had lost in the non-allergy world which included her husband since he did not support her in the daunting task of managing of her son’s allergy. Another mom experienced a similar feeling of isolation as a result of her husband’s lack of support regarding her son’s allergies. She felt very alone since her partner in life was not participating as a partner in managing their child’s allergies. A mother of a severely peanut and dairy allergic child comments that she felt very abandoned and alone in her struggle with the food allergy and took it upon herself to make connections and find the support of others in similar situations. She shares that, “I was depressed and struggling and I needed the support and I needed the friends – I needed someone to talk about these things”. Finally, a mother of a severely peanut and dairy allergic child tells of how she isolated herself in response to her child’s allergies. Specifically, she says that she cut herself off from others because “food was everywhere and it was just too much to deal with”. She seeks help from a mental health professional with these issues and is currently being treated for depression and anxiety relating to her child’s allergies. She is one of two mothers in the study who seeks help from a mental health professional for help in dealing with their child’s food allergy. Both of these mothers depend on their food allergy support group to offer support.

None of the three fathers in the study participate in allergy support groups. The fathers present themselves as much more stoic in dealing with their children’s allergies. One father admits, “I’m probably more of a typical man – I just deal with it”. They limit their personal interactions regarding their children’s allergies to discussions with their wives unless they are in a situation where they had to convey the allergy to others in order to keep their child safe. There is a social stigma attached to the allergy that these parents are faced with which can contribute to their initial isolation and subsequent need for a sense of ongoing belonging or collective legitimization from other parents of food allergic children. These feelings are similar to those experienced by tattoo artists. “Tattooists who view themselves as artists are continually engaged in legitimation talk in order to neutralize the stigma that has been historically associated with tattooing" (Sanders, 1989).

It was not just that their commonality of having a child with a severe food allergy that brought these parents together as much as it was to provide a forum where these parents could gain support from each other in a world that does not generally support the seriousness of food allergies. A vast majority of the study's participants make note of the fact that unless someone really is a parent of a severely food allergic child and has to live that reality day in and day out, there is no way for an outsider to truly be able to appreciate the struggles these individuals face. Study participants generally feel that close friends and family are sympathetic, but only comprehend the situation to a certain extent. Educators are generally seen as sympathetic as well, however, individuals with little or no emotional connection to the child, such as restaurant workers, seem to be the least sympathetic. This variability of social awareness tends to affect the level of group support these parents, specifically mothers, require.

4.4.3. Negative collective group behavior / Hierarchy of food allergies

As previously reported, parents will engage in support groups in order to collectively legitimize themselves in an overall effort to present their children's allergies as bona fide to each other as well as to the outside non-allergic world in a fashion similar to tattoo artists (Velliquette and Murray, 1999). As an extremely interesting caveat to this type of group behavior, inside and outside the support group setting, was the discovery that such group membership actually had the potential for creating negative interactions between parents of children with different allergies and different allergy severities. This surfaced as an emerging theme as parents responded to questions about how they compared their child's allergy management to the management of parents of children with other medical conditions such as epilepsy, diabetes, or bee allergies. The majority of parents did not feel that they had a harder challenge than parents of children with other medical conditions. This part of the interview seemed to serendipitously provide the interviewee with an opportunity to discuss not how they felt about parents of children with other medical conditions, but how they felt about parents of children with other food allergies and allergy severities than their children.

Not all children are afflicted with the same food allergen, the same number of food allergies, or the same severity of allergies. For example, some children are allergic to only one food such as milk, eggs or peanuts while others are allergies milk and peanuts. This presents an interesting and intriguing landscape for parents of food allergic children. It has, in effect, created a *hierarchy of allergies*. This hierarchy tends to be constructed based on two qualifiers. First, it is based on the seriousness of the actual food allergy in general terms. For example, peanut allergies are seen within the medical community as the most deadly of all food allergies in that they claim approximately the same number of lives as the other seven major food allergens combined. However, the parents of a child with a mild peanut allergy may have less of challenge in terms of allergy management than the parent of a child with a moderate to severe milk allergy exhibiting that there are multiple factors that go into this qualifier. In addition to the seriousness of the specific food allergen, a child's allergy appears to be situated on the *food allergy hierarchy* on the basis of how difficult it is to manage logistically. Although peanuts may be more deadly in terms of total number of fatalities, they are viewed by several parents as much easier to avoid. The ease of food avoidance is probably the major contributing factor or qualifier in the way a parent views their child's allergy on this hierarchy of allergies.

The notion of a hierarchy of allergies comes directly from the data in the way study participants describe their challenges regarding their children's allergies with respect to other parents' challenges. The emergence of this theme seems to echo a dynamic seen in what sociologist Darnton (1990) dubbed the "mommy wars" with working mothers on one side of the war and stay-at-home mothers on the other. Both groups of mothers operate within specialized frameworks that support their decision work or not work. "Both stay-at-home and paid working mothers, it is argued, are angry and defensive; neither group respects the other. Both make use of available cultural indictments to condemn the opposing group. Supermoms, according to this portrait, regularly describe stay-at-home mothers as lazy and boring, while traditional moms regularly accuse employed mothers of selfishly neglecting their children" (Hays, 1996:132). Although Hays personally feels that the notion of a "mommy war" has been overblown, there is still a divide that exists today between working and non-working mothers.

A similar type of "allergy war" appears to be taking place among parents of children with different allergies and allergy severities. Several parents' stories illuminate this friction among parents. One mother responded early on in her interview that she noticed a lot of tension between parents of children with different allergies. Allergy support groups were an environment where this type of tension was most obvious. It seems that there is a big divide between parents of peanut allergic children and the parents of children allergic to something other than peanuts. There is an unspoken hostility almost on the part of parents with children who have an allergy other then peanuts. They feel envious and almost jealous of the fact that the majority of research done on food allergies is done on peanuts, not to mention that peanuts are much easier to eliminate out of a whole household's diet unlike milk or eggs. Again, peanuts are the most deadly but probably the easiest food allergen to manage. Peanuts are not present in processed foods to the same extent as something like milk, eggs, wheat or even soy. One father of a severely *peanut and milk* allergic child remarks that his daughter's milk allergy is much more difficult to manage than her peanut allergy. A mother, who also has a *peanut and milk* allergic child, admits that her son's peanut allergy is easier to manage because so much more research has gone into peanut allergies which she feels has resulted in outsiders being more accepting of peanut allergies. She remarks that during support group meetings, there is some talk of the *peanut only* parents at her support group where parents of allergic children with non-peanut allergies such as milk allergies display hostility towards the parents of children with peanut allergies when they make remarks such as "I could only wish for a peanut allergy." In support of this type of allergy war between parents with children with peanut allergies and those without, a mother of a dairy allergic child admits that she feels very jealous, and almost resentful, of parents that only have to manage a peanut allergy. She feels jealous if she learns that a child has outgrown an allergy while her child remains afflicted by her severe milk allergy. She also remarks that she feels very jealous of parents of perfectly healthy children. This particular participant's husband who also participated in the study also remarked that "eliminating dairy out of the diet is very difficult and I get agitated when I hear of parents whining about peanut allergies". Of course, not all parents in the study sensed this tension. One mother of child with several different food allergies comments that during support group meetings, comparisons of allergies are made, but it is not competitive in nature. Basically, she sees the support group as being a source of emotional support given that "everyone, at least on some level, is going through the same thing". Nonetheless, the generalized feeling is that these parents are at odds based on the specific nature of their children's allergies.

4.5 Social management of children's severe food allergies: The Negotiation Of Difference

Sections 4.2, 4.3 and 4.4 expanded on how parents of severely food allergic children managed their children's allergies on a predominately *internal* basis in referring to how they personally handled the physical, emotional and social management of their child's allergy. Examples of *internal management* include the decision to make a home allergen free, where to keep epinephrine shots, or joining an allergy support group. These are more personal interactions that take place within the parent's mind, between mothers and fathers, between parent and child or between parents of food allergic children where there is no external involvement with the outside non-allergic social world. This is different from the way they handle the allergy where outsiders are concerned. One of the challenges that seems to be faced by all parents of severely food allergic children is the external management or *negotiation of difference* that they feel compelled to engage in as they attempt to keep their children safe. Severely food allergic children, without exception, are different physiologically speaking. Their bodies have made the decision to create antibodies against certain food proteins resulting in food allergies which puts them at risk of anaphylaxis and possibly death. The parent of the severely allergic child is very aware of this physical reality and has the responsibility of negotiating the child's "difference" to others. This is done on the child's behalf and for the child's benefit, however, this negotiation often times creates negativity in the lives of the food allergic child and their families. On the one hand, parents have to convey to outsiders that their child is physiologically different, but on the other hand the parent must temper that with their desire for their child not to feel different or be treated differently. This can create a real juxtaposition for the parents in this study. It is here that the ideology of intensive parenting tends to rears it head again as parents attempt to convey their children's allergies to the outside world while at the same time protect their children emotionally and socially as intensive parents.

A *negotiation of difference* is undertaken by parents of severely food allergic children. This negotiation is, in effect, the way parents balance the often contradictory needs of conveying their children's difference as a food allergic individual and buffering or counteracting any negative outcomes associated with the allergy with an emphasis on not wanting their children seen differently or treated differently. How they accomplish this, too, is interesting sociologically. Although no work from the field of sociology has been undertaken on this subject with respect to food allergies, research done by Joseph W. Schneider and Peter Conrad on parents of epileptic children and by Clare Williams on mothers' management of teenage sons with chronic illnesses provide some insight into how parents of allergic children might negotiate difference in their attempts to manage their children's medical condition. Specifically, Schneider and Conrad (1983) expand upon how parents communicate with their child regarding their epilepsy drawing upon Barney Glaser and Anselm Strauss's (1964) *awareness contexts*. The authors find that parents either practice an open or closed parenting style with respect to their child's epileptic condition. "Some adopted an open, matter-of-fact definition of epilepsy as a medical problem. Others pursued an almost complete silence and denial" (Schneider and Conrad, 1983:83) Parents practicing an *open style* viewed their children's epilepsy as a "normal" medical condition which deserved the same credence as other serious medical conditions. The epilepsy was seen as unfortunate, but something that must be accepted and taken in stride. "The themes of maintaining perspective, accepting epilepsy, and going on with one's routine activities and future plans were central in recollections of how 'open' parents helped children cope by supplying such minimizing definitions" (Schneider and Conrad, 1983:84). In contrast, parents utilizing a *closed style* were described as shocked, embarrassed, ashamed and fearful to learn their child's diagnosis. Epilepsy to closed style parents' was anything but normal which was actually more difficult for the child to manage than the physical aspects of their medical condition.

It is possible that parents of very young children with severe food allergies take one of two approaches in communicating with their child about their severe food allergy, also a chronic medical condition. There is a potential for parents of allergic children to attempt to normalize their child's environment by mitigating the effects the allergy has on the child. This could be done by taking more a closed parenting style especially in the case of very young children to the point that the child doesn't have an appreciation for the seriousness of the situation. In their attempts to buffer their child's allergy with normalizing efforts, a parent might run the risk of mismanaging the allergy. Several factors such as the severity of the allergy, the child's age and perhaps the level of parental intensiveness all contribute to how parents will negotiate / manage difference for their children.

Additionally, Clare Williams investigates how young people with chronic illnesses and their main caregivers negotiate responsibility for self-care (Williams, 2000) This main carer is referred to as the *alert assistant* who is, in a sense, invisible and whose work is achieved without the knowledge of the person being assisted. Her study focuses primarily on young men managing diabetes and asthma. One of the ways in which people mange the potential stigma attached to illness is by using the strategy of *passing,* which involves concealing the illness and its effects in order to maintain a conventional self-presentation (Goffman 1963, Strauss and Glaser 1975). Unfortunately, the process of passing can create a potential backlash for the individual with the medical condition. The author finds that in an effort to help their son's minimize the stigma attached to their illness by way of *passing,* "mothers realized the possible adverse consequences of enabling boys to pass successfully. For example, mothers recognized that by helping their sons to pass, boys could be more vulnerable to the illness manifesting itself in public." (Williams, 2000:269) A similar dynamic might be at play with regard to parents of severe food allergic children as they try to buffer or mitigate the effects of their children's allergy and actually make matters worse for the child. Parents do not to want their children to feel different or be treated differently. Parents of food allergic children can engage in various strategies to counteract the social effects of their child's allergy. In the world of food allergies, it is typically the mother that serves as the primary *alert assistant* to the food allergic child. An example of this could include a mother sending an allergen free snack to school which looks very similar to the snack being provided in an effort to avoid the child feeling left out or different from the other children. Unfortunately, as is the case in Clare Williams' work, this can backfire in the event that the "special snack" accidentally gets mixed up with non-safe snacks. How parents manage their children's medical conditions including epilepsy, asthma, and diabetes can be a complicated task with the best of intentions turning out to have negative consequences for the child.

4.5.1. Educating the outside world

Almost all of the parents in the study revealed that after learning of their child's food allergy, that they knew that it would be life altering, but hopefully manageable. The majority of study participants focused initially on the internal management of the allergy first and then turned their focus to external management. One of the ways they would have to change their lives would be to educate others on the potential seriousness of their child's food allergy, which of course was often done in a spirit of intensive parenting (Hays, 1996). Although all of the parents in the study reported that they had reasonable cooperation from others with respect to their child's allergy, on a number of occasions throughout the interviews, parents would explain in detail how they encountered difficulty as they tried to convey their child's difference to others including family, friends, educators and members of society in general such as restaurant workers.

Schools were a big challenge for at least three of the participants. One mother shares how frustrated she felt after learning that her three year old egg allergic child had been given a cupcake which contained egg. She had spent an extensive amount of time educating the school on her son's allergy and had even taken measures to ensure that he had a safe snack to eat. In her words, she says "I've educated these people so heavily, he cannot have egg, he cannot have egg, he cannot have egg!" She was very frustrated at the disregard the school had for the intensity of what could happen to her son. In her son's case, the symptoms of an allergic reaction including coughing and wheezing can go on for two days which means he is sick for two days and she misses work for two days. Her son no longer attends the school the incident happened at and is now in what the mother feels is a safer environment.

Another mother reports a similar situation. This mother's son had accidentally been given a food he was allergic to while at preschool, which resulted in an allergic reaction. Fortunately, the reaction was not severe. The incident created mixed feelings in the mother. She notes that on one hand, she felt a sense of validation in that the teachers were able to see what could happen to her son. In effect, they might now take the allergy seriously and be much more careful. On the other hand, she was very upset with the school given her efforts to educate them on the seriousness of the food allergies her son was afflicted with. She remarks that she was so upset that she had to wait until the following Monday to discuss it with the administrators at the school who assured her it would not happen again.

Finally, another mother found herself incredibly disappointed in her son's teacher. For an end of year party, the teacher took it upon herself to bake a large chocolate chip cookie for the class, which was not safe for the allergic child, not to mention other allergic children in the class, to eat. She was shocked and felt that the teacher was insensitive and should have known better given her best efforts to educate the teacher. She states, "I told them stuff that was safe for him so that they would know". In all of these instances, mothers of food allergic children worked diligently to create safe environments for their children outside the home only to have their messages fall on deaf ears. In the last example, the mother was most upset by the fact that her son was left out and could not participate fully in the class party. As a result of instances like these, the majority of parents in the study do not trust educational facilities to provide their children with allergen free food and, as a result, almost all of the parents in the study send their children's lunches. This is a hardship for families, especially mothers, who often prepare lunches from home.

In addition to encountering difficulty conveying their children's allergies to educators, parents also reported issues with educating friends and family. One mother of a six year old dairy allergic child told a very interesting story about how she and her husband cut ties with their best friends over their child's severe food allergy. The mother revealed that the other couple, who was also the allergic child's legal guardians in the event of her and her husband's death, was not sympathetic at all to their situation with respect to the allergy. The other mother had children who also had some relatively serious medical problems. She made this participant feel like she was overreacting about the allergy and blowing the whole thing out of proportion. She states, "I confronted her about it and she was unapologetic and I completely cut the friendship out". After discussing the situation with her husband, this participant and her husband chose to cut ties with this couple, which truly revealed the lengths that they will go to in order to create a supportive environment for their daughter. Although this is the only study participant to mention that her child's allergy actually led to cutting ties with friends, several other participants did isolate themselves from others for similar reasons such as feeling that outsiders were unsympathetic. However, in these instances, the friction was more subdued and non-confrontational in nature.

Study participants also mentioned that family members were frequently the most difficult people to convince of their child's allergy. On many occasions, children's allergies were not taken seriously by family members. A parent of a severely milk and peanut allergic child revealed that her son was given an allergen containing food by his own uncle which resulted in a severe allergic reaction. This turned out to be the first time the family ever had to use an epinephrine shot. The mother remarks of feeling validated in the fact that it demonstrated to others the seriousness of food allergies. A married couple in the study, interestingly, both told the exact same story when asked to share a story pertaining to their child's allergy. This couple's daughter is severely allergic to milk and peanuts. When the couple initially attempted to educate family members about the allergy it was not received well and the allergy was seen as suspect. While on a family vacation, this couple's child had a relatively intense allergic reaction after accidentally ingesting milk which resulted in her violently vomiting all over a family member's minivan. The parents were relieved that she recovered, but they both felt somewhat validated about their daughter's allergy. The mother shares that "it was very dramatic and given that it was a family reunion there was so much family there and I think that it really surprised some people and maybe that was the first time they took it seriously so I think that's huge". It exhibited the seriousness of the allergy to the skeptical family members and truly assisted these parents in their negotiation of difference for their daughter. The parents made the difficult decision not to take the child to the hospital. The mother of the child remarked that she *would have felt* somewhat guilty taking her daughter to the hospital because it might have inconvenienced everyone else since this incident was during a family gathering. She admits that she also *felt* guilty for not taking the child to the hospital in the event that the reaction had gotten worse. She was conflicted as she negotiated difference for her child.

An extreme example of a parent's negotiation of difference for his child involves the father of a six year old dairy allergic child. As a result of a job change, the family had relocated to a different city where they found that food allergies were very misunderstood. He remarked that this was evident not just in public settings like church but also among doctors and medical providers. The family actually made the decision to move back to where they had moved from in order to not live in an area that displayed such a lack of awareness regarding food allergies. This move back actually involved the father becoming unemployed and was still unemployed at the time of the interview. This family was willing to go to extraordinary lengths to be in an environment that was more "allergy friendly". Another mother in the study remarks that she and her family had to change churches given their previous church's lack of awareness of food allergies. She, too, had spent a considerable amount educating church workers as to the seriousness of her child's allergy. She also mentioned that a language barrier and rotating church school educators also contributed to her decision to change churches.

In terms of going to restaurants, most of the participants in the study went out to eat very little due to concerns over their children's allergies. One of the biggest challenges of eating outside the home for a food allergic individual is ensuring that food is allergen free. It is often difficult for parents to know that the proper steps to keeping their children safe are being undertaken at restaurants, such as providing accurate allergen information and taking precautions to avoid cross contamination. Nonetheless, a majority of parents revealed that they frequented a small number of restaurants they felt were safe. A lot of preventative work was done ahead of time prior to arriving at the eating establishment. Almost all of the participants report that they call ahead and check with a manager before going through the trouble of actually going to the restaurant only to find that it was not allergy friendly. Most parents also reported that they spoke to managers prior to ordering and often times insisted on seeing ingredient labels before agreeing to eat at the restaurant. One mother reports that if the family does ever frequent a restaurant, her food allergic child is not allowed to eat there and she will bring food from home. She does not mention that this bothers the child. This begs the question of whether this is making it easier on the child in terms of physical safety or more difficult on the child in terms of feeling different and left out. Additionally, one mother points out that restaurant workers are difficult to deal with in that, unlike family, friends and other intimate relationships, the workers are not emotionally involved with the child.

Parents in the study also shared how they described their child's allergy to others. This is one area that sees a reasonable amount of variability with some parents being relatively passive about conveying the seriousness of their child's allergy and others being more assertive often utilizing scare tactics to demonstrate the seriousness of the situation. Parents tend to be either more assertive or more passive with respect to how they convey their children's allergies to others. In terms of parents who take a more assertive approach, one mother of a severely peanut allergic three year old admits that she uses scare tactics with teachers in an effort for at least adequate precautions to be undertaken. She says, "So I really just try to scare them to death to where they'll ask me all the time". Another mother reveals that she presents a life and death scenario when educating others about the seriousness of her son's allergy and explains to them what happened in the past in terms of allergic reactions. She works hard to convey to others that he will experience a whole lot more than just "a tummy ache" and that her child could actually die. A mother of a dairy allergic child utilizes similar tactics in that she lets others know right away that her daughter could die as a result of an allergic reaction. She, too, admits that she overplays the allergy in order to get cooperation from others. The father of this child, also a study participant, admits that he wants to get across to people the seriousness of his daughter's allergy. Interestingly, several of the parents in the study who employ a more assertive position also make note of the fact that they do not want to push things too far or ask for special treatment in the event that it will negatively affect their children.

In the spirit of being more passive, a mother of a peanut and milk allergic child explains that she does not want her child's allergy to be a burden on others and tries to do all that she can do to make things easier for others when it comes to managing her son's allergy. She does not feel that she needs to overplay the symptoms to get her point across. Taking a somewhat similar approach, another mother shares that she adjusts the way she talk to others about her daughter's allergy depending upon the attitude of the person she is trying to educate, but at a minimum insists that people recognize her daughter's allergy as serious. One father in the study takes a less alarmist approach wherein he explains to others calmly that the allergy can be fatal, but tries very hard not to alarm others. Another one of the fathers in study mentions that he does not want to be a bully about his son's peanut allergy, but he is not shy about it letting others know that it is a serious medical condition. In his words, "I don't try to be a bully about it but at the same time I just want to make sure they're very clear on that if something – if he were to have a reaction it would be – it could be fatal". It should be noted that there is a relatively high correlation between the approach taken by parents and the seriousness of their child's actual allergy. Not all children in the study appear to have severe allergies and those with less severe allergies tend to have parents that take a less aggressive approach in educating outsiders on the child's allergy.

It is also interesting to see the parallels that can be drawn between the level of assertion / passivity of the study participants' approach in communicating their children's allergies to outsiders and Hattery's (2001) participants in terms of their level of conformity / nonconformity. The more assertive parents in the study are similar to the conformists in Hattery's study in that they are both quite intensive in nature. Just as conformists feel that they should completely devote themselves to their children, the more assertive parents will go to the greatest lengths as well to get their point across. The study participants that take a more passive approach in conveying their children's allergies to others seem more similar to Hattery's pragmatics or innovators in that they attempt to strike a balance between getting their point across and not asking for special treatment. These two types of women in Hattery's study, too, were willing to make certain compromises as long as they were in the best interest of their children.

Drawing upon Garey's (1999) work on *sequencing*, parents in this study appear to be employing similar mechanisms in their quest to function in a predominately non-allergic world. Garey finds that women employ sequencing and weaving tactics in order to meet the needs of their children with respect to working outside the home. Just as women in Garey's study make alterations and juggle their lives to accommodate their children, so do the participants in this study. The family that relocated to a different, more allergy friendly, city is a good example. Instead of sequencing between full-time work, part-time work, or unemployment, these parents are sequencing between allergy friendly and non-allergy friendly cities, churches, friends, and schools as the situation arises in order to accommodate the family's needs based on the allergy. Instead of sequencing their careers, these parents are sequencing major parts of their lives including where they live, where they worship, who they socialize with and where they allow their children to be educated all in response to their children's allergies.

Clearly, participants in the study are not just making minor alterations in their lives, but at times monumental changes including switching schools, cutting ties with long-time friends, changing churches, relocating to a more allergy friendly city, and engaging in scare tactics to convey their child's difference to the outside world. This truly echoes an intensive style of parenting where the child's needs are clearly being put first characteristic of a very child-centered environment involving several emotionally absorbing tactics as revealed in the research data. In negotiating difference for their children, the parents in this study desperately wanted others to understand that their children were different and needed to be treated differently at least with respect to their allergy and when this was not the case they were prepared to take action, often dramatic action, to ensure that their child was in an environment that was sensitive to needs of those afflicted with severe food allergies.

4.5.2. Buffering the allergy / compensation with "special treats"

Conveyance of the child's difference combined with the desire to not have the child feel different or be treated differently are recurrent themes in the data on how these parent's manage their children's allergies which seems to have to potential for putting the parent at a disadvantage. Given the aforementioned lengths that parents go to in order to communicate their children's physical needs, it is almost peculiar that they spend so much energy "buffering" the allergy for the child. Several of the parents in the study attempt to buffer their child's allergy and see to it that their children are not viewed or treated differently. *Buffering* can best be described as a parent's attempt to offset or counteract the negative effects of the allergy by compensating in other ways. One of the ways parents attempt to do this is by providing their children with "special treats". These special treats are often times cupcakes, cookies and other allergen free foods created especially for the child in an effort for the child not to feel ostracized or left out. Again, it is very important for the majority, if not all, of the study's parents to protect their children from feeling different due to the child's allergy.

It is not unreasonable for parents to provide safe food such as safe snacks for their children when the provided food may or may not be allergen free and safe for the child to eat. It is interesting, however, to see the more *intensive parenting* type mechanisms that are undertaken when it comes to the selection of these safe foods. One mother of a three year old peanut allergic child reports that she packs her son's own safe snacks to take to daycare. She admits that "I even make him special snacks that are hopefully *more desirable* than what is being provided". Another mother of a four year old peanut allergic child mentions that "I make sure that he has an alternative, and often times a *more elaborate*, treat". A father in the study remarks that his daughter, at times, actually feels lucky to have her allergy since she sometimes get a *special food* substitute that "the other children wish they could have". Another father mentions that in his daughter's case, he and his wife will anticipate if their daughter is going to be in a stressful situation and head it off at the pass. “At birthday parties, we will take ‘a *nicer and better* ‘safe’ cupcake for her so that she does not feel that she has been ostracized due to her allergy”.

Providing special treats that are safe and free from allergens is not the only way that the parents in the study buffered or tried to compensate for their child’s allergy in an effort to shield the child from the potentially negative social effects of the allergy. Several parents avoid putting their food allergic children in situations where they might feel different due to the allergy. A mother of a three year old egg allergic child will actually leave birthday parties before the cake is cut so that her son will not want for the cake and will not feel different. This same mother admits that she minimizes her son’s exposure to other people when she is not around as to decrease the chance that he will be exposed to his food allergen. Another mother, who is also a child psychologist, stresses the importance of it being okay to be different to her daughter. Effectively, she admits that she and her husband try to *normalize* the allergy to their child when they tell their daughter that yes she is different because of her allergy, but in some way everyone is different. She states, “We try to normalize it in that way – the fact she’s different, well that’s normal – everybody’s different”. Another mother of a peanut allergic son reveals while talking about the emotional effects of the allergy on her son, that she feels that the family does such a good job of accommodating the child that he does not even realize the unique situation of his allergy. Yet another mother confesses that in order to help her daughter feel more comfortable, she will indulge the child and leave a certain situation where the child feels uncomfortable due to her allergy. She admits that she should probably stay and try to help her daughter work through her fear, but she chooses to indulge the child and leave.

It was very fascinating to see the ways parents would anticipate the situations in which their children might feel different and take action preventatively to ensure against a negative social experience where the child might feel different. Again, it is somewhat ironic to see this behavior taking place simultaneously while the parent is often hyper vigilantly communicating the child's physical needs to outsiders. It is almost as if parents will overplay the allergy to others and at the same time mitigate the child's allergy to the child by way of the previously mentioned strategies. In terms of special treatment, parents are concerned that they themselves might be seen as asking for special treatment where their allergic children are concerned, however, they provide special treatment to their children through this buffering process.

4.6 Conclusion

The preceding subsections of Chapter 4 demonstrate the complexities of managing a child's severe food allergy. Clearly, it encompasses the physical, emotional and social. Parents face an assortment of challenges as they attempt to effectively manage their children's severe food allergies. The ideology of intensive parenting is evident throughout the data. Intensive parenting provides a framework for the allergy management to exist within. In terms of physical management, the data analysis in Section 4.2 demonstrates how parents truly struggle with the delicate balance of keeping their children safe without over managing or under management the allergy. While many parents undertook extreme measures to keep their children physically safe, they at the same time struggled with the reality of having to administer life saving medication in the event of a severe allergic reaction. Section 4.3 illustrates the emotional aspects of managing a child's allergy where parents often felt guilty and blamed themselves for their children's allergies. They were frequently overwhelmed and misunderstood by a world that does not fully accept the seriousness of food allergies which had to potential to lead some study participants to seek psychological therapy. From a sociological perspective, sections 4.4 and 4.5 show how parents employed several mechanisms in order to socially manage their children's allergies. Collective legitimization aided these parents in their effort to legitimize their children's food allergies to themselves, to other parents of food allergic children and to the outside world. Part of this collective legitimization process included medicalizing their child's allergy whereby parents overplayed the seriousness of the allergy in order to gain an adequate level of cooperation from the skeptical and uninformed outside world. Finally, parents also delicately negotiated difference for their children. They, on the one hand, required that outsiders be cognizant of their child's allergy and on the other hand worked very diligently to ensure that their children did not feel different or were not treated differently due to the allergy. The exploratory research conducted in this research study clearly demonstrates the difficulty these parents face every day as they attempt to effectively manage their young children's severe food allergies.

CHAPTER 5

DISCUSSION

Based on the results of this exploratory qualitative study on parents' management of their children's severe food allergies, the responsibility of effectively managing children's severe food allergies is a complex undertaking for parents. Although the study results are not generalizable to a larger population, it can be gleaned from the research data that parents do truly struggle to balance safety and normalcy for their children as they manage the allergy physically, emotionally and socially. Several sociological themes did emerge from the data including intensive parenting, collective legitimization, and negotiation of difference as they relate to parents' management of childhood food allergies.

In the spirit of the grounded theory approach proposed prior to the onset of this study, these twelve in-depth interviews with parents of food allergic children allowed for sociological themes to emerge serendipitously from the data. As expected, the parents in the study, for the most part, appeared to be engaging in intensive parenting, particularly intensive mothering as defined by sociologist Sharon Hays (1996). Hays' intensive methods, including child-centered, expert-guided and emotionally absorbing child-rearing, were all demonstrated rather consistently by the parents in the study with respect to their various management techniques. Examples of this include how the parents were very child-centered in their physical management of their children's allergies including the extreme measures that were employed in order to make a child's home completely allergen free. From an emotional management standpoint, parents often blamed themselves for their children's allergy and experienced guilt and other negative emotions as a result of the allergy. The allergies proved to be emotionally absorbing and exhausting for many of the parents in the study. As in intensive parenting, the parents in the study were also expert-guided as they socially managed their children's allergies as they consulted pediatricians, allergists, internet websites and organizations devoted to food allergies. The research demonstrated that these parents were engaging in not only intensive parenting, but at times an almost extreme form of it given the already intensive nature of severe food allergies.

Another interesting theme emerging from the data was the way parents of food allergic children pulled together as a group not only to support each other but in order to legitimize themselves to each other and to the outside world. Food allergies, especially severe food allergies, are not typically taken seriously by the general public. This coupled with the potentially fatal nature of their child's allergy, positioned the parents to partake in what Anne Velliquette and Jeff Murray refer to as *collective legitimization* whereby members of a group will pull together in order to legitimize their cause. In this case, parents of severely food allergic children pulled together through the use of support groups in an obvious effort to legitimize their children's food allergies. Parents also utilized food allergy testing to legitimize the allergy to themselves as well as outsiders. Of special note, was the presence of a hierarchy of allergies that seemed to exist among parents of children with different food allergies and different food allergy severities. Much like the mommy war that has erupted between stay-at-home mothers and working mothers, a divide between parents of children with different allergies and allergy severities has been appreciated in the data. Parents of children with certain allergies and allergy severities seem to harbor various levels of resentment and other negative emotions towards parents of children with other allergies and allergy severities. Specifically, a divide between parents of peanut allergic children and parents of children with non-peanut allergies was prominent in the research data.

The way these parents managed their children's allergies to the outside world also revealed several sociologically fascinating findings. In negotiating risk for their children, many of the parents in the study would go to great lengths to educate others such as teachers on the importance of understanding their child's allergy. They often commented on the difficulty they encountered in this quest. Ironically, as parents would work to convince others that their child was different, they would simultaneously work just as hard to ensure that the child did not feel different and was not treated differently. Interestingly, many parents in the study participated in a "buffering" of their child's allergy in that they would anticipate negative situations that might arise due to the allergy and would work diligently to head these issues off at the pass. One of the main ways that this was accomplished was through the use of "special treats" which was specifically employed in order to offset or counteract any potential negative social effects such as their child feeling ostracized or stigmatized.

These are the main social themes that emerged from the data, however, there were a few other findings worth mentioning. Although it did not fit well into one of the major emerging themes from the data, it is important to note that a large majority of the sample reported that their children's allergies actually positively affected their lives in that they were now much healthier eaters. A number of study participants actually lost weight on their children's allergen-free diets. Cholesterol levels also diminished in a few of the parents most likely as a result of altered lifestyles including eating out less and eating fewer processed foods. In terms of negative effects, many of the parents reported of a loss of spontaneity in their relationships with their spouses as well as within their families in terms of having the freedom to go and do as they would had their child not developed a severe food allergy. Their lives were, in many ways, dictated by the allergy. The physical, emotional and social management of food allergies clearly permeates throughout the lives of parents of the food allergic to the point that almost every decision gives credence to the food allergy.

It should also be noted that this study focused on middle to middle upper class parents. It is reasonable to assume that not all parents from all socioeconomic groups will manage food allergies the same way. There are, in effect, 'hidden' parents of children with severe food allergies within society which the scope of this study did not encompass. For instance, many lower socioeconomic parents of food allergic children do not have access to resources such as the internet, doctors, and prescription medications as did the parents in this study. This will most likely affect their management style. This study employed word of mouth and snowball sampling resulting in a skewed data set representing only middle to middle upper class participants which are potentially at higher risk of being intensive parents to begin with given their social standing. This non-representative sample might have allowed for a false impression or overestimation of intensive parenting on the part of parents of severely food allergic children in general. A more expansive data set would reveal such social class differences.

Managing a child's severe food allergy in today's social climate is a daunting task as has been exhibited by the results of this particular data set. The parents in this exploratory research project demonstrated this difficulty and provided a view into the world of the food allergic individual and their families. In keeping with intensive parenting methods, their management appears to be directly related to the social atmosphere in which they exist. Areas of future research on the topic of parental management of severe food allergies might include delving deeper into how parents actually go about positioning themselves on the hierarchy of food allergies as well as how they determine the seriousness of their child's allergy in that there is concern that some of the parents of the children in this study have perhaps medicalized their children's mild food allergies into severe food allergies which brings up a whole host of sociological issues. Looking beyond parental management, researching how physicians feel and respond to intensive parenting and how they perhaps contribute to the medicalization of allergies as well as other childhood medical conditions as they practice medicine in an environment of intensive parenting.

APPENDIX A

INTERNAL REVIEW BOARD APPROVAL

INTERNAL REVIEW BOARD APPROVAL

RE: Expedited Approval of Protocol

TITLE: *Balancing Safety and Normalcy for Young Children: A Study on the Governing Dynamics Affecting Parents' Management of Children's Severe Food Allergies*

IRB No.: 07.233s

The University of Texas at Arlington Institutional Review Board (UTA IRB) has determined that this research is eligible for expedited review in accordance with Title 45 CFR 46.110(a)-(b)(1), 63 FR 60364 and 63 FR 60353, category (7).

The IRB Chairman (or designee) approved the protocol effective June 20, 2007. IRB approval for the research shall continue until June 19, 2008. In order for the research to continue beyond the first year, Continuation Review must be completed within the month preceding the date of expiration indicated above. A reminder notice will be forwarded to the attention of the Principal Investigator (PI) at that time.

The approved subject sample size is 15.

APPENDIX B

INFORMED CONSENT FORM

INFORMED CONSENT

PRINCIPAL INVESTIGATOR: Leslie B. Graceffo

TITLE OF PROJECT: Balancing Safety and Normalcy: A Study on the Governing Dynamics Affecting Parents' Management of Children's Severe Food Allergies

This Informed Consent will explain about being a research subject in a research study. It is important that you read this material carefully and then decide if you wish to be a volunteer.

PURPOSE: The purpose of this research study is to attempt to reveal and better understand the allergy related management techniques employed by parents and other primary caregivers of severely food allergic young children as they attempt to provide a physically safe as well as an emotionally healthy environment for the child. Research study results may provide a better understanding of severe food allergy management techniques which might aid in better overall management of severe food allergies in young children on the part of parents and other primary caregivers. Additionally, research study results might aid in the heightening of severe food allergy awareness among parents, caregivers and other members of society.

DURATION: Twelve to fifteen participants will be selected for this research study. Each participant will be interviewed for approximately one to two hours. It is possible the interview will be less than one hour or more than two hours. The research site will be the home of the interviewer, the home of the interviewee or an agreed upon neutral meeting location. There is also the possibility that the interview will take place over the telephone.

PROCEDURES: This research study consists of an in-depth interview guide. You will be asked aloud approximately 10 to 12 questions on the research topic. The interview will be tape recorded and later transcribed into typewritten form.

_______ Subject Initials

PRINCIPAL INVESTIGATOR: Leslie B. Graceffo

TITLE OF PROJECT: Balancing Safety and Normalcy: A Study on the Governing Dynamics Affecting Parents' Management of Children's Severe Food Allergies

POSSIBLE RISKS / DISCOMFORTS:

There are no known or anticipated risks or discomforts associated with this research study.

POSSIBLE BENEFITS:

A potentially better understanding of severe food allergy management techniques might occur as a result of participating in this research study. Additionally, published research study results might lead to better understanding and better management of young children's severe food allergies.

ALTERNATIVE PROCEDURES / TREATMENTS:

There are no possible alternative procedures if you elect not to participate in this study.

CONFIDENTIALITY:

Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in Professor Bob Kunovich's office within the UTA Department of Sociology for at least three (3) years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA IRB and personnel particular to this research (individual or department) have access to study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

FINANCIAL COSTS:

There are no possible financial costs to you as a participant in this research study.

_______ Subject Initials

PRINCIPAL INVESTIGATOR: Leslie B. Graceffo

TITLE OF PROJECT: Balancing Safety and Normalcy: A Study on the Governing Dynamics Affecting Parents' Management of Children's Severe Food Allergies

CONTACT FOR QUESTIONS:

If you have any questions, problems or research-related medical problems at any time, you may call Bob Kunovich, Ph.D. at 817/272-3796 or contact Heather Jacobson, Ph.D. at 817/272-1282. You may call the Chairman of the Institutional Review Board at 817/272-1235 for any questions you may have about your rights as a research subject.

VOLUNTARY PARTICIPATION:

Participation in this research study is voluntary. You may refuse to participate or quit at any time. If you quit or refuse to participate, the benefits (or treatment) to which you are otherwise entitled will not be affected. You may quit by calling the researcher, Leslie Graceffo whose number is 817/683-6822. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about staying in the study.

By signing below, you confirm that you have read or had this document read to you. You will be given a signed copy of this informed consent document. You have been and will continue to be given the chance to ask questions and to discuss your participation with the investigator.

You freely and voluntary choose to be in this research project.

PRINCIPAL INVESTIGATOR

____ Date

SIGNATURE OF VOLUNTEER

____ Date

Last Revised 06/12/07
Page 3 of 3 ______ Subject Initials

APPENDIX C

IN-DEPTH QUALITATIVE INTERVIEW GUIDE

In-Depth Interview Guide

Question 1: How and when did you come to find out about ____________ allergy?

- Was it as a result of a reaction or through some other means?
- What was your initial reaction to finding out about the allergy?
- What feelings or emotions did you experience?
- What was your next step given this newfound knowledge?

Question 2: Could you tell me a story pertaining to ____________ allergy that tends to stand out in your mind?

- Is it about a reaction?
- If so, where did the incident occur?
- If so, were you with your child at the time?
- If so, were you prepared to offer treatment if necessary?
- If so, how did your child handle the incident?

Question 3: Has ____________had any additional reactions (if applicable from Question 2)?

- How was this different than the first reaction?
- How were you prepared this time?
- Did you learn anything for the incident?

Question 4: How do you attempt to keep _______________ physically safe?

- How do you do this at home, at school and in public settings such as restaurants?
- Do you have life-saving prescription drugs in the event of an emergency?
- How do you feel about administering life saving medicine to your child?
- Have you ever had to use life saving medicine for the child?

Question 5: How do you attempt to communicate ____________ needs to others?

- How do educate family, friends, teachers, medical providers and the general public?
- Is this a challenge for you?
- Do you feel you have reasonable cooperation from others?

Question 6: How does ____________ allergy affect him or her emotionally and socially?

- Does the allergy negatively affect ____________ (emotionally or socially)
- Does ____________ have issues with anxiety or feel ostracized because of his or her allergy?
- How does the allergy affect ____________ quality of life?
- How do you talk to ____________ about their allergy?
- How do you help ____________understand and deal with their feelings about their severe allergy?

Question 7: How do you manage the emotional and social aspects of ____________ allergy?

- Do you feel that the allergy negatively affects you?
- Do you feel that the allergy positively affect you?
- How does the allergy affect your quality of life?
- Do you talk to others about these feelings?

Question 8: How does ____________ allergy affect other family members?

- Does managing the allergy cause problems between family members such as between siblings?
- Do you think your family's quality of life suffers because of the allergy?

Question 9: How would you compare the way you manage ___________allergy to the way parents of children with other medical problems might manage their child's allergy?

- How about children with cancer?
- How about children with diabetes?
- How about children with insect allergies such as a bee allergy?

Question 10: How has the allergy changed over time?

- How has it gotten better?
- How has it gotten worse?
- How has the management changed?

Question 11: Looking ahead, what comes to mind when you think about the future in terms of ____________ allergy?

- How do you feel about a cure for ____________severe food allergy?
- How does ____________ feel about a cure?
- How do you or ____________feel about vaccines?
- How do you or ____________feel about allergy testing (skin testing, food challenges, or blood tests)?

Question 12: Would you like to add anything concerning ____________ allergy that we have not already discussed?

APPENDIX D

DEMOGRAPHIC FACE SHEET

Demographic Face Sheet

1. What is your sex? ______ Male ______ Female

2. What is your date of birth? ______ Month ______ Day ______ Year

3. Which category best describes you?

______ White non-Hispanic	______ American Indian
______ African-American	______ Asian
______ Hispanic	______ Other

4. What is the highest grade of school you have completed?

______ Less than 12th grade	______ Associate Degree
______ High School Graduate / GED	______ Bachelor Degree
______ 1-3 years of college but no but no degree	______ Post Bachelor work but no degree

______ Graduate Degree, please specify ________________

5. Are you currently employed outside the home? ______ yes ______ no

If yes, ______ full-time ______ part-time ______ part-time seasonally/temporarily

6. What is your occupation?

____

7. Which category describes you?

____ Single ____ Married ____ Cohabitating ____ Divorced ____ Other

8. If married or cohabitating, what is the date of birth of your spouse/partner?

______ Month ______ Day ______ Year

9. Which category best describes your spouse/partner?

______ White non-Hispanic	______ American Indian
______ African-American	______ Asian
______ Hispanic	______ Other

10. What is the highest grade of school your spouse/partner has completed?

______ Less than 12th grade

______ High School Graduate / GED

______ 1-3 years of college but no
but no degree

______ Graduate Degree, please specify _______________

______ Associate Degree

______ Bachelor Degree

______ Post Bachelor work
but no degree

11. What is your spouse's/partner's occupation?

____

12. Please list the names and ages of the people you live with.

Name	Age
____	_______
____	_______
____	_______
____	_______
____	_______

13. Food allergic individuals in your family including yourself.

Name	Date of Diagnosis	Allergy & Severity (Low, Moderate, High)

14. Which category is appropriate for your approximate household income last year?

______ Up to $14,999

______ $15,000 - $29,999

______ $30,000 - $49,000

______ $50,000 - $74,999

______ $75,000 - $99,999

______ $100,000 - $149,999

______ $150,000 - $199,999

______ $200,000+

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