

**‘NEVER REALLY FREE’:
ANAPHYLAXIS AND THE FAMILY LEISURE
EXPERIENCE**

by

Kathleen Wilson-Forrest

A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Master of Arts
in
Recreation and Leisure Studies

Waterloo, Ontario, Canada, 2007
© Kathleen Wilson-Forrest 2007

Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Kathleen Wilson-Forrest

ABSTRACT

This qualitative study utilized a systems theory approach and followed the premise that families are systems that seek a balanced state, interact with their environment, and are goal directed to explore the impact of anaphylaxis on families from a parental perspective. The purpose of this study was to explore the role of family leisure in families while living with a child diagnosed with anaphylaxis. This was done by exploring parental meanings and experiences of living with anaphylaxis and how this impacted their family leisure. Five research questions guided the inquiry relating to experiences and meanings of anaphylaxis, experiences and participation in family leisure, valuations and meanings of family leisure, caregiving as a constraint to family leisure, and gender considerations.

A local support group for families and individuals living with anaphylaxis (WRASE) was contacted and aided in identifying parents who would be interested in participating in this study. Specific attention was given to obtaining a sample that included different allergies, ages of children, and number of children in the household. Four families were selected and both parents were interviewed separately in all but one case.

Four core themes emerged from the in-depth interviews and included An Emotional Journey, Seeking Community Support and Dealing with Negative Feedback, Impact on Family Leisure, and The Increased Domestic Workload and Changing Role of Mother. In essence, parents experienced intense feelings of fear, paranoia, and stress as they sought to manage their child's allergy and these feelings were just as intense during their family leisure time. Role changes and strain were particularly severe for the mothers in this study.

The parents of children with anaphylaxis have received little attention in social science research to date. This research adds to the literature on chronic illness and also offers new insight into how anaphylaxis affects family leisure. Key findings in this area were the lack of opportunities for travel and social isolation. Furthermore, it was found that leisure, although often thought to be beneficial in managing stress and improving family functioning, may not be available to those living with anaphylaxis.

Acknowledgements

First and foremost I would like to thank my sons Devin and Jarod for blessing me with your smiles and love. Without you both this project would not have been attempted nor would it have held such deep meaning for me. You have taught me to embrace the unexpected and enjoy all life has to offer.

To my supervisor Dr. Susan Shaw: You taught me that every story is valuable, even my own—a trait of a truly gifted researcher. I am grateful for your support and understanding through the last few years.

To my committee members, Dr. Sherry Dupuis and Dr. Diana Parry: Thank-you both for your advice and support throughout my graduate career. The experience you have shared with me is genuinely appreciated.

Finally, to my family and friends: I am lucky to have such supportive people in my life. The praise and encouragement you gave me was inspiring and I could not have gotten this far without you. A special thank-you to my parents for your commitment and many forms of support!

TABLE OF CONTENTS

AUTHOR’S DECLARATION	II
ABSTRACT	III
ACKNOWLEDGEMENTS	IV
PROLOGUE	1
CHAPTER 1: INTRODUCTION	3
CHAPTER 2	7
PLANNING FOR THE JOURNEY: THE LITERATURE REVIEW	7
WHAT IS A FAMILY?	7
AN INTRODUCTION TO THE MODERN FAMILY	8
FAMILY LEISURE	10
<i>Leisure and Marital Satisfaction</i>	10
<i>Leisure and Families with Children</i>	11
<i>Core and Balance Model</i>	12
CHRONIC CHILDHOOD ILLNESS AND THE FAMILY	15
<i>The Effects of Chronic Illness on the Family</i>	16
<i>Mothers of Chronically Ill Children</i>	18
<i>Fathers of Chronically Ill Children</i>	19
<i>The Chronically Ill Child</i>	20
<i>Stress vs. Crisis</i>	21
<i>General Coping Theories</i>	22
<i>Introduction to the Family Adjustment and Adaptation Response (FAAR) Model</i>	23
LEISURE AS A COPING STRATEGY.....	24
<i>Beyond Stress: The Role of Positive Psychological States</i>	26
<i>Constraints to Leisure and Leisure as a Coping Strategy</i>	29
SUMMARY OF LITERATURE REVIEW	33
CHAPTER 3	36
PACKING FOR THE JOURNEY: METHODOLOGY	36
THEORETICAL FRAMEWORK.....	36
SENSITIZING CONCEPTS.....	37
PURPOSE.....	39
THE USE OF GROUNDED THEORY	40
PARTICIPANT RECRUITMENT	41
SUMMARY OF PARTICIPANTS.....	42
DATA COLLECTION STRATEGIES	44
VALIDATION OF FINDINGS	45
ETHICAL CONSIDERATIONS	46
CHAPTER 4: EMERGING THEMES	48
THE “EMOTIONAL PAYMENT” OF ANAPHYLAXIS	48
THEME 1: AN EMOTIONAL JOURNEY	48
1.1 <i>Fear, Shock, Paranoia: The Early Emotional Impact</i>	48
1.2 <i>Resurfacing Emotions: Change and the Ongoing Search for Security</i>	51
THEME 2: SEEKING COMMUNITY SUPPORT AND DEALING WITH NEGATIVE FEEDBACK	53
2.1 <i>Educating Family and Friends</i>	54
2.2 <i>Educating the Educators: Ensuring Safety at School</i>	57
THEME 3: IMPACT ON FAMILY LEISURE.....	60

4.1 <i>Fear vs. Risk: The Issue of Safety in Family Leisure</i>	61
4.2 <i>Freedom to Explore: The Desires and Difficulties of Travel</i>	62
4.3 <i>Social Eating: The Staple of Family Leisure</i>	65
THEME 4: THE INCREASED DOMESTIC WORKLOAD AND THE CHANGING ROLE OF A MOTHER.....	67
4.1 <i>The Physical Domestic Workload</i>	67
4.2 <i>The Emotional Domestic Workload</i>	69
4.3 <i>The Changing Role of a Mother</i>	74
SUMMARY OF THEMES	76
CHAPTER 5: DISCUSSION.....	79
TOWARDS UNDERSTANDING: EMERGENT THEMES AND INSIGHTS.....	79
<i>The Emotional Journey</i>	79
<i>Seeking Community Support and Dealing with Negative Feedback</i>	82
<i>Impact on Family Leisure</i>	83
<i>The Increased Domestic Workload and the Changing Role of Mother</i>	87
<i>A Comment on the Role of Fathers</i>	89
STUDY SIGNIFICANCE.....	91
<i>Theoretical Significance</i>	92
LIMITATIONS	92
FUTURE DIRECTIONS	93
FINAL THOUGHTS	95
REFERENCES	96
APPENDICES	103
APPENDIX B: INFORMED CONSENT FORM	106
APPENDIX C: SEMI-STRUCTURED INTERVIEW GUIDE.....	107
APPENDIX D: FEEDBACK LETTER TO PARTICIPANTS	108

PROLOGUE

Even though I am a mother of a child with a life-threatening allergy, I really did not know what to expect from this study. I was relieved to hear that I was not the only person experiencing the intense emotional challenges of anaphylaxis.

My journey began before my son had even had a reaction. He was an unsettled baby who rarely slept and with a family history of allergies I began eliminating foods from his diet in an attempt to identify a cause for his discomfort. When I was sure there was an undiagnosed food allergy I attempted to convince our allergist, who assured me that my son's symptoms were not allergy related. After my son tested positive (extremely positive) for a peanut allergy my "mother's instincts" were never questioned again by anyone, including our allergist!

After the diagnosis I remember crying at the thought of not being able to take my son out for an ice cream cone and spending some special time with just the two of us over a treat at the local Dairy Queen. Then I felt so guilty for being upset by something that seemed trivial in the grand scheme of life. He was healthy and all we had to do was avoid peanuts. Right? Not so easy as I soon discovered. Specifically, I remember lying on my son's floor beside his bed (my husband did too) for two nights when he accidentally ate something containing walnuts during Christmas dinner at my aunt's house (he is allergic to peanuts but cross-contamination is always a concern and he was never tested for tree nuts). We were both so fearful that he would have a reaction in his sleep and we would find him dead in the morning that neither of us slept for two nights.

I too have cringed when my son talks about dying and have tried to focus on educating him rather than making him fearful; the fear is my burden and should not be

his. I have learned that all parents must give up some amount of control over their children as they grow up but for me, and other parents with children with severe allergies, the loss of control equals an intense amount of fear, probably many times more severe than normal. But I also know that I am lucky to have a level of understanding from everyone in my life and he has an entire crew trying to keep him safe.

I worry for those living with allergies that are not as “easy”. My heart goes out to the families in my study living with life-threatening milk and egg allergies, whose children experience more restrictions than my son ever will, and parents who must experience crippling fear every day of their lives. It is my hope that this study is another step in bringing the issue of anaphylaxis to the forefront of social science research and will aid in the development of support for the families who live with life-threatening allergies.

CHAPTER 1: INTRODUCTION

Family leisure, although compromised by a lack of time, is still highly valued as a means of achieving family cohesion and solidarity (e.g. Carisse, 1975; Holman & Jacquart, 1998; Orthner & Mancini, 1990). Shared leisure is also found to relate positively to marital satisfaction (Hill, 1988; Holman & Jacquart, 1998) and as a result to parental satisfaction (Freysinger, 1994).

Even though family leisure is highly valued by parents (Shaw & Dawson, 2001), studies have also shown that there is a discrepancy between what activities mothers and fathers consider to be leisure (Horna, 1989; Shaw, 1985a, 1992, 1997). Shaw (1985a) explains that “activity-type” descriptions of leisure time do not fully capture the meanings and experiences of the individual. Furthermore, mothers are found to carry out much of the work associated with family leisure time including planning and clean up (Shaw, 1992).

The modern family is characterized as being time stressed (General Social Survey, 1999) as the majority of families now have both parents working outside the home. However, there is still a lack of shared responsibility in regard to household chores between men and women (Hochschild, 1998; Kay, 1998) and, when there is an effort to share, it is still the woman who must delegate and follow-up to ensure the needs of the household are met (Kay, 1998). In addition, children are increasingly overscheduled in their “free time” which leads families to feel stressed and under connected (Doherty & Carlson, 2003).

When a child within a family is diagnosed with a chronic illness, the family unit is greatly affected and stress levels are likely to increase. The daily demands of the illness

put a great amount of stress on the time crunched family (Calem et al., 2003; Hamlett, Pellegrini & Katz, 1992; Kazek et al., 1998; Knafl & Deatrick, 1987; Miller et al., 2000; Wallander & Varni, 1998; Young, Dixon-Woods, Findlay & Heney, 2002). In most situations it is the mother who takes on the role of primary caregiver to the ill child with fathers and other family members offering “help” or respite care (Mandell, Curtis, Gold & Hardie, 2005; Young et al., 2002). The increase in family responsibility has major consequences for a mother’s time use. There is often a need to be physically close to the child (Mandell et al., 2005; Young et al., 2002) and a sense that personal space and free time is not acceptable and must be legitimized (Young et al., 2002).

The way in which a family copes with chronic illness is important for the psychosocial development of the child (Hamlett et al., 1992) and may affect the clinical course of the illness itself (Tansella, 1995). Although most families cope well (Hamlett et al., 1992; Wallander & Varni, 1998) there is a possibility for maladjustment issues for both the children and mothers (Calem et al., 2003; Compas, Howell, Phares, Williams & Ledoux, 1989; Wallander & Varni, 1998). The possibility of post-traumatic stress also has been documented in families of children who have survived cancer (Kazek et al., 1998).

One way in which families may cope with stress associated with chronic illness is through leisure. It is widely postulated that leisure activity acts as a buffer to stress (Coleman, 1993; Coleman & Iso-Ahola, 1993; Hutchinson, Loy, Kleiber & Datillo, 2003; Iwasaki & Mannell, 2000). Leisure pursuits offer benefits such as social support and interaction (Coleman & Iso-Ahola, 1993), mood adjustment (Hutchinson et al., 2003; Iwasaki & Mannell, 2000) as well as a time to reconnect with one’s spouse (Schneider,

1999). New literature has linked leisure activity with post-traumatic growth opportunities furthering the notion that appreciating the stressful situation whenever possible has real benefits to long-term coping.

Although leisure as a method of coping with chronic illness is beneficial, there are also constraint issues evident for every family member. The daily responsibility of caring for an ill child can consume the remainder of any free time that may have existed, especially for mothers. Since women often experience a larger number of leisure constraints (Jackson & Henderson, 1995), there is a compound effect of a child's diagnosis of chronic illness leading to a greater lack of personal leisure for women. In contrast, men also experience a decrease in leisure time, but they may be better able to demand personal leisure time and make it a priority (Schneider, 1999). Finally, the child who is chronically ill must face issues such as fatigue, medication side effects (Turner, 1998) and fear of being teased (Worchel-Prevatt et al., 1988).

It is unclear at this time whether a lack of personal leisure or unfulfilling personal leisure has implications for satisfaction experienced during family leisure. In other words, do individuals need both satisfying individual and family leisure to feel satisfied with family life? Likewise, the concept of fear as a constraint has yet to be linked with the chronic illness literature but may provide valuable insights into family leisure behaviour and experience. It becomes evident therefore that with so many factors involved, family leisure may become a challenge rather than a coping strategy for families coping with the chronic illness of a child.

Past research in this area has highlighted several solutions to challenges related to personal and family leisure from both an illness perspective (e.g. Hamlett et al., 1992;

Mailick, Holden & Walter, 1994; Young et al., 2002) and a societal perspective (e.g. Berry & Rao, 1997; Hochschild, 1998). Social support, education and role negotiation have all been dominant themes in this regard. However, further understanding is needed in the areas of the perceived impact of childhood chronic illness on family leisure choices and activities, the perceptions of fathers and siblings of chronically ill children, and issues faced by families of different social classes and ethnicities. In addition, specific illnesses may provide unique insights into leisure research and it may be beneficial to investigate them individually. Life threatening allergies (anaphylaxis), for one, has been only minimally investigated from a psycho-social perspective and never before from a leisure studies perspective.

Anaphylaxis is a potentially life threatening allergy. Potential allergens include but are not limited to nuts, latex, egg, shell fish, and insect venom. There are approximately 800,000 Canadians living with anaphylaxis, of whom many are children who require an injection of epinephrine to avoid death during an anaphylactic reaction (Anaphylaxis Canada, 2003). As a consequence, many families live in fear (Merz, 2003) and may experience significant psychological distress and social restrictions (Primeau et al., 2000). Most recent research has likened living with anaphylaxis to living with a chronic illness (Mandell et al., 2005). However, there has been no previous research looking at anaphylaxis and leisure. More specifically, anaphylaxis has been linked to the chronic illness literature but there has been no research exploring the unique challenges that families living with anaphylaxis face in terms of planning and enjoying family leisure experiences. The purpose of this study is to explore the experiences and meanings of family leisure among parents who have a child diagnosed with anaphylaxis.

CHAPTER 2

PLANNING FOR THE JOURNEY: THE LITERATURE REVIEW

What is a Family?

It is becoming increasingly difficult to define the term family; however, according to Copeland and White (1991) there are four characteristics that set families apart from other small groups and, therefore, must be acknowledged in family research. First, families have a shared history that often involves ethnic or religious values. Family members “bring to every interaction expectations about each other based on extended prior experience and family myth” (p.5). Second, families have expectations of a shared future. Experiences shared by family members, positive or negative, will be re-visited and built upon through future interactions. In other words, family experiences do not happen in a vacuum to be left in the past. Every experience and interaction becomes part of the family’s future. Third, although unclear how specific biological traits are inherited, shared biology may result in greater bias toward member similarity. In essence, biological similarity may be valued more than other group characteristics. Fourth, there is a built-in power hierarchy in families. This hierarchy “is less obvious or nonexistent in other groups” (p.5) and is partially determined by generational influence, culture-wide expectations, age differences, and idiosyncratic family history. In summary, whether families are defined as nuclear, extended, same-sex, or otherwise, it is important to recognize the unique features that families have that distinguish them from other groups of individuals.

An Introduction To The Modern Family

The face of the modern family has become one that is overworked and time stressed resulting in a lack of time to spend together. In 1998 about 21% of all women and 16% of all men aged 15 years and over perceived themselves as time-stressed (General Social Survey, 1999). This statistic represents a 4 to 5% increase in time stress since 1992. In addition, 4.9 million respondents to the General Social Survey felt that there was not enough time for family and friends. In the short term future it is expected that this quick pace of life will continue to accelerate and that people will increasingly question the meaning and purpose of their lives (Henderson, Bialeschki, Shaw & Freysinger, 1996). In essence, “[f]amilies, which were once havens for individuals who were stressed by external pressures, increasingly are challenged to meet individual emotional needs” (McKenry & Price, 2000).

Children themselves are also becoming time-stressed. The trend for over scheduling of children’s lives has led to under connected family units (Doherty & Carlson, 2003). The need to involve children in multiple activities may be a response to the limited time parents have available to spend with their children. That is, a structured environment may be needed to supervise the children before their parents come home from work.

Once at home, many families still face a second shift of housework and other chores. In most cases the mother is the one who takes on the majority of this extra work (Hochschild, 1998; Kay, 1998). When there is an effort to share the household responsibilities it is still the mother who must delegate and supervise to ensure it is done.

Kay (1998) terms this role as “proactive domesticity”. As a result, the mother is never completely relieved of the unequal division of household labour.

There appears to be a societal belief that the modern family is more egalitarian today than in previous generations. However, in actuality, there has been very little progress toward this ideal. LaRossa (1998) argues the reason for this is because the culture of fatherhood has changed without the conduct of fatherhood following. In other words, it has become socially acceptable for the man in the household to share childcare and household responsibilities with his wife. Parental leaves are now offered at the birth of a new child and, in Canada at least, each parent has equal opportunity to spend time at home caring for the needs of the family. However, the behaviour of men shows that they are not necessarily taking on these new social roles. There are still very few households that are equally sharing family responsibilities, which suggest the need for further understanding of modern family roles. As Kay (2006) states, “(t)he circumstances surrounding fatherhood are therefore complex and contradictory: it is increasingly unclear what the role of a father is, and perhaps even less clear what it ‘should’ be” (p. 134).

Berry & Rao (1997) explain some of the challenges of changing family roles eloquently:

Fathers and mothers are negotiating new roles, for which they probably did not have role models in their own parents, within a workplace exosystem that has typically not been supportive of the needs of working parents of either gender (p. 396).

Just like the culture or expectations of fatherhood has changed faster than the conduct (behaviour), we could also infer that the culture of the modern family has exceeded the

behaviour of individual family members. This discrepancy between what is dreamed of and what is actually achieved can add another dimension of stress on a family, which in turn, seeps into all areas of family life including leisure (Shaw, 1997).

Family Leisure

Many parents value family leisure time as a means of achieving family cohesion and solidarity (Carisse, 1975; Holman & Jacquart, 1998; Orthner & Mancini, 1990). It is expected that sharing time together in a fun and enjoyable fashion will bring the family closer together. Family leisure also is used to socialize and teach values to young children (Carisse, 1975; Shaw & Dawson, 2001). Though desired and valued, family leisure can also be a source of conflict and stress (Orthner & Mancini, 1990) between family members.

Leisure and Marital Satisfaction

Three leisure patterns of couples were originally identified by Orthner in 1975. The leisure patterns were described as either being joint, parallel, or independent. Joint leisure involves the interaction of at least two people during a shared activity. Parallel refers to a shared activity with little interaction, such as television viewing, and independent refers to individual leisure participation.

It is believed that joint leisure relates positively to marital satisfaction (Hill, 1988; Holman & Jacquart, 1998) and that lower amounts are associated with “greater likelihood of marital disruption” (Hill, 1988, p 447). In Holman and Jacquart’s (1998) study of 318 married individuals, they found that women saw high levels of joint leisure activity to be a resource for dealing with stressful events. In addition, it was the amount of communication during these joint activities that related positively to marital satisfaction

rather than the shared activity itself. In addition, Dyck and Daly (2006) found that fathers “played an important role in instigating couple time whereas mothers played a significant role in its implementation” (p. 201). Furthermore, planning couple time away from children can be challenging as childcare becomes a prerequisite (Dyck & Daly, 2006).

Leisure and Families with Children

Individual leisure alters greatly with the birth of a child and parents tend to choose new activities that include their children (Hill, 1988; Horna, 1989). Leisure time with their children is highly valued by parents (Shaw & Dawson, 2001) and parents use this time to teach values and to socialize their children (Carisse, 1975). Shaw and Dawson (2001) use the term “purposive leisure” to describe their similar findings of the use of family leisure to facilitate the learning of social values and norms.

In a study of 337 married Euro-American parents, Freysinger (1994) found leisure had a significant impact on men’s parental satisfaction, but not on women’s. This finding supports the difference between what is defined as a family leisure activity by men and by women (Horna, 1989; Shaw, 1985a, 1992, 1997). The activity-type definition of leisure does not fully acknowledge individual experiences and meanings (Shaw, 1985a) and what men may consider to be fun and enjoyable may in fact be considered work by women. Such (2006) also found a sharp contrast between men’s and women’s experiences of leisure. Specifically she found that “children became closely tied to meanings of leisure (for men) so that ‘time spent with the children’ was, for the most part, time that resembled leisure” (p. 193). This was not found to be the case for the women in the same study.

When Shaw (1985b) used her earlier data to explore the inequality of leisure, she found that family workload negatively affected a women's leisure time more than men's. Not only were there family responsibilities to attend to before leisure time, there often was work to be done during leisure as well. In family leisure, much of the workload of planning, organizing, clean-up, and individual enjoyment becomes the mother's responsibility (Shaw, 1992). There also are large inequalities when it comes to personal leisure time between men and women (Shaw, 1985b) and women experience more constraints to leisure than do men (Jackson & Henderson, 1995). Therefore, with less personal free time much of a women's leisure time is spent with her family. This suggests that women may not be able to participate in meaningful leisure experiences if their individual leisure time is limited and their family leisure is perceived as work. This situation may have serious implications for using leisure as a coping strategy as discussed later.

Core and Balance Model

The Core and Balance Model of family leisure is based on a systems theory perspective which suggests that as a system, families have a need for both stability and novelty and seek a dynamic state of homeostasis (Zabriskie & McCormick, 2001). Stability is expressed through the need for consistency in interactions, structure, and relationships within the family, whereas, novelty is expressed through the need for new experiences, inputs, and challenges. By obtaining both stability and novelty, families are able to maintain a state of balance that results in an acceptable level of system functioning.

More specifically, Iso-Ahola (1984) developed the concept of the need for both change and stability within the context of family leisure. Furthermore, Kelly (1999) described two different patterns that become evident when both change and stability are sought. The first pattern consists of activities that are consistent and accessible. The second pattern then consists of activities that offer variety and are less accessible. These two patterns form the basis for the Core and Balance Model.

Like Kelly (1999), the Core and Balance Model suggests that there are two general categories or patterns of family leisure; (1) Core and (2) Balance, which are used to meet the needs of stability and change within a family system.

1. Core Family Leisure Patterns

Core family leisure patterns consist of activities that are common, low-cost, relatively accessible, often home-based, and done frequently. They often require little planning and resources, they are spontaneous and informal. Typical examples of core activities may include watching television, playing board games, playing in the yard, or playing at the neighbourhood park. Core patterns are thought to serve a particular function within the family system. “It is in this context of leisure that family members can safely explore boundaries, clarify family roles and rules, and practice ways to enforce them. This is also the context in which family members often are consoled, rewarded, refreshed, and rejuvenated” (Zabriskie & McCormick, 2001, p. 283). It is hypothesized that core family leisure leads to an increased perception of family closeness and cohesion.

2. Balance Family Leisure Patterns

On the contrary, balance leisure patterns consist of activities that are less common and less frequent, thus inducing novel experiences. These activities require more

resources than core activities and are usually not home-based, require substantial planning, are less spontaneous, and more formal. Family vacations, most outdoor recreation activities, special events, and special outings to places such as theme parks are typical examples of what may be considered balance activities. The function served through balance patterns is that “[b]alance activities likely require that family members negotiate and adapt to new input, experiences, and challenges” (p. 284). It is hypothesized that balance patterns relate positively to perceptions of family adaptability, or the ability to meet new challenges and demands faced by the family.

Preliminary testing of this model has yielded both expected and unexpected results (Zabriskie & McCormick, 2001, 2003). In the first trial using 138 undergraduate university students, results did not support the dichotomy that was expected (i.e., that core patterns relate to perceptions of family cohesiveness and balance patterns relate to perceptions of family adaptability). Both core and balance patterns were significantly related to both cohesion and adaptability, although core patterns showed a stronger positive relationship with perceptions of cohesion. The follow-up study used a sample of one parent and one child (aged 12-15 years) from a total of 179 families. For the parents, results showed that, in general, “family leisure activity appeared to be more strongly related to family satisfaction for parents than it was for their children” (Zabriskie & McCormick, 2003, p.180). This finding supports earlier research by Shaw & Dawson (2001) that suggests parents have a broader perspective in reference to the benefits of using leisure to teach values and life lessons to their children. However, Zabriskie and McCormick also found that core leisure was the only factor that held a significant positive correlation to the youth’s perceptions of family satisfaction. In other words,

there was no significant correlation linking balance activities and the youths' perceptions of family satisfaction or adaptability. The need for stability and consistency in family patterns is important at this developmental stage and seems to be achievable through core family leisure activities.

In summary, this research suggests and offers preliminary findings that different leisure patterns serve different functions within a family system. It also highlights the importance of not extrapolating study results of married couples or individual family members, to the family as a whole.

In terms of families living with anaphylaxis, the Core and Balance Model may provide a useful preliminary framework for discussing the different functions family leisure may have. For instance, balance leisure activities may become particularly problematic as protection of the allergic child becomes harder to ensure outside of the home. Therefore, if only core activities are perceived to be available to a family what are the implications for family satisfaction? It is important to begin to explore the function of family leisure activities and their relationship to family satisfaction rather than simply discussing participation rates. The Core and Balance Model, although not fully developed, does offer additional insights into the family leisure experience.

Chronic Childhood Illness and the Family

We now enter another dimension of the modern family. What happens when a child is diagnosed with a chronic illness in an already time stressed household? What happens to the gender roles that couples are struggling to redefine? What are the impacts on family leisure? To answer these questions, we must first define chronic illness and discuss its impacts on daily family life.

There are many definitions of chronic illness in the literature. For the purpose of this study, the definition put forth by Pless and Pinkerton (1975) has been adopted:

A chronic physical disorder is one that (1) interferes with daily functioning for more than 3 months in a year, or (2) causes hospitalization lasting more than 1 month in a year, or (3) is thought at time of diagnosis to do either.

(cited in Wallander & Varni, 1998, p. 29)

This particular definition has been adopted for a number of reasons. First, the inclusion of the variable “interference of daily functioning” allows for the inclusion of illnesses that may not require hospitalization at all, or if so, only for a brief period. Illnesses such as diabetes, haemophilia, anaphylaxis, and asthma all need daily care and monitoring without hospitalization unless there is an emergency. The second important part of this definition is that perception of the illness is given credibility in the characterization of chronic illness. This means that an illness which manifests in daily anxiety also could be included in this category. Therefore, a chronic illness no longer becomes a medical diagnosis but rather an individual diagnosis which discourages blanket approaches in treatment and understanding.

The Effects of Chronic Illness on the Family

The daily demands of an illness puts a great amount of stress on the family unit (e.g. Kazek et al., 1998; Miller et al., 2000; Patterson, 1988; Wallander & Varni, 1998; Young et al., 2002). Mailick et al. (1994) found “large and significant positive correlations...between the perceived impact of the illness in the areas of financial burden, social and familial isolation and personal strain” (p. 106). Similarly Primeau et al. (2000) found families living with anaphylaxis experienced more disruption in the familial/social dimension of family relations. In addition, families that have a child with a chronic

illness have smaller support networks (Kazek et al., 1998) and the children with an illness as well as their mothers are seen as vulnerable to difficulties related to adjustment (Calem et al., 2003; Compas et al., 1989; Wallander & Varni, 1998). As survival rates increase, more families will be living with life-long conditions and their related problems.

Therefore, daily stress is compounded over a life time and as a result “even the most minor of chronic and recurring conditions can have considerable impact on child and family” (Turner, 1998, p. 46).

A child with a chronic illness appears to be more likely to exhibit signs of behavioural problems and is 8 to 17% more likely to suffer from psychiatric disorders as well (Cadman, Boyle, Szatmari & Oxford, 1987). For example, Calem et al. (2003) found that the level of behavioural problems in children with asthma was higher than in healthy children. This could be explained in part by the need to avoid upsetting the child and causing an attack. Thus, parents may excuse bad behaviour in the effort to keep the child content and happy in order to minimize serious wheezing episodes. Supporting this, an experiment conducted by Walker, Garber and Van Slyke (1995) discovered that “children described as having physical symptoms associated with a medically explained organic illness were held less responsible for misbehaviour” (p. 341). In addition, they found that younger children were seen to be less responsible and boys were judged harsher than girls.

Parents are also at risk for emotional or psychological disorders. For mothers, there may be an increase in the incidence of depression when there is a child in the household with a chronic illness (Calem et al., 2003). Post-traumatic stress syndrome also has been linked to families living with chronic illness. For example, Kazek et al.

(1998) found that parents of pediatric cancer patients suffered substantial stress and there was still a fear of death more than five years after treatment ended. In addition, the subjective perceptions of the disease itself were found to be more important in predicting post-traumatic stress than the objective characteristics of the disease.

Unfortunately, death may still be the end result of some childhood chronic illnesses. When this occurs, “families of chronically ill children often do not experience the community support that typically surrounds the death of a child” (Turner, 1998, p. 47). Upon the death of a child, the parents become isolated a second time. While living with chronic illness many families lose friendships and narrow their social circle to other families with chronic illness and, therefore, when the child dies the current social circle can no longer relate in a meaningful way. In some instances the death may be viewed as a relief by friends and family and an end to suffering for the child (Turner, 1998). As well as the sense of isolation, the need for daily care is gone and the parents now experience empty hours that highlight the fact that the child has passed.

Mothers and fathers may experience the effects of chronic illness in the family quite differently. As each is adjusting to a new lifestyle there are many challenges and issues unique to both. Of course, there are also significant effects on the ill child especially centred on school life and peer relations.

Mothers of Chronically Ill Children

Much of the primary care of an ill child falls on the mother with the fathers offering help or respite care (Mandell et al., 2005; Young et al., 2002). Young et al. found that “mothers experience many of the consequences of chronic illness, including biographical disruption, compromise in role function and deterioration of quality of life”

(p. 1837). In other words, there is a severe split between what their lives were like before the diagnosis and what their lives are like after. For many women, the diagnosis of their child with a chronic illness brings on a whole new set of roles and responsibilities that do not fit with their past life. In some cases, mothers described a grieving process for their former selves (Young et al., 2002).

Mothers often feel an obligation of proximity to their ill child. In the situation of cancer, Young et al. (2002) found that mothers would spend days or weeks at their child's bedside in the hospital ward, which resulted in feelings of isolation and a compromised ability to function in other roles. At the same time, “[g]uilt, conflict and regret” were experienced often by these mothers when away from other children at home (p. 1839). In addition, mothers felt that any personal time needed to be legitimized and occurred infrequently.

Mandell et al. (2005) also discovered the theme of proximity and the need to stay close in their study of families living with anaphylaxis. In many cases, the mothers chose to remain at home or left their jobs to stay at home and close to their children in case of an emergency. This decision has serious implications for financial stability as well as increased role strain for the mothers themselves.

Fathers of Chronically Ill Children

As mentioned earlier, fathers are often seen as helping the mothers but not taking the same level of responsibility. In the study by Mandell et al. (2005) the decision as to which parent would participate in the interview was left up to the couples themselves with the premise that the most involved parent be the one to participate. In 12 families,

the mother was the only parent who volunteered. Three families requested that both parents participate and only two families had only the father volunteer.

A study of fathers who had sons with autism found that the degree to which fathers were involved in the daily care of their sons depended on:

- a) the presence of other caregivers,
- b) the prevalence of traditional roles in the family,
- c) the influence of work demands,
- d) the degree of perceived 2nd shift (i.e., the fathers understood the heavy workload waiting to be done), and
- e) the needs of the child

(Schneider, 1999, p. 52).

Each of the males interviewed in the study recognized the larger contribution of their wives and were grateful for this.

There has been very little research on fathers with children with chronic illness and much of the information has been relayed second hand by mothers or researchers themselves. There is a strong need to further understand the perceptions and experiences of fathers of children diagnosed with a chronic illness that goes beyond describing behaviour. The perceptions of fathers and the meanings they attach to caring for a child with a chronic illness is lacking in the current literature.

The Chronically Ill Child

Perhaps the most challenging aspect of chronic illness on the child, after medical treatment, is the absence from school. Chronically ill children have difficulty re-entering school due to fear of teasing, anxiety about keeping up, and the loss of friends (Worchel-Prevatt et al., 1988). When there is a short absence or no missed days, a chronic health condition may interfere with a child's performance at school even if there is no impact on intellect (Turner, 1998). Turner (1998) lists many barriers to optimal performance in

school including fatigue, medication side-effects, altered expectations of teachers, preferential and prejudicial treatment, and psychosocial maladjustment. Children may feel stigmatized upon returning to school and feel as though they no longer fit in with their peer group. Thus, children may need additional attention and support from parents and teachers to help them deal with these challenges.

How Do Families Cope with Chronic Illness?

Stress vs. Crisis

At this point it would be of benefit to clarify the terms stress and crisis. It is crucial to understand that stress and crisis are not interchangeable terms and their roles and impacts on a family are very different.

Stress can be defined as a “state of changed or disturbed equilibrium” (McKenry & Price, 2000, p.11). Stress within the family is not inherently bad, but rather its impact depends on both the amount of stress involved and the family member’(s) perceptions of the stressor event. For example, one member may find an event highly stressful yet another member may not find the same event stressful at all. In addition, stress is considered a continuous variable and may always be present in differing amounts. Crisis, on the other hand, is considered a dichotomous variable. It can be either present or not present and can be defined as “(a) a disturbance in the equilibrium that is so overwhelming, (b) pressure that is so severe, or (c) change that is so acute that the family system is blocked, immobilized, and incapacitated” (McKenry & Price, 2000, p. 11). During a crisis state a family is no longer functioning adequately rather than experiencing a state of disturbed equilibrium.

General Coping Theories

Many researchers agree that family functioning predicts how well a family adjusts to the diagnosis of a chronic illness. In fact, “the family acts as a recipient of the stresses associated with the child’s illness and has the greatest impact on the psychological adjustment and outcome of the child” (Hamlett et al., 1992, p. 46). However, even with the increase of stress and the potential for maladjustment, most families cope quite well (Hamlett et al., 1992; Wallander & Varni, 1998).

Two fundamental ways of coping have been suggested by Miller et al. (2000) which are: (1) an effort to be in control of the situation, and (2) the management of negative emotions associated with the stressful event. In coping with a child with anaphylaxis, Mandell et al. (2005) used the term “The Goldilocks Principle” (p. 16) to describe living with just the right amount of anxiety that protects the child, but does not give rise to negative outcomes such as overprotection. There appears to be a real balancing act in coping with chronic illness: not only does life go on outside the family, but the daily stresses associated with the illness itself must be attended to as well.

Social supports are seen to be very important methods of coping (Kazek et al., 1998; Malick et al., 1994; Mandell et al., 2005; Miller et al., 2000; Wallander & Varni, 1998). However, men may not use social support in the same way that women do (Schneider, 1999). In Schneider’s study, fathers of sons with autism discussed how they avoided formal social support for two reasons. First, they felt they were only dwelling on the negative by going to formal support groups and the second reason centred on the difficulty they had expressing personal feelings. Subsequently, much of the formal support was sought out by the mothers and relayed to the fathers within the home

environment. Therefore, perception of meaning becomes the backbone of many coping models such as the Family Adjustment and Adaptation Response Model. This model is introduced in the following section.

Introduction to the Family Adjustment and Adaptation Response (FAAR) Model

The basis of the FAAR Model is comprised of four themes that have arisen out of the chronic illness and family literature (all information from Patterson, 1988 unless otherwise stated). These themes include: (1) demands, (2) capabilities, (3) meanings, and (4) outcomes. The FAAR Model follows the belief that families attempt to maintain balanced functioning by using their capabilities to meet their demands. Subsequently, “[t]he meanings the family ascribes to what is happening to them (demands) and to what they have for dealing with it (capabilities) are a critical factor in achieving balanced functioning” (p. 76).

Balanced functioning occurs in one of two phases within the model: family adjustment and family adaptation. The family adjustment phase illustrates how families resist major change through meeting demands with existing capabilities. If unsuccessful, a crisis appears and leads to the second phase, family adaptation. In this phase families attempt to restore the balance lost by: (a) acquiring new resources and coping behaviours, (b) reducing the demands they must deal with, and/or (c) changing the way they view their situation.

The outcomes within either stage of the FAAR Model are conceptualized on a continuum from good to poor with good outcomes described as: (a) positive mental health of family members, (b) optimal role functioning of individual members, and (c) maintenance of a family unit which can accomplish its life cycle tasks. Families may

begin the cycle from family adjustment to family adaptation for a variety of reasons. Such reasons may include normal developmental changes within the family (a child becoming an adolescent) or with the occurrence of a major life stressor, such as the diagnosis of a chronic illness. As each family is different, each will experience situations differently and one cannot predict which will lead to a positive outcome. Instead, the meanings a family ascribes to a particular experience rather than an objective evaluation of the situation is a key factor in the process of family adaptation to a stressful experience (Patterson & Garwick, 1998).

Adding to the work of Patterson (1988), Patterson and Garwick (1998) “...propose that families, as a whole, construct and share meanings on three levels: (1) specific stressful situations; (2) their identity as a family; and (3) their view of the world” (p. 75). Since leisure has been postulated to enhance family cohesion and identity, using leisure as a coping strategy is also important to explore.

Leisure as a Coping Strategy

It is widely argued that leisure activity acts as a buffer to stress (Coleman, 1993; Coleman & Iso-Ahola, 1993; Hutchinson et al., 2003; Iwasaki & Mannell, 2000). Leisure allows for social interaction and support, and the perception of availability of such support is considered to be more important than the actual support received (Coleman & Iso-Ahola, 1993). This re-iterates the importance of perception rather than actual measures when thinking about chronic illness and stress. In a supporting study, Iso-Ahola and Park (1996) found that the social role of leisure may be more important than intrinsic motivation and perceived freedom.

Recently, the understanding of leisure as a coping strategy has become more dynamic. A model was proposed by Iwasaki and Mannell (2000) that separated coping beliefs and coping strategies. They explained that general leisure beliefs act as a *buffer* to stress and there is more impact when stress is high. Coping strategies, or specific leisure behaviours, act as *mediators* to stress. Personality is the defining point of beliefs, or what the individual feels is valuable, whereas the situation is the defining point of an action or a strategy.

For example, when a person is taking a vacation to reduce stress in a very unstructured setting without any external control, she or he may be likely to show behaviours reflective of her or his personality or characteristics (e.g. reading for an introvert) [coping belief]. In contrast, when situational influences are stronger, people are more likely to display coping actions...in response to a situation. For example, after a person has been intensely working alone for several straight days, she or he may be likely to become motivated to socialize with others...even though she or he is an introvert [coping strategy]

(Iwasaki & Mannell, 2000, p. 167).

In either context, leisure is used as a method of relieving excessive stress. In addition, mood management is also a possible benefit of leisure coping (Iwasaki & Mannell, 2000). This suggests that people specifically seek out a leisure experience in order to elevate their mood or lift their spirits and return refreshed to the task at hand.

In terms of chronic illness, Hutchinson et al. (2003) “examined how individuals used leisure in coping with a traumatic injury or onset of a chronic illness” (p. 144). They found that leisure activities act as a buffer from immediate stressors and also as a source of motivation to sustain other coping efforts. Participants in this study saw mood adjustment as an outcome of meaningful and enjoyable engagement rather than a specific

coping strategy. It was found also that “leisure helped study participants to experience a sense of connection or continuity with their past” (p. 149) and that their leisure choices were “connected symbolically to important values, beliefs, sense of self and personal histories” (p. 155). In other words, continuing with a leisure interest after a traumatic injury was sustained or a chronic illness was diagnosed allowed for a flow or connection from a past life to their new life. This eased the amount of stress experienced during transition from their past “healthy” lives.

Leisure also may be used to reconnect families during a stressful period. Schneider (1999) found in her study of fathers with sons who have autism that family recreation was used as a chance to spend time with their wives since there was no opportunity for couple leisure. In addition, these men highly valued personal recreation as a way of restoring focus and energy.

Beyond Stress: The Role of Positive Psychological States

While examining prior research and theory development on leisure, stress and coping, Kleiber, Hutchinson and Williams, (2002) raised a number of concerns. In essence, their concerns revolved around the lack of clarity regarding the theorized relationships within leisure, stress and coping literature. They suggested that not only is it unclear how leisure activity moderates the impact of stressful events but that evidence surrounding the social support hypothesis is ambiguous. In particular, they highlighted the lack of clarity regarding the timing of social involvement in relation to the onset of life stress. In other words, is social involvement prior to the onset of stress, or subsequent to the onset, the key to its effect on health?

As for methodology, Kleiber et al. (2002) question the effectiveness of quantitative measures for extracting deeper meaning within the context of leisure and coping. Following Iwasaki and Smale (1998), Kleiber et al. (2002) propose that “understanding the context and meaning of the stress-leisure-coping experiences requires attention to the particular life story that is evolving for an affected individual and how disruption in that personal narrative is resolved” (p. 223). It is through such inductive examination that the dynamic process of coping can be seen and further conceptualized.

Even as Kleiber et al. (2002) expressed their concerns over previous theory development they also acknowledged the importance of these theories in guiding future research. In particular, they sought to expand on the work of Iwasaki and Mannell (2000) by offering “several specific propositions for how leisure may be a resource in coping...” as informed by “...the research by Folkman, Lazarus and others on pleasant events in the coping process” (p. 223). In particular, Folkman (1997) discovered that positive psychological states had been largely ignored in coping research and yet are profoundly relevant to examining how individuals cope with severe stress. Folkman found that in her study of informal caregivers of men with AIDS, positive psychological states (in addition to high levels of negative states) were reported by more than 99% of the caregivers;

For the most part, these events were ordinary events of daily life that in less stressful moments might not even have been noted. We believe the occurrence of these positive events were not random. Rather, caregivers created them deliberately by planning positive events, noting positive events when they occurred serendipitously, or infusing neutral events with positive meaning, as a way of having a few moments of relief from the intense stress

(Folkman & Moskowitz, 2000, p. 116).

As a result of these findings, Folkman has offered a revised version of the original model created by Lazarus and Folkman (1984) to include the role of positive psychological states in the coping process.

Linking the work by Folkman (1997) to leisure research and theory, Klieber et al. (2002) suggest that even though the events described in Folkman's study "may not actually be regarded as leisure at the time, they are significant in demonstrating the importance of positive affect in the coping process and in suggesting one of the ways leisure experience may serve as an important coping resource" (p.221). They offer four functions that leisure may play in coping with stress from being self-protective (as seen in propositions one and two), to allowing for self-restoration and personal transformation (as seen in propositions three and four). The propositions are as follows:

Proposition 1: Leisure activities buffer the impact of negative life events by being distracting.

Proposition 2: Leisure activities buffer the impact of negative life events by generating optimism about the future.

Proposition 3: Leisure activities buffer the impact of negative life events by aiding in the reconstruction of a life story that is continuous with the past.

Proposition 4: Leisure activities are used in the wake of negative life events as vehicles for personal transformation.

As can be seen with the work of Kleiber et al. (2002), there has been a shift from conceptualizing coping as a method to fix the problem that is causing stress to appreciating the benefits and personal growth that may result from stressful situations. However, the practical implications of this conceptualization remain unclear, and

additional research is needed within the leisure field on the topic of leisure, stress, and coping. What is clear is the fact that the use of leisure as a coping method rests on the assumption that one has access to such resources, and that leisure is relatively unconstrained.

Constraints to Leisure and Leisure as a Coping Strategy

Previous constraints literature has conceptualized constraints into three categories, interpersonal, intrapersonal and structural (Crawford & Godbey, 1987). Intrapersonal constraints involve individual psychological states and attributes and may include such factors as stress, depression and anxiety. Interpersonal constraints include factors affected by relationships between persons and interact with preferences for an activity rather than between preference and participation. For example, not having a companion to participate with in a leisure activity may mean a person is less likely to want to pursue particular activities. Finally, structural constraints may intervene with both preferences for and participation in a particular activity. Structural constraints may include such factors as family life-cycle stage, family financial resources, season, and climate.

The difficulty in measuring constraints rests in the fact that particular constraints may not be static across time, may not fit only one category (intrapersonal, interpersonal or structural), or may be unique to certain individuals and may not be generalizable (Jackson, 1988). Crawford, Jackson and Godbey, (1991) proposed that these three categories act in a hierarchy with intrapersonal constraints needing to be addressed first, interpersonal constraints being addressed second, and structural constraints being addressed last. The premise is that constraints are encountered in a systematic order and

if not negotiated (overcome) the result is non-participation. However, if the constraint can be negotiated then the next category of constraint is encountered and addressed.

The issue of an internal/external dichotomy in the classification of constraints has been raised by researchers such as Henderson, Stalnaker and Taylor, (1987) and Jackson (1988). Henderson et al. (1987) categorized constraints as intervening or antecedent, but still in terms of external (intervening) or internal (antecedent). A constraint may in fact fit into different categories depending on how it is viewed. For example, a time constraint could be perceived in terms of the lack of willingness to give up other pursuits to make time for a particular activity (internal) or the demands of work and home schedules (external). The difficulty in the comparison of findings and forming generalizations has been noted due to differing conceptualizations and measuring of leisure constraints (e.g., Jackson, 1988).

As the field of leisure constraint research has evolved, the definition of constraints has as well. Jackson (1997) suggests that a more recent and preferable definition of constraints is “factors that are assumed by researchers and perceived or experienced by individuals to limit the formation of leisure preferences and to inhibit or prohibit participation and enjoyment in leisure” (p. 461). Such an expanded definition allows for the divergence from participation as an outcome mentality that had been prevalent in the past. In addition, there has been a call for researchers to reach the deeper meanings that lie behind typical constraint responses (Henderson, 1997; Samdahl & Jekubovich, 1997). Specifically, Henderson (1997) argues that time and money as common constraint responses to survey questions does not describe the other meanings that lie behind such responses. She goes on to suggest that the definition of activity has also been too narrow

and agrees that research must move beyond viewing activity as an outcome and towards activity as a means for achieving deeper social goals.

In a family living with chronic illness, constraints may be particularly relevant to mothers and the chronically ill child. For example, an “ethic of care” acts as a major intrapersonal constraint for women as they respond to the needs of others before their own (Henderson and Allen, 1991). This feeling that the needs of others are more important than one’s own needs can manifest itself in negative ways. For example, mothers of children hospitalized with cancer often feel the need to legitimize time for themselves, and as a result, rarely take the opportunity. Therefore, women tend to downplay their own needs and as a consequence may lead professionals to downplay them as well (Young et al., 2002). This can leave mothers of ill children particularly vulnerable to extreme stress with few avenues for support. Unfortunately, using leisure as a coping strategy for such stress may not be feasible for these mothers.

Although men feel their leisure time has lessened after the diagnosis of a chronic condition they may be better able to demand or make time for their leisure (Schneider, 1999). There has been very little research in this area and a general conclusion may not be possible or appropriate. However, as men usually experience fewer constraints to leisure in the first place, they may already be in a better position to continue a leisure interest after their child has been diagnosed.

Chronically ill children also may experience constraints to leisure and these may be specific to their particular condition. For example, anaphylactic children (those with life threatening allergies) may miss out on events that involve food such as birthday parties and other social gatherings. Asthmatic children may not be able to fully

participate in active leisure pursuits as they may induce a wheezing attack. Other chronic illnesses may require constant medical interventions lessening the time available for leisure as well as in situations of hospitalization or bed confinement. Many of these constraints could be categorized as structural as there has been little research on the personal impact of these factors or how they might be conceptualized as intrapersonal or interpersonal constraints.

Fear as a constraint has been explored in relation to fear of violence within leisure environments but it may also become relevant to families living with chronic illness. In particular, the fear of an anaphylactic reaction may require families to act in ways similar to those described by young women fearful of violence. Whyte and Shaw (1994) describe how the young women in their study reported altering their participation as a result of fear by: (a) reducing night participation, (b) participating with other people, and (c) modifying where they participated. In addition, these alterations led to a decrease in enjoyment gained from the activities they participated in. It is important to further explore the role fear plays in family leisure participation and enjoyment among families with anaphylaxis, particularly since a reaction can be life-threatening. It has been found that families living with anaphylaxis “continue to experience constant uncertainty throughout their lives regarding the risk of accidental ingestion” (Primeau et al., 2000, p.1136). Mullins (2002) explains that peanuts and tree nuts are hard to avoid because they are used widely, the allergy tends to persist (children do not usually grow out of a nut allergy), and small amounts can trigger symptoms. Therefore, similar activity modifications as noted above may be seen within such families in an effort to minimize exposure.

Summary of Literature Review

The informing literature discussed above has come from the areas of sociology, social work, leisure, stress and coping, and family research. Four broad categories of research form the basic background for this study and consist of the following topics: (1) Family Time and Family Leisure, (2) Chronic Illness, (3) Leisure and Coping, and (4) Leisure Constraints. Each broad area may offer significant insight during the data analysis of this proposed study.

1. Family Leisure

The literature on family leisure suggests that family leisure is desirable, though not always enjoyable. In addition, parents place great importance on providing new and challenging experiences for their children and use leisure to accomplish this. What becomes of interest for this study is what happens when there is an interruption in family leisure. Does anaphylaxis in particular impact the opportunities parents have in planning and enjoying family leisure activities? Does anaphylaxis change the meaning and experience of family leisure for parents, and if so, how?

2. Chronic Illness

Previous research, and particularly research by Mandell et al. (2005), shows that anaphylaxis can be linked to chronic illness research. The challenges and stresses highlighted within this literature provide a broad understanding of the potential impact of anaphylaxis on a family. However, it is also important to realize that each condition is unique and a blanket understanding is not possible or desirable for the long term.

3. Leisure Coping Literature

Leisure may offer specific coping benefits to families that are facing stressful situations helping them to maintain equilibrium. It has been suggested that leisure offers benefits such as relaxation, rejuvenation, and mood enhancement through escape and or distraction. Families living with a chronic condition may consciously use leisure to gain such benefits. How leisure is used by families living with anaphylaxis is of interest in this study.

4. Leisure Constraints

Of particular interest within the constraints literature is the role that fear may play in impacting participation in, and enjoyment of, family leisure pursuits. The anxiety and fear of a potential life-threatening reaction has yet to be explored from a leisure perspective and may provide invaluable information to leisure researchers. The use of quantitative methods has been questioned in addressing the impact constraints have on leisure lifestyles (Samdahl & Jekubovich, 1997). There has been a call for understanding the deeper social motives to leisure participation rather than participation as an outcome and therefore, qualitative research methods may be of value.

The issue of family versus personal leisure, and the meanings attached to these, may also be considered as part of leisure constraints. The need to spend time with one's family sometimes has negative implications for personal leisure time and may be of concern if personal leisure is used as a coping strategy for stress. In contrast, having time for personal leisure may have positive implications for family leisure. If a parent is refreshed and happy, the time spent with family may be more enjoyable. The relationship between family and personal leisure appears to be complex and perhaps circular. Thus, it

is important to realize that one's personal time has implications for family time and visa versa.

5. Other Important Considerations

The literature identifies gender as an important concept when exploring both individual and family leisure. In addition, the caregiver role may be very different for mothers and fathers especially when there is a chronic condition in the household. However, these differences (and similarities for that matter) are not fully understood, and the issue of gender needs to be taken into consideration when examining family leisure.

Finally, the influence of siblings within a household has rarely been explored and most often has only been given minimal mention in the literature reviewed for this study. How siblings influence families living with anaphylaxis is largely unexplored. What is known is that siblings often must live by the rules set to protect the allergic child (Mandell et al., 2005). Sometimes siblings act as if they too have a life-threatening allergy in an effort to maintain a high state of protection for their brother or sister. The experiences of these siblings and the implications of living as if they had an allergy when they do not are unclear.

The goal of this literature review is to provide a broad understanding of previous research in order to aid in the data analysis of this study. With little prior social or psychological research on anaphylaxis and the family, there is a need for an open-ended approach to conducting research on this topic.

CHAPTER 3

PACKING FOR THE JOURNEY: METHODOLOGY

Theoretical Framework

Systems theory is a relatively recent framework as most of its evolution has occurred in the 20th century. There are four basic assumptions for general systems theory that apply to both living and non-living systems (Klein & White, 1996).

1. All parts of the system are interconnected.
2. Understanding is only possible by viewing the whole.
3. A system's behaviour affects its environment and in turn the environment affects the system.
4. Systems are heuristics, not real things.

In essence systems theory is not concerned with isolating Cause A from Effect B and, therefore, believes systems, such as families, must be considered in their entirety.

The guiding concept behind systems theory defines a system as such "because it affects its environment and can be distinguished from its environment" (Klein & White, 1996, p. 157). In addition systems include the concepts of boundaries, rules of transformation, feedback, variety, equilibrium and subsystems. Families then can be expressed as a system that is goal-directed, seeks homeostasis, and has a control subsystem. In addition, families are systems that seek a balanced state, contain various subsystems (marital subsystem, sibling subsystem, etc.), and interact with their environment.

The benefit of using a systems theory approach is that it contains general ideas that can be applied across diverse contexts (Klein & White, 1996). This allows for guidance during data collection and analysis in many types of studies. In addition, systems theory has proven useful in studying marital and family communication and interaction (Klein & White, 1996). Since this study is concerned with exploring family interactions both from internal and external relationships, systems theory appears to be appropriate as a guiding theoretical framework.

Sensitizing Concepts

There were four major sensitizing concepts gleaned from the review of relevant literature that guided both the data collection and interpretation of the family as a system of relationships and interactions.

1. Family leisure as desirable and purposive.

Parents plan and participate in family leisure pursuits in order to enjoy quality time together and have fun outside of their daily routines. However family leisure is also used for a deeper purpose in many instances. Developing family bonds, teaching moral values, skill acquisition, and stress reduction may all be examples of ulterior motives that may affect the goal-directed behaviours of families.

2. Role of caregiver.

Caring for a chronically ill child has many consequences for families and parents. Time-stress, role-strain, fatigue, and loss of personal freedom may be present at any given time. As well, financial consequences could have major implications for families with chronic illness. Any of these consequences could have major influence on participation and enjoyment in family or personal leisure.

In addition, there is evidence of positive rewards associated with caregiving that influences the meanings that parents attach to situations and activities. For some, enjoyment is derived from more subtle sources and may offer deeper pleasure than what would be obvious to an outside observer. Therefore, these positive aspects must also be considered during the interpretive phase of this study.

3. Fear as a constraint.

Fear, for the most part, has been explored from a violence towards women perspective. However, fear may also be particularly relevant to families living with anaphylaxis. Intuitively one assumes fear of exposure to a life-threatening allergen must influence families planning and participation in leisure activities, yet this constraint has not been explored until now.

4. Gender influence.

The leisure and chronic illness literature has explored the influence of gender from various perspectives. From a leisure studies perspective, gender differences have been discussed in relation to the opportunity and participation in personal leisure, as well as one's role in family leisure. In terms of the chronic illness literature, much focus has been placed on a mother's role in caring for an ill child and the implications for role-strain and stress. Although exploring gender differences is not the sole purpose of this project, it is clear that gender must be considered as a potentially important concept.

Purpose

The purpose of this study was to explore the role of family leisure in families while living with a child diagnosed with anaphylaxis. This was done by exploring parental meanings and experiences of living with anaphylaxis and how this impacted their family leisure. The study was guided by the following research questions.

1. Experiences and Meanings of Anaphylaxis for Parents
 - i) What feelings are associated with the initial diagnosis of anaphylaxis?
After the initial diagnosis?
 - ii) What are the demands placed on a family newly diagnosed and how do parents learn to cope with these demands? What causes the level of, or type of demands, to change?
 - iii) What role does the outside community play in supporting families living with anaphylaxis?
2. Experiences and Participation in Family Leisure
 - i) What family activities do these families participate in?
 - ii) What is involved in the planning process for family activities? Is there a difference between home-based and other activities?
 - iii) What are the settings/contexts of these family activities?
 - iv) How are family leisure activities experienced by the family?
3. Valuations/Meanings of Family Leisure
 - i) How do parents describe or think about family leisure? What do parents see as the purpose of family leisure? What are the most important functions of family leisure?

- ii) What are the perceived benefits of family leisure?
- iii) Are there any negative outcomes of family leisure?

4. Caregiving as a Constraint

- i) What challenges do these parents encounter when planning for/participating in family leisure activities? At what point do these difficulties become constraints?
- ii) What role does fear play in the lives of these families? Time-stress? Balancing needs of different family members?
- iii) How is family leisure experienced?

5. How do these experiences, valuations and constraints vary by gender?

The Use of Grounded Theory

The data for this interpretive study were collected and coded using grounded theory methodology (Strauss, 1987). The overall aim was to form preliminary theory or understanding that could be used to direct further research on the topic of anaphylaxis and leisure.

An inductive grounded theory approach was chosen for this particular study for two reasons. The first reason centers on the lack of research on living with anaphylaxis, particularly research with a leisure focus. Therefore, it was important to explore this topic from an open-ended approach in order to draw out relevant information that would be almost impossible to know beforehand. A quantitative study would have required more preliminary information than was available at this time and thus would not serve the end purpose of allowing the participants to discuss what was important to *them*. Secondly, a grounded theory approach encourages the analysis of data from a holistic

perspective. The data are first analyzed without established theory and then they are analyzed in respect to existing theory. In other words, the data speaks for themselves, but their role and contribution to existing theory is also a key element in the analysis process. The process itself will be explained in further detail in the following paragraphs.

One of the key characteristics of grounded theory methodology is the constant comparison of data during the collection procedure and the emergent theory development from the data themselves. Therefore, theoretical coding (Strauss & Corbin, 1998) based on careful analysis of the data, and with reference to sensitizing concepts if and where appropriate, took place throughout the data collection in order to generate preliminary grounded theory. In essence, the goal was the formation of a holistic understanding of the effect of anaphylaxis on family leisure rather than a descriptive account of the families interviewed (Strauss & Corbin, 1998).

Participant Recruitment

The participants for this qualitative study were selected through purposive sampling of families with one child with a life threatening allergy diagnosed at least one year prior to this study. Families were contacted through the local anaphylaxis support group, WRASE (Waterloo Region Anaphylaxis Support and Education). An information letter was distributed by a support group executive through both email and postal mailings. In total it is estimated that these mailings reached 169 families. After one month, 10 families had expressed interest in participating in the study and a total of 4 families were selected based on family and allergy characteristics. It could be suggested that a low response rate would be expected from a sample population that may be severely time-stressed; however, it is also possible that a second request for participants

may have yielded additional responses. Although the response rate seemed low, the families that did respond had diverse characteristics that allowed for a sample that included different family structures (i.e., number of children within the household, number of children within the family with allergies) and types of allergies and therefore no additional requests for participants was required.

Both mothers and fathers were interviewed and this occurred separately in all but one case. The separate interview procedure was used to encourage individual perceptions and to alleviate childcare issues. The interviews occurred at the participants' homes as well as public places of some participant's choosing when the shielding of any children within the home was an issue. As with any topic where death or fear may be an area of questioning, it was important that children within the home not be present in the room during the interview and each family was given the choice of interview location. Every effort was taken to ensure the comfort of both the participants and the children within the household.

Summary of Participants

Participants were selected from a short list of interested families. Attention was given to specific anaphylaxis triggers, family size, and ages of the children in each family. Every effort was taken to ensure a variety of family characteristics in order to obtain as diverse a sample population as possible. Pseudonyms were used for both the parents and their children to ensure confidentiality. The following briefly describes each of the four families involved in this study.

1. Leslie and Peter

Leslie and Peter have three young sons, Adrian who is nine years old, Jordon who is five years old, and Robert who is two years old. Their eldest son, Adrian, has outgrown all of his allergies but as a younger child was allergic to dairy, egg, wheat, citrus, peanut, and pineapple. Currently, Jordon and Robert both have severe life-threatening allergies to egg and Jordon also is allergic to dairy, nuts, coconut, and possibly soy.

Recently Leslie has returned to work teaching part-time and Peter, who once travelled extensively for work, is now working full-time close to home.

2. Beverly and John

Beverly and John have the oldest children involved in this study. Brooke is 11 years old and is severely allergic to peanuts, peas, and soy. Her brother, Brian is 13 and has no life-threatening allergies.

Beverly has also recently returned to her teaching job part-time. John works full-time outside of the home.

3. Rachel and Kevin

In contrast, Rachel and Kevin have the youngest children involved in this study and both have life-threatening allergies. Joshua is four years old and is severely allergic to nuts and has also reacted to strawberries. His sister Katie is three years old and is also severely allergic to nuts as well as egg.

Rachel and Kevin both work full-time outside of the home.

4. Sarah and Jim

Sarah and Jim have three children, Christine who is 11 years old, Emma who is nine years old, and Paul who is two years old. Christine and Paul currently do not have

any severe allergies. However, Emma suffers from the greatest number of allergies of anyone included in this study and has had two anaphylactic reactions requiring the epipen since being diagnosed. Emma is allergic to nuts, legumes, fish, preservatives, antibiotics, and also suffers from exercise induced anaphylaxis as well as being lactose intolerant.

Jim runs his own business outside of the home and Sarah has recently left her full-time job in order to attend to Emma's demanding health needs. Sarah also helps Jim with his business.

Data Collection Strategies

Data were collected through open-ended interviews conducted face to face with a semi-structured interview format. The interview guide was structured following the research questions outlined earlier and focussed on parental experiences and meanings of anaphylaxis, experiences and participation in family leisure, valuations and meanings of family leisure, the notion of caregiving as a constraint, and gender implications (See Appendix C). Probes were used as necessary to explore issues contained in the research sub-questions. The follow-up of emergent themes was a priority and determined the specific direction of topics and direction within each interview session and any subsequent interviews beyond the initial interview guide. The interviews were audio recorded and transcribed verbatim with the consent of each participant. A research journal was kept to record reflective notes on my own thoughts and feelings about the process and each interview session. Such reflective writing allowed me to acknowledge the emotions that I shared with the parents I interviewed and served as a valuable outlet during this project. In this journal, analytic notes were also kept in order to record

thoughts on developing analysis while data were still being collected. The interviews lasted approximately 45 minutes to 1½ hours, and 3 ½ hours for the couple who were interviewed simultaneously.

Data Analysis

The coding followed the process described by Strauss (1987) and consisted of open, axial and selective coding of data into substantive codes. To begin with, new codes were developed from the data within each interview transcription. Secondly, these open codes were analyzed and reassigned into new substantive codes to reduce overlap and link similar constructs. The relationships among substantive codes were further analyzed and coded using theoretical codes. The purpose of this type of coding paradigm is to ensure the relevance of the codes themselves to the phenomena being studied (Strauss, 1987) such as anaphylaxis and family leisure. Therefore, emergent themes were analyzed through constant comparison during both data collection and final analysis. As well, data from the research journal were also included in the interpretation of findings.

In essence, open coding began after each individual interview was transcribed. After an interview was coded it was compared and contrasted to any previous coded data. Gender differences were also given attention during this stage. The final step was to compare the coded data in its entirety to the research questions. This process ensured that coding was developed using the data itself rather than using the research questions as a blueprint.

Validation of Findings

To ensure the credibility of this project (see Lincoln & Guba, 1985) the following processes took place:

- 1) Peer debriefing and negative case analysis were both aided by the expertise of the project supervisor during regular correspondence. This process allowed for objective feedback and direction which not only aided in the development of themes and understanding, it also allowed for additional clarification when writing for an audience who may not be familiar with anaphylaxis.
- 2) Member checking occurred throughout the data collection as participants were provided a summary of their original transcript in order to confirm, reiterate or add to my interpretation of the interview. In addition, a summary of emergent themes and findings were offered to the interested participants for feedback during a focus group meeting before the final report was written. The focus group meeting took place at a public recreation facility in a private meeting room and lasted approximately one hour. Only three of the eight participants were able to attend due to childcare issues and one family moving out of the city. It was during this meeting that many of the emerging themes were verified as being representative of the personal stories of the parents. However, the issue of security led to an interesting discussion of the fear that these parents experience on a daily basis and became an important addition to the themes as described in Chapter 4.

Ethical Considerations

Informed consent was obtained before each interview occurred. The interview participant was informed of the right to decline to answer any questions and that he or she could withdraw from the process at any time and withdraw the use of any previously

collected information. Medical information was also disclosed during the interview and was kept confidential.

My own experiences were acknowledged throughout the research study as I actively shared my experiences with the parents during each interview. These experiences brought many insights and sensitivities to the research study. Without first hand knowledge of anaphylaxis, such a topic may not have been pursued to begin with. In addition, given my own experience, a more meaningful rapport was fostered with the individuals participating in this study. However, I recognized that vigilance was required in assessing how experiences and opinions influenced the analysis process, and therefore, an ongoing self-reflective process was key as there were differences in how I perceived similar events in my life as compared to some of the parents to whom I spoke.

Finally, the issue of death was explicitly talked about during the interviews and therefore it was important to shield any children in the household from hearing what was being talked about. This was addressed with each participant before the date of the interview. All interviews were conducted without the presence of children.

CHAPTER 4: EMERGING THEMES

THE “EMOTIONAL PAYMENT” OF ANAPHYLAXIS

As previously discussed, anaphylaxis is a relatively new field of inquiry both in medical and social science disciplines. As a result, priority has been placed on research that potentially may save lives, consequently, exploring and understanding the emotional impact on families affected has received much less attention. During the exploration of themes in this study it became clear that the emotional impact of anaphylaxis is significant, constant and evident from the first allergic experience.

The major themes that emerged in this study deal not only with the heavy emotional burden that living with anaphylaxis has on a family but also the impact it has in their daily lives. From diagnosis, to impact on domestic workload, to leisure pursuits, life-threatening allergies affect a family in a number of ways as explored through the following themes.

Theme 1: An Emotional Journey

1.1 Fear, Shock, Paranoia: The Early Emotional Impact

The initial period following a diagnosis of anaphylaxis is characterized by feelings of shock, fear, and paranoia for parents and is obviously extremely stressful to all members of the family. Unless there is a history of allergies in the family, the diagnosis of a life-threatening allergy comes as a complete shock to the parents. There is often no warning and a family's life changes in a dramatic way very quickly representing a crisis situation in the family. The shock experienced by the parents in this study went beyond being merely surprised. The initial diagnosis meant that parents had just been told that

there is a serious threat against their child which could be fatal and that this threat would be life-long. Leslie described her feelings of shock as she entered the drugstore to get her child's first Epi-pen immediately following her child's diagnosis;

"I remember filling my first prescription for an Epi-pen and feeling like everything was in slow motion. Is that a sign of extreme stress? That's how it felt. I was standing in the drug store with my toddler trying to keep him from grabbing all the chocolate bars at the front cash, which I was now just beginning to realize could kill him, and the pharmacist was explaining how to use this thing I really didn't want to have in my purse."

A significant amount of the shock experienced immediately following a diagnosis of a life-threatening allergy came from realizing how pervasive a particular allergen is in everyday life. Once parents are told that they can no longer expose their child to peanut butter, or milk, or any other common food, they begin to realize how often they do come into contact with that food or ingredient. As Leslie experienced, a trip to the drugstore to fill a prescription for life-saving medicine for a reaction means navigating past the allergen against which you are trying to protect your child.

For some, fully understanding that something as mundane as food can be deadly to their child became a challenge immediately following a diagnosis.

"[It's a] pretty scary experience and then there's living through that denial where your kid can die from eating something." Jim

For many parents learning how serious their child's allergy was became frightening. The fear of exposure was all consuming, especially immediately following their child's diagnosis. Every food and every situation became a potential threat against their child.

"...after reading it gets quite scary knowing that with even just a trace amount she could die...At the time it was very scary and we were really paranoid about everything in the house, anywhere." John

"I remember seeing a sign for Reese's Peanut Butter Cups on a city bus and feeling like someone was pointing a loaded gun at my child." Leslie

For the parents in this study, it seemed as if everywhere they turned they were confronted by a potentially fatal allergen. This resulted in intense feelings of paranoia and fear regarding their abilities to protect their child.

Furthermore, since a diagnosis of anaphylaxis affects every member of the family, extra attention was typically also given to other children within the household. Managing the personal needs of every child was difficult and worrisome for parents. Early on it became clear that the family would have to change its lifestyle significantly and this meant that siblings would experience such change as well. Understanding how other children in the household may be impacted was an added concern and presented additional challenges.

“There’s also the stress of having one child who can eat anything and another with allergies. How do I keep Jordon safe in our kitchen when Adrian wants to use the cheese grater to grate cheese for his pizza? How do I tell Adrian we can’t eat in any restaurants because they don’t have anything Jordon can eat?” Leslie

However, it was not just the parents who were worried about the well-being of the family member with anaphylaxis; siblings also feared for the safety of their brother or sister. Understanding the threat against their sibling is difficult and emotionally upsetting for these children.

“When she was first diagnosed, and in the early years of it, to this day still, he [brother] would be very careful about eating anything that had peanuts or peanut butter. He doesn’t eat anything with that. If he accidentally got something, and that has happened before, he gets upset. He doesn’t want to eat anything that she’s allergic to.” Beverly

In essence, all family members experienced differing degrees of emotional upset as they began to understand and cope with their new situation. In order to cope, it became crucial that action was taken to reduce the potential for allergen exposure. However, this

was occurring simultaneously with experiences of intense feelings of paranoia and fear. The following sub-theme describes the type of action plans that were often put into place in order to cope with a life-threatening allergy immediately after a diagnosis.

1.2 Resurfacing Emotions: Change and the Ongoing Search for Security

As soon as a diagnosis or reaction occurred there was an immediate need for rules/routines to be established within a household. At the same time, parents were trying to educate themselves as quickly as possible in order to learn as much as they could about keeping their child safe as possible. There was no “grace period”, and changes occurred immediately.

The new rules included actions such as not eating any food without first reading the ingredient label or calling the manufacturer. Also, always carrying an epi-pen was necessary and routines were then used as heuristics to make coping easier. One typical routine was to always shop at the same grocery store and buy the same brands that had already been researched, eating at the same restaurants, socializing with the same friends and family. These and other repetitive practices seemed to result in feelings of relative security.

“I think it’s just become part of your life. It’s always in the background, it never leaves you but you do the same things. You buy the same groceries; you go to the same restaurants...” Beverly

Although rules and routines were helpful and required in order to cope with the heavy demands of protecting a child with severe allergies, they were only effective if other changes did not occur. However, some changes could not be avoided and some could not be anticipated. These occurrences required families to adjust quickly in order

to establish a new state of normal in order to prevent feelings of paranoia and fear from resurfacing.

“I go through...it’s kind of like up and down...and it’s when things change. Like when Jordon started JK it was huge and when he started preschool, it was the same thing and it’s a phase, figuring out what we need to do in a real situation to keep him safe and also what additional things he needs to learn to take a bit of the responsibility for himself. When he started JK, all of a sudden he had to wear the Epi-pen and I was really paranoid about that. So it’s when things change like that that I get stressed again and then once we get used to it, things settle down.” Leslie

When asked about their opinions in regard to feeling safe or secure, parents attending the focus group meeting were quick to express that they did not feel completely secure at any time nor did they ever expect to. For these parents, security was a myth and paranoia and fear was experienced every time a new situation was encountered.

Parents coped with change and uncertainty by establishing emergency plans for as many different scenarios as possible. Each family needed to plan for a life-threatening situation and ensure that it would work should a reaction occur. An Epi-pen would only buy time in order to obtain medical treatment and had to be administered immediately to ensure survival. Therefore, time was of the essence in an anaphylactic emergency and plans had to be in place prior to that occurring. Emergency plans became increasingly more difficult as more people and situations were involved in a child’s life as highlighted below:

“...when you see a child having a reaction, then it makes you think about all the other activities that she’s involved in with school and all these different things and how the emergency plan is going to work and all this stuff. It makes you really think about all the different scenarios that you’re in as a family and where you’re going and all these different things and you can’t take that chance that the epinephrine’s not going to work...I wouldn’t wish it upon anyone to have to give their child the Epi-pen but there are benefits to having it happen because then you learn what’s

missing. Where the communication is lacking, with the school, with everything.” Sarah

As can be seen, entrusting someone with protecting, and possibly saving, their child’s life was very difficult for some parents. At the same time it was understood as a necessity unless the child was to remain at home or with parents for his/her entire childhood.

Therefore public knowledge of what an anaphylactic reaction looks like and what to do to help is crucial and became the focus of many parents.

Theme 2: Seeking Community Support and Dealing with Negative Feedback

It can be argued that no other disability or disease requires support and understanding from the community in order to ensure a child’s safety and possibly save his or her life to the same degree as anaphylaxis. There are certainly other health conditions that rely on community support, but in terms of anaphylaxis, a lack of community support or understanding can lead to a very serious or fatal situation.

Individuals living with anaphylaxis are potentially exposed to allergens through every situation they encounter including interacting with friends and family, attending schools and daycares, grocery shopping, and interacting with the public as a whole. The families in this study often felt the need to advocate to the people involved with their children to get them to follow practices that would decrease the risk of exposure to a potentially dangerous allergen. Sometimes this meant educating but sometimes it meant attempting to change the attitudes of people who came into contact with their children. This could be a time-consuming and emotionally draining experience for the family.

“It affects you where you go, where you live, with the hospitals, where you’re going to take your kids. There doesn’t seem to be enough knowledge out there. Then you get the people who are like ‘she’s fine’. Like the paramedic, like the fireman, like you know...you get these people who don’t care. It’s like, ‘it’s not my kid.’... We should do a movie. I think it would be a hell of a lesson for people. Just do a movie of something like that is real life of what some families go through out there. They don’t know the half of it.” Jim

The process of gathering support often began with friends and family, and depending on the age and situation of the child, followed with schools and daycares. Unfortunately, negative feedback was often experienced and this made the process even more challenging for the parents.

2.1 Educating Family and Friends

After the initial diagnosis, the first rules and routines that were established involved the immediate family. The second step was often to educate extended family and friends about the allergy and what rules/routines must be followed to ensure safety. This second step also needed to happen quickly and often occurred at the same time that the immediate family was learning to cope. The task of disseminating knowledge to people outside the immediate family was a huge challenge and sometimes was quite draining for the parents; they felt a strong responsibility to do this, but felt they needed to be careful how they went about this task.

“I think the hardest thing is educating people. They’ll never know what I know because I’m dealing with it every day but there’s a balance between educating them enough so that Jordon can be safe there and not making them upset.” Leslie

Educating others became particularly important when other family members (i.e., grandparents) were involved in childcare. Again, feelings of “being mean” or upsetting others was brought up even when educating grandparents.

“I told all family members that there will be no peanuts and that was hard. My mom is very laid back so she now has a cupboard where she’s allowed to keep her peanut butter and anything with peanuts. She’s getting better. There’s still stuff that I have to make them put away and you feel like you’re being mean.” Rachel

In some instances it took a lot of energy to convince family members that the allergy was real and may be fatal if not taken seriously.

“My mother just doesn’t get it. ‘I’ve raised you all and you all turned out fine.’” Rachel

Not having immediate support from extended family members resulted in added stress and feelings of helplessness for these parents. It was suggested by the parents that obtaining support and understanding from family should be easy and unconditional. Unfortunately, many parents faced scepticism early on by family members who did not believe the seriousness of the diagnosis. Time and diligence were seen as the key to educating those that were not initially open to understanding the allergy.

“In the beginning they thought it was just a typical allergy. It took them a long time to get clued in to how serious it was.” Kevin

Close friends that the family socialized with were also important to educate. However, it was not always easy to ask these friends to change their habits or change the food that they served. Even friends who had the best of intentions needed constant reminders to ensure there would be no risk of exposure when the family came to visit. The parents recognized that it was difficult to remember to be diligent when not living with the constant threat of a reaction, but it meant that the parents had to be extra vigilant to remind their friends and check all food.

“Most of our friends still forget.” Rachel

“For the most part people are pretty good. I also realize that people are human and can make mistakes even though they’re well intentioned. There have been a lot of mistakes. Not that I haven’t caught them but there have been situations with people who just slip up on something. It just happens.” Beverly

The parents in this study felt that they were fighting a slow uphill battle in many instances. The time taken to educate others and then wait for support was frustrating. In addition, not being able to relate to friends regarding the stress of living with a life-threatening allergy was also very isolating. Not having someone to confide in and talk with increased the feelings of loneliness family members already felt. In some cases a diagnosis of a life-threatening allergy resulted in the loss of friends who either became frightened or felt they could no longer relate in a meaningful way.

“I think they’re just...they don’t know how to deal with it. Yeah, I mean you figure it’s a hell of a challenge for us imagine somebody who doesn’t know anything about it. For them, it must be like, how are we going to do this. I know with these friends of ours, the ones that do go out of their way to do it, for they’re always afraid. But as least they do it and are asking questions, but the other ones [friends], they don’t even bother.” Jim

Leslie spoke of countering her feelings of isolation by actively seeking out other parents living with anaphylaxis to socialize with.

“No one can totally relate to what I deal with everyday and that’s lonely sometimes...That’s what reduces my stress. Being able to go out and talk to other parents who have the same issues I have...Being able to talk to them and realize I’m not the only one that’s dealing with this...Without being able to talk and meet each other you can feel very isolated.” Leslie

In essence, the process of educating extended family and friends began with convincing others that the allergy was in fact serious and then always checking to ensure that everyone remembered to remove the allergen. This meant that parents had to be

constantly vigilant in every situation: and strained or lost relationships with family and friends were sometimes the result.

2.2 *Educating the Educators: Ensuring Safety at School*

School time was a very emotional and difficult time for some families with anaphylaxis. In some cases this was the first time their child was left in the care of someone else and the issue of trust was fundamental. The passing of Sabrina's Law (a law that requires every school to provide an action plan to ensure safety) in 2006 has made important strides to ensure the safety of every child with severe allergies in school. However, the introduction of the Balanced School Day has presented additional challenges to some families. In the region where this study is based, the school day is now divided by two nutrition breaks that consist of equal meal times and recess times. For example, a nutrition break may consist of 20 minutes of meal time and 20 minutes of recess time. Unfortunately the short lunch break means that many children are not able to return home to eat lunch. This has resulted in added stress for families that could otherwise have brought their child home to eat in a more controlled environment.

In addition, different schools have different policies for the storage of Epi-pens. Some parents found they had to fight for the right of their child to carry an Epi-pen on their body. This conflict was stressful and frightening since the parents felt the school was not acting responsibly in keeping life-saving medication near their child.

“See, that’s an issue that I had with the school. You lock it [Epi-pen] in the office, you have literally seconds to get it to them and if someone is not there, you have to find the key and get it to them. When Erika started JK, she wore it around her waist and they were like, ‘oh no, that’s dangerous’ and I said ‘oh no, it’s dangerous if she doesn’t wear it’. ‘Well what if the other kids grab it?’ ‘Well Erika knows not to let other kids grab it and you’re going to have to teach the kids in the classroom not to grab it because this is my child’s life’.” Sarah

Advocating to the school was particularly complicated because families were not only dealing with a variety of people; they were also dealing with policies and procedures that may take time to change. However, when support was provided families were able to keep moving forward in their efforts to protect their child. Unfortunately, not every situation resulted in support and understanding.

Many schools are now nut free/peanut free but the families in this study still experienced negative feedback from other families that did not want to be restricted in terms of packing lunches and snacks for their children.

“No, I don’t like the ignorance of other people. That is really a challenge to me. One day I was over at Zehr’s looking for peanut free snacks to send to the daycare and wanted the labels on it so that I could give it to the daycare and there was a lady there that goes to my church. I told her I was there looking for these peanut free things and I didn’t say why and she came out with ‘Holy cow, that whole God damned peanut thing, I can’t even send my kid [to school] with peanut butter’, and she’s a woman of the church! That just drives me. ... So that is the biggest challenge...[people] just not getting the drift of it.” Rachel

“Because I have a child with a nut allergy, I guess I was the target for a couple of women...[They said]” Our children should not have to be told that they cannot bring things to school and that it should be a nut-free school’she was using the survey of the council to get her dig at me.” Sarah

Similar to the experience of educating family and friends, ensuring their child’s safety at school was a balancing act as well. Families were constantly balancing the needs of their child against the feedback of others who were affected by necessary restrictions. It is important to understand that the families in this study were intensely aware of the sometimes negative or reluctant attitudes of others while they were advocating for the protection of their child. Sometimes even with policies in place it was the mother’s responsibility to enforce these policies and ensure that they were followed.

Again, backlash and negative comments may be directed at a mother who is seen as “pushy” or “demanding”.

“...[In my children’s] first daycare I was the one really starting to enforce the rules within the centre. They said they were peanut and nut free when I signed up but they weren’t, and they really didn’t know what that meant. They didn’t have any policies in place. They probably still don’t but I was sort of the mother hen over there and it’s a teaching daycare so they should be on top of this stuff and they weren’t and they probably still aren’t. I had a lot of comments to me about you were the one that wanted this rule. So they [her children] are at another daycare now where they already had a policy in place.” Rachel

Such negative reactions were not just experienced by parents in this study but also by the children themselves. The disparity between the parents’ need for others to understand and support their actions and the resultant negative response was frustrating and led some families to feel alone in their struggle.

Even though the task of continuing to educate the public may seem daunting, there has also been significant improvement which was noted by the parents. This provided some respite from the daily stress of checking and re-checking and educating and re-educating. These small improvements lessened the daily sense of frustration and gave parents hope that their child could in fact live with, and grow old with anaphylaxis.

“...I think by nature of people’s awareness and the press that it’s got and the fact that the allergy has been in the public forefront for an extended period of time, it is a lot easier to manage because schools are peanut free for the most part. Ours is professing to be, or attempting to be. Restaurants are changing their menu to not include nut products or peanuts or you’ll see them say we operate a nut free facility. Those things can’t help but influence parents and how...like you don’t have to worry as much when your kids go out for Halloween, if everything is nut free, great. Halloween doesn’t become the stressful event for some that it had been in the past.” Peter

It is interesting to note that knowledge was seen as the key to protecting children with allergies. Allergen free places like schools were acknowledged as an extremely important exception rather than the rule. In other words, parents living with anaphylaxis realized that eliminating all allergens everywhere was completely out of the realm of possibilities and for this reason public education was essential.

“I don’t agree with nut free, you can’t ever be free of anything, but I agree with people, people understanding how dangerous nuts can be to other people. The consideration and the compassion is what’s needed for everything in this world and that goes for people with disabilities, any kind of challenge that they have. You need compassion, you need to be human and look at them and think, ‘how can I make their lives easier?’ That’s all that we ask for, for everybody, not just for children with allergies but for everybody who has a challenge that affects their life. How do you make it easier?” Jim

Knowing that others are at least aware of, and respectful of, life-threatening allergies lessened the sense of isolation felt by the families.

Theme 3: Impact on Family Leisure

The emotional journey following diagnosis, and the challenges that parents faced in seeking community support and understanding impacted all aspects of family life, including leisure. Family leisure was seen as precious to every family in this study. Each parent expressed the desire to spend time together as a family and that leisure time was especially valuable. When asked what activities they enjoyed together as a family, common answers were playing games, seasonal sports, watching movies, playing at parks and in backyards, and for some, travelling. Some of the participants highlighted that there was a difference between spending leisure time together and being together during daily activities. For these participants, leisure time was seen as more satisfying than time spent in other activities.

*“We’ve had a couple of nights when we just played games or watched a movie. So, just being with the children as opposed to running around.”
John*

“If you were to ask me this in June I would have told you that I was not at all satisfied [with our family leisure]. I’m enjoying it a lot more this year and we are making a conscience effort as a family to have family time. So, playing games, watching a movie, going out and doing things. We did leisure activities as a family before...but it was just too much driving last year.” Beverly

Severe allergies made family leisure time more difficult to plan both in terms of time and logistics. For one family in this study the time available for family leisure was severely limited due to their daily routine.

“We’re saying we have to find some way...I feel like all I’m doing right now is in the kitchen and because we have to keep the house so clean to control dust, normal everyday dust and stuff, we’re cleaning everyday and we think, gosh, we just have to find time to just go for a walk and do things like that...” Sarah

For other families the logistical planning of leisure time was greatly effected by severe allergies. Any location where there was food was a potentially hazardous area for these families and they needed to meticulously plan how they were going to keep their loved one safe while enjoying quality time together doing something they all wanted to do.

4.1 Fear vs. Risk: The Issue of Safety in Family Leisure

For this particular population, family leisure was both difficult to plan and difficult to manage emotionally. As mentioned earlier, families living with anaphylaxis live in a world of constant vigilance and threat of potentially fatal allergic reactions and their leisure time is not exempt from such stress. Therefore, a balance was sought between risk and fear in order to enjoy leisure time together.

Any parent of a child with life-threatening allergies would say they experience some sense of fear every day of their lives. The impact of fear was evident for the

parents in this study when it was debilitating and prevented the family from participating in an activity or leisure pursuit. Many of the families spoke of managing fear by mentally weighing the risks involved in a particular situation. Risk was used as a measure for the amount of fear experienced. In other words, the higher the risk of allergen exposure, the higher the amount of fear experienced. It was this combination of high risk and high fear that prevented families from participating in certain leisure pursuits.

“I always knew that she was very allergic but it seems now that it’s even more so. She’s at the highest end of everything. I’ve always been careful but now I will be more diligent. There will be nothing left to chance. Usually when we go away, we pick a very nice place, we will call ahead, talk to them and if we’re comfortable, there will be one nice dinner out so that as a family we’ve had a special time. I will have to think twice about it this time.” Beverly

“Has it stopped us from doing things? Oh yeah. In some respects it has to.” Peter

Planning and taking precautions, like carrying Epi-pens, were used to reduce risk and thus reduce the amount of fear. One of the difficulties the parents faced was that leisure pursuits are often dynamic and involve different locations, people, and environments. Not only did this make planning time-consuming but it meant thinking about the potential risks for any new environment or activity. Therefore, families often repeated experiences in which they felt relatively safe.

“We sort of know where to go now. We don’t go to Moose Winooskey’s...they have peanuts. We’re sort of habit types where we get familiar with where to go.” Kevin

4.2 Freedom to Explore: The Desires and Difficulties of Travel

Since new situations could be troublesome for this population, their ability to explore new places and enjoy new experiences was severely impacted. The difficulty associated with travel was discussed by every participant as was dining out at restaurants,

whether close to home or otherwise. When asked what their “leisure wish” would be if they did not have to worry about allergies, every study participant said they would like to travel together as a family if the finances were available. Often the allergy and money required were seen as mutual constraints to travelling as a family.

Allergies aside, money aside,...I think that would be great...it'd be something I'd love to do with them as a family.” Peter

It was during the discussion of travel that many parents acknowledged the impact of being a one-income family on their leisure lives.

However, despite the challenges, travel was epitomized as the ultimate family experience and was viewed as a way to connect without the interruptions of daily life they experienced at home.

“Travelling is a priority for me, but part of the reason for that is it's uninterrupted family time. The only time when friends aren't calling, we're not working so it's something that we all really look forward to.” John

One of the benefits of family travel is being able to explore new cultures and locations and broaden one's knowledge of the world. As Beverly explained, this type of travel was valued, especially for the benefits it provided to the children in the family. Parents also took pleasure exposing their children to new experiences.

“I enjoy experiencing things through my children's eyes. I love to expose them to different things that they wouldn't otherwise see. I'm a teacher so I like the learning that happens when we're travelling the country or we'll go to a new place and see some of the culture. It's educational as well as enjoyable quality family time.” Beverly

“...there's so many things in this world you could expose the boys to; different countries, places...it would really broaden their experience.” Peter

Unfortunately, the reality was that travel was extremely difficult and stressful for these families living with anaphylaxis. Being away from home meant families had to eat away from home.

“All these out of town activities tie in to eating in restaurants. How do we travel, even if it’s only an hour away to go to Toronto, if we can’t eat in restaurants? When Adrian was just allergic to peanuts it was still possible. Now that Jordon is allergic to milk and eggs as well as all the nuts it’s impossible to eat out.” Leslie

As a result of these problems, families had to plan extensively where they were going, for how long, and know beforehand if there were safe places to eat during their trip. Clearly this planning and need for knowledge ahead of time completely eliminated any spontaneity.

“Travel is another one, you can’t just pick up and go somewhere... With the milk and egg allergy you can’t, it permeates everything, there’s cross-contamination issues with everything. So you really have to plan what you’re going to do, plan where you’re going to eat.” Peter

One option was packing enough safe food for the duration of the trip. However, unexpected delays could mean running out of food before returning home. As mentioned earlier, these unanticipated situations were often the root of stress and even fear among these families.

Fortunately allergic reactions are often preventable and this meant that some families would take solace in the fact that their vigilance was indeed paying off when their child did not experience a reaction. Even so, the reality was that allergic reactions are possible and fatal reactions do occur. As one mother stated, if her child were to have an allergic reaction while travelling she might decide to stop travelling completely.

“I think that if we had experienced Brooke having a reaction to something especially if it was while we were travelling, it would probably stop us. I

can't imagine being in the car driving somewhere and she has a reaction. We just fortunately haven't had that." Beverly

However, the desire to travel was still strong among the families in this study. Many recognized that the benefits they expected from family travel would outweigh the extra planning required to make a trip possible.

"I would say we should go, be great for the kids and Leslie's first reaction was 'what about the food allergies, what about everything?' And I said 'you're right we have to think about that'. It's one of those situations where it would be a lot easier to just stay home but it's important to try and make it work." Peter

4.3 Social Eating: The Staple of Family Leisure

For many families, spending time with relatives and friends was both a common and enjoyable activity. As mentioned previously in the context of travel, parents in this study saw exposing their children to new situations and people as being important. Parents saw social gatherings as an opportunity to nurture family ties and enjoy the company of others.

"I think it's important...it's important for the kids, in my opinion, to be involved in the lives of their family. My sister would be up there [at the lodge], my mother and father, and their aunts, their great-aunts, their cousins would be up there. So, I think that it's important that they have the opportunity to go up there and have a great time." Peter

Unfortunately many family and social gatherings involve food and the larger the gathering, the more food present. This meant that controlling allergen exposure became increasingly more difficult as more people were involved.

"I think it's the holiday time...any time there is a family get-together is when my meter goes up." Leslie

"Most families just hop in the van and go to East Side Mario's for dinner or go to a family gathering where there is a pot-luck dinner and not worry

about the kids eating something. We have to [worry] and there is an emotional payment it takes.” Peter

Preparing for the unexpected takes time and was emotionally draining. When the event was seen as important, having to miss out would be disappointing.

“All of the family is going and he [husband] has one cousin that’s flying in from California with his three kids and I know it will be a lot of fun for my kids and a lot of fun for me but it’s a half hour drive from a hospital, it’s winter time and if there’s a huge snowstorm what do we do? Who knows what’s in that kitchen and dining room...So we’re deciding right now whether or not my husband is going to go by himself or if we’re all going to go. It worries me. It’s a huge worry.” Leslie

In some cases families opted to become the host of most family and social gatherings in order to exercise some control over the environment and food. This resulted in a great amount of preparation and work but in some cases there was really no other option.

“Everything is done at our house. Like Christmas, it’s always been done at our house. At least we know she’ll enjoy her day. She [daughter] won’t feel sick, she won’t have problems breathing, she won’t have an asthma attack. It’s better for her so our friends come here, we invite people for dinner, we try to do things like that.” Sarah

As a result, families with life-threatening allergies either accept a large amount of extra work to participate in social gatherings or experience a decline in the number of social events on their leisure calendars.

“Everyone else [friends], they don’t invite us because I guess it’s too much work. It’s not that we have had a fight, we just don’t hear from them. If we don’t invite people over, we won’t see them. So they’ll come here but you know, we don’t hear from them at all, they don’t call us anymore or anything like that so if there’s something going on with our old group of friends, they’ll go around to each other but we don’t get a phone call to say would you like to come. It’s hurtful but what can you do?” Sarah

When a decline in opportunities for friendship and social leisure was seen it was often associated with the concern over allergen exposure. This lack of social leisure further

added to the isolation experienced by the parents in this study. In addition, the parents who did not feel their social leisure was negatively impacted by anaphylaxis used phrases like “we are lucky that we have such good friends” that indicated they expect such negative consequences but have not yet experienced any.

Theme 4: The Increased Domestic Workload and the Changing Role of a Mother

The majority of life-threatening allergies are food related and this results in a significant increase in domestic workload. The domestic responsibilities of grocery shopping, food preparation, planning social gatherings, and childcare are all affected. Furthermore, in the case of anaphylaxis there may be an increase in time required for daily care since other medical conditions needing treatment such as asthma and eczema may be present. In addition, because the mother is often the parent gathering information it is also typically up to her to act as gatekeeper to this information and ensure it is passed on to those who need it while possibly enduring negative feedback. Finally, besides dealing with her own stress and emotions it is also often seen as a mother’s responsibility to ensure that her family is emotionally healthy. For all of these reasons the roles and responsibilities of the mothers in this study is particularly important to understand.

4.1 The Physical Domestic Workload

The most obvious increase in physical domestic workload occurred whenever food was involved. Families living with a food allergy experience an increase in time needed to complete grocery shopping and planning meals for the family and, for the most part, it was the mothers in this study who assumed the bulk of the responsibility for this work. Dealing with the limits on processed foods was often frustrating and meant that

many foods had to be prepared from scratch. This was extremely time consuming and took creativity and planning which was at times overwhelming for the mothers:

“I remember crying on our back porch because I couldn’t find any bread that was safe for Adrian. At that point he was allergic to milk, eggs, peanuts, tree nuts, citrus and wheat...I remember vowing to myself I would do everything I could to protect my child and to make his life as normal as possible. That’s when I started experimenting with baking. I have made hundreds of birthday cakes, pancakes, muffins and cookies. The best reward for me is when my kids, and their friends who can eat anything, devour what I’ve baked and don’t miss what’s not in it.” Leslie

“It’s a challenge to be creative when you’re going, ok, you can’t use spices and she reacted to some spices but it was a mixed spice so we really don’t know what was in it. It was one of those things where it was a steak mix so we don’t know what she reacted to....Packing lunches for school, its like oh God, what can I put in her lunch. It sounds so silly because you think back to when we were growing up, there was not a lot of preserved stuff or prepared cookies or anything. Our parents made everything. Well I get busy, I run Jim’s business, I have three kids and then you’ve got the baby at home and I’m trying to think ok, I’ve got to bake some muffins or something for a snack for tomorrow...” Sarah

Furthermore, occasions that are usually small reprieves for most parents were not experienced in that way when living with anaphylaxis. Birthday parties and dinners out were as much work, if not more, for these mothers. Often additional food had to be provided in these situations and any sense of a “break” was lost when mothers opted to accompany their child to birthday parties in order to ensure his or her safety.

“We recently went to a friend’s house for dinner and she was very careful to cook a plain roast with just carrots and potatoes... We were eating and Adam started getting hives behind his knee. He laid on the couch with a cold cloth behind his leg and said to me ‘Mommy, can you bring something for me to eat next time?’ I have no idea what gave him the hives but I know how sensitive he is and if any baking pan or utensils had traces of dairy, eggs or nuts that’s all it would take to give him a reaction. Next time I will bring his food.” Leslie

“Jordon went to a birthday party on the weekend and all the other parents dropped off their kids, I was baking all morning so he could have

something to eat there and I stayed there because who knows what's in that big play land that they're running around in. Other kids would be dropped off at friend's houses for birthday parties and there's so much planning involved in doing it and educating the people that he's going to be with and then trusting them to know what to do if something happens.”
Leslie

Many children with food allergies also experience varying degrees of asthma and eczema. Daily care for these conditions is demanding, may result in hospital stays, and can be very taxing for a family because of the extra work.

“Several years back it was really bad where over a month or two she was in the hospital about three times.” John

“Jordan's asthma has had a huge impact on our lives. He was not quite a year old when he got his first puffer and breathing tube as we call it.”
Leslie

Although hospital stays were relatively short (often only 1 night) they significantly disrupted an already burdened schedule. The children in this study who experienced eczema and asthma often had rigid dosing schedules and care routines to follow which sometimes occupied a considerable amount of time, and this, again, was usually the mother's time.

“...also her night-time routine, she has to have a bath and then we do her creams, she has to sit in the bath for 20 minutes with the oil then we have to do her creams. Bath time is usually about an hour so then you think, she needs to be in bed by 8:00 because she wakes up so much that she won't get up in the morning....” Sarah

4.2 The Emotional Domestic Workload

The mothers in this study realized early on that they would be the primary person responsible for their children's safety, with little conclusive expert advice. For instance, during pregnancy moms are expected to follow certain rules to ensure their unborn child receives the proper nutrition and care. However, there is an ambiguous message from

doctors about what foods to avoid during pregnancy in order to prevent introducing a potential allergen. Some of the mothers reported sense of guilt when their child developed an allergy to something she had eaten while she was pregnant. Some mothers discussed the fact that they thought they were doing everything “right” while they were pregnant and yet they were still concerned they may have inadvertently caused their child’s allergy.

“I nursed her. My son barely nursed because it didn’t work out. He’s the healthier of the two. I was by the book. I didn’t take a drop of alcohol or anything. They didn’t say anything about peanut butter. Now they’re saying not to eat peanut butter or nuts.” Beverly (daughter severely allergic to nuts)

Sometimes an allergy presented itself in the form of colic during infancy and it was very difficult to determine the offending food or to get support from a doctor without a clear allergic symptom.

“I remember feeling very helpless when Adrian was a baby and I couldn’t figure out why he was crying so much. Everyone had advice about what worked for their babies and nothing seemed to work for him. I took him to my mom’s family doctor when he was a couple of months old, wanting another opinion because my doctor was no help, and the doctor told me he was ‘thriving’ because he was gaining weight. I’ll never forget those words because in my mind something was not right that this child could cry as much as he did.” Leslie

Having a child cry constantly without appropriate advice or support from doctors can be stressful to parents and can equal distress years later (Rautava, Lehtonen, Helenius & Sillanpää, 1995). A time that was supposed to be full of wonder and love turned into desperation for one family as described below;

“I remember when Jordon was young, whether it was colic or food allergies the first year for him, I’ve never known sleep deprivation like I did with him. I remember at the time I was in Toronto and I remember it was February or March, so it was 3 months after he was born and I was driving home one evening, it was probably 7:30/8:00 at night, dark,

snowy...you know the kind of flurries that come right at the car and they're kind of blinding. I remember turning the radio up as loud as it would go, rolling the windows down, smoking a cigarette, I don't smoke normally,...I was slapping my face keeping myself awake during the drive home knowing that when I got home I was probably going to be up all night with a colicky or a baby who had food allergies. We didn't know why he was crying all the time but he was. You get so angry, not at him, but at the situation and you say 'oh God just get me through this'. You can understand how when a couple has kids it just breaks a marriage apart. The emotions you go through." Peter

This presents a very difficult challenge for families faced with a relatively new condition such as anaphylaxis that does not have a strong medical research base.

Confusion and frustration were often encountered as moms sought to advocate to their child's doctor or medical professional to convince them that their concerns were valid.

"It's like suddenly a light bulb has gone off and he realizes I'm not a paranoid mother and so then he changed his attitude." Sarah

"Yeah, and they think, oh, you're just panicking, I mean, she's got a couple of hives. They don't know what it was like before she had the epinephrine and then you start to question yourself, you doubt yourself. You're a paranoid mother because everyone else is telling you there's nothing wrong and so you start to beat yourself up." Sarah

Even with a supportive doctor and a diagnosis it can be difficult to recognize a reaction. Both mothers and doctors have been caught off guard with a reaction that strays from the narrow text book definition. As a result, moms are expected to recognize a reaction that a doctor may not be able to explain to them.

"They actually fed it to her (salmon) at Sick Kids because it didn't show on her skin. Nine to ten hours later that's when she had the reaction. She was asleep. They've said they've never seen it; they're baffled. They're supposed to be the one's who know." Sarah

"When Emma had these reactions, the weird reaction where there's no hives, now we've learned her blood pressure is dropping. It's just as serious as the hives if not more because you're looking for the hives and I've had to go back in and say 'ok, don't look for hives, if you see her changing colour, give her the Epi-pen'." Sarah

One mother recounted the story of how her son had a reaction to his brother's vomit beside him which highlights the fact that a mother can do everything she can think of and still be surprised by an allergen exposure. Another mother who had to administer the Epi-pen found it very difficult to remain calm and do what was needed to save her child. It was an extremely traumatic experience and shows just how much responsibility is placed on mothers to recognize and react in an emergency.

"I wasn't able to speak that time. I remember giving the Epi-pen and trying to get air in but I told myself after that time you have to think, you have to do this." Sarah

Not only did the mothers need to recognize an emergency themselves, the responsibility of coordinating an emergency plan fell solely on their shoulders as well. Consequently, they reported a great burden of emotional stress due to the fear of someone else not being able to recognize an emergency.

In addition to their own emotional health, mothers were focussed on ensuring that their children were coping with their own challenges. Specifically, children with life-threatening allergies live with restrictions everyday and it can be overwhelming for a child to feel that he or she is giving up something that no one else has to. Trying to ensure that their child did not miss out on treats was always a challenge for moms and often in the forefront of their minds.

"I think what was the hardest then was the fact that because she was 4 she had been able to live a normal life and was old enough to realize, it happened at Christmas time, she couldn't have the snacks that everyone else was having. Every week someone brought in a snack. That changed and she couldn't go to the same restaurants and she couldn't have the same treats, we couldn't buy some of the same ice creams. For her, I think that adjustment was quite hard because she was old enough. Had she been diagnosed as a younger child she wouldn't really realize what was taken away from her." Beverly

Making and keeping friends was also difficult for some children with severe allergies and this was upsetting for a child because belonging to a peer group is very important especially at certain ages. Sometimes children with allergies were left out of social peer gatherings due to the fear of others and this affected the mothers greatly.

“I feel bad for her because she doesn’t get invited to friends’ houses or birthday parties. She used to...It’s been difficult for her to have friends. We did a lot in school as well because now she’s in the eco room so they’re all like ‘you can’t play with us because you have too many allergies’.” Sarah

Seeing their children avoided or even ostracized was extremely painful for the mothers. To aid their children the mothers often advocated for their children to other parents. For example, some mothers made phone calls to the parents of their children’s friends in order to educate them on anaphylaxis in the hopes of alleviating any fear or resistance. When this failed it was often left to the mother to console her child and help him or her cope with their feelings.

Since allergic reactions are preventable and reasonably rare, mothers often concentrated on the prevention of reactions. Unfortunately reactions do occur and are extremely traumatic for all involved. It is not just the parents who experience the trauma but also the children themselves. One family had such an experience and their daughter is struggling now with the emotional aftermath of a near fatal reaction.

“We’ve seen a huge change in her emotionally and the bullying at school added a lot of stuff so she’s just not been dealing well with anything...she thinks she’s going to die, like she feels very vulnerable and after having more of these tests come back...she doesn’t want to go because she’s afraid. She tells us all the time, ‘I don’t want to go to Sick Kids’....I think it is the fact that Emma wants to be normal and because she doesn’t feel normal and she has high, high anxiety because she went to bed and had this reaction. At bedtime, that’s it. She doesn’t want to go to bed...” Sarah

Probably the most emotionally charged aspect of severe allergies is the fact that death is a possibility. It may be preventable and even rare, but it is a reality and many mothers found that they needed to talk proactively with their child about his or her own mortality. Children with life-threatening allergies learn at a very young age that they could die from something as mundane as food but the mothers in this study found the topic of death, though a necessity, disturbing to hear second-hand.

“It breaks my heart when I hear the kids say ‘Jordon, that could kill you’, but I know they are trying to help him and trying to deal with it themselves.” Leslie

In the region that this study took place, there is no support group for children and therefore it is up to the parents to ensure their children are dealing with the emotional impact of anaphylaxis and their allergy. Again, it was the mothers who reported concern over their children’s emotional state and bore the responsibility of providing continuous emotional support.

4.3 The Changing Role of a Mother

As with any major medical diagnosis, there is a need to seek out relevant information in order to cope and maintain a state of homeostasis. In terms of a diagnosis of anaphylaxis there is not only a need to assemble information but to pass it on to other people involved in a child’s life. In every family interviewed for this study it was the mother’s responsibility to gather, manage, and disseminate such information to her spouse and others. Learning how to manage an allergy became time-consuming and an on-going process.

*“I’ve really immersed myself in education for a year and a half...”
Beverly*

The fathers in this study explicitly spoke of how their wives assumed all of the responsibility for collecting information and educating the family. In most cases, the information the fathers gained on anaphylaxis was directly told to them by their wives.

“Robin learned it and told me.” Kevin

“She knows far more about it than I do. She’s done all the research, all the reading. For example, the seminar the other night, she asked if I wanted to go and I said ‘yeah I’d go’ then I’d sit there, it’s not that I don’t want to go but you would ask more detailed questions and you’d get more out of it than I would. It’s not that it wouldn’t be a good learning opportunity for me, really we both should go but if one of us is going to go, you’re going to get more information and you’ll be able to get more detailed information than I would and in that regard I think you should be the one to go. And that is how the decision went.” Peter

Many mothers took on the additional responsibilities at schools, daycares, and various associations in order to educate and provide information for policy planning.

“...I became very involved in the local group and I joined the Speaker’s Bureau and I was trained through Anaphylaxis Canada and I helped write the school board procedures. It has taken a long time but it was a cause I felt I needed to give to. So although I never wanted to be a speaker and I really didn’t want to put the time into the procedures, I felt that I had something to offer and that was more important than anything...” Beverly

With increasing demands, both physical and emotional, many mothers decided to give up their employment, work only on a part-time basis, or remain at home after their maternity leave. In many cases they felt they had no other reasonable option as the responsibilities of raising a child with anaphylaxis became a full-time job itself.

“It was when Adrian had all his allergies that I was working full time, I couldn’t do it. I was cooking all weekend for him so that I had food to feed him during the week.” Leslie

As in similar studies, (particularly Mandell et al., 2005) the mother’s decision to remain home was born out of a combination of increased domestic workload and the fear of

relinquishing responsibility to a daycare or other care provider. This was also a common concern for the mothers in this study.

“She was 4 and I had taken some time off before she went to school and I extended it and I actually took a year and a half off. I didn’t feel comfortable enough to send her off to school.” Beverly

Although not fully discussed in the interviews it was suggested by some parents that raising a family on a single income had significant impact on a disposable income. As explored earlier, this decrease in disposable income was as much a deciding factor in regards to family leisure, specifically travel, as dealing with the allergy itself.

Summary of Themes

As explored through the emerging themes of this study, the families living with anaphylaxis experienced a deep emotional impact that continued past the initial diagnosis. Feelings such as fear, shock, and paranoia were experienced by all the parents interviewed for this study and impacted all areas of their lives. The initial shock of a diagnosis of a life-threatening allergy was followed by intense feelings of fear and paranoia as parents realized how pervasive a particular allergen was in their daily lives. To these parents a usually harmless food had become a very serious, and potentially fatal, threat to their children. The emotional impact following diagnosis led to action plans that were used to decrease the risk of accidental allergen exposure. However, when a new situational threat was encountered the parents reported that their earlier feelings of fear and paranoia resurfaced. Therefore, any feelings of security were relatively short-lived and provided little comfort to the parents.

Furthermore, difficulties surrounding community support created feelings of isolation for the parents in this study. Parents discussed how the lack of support and

negative reactions from the community led them to feel alone and frustrated. In addition, some parents experienced the loss of friendships and family relationships as a direct result of their child's allergy. Social leisure was often identified in the interviews as being negatively affected by the need to limit the risk of allergen exposure. Even when parents did not experience any direct negative consequences they spoke of feeling "lucky" and thankful that they had family and friends who understood and were accommodating as if they realized their situation was uncommon.

The increased feelings of anxiety, fear, and paranoia coupled with the problems with community support made family time and family leisure much more challenging. In order to participate in family activities, parents often needed to undertake a considerable amount of pre-planning and information gathering. For some types of leisure, the risk involved was too high and those activities were avoided. Travel was described as being particularly difficult and therefore home-based activities were the commonly chosen alternative.

In general, it was the mothers who were primarily responsible for planning and facilitating family leisure in addition to taking on much of the increased domestic workload. In contrast, fathers accepted a more supportive role within the family and followed the lead of their wives in terms of allergy management. As a consequence of their new and demanding role, many mothers remained at home at least part-time. These mothers felt they had no other viable option as their new responsibilities constituted more than a full-time commitment.

The themes discussed in this chapter show that anaphylaxis affects families in many different ways. Allergen management is more than following dietary restrictions

and affects each and every member of a family. The experiences of living with anaphylaxis encompass intense emotional journeys and new role responsibilities for everyone, especially mothers.

CHAPTER 5: DISCUSSION

This study utilized a systems theory approach and followed the premise that families are systems that seek a balanced state, interact with their environment, and are goal directed to explore the impact of anaphylaxis on families, especially parents, and to examine its impact on family leisure practices. Five research questions guided the inquiry relating to experiences and meanings of anaphylaxis, experiences and participation in family leisure, valuations and meanings of family leisure, caregiving as a constraint to family leisure, and gender considerations.

Since parents of children with anaphylaxis have received little attention in social sciences research and never from a leisure perspective, this study provides new insight into how anaphylaxis affects parents and families, including its effect on family leisure. Thus it adds to existing literature on chronic illness as well as to the leisure literature.

Towards Understanding: Emergent Themes and Insights

Four emergent themes were discussed in the previous chapter, The Emotional Journey, Seeking Community Support and Dealing with Negative Feedback, Impact on Family Leisure, and The Increased Domestic Workload and the Changing Role of Mother. The following discussion reviews the emergent themes found in this study and provides comparisons and contrasts to existing literature after which study significance, limitations, future directions, and final thoughts are offered.

The Emotional Journey

This core theme focused largely on the early emotions surrounding a diagnosis of anaphylaxis and how the families adjusted to their new lifestyle. All parents described

intense feelings of fear, paranoia and shock immediately following their child's diagnosis and how such feelings arose from coming to understand how pervasive the allergen was and that it was a significant threat to their child's life. At the same time, parents expressed that they felt an urgent need to learn how to limit allergen exposure and many were worried about the impact the changes in the family's lifestyle would have on siblings without allergies. Finally, parents expressed how their feelings of fear and paranoia only subsided to reappear when new situations were encountered, thus these feelings remained close to the surface and were never fully absent.

These findings are similar to Eiser's (1987) four stages of reaction to the diagnosis of a life-threatening condition. She describes the four stages as;

1. shock or disbelief
2. denial:
 - described as a longer period during which parents may seek alternative opinions and/or experience anger and frustration
3. intellectualisation:
 - during this phase parents actively seek to learn and understand their child's condition but may also experience feelings of guilt "questioning if they sought medical advice early enough, or if they precipitated the disease by some action of their own" (p. 224).
4. adaptive phase:
 - this is the longest phase during which the family learns to manage the illness and its demands

Austin (1990) also describes four phases of adaptation to a chronic illness such as asthma, which include disbelief or denial, anger, information seeking, and acceptance. Both authors describe phases that resemble reactions exhibited by the parents in this study. Specifically, all the parents in this study described being shocked and some experienced varying degrees of denial. The mothers then sought out information and relayed it to other family members and persons of interest. All parents discussed rules and routines that were implemented as they began to adapt to their new life-style. However, constant

vigilance was required and families would return to the intellectualisation or information seeking phase often as new developmental stages were encountered or new information was discovered. Thus, the need for vigilance was constant and this produced a high level of stress for the parents in this study. This type of pattern was also described by Mandell et al. (2002). Similarly, it is the belief within the chronic illness literature that daily stressors and uncertainty may lead to an increase in psychological symptoms more so than single major life events (Eiser, 1987; Compas et al., 1989). Therefore the cumulative impact of anaphylaxis may be particularly important to understand before effective support can be offered to these families. This is because a single point in time may not provide enough detail for assessment.

Turner (1998) lists additional impacts of chronic illness on families, such as greater financial strain, negative effect on mothers' careers, and the risk of social isolation as "[f]atigue and worry may interfere with their ability to relax and enjoy friends and be good company" (p. 47). Further, with respect to anaphylaxis, Primeau adds, "[i]t is anticipated that the frustration from avoidance of numerous food products,...combined with the fear of accidental ingestion, lead to significant psychological distress and social restrictions compromising patient and family well-being" (Primeau et al., 2000, p 1136). Mandell et al. (2005) found similar consequences in their study of families living with anaphylaxis, particularly negative consequences on mothers' careers and inadequate social support. The results of this study are consistent with Mandell et al. (2005) and Turner (1998) with regard to impacts of chronic illness on the family.

However, the impacts of anaphylaxis are not contained exclusively within the immediate family. Anaphylaxis must be managed in public where the actions of another

person could prove potentially fatal. As a result, parents of children with anaphylaxis are often required to seek support from others and endure negative feedback in order to ensure the safety of their children. The following sections explore this issue from the perspective of daily life and family leisure.

Seeking Community Support and Dealing with Negative Feedback

Parents in this study discussed at length the difficulties they experienced regarding the lack of public education about life-threatening allergies. These parents often encountered negative reactions when they attempted to educate others or initiate changes that would protect their children. Such negative reactions were common from extended family members, friends, and members of the general public and resulted in high levels of frustration and feelings of isolation for the parents, especially the mothers.

Within the social science literature, the quality of life of persons living with anaphylaxis and their family had not been explored prior to a few years ago (Primeau et al., 2000) and has received little attention to date (Mandell et al., 2005). However, the lack of social support and the negative impacts anaphylaxis has on relationships has been key findings by both Primeau et al. (2000) and Mandell et al. (2002; 2005). A positive perception and interpretation of social support is thought to protect against emotional distress when coping with a chronic illness (Wallander & Varni, 1998), but Primeau et al. (2000) found that coping with a peanut allergy leads to greater impairment in social interactions compared to living with a rheumatological disease. This is thought to be because of the restrictions associated with severe allergies. Mandell et al. (2005) also found that relationships were often disrupted due to the lack of understanding of

anaphylaxis, people's unwillingness to accommodate the family's needs, and even frank hostility. This results in a greater sense of isolation.

The results of this study offer additional detail into the struggles encountered by parents seeking to obtain support from extended family members, friends, and the community. This type of support was seen to be vitally important because allergen exposure could result in serious consequences. For the parents, educating and seeking to obtain compliance with necessary restrictions from others was a stressful and time-consuming task. When parents encountered resistance from others they either chose not to associate with such people if at all possible or they became even more active as advocates for change. Unfortunately both of these pathways exacerbated feelings of isolation. Although isolation as a theme has been mentioned in previous literature (e.g. Mandell et al., 2005), the results of this study indicate that feelings of isolation are directly related to one's role of advocate or educator. In other words, the need to ask others for support made parents feel like there was a division between themselves and others, or between those who understood allergies, and those who did not. This translated into parents feeling like they were part of a minority and not like other families who do not have the same kind of needs.

Impact on Family Leisure

Although leisure was highly valued and engaged in often, it was also a common area of challenge for the families. Social gatherings and travel were difficult due to the demands of planning and the amount of risk involved and this led to further feelings of isolation.

The dynamic nature of leisure, which often involves different locations, people, and environments often increased feelings of fear for the parents in this study. Travel was particularly challenging and often was not seen as an option, or a less appealing alternative was chosen in an attempt to reduce the amount of risk and subsequent feelings of fear. This was highlighted when the parents reported that their “leisure wish” was to be able to travel safely as a family anywhere they wanted to. For all of them, this was an unobtainable ideal.

Many researchers corroborate the belief that social support is beneficial to the adjustment of the family when living with chronic illness and other forms of stress (e.g. Kazek et al., 1998; Mandell et al., 2002; Tunali & Power, 2002; Wallander & Varni, 1998), and can be achieved within a leisure environment (e.g. Coleman, 1993; Coleman & Iso-Ahola, 1993; Hutchinson et al., 2003). However, social support was often difficult to obtain for those living with life-threatening allergies. Social isolation affected family leisure opportunities due to the fact that social networks were smaller and large gatherings were avoided in order to control allergen exposure. Moreover, even small trips and small social gatherings created many challenges for parents, as they sought to ensure that these events were safe for their children. A key finding of this study was the fact that parents felt overwhelmed at times in terms of the amount of pre-planning required to participate safely in many family leisure activities and this workload increased significantly for activities further from home.

The work associated with planning and participating in family leisure is not a new concept (Shaw, 1985a; 1992) and has been documented as being severe in families with a child with a developmental disability (Mactavish & Schleien, 2004). However, families

living with anaphylaxis must manage increased planning demands in addition to assessing the amount of risk involved in participating in certain activities or traveling to different locations. Given that accidental ingestion is more common outside the home (Sicherer, Furlong, Muñoz-Furlong, Burks & Sampson, 2001), the fear of experiencing a reaction away from home would be expected in this population.

The impact of the fear of an allergic reaction during family leisure time is similar in some ways to experiences reported by Whyte and Shaw (1994) in their study of fear of violence as a leisure constraint for women. Specifically, Whyte and Shaw noted that fear led the women in their study to either reduce their participation in leisure or alter their patterns of participation which resulted in a reduction of enjoyment. Similarly, all of the families in this study discussed reducing their participation in activities such as dining out at restaurants or travelling, and all had at times chosen not to participate at all if they felt the risk of exposure was too high.

In addition, this study supports the work of Weinblatt and Navon (1995) who described how individuals negatively viewed leisure and actively avoided it as a means of coping with the hardships of caregiving. Although viewed from a different perspective, the results of this study also seem to support the idea that some forms of leisure may be viewed as threatening and may be actively avoided. For example, one mother noted that if her daughter were to have an allergic reaction while they were traveling they probably would decide to stop traveling permanently due to their fear of another reaction.

The lack of opportunities to travel safely and to socialize with family and friends was seen as disappointing by the parents. They viewed such limitations as missed opportunities to expand their children's sense of culture, family, and the world in general.

Like parents in previous studies of family leisure (Shaw & Dawson, 2001), the parents in this study valued family leisure for the many benefits it could provide. However, they faced much greater restrictions compared to other families because of the challenges associated with attending family gatherings or accompanying friends on outings and trips.

It was also evident that there was a clear division between the types of activities that parents spoke of as being constrained or problematic, and those that they participated in regularly. This distinction between types of activities relates to the Core and Balance Model put forth by Zabriskie & McCormick (2001). The results of this study suggest parents of children with anaphylaxis focus their family leisure time more on home-based activities or core activities. Specifically, activities such as going for walks, watching movies, playing in the yard or at neighbourhood parks were engaged in often, but balance activities such as traveling, or attending theme parks were described as being constrained. Given that balance activities are hypothesized to result in a positive perception of family adaptability (Zabriskie & McCormick, 2001) such activities would seem particularly advantageous to families living with chronic illness. Unfortunately these were the activities that were feared, avoided, or problematic for the families in this study. Clearly, more research is needed to explore how different activities contribute to family functioning. Nevertheless, populations that experience a bias in opportunity to either core or balance activities may provide valuable insight for this path of inquiry.

Little attention has been paid to issues of leisure or family leisure in the existing literature on chronic illness. This study contributes to that literature by exploring the impact of anaphylaxis on family activities. It has shown the importance of this form of leisure for families living with anaphylaxis. This study also contributes to the family

leisure literature by revealing the tremendous difficulties associated with managing allergen exposure in a variety of family leisure situations and environments.

The Increased Domestic Workload and the Changing Role of Mother

It was evident throughout the interviews that mothers assumed much of the increase in physical domestic workload (i.e., cooking from scratch, daily cleaning to reduce environmental allergens, and grocery shopping) associated with managing their child's allergies. Secondly, mothers assumed a large emotional workload as some experienced feelings of guilt that they may have inadvertently caused their child's allergy during pregnancy. Third, many expressed their constant concern over their children being left out of events due to their allergy, and they were worried about how their children were coping with restrictions and fear surrounding a reaction. In addition, mothers took on the added work of being responsible for their child's safety. This was also emotionally draining due to the fact that the locus of responsibility rested solely on their shoulders and was a large burden to bear. This increase in workload, both physical and emotional, led the mothers to adopt new roles both within and outside of the family. These new roles were time consuming and often described in terms of a life-long role that requires years to master. The majority of mothers reduced the amount of time devoted to paid work in order to accommodate these new roles and to fulfill their perceived need to be physically close by their child at all times in case of an emergency. Young et al. (2002) indicate that this "obligation of proximity" (p. 1837) comes at a high price to self-identity, a mother's own needs, and other role functions as they become consumed with caring for their children. Similarly, mothers of children with autism "placed more emphasis on parental roles and less emphasis on career" (Tunali & Power, 2002, p. 29)

and subsequently redefined what equals fulfillment in their lives in order to adjust to their role shift.

The need for constant vigilance both inside and outside the home led many families to designate one primary parent to this job. In this study it was the mothers who took on this responsibility as most of them had not yet returned to the workplace. This also meant that it was the mothers who were responsible for conversing with doctors and other health professionals, as well as school personnel. It was the mothers who assumed the role of advocator and educator in most situations.

As the mothers became advocates and protectors of their children, they often were the target for negative comments and reactions. This need to protect their children was often characterized as being perceived by others as a “paranoid mother” or being pushy, even within the medical community. Mandell et al. explain that such “...anxiety is frequently interpreted as overreaction, overprotection, a sign of a neurotic mother, or the result of alarmism in the patient community” (2002, p.96). Consequently, mothers often felt that their instincts and their opinions were not taken seriously.

Similarly, mothers also accepted a major portion of the emotional work associated with managing anaphylaxis. The mothers described feeling a strong responsibility to absorb any negativity directed at the family in order to shield their children from having to experience it as well. As a result, the mothers actively sought to provide alternatives in restrictive situations to ensure that their children were not left out or ostracized. This desire to lessen their children’s burden was also found in Young et al.’s study of mothers of children with cancer. This “...particularly strong theme...[describes] their emotional

interdependence with their children, and a suggestion that they ought to share in or help to carry the burden of their children's experiences" (2002, p. 1841).

Finally, since mothers were more involved in managing their children's allergies, they were also the parent largely responsible for planning and ensuring safety during family leisure activities. Although previous literature has identified the fact that mothers are often the parent responsible for planning and facilitating family leisure (e.g. Shaw, 1985a; 1985b; 1992), the increased demands faced by those living with anaphylaxis means a significant amount of extra work in this regard. Clearly, fathers were involved in the decision making and facilitation of family leisure as well. However, it was usually up to the mothers to identify and "troubleshoot" potential risks. This need to foresee trouble meant that even more time was devoted to planning and organizing any leisure activity for the mothers.

The large amount of physical and emotional work discussed above became a full-time commitment for the majority of mothers in this study. Many expressed concern over whether they would be able to return to full-time paid work and still be as vigilant and available for their children. The impact of these demands on mothers' personal lives, including personal leisure, is an area worthy of further investigation.

A Comment on the Role of Fathers

The centrality of the mother's in families with anaphylaxis occupied much of the conversation with both mothers and fathers in this study. The role of father was given less attention, but is a topic that also deserves comment.

During their interviews, fathers described the large amount of physical and emotional responsibility assumed by their wives and spoke of their own role as being

mostly supportive. This helping or supporting role has been documented in research in families living with autism (Schneider, 1999), cancer (Young et al., 2002), and anaphylaxis (Mandell et al., 2002) as well as in average modern families (Berry & Rao, 1997).

However, “parental stress experienced by fathers has received limited research attention” (Berry & Rao, 1997, p. 398) and as suggested by the results of this study, may be overshadowed by the attention given to mothers during data collection and analysis. In terms of the impact on children, Compas et al. (1989) argue that

[f]rom the perspective of a cognitive model of stress...fathers’ symptoms held considerably greater emotional meaning for...young adolescent boys and girls than did symptoms of psychological distress displayed by their mothers. Given the higher base rate of a variety of symptoms reported by mothers in this sample, fathers’ symptoms may be more salient and have greater impact because they occur less often (p. 556).

It is therefore possible that what a father does in a ‘supportive role’ may have just as much impact on family functioning as a mother’s ‘central role’ and should not be seen as any less important.

Obviously more research needs to be done to further explore the stresses and strains experienced by fathers and how they react to these challenges. The research methods employed may need to be modified to ensure fathers are given every opportunity to discuss their feelings in the most comfortable way possible. It appears without specific targeting of fathers’ perspectives it may be difficult to uncover these complex issues and the significance of the role that fathers play in families with anaphylaxis and other chronic illnesses.

Study Significance

This study offers insight into the experiences and perspectives of a population that has been given little or no attention in the chronic illness or the leisure research literature. The emotional challenges faced by parents in this study offers support to recent work on the effects of chronic stressors on family functioning. The study indicates that families living with anaphylaxis require immediate and continuous emotional support beyond purely medical information. Furthermore, the focus on leisure revealed additional issues and challenges for parents. In particular, the challenges documented in regards to travel, and the experiences of social isolation indicate that this population is severely constrained in their opportunities for certain leisure pursuits. Some links have been suggested between this study and the concept of a “flight from leisure” (Weinblatt & Navon, 1995), as well as the role of fear in planning and experiencing leisure (Whyte & Shaw, 1994). In addition the study expands the research on family leisure by paying attention to the additional constraints to leisure experienced by families with a child with anaphylaxis.

The number of children diagnosed with allergies is increasing and in 2001 56% of Canadians reported knowing someone with a peanut or a nut allergy (Ipsos-Reid, 2001). This study indicates that it is not just health services and educational institutions that need to be prepared for, and respond to, this situation, and provide support for parents. The leisure services industry also needs to take account of this situation and to respond in appropriate ways if leisure opportunities are going to be available for all families. This study represents a first step towards identifying and understanding the leisure needs of families with anaphylaxis.

Theoretical Significance

Systems theory, as described in Chapter 3, is based on the idea that systems need to be viewed as a whole and that understanding cannot be achieved only by analyzing individual parts (Klein & White, 1996). Therefore, this study sought to look beyond simply the experiences of children with allergies and their mothers, to include fathers' experiences as well as parental insights into the experience of siblings. As a result, a fuller understanding of anaphylaxis and its impact on families was achieved.

In addition, this study showed that all members of the family are deeply affected by having a child with anaphylaxis. In some ways the effects on different family members were similar, but there were also differences in the nature and degree of effect and on responses. In addition, the responses of individual family members (e.g., mothers) affected the responses of other family members and the adjustment of the family as a whole (the system).

Finally, systems theory assumes that a system is not isolated from its environment (Klein & White, 1996) and that we must take into account the effect of external relationships. In this study, the effects of anaphylaxis went beyond the immediate family and included interactions with extended family, friends, schools and daycares, and the community at large. The different ways in which the family interacts with, affects, and is affected by community and community responses was explored in this study and should continue to be taken into account when studying the impact of anaphylaxis.

Limitations

This study was conducted with two-parent families of which the majority were Caucasian, English speaking Canadians. Specific issues, concerns and challenges may be

different for different types of families. Further research is needed with parents living in different circumstances. In particular, single parents may have even greater difficulties with the parenting workload alone, and families who speak limited English may have difficulty reading labels or communicating needs. In this study information was relayed through the parents rather than directly from children. Thus the interactional processes between individuals within a family and the experiences of the children themselves were not fully explored. Further research is needed to explore these issues as well.

Future Directions

The primary aim of this study was to expand on the limited amount of research exploring the psycho-social affects of anaphylaxis on families. However, much of the data collected in this study was from families seeking to prevent reactions and did not include families that have had to administer the epi-pen (with the exception of one family). It is essential that future research include stories from those who have experienced what so many families are desperately trying to avoid in order to gain a more complete understanding of the impact of life-threatening allergies. Specifically, post-traumatic stress may be present for both the allergic individual and other family members after a life-threatening reaction. This issue was addressed by one family in this study, but there is a lack of discussion in the literature about the subsequent consequences of this type of experience. Mullins (2002) noted that “[r]eactions are frightening for the patient, their family and other caregivers” (p. 59) but there has been no follow-up investigation with patients after a severe allergic reaction to discover long-term implications of such an event. Recent recruitment efforts for a study testing a new

immunodrug elicited little response as individuals did not want to chance reliving an allergic reaction, even in a controlled setting with medical services (Merz, 2003).

Secondly, the voices of children living with anaphylaxis need to be heard in future research. Intense peer-pressure and bullying has been noted in literature on anaphylaxis (e.g. Mullins, 2002), but there has been no research conducted with children and teens themselves to explore these phenomena, or any other area of their lives. Mandell et al. (2005) reported that all the parents involved in their study described their children as having experienced negative feelings in regard to restrictions on activities such as birthday parties and school trips. Worchel-Prevatt et al. (1998) emphasize the importance of positive experiences at school and within peer groups since “[a] positive experience at school can help children achieve a sense of mastery and control, increase self-esteem, promote fulfilling peer relationships, and decrease emotional trauma resulting from [their] disease” (p. 261). One family in this study did indicate that their daughter had been a victim of bullying directly related to her allergies and that she experienced emotional distress while being segregated in an “eco-room” (a room designed to reduce allergen exposure). In addition, children may experience family leisure differently than their parents as described in previous studies (e.g. Zabriskie and McCormick, 2001) and therefore the parental experiences described in this study cannot be assumed to be the same as they would be for the children. It would be extremely beneficial to conduct further studies from the perspective of children and teens living with anaphylaxis in order to begin to understand how their lives are impacted by life-threatening allergies.

Finally, in regards to leisure, we must ask what consequence does the lack of spontaneity and lack of ability to travel have on families. Are there specific benefits

associated with being spontaneous or traveling that these families are missing? This needs to be explored as well as the impact on the travel industry if they are losing this portion of the market. Could allergy friendly destinations increase the potential North American market?

Final Thoughts

I found the process of completing this project extremely rewarding and I felt a strong bond with the parents who participated in this study. I hope they found sharing their stories as rewarding as I did telling them. It is our hope as a group to use this project as a means to raise awareness of the challenges facing families living with anaphylaxis and begin to offer support to those who will face such a diagnosis in the near future.

REFERENCES

- Austin, J.K. (1990). Assessment of coping mechanisms used by parents and children with chronic illness. Maternal Child Nursing, 15, Pp 98-102.
- Anaphylaxis Canada (2003). [Website Available Online] www.anaphylaxis.ca
- Berry, J.O., & Rao, J.M. (1997). Balancing employment and fatherhood: A systems perspective. Journal of Family Issues, 18(4), Pp 386-402.
- Cadman, D., Boyle, M., Szatmari, P., & Oxford, D.R. (1987). In J.L. Wallander and J.W. Varni (1998). Effects of pediatric chronic physical disorders on child and family adjustment. Journal of Child Psychology and Psychiatry, 39(1), Pp 29-46.
- Calem, R., Gregg, L., Simpson, B, Morris, J., Woodcock, A., & Custovic, A. (2003). Childhood asthma, behaviour problems and family functioning. Journal of Allergy and Clinical Immunology, 112(3), Pp 499-504.
- Carisse, C. (1975). Family and leisure: A set of contradictions. The Family Coordinator, 24(2), Pp 191-197.
- Coleman, D. (1993). Leisure based social support, leisure dispositions and health. Journal of Leisure Research, 25(4), Pp 350-361.
- Coleman, D., & Iso-Ahola, S.E. (1993). Leisure and health: The role of social support and self-determination. Journal of Leisure Research, 25(2), Pp 111-128.
- Compas, B.E., Howell, D.C., Phares, V., Williams, R.A., & Ledoux, N. (1989). Parent and child stress and symptoms: An integrative analysis. Journal of Developmental Psychology, 25(4), Pp 550-559.
- Copeland, A.P., & White, K.M. (1991). *Studying Families*. Newbury Park: Sage Publications.
- Crawford, D.W., & Godbey, G. (1987). Reconceptualizing barriers to family leisure. Leisure Sciences, 9, Pp 119-127.
- Crawford, D.W., Jackson, E.L., & Godbey, G. (1991). A hierarchical model of leisure constraints. Leisure Sciences, 13, Pp 309-320.
- Doherty, W., & Carlson, B. (2003). Overscheduled kids, underconnected families. In *Take back your time: Fighting overwork and poverty in America*. John de Graaf (Ed.) Pp 38-45. Barrett-Koehler Inc.

- Dyck, V., & Daly, K. (2006). Rising to the challenge: Fathers' role in the negotiation of couple time. Leisure Studies, 25(2), Pp 201-217.
- Eiser, C. (1987). Chronic disease in childhood. In *Coping with disorder in the family*, Orford, J. (Ed.), Pp 217-237. Croom Helm Ltd.
- Freysinger, V.J. (1994). Leisure with children and parental satisfaction. Journal of Leisure Research, 26(3), Pp 212-226.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. Social Science and Medicine, 45(8), Pp 1207-1221.
- Folkman, S., & Moskowitz, J.T., (2000). Stress, positive emotion and coping. Current Directions in Psychological Science, 9, Pp 115-118.
- General Social Survey: Time use. (1999). The Daily. Statistics Canada [Online] Available: www.statcan.ca/Daily/English/991009/d91109a.htm
- Hamlett, K.W., Pellegrini, D.S., & Katz, K.S. (1992). Childhood chronic illness as a family stressor. Journal of Pediatric Psychology, 17(1), Pp 33-47.
- Henderson, K.A. (1997). A critique of constraints theory: A response. Journal of Leisure Research, 29(4), Pp 453-457.
- Henderson, K.A., & Allen, K.R. (1991). The ethic of care: Leisure possibilities and constraints for women. Society and Leisure, 14(1), Pp97-113.
- Henderson, K.A., Bialeschki, M.D., Shaw, S.M., & Freysinger, V. (1996). *Both Gains and gaps: Feminist perspectives on women's leisure*. State College, P.A.: Venture Publishing.
- Henderson, K.A., Stalnaker, D., & Taylor, G. (1987). Personality traits and leisure barriers among women. Paper presented at the Fifth Canadian Congress on Leisure Research, Dalhousie University, Nova Scotia, May 1987.
- Hill, M.S. (1988). Marital stability and spouses shared time. Journal of Family Issues, 9(4), Pp 427-451.
- Hochschild, A. (1998). The second shift: Employed women are putting in another day of work. In *Men's Lives* (4th ed.), M.S. Kimmel and M.A. Messner, (Eds.), Pp 237-249. Allyn and Bacon.
- Holman, T., & Jacquart, M. (1998). Leisure activity patterns and marital satisfaction: A further test. Journal of Marriage and the Family, 50(1), Pp 69-77.

- Horna, J. (1989). The leisure component of the parental role. Journal of Leisure Research, 21(2), Pp 228-241.
- Hutchinson, S.L., Loy, D.P., Kleiber, D.A., & Dattilo, J. (2003). Leisure as a coping resource: Variations in coping with traumatic injury and illness. Leisure Sciences, 25, Pp 143-161.
- Ipsos-Reid (2001). Awareness of peanut or nut allergies amongst Canadians. Retrieved from www.anaphylaxis.ca/content/whatsnew/hot_topics.asp. October, 2003.
- Iso-Ahola, S.E. (1984). Social psychological foundations of leisure and resultant implications for leisure counselling. In E.T. Dourl (Ed.) *Leisure counselling: Concepts and applications*. Springfield, IL: Charles C. Thomas.
- Iso-Ahola, S.E., & Park, C.J. (1996). Leisure related social support and self-determination as buffers of stress-illness relationship. Journal of Leisure Research, 28, Pp 169-187.
- Iwasaki, Y., & Smale, B.J. (1998). Longitudinal analyses of the relationships among life transitions, chronic health problems, leisure and psychological well-being. Leisure Sciences, 20, Pp 25-52.
- Iwasaki, Y., & Mannell, R. (2000). Hierarchical dimensions of leisure stress coping. Leisure Sciences, 22, Pp 163-181.
- Jackson, E.L. (1988). Leisure constraints: A survey of past research. Leisure Sciences, 10, Pp 203-215.
- Jackson, E.L. (1997). In the eye of the beholder: A comment on Samdahl & Jekubovich (1997), "A critique of leisure constraints: Comparative analyses and understandings". Journal of Leisure Research, 29(4), Pp 458-468.
- Jackson, E.L., & Henderson, K.A. (1995). Gender-based analysis of leisure constraints. Leisure Sciences, 17, Pp 31-51.
- Kay, T. (2006). Editorial: Fathering through leisure. Leisure Studies, 25(2), Pp 125-131.
- Kay, T. (1998). Having it all or doing it all? The construction of women's lifestyles in time-crunched households. Society and Leisure, 21(2), Pp 435-454.
- Kazek, A.E., Stuber, M.L, Barakat, L.P., Meeske, K., Guthrie, D., & Meadows, A.T. (1998). Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. Journal of the American Academy of Child and Adolescent Psychiatry, 37(8), Pp 823-831.

- Kelly, J.P. (1999). Leisure behaviours and styles: Social, economic, and cultural factors. In E.L. Jackson & T.L. Burton (Eds.) *Leisure studies: Prospects for the twenty-first century*. State College, P.A.: Venture.
- Kleiber, D.A., Hutchinson, S.L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences*, 24, Pp 219-235.
- Klein, D.M., & White, J.M. (1996). *Family theories: An introduction*. Thousand Oaks: Sage Publications.
- Knafl, K.S., & Deatrick, J.A. (1987). Conceptualizing family response to a child's chronic illness or disability. *Family Relations*, 36(3), Pp 300-304.
- LaRossa, R. (1998). Fatherhood and social change. In *Men's Lives* (4th ed.). M.S. Kimmel and M.S. Messner (Eds.), Pp 237-249. Allyn and Bacon.
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- MacTavish, J., & Schleien, S. (2004). Re-injecting spontaneity and balance in family life: Parent's perspectives on recreation in families that include children with developmental disability. *Journal of Intellectual Disability Research*, 48(2), Pp 123-141.
- Mailick, M., Holden, G., & Walter, V. (1994). Coping with childhood asthma: Caretaker's views. *Health and Social Work*, 19(2), Pp 103-111.
- 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. *Allergy and Clinical Immunology International*, 14, Pp 96-101.
- Mandell, D., Curtis, R., Gold, M., & Hardie, S. (2005). Anaphylaxis: How do you live with it? Informational and support needs for family coping. *Health and Social Work*, 30(4), Pp 325-336.
- Merz, B. (2003). Studying peanut anaphylaxis. *The New England Journal of Medicine*, 348(11), Pp 975-978.
- McKenry, P.C., & Price, S.J. (2000). Families coping with problems and change; A conceptual overview. In McKenry & Price (eds.) *Families and change* (2nd Ed.). Thousand Oaks: Sage Publications.

- Miller, R., Sabin, C.A., Goldman, E., Clemente, D., Sadowski, H., Taylor, B., & Lee, C.A. (2000). Coping styles in families with haemophilia. Psychology, Health and Medicine, 5(1), Pp 3-12.
- Mullins, R. (2002). Anaphylaxis. Current Therapeutics, 23(2), Pp 59-64.
- Orthner, D. (1975). In T.B. Holman and M. Jacquart (1988). Leisure activity patterns and marital satisfaction: A further test. Journal of Marriage and the Family, 50(1), Pp 69-77.
- Orthner, D., & Mancini, J.A. (1990). Leisure impacts on family interaction and cohesion. Journal of Leisure Research, 22(2), Pp 125-137.
- Patterson, J.M. (1988). Chronic illness in children and the impact on families. In Chilman, C.S., Nunnally, E.W. & Cox, F.M. (Eds.), *Chronic illness and disability*. Newbury Park: Sage Publications.
- Patterson, J.M., & Garwick, A.W. (1998). Theoretical linkages: Family meanings and sense of coherence. In McCubbin, H.I., Thompson, E.A., Thompson, A.I., & Fromer, J.E. (Eds.), *Stress coping, and health in families: Sense of coherence and resiliency*. Thousand Oaks: Sage Publications.
- Pless, I.B., & Pinkerton, P. (1975). In J.L. Wallander and J.W. Varni (1998). Effects of pediatric chronic physical disorders on child and family adjustment. Journal of Child Psychology and Psychiatry, 39(1), Pp 29-46.
- Primeau, M.N., Kagan, R., Joseph, L., Lim, H., Dufresne, C., Duffy, C., Prhcal, D., & Clarke, A. (2000). The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children. Clinical and Experimental Allergy, 30, Pp 1135-1143.
- Rautava, P., Lehtonen, L., Hlenius, H., & Sillanpää, M. (1995). Infantile colic: Child and family three years later. Pediatrics, 96(1), Pp 43-47.
- Samdahl, D.M., & Jekubovich, N.J. (1997). A critique of leisure constraints: Comparative analyses and understandings. Journal of Leisure Research, 29(4), Pp 430-452.
- Schneider, M.A. (1999). Silent partners: Exploring the lived experience of fathers of children with autism. Unpublished Master's Thesis, University of Waterloo, Waterloo, Ontario, Canada.
- Shaw, S. (1985a). The meaning of leisure in everyday life. Leisure Sciences, 7, Pp 1-24.
- Shaw, S. (1985b). Gender and leisure: Inequality in the distribution of leisure time. Journal of Leisure Research, 17(4), Pp 266-282.

- Shaw, S. (1992). Dereifying family leisure. Leisure Sciences, 14, Pp 271-286.
- Shaw, S. (1997). Controversies and contradictions in family leisure. Journal of Leisure Research, 29(1), Pp 98-112.
- Shaw, S., & Dawson, D. (2001). Purposive leisure: Examining parental discourses on family activities. Leisure Sciences, 23, Pp 217-231.
- Sicherer, S., Furlong, T., Muñoz-Furlong, A., Burks, A. & Sampson, H. (2001). A voluntary registry for peanut and tree nut allergy: Characteristics of the first 5149 registrants. Journal of Allergy and Clinical Immunology, 108(1), Pp 128-132.
- Strauss, A. (1987). *Analysis for social scientists*. Cambridge, N.Y.: Cambridge University Press.
- Strauss, A., & Corbin, J. (1998). Grounded theory methodology: An overview. In Denzin, N.K., & Lincoln, Y.S. (Eds.) *Strategies of qualitative inquiry*. Thousand Oaks: Sage Publications.
- Such, E. (2006). Leisure and fatherhood in dual-earner families. Leisure Studies, 25(2), Pp 185-199.
- Tansella, C.Z. (1995). Psychosocial factors and chronic illness in childhood. European Psychiatry, 10, Pp 297-305.
- Tunali, B., & Power, T. (2002). Coping by redefinition: Cognitive appraisals in mothers of children with Autism and children without Autism. Journal of Autism and Developmental Disorders, 32(1), Pp 25-34.
- Turner, J.L. (1998). Children with chronic illness. Medical Update for Psychiatrists, 3(2), Pp 45-48.
- Wallander, J.L., & Varni, J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. Journal of Child Psychology and Psychiatry, 39(1), Pp 29-46.
- Walker, L.S., Garber, J., & Van Slyke, D.A. (1995). Do parents excuse the misbehaviour of children with physical or emotional symptoms? An investigation of the pediatric sick role. Journal of Pediatric Psychology, 20(3), Pp 329-345.
- Weinblatt, N. & Navon, L. (1995). Flight from leisure: A neglected phenomenon in leisure studies. Leisure Sciences, 17, Pp 309-325.
- Whyte, L.B., & Shaw, S.M. (1994). Women's leisure: An exploratory study of fear of violence as a leisure constraint. Journal of Applied Recreation Research, 19(1), Pp 5-21.

- Worchel-Prevatt, F.F., Heffer, R.W., Prevatt, B.C., Miner, J., Young-Saleme, T., Horgan, D., Lopez, M.A., Rae, W.A., & Frankel, L. (1988). A school reentry program for chronically ill children. Journal of School Psychology, *36*(3), Pp 261-279.
- Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in crisis: Conceptualizing mothers of children with cancer. Social Science and Medicine, *55*, Pp 1835-1847.
- Zabriskie, R.B., & McCormick, B.P. (2001). The influences of family leisure patterns on perceptions of family functioning. Family Relations, *50*(3), Pp 281-289.
- Zabriskie, R.B., & McCormick, B.P. (2003). Parent and child perspectives of family leisure involvement and satisfaction with family life. Journal of Leisure Research, *35*, Pp163-189.

APPENDICES

Appendix A: Introduction Letter to Support Group

Hello!

My name is Kathleen Wilson-Forrest and I am conducting a study on anaphylaxis and leisure as my master's thesis under the supervision of Dr. Susan Shaw.

Thank you for taking the time to look at this letter. Living with a child with anaphylaxis has many challenges and it is not easy to find extra time to devote to a research study. However, without co-operation from families we cannot hope to expand on the limited amount of knowledge concerning what it is *really* like to live with a child diagnosed with a life-threatening allergy.

The purpose of this study is to explore the parental perceptions of family leisure while living with a child diagnosed with a severe life threatening allergy. There has been no prior research conducted on the issues related to safe and meaningful leisure opportunities for families who must be vigilant in protecting their children from allergens in a public place. Through this study we will be better able to highlight some of the important issues facing families and understand what could be done to alleviate some of the pressures that exist.

If you have a child diagnosed with a life-threatening allergy and feel this study would interest you and you have approximately one hour to spare, please read on.

Ideally your child's allergy would have been diagnosed at least one year ago and I would like to spend approximately one hour to discuss how a life-threatening allergy affects how you plan and participate in family leisure activities. I am hoping to interview both mother and father within the same family separately, if possible, and single parents are valuable and encouraged to participate as well. As you are aware, the stresses and emotional impact of living with anaphylaxis can be difficult. Therefore, it is important to remember that if you choose, sensitive topics such as fear may be discussed during the interview. Interviews may be conducted at your residence or a mutually agreed upon public location. Each parent will be interviewed separately and privately. This allows the possibility for one parent to assume child-care responsibilities and also protects the children within the household from any issues discussed during the interview itself. It is encouraged that arrangements be made for children in the household not to be present in the same room during the interview. If you have any concerns regarding this please feel free to discuss this with me further before the interview.

Participation in this study is voluntary. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising the researcher. With your permission, the interview will be tape-recorded to facilitate collection of information, and later transcribed for analysis. With your consent, direct anonymous quotes will be used in the final thesis. Shortly after the interview has been completed, I will send you a copy of the

transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. All information you provide is considered completely confidential. Your name will not appear in any thesis or report resulting from this study. Data collected during this study will be retained for three years in a locked office. Only researchers associated with this project will have access. You may also request a copy of the executive summary of results to review and provide feedback on prior to the final report write-up.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me by email at kmwilson@ahsmail.uwaterloo.ca. You can also contact my supervisor, Professor Susan Shaw at (519) 888-4567 ext. 5019 or email sshaw@healthy.uwaterloo.ca.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of this office at (519) 888-4567 Ext. 6005.

If you are interested in becoming involved in this study please contact me by email at kmwilson@ahsmail.uwaterloo.ca and provide me with a telephone number and time of day to call you so we can arrange a time to meet.

Thank you so much for your time and I look forward to meeting you in person.

Sincerely,

Kathleen Wilson-Forrest
Graduate Student
University of Waterloo
Department of Recreation and Leisure Studies

Appendix B: Informed Consent Form

I agree to participate in a study being conducted by Kathleen Wilson-Forrest of the Department of Recreation and Leisure Studies, University of Waterloo under the supervision of Professor Susan Shaw. I have made this decision based on the information I have read in the Information Letter. In addition I have had the opportunity to receive any further details I wanted about the study. I understand that I may withdraw from the study at any time, without penalty, by telling the researcher.

I also understand that this project has been reviewed by, and received ethics clearance from the Office of Research Ethics at the University of Waterloo, and that I may contact this office if I have any concerns or comments resulting from my involvement in the study.

CONSENT FOR AUDIOTAPING INTERVIEW AND USE OF ANONYMOUS QUOTATIONS

Please check yes or no in the boxes provided.

I agree to the interview being audio-taped to facilitate the collection of information with the understanding that all information which I provide will be held in confidence and I will not be identified in the thesis, summary report, or publication. I understand that I may withdraw this consent at any time without penalty by advising the researcher.

YES NO

I agree that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I am aware that I may withdraw my consent at any time by advising the researcher.

YES NO

Participant Name (Please print): _____

Participant Signature: _____

Witness Name: _____

Witness Signature: _____

Date: _____

Appendix C: Semi-Structured Interview Guide

First of all, let me thank you again for agreeing to participate in this study. We often become advocates for our child with anaphylaxis and the more information we can collect and record on paper the easier this process will be in the future. I am very excited about finding out about your experiences and how this has affected your life. I believe the information collected will be invaluable to a number of organizations seeking to protect our children. I will also like to remind you at this time that you may decline to answer any questions that you wish.

1. Could you tell me a little bit about <child's name>? (If there are siblings): Could you also tell me a little bit about <child's name>'s siblings?
2. When was your child(ren) diagnosed with their life-threatening allergy? How did you feel at that time? How do you feel now?
3. How has your family adapted to living with anaphylaxis?
4. Do you find that you are able to spend leisure time together as a family? If not, what prevents you from spending time as a family? What kinds of family leisure activities do you do on a regular basis? Not so regular basis? Who usually participates in these activities? Where do these activities take place? How would you describe your experience during these activities? How would you describe your level of satisfaction with your family leisure?
5. How would you describe the process of planning for family activities? (probe) Who does the planning/organizing? What do you find particularly challenging when planning family time?
6. Has your choice of activities been affected since your child's diagnosis? If so, how?
7. Are there any family activities that you feel you cannot participate in with your child? Places you cannot go to participate? Why? [Fear: probe]
8. If there are siblings: What do you feel has been the impact, if any, on your other children?
9. Are there any benefits of family leisure for the family as a whole, for you personally, for your children? Are there any negative outcomes that you can tell me about?
Probe: Is it difficult to plan an activity that everyone enjoys?
How disappointed are you if a family activity does not meet your expectations?
Does family time use up all of your own free time?
10. If you were given a chance to do anything together as a family, anywhere you choose, without being concerned about potential reactions what would you do?

Appendix D: Feedback Letter to Participants

UW department letterhead

Dear (Name),

I am writing to thank-you for taking the time to speak with me on (date). I appreciate immensely the input you gave towards this project and it was a pleasure meeting you.

I have included a brief summary of our meeting which highlights the major issues I felt were discussed. Please review this and feel free to comment further on anything you feel I have missed, misrepresented, or issues that have arisen since our meeting. Your continued input is much appreciated. You may also contact Dr. Susan Sykes of our Office of Research Ethics At 519-888-4567 ext. 6005 if you have any concerns or questions regarding your involvement in this study.

Thank-you again for your time and I look forward to receiving your comments within the next two weeks.

Sincerely,

Kathleen Wilson-Forrest
MA Candidate
Department of Recreation and Leisure Studies
University of Waterloo