
Theses, Dissertations, and Projects

2014

Exploring resources for caretakers of children with food allergies

Claudia A. Shapiro
Smith College

Follow this and additional works at: <https://scholarworks.smith.edu/theses>



Part of the [Social and Behavioral Sciences Commons](#)

Recommended Citation

Shapiro, Claudia A., "Exploring resources for caretakers of children with food allergies" (2014). Masters Thesis, Smith College, Northampton, MA.
<https://scholarworks.smith.edu/theses/824>

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact scholarworks@smith.edu.

Claudia Shapiro
Exploring Resources for
Caretakers of Children
with Food Allergies

ABSTRACT

This study explored the resources and supports caretakers of children with food allergies currently have available to them. In addition, resources that caretakers do not feel are currently available to them, but believe would be helpful, were examined. *Sample.* Convenience sample recruited online through Facebook and parent list-serves, and from fliers put up on several allergy clinics in the Boston area. *Methods.* Participants completed an online survey through www.surveymonkey.com where they identified food allergy related resources that they currently have available, in addition to those they would like to have. *Findings.* The small sample size (N=26) and the lack of diversity in participants' race, gender, and level of education, limits the generalizability of the findings. The results indicated that there are a number of resources that could easily be made available to caretakers of children with severe food allergies. Additionally, the majority of participants had never met with a social worker to provide resources and supports to cope with their child's food allergy.

Based on these findings, it is recommended that families raising children with severe food allergies should have the opportunity to meet with a social worker to receive resources, referrals, and support at diagnosis of the food allergy and at regular check-ins throughout the child's development.

**EXPLORING RESOURCES FOR CAREGIVERS OF CHILDREN WITH FOOD
ALLERGIES**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

Claudia Shapiro

Smith College School for Social Work
Northampton, MA 01063

2014

ACKNOWLEDGEMENTS

I would like to take the time to acknowledge several people without whom this project would not have been possible. First, I would like to thank Hannah Karpman, who provided hours of advice and support as my thesis advisor. Next, I wish to acknowledge Sherri Ettinger, who went out of her way to post a link to my study on several online list serves, and to connect me with Dr. Jordan Scott, who was willing to help recruit participants through his private allergy clinics. Thank you to all of my friends within the Smith community who sent a link to the survey to their friends with allergic children. Matthew Allen, as always thank you for your encouragement, and for the hours you spent listening to me discuss my thesis topic.

Finally, a giant thank you to my parents, not only for your unwavering support along this journey, but for successfully raising a child with food allergies, when the current literature, and most of the resources and supports mentioned in this study, were not yet available.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES	iv
CHAPTER	
I INTRODUCTION.....	1
II LITERATURE REVIEW.....	3
III METHODOLOGY	15
IV FINDINGS	19
V DISCUSSION.....	26
REFERENCES	32
APPENDICES	
Appendix A: Smith College HSR Approval Letter.....	34
Appendix B: Flier to Recruit Participants.....	35
Appendix C: Consent to Participate in a Research Study.....	36
Appendix D: Survey Questions.....	38

LIST OF TABLES

Table

1.	Demographic Characteristics of the Caregiver.....	20
2.	Demographic Characteristics of the Child	21
3.	Allergic History of the Child.....	22
4.	Epinephrine Administration	22
5.	Resources and Supports.....	23
6.	Additional Resources and Supports.....	24

CHAPTER I

Introduction

This study explores the resources available for caregivers of children with severe food allergies. While much of the literature demonstrates that children with food allergies and their parents experience anxiety and stress related to food allergies, there is a lack of support for what resources parents and their children use to alleviate that anxiety. As someone with a severe food allergy, growing up when allergies were less common, this is an issue that I felt needed to be further researched. It is possible to live a normal, healthy life while successfully managing food allergies, and the tools and resources to do so should be provided to families who are struggling with understanding and managing a child's allergy. It is important to understand what resources parents currently find helpful, and those that they wish they were available, so professionals, specifically social workers, can provide tools and supports to these families.

The methodology for this study was approved by the Smith College Human Subjects Review Committee (Appendix A). The sample of this study was a convenience sample of 26 caregivers of children with food allergies who were recruited through online parent list-serves, Facebook, and from several Allergy Clinics in the Boston area.

Participants completed an online survey that provided demographic information about themselves, as well as their children, and information about the resources and supports that they currently use to manage their child's allergy, and those that they would like to have access to.

The results of this study showed that while most of the caregivers felt they had reliable resources currently available, there were several areas that they felt more support would be beneficial. These areas included resources that educate the general public on the severity and management of food allergies, as well as reliable contacts that could be reached to answer specific questions. However, these results are not generalizable to the population at large due to the participants being mostly white, well-educated individuals living in urban or suburban areas.

Of note, only 1 participant had met with a social worker specifically regarding their child's food allergy. The findings suggest that a social worker, who met with families at diagnosis of a child's food allergy, as well as at regular check-ins throughout the child's development, could assess a family's understanding of and anxiety around the child's allergy, and provide psychoeducation, referrals, resources, and support. Future research could explore the anxiety levels and general understanding of parents before and after meeting with a social worker at a visit to address their child's food allergy, and further explore which resources are found to be most helpful.

CHAPTER 2

Literature Review

Impact on Parents

Previous literature has shown that having a food allergy significantly impacts a child's quality of life (Sicherer, Noone & Muñoz-Furlong, 2001; Brantlee Broome-Stone, 2012). The lives of a child's family members are also impacted by the child's food allergies. Because there is currently no cure for food allergies, preventing food-induced anaphylaxis and severe health consequences requires strict avoidance of allergens and management of allergic reactions (Food Allergy Research & Education, 2013). Managing food allergies from day-to-day is a great responsibility that is usually taken on by the child's primary caregiver. This constant management can be seen as a burden, and can put an emotional strain on the parent (Valentine & Knibb, 2011). Research shows that having a food allergic child has significant impact on both the quality of life and the psychological distress of parents (Cummings et al., 2010). As a result, mothers of children with food allergies have reported significantly higher anxiety levels than the normal population, due in part to "taking precautions on a daily basis, and the constant concerns about potential accidental ingestion" (Cummings et al., 2010, 593). Data has shown that in addition to affecting parental anxiety levels, food allergies significantly impact many aspects of a family's daily life (Bollinger et al., 2006; Rouf, White & Evans, 2011; Komulaien, 2010). The literature demonstrates that managing a child's food allergy has a significant impact on the lives

of caretakers in multiple domains, and suggests that more clinical interventions are needed to address these families' issues.

How Parents' Lives are Impacted by Child's Food Allergy

Emotionally. Raising a child with a severe food allergy invokes many emotions. Several studies indicate that parents of children with food allergies experience anxiety. LeBovidge et al., (2005) found that the majority of parents they interviewed think about their child's allergy daily, and more than half "frequently feel afraid about their child's safety because of allergies" (473). In a study by Komulaien (2010) close to one-fifth of participants reported "at least one extremely strong feeling of anxiety during the week in connection with the child's food allergy" (293). These feelings of anxiety and fear make sense within the context of food allergies and the constant efforts one must make to avoid allergens. Some anxiety is to be expected, and many believe it may be helpful in remaining vigilant to prevent reactions (Klennert & Robinson, 2008; LeBovidge, 2005). However, parents must also be able to manage a balance of understanding the severity of their child's allergy while managing this anxiety to avoid experiencing a "dysfunctional level of stress and fear" (Klennert & Robinson, 2008, 197).

Other emotions that have been reported by parents of children with food allergies were sadness, anger, and guilt. Following diagnosis, parents reported feelings of trauma, grief, paranoia, depression, and even anger towards the allergic child (Gupta et al., 2008; Rouf et al., 2011). The literature also shows that guilt is a common response to learning a child has a life-threatening food allergy (Gupta et al., 2008). This is particularly true of mothers who have had to stop breastfeeding sooner than they would have liked because their child had reactions as a result of food eaten by the mother (Alanne et al., 2011). The emotional impact of caring for a child

with a severe food allergy takes a toll on many parents, and families could benefit from interventions that address the feelings they associate with managing food allergies.

Social. One of the domains of parent and family life affected by a child's food allergy that is prevalent throughout the literature is the social domain. Studies show that parents have reported that food allergies significantly affect family social activities, and that parents themselves have poorer social relationships as a result of their child's allergies (Bollinger et al., 2006; Gupta et al., 2008; Valentine & Knibb, 2011). The anxiety that many parents experience related to their child's allergy limits the social gatherings they attend, and affects their ability to trust others to care for the child in their absence. This impacts the parents' engagement in social activities with and without their children.

Family Activities. Social activities that involve the entire family are affected by a child's food allergy. Parents have reported that leaving home with their food allergic child is difficult because of the preparation time required (Cohen, Noone, Muñoz-Furlong & Sicherer, 2004). In one study, nearly one-fifth of parents reported that "holiday and vacation plans have been restricted because of the child's food allergy" (Komulaien, 2010, 293). Caretakers of children with food allergies have also reported anxiety and fear around eating out at restaurants, in addition to feeling left out from social events (Valentine & Knibb, 2011). Parents have reported that they avoid eating in restaurants because of their children's food allergies, and that when they did eat in restaurants they felt their choices were limited (Bollinger et al., 2006; Komulaien, 2010). Concerns about maintaining an allergic child's safety in social situations impacts the frequency that families participate in activities together.

Concerns about Childcare. Parents' social activities without their children are also affected by the child's allergies. Literature has found that parents have difficulty entrusting the

care of their child to others (Gupta et al., 2008; Rouf et al., 2011; Alanne et al., 2011). In some studies, mothers have reported that their children's food allergies caused them to stop working outside of the home choosing instead to be homemakers, making them more available to their child (Gupta et al., 2008; Mandell et al., 2002). Negotiating trust with others was seen as both difficult and necessary to leaving an allergic child in the care of others. Rouf et al., (2011) found that trust was based on others "having an appropriate perception of risk, parents perceiving them as competent, experience of allergy, and taking the allergy seriously but not becoming overwhelmed by it" (56). It is difficult for parents to rely on others to look after their children and prevent allergic reactions in the ways they themselves do (Alanne et al., 2011). Even when parents do trust someone else to care for their allergic child, the amount of preparation required to leave their child in the care of others caused additional burden to these families (Komulainen, 2010). Additionally, research has found that trust "was extremely difficult to re-establish once it had been broken due to others unintentionally putting the child at risk" (Rouf et al., 2011, 56). When mistakes in caring for a child's allergy were made by close family members, parents reported a bigger impact, and more difficulty establishing trust in others (Rouf et al., 2011). As a result, parents may choose to stay home with their child rather than risk leaving a child in the care of others, thus limiting their own social life.

Concerns about Child Growing Up "Normally". Due to the difficulties establishing and maintaining trust for others to care for allergic children, parents also worry about sending their children to social activities that are developmentally appropriate. Parents have reported that the process of "letting go and handing over responsibility for their child's care to others was difficult as it meant losing some control, creating feelings of anxiety and vulnerability" (Rouf et al., 2011,

55). Again, some anxiety is protective; however, when anxiety becomes disproportionate can lead to unnecessary restrictions on the social activities of all family members (Rouf et al., 2011).

This separation anxiety becomes problematic when children reach the age at which they are expected to attend school and other social activities, and they begin to navigate relationships with peers in addition to those within their family (Davies, 2011). Sending their allergic child to school is a source of anxiety for parents because it is not guaranteed that teachers and other school personnel understand the severity of the allergy. Bollinger et al., (2006) found that 10% of the caregivers that participated in their study reported that they do not send their child to school because of their food allergy (417). In fact, research shows that the majority of allergic reactions occur outside of the home and are unpredictable (Pumphrey, 2004). Therefore, some level of parental anxiety may be protective; however, when children are isolated from social activities as because of their allergy, their parents' anxiety and overprotection becomes problematic.

Parents have also reported concern about allowing their allergic child to participate in social activities with other children including, but not limited to, playing at friends' houses, daycare or aftercare, parties, sports, camp, sleepovers, and field trips (Bollinger et al., 2006; Cummings et al., 2010; Komulaien, 2010). The anxiety and perceived risk of allowing their child to attend social activities is so high, that many parents have reported avoiding or preventing their child from attending, (Bollinger et al., 2006; Cummings et al., 2010). Parents may feel that have to choose between worrying about their child's safety at school and allowing their child to gain independence and autonomy, develop their own relationships with peers, which could add another level of anxiety and concern to the situation.

Literature shows that while parents limit their child's social activities, they also worry about their child having a normal childhood. Parents have reported the challenge of protecting

their children from allergic reactions, while also maintaining, “an inclusive, ‘normal’ life and not being defined or excluded by the allergy” (Rouf et al., 2011, 60). This is a difficult balance to strike, and often times parents express concern about the impact that increased protectiveness has on a child’s development (Cummings et al., 2010). Parents accompanying allergic children to social events, such as birthday parties, past the age that it is normal to do so, worry about how they are affecting their child’s social development, including autonomy and control (Mandell et al., 2002).

Parents also worry about how their child’s allergy may be stigmatized, and affect their social relationships. Research has shown that parents are “reluctant to let their child be defined by their allergy” and help their child to develop a positive self-concept (Rouf et al., 2011). Nevertheless, parents have reported concerns that their child will be “ostracized” at lunchtime and targeted by bullies (Rouf et al., 2011; Valentine & Knibb, 2011). Studies suggest that parents of allergic children make an effort to normalize their child’s condition and to minimize potential differences between the child and their non-allergic peers (Rouf et al., 2011). Despite these concerns that many parents have about their children having a normal social development, parents in a study by Komulaien (2010) report that they believe their children had a normal childhood, despite having a food allergy.

Food. Research has shown that the lives of parents of food allergic children are also impacted by concerns around food. Grocery shopping was reported to be a frustrating and overall negative experience for parents, who felt they had to make extra shopping trips or go to multiple supermarkets to provide food for their family (Valentine & Knibb, 2011). Grocery shopping was also difficult because of cross-contamination concerns, including the risk of trace contaminants, and food labeling issues such as mislabeling and inconsistent labeling (Mandell, et al., 2002).

Because of these concerns, and the fact that ingredient lists on products regularly change to include potential allergens, a basic errand such as grocery shopping becomes both time consuming and frustrating.

Meal preparation was also reported to be affected by a child's food allergy, especially in regards to the time spent preparing allergen-free meals (Bollinger et al., 2006; Cohen et al., 2004). Many parents reported that the extra time required to prepare meals made them feel troubled within the past week (Komulaien, 2010). A study by Crowley, Williams, and Brown (2012) found that not only does the preparation time concern parents of children with food allergies, but mothers of children with restricted diets have reported challenges in preparing a meal the entire family enjoys while complying with one child's food restrictions. It was reported in this study that pleasing "both their child and their entire family with food was of strong importance to these mothers...At the same time as seeking to please one child, the mothers experienced pressure to continue to please other family members" (Crowley et al., 2012, 274).

A restricted diet also led parents to worry about their child's nutrition and health, and to feel burdened by these concerns (Komulaien, 2010). Ensuring that their child has a balanced diet is difficult when parents feel restricted by the choices available. Parents have reported that they have a hard time introducing new foods into their children's diets, which "aroused the hope of finding them suitable and if they, too, caused symptoms and had to be avoided the disappointment was enormous" (Alanne et al., 2011). Feeding an allergic child becomes difficult for caregivers who feel pressure to provide proper nutrition to their child while avoiding allergens, and not feeling burdened if new foods do not work out.

Ability to Educate Others. Another aspect of having a child with a severe food allergy that greatly impacts the family's quality of life is the lack of education and understanding around

food allergies in the general public. Parents have reported for feeling responsible for educating others on their child's food allergy, particularly extended family, school personnel, friends, and other parents who may be caring for their child (Rouf et al., 2011). Parents have also reported frustration around "constantly having to explain about the allergy to other people" (Alanne et al., 2011).

Partner/Co-Parent. Studies have reported that parents of children with food allergies experience marital distress as a result of differences in the perceived impact and appropriate management of their child's allergy (Gutpa et al., 2008; King, Knibb & Hourihane, 2008). Parents differed in their understanding of the measures required to protect the child with mothers tending to shelter their children more than fathers (Gupta et al., 2008). King et al. (2008) found that mothers reported trait anxiety and perceived stress levels that were significantly higher than the reported norm mean values, while fathers' scores were equal to or lower than norm mean values. These differences can lead to marital tension, and tension within the entire family system, which is supported by findings that divorce rates are higher in parents of children with chronic illnesses than healthy children (King et al., 2008). Mandell et al. (2002) found that mothers reported being responsible for the day-to-day management of children's allergies while fathers took on more of a "helping" role, rather than sharing the responsibility. This could also explain why fathers have been found to have less information and be less vigilant in preventing allergic reactions than mothers (Mandell et al., 2002). Despite the risk that having a child with a severe food allergy can negatively impact a marriage, co-parents have reported in several studies that they are in agreement about the severity of the child's allergy, how to manage their child's allergy, and that the allergy has not caused strain on the relationship (Goosens et al., 2013;

LeBovidge, et al., 2005). The literature demonstrates that it is crucial for co-parents to share an understanding of the severity of their child's allergy and how to manage it most effectively.

General Public. One of the factors that nearly every study has found to impact parents of children with severe food allergies is the lack of understanding by the general public (Alanne et al., 2011; Gupta et al., 2008; Le Bovidge et al., 2006; Mandell et al., 2002; Masia, Mullen & Scotti, 1998; Rouf et al., 2011). The general public has many misconceptions about food allergies, which leads parents to feel responsible for educating others about their child's allergy (Gupta et al., 2008; Rouf et al., 2011). This is particularly true for school personnel, friends, extended family, and other people who care for the child, and parents have expressed concern that other individuals do not understand the severity of the allergy or are unwilling to make accommodations to keep the child safe (Goosens et al., 2013; LeBovidge et al., 2005). The lack of understanding also contributes to stigmatizations, and parents have expressed discomfort and feelings of being judged when explaining their child's food allergy (Gupta et al., 2008; Masia et al., 1998; Rouf et al., 2011). This lack of understanding by the general public, and the perception that parents are being excessively cautious about their child's allergy, contributes to the difficulty these families have in attending social events and leaving children in the care of others.

Clinical Implications

Overview. Although there is a great deal of literature that demonstrates the negative impact caring for a child with severe food allergies has on parents, the research is limited on how to address this issue clinically. The majority of the clinical interventions suggested in the literature are based on addressing the specific stressors, rather than empirical evidence that shows which interventions are most appropriate.

Education. Many studies have proposed more opportunities and tools to educate parents, children, and the general public about the food allergy and how to manage it. Research suggests that parents receive information from a physician in addition to written recommendations for managing the allergy at diagnosis, as well as at predictable milestones such as when children begin school and enter adolescence (Hu et al., 2007; Klinnert & Robinson, 2008; Mandell et al., 2002). Parents should also be provided with tools to educate the child at different ages, such as books or developmentally appropriate videos (Hu et al., 2007). By providing both the parents and children with reliable information they are more likely to understand the allergy and manage appropriately, as well as effectively educate others.

Support Groups. Studies have shown that parents of children with food allergies could benefit from having more support and settings where they are able to discuss and process the impact their children's allergies have on family life (Crowley et al., 2012; Komulaien, 2010; LeBovidge et al., 2008; Mandell et al., 2002; Rouf et al., 2011). LeBovidge et al. (2008) studied the effects of a half-day workshop that included both parent and children support groups. While the allergic children played, parents were given a presentation by a pediatric psychologist and then had a group discussion. The majority of parents, and children, rated the program favorably, and especially valued the opportunity to network with other families who live with food allergies. Research has also suggested that parents join a patient organization, such as an anaphylaxis or food allergy organization, to receive reliable information in addition to support (Goosens et al., 2013; Mandell et al., 2002; Rouf et al., 2011). By joining groups for parents of children with food allergies, parents have more access to both educational resources and social supports, providing a place to share coping skills as well as process negative emotions.

Referrals. Studies have also recommended that parents of children with food allergies be referred to outpatient providers to address the issues around their children's allergies. Although Hu et al. (2007) reported that a minority of newly diagnosed families had been referred to a dietician; a dietician could help families to identify foods the allergic child could safely eat, and provide suggestions for maintaining a healthy and balanced diet (Mandell et al., 2002). Parents have also reportedly found nurse-led information sessions valuable for receiving consistent and reliable information (Hu et al., 2007). These professionals could also provide families with resources that research has found to be helpful to families, including shopping guides to assist with following an allergen-free diet, and trustworthy websites to receive more information (Crowley et al., 2012; Hu et al., 2007). Families may not be aware of the assistance that dieticians and nurses could provide, or may not know how to find a reliable professional, so it would be beneficial if they received referrals from a physician or social worker.

Research has also suggested that families be referred to mental health services, such as social workers or psychologists, to address the psychological affects of caring for a child with a severe food allergy (Alanne et al., 2011; Cummings et al., 2010; King et al., 2008; Klinnert & Robinson, 2008; Mandell et al., 2002; Masia et al., 1998; Rouf et al., 2011) The literature suggests that both individual therapy and couples therapy for co-parents could be helpful in coping with a child's allergy (Alanne et al., 2011; Klinnert & Robinson, 2008; Mandell et al., 2002). The majority of studies recommend integrated family based approaches to address the psychological impact the child's allergy has on the entire family system (King et al., 2008; Klinnert & Robinson, 2008; Mandell et al., 2002; Rouf et al., 2011). Therapy can assist families in developing coping strategies, learning behavioral strategies such as cognitive restructuring or distraction to alleviate anxiety, developing a safety plan, and engaging in role-play scenarios, in

addition to processing the emotions associated with the allergy (LeBovidge et al., 2008; Masia et al., 1998; Rouf et al., 2011). Regardless of whether the therapy is individual, couple, or family based, psychological services are believed to be helpful for families coping with a child's allergy.

Limitations. Though the literature provides a great deal of information regarding the affects of caring for a child with a food allergy, there are limitations. Much of the research has been published in other countries including Australia, (Crowley et al., 2012; Hu et al., 2007) Finland, (Alanne et al., 2011; Komulainen, 2010) the Netherlands, (Goosens et al., 2013) and the United Kingdom, (Cummings et al., 2010; Cummings et al., 2010; Rouf et al., 2011; Valentine & Knibb, 2011). The findings from these studies may not be generalizable to populations in the United States. The majority of research studies recruited participants from allergy clinics and food allergy support organizations, so these participants may not experience the same stressors as parents who are not members of such organizations. Lastly, the participants in the majority of these studies were mostly mothers with high levels of education and high socioeconomic statuses. Therefore, it is important to recognize that the results from the literature may not reflect the views of mothers, fathers, and other primary caregivers who have lower levels of education and/or socioeconomic status. While the literature does provide a number of clinical implications based on the identified stressors that result from raising a child with a severe food allergy, there is limited research on the interventions and resources that these parents have access to, have used in the past or are currently using, and which are found to be the most helpful.

CHAPTER 3

Methodology

Formulation

Previous studies show that having a child with a food allergy significantly affects the quality of life of parents. Research suggests that being responsible for the day-to-day management of a child's allergy leads to emotional strain (Valentine & Knibb, 2011). Data shows that almost all aspects of a family's daily life are affected when caring for a food allergic child, from preparing meals to attending social gatherings (Bollinger et al., 2006). While the literature has outlined the challenges for these families, it has not surveyed the current available and/or needed resources to see if existing services are designed to meet these challenges. This study is an experimental investigation into the resources that are already available for the families of children with food allergies and what additional resources families would find useful. The purpose of the study is to gain a better understanding of the resources that are already available for the families of children with food allergies, as well as identify other ways that social workers can support these families. The researcher expects to find that while parents currently have a number of supports in place, they are eager for more resources. It is also expected that these families infrequently consult with professionals, including social workers, who could provide support and access to various resources to cope with a child's food allergy.

Subjects. This study will have at least 50 participants who identify as caregivers of a child with a food allergy. The allergic child will be between four to twelve years old. This age range was decided because children will be old enough to attend daycare or school, and parents will be managing their feelings on having other adults (teachers, school nurse, etc.) managing their child's allergy during the day. At the same time, children who are 12 years and younger will still be relying heavily on their parents' supervision and management of their allergy, unlike adolescents who have more autonomy. Participants will be at least 18 years old, and identify as any race or gender. No vulnerable populations will be included in this study, so participants will not be under 18 years of age, currently pregnant, currently incarcerated, educationally and/or economically disadvantaged, or have a physical and/or mental disability. For feasibility, selection will not be randomized, but rather it will be a convenience sample. Participants will be recruited from two online list-serves for mothers in the Boston area, "Garden Moms" and "Newton Mamas", both on www.bigtent.com. Members of these list-serves will be able to read the recruitment letter, and if they meet eligibility requirements and are interested in participating, will be able to follow a link to the online survey site. To increase generalizability to include more participants than mothers who are members of the list-serves, a recruitment letter and link to the study will also be posted on Facebook. A flyer was also created and posted in several allergy clinics in the Boston area.

Data Collection. Participant's responses will be collected using an online survey through www.surveymonkey.com. Questions regarding participants' demographic such as age, racial identification, level of education, and relationship to child will be asked. Next, participants will be asked to provide more information about the food allergic child, including age, the type of school or daycare they attend, and their strengths. Participants then will be asked to provide

information about resources they have available to them to assist in caring for an allergic child, and whether they have used any of these resources. Finally, caretakers will be asked to endorse what they would find most beneficial in assisting their care of the allergic child. Anonymity is optional in surveys through Survey Monkey therefore this option will be chosen to assure anonymity.

All research materials including recordings, transcriptions, analyses and consent/assent documents will be stored in a secure location for three years according to federal regulations. In the event that materials are needed beyond this period, they will be kept secured until no longer needed, and then destroyed. All electronically stored data will be password protected during the storage period.

There are no expected risks for participants; however, there is a chance that participants may experience emotional discomfort or distress as a result of answering survey questions. In order to protect participants from feeling uncomfortable or distressed, participants will be notified at the beginning of the survey that they might feel uncomfortable answering some of the questions and that their participation is completely voluntary. This will also include information that they have the right to skip any question on the survey. Following the survey, participants will be encouraged to contact the researcher with any questions or concerns they have regarding the survey. Additionally, participants will be encouraged to contact their local crisis center or therapist if they have any lingering discomfort or distress. Contact information for local support services will be provided following the survey.

Data Analysis. The data will be analyzed using statistical software. Potential differences among demographics will be explored using simple comparisons between means, medians, and modes. The resources and supports that parents believe would be most helpful will be compared

with those they believe are currently available to better understand what can be done to support parents of children with food allergies. In addition, the resources that parents would find helpful but do not currently feel are available to them will be explored. This information will allow social workers to identify ways to increase awareness about helpful resources that do exist in the community, in addition to exploring resources that could be created for these families.

CHAPTER 4

Findings

The purpose of this study was to gain a better understanding of the supports that caregivers of children with food allergies currently have available, and what they believe would be helpful. This chapter includes a description of the results of the survey including demographic information about the participants, demographic information about participants' allergic children, the allergic histories of children, and information on the resources and supports that families have and would find helpful to cope with their child's allergy.

The online survey was completed by 26 individuals who met inclusion criteria and were recruited through Facebook and online list-serves. Participants ranged in age from 33 to 60, with a mean of 39.69 and a median of 38. The sample contained individuals living in 11 different states (including Canada), with the majority of participants living in Massachusetts (n=11).

Table 1
Demographic Characteristics of the Caregiver (N=26)

	Frequency	Percent
Race/Ethnicity		
White/Caucasian	23	88.46
“Mixed”	1	3.85
No Response	2	7.69
Level of Education		
High School	2	7.69
Undergraduate	12	46.15
Graduate	10	38.46
PhD	2	7.69
Type of Area Living In		
Urban	16	61.54
Rural	3	11.54
Suburban	3	11.54
No Response	4	15.38
Relationship to Child		
Mother	24	92.30
Father	1	3.85
Grandparent	1	3.85

The majority of participants identified as white/Caucasian (n=23), reported having at least an undergraduate degree (n=24) and was the mother of an allergic child (n=24). One participant was the father of an allergic child, and one was the grandparent. The grandparent was the only participant who did not identify as the primary caregiver for the allergic child.

Table 2
Demographic Characteristics of the Child (N=26)

	Frequency	Percent
Age in Years		
4	4	15.38
5	4	15.38
6	2	7.69
7	2	7.69
8	3	11.54
9	1	3.85
10	2	7.69
11	1	3.85
12	7	26.92
School/Daycare		
Private	12	53.85%
Public	14	46.15%
Number of Siblings		
0	2	7.69
1	17	65.38
2	3	11.54
3	4	15.38

The allergic children of participants ranged in age from 4 to 12 years, with a mean of 8.08 and a median of 8. All of the children currently attend school or daycare, with 53.85% attending public school/daycare and 46.15% attending private. The majority of allergic children also had at least one sibling (n=24).

Allergic History. Caregivers responded to several questions regarding the history of their child's food allergy. The age that children were diagnosed with a food allergy ranged from 4 months of age to 11 years with a mean of 3.33 years and a median of 1.75 years. The majority of children were taken to an allergist to confirm their food allergy (n=24). All of the children whose food allergies were confirmed by an allergist were prescribed epinephrine to manage their allergy in the event of anaphylaxis.

Table 3
Allergic History of Child (N = 26)

	Frequency	Percent
Age of Diagnosis		
Less than 1 Year	3	11.54
1 Year	1	3.85
15 months	5	19.23
16 months	1	3.85
18 months	3	11.54
2 Years	4	15.38
3 Years	3	11.54
5 Years	1	3.85
7 Years	1	3.85
10 Years	1	3.85
11 Years	3	11.54
Confirmed by Allergist		
Yes	24	92.31
No	2	7.69
Prescribed Epinephrine		
Yes	24	92.31
No	2	7.69

Participants whose allergic child was prescribed epinephrine to manage allergic reactions also provided information on who knows how to administer the medication in the event of an allergic reaction.

Table 4
Epinephrine Administration

	Frequency	Percentage
Who knows how to administer epinephrine?		
Myself	23	95.83
My Child	11	45.83
Household Members	24	100
Extended Family	17	70.83
Additional Caretakers	15	62.50
Teacher	21	87.50
Parents of Child's Friends	12	50
Child's Friends	2	8.33

Other responses included the nurse at the child's school (n=2) and the office staff at the child's school (n=1).

Resources and Supports. Participants provided information about the resources and supports that they have access to for their child's food allergy.

Table 5
Resources and Supports (N=26)

	Frequency	Percent
What resources have you and/or your family used in the past to learn about food allergies?		
Pamphlets	14	53.85
Videos	8	30.77
Books	16	61.54
Internet	25	96.15
Advice from Physicians	25	96.15
Advice from Friends	21	80.77
What kinds of supports have you and/or your family used surrounding your child's food allergies?		
Local Support Groups	6	37.50
Online Support Groups	14	87.50
Are you aware of local support groups for parents of children with food allergies?		
Yes	11	42.31
No	15	57.69
What professionals have you and/or your family seen as a result of your child's food allergies?		
Allergist	24	92.31
Pediatrician	25	96.15
Dietician	8	30.77
Nurse	6	23.08
Social Worker	1	3.85
Therapist	3	11.54

Almost all of the participants reported that they have used the internet and advice from Physicians to learn about food allergies (n=25). A number of participants also used local support groups (n=6) and online support groups (n=14) to cope with their child's food allergy.

Participants also reported receiving support from national support groups, blogs, and friends. The majority of participants were aware of local support groups for parents of allergic children

(n=15). Of the participants who use support groups (n=6), over 80% are active in online support groups, while only a third of participants reported attending support groups in person. Half of the participants who attend support groups find it helpful for sharing recipes, advice, and support. Of the participants who do not attend support groups, (n=20) 20% reported that they did not feel a support group was necessary for them, 25% reported they were not aware of support groups, and 10% reported that they were not any support groups in their area. Other participants reported that they did not attend support groups because it could "fuel paranoia" (n=1), that their child has "too many allergies" (n=1) and that they "don't like groups" (n=1).

While the majority of participants saw an allergist (n=24) and/or pediatrician (n=25) as a result of their child's food allergies, much fewer participants saw other professionals, such as a dietician (n=8), nurse (n=6), social worker (n=1) or therapist (n=3).

Table 6
Additional Resources and Supports (N=26)

	Currently Have Available		Would Find Helpful	
	Frequency	Percent	Frequency	Percent
Practical tips for keeping a safe home	18	69.23	11	42.31
Practicing Epi-pen	19	73.08	9	34.62
Food brands that are safe	23	88.46	13	50
Coupons for safe food	4	15.38	20	76.92
"Chef Cards" for Restaurants	3	11.54	20	76.92
Educational information for schools	14	53.85	12	46.15
Educational information for extended family	11	42.31	11	42.31
Educational information for other parents	8	30.77	13	50
Educational information for other caretakers	7	26.92	13	50
Educational information for child at different ages	7	26.92	13	50
Books	13	50	8	30.77
Videos	6	23.08	7	26.92
Support groups in the area	7	26.92	9	34.62
Contact info of other parents with allergic children	16	61.54	8	30.77
Dieticians in the area	5	19.23	10	38.46
Blogs for parents of allergic children	15	57.69	7	26.92
Reliable websites	19	73.08	11	42.31
Allergy Hotline to answer questions 24/7	2	7.69	16	61.54
Nurse-led information sessions	0	0	7	26.92

The resources and supports that are most frequently accessed by caregivers of children with food allergies are food brands that are safe (n=23), practicing epi-pen (n=19), reliable websites (n=19) and practical tips for keeping a safe home (n=18). The resources and supports that caregivers reported they would find most helpful were coupons for safe food (n=20), "chef cards" for restaurants (n=20) and an allergy hotline to answer questions 24/7 (n=16).

Participants also suggested additional resources that would be helpful (n=11). These suggestions included better tools for educating the general public (n=3), with one participant suggesting a public service announcement. Participants also recommended better education for teachers, students, parents, and school personnel to avoid reactions (n=3), and one participant recommended a daycare that is specifically for children with food allergies. Another suggestion was for more awareness from restaurants (n=2), and one participant suggested there be allergy information on all restaurant websites. Legislation around food allergies was suggested (n=3) to provide clearer and more accurate information on foods containing allergens in both restaurants and on food labels, as well as mandates for public schools to have education on the issue. Lastly, one participant suggested advice on managing anxiety for adolescents with food allergies and tips on teaching skills to allergic children at different stages of development.

CHAPTER 5

Discussion

The literature demonstrates that both children with food allergies and their parents experience stress and a lower quality of life as a result of managing a food allergy. However, there are very few studies that currently explore the resources and supports that these families currently have access to and those they would like to have available. There is also limited research on the professionals families see to assist with managing a food allergy. The responses collected for this study provide a better sense of what some parents of children with food allergies currently find helpful, as well as resources that they would like to have in the future.

Resources and Supports to Manage Allergy. While the majority of parents who responded to the survey identified having access to food brands that are safe, reliable websites, and practical tips for keeping a safe home, the other resources listed did not seem to be as readily available. When comparing the resources that parents identified as currently having available with those that they would find helpful, a number of the resources stood out.

Food. While only 15.35% of participants (n=4) reported that they had coupons for safe food available, 76.92% (n=20) reported that they would find this helpful. Similarly, only 11.54% (n=3) of parents reported they have access to "chef cards" for restaurants (cards to be provided to chefs at restaurants that clearly indicate what a child is allergic to) 76.92% (n=20) reported they would find this helpful. These resources are not difficult for parents to have and use; however,

for some reason, despite the help they would provide these families, parents do not currently feel they are available to them.

It is somewhat surprising, given the high levels of education, that most of the parents surveyed do not currently have access to coupons for safe foods and chef cards, since these can be found on the Internet. It is possible that these are resources that they had not thought to seek out, or that they do not know where to look. These types of resources that specifically make feeding a food allergic child less stressful, both at home and in restaurants, need to be identified and available to families raising a child with a food allergy. A social worker that practices in an allergy or pediatric clinic could provide these types of concrete tools to families who are raising a child with food allergies.

Educational Information. Resources to educate the general public about food allergies and the management of allergies were identified both by the literature (Gupta et al., 2008) and participants as something that would be helpful for this population. While over 50% (n=14) of participants reported that they have educational information for schools available to them currently, the remaining participants (n=12) all reported that they would find this helpful. Additionally, 42.31% (n=11) of participants reported they currently have resources to educate extended family on their child's food allergy, and 42.31% (n=11) reported they would find this helpful. Less than one third of participants had educational information for other parents, educational information for other caretakers, and educational information for their child at different ages currently available to them; however, 50% (n=13) of parents reported that they would find these resources helpful. These findings are consistent with the literature, which reports that the general public has many misconceptions about food allergies, and that this makes it difficult for parents to trust others to care for their child in their absence. Similar to resources

that make shopping and dining out easier for parents of food allergic children, these types of educational resources are available and could make huge differences in the management of a food allergy.

Professional Resources and Supports. None of the caretakers who participated in the study reported having nurse-led information sessions available; however, over a quarter (n=7) reported that this was something they would find helpful. This type of session would allow parents to have their questions answered by a professional, and would provide an opportunity to meet other families who are also managing a child's food allergy. Similarly, only 19.23% (n=5) of participants reported they had dieticians in the area available to them, while 38.46% (n=10) reported they would find this helpful. This would be helpful for parents who are struggling to find safe, healthy foods that their child is willing to eat, as well as basic psychoeducation about having a balanced diet. Only 7.69% (n=2) of participants reported they have access to an allergy hotline to answer questions 24/7, but 61.54% (n=16) reported they would find this helpful. There seem to be at least two national hotlines (Asthma and Allergy Foundation of America and Food Allergy and Anaphylaxis Network) that are open from 9:00 a.m. – 5:00 p.m. (EST) Monday through Friday. This is important information to provide to families living with food allergies, and the development of a 24/7 hotline to answer allergy related questions would further assist families struggling with managing a child's food allergies.

It is possible that, like chef cards and coupons for safe foods, parents have not thought to find a hotline to address allergies, but once the idea was introduced, they felt it would be helpful to answer specific questions, and as a result alleviate some anxiety. A social worker who meets with families with food allergic children would be able to gather various types of resources, including national hotlines, organizations, websites, and books, to provide to these parents so

they are aware of what is available to them. Helping families to become aware of the resources and supports that are available, and identifying which would be best for each specific family to use, is something that a social worker could do to.

Limitations. While the survey provided important information about the resources and supports that families dealing with a child's food allergy currently, and would like to, have access to, there are some limitations to the generalizability of this study. The survey was online, and participants were mainly recruited through online list-serves and Facebook, so all of the participants required internet access to participate. Although the sample included a wide range of ages and residents of 10 states plus Canada, there was otherwise not very much diversity. Of the 26 participants, 23 identified as White or Caucasian, 1 identified as "mixed" and 2 did not report their racial identity. The sample was also highly educated, with the majority of participants (n=24) having at least an undergraduate degree, and 46.15% (n=12) with a graduate degree or higher. The participants' high level of education suggests a higher socioeconomic status (SES). Both a higher level of education and SES will likely increase the number of supports and resources that these families have access to; therefore these results are not generalizable to the general population. These demographics are consistent with limitations from the literature. The majority of participants also currently live in either urban or suburban environments (n=19), which would provide access to more resources and supports than families who are living in rural environments. Finally, consistent with most of the current literature, the majority of participants (n=24) were mothers. This could affect the responses collected, because it is possible that fathers, or other caregivers, would report having different resources available and helpful.

Implications for Social Work. The findings from this study imply that families of children with food allergies could strongly benefit from working with a social worker. When a

child is first diagnosed with a food allergy, a social worker would be able to assess the parents' levels of anxiety, understanding of the severity, and knowledge of how to manage the allergy. Psychoeducation could be provided to educate parents on how to manage the child's allergy and keep the household safe. The social worker could also provide various resources for the family, including reliable websites and blogs, national organizations, support groups that are local and online, and other concrete tools such as books and videos. Tools to educate others about the child's allergy, including but not limited to extended family and other caretakers, could also be provided. Any referrals that the family required at that time, such as individual and/or family therapy, and a dietician, could be provided.

The social worker could be contacted when families had questions or concerns, or needed additional resources between appointments. They could then meet again with the social worker at major milestones, to be provided educational information for schools as the child reaches school age, information to educate other parents, and educational resources for the child (and her peers) at different stages of her development. The parents' anxiety would be reassessed at developmental milestones, and referrals made as needed. As the child gets older, they may benefit from individual therapy, support groups, and/or family therapy. Additionally, siblings may benefit from therapy to discuss their feelings about living with a food allergic sibling. A social worker could also provide families with new literature and evidence-based studies that they may not have access to on their own.

Future Research. The field needs to continue this sort of research with larger, and more diverse, populations. Similar studies could be conducted recruiting participants from schools within communities with lower SES, less educated parents, and more rural environments. It will be important to gain a better understanding of what resources are available to families with less

privilege. Additionally, studies that can examine what resources are actually available in a community, rather than just what parents perceive to be available, would be helpful in identifying which resources are being used, and what can be created.

It would also be interesting to have a study with a social worker within an allergist and/or pediatric office working with families whose children are diagnosed with food allergies. A pre and post-test could be administered, assessing the parents' knowledge of food allergies, anxiety, and resources/supports before and after meeting with a social worker. This could be a longitudinal design, tracking the same families at different appointments, to get a sense of the resources and supports that are being used, and the parents' knowledge and anxiety. A study of this kind could determine whether a social worker working with families of a child with food allergies is helpful, and what domains they are the most valuable.

References

- Alanne, S., Laitinen, K., Söderlund, R., & Pavilainen, E. (2011). Mothers' perceptions of factors affecting their abilities to care for infants with allergy. *Journal of Clinical Nursing, 21*, 170-179.
- Bollinger, M. E., Dahlquist, L. M., Mudd, K., Sonntag, C., Dillinger, L., & McKenna, K. (2006). The impact of food allergy on the daily activities of children and their families. *Annals of Allergy, Asthma, & Immunology, 96*, 415-421.
- Brantlee Broome-Stone, S. (2012). The Psychosocial Impact of Life-Threatening Childhood Food Allergies. *Pediatric Nursing, 38* (6). 326-330.
- Cohen, B. L., Noone, S., Muñoz-Furlong, A., & Sicherer, S. H. (2004). Development of a questionnaire to measure quality of life in families with a child with food allergy. *Journal of Allergy and Clinical Immunology, 115*(9), 1159-1163.
- Crowley, E. T., Williams, L. T., & Brown, L. J. (2012). How do mothers juggle the special dietary needs of one child while feeding the family? A qualitative exploration. *Nutrition & Dietetics, 69*, 272-277.
- Cummings, A. J., Knibb, R. C., Erlewyn-Lajeunesse, M., King, R. M., Roberts, G., & Lucas, J. S. A. (2010). Management of nut allergy influences quality of life and anxiety in children and their mothers. *Pediatric Allergy and Immunology, 21*, 586-594.
- Cummings, A. J., Knibb, R. C., King, R. M., & Lucas, J. S. (2010). The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: a review. *Allergy, 65*, 933-945.
- Davies, D. (2011). *Child Development; A Practitioner's Guide* (3rd ed.). New York, NY: The Guilford Press.
- Food Allergy Research & Education. (2013). Facts and Statistics. In *Tools and Resources*. Retrieved from <http://www.foodallergy.org/facts-and-stats?>
- Goossens, N. J., Flokstra-de Blok, B. M. J., van der Meulen, G. N., Botjes, E., Burgerhof, H. G. M., Gupta, R. S., Springston, E. E., Smith, B., Duiverman, E. J., & Dubois, A. E. J. (2013). Food allergy knowledge of parents – is ignorance bliss? *Pediatric Allergy and Immunology, 24*, 567-573.

- Gupta, R. S., Kim, J. S., Barnathan, J. A., Amsden, L. B., Tummala, L. S., & Holl, J. L. (2008). Food allergy knowledge, attitudes and beliefs: Focus groups of parents, physicians and the general public. *BMC Pediatrics*, 8 (36).
- Hu, W., Grbich, C., & Kemp, A. (2007). Parental food allergy information needs: a qualitative study. *Archives of Disease in Childhood*, 92, 771-775.
- King, R. M., Knibb, R. C., & Hourihane, J. O'B. (2008). Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy*, 64, 461-468.
- Klennert, M. D., & Robinson, J. L. (2008). Addressing the Psychological Needs of Families of Food-Allergic Children. *Current Allergy and Asthma Reports*, 8, 195-200.
- Komulainen, K. (2010). Parental Burden in Families with a Young Food-allergic Child. *Child Care in Practice*, 16 (3), 287-302.
- LeBovidge, J. S., Stone, K. D., Twarog, F. J., Raiselis, S. W., Kalish, L. A., Bailey, E. P. & Schneider, L. C. (2005). Development of a preliminary questionnaire to assess parental response to children's food allergies. *Annals of Allergy, Asthma & Immunology*, 96, 472-477.
- Lebovidge, J. S., Timmons, K., Rich, C., Rosenstock, A., Fowler, K., Strauch, H., Kalish, L. A., & Schneider, L. C. (2008). Evaluation of a group intervention for children with food allergy and their parents. *Annals of Allergy, Asthma & Immunology*, 101, 160-165.
- Mandell, D., Curtis, R., Gold, M., & Hardie, S. (2002). Families Coping with a Diagnosis of Anaphylaxis in a Child; A Qualitative Study of Informational and Support Needs. *ACI International*, 14 (3), 96-101.
- Masia, C. L., Mullen, K. B., & Scotti, J. R. (1998). Peanut allergy in children: Psychological issues and clinical considerations. *Education & Treatment of Children*, 21 (4), 514-531.
- Pumphrey, R. (2004). Anaphylaxis: can we tell who is at risk of a fatal reaction? *Current Opinion in Allergy and Clinical Immunology*, 4, 285-290.
- Rouf, K., White, L., & Evans, K. (2011). A qualitative investigation into the maternal experience of having a young child with severe food allergy. *Clinical Child Psychology and Psychiatry*, 17 (1), 49-64.
- Sicherer, S. H., Noone, S. A., & Muñoz-Furlong, A. (2001). The impact of childhood food allergy on quality of life. *Annals of Allergy, Asthma, & Immunology*, 87, 461-464.
- Valentine, A. Z., & Knibb, R. C. (2011) Exploring quality of life in families of children living with and without a severe food allergy. *Appetite*, 57, 467-474.

Appendix A

Smith College Human Subjects Review Committee Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

November 12, 2013

Claudia Shapiro

Dear Claudia,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Hannah Karpman, Research Advisor

Appendix B

Flier to Recruit Participants

Exploring Resources for Caretakers of Children with Food Allergies

Currently looking for participants who are willing to complete an online survey (approximately 20 minutes long) for a master's thesis

Participants must be:

- **The caregiver of a child with a severe food allergy that has been diagnosed by a doctor**
- **Over 18 years old**
- **The child must be between 4-12 years old**

If you are willing and meet the above criteria, please take the provided link below for the survey

Feel free to contact with any questions:

Claudia Shapiro

Smith College School for Social Work

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

<https://www.surveymonkey.com/s/9GTQ8V6>

Appendix C

Consent to Participate in Research Study

**Consent to Participate in a Research Study
Smith College School for Social Work
Northampton, MA**

Title of Study: Exploring How Social Workers Can Provide Support to Primary Caregivers of Children with Severe Food Allergies

Investigator: Claudia Shapiro, SSW,

This is a research study that is exploring resources and supports that are available for caregivers of children with severe food allergies. This study hopes to gain a better sense of which resources are currently being used by caregivers of allergic children, as well as services that could be made available to this population in order to decrease the distress some families experience managing a child's food allergy.

.....

Introduction

- You are being asked to be in a research study of resources available to support caregivers of children with severe food allergies.
- You were selected as a possible participant because you are the caregiver of a child between the ages of 4 and 12 years who has severe food allergies. You received a link to the study survey through a list serve or Facebook, or forum or blog site, and expressed interest in participation.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to gain a better understanding of the resources that are already available for the families of children with food allergies, as well as identify other ways that social workers can support these families.
- This study is being conducted as a research requirement for my master's in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to participate in an online survey (through www.surveymonkey.com) that will take approximately 20 minutes. The survey will ask for information regarding resources and supports regarding your child's food allergy, what you have used in the past, and what you would find helpful to have access to in the future.

Risks/Discomforts of Being in this Study

- There are no reasonable foreseeable (or expected) risks. However, there is a chance that participants experience emotional discomfort or distress as a result of answering the survey questions.
- If any emotional discomfort is experienced following participation in this survey, please contact your therapist or local crisis center. A list of crisis hotlines will be included following this study. Please be sure to print or save a copy of this list for your records.

Benefits of Being in the Study

- The benefits of participation are to identify areas where caretakers might seek help and/or support regarding their child's food allergy, and to gain awareness about resources that caretakers may not know exist in their area.
- The benefits to social work/society are: to gain a better understanding of which resources are currently used by families with a food allergic child, any barriers that prevent families from using certain resources, and where more supports need to be made available to these caretakers and their families.

Confidentiality

- This study is anonymous. We will not be collecting or retaining any information about your identity.
- However, it is possible that your answers may identify you. Please be careful not to provide any identifying information in your responses. If identifying information is provided, it will not be included in the final paper.

Payments/gift

- I'm sorry that I won't be able to pay you for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. All questions are voluntary and you may skip any question.

I Agree

I Disagree

Appendix D

Survey Questions

How old are you? _____

In what state do you live? _____

What type of area do you currently live in?

Urban Environment

Rural Environment

Other (please specify) _____

What is the highest level of education you have completed?

High School

Undergraduate

Graduate

PhD

Other (please specify) _____

How do you identify racially? _____

Do you have a child with one ore more food allergies?

Yes

No

What is your relationship to this child?

Mother

Father

Grandparent

Other (please specify) _____

Are you the primary caregiver to this child?

Yes

No

How old is your allergic child? _____

Does your child have any siblings? If yes, how many? _____

Does your child attend school or daycare?

Yes – Public

Yes – Private

No

What are your child's 5 greatest strengths? _____

How old was your child when their food allergy was diagnosed? _____

Was your child taken to an allergist to confirm this food allergy?

Yes

No

Was your child prescribed epinephrine (Epi-pen) for his/her allergy?

Yes

No

If yes to the previous question, who knows how to administer Epi-pen?

Myself

My Child

Household Members

Extended Family

Additional Caretakers

Teacher

Parents of child's friends

Child's friends

Other (please specify) _____

What resources have you and/or your family used in the past to learn about food allergies? (check all that apply)

Pamphlets

Videos

Books

Internet

Advice from Physicians

Advice from Friends

Other (please specify) _____

What kinds of supports have you and your family used surrounding your child's food allergies? (check all that apply)

Local Support Groups

Online Support Groups

Other (please specify) _____

What professionals have you and/or your family seen as a result of your child's food allergies?

Allergist

Pediatrician

Dietician

Nurse

Social Worker

Therapist

Other (please specify) _____

Are you aware of local support groups for parents of children with food allergies?

Yes

No

Do you attend any support groups? If yes, do you find it helpful, if not, why not?

Which of the following do you currently have available to you?

Practical tips for keeping a safe home

Practicing Epi-pen

Food brands that are safe

Coupons for safe food

"Chef Cards" for Restaurants

Educational information for schools

Educational information for extended family

Educational information for other parents

Educational information for other caretakers

Educational information for child at different ages

Books

Videos

Support groups in the area

Contact info of other parents with allergic children

Dieticians in the area

Blogs for parents of allergic children

Reliable websites

Allergy Hotline to answer questions 24/7

Nurse-led information sessions

Other (please specify) _____

Which of the following would you find helpful?

Practical tips for keeping a safe home

Practicing Epi-pen

Food brands that are safe

Coupons for safe food

"Chef Cards" for Restaurants

Educational information for schools

Educational information for extended family

Educational information for other parents

Educational information for other caretakers

Educational information for child at different ages

Books

Videos

Support groups in the area

Contact info of other parents with allergic children

Dieticians in the area

Blogs for parents of allergic children

Reliable websites

Allergy Hotline to answer questions 24/7

Nurse-led information sessions

Other (please specify) _____

Do you have suggestions for additional resources that you would find helpful?

Contact List in Case of Emotional Issues

Massachusetts 24/7 Social Service Hotline: 877-211-MASS (6277)

Parental Stress Hotline: 1-800-632-8188

Samaritans: Massachusetts 24-Hour Crisis Intervention/Suicide Hotlines:

Boston Hotline: 617-247-0220

Suburban West Hotline: 508-875-4500