

University of Windsor

## Scholarship at UWindor

---

Electronic Theses and Dissertations

Theses, Dissertations, and Major Papers

---

1998

### An examination of the effects of family demands and resources on adaptation in families of children with diabetes.

Mary Teresa Lapos. Chick  
*University of Windsor*

Follow this and additional works at: <https://scholar.uwindsor.ca/etd>

---

#### Recommended Citation

Chick, Mary Teresa Lapos., "An examination of the effects of family demands and resources on adaptation in families of children with diabetes." (1998). *Electronic Theses and Dissertations*. 1034.  
<https://scholar.uwindsor.ca/etd/1034>

This online database contains the full-text of PhD dissertations and Masters' theses of University of Windsor students from 1954 forward. These documents are made available for personal study and research purposes only, in accordance with the Canadian Copyright Act and the Creative Commons license—CC BY-NC-ND (Attribution, Non-Commercial, No Derivative Works). Under this license, works must always be attributed to the copyright holder (original author), cannot be used for any commercial purposes, and may not be altered. Any other use would require the permission of the copyright holder. Students may inquire about withdrawing their dissertation and/or thesis from this database. For additional inquiries, please contact the repository administrator via email ([scholarship@uwindsor.ca](mailto:scholarship@uwindsor.ca)) or by telephone at 519-253-3000ext. 3208.

## **INFORMATION TO USERS**

**This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.**

**The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.**

**In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.**

**Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.**

**Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.**

**Bell & Howell Information and Learning  
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA  
800-521-0600**

**UMI<sup>®</sup>**



**AN EXAMINATION OF THE EFFECTS OF  
FAMILY DEMANDS AND RESOURCES ON ADAPTATION IN  
FAMILIES OF CHILDREN WITH DIABETES**

by

**Mary T. Lapos Chick**

**A Thesis  
Submitted to the Faculty of Graduate Studies and Research  
through the School of Nursing  
in Partial Fulfillment of the Requirements for  
the degree of Master of Science at the  
University of Windsor**

**Windsor, Ontario, Canada**

**1998**

**© 1998 Mary T. Lapos Chick**



**National Library  
of Canada**

**Acquisitions and  
Bibliographic Services**

**395 Wellington Street  
Ottawa ON K1A 0N4  
Canada**

**Bibliothèque nationale  
du Canada**

**Acquisitions et  
services bibliographiques**

**395, rue Wellington  
Ottawa ON K1A 0N4  
Canada**

*Your file Votre référence*

*Our file Notre référence*

**The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.**

**The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.**

**L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.**

**L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.**

**0-612-52452-3**

**Canada**

## ABSTRACT

**This study investigated family demands, resources, and adaptation in families of children with Type 1 diabetes. The Resiliency Model of Family Stress, and Adaptation (McCubbin & McCubbin, 1993) provided the conceptual framework. A convenience sample included 75 families from a local pediatric clinic (56.8% response rate) who responded to a mailed questionnaire. Instruments included measures of caregiving demands, family resources, family functioning and the child's most recent glycosylated hemoglobin value. There were significant differences in caregiving demands between mothers of younger children (13 and below) and mothers of older children (14 and above). Mothers of younger children reported more caregiving demands. Correlational analysis identified significant relationships between the Feetham Family Functioning score (FFFS) and Caregiving Demands. Significant correlations were also found between the Family Apgar score and the FFFS and the family resources of Family Hardiness, Mastery & Health, Esteem and Communication, and Coping. Family support was not significantly correlated with the Family Apgar score or the FFFS discrepancy score. The child's metabolic control was significantly correlated with coping but not significantly related to Caregiving Demands or the other family resources. Hierarchical regression analyses indicated (a) child age, duration of diabetes, and Coping were significant predictors of the Family Apgar score (b) Caregiving Demands was a significant predictor of the Feetham Family Functioning discrepancy score, and (c) Coping and Family Support predicted the child's metabolic control. Recommendations for future research and implications for nursing practice are included.**

## DEDICATION

**To my family, especially my husband Steven, my children Jacqueline, Natalie, Christina, and Julia, my parents John and Bernadette Lapos, my parents-in-law Dr. John and Donna Chick, and my grandmother Mrs. Blanche Beneteau.**

## **ACKNOWLEDGEMENTS**

**To my advisor, Dr. Sheila Cameron, my deepest appreciation is extended for her efforts and encouragement throughout the process of developing and implementing this thesis. My dearest thanks is also extended to my internal reader, Dr. Sharon McMahon, and to my external reader, Dr. Kathryn Lafreniere for their encouragement and assistance with this thesis.**

**A sincere thank you is extended to Dr. Suzanne Feetham for the use of the Feetham Family Functioning Survey; Dr. H. I. McCubbin and Dr. Anne I. Thompson of the Family Stress, Coping and Health Project for the use of the CHIP, FHI, and FIRM; and to Dr. M. McCubbin & colleagues for the use of their instrument The Care of My Child with diabetes.**

**This study would not have been possible without the support of Dr. A. Kidd, endocrinologist, and Ms. Sally Lewis, Coordinator of the clinic from which the sample was drawn, and sincere appreciation is extended to both of these caring professionals. Thank you also to clinic nurse Gemma Sorgi for her assistance. A resounding thank you is also sent to all of the families who took time from their busy schedules and participated in this study.**

**Thank you to Mrs. Kathryn Foley, a friend and colleague who assisted by ensuring that the questionnaire was worded correctly for the parents.**

**I wish to thank my family for their support and encouragement. To my parents, John and Bernadette Lapos, who have always supported my educational endeavours and particularly to my father who devoted many hours to child care. I would also like to**



**thank husband's parents, Dr. John and Donna Chick for their support and encouragement and especially for their assistance with child care. To my husband, Steven, who provided encouragement and support throughout my education, and always assisted at the most difficult times. To my children, Jacqueline, Natalie, Christina, and Julia, a sincere thank you for your patience throughout this research.**

## TABLE OF CONTENTS

<b>ABSTRACT</b>	<b>iii</b>
<b>DEDICATION</b>	<b>iv</b>
<b>ACKNOWLEDGMENTS</b>	<b>v</b>
<b>TABLE OF CONTENTS</b>	<b>vii</b>
<b>LIST OF TABLES</b>	<b>x</b>
<b>CHAPTER 1</b>	
<b>INTRODUCTION</b>	<b>1</b>
Statement of the Problem	1
Background and Significance of the Problem	4
Family and Diabetes Management	4
Conceptual Framework	6
<b>CHAPTER 2</b>	
<b>REVIEW OF THE LITERATURE</b>	<b>10</b>
Diabetes as a Crisis	10
Parental Emotional Responses to Diagnosis	10
Diabetes Management	14
Family Characteristics	20
Roles	20
Other Characteristics	22
Family Resources	25
Hardiness	27
Social Support	30
Coping	35
Adaptation	39
Conclusion	41
Research Questions	42
Hypotheses	43
<b>CHAPTER 3</b>	
<b>METHODS AND PROCEDURES</b>	<b>45</b>

Research Design	45
Methods	45
Conceptual Framework	45
Participants	46
Measurement Methods	47
Measures/Instruments	47
Procedures	53
Data Collection	53
Data Analysis	55
Assumptions	59
Limitations	59
 CHAPTER 4	
RESULTS	60
Research Questions	60
Question 1	60
Question 2	62
Question 3	62
Question 4	64
Question 5	65
Question 6	67
Hypotheses	73
Hypothesis 1	73
Hypothesis 2	74
Hypothesis 3	74
Hypothesis 4	75
Hypothesis 5	76
Hypothesis 6	76
 CHAPTER 5	
DISCUSSION	78
Recommendations for Future Research	89
Implications for Nursing	91
REFERENCES	93
APPENDIX A	
Figure 1 The Resiliency Model of Family Stress, Adjustment, and Adaptation	102

<b>APPENDIX B</b>	
<b>Letter of Support</b>	<b>103</b>
<b>APPENDIX C</b>	
<b>Letter of Information for the Families</b>	<b>104</b>
<b>APPENDIX D</b>	
<b>First Reminder Letter</b>	<b>105</b>
<b>APPENDIX E</b>	
<b>Letter of Introduction for Second Survey</b>	<b>106</b>
<b>APPENDIX F</b>	
<b>Final Reminder Letter</b>	<b>107</b>
<b>APPENDIX G</b>	
<b>Demographic Questionnaire</b>	<b>108</b>
<b>VITA AUCTORIS</b>	<b>109</b>

**LIST OF TABLES**

<b>TABLE</b>		<b>PAGE</b>
<b>1</b>	<b>Ranges, Means, Standard Deviations, and Reliabilities of Measures</b>	<b>63</b>
<b>2</b>	<b>Correlation Matrix, Means, and Standard Deviations for Measured Variables</b>	<b>66</b>
<b>3</b>	<b>Summary of Hierarchical Regression Analysis for Variables Predicting Family Apgar</b>	<b>68</b>
<b>4</b>	<b>Summary of Hierarchical Regression Analysis for Variables Predicting Feetham Family Functioning Discrepancy Score</b>	<b>69</b>
<b>5</b>	<b>Summary of Hierarchical Regression Analysis for Variables Predicting Child's Metabolic Control</b>	<b>70</b>

## CHAPTER ONE

### INTRODUCTION

#### Statement of the Problem

Although medical researchers Fantus & Dupré (1995) indicate that the goal of the twenty-first century is prevention of insulin-dependent diabetes mellitus (IDDM) and non-insulin dependent diabetes mellitus (NIDDM), diabetes currently affects more than 500,000 people in Ontario. Projected increases to more than 800,000 are expected by the year 2000 (Canavan, 1994). Diabetes is reaching epidemic proportions in Aboriginal persons (Anderson, 1994; Canavan, 1994), and seniors (Canavan, 1994). It is anticipated that debilitating and/or life-threatening complications will occur in 40% of those with the disease (Canavan, 1994). Furthermore, the direct cost in Ontario for diabetes in 1992/93, not including outpatient data, was \$832 million (Anderson, 1994).

IDDM, currently referred to as Type 1 diabetes (Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus as cited in Fantus, Delovitch, & Dupré, 1997) is the most common endocrine disease or metabolic disorder of childhood (Menon & Sperling, 1988; Murphy, 1994). The risk of Type 1 diabetes is highest when compared to other chronic diseases of children and occurs approximately three times more frequently than leukemia and four times more frequently than multiple sclerosis (Cruickshanks et al., 1985). Type 1 diabetes is reported to affect between one in three hundred to one in six hundred individuals by the age of twenty years (Daneman, 1990). Globally, the most important risk factor is place of residence, with those living further from the equator at greater risk of developing Type 1 diabetes (Drash as cited in Radak,

1990). Some geographic variability may occur within countries, as evidenced by the fact that the incidence in Toronto and Montreal is 10 cases per 100,000 children, whereas the incidence on Prince Edward Island is 30 cases per 100,000 children (Drash as cited in Radak, 1990).

Moreover, Type 1 diabetes is associated with a significant increase in morbidity and mortality (Daneman, 1994; Zinman, 1993). In fact, life expectancy of those afflicted may be reduced by an average of one-third due to complications (Daneman, 1994). These complications are microvascular, which include retinopathy, nephropathy, and neuropathy, as well as macrovascular, which include cardiovascular, cerebrovascular, and peripheral vascular disease (Daneman, 1994; Zinman, 1993). Forty per cent of those with Type 1 diabetes develop nephropathy (Ministry of Health, 1995). Diabetes is the leading cause of blindness (Canavan, 1994; Zinman, 1993), and is responsible for 25 to 40% of end stage renal disease (ESRD) (Barnie, 1994; Canavan, 1994; Zinman, 1993), as well as 40 to 50% of nontraumatic amputations (Canavan, 1994; Zinman, 1993). The recent results of the nine year Diabetes Control and Complications Trial (DCCT) have supported intensive treatment, which achieves and maintains hemoglobin A<sub>1c</sub> levels close to the normal range, in order to delay the microvascular complications of diabetes (Daneman, 1994). The enormity of these complications is reflected by the fact that the Ministry of Health of Ontario has identified diabetes as a strategic priority with a five year goal of reducing by half the number of people with diabetes who experience amputations, blindness, and kidney failure (Ministry of Health, 1995). Results of studies indicate that parents of children with diabetes are worried about the complications of the

disease (Dashiff, 1993; Faulkner, 1996; Moyer, 1989; Vandagriff, Marrero, Ingersoll, & Fineberg, 1992).

The diagnosis of diabetes in a child is a significant event which may result in a family crisis. Parental emotional reactions to the diagnosis of diabetes in their child have been reported in the literature (Almeida, 1995; Edwards, 1987; Faulkner, 1996; Hodges & Parker, 1987; Koizumi, 1992; Papatheodorou, 1985). The literature suggests that these responses range from all emotional stages of grief to crisis reactions. Prolonged negative parental response has also been documented (Almeida, 1995; Hodges & Parker, 1987; Warzak, Ayllon, & Delcher, 1993). A number of concerns have been identified by parents which include diabetes management, coping with the imposed restraints, dealing with school problems, working with the health care team, achieving overall control, worry about the threat of complications, diet, financial burden, weight control, and dietary cheating (Hodges & Parker, 1987; Faulkner, 1996; Gallo, 1991; Moyer, 1989; Vandagriff et al., 1992). One study found that parents have immediate and ongoing needs for information, support, and help with aspects of child care and development regardless of age or duration of the disease (Moyer, 1989).

Diabetes management is a major concern for parents of children with IDDM, necessitating permanent changes in lifestyle. Diabetes affects the lifestyle of the entire family due to the numerous and time-consuming demands required for successful management (Betschart, 1993; Menon & Sperling, 1988; Travis et al., 1985). Successful management is dependent primarily on the parents (Menon & Sperling, 1988), but the



responsibility for the daily management of the diabetes regime is typically assumed by the mother (Faulkner, 1996; McCarthy & Gallo, 1992; Moyer, 1989).

## Background and Significance of the Problem

### Family and Diabetes Management

Recently, a shift has occurred from practitioner or hospital-managed care to community based care. As a result, patients and their families have become more responsible for assuming diabetes management as soon as possible following diagnosis. The advances in knowledge and the development of new tools to assist in the daily management of diabetes have resulted in a tremendous burden for self-management of diabetes on patients and their families (Becker as cited in Betschart, 1993; Wysocki & Wayne, 1992). Ongoing support, education and daily changes of insulin, diet, and exercise are necessary to achieve successful management (Betschart, 1993). The goals for children, adolescents, and their families are the attainment of normal growth and development, optimal glycemic control, positive psychosocial adjustment, and the prevention of both acute and chronic complications of diabetes (Betschart, 1993).

Unfortunately, the desire to maintain optimal glucose levels can increase the risk of hypoglycemia, which is not only a life-threatening complication of diabetes management, but may result in irreversible brain damage or central nervous system impairment (Betschart, 1993). Another acute complication is diabetic ketoacidosis (DKA) which is the most common cause of death in children and adolescents with IDDM (Scibillia et al. as cited in Betschart, 1993). DKA is usually present at diagnosis, and

may occur later during periods of intercurrent illness (Betschart, 1993). Thus it is important for families and caregivers to respond appropriately given these two potential life-threatening acute complications.

Diabetes affects the lifestyle of the entire family and the successful management of diabetes is dependent primarily on the parents (Menon & Sperling, 1988). The demands of diabetes have been identified as multiple and "relentless" with a minimum of twenty to thirty minutes per day required to carry out the responsibilities of blood glucose monitoring and recording, monitoring the diet, preparing and administering insulin injections, and making insulin dosage adjustments (Travis et al., 1985). Blood glucose monitoring is generally done before meals and at bedtime, with additional tests required during periods of illness or when symptoms of hypoglycemia or ketonuria occur (Betschart, 1993). Insulin injections are required two to three times per day and include both intermediate and short acting insulins, necessitating mixing these types in one syringe by the child, parent, or caregiver (Betschart, 1993). Nutrition and meal planning including food choices, portion sizes, and the timing of three daily meals and three daily snacks are also important (Betschart, 1993). A consistent daily schedule is very important with deviations of no more than one hour recommended (Betschart, 1993). Exercise is encouraged but requires that additional food and perhaps less insulin be taken beforehand (Betschart, 1993). The seriousness of the demands is highlighted by the fact that the child's immediate health is related to the insulin dosage, with too much causing hypoglycemia and too little leading to diabetic ketoacidosis (DKA), both of which can lead to morbidity and mortality (Travis et al., 1985).

The responsibility for the daily management of the diabetes regime and ultimate health of the child typically rests with the mother (Faulkner, 1996; McCarthy & Gallo, 1992; Moyer, 1989) with mothers reported as primarily responsible for meal preparation, requiring extra time for grocery shopping to read labels, and assuming the roles of managers, teachers and caregivers for the diabetes (Faulkner, 1996). Mothers of children with diabetes as compared to mothers of healthy children have reported their children as more demanding, and described themselves as less attached to their children, less healthy, and receiving less support from husbands as compared to mothers of healthy children (Hauenstein, Marvin, Snyder, & Clarke, 1989). Parents have identified obstacles of home monitoring and recording, meals, as well as estimating insulin requirements during illness, increased activity, and at bedtime (Warzak et al., 1993). The strict schedules and routines have been identified as very difficult (Wysocki, Huxtable, Linscheid, & Wayne, 1989). Yet professionals document that although dealing with the daily rigors of management can be overwhelming for parents, families that adapt well function effectively with few limitations other than those imposed by the diabetes (Betschart, 1993).

### **Conceptual Framework**

The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) provides the conceptual framework for this investigation (Appendix A). The model is based on the work of Reuben Hill (1949, 1958, as cited in McCubbin & McCubbin, 1993) and has evolved from its' predecessors: the ABCX Model (Hill, 1949 as cited in McCubbin, Thompson, & McCubbin, 1996), the Double ABCX Model (H.I.

McCubbin & Patterson, 1981 , 1983a, 1983b, as cited in McCubbin & McCubbin, 1993), the Family Adjustment and Adaptation Response (FAAR) Model (H. I. McCubbin & Patterson, 1983b; Lavee, H. I. McCubbin & Patterson, 1985 as cited in McCubbin, Thompson, & McCubbin, 1996), and the Typology Model of Adjustment and Adaptation (McCubbin & McCubbin, 1987, 1989, as cited in McCubbin & McCubbin, 1993).

The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) encompasses two phases, namely, the adjustment phase, and the adaptation phase. The following is a summary of these phases.

The adjustment phase begins with the illness stressor, such as a cold or short term acute illness in a family member. Family adjustment to the stressor is determined by the following interacting components. The illness stressor interacts with several variables, namely, the family's vulnerability, which is determined by the pileup of concurrent life changes, or stressors, strains, and transitions; the family typology, or established patterns of functioning; the family's resources; the family's appraisal of the stressor; and the family's problem solving and coping strategies, which ultimately determine the level of adjustment. The level of adjustment ranges along a continuum from bonadjustment to maladjustment. Bonadjustment occurs when established patterns of functioning continue, whereas maladjustment occurs when a family crisis arises that requires changes in the established or usual patterns of functioning, as in the case of chronic illness (McCubbin & McCubbin, 1993).

The adaptation phase of the model begins when an illness becomes a family crisis, necessitating changes in the family's established patterns of functioning. Illnesses in the

family often cause family crises (McCubbin & McCubbin, 1993) especially when caring for families and members with chronic illness (McCubbin, 1993) as is undoubtedly the case in families caring for a child or adolescent with IDDM. The level of family adaptation is determined by the following interacting variables, namely, the pileup of demands (AA) imposed by the illness, family life-cycle changes, and strains, the family's level of regenerativity or resiliency (R) which is partially determined by both the family's new and established patterns of functioning, the family's resources (BB) including family strengths, capabilities, and social support (BBB), the family's appraisal including their perception of the illness situation, and the family's problem solving and coping abilities (PSC) (McCubbin & McCubbin, 1993; McCubbin, 1993).

Family adaptation is the outcome of the family's efforts over time to achieve a new level of coherence and functioning, and ranges on a continuum from optimal bonadaptation to maladaptation (McCubbin & McCubbin, 1993; McCubbin, 1993). Bonadaptation involves optimal growth and development of family members, and a mutually supportive relationship between the family and community (McCubbin & McCubbin, 1993; McCubbin, 1993). Families may not achieve adaptation, resulting in maladaptation, requiring a return to the crisis situation (McCubbin & McCubbin, 1993).

The examination of family demands and family resources including family hardiness, mastery & health, esteem & communication, coping, family support, and their relationship to adaptation in families of children with Type 1 diabetes is an area relevant for nursing research. Nurses provide nursing services, care, and education for these children and their families at the time of diagnosis as well as during subsequent

hospitalizations, scheduled clinic appointments, and in the community. Families, however, are ultimately responsible for diabetes management of their children in the home and community setting. It has been documented that current advances in knowledge and technology have resulted in a tremendous burden for self-management of diabetes on patients and their families (Becker as cited in Betschart, 1993; Wysocki & Wayne, 1992). Knowledge of family demands, resources, and their relationship to family adaptation in these families will enable nurses to design nursing interventions which focus on the promotion of family health and adaptation possibly through the minimization of family demands, and the improvement or maintenance of family strengths/resources.

The focus of this investigation is on the adaptation phase of the model, as the diagnosis of Type 1 diabetes may precipitate a family crisis, and requires changes in the family's usual ways of functioning due to the imposed diabetes management regimen and assumption of the caregiver role. Of the studies reviewed, only one examined family stress and resources in families of children with recently diagnosed diabetes. No studies were found examining family hardiness in families of children with diabetes. Therefore, the purpose of this study is to examine family demands, family resources including family hardiness, mastery & health, esteem & communication, coping, family support, and family adaptation in families of children with Type 1 diabetes.

## CHAPTER TWO

### REVIEW OF THE LITERATURE

In this section, the literature relating to families of children with diabetes will be reviewed using the Resiliency Model as a framework for addressing the literature.

Specifically, the research will be addressed in the following areas, namely, (a) diabetes as a crisis and related stressors, (b) family characteristics (c) family resources including hardiness and social support, (d) family appraisal and coping, and (e) family adaptation.

#### Diabetes as a Crisis / Stressors

The diagnosis of diabetes in a child and its subsequent imposed management is a crisis for the entire family resulting in a variety of emotional responses. Stress in parents of children with diabetes has been documented in the literature (Hatton, Canam, Thorne, & Hughes, 1995; Hauenstein et al., 1989). The literature suggests that families of children with diabetes experience numerous demands, and that these demands are increasing due to recent technological advances in diabetes management (Wysocki & Wayne, 1992). These demands of the regimen lead to tremendous guilt for parents, particularly in situations when the parents, for one reason or another, do not meet them (Betschart, 1987). This section of the review will examine the existing research on emotional responses to diagnosis followed by reactions to diabetes management.

#### Parental Emotional Responses to Diagnosis

A number of parental emotional responses to the diagnosis have been documented, ranging from feelings of grief to guilt and crisis reactions (Almeida, 1995;

Edwards, 1987; Faulkner, 1996; Gallo, 1991; Hatton et al., 1995; Koizumi, 1992; Kovacs et al., 1985; Papatheodorou, 1985). The following is a review of these studies.

Initial reactions of parents to the diagnosis of diabetes in their child include possible relief that it is not terminal, a sense of overwhelming responsibility due to the demands of the disease, disbelief, resentment, self pity, and an acknowledgement of the expense of the disease (Papatheodorou, 1985). Shock (Faulkner, 1996; Gallo, 1991; Koizumi, 1992; Papatheodorou, 1985), denial (Faulkner, 1996, Papatheodorou, 1985), disbelief (Gallo, 1991), severe strain and anxiety (Koizumi, 1992), and anger (Faulkner, 1996; Papatheodorou, 1985) have been reported. Resentment toward the child (Warzak et al., 1993) and annoyance for getting sick (Koizumi, 1992) have also been found in recent investigations. Guilt is very common (Koizumi, 1992; Papatheodorou, 1985). In addition, sorrow (Koizumi, 1992; Papatheodorou, 1985), grieving (Almeida, 1995; Edwards, 1987; Hodges & Parker, 1987, Papatheodorou, 1985), and crisis reactions have been documented (Edwards, 1987).

Almeida (1995), in her review of the literature on grief in parents of children with diabetes, found that little empirical research has focused on parents' reactions to the diagnosis of diabetes in their children. Clinical observation and research were cited, however, supporting the prevalence of grief in these parents. Similarly, Edwards (1987) in a review of the initial reactions to diabetes, concluded that grief responses and crisis reactions are evident during the initial period of the diagnosis in the pediatric client and family. Papatheodorou (1985), in a book chapter on diabetes and the family, also documented a number of reactions to diagnosis including shock, disbelief, resentment,



anger, guilt, self pity, sorrow, and grieving which she identified as normal responses to crisis, trauma, and loss.

A Canadian study that investigated parents' perceptions of caring for an infant or toddler with diabetes used a theoretical purposive sample of eight two parent families who had been managing an infant or toddler with diabetes for at least two months (Hatton et al., 1995). Three distinct phases in the parents' experiences were found, namely, diagnosis and hospitalization, adjustment to care at home, and long term adaptation. Diagnosis and hospitalization were described as very difficult for the parents. Fearful family members, grandparents, and friends, were described as having difficulty providing support and they sometimes withdrew. Loss of support with a pile up of several stressors resulted in common emotional responses which included "shock, anger, fear, grief, guilt, sadness, frustration, exhaustion, blaming each other and themselves, feeling totally overwhelmed by the whole sequence of events, feeling helpless and hopeless, feeling inadequate as parents, and feeling out of control" (p. 572). Anger and frustration were often directed at health professionals and spouses.

In a qualitative study of American family responses to children with diabetes and their influence on self-care, Faulkner (1996) interviewed individuals from seven rural families, with five of the families being members of a support group and receiving care from pediatric endocrinologists. Orem's (1991) theory of self-care (as cited in Faulkner, 1996) was used as a framework. The children with diabetes ranged in age from nine to twelve years and length of time since diagnosis ranged from one to nine years. Parents discussed the effects on family life following diagnosis including their emotional

responses to diagnosis. Many parents, particularly mothers, regardless of the length of time since diagnosis, reminisced about their child's diagnosis in great detail, expressing emotional reactions of shock, denial, or anger, and fear of the child dying (Faulkner, 1996).

In a longitudinal prospective study of initial responses of parents to the diagnosis of diabetes in their children, Kovacs et al. (1985) found that parents, and particularly mothers, were preoccupied and worried almost all of the time. Children ranged in age from eight to thirteen years. The strain of living with diabetes was found to generate mild and subclinical depression, anxiety, and distress. Mothers were found to be more affected than fathers with approximately one quarter developing a mild grief reaction. Over the course of one year, both parents were significantly less depressed, distressed and anxious. However, mothers were significantly more depressed and anxious than fathers. Parental concern and worry also decreased by the end of one year, with 52% of mothers reportedly mildly worried and 29% of mothers remaining concerned most of the time. Parents were initially assessed two to three weeks following their childrens' discharge from hospital after diagnosis. The subjects in this study were predominantly middle class, Caucasian, two-parent families.

An investigation of Japanese mothers' responses to the diagnosis of diabetes in their children used a semi-structured interview guide developed by the author, and a Japanese version of the State Trait Anxiety Inventory (STAI, Toyoma, Suehiro, & Niisato as cited in Koizumi, 1992) (Koizumi, 1992). Ages of the children ranged from one to fifteen years. Mothers were interviewed and given the STAI six times, i.e., immediately

after diagnosis, and after, three, six, twelve, eighteen, and twenty-four months.

Consistent with their use of grief and crisis theories, stages of shock, defensive retreat, acknowledgement, and adaptation were observed. All of the mothers experienced shock, severe strain, anxiety, and anger with eleven of the mothers reporting guilt feelings. It was found that even during the acknowledgement stage, many mothers cried during the interviews and verbalized becoming depressed about their child's future more than once a day.

In summary, a range of emotional responses have been observed in parents of children of various age groups diagnosed with Type 1 diabetes. From the limited research data available, these responses can be subsumed within the predominant themes of grief and crisis.

### **Diabetes Management**

Diabetes management presents significant challenges for parents of children with Type 1 diabetes. Management involves diet, exercise, insulin, and self blood glucose monitoring with the goal of attaining blood glucose levels as close to normal as possible in order to avoid the development of both acute and chronic complications. With advancing technology in recent years, the expectations for diabetes management have increased, resulting in a greater impact on those responsible for this management, namely, parents and families in the case of children and adolescents with diabetes.

The responsibility for diabetes management has been documented as a major stressor or concern for parents of children with diabetes (Hatton et al., 1995; Hodges & Parker, 1987) as well as having a major impact on family life (Faulkner, 1996) with

mothers of various age groups reportedly terminating employment (Gallo, 1991; Hatton et al., 1995; Wysocki et al., 1989). Specifically, concerns regarding scheduling, coping, insulin reactions, denial of insurance, financial burden, support, the development of complications, diabetes management, effects on growth and development, and future outcomes have been described (Banion, Miles, & Carter, 1983; Faulkner, 1996; Hatton et al., 1995; Hodges&Parker, 1987; Vandagriff et al., 1992; Wysocki et al., 1989). In addition, the daily demands of management have resulted in tremendous guilt in parents of children and adolescents with diabetes (Betschart, 1987; Dashiff, 1993). Furthermore, continued parental responses of grieving (Almeida, 1995; Hodges & Parker, 1987), sadness (Dashiff, 1993), fear, worry (Dashiff, 1993), guilt (Betschart, 1987; Dashiff, 1993; Hodges & Parker, 1987; Warzak, et al., 1993), and anger (Dashiff, 1993; Warzak et al., 1993) directed at themselves as well as their children (Hodges & Parker, 1987) of all age levels and at various times following diagnosis have occurred.

Bringing the child home from the hospital and assuming responsibility for diabetes management was identified as devastating for Canadian parents of infants and toddlers (Hatton et al., 1995). Feelings of vulnerability and fear were expressed. Major lifestyle changes were required. Multiple losses were identified, including a loss of freedom, a loss of flexibility, a loss of spontaneity, a loss of their former support systems, and the loss of the joy of life. Blood sugar fluctuations and parents' inability to anticipate or control hypoglycemia and hyperglycemia, resulted in feelings of stress and frustration for the parents. Blood testing was perceived as a multiple stressor due to the need to perform frequent blood sugars, and the ability to interpret and react appropriately. The

parents were also concerned about the effect of diabetes management on the child's growth and development. They felt "...incompetent., ...overwhelmed..., emotionally drained, exhausted, wrapped up in their grief and afraid" (p. 573). Some parents described thoughts of suicide during the first week. Parents described surviving during this phase, and ultimately shared responsibilities and began to seek support.

Similarly, in an earlier study investigating mothers' problems with diabetes management, the areas that were found to be most problematic included future concerns, hypoglycemia, and diabetic control (Banion, Miles, & Carter, 1983). At the time of this study, home blood glucose monitoring was not used. Other problem areas included urine testing, stigma, insulin injections, dietary management, time demands or scheduling, and independence/dependence. The lowest ranked problems were availability of help/support and finances. The ages of the children ranged from one to seventeen years. Mothers of younger children and those who were diagnosed at a younger age were more concerned about hypoglycemia. Insulin injections were of more concern to mothers of children with shorter duration of diabetes. Mothers of lower socioeconomic status, single mothers, and mothers of young children were more concerned about receiving help and support. Financial concerns were associated with both single mothers and those of lower socioeconomic status (Banion et al., 1983).

In Faulkner's (1996) previously cited study of family responses to children with diabetes ranging in age from nine to twelve years, parents also expressed concerns about current diabetes management and "future outcomes." The effects on the family and family roles were found to be the two major categories of parents' responses to children

with diabetes. The effects on the family in order of decreasing frequency were reminiscing about the diagnosis, diet changes, scheduling, coping, insulin reactions (or hypoglycemia), and diabetes management.

Diabetes management was also identified by Hodges & Parker (1987) as one of the parents' major concerns in their investigation of parents of school aged children with diabetes. Four major areas of concern were identified; namely, diabetes management including the necessary knowledge and understanding; coping with the restraints imposed by the diabetes on a daily basis; dealing with school problems; and working with health care professionals. Management concerns included insulin dose adjustment, insulin schedules, insulin types, testing type and accuracy, managing the ill child, future medical developments, and disease effects on child development. Coping with restraints imposed by the illness such as the inclusion of dietary sweets, discipline, scheduling, sibling problems, as well as economic restraints such as purchasing disease-related items and the inability to obtain insurance were identified. Coping with these concerns resulted in fear, anxiety, frustration, anger directed at their children and themselves, a sense of isolation from normal families due to lifestyle changes, guilt (especially with family history of the disease), overprotection, and desperation.

In another study of 93 parents of 3 to 20 year olds with diabetes with a disease duration of 0.2 years (2.4 months) to 14 years, no correlation was found between parental worry as measured by a modified version of the Diabetes Quality of Life (DQOL) measure (DCCT research group as cited in Vandagriff et al., 1992) and metabolic control as measured by the child's glycosylated hemoglobin (HbA<sub>1c</sub>) (Vandagriff et al., 1992).

This study used a convenience sample from a pediatric outpatient clinic. Parents of younger children were found to have more worry, but the sources of most worry were the same regardless of age or disease duration. These concerns included worry about the development of complications, the possibility of denial of insurance, preoccupation with diabetes, overprotectiveness, and the development of diabetes in their other children. More parental worry was associated with perceived poorer health status regardless of the child's age or duration of diabetes.

Stress in parents of children with diabetes, as measured by the Parenting Stress Index (PSI), was also investigated (Hauenstein et al., 1989). The results were subsequently compared to an age matched control group from the original normative sample of the PSI. The mean age of the children with diabetes was 11.1 years. Approximately one-half of the mothers reported child-domain stress scores above the 70th percentile, and approximately one-third reported parent-domain stress scores above the 70th percentile. No age or sex differences of the children were found with the exception of parents of boys reporting higher levels of distractibility in their children. No group differences in overall maternal stress were found, but mothers of children with diabetes reported their children to be more demanding, and described themselves as less attached to their children, less healthy, and receiving less support from husbands. Glycosylated hemoglobin was not affected by child-domain or parent-domain stress. Those children who used self blood glucose monitoring as opposed to urine testing, and those who tended to be distractible (described as very active and inattentive), had the lowest glycosylated hemoglobin, indicating better metabolic control.

Furthermore, Betschart (1987) found that the demands of diabetes management have resulted in tremendous parental guilt. In this study of 145 parents of 86 children with diabetes ranging in age from 5 to 18 years, 41% indicated guilt about diet issues, and only 11% indicated no guilt feelings. Guilt-producing situations included instances of unsupervised testing, changes in schedule, delayed or unbalanced meals, sleeping in, and painful injections. The author concluded that the parents had additional needs that were not being met (Betschart, 1987).

Similarly, Moyer (1989) found that many parents have immediate and ongoing needs for information, support, and help with aspects of child care and development regardless of age of the child or duration of the disease. Furthermore, McCarthy & Gallo (1992) found that the impact of a twelve-year old boy's diabetes who was diagnosed at sixteen months of age increased over time on all family members, with all family members agreeing that the mother was most affected.

With respect to diabetes management, parental lack of trust in babysitters, day-care centres, teachers, and health care professionals has been documented (Gallo, 1991; Hatton et al., 1995; Hodges & Parker, 1987; McCarthy & Gallo, 1992; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994; Wysocki et al., 1989). Mothers of infants, toddlers, preschoolers and school aged children have reported an inability to find trustworthy babysitters and have terminated employment (Gallo, 1991; Hatton et al., 1995; Stewart et al., 1994; Wysocki et al., 1989). A lack of trust in the health care team and insensitivity to their grief and anxiety early in the disease was found in a group of parents of children during a support group (Hodges & Parker, 1987).



In summary, findings of studies indicate that parents of children with Type 1 diabetes of various age groups have many concerns related to diabetes including scheduling, coping, insulin reactions, denial of insurance, financial burden, support, complications, diabetes management, effects on growth and development, and future outcomes. Future concerns, including the threat of potential acute and chronic complications, were evident. The demands of diabetes management were found to result in parental guilt. With recent advances in technology, management demands have increased and the impact on families over time remains unclear.

### **Family Characteristics**

Family variables and their relationship to health outcomes have been investigated in some studies. Several found that the mother typically assumes the caregiver role for diabetes management. The following is a review of studies with respect to family roles, other characteristics such as demographics, and family variables related to health outcomes.

### **Roles**

It is apparent from the literature that the mother assumes most of the responsibility for diabetes management and the ultimate health of the child (Dashiff, 1993; Faulkner, 1996; Gallo, 1991; McCarthy & Gallo, 1992; Moyer, 1989). Mothers of infants, toddlers, preschoolers, and school-aged children have reported terminating employment as a result of being unable to find a trustworthy babysitter (Gallo, 1991; Hatton et al., 1995; Wysocki, et al., 1989). In Faulkner's (1996) study, mothers were found to assume roles of managers, teachers, and caregivers, whereas fathers were found

to assume roles of breadwinners, leaders, and disciplinarians. Mothers assumed most of the responsibility for diabetes management, as well as the responsibility for teaching others about diabetes, including school teachers, children, and other parents. Mothers were also responsible for meal preparation and required additional time for grocery shopping (Faulkner, 1996). However, some fathers of infants and toddlers reported rearranging work schedules to assist with glucose testing and insulin injections (Hatton et al., 1995). Surprisingly, little research literature has addressed caregiver burden of mothers of children with diabetes.

In Faulkner's (1996) study, interviews with the children with diabetes revealed the family influence on their self-care activities. Although sources for learning about diabetes and self-care were varied, 5 of the 7 children identified their mothers as influencing their self-care. Less frequently identified were diabetes camp, doctors, nurses, publications, fathers, diabetes classes, and grandparents with diabetes. Although all children were able to inject their insulin, they did not consistently do so, and predominantly relied on mothers during busy times such as school day mornings. Mothers were also described as maintaining the diet. "Reminding" and "making sure" that the diabetes regimen was followed were the two categories discovered to influence the self-care activities of the children. Parents were described as taking the responsibility of informing the children when to test blood sugar, administer insulin, and eat. Siblings were described as occasionally reminding the children.

The literature suggests that the mother typically assumes responsibility for diabetes management. Some fathers played a more active role in the case of infants and toddlers.

### Other Characteristics

Mothers of lower socioeconomic status with preschoolers with IDDM were found to report more child behaviour problems, higher levels of psychosocial stress, and more satisfying relationships with health professionals (Wysocki et al., 1989). Lower socioeconomic status was also associated with mothers' financial concerns, and greater concern with help and support (Banion, Miles, & Carter, 1983). Mothers of younger children were found to have more concern with help, support, hypoglycemia (Banion et al., 1983) and more worry (Vandagriff et al., 1992). Vandagriff et al. (1992) also found that worries were the same regardless of age or disease duration. In contrast, Auslander, Bubb, Rogge, & Santiago, (1993) found no differences in metabolic control based on age, gender, race, or socioeconomic status. It is evident that the findings with respect to demographics are conflicting.

Certain family characteristics have been purported to be associated with effective control, adherence problems, and psychosomatic families (those with a poor adjustment to diagnosis) (Almeida, 1995; Sargent, 1985). John Sargent (1985), a clinical associate professor of pediatrics and psychiatry in pediatrics, outlined family characteristics associated with effective control of diabetes, adherence problems, as well as psychosomatic families. Family characteristics associated with good control include "family emotional supportiveness, parental role flexibility, effective communication

patterns, joint decision making, effectiveness in actually controlling the child's behaviour" (p. 212), effectiveness in seeking medical care, and paternal involvement in the initial diabetes education (Sargent, 1985). Family characteristics associated with adherence problems include "poor parental leadership, marked overt marital strife, may be serious external stress, may have generalized and discipline problems with all children, justification of poor control and ineffective implementation of illness management regimen, or, emotional distance of both parents from child leading to inadequate supervision of child" (p. 224). Family characteristics of psychosomatic families where children experienced recurrent and frequent episodes of DKA included "enmeshment, overprotectiveness, rigidity, lack of resolution of family conflict, and involvement of the symptomatic child in unresolved parental conflict" (p. 220).

Almeida (1995), in her review, discussed unresolved grief and dysfunctional family dynamics including a review of the psychosomatic family. Conversely, she identified that children with diabetes who achieve good metabolic control and psychosocial adjustment live in families that are cohesive, allow emotional maturity, are supportive of individual endeavours, are open to input from others, are flexible in response to change, and demonstrate effective methods of resolving conflict.

Implications for practice, including the use of group work as an effective intervention promoting adaptation for parents, were discussed. A need for future research to explore the grief experienced by parents in order to implement interventions to avoid maladaptive reactions was described.

The research literature also includes findings with respect to family variables and outcomes of children's health status, typically measured by glycosylated hemoglobin (HbA<sub>1c</sub>). These findings regarding HbA<sub>1c</sub> are conflicting. Kovacs et al. (1989) in a prospective study of families of eight to thirteen year olds diagnosed with diabetes, found that quality of family life and quality of marriage did not predict metabolic control as measured by glycosylated hemoglobin over a six year period. The small sample size (n=85 initially with 10 dropouts and 1 death) was identified as a limitation of this investigation. Wysocki (1993), in an investigation of parents and adolescents ranging in age from eleven to eighteen years diagnosed with diabetes for at least 3 months, reported that multiple regression analyses demonstrated that families with better communication and conflict resolution skills were strong predictors of better diabetic control as measured by glycohemoglobin.

In a study of sixteen adolescents and their parents investigating adolescent and family factors affecting the adolescent's metabolic control, adolescent depression was the only statistically significant correlate (Lawler, Volk, Viviani, & Mengel, 1990). Other variables of family cohesion, social support (young adult), and family emotional health, were not statistically significant (Lawler et al., 1990). These findings were attributed to the small sample. In contrast, more cohesion and less conflict among family members as reported by adolescents, ages 11 to 19 years diagnosed with IDDM for at least one year, was associated with better metabolic control (Anderson, Miller, Auslander, & Santiago, 1981).

### Family Resources

Family resources may include personal resources of family members such as intelligence, knowledge and skills, health, personality traits that promote coping, mastery, and self-esteem. In addition, family system resources such as cohesion, adaptability, family hardiness, and family problem-solving are included (McCubbin & McCubbin, 1993).

In a critique of research on diabetes and the family, Anderson and Auslander (1980) concluded that the identification of family strengths, successful coping strategies, and resources such as extended family, the child's friends, diabetes organizations, and parent support groups were overlooked. The role of outside sources of support and stress on family adaptation to diabetes was identified as an area for future research (Anderson & Auslander, 1980). In light of this, it was surprising to find that very few studies of family resources have been done in families of children with IDDM. The following is a review of these studies.

In a study of family stress and resources in children recently diagnosed with diabetes using the Family Adjustment and Adaptation Response (FAAR) (McCubbin & Patterson, 1982, 1983, as cited in Auslander et al., 1993), family stress, family resources and the health status of 53 children with IDDM were investigated in a sample from an outpatient diabetes clinic one year following diagnosis. All children were less than eighteen years with a range of 2.2 to 18.0 ( $M=11.1$ ). Measures included glycosylated hemoglobin ( $HbA_{1c}$ ) to measure metabolic control; serum C peptide to measure the level of endogenous insulin (described as a potentially confounding variable); the Family

Inventory of Life Events (FILE) (McCubbin & Patterson, 1987 as cited in Auslander et al., 1993) to measure family stress; the Family Inventory of Resources for Management (FIRM) (McCubbin & Comeau, 1987 as cited in Auslander et al., 1993) to measure both parents perceptions of family resources; the Coping Health Inventory for Parents (CHIP) (McCubbin et al., 1982, as cited in Auslander et al., 1993) to assess parental coping behaviours; and questionnaires developed by Johnson et al. (1982 as cited in Auslander et al., 1993) to assess knowledge and problem-solving regarding diabetes management.

Fathers' reports of greater total family resources and higher levels of communication and cooperation were correlated with children in better metabolic control whereas fathers' reports of higher total family stress was correlated with children in poorer metabolic control. Surprisingly, mothers' reports of family stress and resources were not significantly correlated with the children's metabolic control (Auslander et al., 1993).

Multiple regression analysis was conducted on fathers' reports and included 31 families. Total family resources was a significant predictor of HbA<sub>1c</sub> (measure of metabolic control) accounting for 24 percent of the variance when controlling for C peptide (measure of endogenous insulin). Family stress predicted 37 percent of the variance in HbA<sub>1c</sub> when controlling for C peptide. To determine direct and indirect linkages between these variables and metabolic control, both total family stress and total family resources were entered while controlling for C peptide. Family stress made significant contributions to HbA<sub>1c</sub> when controlling for family resources and C peptide. The authors concluded that, consistent with the FAAR model, family stress was directly

linked to the child's health status (measured by HbA<sub>1c</sub>) whereas the family resources were indirectly linked to the child's health status (Auslander et al., 1993).

### **Hardiness**

Kobasa (1979) first introduced the concept of hardiness in a study of executives. Those demonstrating more hardiness as defined by a stronger commitment to self, an attitude of vigorousness to the environment, a sense of meaningfulness, and an internal locus of control, demonstrated lower subsequent incidence of illness, even with high stress levels, as compared to those demonstrating less hardiness (Kobasa, 1979). Hardiness was found to have important buffering effects upon stressful life events (Kobasa, 1979; Kobasa, Maddi, & Courington, 1981; Kobasa, Maddi, & Kahn, 1982) protecting against concurrent and future illness (Kobasa, Maddi, Puccetti, & Zola, 1985).

Based on Kobasa's concept of hardiness, the Health Related Hardiness Scale (HRHS) was developed for use with populations experiencing chronic illness (Pollock, 1986). Similarly, the Family Hardiness Index (FHI) was developed to measure family hardiness (McCubbin, McCubbin, & Thompson as cited in McCubbin, Thompson, & McCubbin, 1996). Family hardiness includes the "family's co-ordinated commitment or its working together to manage difficulties, its confidence in being able to handle problems; its emphasis on viewing hardships as challenges and the seeking of new life experiences as challenges; and its sense of internal control rather than being the victim of circumstances" (McCubbin, Thompson, & McCubbin, 1996, p. 239-240). Few studies have been found investigating family hardiness in families with chronically ill children.



**Failla & Jones (1991) investigated family hardiness in a convenience sample of 57 mothers of a developmentally disabled child six years of age or younger. The relationships between family hardiness and family stressors, family appraisal, coping, social support, and satisfaction with family functioning were determined. Predictors of satisfaction with family functioning were also determined. Instruments included the Family Hardiness Index (FHI) (McCubbin, McCubbin, & Thompson as cited in Failla & Jones, 1991); the Family Stress Index (FSI) (H. McCubbin as cited in Failla & Jones, 1991); the Norbeck Social Support Questionnaire (NSSQ) (Norbeck, Lindsey, & Carrieri as cited in Failla & Jones, 1991); the Family Coping-Coherence (H. McCubbin as cited in Failla & Jones, 1991); the Coping Health Inventory for Parents (CHIP) (H. McCubbin et al. as cited in Failla & Jones, 1991); and the Feetham Family Functioning Survey (FFFS) (Roberts & Feetham as cited in Failla & Jones, 1991). The relationship between family hardiness and family stressors was small and nonsignificant. There were significant positive correlations between family hardiness and family coherence, functional support, and satisfaction with family functioning. Multiple regression analysis indicated that family hardiness, total functional support, family stressors, and parental age accounted for greater than 42 % of the variance in predicting satisfaction with family functioning. The authors concluded that the results were similar to previous research results measuring individual hardiness, i.e., "hardiness acts as a resistance resource" (p. 45) decreasing the effects of stress, increasing "the use of social support" (p. 45), and promoting adaptation. Limitations of this cross-sectional study include the use of a convenience sample, with**

only mothers' responses analyzed. Rationale was provided for the investigation of mothers' responses.

Snowdon, Cameron, & Dunham (1994) examined the relationships between stress, coping resources of mastery, health, esteem, communication, family hardiness, social support, and satisfaction with family functioning in a convenience sample of fifty families of children with disabilities. All families cared for the children in their homes and used respite care. The ages of the children ranged from 2 to 37 years ( $M=11.7$ ). Measures included the esteem and communication subscales as well as the mastery and health subscales of the Family Inventory of Resources for Management (FIRM) (McCubbin & Thompson as cited in Snowdon et al., 1994) to measure "internal coping resources" (p. 67), the FHI (McCubbin & Thompson as cited in Snowdon et al., 1994), the NSSQ (Norbeck, Lindsey, & Carrieri as cited in Snowdon et al., 1994), and the FFFS (Feetham & Humenick as cited in Snowdon et al., 1994). Hierarchical regression analysis indicated that 57 % of the variance in family functioning satisfaction was "predicted by mastery and health and social support from spouse and friends" (p. 73). Hardiness was not a significant predictor, but was found to significantly correlate with the number of child conditions, as well as coping resources. It was suggested that hardiness may have an indirect effect on family functioning satisfaction through social support.

In a study of parents of children with asthma, using the Resiliency Model (1993), a significant positive relationship between family hardiness and family type was found but no significant relationship was found between family hardiness and family stressors (Donnelly, 1994). The ages of these children ranged from one to five years. Future

research involving other chronic diseases including diabetes was suggested (Donnelly, 1994).

Currently, M. McCubbin is conducting a longitudinal study of families with children diagnosed with chronic conditions including diabetes and is testing all aspects of the model including family hardiness (personal communication, 1996). More recently, Huang (1995) in a critical review of hardiness and stress, identified that family hardiness "merits further investigation" (p. 88). The role of family hardiness is unclear due to conflicting reports in the literature. No studies of hardiness in families of children with IDDM have been found. Further study of this variable is indicated, especially in this population where management of this potentially life threatening disease is so important in avoiding both acute and chronic complications.

### Social Support

In her review of the literature, Stewart (1993) found that many different definitions of social support were described. She defined social support as "interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and reliable alliance..." which "...improve coping, moderate the impact of stressors, and promote health..." (p. 7). She elaborated that social support may not be accessible or beneficial. Social support was interpreted within coping theory as a coping resource (Stewart, 1993). Furthermore, measurement issues were acknowledged as a concern with the construct of social support. For example, size of the social network does not necessarily indicate availability of or satisfaction with social support (Stewart, 1993). The use of social support instruments measuring size of the social network would

not indicate satisfaction with various sources of social support. Furthermore, the degree of helpfulness of sources of social support would not be measured. Few studies have been done investigating social support in families of children with diabetes. The following is a review of these studies.

As described earlier, mothers have described an inability to find a trustworthy babysitter with some reportedly terminating employment at the time of diagnosis (Gallo, 1991; Hatton et al., 1995; Stewart et al., 1994; Wysocki et al., 1989) or not seeking employment due to diabetes related demands (McCarthy & Gallo, 1992). Furthermore, feelings of social isolation have been described by parents of children with IDDM (Gallo, 1991; Hatton et al., 1995; Hodges & Parker, 1987; Stewart et al., 1994). A lack of confidence in teachers, a lack of trust in the health team (Hodges & Parker, 1987) and a loss of confidence in the physician have also been reported (McCarthy & Gallo, 1992).

Wysocki et al. (1989), in the previously cited study investigating adjustment to diabetes in preschoolers and their mothers, found that the items with the highest mean scores from the PDBC included those reflecting a lack of trust in babysitters and day-care centers. Similarly, Hatton et al. (1995) in the previously cited study of parents of infants and toddlers, found at least three of the seven mothers interviewed were required to give up employment and became full-time homemakers following the diagnosis. In a study of parents of adolescent girls, most reported a lack of extended family, relatives, or friends who were capable of overseeing the regimen, with only two parents found to report adults competent enough to care for the adolescent daughter, and these were friends as opposed to relatives (Dashiff, 1993). Several of the mothers expressed the desire to talk with other

parents or to be part of a support group (Dashiff, 1993). Hodges & Parker's (1987) previously cited study of parents during a support group discovered a lack of confidence in teachers' abilities to manage their children with Type 1 diabetes, with several parents reporting insulin reactions that were unrecognized by teachers. In this same study, insensitivity of the medical staff to their anxiety and grief initially, too much diabetes education within a short time frame, and a lack of trust in the health care team were also expressed (Hodges & Parker, 1987). A loss of confidence in the physician was also expressed by parents of a twelve year old male (McCarthy & Gallo, 1992). Studies have also found parents to seek support (Hatton et al., 1995; Dashiff, 1993).

Sources and types of social support have been studied in Canadian mothers of children with chronic conditions. Stewart et al. (1994), in a qualitative study, investigated the sources and types of support received by mothers of children with chronic conditions in relation to caregiving demands, as well as the appropriateness of the support. In addition, stressful and supportive interactions with partners and professionals were investigated. Home interviews were conducted with a total of ninety randomly selected mothers of children with chronic conditions who visited a children's hospital, thirty of whom had children with spina bifida, cystic fibrosis, and diabetes respectively. When the data were analyzed separately based on the three diagnoses and compared, only significant differences in demographics between groups were found. There were only minute differences in burden and support reported. Based on these findings of few differences between groups, the authors' pooled the data, citing that the use of a non-categorical approach to the study of responses to chronic illness was recently

recommended (Perrin et al. as cited in Stewart et al., 1994). Findings included descriptions of primary caregiver demands related to physical care, care during illness, and developmental needs (Stewart et al., 1994). Lack of time to meet their own needs, fatigue, and the need for respite, or time for their own health maintenance were described by most of the mothers. The impact of the child's care on family roles, relationships, and mother's out of home activities including employment, friendships, and social gatherings were also described by most of the sample. Half of the mothers mentioned the impact on the spousal relationship and on homemaking. Social isolation and the need for a confidante (in the authors' words- "someone to listen to them") were described. One mother of a child with diabetes described her wish to sleep in for a day and not have to fight with her child to take insulin and eat breakfast. The pervasive nature of the child's condition was described by others.

Mothers reported profound isolation in illness management, even though they identified several types and sources of support (Stewart et al., 1994). Gaps were perceived in the availability of both peer and health professional support. Most of the respondents identified husbands, family members, and health professionals as important sources of support. Support from friends and illness peer groups was also discussed. Two-thirds of the mothers were employed, yet several received limited assistance with housework or other relief. The mothers reported both supportive and stressful interactions with predominantly partners and health professionals. The authors concluded that the mothers were isolated, and received inadequate support. Partners provided some instrumental but little emotional support, and health professionals provided only

informational support related to the child's illness, but did not discuss developmental needs.

Access to specialist diabetes nurses can also be considered a source of social support. Moyer (1989) attempted to describe the needs and concerns of parents whose children have diabetes, and to compare the needs and concerns of parents who did and did not have access to specialist diabetes nurses. The sample consisted of ten to eighteen year olds with diabetes and their parents. Measures included Hymovich's Chronicity Impact and Coping Questionnaire (CICI:PQ) (Hymovich as cited in Moyer, 1989), a measure of parents' need for information, and a measure of concern. Acceptable reliability of CICI:PQ was cited. However, reliability and validity of the other two measures were not reported. Almost all interviews were completed with the mother. The mother was identified as responsible for diabetes management even when both parents were present. An ongoing need for information was identified in both groups irrespective of the presence of a diabetes nurse specialist. Duration of time since diagnosis or age of the child made no difference in the number of topics in which parents required information.

However, the parents with a nursing specialist in diabetes care reported a broader range of needs which were related to growth and development as opposed to illness focused, and the parents were more likely to expect and receive ongoing help and support with their needs (Moyer, 1989). Parental levels of concern were reportedly slightly higher in the group with specialist nurses, but the difference was noted as not statistically significant. It was concluded that although parents felt they were coping well with the

daily diabetes management, several had immediate and ongoing needs for information, support, and help with many areas of their child's care and development (Moyer, 1989).

### **Coping**

Lazarus and Folkman (1984) in their seminal work on stress, appraisal, and coping, viewed coping as a process and defined it as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Two types of coping were described, namely, emotion-focused coping, thought to be beneficial following an appraisal that nothing can be done to modify the situation, and problem-focused coping, thought to be beneficial following an appraisal that the situation is manageable or changeable (Lazarus, 1993). Emotion-focused coping strategies include avoidance, minimizing, distancing, "selective attention, positive comparisons," focusing on the positive, experiencing emotional distress, and "cognitive reappraisal" (p. 150-151). Problem-focused coping strategies are described as similar to problem solving strategies which are predominantly focused on the environment, but also include strategies focused on the self such as learning new skills, and problem-focused cognitive reappraisals (Lazarus & Folkman, 1984).

The following is a review of studies with findings related to coping in families of children with diabetes. In the literature reviewed above, coping was addressed in some of the studies, but these generally involved other variables and were reported in the appropriate sections.



Coping strategies that were developed and used by mothers of infants and toddlers with diabetes during the first phase of diagnosis and hospitalization were "being assertive" and acting as their child's advocate, "dealing with their child's needs," "realizing that the complex regimen" was necessary for their child's survival, "seeking support" especially from hospital staff, "accepting a lack of support from fearful relatives and friends", "looking for a cause," "considering alternatives," and "clinging to hope for an early cure" (Hatton et al., 1995, p. 572). Most of these coping strategies were emotion-focused. Coping strategies that developed during the second phase of caring for the child at home included being very careful and methodical with diabetes management. Parents assumed sharing of responsibilities, established trust and reliance on health professionals for support and advice, and acknowledged the need to trust others and to seek support. Coping strategies that developed during adaptation included "taking charge of the situation, trusting others, and building support systems" (Hatton et al., 1995, p. 574). Both emotion-focused and problem-focused strategies were evident with these parents.

In a study of families of children with recently diagnosed diabetes, parental coping was measured using the CHIP (McCubbin et al. as cited in Auslander et al., 1993). Both parents ranked coping patterns similarly with maintaining family integration, cooperation and an optimistic outlook as the most helpful strategy, followed by medical communication, and social support (Auslander et al., 1993). Although mothers reported greater use of all coping behaviours, both parents ranked them similarly. These coping behaviours included believing the child was getting the best medical care, trusting the

spouse for support, ensuring that the treatments were followed, believing that the medical professionals were working in their family's best interest, and ensuring that the child was assessed regularly.

Faulkner (1996) found that parents of nine to twelve year olds identified personal mechanisms and sources of strength for coping with the child's illness. However, only one parent's narrative on coping was provided with faith in God identified as a source of strength. In another study, coping methods of parents of children ranging in age from five to eighteen years included expressing anger in some form (32%), trying again (14%), talking with friends/hospital staff (10%), compensating the child (8%), learning more (7%), talking with spouse (4%), rationalizing (4%), using religion (4%), relaxing activity (3%), doing nothing (3%), and eating (3%) (Betschart, 1987). The author noted that approximately one-third coped well, one-third coped adequately, and one-third had difficulty coping (Betschart, 1987). Both emotion-focused and problem-focused strategies were evident in these studies.

Dashiff (1993), in the previously cited study of adolescent girls, found that parents tried to alleviate their emotional distress in four major ways, namely, overseeing the illness and regimen, distancing themselves, communicating about the illness with each other and/or the daughter, and accessing and obtaining support. The first two were the most prevalent. Mothers predominantly were concerned with overseeing the illness, whereas fathers predominantly used distancing. In addition, these families grew more cohesive and increased participation in parental roles required for diabetes management while sacrificing the spousal relationship (Dashiff, 1993). Both emotion-focused

strategies and problem-focused strategies were evident with these parents.

Japanese mothers' coping strategies were identified in a study of responses to the diagnosis of diabetes (Koizumi, 1992). The nine types of coping strategies reported included "getting knowledge, gaining confidence in managing family life with IDDM, thinking positively of family life with IDDM, expressing the stress, unburdening self, resignation, holding out, believing in religions, and getting cooperation from family members" (p. 158). The twelve mothers who thought it was easy to cope with the diagnosis had constant low anxiety scores, no physical symptoms of illness, and a shorter period of adaptation ranging from two to nineteen months. These same mothers also had support from their husbands or others, no reported guilt feelings, few or no preconceptions about diabetes, and children with better control and few negative responses to the illness. Many mothers of the group who coped well used obtaining knowledge as a coping strategy (Koizumi, 1992). Most of the coping strategies reported by these mothers were emotion-focused. However, obtaining knowledge and cooperation from family members were examples of problem-focused coping strategies.

In conclusion, relatively few studies have investigated coping in parents of children with diabetes. Strategies reported included both emotion-focused and problem-focused. Only one Canadian study of infants and toddlers was found. The other studies included predominantly American samples.

### Adaptation

Few studies have investigated family adaptation to the diagnosis of diabetes in a child. Investigators tend to study family variables and their relationship to health outcomes of the child such as glycosylated hemoglobin measures. Adaptation measures that have been addressed include the health status of the child or child's measure of metabolic control (glycosylated hemoglobin or HbA<sub>1c</sub>) as a dependent variable indicating adjustment or adaptation, and family functioning. These studies were addressed earlier.

In the previously cited qualitative study of parents of infants and toddlers, it was found that even during the long-term adaptation phase, the parents identified multiple stressors (Hatton et al., 1995). Major stressors during this phase related to the child's growth and development. Frustrations and fears regarding their child's future emerged. For some, decisions regarding future children was a source of distress. "Recurring sadness, frustration, anger, fear, anxiety, and perceived loss of control" were described by parents during periods of fluctuating, "uncontrollable blood sugar levels" (p. 574).

Only one study was found investigating adjustment to diabetes in preschoolers and their mothers (Wysocki, Huxtable, Linscheid, & Wayne, 1989). Twenty preschoolers with diabetes, between the ages of twenty-four and seventy-two months of age with diabetes of at least three months duration, and their mothers, were studied. Mothers of preschoolers with diabetes viewed their children as having more internalizing symptoms such as sleep problems. Higher levels of stress related to the preschoolers were reported. Higher maternal stress was significantly correlated with the Preschool Diabetes

Behaviour Checklist (PDBC) total, and four of the Preschool Diabetes Opinion Survey (PDOS) scales, namely, manipulativeness, stigma, attitudes towards medical staff, and family interruption. Scores on the stigma, observation/detection of insulin reactions, and the family interruption scales of the PDOS were significantly lower than a standardization sample of a comparison group of mothers of six to nineteen year olds with diabetes, indicating less favourable adjustment. However, the mothers rated their preschoolers as less manipulative regarding diabetes as compared to the comparison group. Mothers who perceived more differential treatment because of diabetes and more diabetes-related family disruption reported more diabetes related behaviour problems. The authors of this cross-sectional study acknowledged the reliability of the PDBC as inflated and a limitation of the small sample size.

Few studies have been published using the Resiliency Model or its predecessors in families of children with diabetes. Gallo (1991) described a case study of family adaptation to diabetes with a family from a previously studied sample. An eight year old girl diagnosed with diabetes three months prior to the first interview was selected. Two interviews with both parents were conducted twelve months apart using a family adaptation model adapted from McCubbin & Patterson (as cited in Gallo, 1991). All aspects of results were described according to the model including pile-up of demands, prior strains, consequences of family efforts to cope, family perceptions, family resources, and adaptation. The mother terminated employment soon after the diagnosis, and was responsible for diabetes management. It was found that the family changed its perception of the situation. Specifically, the mother accepted the situation and viewed it

as a challenge. The family also increased and strengthened previous and new resources including social support. They acquired the skills necessary for diabetes management, found new meaning, fostered open communication, and "maintained family stability, cooperation, and organization" (p. 83). The author found that the parents continued to "find mutual support, intimacy, and satisfaction in each other and in their home life...and strived to make decisions... in a nonconflictual manner" (p.83). The author concluded that support was evident for the model. Although data were collected longitudinally over two points in time, only one family with an eight year old daughter was investigated. Validation of the findings with the participants was not discussed.

Other studies have used the child's glycosylated hemoglobin (HbA<sub>1c</sub>) as an outcome measure. In the previously cited study of family stress and resources, the adaptation measure that was used was the child's HbA<sub>1c</sub> (Auslander et al., 1993). Other studies have also used the HbA<sub>1c</sub> as a measure of adaptation (Hauenstein et al., 1989; Vandagriff et al., 1992). Family measures of adaptation were not used in these studies. Few studies have used family measures to measure family adaptation. Family functioning and the child's HbA<sub>1c</sub> have been used. Moreover, very few Canadian studies have been done.

### Conclusion

In conclusion, empirical data suggest that family resources in the non diabetic family are positively associated with adaptation, and that the pileup of family demands is negatively associated with adaptation (McCubbin, 1993). Of the studies reviewed, only one examined these variables in families of children recently diagnosed with diabetes and

variables were not measured over other points in time. In addition, no studies were found examining family hardiness in families of children with diabetes. Clearly, there is a paucity of research in this area. Therefore, this research will examine these variables in families caring for a child with diabetes. The purpose of this research will be to examine the relationships between family demands, family resources including family hardiness, mastery & health, esteem & communication, coping, family support, and family adaptation in families of children with diabetes.

### Research Questions

1. What are the demographic characteristics of families of children with diabetes?
2. What are the health-related characteristics of children with diabetes? (age and gender of child, age at diagnosis, length of time since diagnosis, number of insulin injections per day, number of glucose tests per day)
3. What family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), family support (BBB), and family adaptation (XX) are reported by families of children with diabetes?
4. What are the type and magnitude of relationships among demographic characteristics, health-related characteristics, family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), family support (BBB), and family adaptation (XX) in families of children with diabetes?
5. Considering family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), and family support (BBB), which are the best predictors of family adaptation (XX)?

### Hypotheses

1. It is expected that there is a negative relationship between caregiving demands (AA) and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that higher caregiving demands will be associated with poorer adaptation.
2. It is expected that there is a positive relationship between the family resource (BB) of family hardiness and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that higher levels of family hardiness will be associated with better family adaptation.
3. It is expected that there is a positive relationship between the family resource (BB) of mastery/health and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that higher levels of mastery/health will be associated with better family adaptation.
4. It is expected that there is a positive relationship between the family resource (BB) of esteem/communication and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that higher levels of esteem/communication will be associated with better family adaptation.
5. It is expected that there is a positive relationship between the family resource (BB) of family coping (PSC) and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that coping will be associated with better family adaptation.
6. It is expected there is a positive relationship between the family resource (BB) of family support (BBB) and family adaptation (XX) in families of children with diabetes.



**Specifically, it is expected that family support (BBB) will be associated with better family adaptation (XX).**

## **CHAPTER THREE**

### **METHODS AND PROCEDURES**

#### **Research Design**

A descriptive correlational design was used for this investigation. This design was warranted given the current state of the science. Brink and Wood (1989) state that the correlational design is used when a relationship among variables is suspected and supported by the literature or previous research. In addition, they state that the purpose of the correlational study is to describe relationships among variables. In order to advance the state of the science, the precise description of the relationships among the variables is needed (Brink and Wood, 1989). Furthermore, results from this type of study may also provide support for a theory (Brink & Wood, 1989).

#### **Methods**

##### **Conceptual Framework**

The conceptual framework used for this study is The Resiliency Model of Family Stress, and Adaptation (McCubbin & McCubbin, 1993) as described in chapter one. This study focused on the following components of the model: (a) family demands (AA), (b) family resources (BB) of family hardiness, mastery & health, esteem & communication, family support (BBB), (c) coping (PSC), and (d) family adaptation (XX).

For the purposes of this research, family included units which included mothers caring for a child with diabetes ranging from birth to twenty-one years. Mothers/primary caregivers were asked to complete the questionnaires, as the literature suggests that they typically assume the responsibility for diabetes management. Uphold and Strickland

(1989) state that one family informant may be used when the researcher assumes that one individual is the most accurate and knowledgeable member as in the case of a primary care provider for an ill member.

### Participants

The correlational design typically includes a large random sample of the population. However, when the investigator is unable to use a random sample, a convenience sample may be used (Brink & Wood, 1989). A convenience sample comprised of families caring for a child/adolescent with Type 1 diabetes who access a pediatric outpatient diabetes clinic in Windsor, Ontario, was used. All families who consented to participate, and who met the following criteria, namely, the abilities to speak English, to read and write, and to provide informed consent were included.

The use of a convenience sample limits external validity, and hence, generalizability of the findings (Brink & Wood, 1989). Although many biases may occur in the convenience sample, serious biases do not always exist (Burns & Grove, 1997). Therefore, data were gathered to provide for a complete description of the sample in order that others may assess its representativeness (Brink & Wood, 1989). This information assisted the author to evaluate possible sampling biases (Burns & Grove, 1997).

Ethical approval to implement this research study was obtained from the Windsor Human Research and Ethics Committee and from the University of Windsor School of Nursing Research Committee.

## **Measurement Methods**

### **Measures/Instruments**

Measures included the following.

#### **Demographic data**

Demographic data were collected including number of people in the household, marital status of parents, age of the family respondent, age of partner (where applicable), highest education level attained by both parents, occupation of both parents, and current employment status including full/part time of both parents. Data on cultural background, family history of diabetes, and gender and ages of other children in the family were also collected.

#### **Health Characteristics**

Age and gender of the child with IDDM, age at diagnosis, and length of time since diagnosis were collected. Number of insulin injections, and number of glucose tests per day were also collected.

#### **Family demands (AA)**

The Care of My Child (Diabetes) instrument (McCubbin, Oberst, Cornwell, & Espenshade, 1993) measures caregiving demands of parents of children with diabetes. The instrument contains 19 items referring to caregiving activities ranging from giving insulin injections to obtaining child care. Responses are given on a likert type scale to address time spent on each activity and effort/difficulty associated with each activity. Alpha reliabilities (Cronbach's) of the resulting demands (time x effort) and validity have been provided by the author. Reliabilities of demands range from 0.86-0.90 for both

mothers and fathers. Validity was addressed by the following correlations. Mothers' caregiving demands were positively correlated with family demands (FILE), total coping score (CHIP), and family incendiary communication, whereas these demands were negatively correlated with family adaptation, family hardiness, family affirming communication, and perceived social support (PRQ-Part 2). Fathers' caregiving demands were positively correlated with fathers' well being (GHQ-20) (higher scores indicate poorer well being), family demands, family incendiary communication, and psychological stability (coping scales on CHIP), and were negatively correlated with family hardiness (FHI), family adaptation, perceived social support, and family affirming communication (McCubbin, 1996).

#### Family Resources (BB)

##### Family Hardiness Index (BB)

The Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1986) was devised to measure family hardiness as an adaptation and stress resistance resource which would act as a buffer or mediating factor in shielding the family from the effects of stressors and promote family adaptation over time (McCubbin, Thompson, & McCubbin, 1996). Family hardiness includes a sense of control, a view of change as beneficial, and an active response in managing stressful occurrences. The instrument includes twenty items reflecting three subscales of co-ordinated commitment, challenge, and control (McCubbin, McCubbin, & Thompson, 1996). Responses range from mostly false, to mostly true. Internal reliability for the FHI was reported as .82 (Cronbach's alpha) (McCubbin, Thompson & McCubbin, 1996). Test-retest reliability was reported as .86

(McCubbin, Thompson & McCubbin, 1996). Validity was addressed by the following correlations. Hypotheses that Family Hardiness would be correlated with other measures of family strengths including Family Flexibility (Faces 11-Olson, Porter, & Bell, 1982), Family Time and Routines (FTRI-McCubbin, McCubbin, & Thompson, 1986) were confirmed (McCubbin, Thompson, & McCubbin, 1996).

#### Family Inventory of Resources for Management (BB)

The Family Inventory of Resources for Management (FIRM) was developed by McCubbin, Comeau, & Harkins (as cited in McCubbin, Thompson, & McCubbin, 1996) to assess a family's resources. Two scales of the FIRM were used to assess family strengths, namely, esteem and communication, and mastery and health. The esteem and communication scale includes fifteen items and measures support resources in six areas which include family esteem, communication, mutual assistance, optimism, problem solving, and encouragement of autonomy among family members (McCubbin, Comeau & Harkins, in McCubbin, Thompson, & McCubbin, 1996). The mastery and health scale includes twenty items and measures support resources in three areas which include sense of mastery over family events and outcomes, family mutuality, and physical and emotional health. The internal reliability for the esteem and communication scale and the mastery and health scale were reported as .85 and .85 (Cronbach's alpha) respectively (McCubbin, Comeau & Harkins as cited in McCubbin, Thompson, & McCubbin, 1996). Support for the validity of FIRM was reported through findings of significant positive correlations between the FIRM scales and the Family Environment Scales (Moos, 1976 as cited in McCubbin, Thompson & McCubbin 1996) of cohesion, expressiveness, and

organization, as well as findings of negative correlations between family conflict and the FIRM scales (Comeau, 1985 as cited in McCubbin, Thompson & McCubbin, 1996).

#### Coping Health Inventory for Parents (PSC)

The Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin & Cauble, 1979 as cited in McCubbin, Thompson & McCubbin, 1996) was developed to determine parental appraisal of coping responses to management of the chronically ill child. Coping is considered an active process which includes the use of existing resources as well as the development of new resources in order to strengthen the family and decrease the impact of stressors (H. I. McCubbin as cited in McCubbin, Thompson, & McCubbin, 1996). M. A. McCubbin and H. I. McCubbin (1989) identify that coping behaviours are considered a part of family resources (BB) and problem solving coping (PSC) in the Resiliency Model (as cited in McCubbin, Thompson, & McCubbin, 1996). CHIP includes three subscales designed to measure three coping patterns. For the purposes of this study, only those questions pertaining to Coping Pattern 1, namely, family integration, co-operation and an optimistic definition of the situation, will be used (McCubbin, Thompson & McCubbin, 1996). This is measured by 19 items which refer to nineteen behaviours that strengthen family, relationships, and outlook. Reliability of 0.79 (Cronbach's alpha) for Coping Pattern 1 was reported (McCubbin, Thompson, & McCubbin, 1996). The authors cite support for validity of the instrument. Specifically, validity assessments of CHIP were made using the Family Environment Scale (Moos, 1976 as cited in McCubbin, Thompson, & McCubbin, 1996) and child health characteristics in a study of families of children with cystic fibrosis (H. I. McCubbin &

M. A. McCubbin, 1983 as cited in McCubbin, Thompson & McCubbin, 1996). Mothers use of Coping Pattern 1 was positively associated with both family cohesiveness and improvements in the child's health as measured by height, weight, and pulmonary functioning (McCubbin Thompson, & McCubbin, 1996).

#### Family Support Scale (BBB)

Dunst, Jenkins & Trivette (1984) developed the Family Support Scale to measure the helpfulness of various sources of support to families with young children (as cited in Dunst, Trivette, & Deal, 1988). Eighteen items and two open-ended items are included. Sources of support range from spouse, parents, and professional agencies, with two open-ended areas for respondents to identify additional sources of support not identified in the instrument. Responses range from not at all helpful to extremely helpful. The authors cite support for reliability and validity of the instrument (Dunst, Trivette, & Deal, 1988). Specifically, in a study of 139 parents of preschool children who were retarded, handicapped or developmentally at-risk, coefficient alpha was .77, and split-half reliability was .75. The test-retest reliability, with scores obtained one month apart, was .75 for the eighteen items and .91 for the total scale. Test-retest reliability, with scores obtained eighteen months apart, were .41 for the eighteen items and .47 for the total scale (Dunst, Trivette, & Jenkins, 1988).

#### Family Adaptation (XX)

##### The Family Apgar (XX)

The Family Apgar (Smilkstein, 1978) is a questionnaire consisting of five questions reflecting family function. Satisfaction with five areas of family function are



addressed, namely, adaptability, partnership, growth, affection, and resolve (Smilkstein, 1978). Specifically, the items measure satisfaction with assistance received from the family, problem solving and communication, freedom to pursue activities facilitating growth, expression of affection and response to feelings, and time spent together (Smilkstein, 1978). Responses range from "almost always" to "hardly ever" (Smilkstein, 1978). McCubbin & McCubbin (1987) recommend the use of this instrument to provide an overview of family function.

Validity was addressed by group comparisons. A community sample scored significantly higher than an outpatient psychiatric group (Fink, 1995), with higher scores indicative of greater function (Smilkstein, 1978). In addition, the Family APGAR correlated with both the Pless-Satterwhite (1973) Family Function Index (FFI), and with clinicians' evaluation of family function with resulting correlations of .80 and .64, respectively (Fink, 1995).

#### The Feetham Family Functioning Survey (XX)

The Feetham Family Functioning Survey is an instrument designed to systematically assess family functioning (Feetham & Humenick, 1982). The items were derived from a review of the literature and from the author's clinical observations. It emphasizes three areas of family functioning in terms of relationships, namely, the relationships between the family and (a) larger social units, (b) subsystems, and (c) the individual. It is measured by the parents perception of the degree to which a function exists as compared to how much they believe the function should exist in their family. Questions assess areas of family functioning including household tasks, child care,

marital relations, interaction with family and friends as well as with children, involvement with the community, and sources of emotional support. Respondents are asked to rate how much a function exists, how much they believe it should exist, and the importance. A discrepancy score is obtained by calculating the difference between the scores. Alpha coefficients for the total score of "how much there is" was 0.66, for "how much there should be" was 0.75, for the "how important this is" 0.84, and for the discrepancy scores, 0.81. Low discrepancy scores are indicative of higher levels of satisfaction with family functioning. Test-retest reliability was reported as 0.85 over a two week interval. Content, concurrent, and construct validity were also reported (Feetham & Humenick, 1982).

#### Glycosylated Hemoglobin

The child's most recent glycosylated hemoglobin result was also obtained from the medical record. These results were obtained from different laboratories, and thus, were standardized to allow comparison.

#### Procedures

##### Data Collection

Data collection was done according to the following as suggested by Burns & Grove (1997). A codebook was developed that included each variable name, definition, abbreviated name, description, and the range of potential numerical values (Burns & Grove, 1997).

A master list of names was compiled at the clinic. Each name was assigned a code number beginning at 101. Names and corresponding coding was done at the clinic.

The clinical coordinator of the clinic was in charge of the mailing list and code numbers to ensure confidentiality. To facilitate completion of the surveys, all measures and instruments were given to the participants in booklets. All research surveys (booklets) were coded with the family's corresponding code number. A research package was mailed from the clinic to all families who met the criteria for inclusion with the cost assumed by the researcher. Mothers/primary caregivers were asked to complete the surveys. A joint letter of support from the clinic physician and the clinical coordinator (Appendix B) as well as an information letter from the investigator (Appendix C) requesting their participation and explaining the purpose of the study were included. The investigator also enclosed a coffee and tea bag sample with a sentence in the letter to take a break and enjoy a beverage while filling out the survey. These strategies have been found helpful in order to increase the response rate (Burns & Grove, 1997). A stamped author-addressed envelope was included. Due to the possibility of a postal strike, a note was included which outlined two alternatives for return of the survey in the event of a strike.

A postal strike did occur, and the reminder letter was sent following the resumption of postal services four weeks after the first mailing. For those who had not yet responded at three weeks following the reminder, a follow-up letter including a new survey with the same coding was mailed. A reminder letter was sent two weeks following this mailing. The author carefully recorded receipt of the surveys. The response rate was calculated and reported.

Participation was voluntary, and the participants could choose to withdraw from the study at any time which in no way would affect the services that they were receiving. Consent was indicated by return of the questionnaires. Confidentiality was maintained. Individual results based on the code number (not names) were only accessible to the author and were kept under lock and key. The results of the study were disseminated as a collective group profile with no identification of individuals or families.

### **Data Analysis**

All data were formatted for analysis. Data analysis was completed based on the study questions using SPSS for Windows. With this design, the use of instruments with documented reliability and validity is important (Brink & Wood, 1989). Reliability was estimated for all instruments with the population (Brink & Wood, 1989). These estimates were made using the study data (Brink & Wood, 1989). Specifically, Cronbach's alpha coefficient was used to determine reliability. This is a test of internal consistency and examines the degree to which the items in an instrument measure the same construct (Burns & Grove, 1997). A reliability of .80 is acceptable for a well-developed instrument whereas a reliability of .70 is acceptable for a newly developed instrument in accordance with published guidelines (Burns & Grove, 1997).

**Data analysis focused on the research questions.**

- 1. What are the demographic characteristics of families of children with diabetes?**

Categorical, demographic data were analyzed using descriptive statistics including percentages and measures of central tendency as well as measures of dispersion in order to give a complete description of the sample.

**2. What are the health-related characteristics of the children with diabetes?**

Age at diagnosis, length of time since diagnosis, number of insulin injections per day, and number of glucose tests per day were analyzed using descriptive statistics in order to give a complete description of the health-related characteristics of the children with diabetes.

**3. What family demands (AA), family resources (BB) (family hardiness, mastery/health, esteem/communication), coping (PSC), social support (BBB), and family adaptation (XX) are reported by families of children with IDDM?**

Reliability of the instruments was determined using Cronbach's Alpha. Subsequently, each of the variables of demands, resources of family hardiness, mastery & health, esteem & communication, coping, social support, as well as adaptation were analyzed using means, ranges, and standard deviations in order to provide a complete description of the sample. Comparisons were made between this sample and standardization samples.

**4. Are there differences in family demands between families of older children and families of younger children with diabetes?**

To answer this question, t tests were done to measure the differences between groups (families of children 14 years of age and older and families of children 13 years of age or younger).

**5. What are the type and magnitude of the relationships between demographic characteristics, health-related characteristics, family demands (AA), family resources**

**(BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), family support (BBB), and family adaptation (XX) in families of children with IDDM?**

The degree of association between the continuous variables, namely, demographic characteristics, health-related characteristics, demands (AA), resources (BB) of esteem & communication, mastery & health, family hardiness, coping (PSC), family support (BBB), and adaptation (XX) were analyzed using the Pearson Product Moment Coefficient (Pearson's  $r$ ). These correlational analyses were used to determine the degree of linear association between the variables. Noncontinuous variables were treated in other ways including  $t$  tests and chi squares.

Correlations were examined among the independent variables for evidence of multicollinearity, namely, when the independent variables are strongly correlated. Although there is no effect on predictive power, it leads to concerns regarding generalizability. A bivariate correlation of greater than .65 is considered evidence of multicollinearity by most researchers although some use a correlation of at least .80 (Schroeder, 1990 as cited in Burns & Grove, 1997). For the purposes of this investigation, a correlation of .70 was used.

**6. Considering health characteristics, family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), and family support (BBB), which are the best predictors of family adaptation (XX)?**

Based on the literature, information on the variables of interest, namely, (a) health characteristics including the child's age, length of time since diagnosis, (b) family demands (AA) of caregiving demands, (c) internal resources (BB) of family hardiness,

mastery & health, esteem & communication, and coping (PSC), and (d) external resources of family support (BBB), were examined in the regression model. Hierarchical regression analyses (HRA) were conducted to test the model. The dependent variables included family adaptation (XX), namely, satisfaction with family functioning and a measure of child metabolic control. Three HRA were conducted; one using the Family Appgar, a second using the Feetham Family Functioning Survey, and the third using the standardized glycosylated hemoglobin value as criterion variables. HRA was conducted in order to determine the significance of the model, and to determine the amount of variance in family adaptation and the child's metabolic control accounted for by the variables of child health characteristics, family demands, family resources of family hardiness, mastery & health, esteem & communication, coping, and family support. Independent variables that will be effective predictors should have strong correlations with the dependent variable but weak correlations with the other independent variables (Burns & Grove, 1997). The variables were entered as follows: (1) child's age, time since diagnosis, (2) caregiving demands; (3) internal resources of family hardiness, mastery/health, esteem/communication, and coping, and (4) external resources of family support.

According to Norman & Streiner (1994), the sample size should be 5 (or 10) times the number of variables for HRA. The sample size was adequate for the number of variables included in this study. In addition, using Cohen's (1992) power table, the anticipated sample size was adequate for the number of independent variables (for HRA;  $n = 76$  for power = .80, significance level of .05, medium effect size and three

independent variables; or  $n = 97$  for power = .80, significance level of .05, medium effect size and six independent variables).

### Assumptions

Diabetes is a significant problem during childhood. The diagnosis of diabetes in a child (infant, toddler, preschooler, school-age or adolescent) is a stressful event for the entire family, and particularly for the mother who typically assumes responsibility for diabetes management.

Diabetes related demands can be a continuing source of stress for the family, especially during times of normative transitions such as entrance into new developmental stages.

It is assumed that the mother/primary caregiver is the most accurate and knowledgeable member of the family as she is the primary care provider for the child.

### Limitations

A limitation of this study is the use of a convenience sample. External validity or generalizability is limited due to the use of a single pediatric outpatient clinic. Those families who do not utilize the clinic or who chose not to participate were not represented.

Another limitation is the use of self-report measures. Lazarus & Folkman (1984) identify that self-report contributes to the problem of common method variance. These authors, however, recommend the use of self-report measurement of stress, appraisal, and coping, despite the scientific limitations, identifying that the advantages of self-report such as cost-effectiveness and practicality outweigh the disadvantages.



## CHAPTER FOUR

### RESULTS

Data were coded and analyzed using SPSS. Data analysis was focused on the research questions and hypotheses. Results are reported according to the research questions and hypotheses.

#### 1. What are the demographic characteristics of families of children with diabetes?

Seventy-five of one hundred and thirty-two families responded to the survey with a response rate of 56.8%. The mother completed the survey in 93.9% of the cases whereas the father completed the survey in 6.7% of the cases. The respondents indicated that the mother was the primary caregiver in 64.9% of the families, both mother and father in 22.1% of the families, the mother and child in 2.6% of the families, the father in 3.9% of the families, and the child him/herself in 3.9% of the families.

The children with diabetes ranged in age from two to twenty-one years, with a mean of 12.5 and median of 14 years of age respectively. Of these, 51.9% were male and 48.1% were female. Most of the children lived at home with their parents, namely, 94.8%, and 3.9% lived away at university.

Mothers' ages ranged from 26 to 54 years, with a mean and median of 41 years. Fathers ages ranged from 28 to 60 years, with a mean of 42.8 and median of 42 years. The country of birth was identified as Canada for 81.1% of the mothers and 76.7% of the fathers. European countries including England, Holland, Belgium, Italy, Malta, France,

Germany, Poland, and Yugoslavia were identified as the places of birth for 11.4% of the mothers, and 20.5 % of the fathers. Africa or the Middle East was identified as the place of birth for 1.4% of the mothers, and 2.7% of the fathers. The United States was identified as the place of birth for 6.8% of the mothers.

Most of the parents were married, namely 87.8%. Of the remainder, they identified their marital status as separated (1.4%), divorced (6.8%), widowed (2.7%), or remarried (1.4%). None of the parents were single. Parents' educational level ranged from completion of grade school to university. Secondary school was completed by 35.1% of the mothers and 31.9% of the fathers. College or university was completed by 41.9% of the mothers and 40.3% of the fathers.

The majority of the mothers and fathers were employed, namely 79.7% and 92.8% respectively. Most were employed full-time, namely 43.2% and 89.7% respectively. Part-time employment was reported by 36.5% of the mothers. Mothers' occupations ranged from "menial service workers" to "administrators" and fathers' occupations ranged from "menial service workers" to "higher executives" according to classifications on the Hollingshead Four Factor Index of Social Status (1975). The socioeconomic status score as determined by the Hollingshead Four Factor Index of Social Status has a potential range from 8 to 66. The mean for this sample was 37.88 (SD = 9.59), which indicated the average family score was at the upper limit of the middle social stratum (range of middle = 39-30) as identified by Hollingshead.

The number of persons in the home ranged from 2 to 8 or more, with a mean of 4.1, median of 4.0, and mode of 4. The number of siblings ranged from 0 to 4, with the

majority (45.5%) having one sibling. The majority of the children with diabetes were identified as the youngest child in the family (53.9%), and were followed by the oldest (18.4%), the middle child (6.6%), the second oldest (3.9%), and a twin (1.3%).

## **2. What are the health-related characteristics of the children with diabetes?**

Sixty percent of the respondents identified a family history of diabetes. The age at diagnosis ranged from less than one year to 16 years with a mean of 6.4, and median of 6.0 years. Duration of diabetes ranged from 3 to 194 months with a mean of 72.3, median of 53, and standard deviation of 53.2 months. The number of injections per day ranged from one to four with the majority (58.4%) on two injections per day. Self blood glucose monitoring ranged from one to six per day. The majority indicated no hospitalization for the previous year (80.5%). Of those that indicated hospitalization within the past year, 14.3% were hospitalized once, and 5.2% were hospitalized twice.

## **3. What family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), social support (BBB), and family adaptation (XX) are reported by families of children with diabetes?**

Each of the variables of family demands, resources of family hardiness, mastery & health, esteem & communication, coping, family support, and adaptation measures were analyzed using means, ranges, and standard deviations in order to provide a complete description of the sample. Cronbach's alpha coefficient was used to determine reliability for all instruments based on the study data. (See Table 1).

Table 1

**Range, Means, Medians, Standard Deviations, and Reliabilities of Measures (N = 75)**

Measure	M	Mdn	SD	Range	Possible Range	Cronbach's alpha
Caregiving demands	2.16	2.05	0.70	1.07–4.12	1–5	.95
Family hardiness	47.80	49.00	6.28	26–59	0–60	.80
Mastery & health	40.24	42.00	10.00	17–54	0–60	.90
Esteem & Comm.	36.83	38.00	5.04	26–45	0–45	.83
Coping	48.12	49.00	5.89	25–57	0–57	.75
Family support	33.13	32.00	11.78	14–66	0–90	.80
Family Apgar	7.20	7.00	2.21	0–10	0–10	.78
Feetham discrepancy score	19.35	17.00	13.12	0–53	0–150	.83
Glycosylated hgb.% > upper limit of lab.	23.49	20.00	24.95	-16–88		

Caregiving demand scores ( $M = 2.16$ ,  $SD = 0.70$ ) were somewhat lower than those obtained by McCubbin ( $M$  [ $SD$ ] Time1 & Time 2 =  $2.62$  [ $.51$ ] &  $2.42$  [ $.57$ ]) respectively in children less than 12 years with diabetes for at least 1 year, results taken one year apart) (McCubbin, personal communication, 1997). Family hardiness scores ( $M = 47.80$ ,  $SD = 6.28$ ) were similar to mothers of children with diabetes (Time1  $M = 46.42$ ,  $SD = 6.11$ ) and fathers of children with diabetes (Time1  $M = 45.24$ ,  $SD = 6.2$ ) (McCubbin, Thompson, & McCubbin, 1996). Mastery and health scores ( $M = 40.24$ ,  $SD = 10.00$ ) were similar to reported scores (standard  $M = 39$ ,  $SD = 9$ ). Esteem and communication scores ( $M = 36.83$ ,  $SD = 5.04$ ) were similar to reported scores ( $M = 35$ ,  $SD = 6$ ). Coping scores ( $M = 48.12$ ,  $SD = 5.89$ ) were somewhat higher than another study of mothers of children with diabetes (Time 1  $M = 44.40$ ,  $SD = 6.30$ ). Family functioning discrepancy scores ( $M = 19.35$ ,  $SD = 13.12$ ) were lower than those obtained by Snowdon, Cameron & Dunham (1994) in a study of families of children with disabilities ( $M = 33.17$ ,  $SD = 14.96$ ). A lower score indicates higher satisfaction with family functioning.

#### **4. Are there differences in family demands between families of older children and families of younger children with diabetes?**

Results of  $t$  tests indicated that age has a significant effect on caregiving demands. Mothers of children 13 years of age or younger reported significantly higher caregiving demand scores than mothers of children ages 14 or older ( $t$  [ $74$ ] =  $3.00$ ,  $p < .05$ ).

**5. What are the type and magnitude of relationships between demographic characteristics, health-related characteristics, family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), family support (BBB), and family adaptation (XX) in families of children with diabetes?**

The degree of association between the continuous variables was analyzed using the Pearson Product Moment Coefficient (Pearson's  $r$ ). Significant negative correlations were found between caregiving demands and the variables of age of diagnosis, child age, mother's age, and father's age. Coping was significantly related to duration of diabetes. Family support was positively correlated with number of glucose tests per day, and negatively correlated with the variables of child age, and both mother's and father's ages.

Significant positive correlations were found between family hardiness and the variables of mastery & health, esteem & communication, coping, and the Family Apgar score. Significant positive correlations were found between mastery & health and the variables of esteem & communication, coping, and the Family Apgar score. Esteem and communication positively correlated with the variables of coping, and the Family Apgar score. Significant positive correlations were found between family support and the variables of coping and caregiving demands. The Feetham Family Functioning discrepancy score positively correlated with caregiving demands. Significant negative correlations were found between the Feetham Family Functioning discrepancy score and the variables of family hardiness, mastery & health, esteem & communication, coping, and the Family Apgar. The glycosylated hemoglobin above the upper limit positively correlated with coping and the Family Apgar. (See Table 2).

Table 2

Correlation Matrix, Means, and Standard Deviations for Measured Variables in Families of Children with Diabetes (N=75)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16 <sup>a</sup>	17 <sup>a</sup>
<b>Child-Parent Characteristics</b>																	
1. Child Age	1.00																
2. Age Diagnosis	.57***	1.00															
3. Duration Diabetes	.61***	-.30**	1.00														
4. # Injections/Day	.32**	.29*	.11	1.00													
5. # Glucose Tests/Day	-.47***	.00	-.58***	.10	1.00												
6. Mother's Age	.70***	.32**	.50***	.21 <sup>†</sup>	-.35**	1.00											
7. Father's Age	.76***	.45***	.46***	.20	-.32**	.87***	1.00										
8. SES score	.03	-.03	.04	.04	-.12	.05	.03	1.00									
<b>Family Demands</b>																	
9. Caregiving demands	-.35**	-.34**	-.10	-.10	.22 <sup>†</sup>	-.34**	-.41***	-.03	1.00								
<b>Resources</b>																	
10. Family Hardiness	.07	-.05	.13	-.03	-.10	.02	-.02	.03	-.17	1.00							
11. Mastery & Health	.00	-.06	.06	-.04	.02	-.13	-.07	.15	-.21 <sup>†</sup>	.61***	1.00						
12. Esteem & Communication	.03	-.07	.10	-.02	-.05	.04	-.03	.06	.02	.63***	.54***	1.00					
13. Coping	.18	.23*	-.02	.06	-.05	.02	.03	.11	-.04	.54***	.35**	.50***	1.00				
14. Family Support	-.23*	-.17	-.10	-.00	.27*	-.36**	-.32**	.03	.30*	.19 <sup>†</sup>	.21 <sup>†</sup>	.17	.34**	1.00			
<b>Dependent Variables</b>																	
15. Family Apgar	-.01	-.12	.11	.12	-.02	-.04	-.10	-.09	-.11	.48***	.37**	.51***	.52***	.19 <sup>†</sup>	1.00		
16. Family Functioning																	
Discrepancy Score <sup>a</sup>	-.10	.15	-.27*	-.01	.09	-.14	-.05	-.00	.38**	-.42***	-.41***	-.31**	-.26*	-.15	-.39**	1.00	
17. Glycosylated Hemoglobin																	
percent above upper limit <sup>a</sup>	.10	.01	.08	.05	-.11	.05	.02	.05	.17	.09	.10	.18	.31**	-.05	.28*	.08	1.00

Mean 12.47 6.42 72.34 2.40 3.15 41.04 42.76 37.88 2.16 47.80 40.24 36.83 48.12 33.13 7.20 19.35 23.49

Standard Deviation 5.18 4.23 53.18 0.73 1.12 6.67 6.46 9.59 .70 6.28 10.00 5.04 5.89 11.78 2.21 13.12 24.95

<sup>a</sup>Scoring is such that lower scores indicate more positive outcome.

<sup>†</sup>  $p < .10$ , \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Correlations were examined among the independent variables for evidence of multicollinearity. Using a correlation of .70, no evidence of multicollinearity was found. (See Table 2).

6. Considering health characteristics, family demands (AA), family resources (BB) (family hardiness, mastery & health, esteem & communication), coping (PSC), and family support (BBB), which are the best predictors of family adaptation (XX)?

Based on the literature, information on the variables of interest, namely (a) health characteristics including the child's age, length of time since diagnosis, (b) family demands (AA) of caregiving demands, (c) internal resources (BB) of family hardiness, mastery & health, esteem & communication, and coping (PSC), and (d) external resources of family support (BBB) were examined in the regression models. Three HRA were conducted using the Family Apgar, the Feetham Family Functioning discrepancy score, and the child's most recent glycosylated hemoglobin level above the upper limit for the particular laboratory. These analyses are presented in Tables 3 through 5 respectively.

The variables were entered as follows: (1) child's age, length of time since diagnosis, (2) caregiving demands, (3) internal resources of family hardiness, mastery & health, esteem & communication, and coping, and (4) external resources of family support. According to Norman & Streiner (1994), the sample size should be 5 (or 10) times the number of variables for HRA. The sample size was adequate for the number of variables included in this study. In addition, using Cohen's (1992) power table, the



Table 3

**Summary of Hierarchical Regression Analysis for Variables Predicting Family Apgar (N=75)**

Variable	B	sr <sup>2</sup>	R <sup>2</sup> change
<b>Step 1</b>			
Child age	-.14	.01	
Duration diabetes	.29	.05 <sup>†</sup>	.05
<b>Step 2</b>			
Child age	-.21	.02	
Duration diabetes	.31	.06 <sup>†</sup>	
Caregiving demands	-.14	.02	.02
<b>Step 3</b>			
Child age	-.32	.05*	
Duration diabetes	.30	.05*	
Caregiving demands	-.18	.02	
Family hardiness	.04	.00	
Mastery & health	.01	.00	
Esteem & comm.	.25	.03 <sup>†</sup>	
Coping	.41	.10**	.34
<b>Step 4</b>			
Child age	-.31	.04*	
Duration diabetes	.30	.05*	
Caregiving demands	-.20	.03	
Family hardiness	.04	.00	
Mastery & health	-.02	.00	
Esteem & comm.	.26	.03 <sup>†</sup>	
Coping	.38	.07**	
Family support	.06	.00	.002

<sup>†</sup>p < .10; \*p < .05; \*\*p < .01; \*\*\*p < .001

R<sup>2</sup> model = .41\*\*\*

R model = .64\*\*\*

Table 4

**Summary of Hierarchical Regression Analysis for Variables Predicting Feetham Family Functioning Discrepancy Score (N = 75)**

Variable	B	sr <sup>2</sup>	R <sup>2</sup> change
<b>Step 1</b>			
Child age	-.11	.01	
Duration diabetes	-.19	.02	.07
<b>Step 2</b>			
Child age	.10	.01	
Duration diabetes	-.25	.04 <sup>†</sup>	
Caregiving demands	.43	.15***	.15
<b>Step 3</b>			
Child age	.12	.01	
Duration diabetes	-.20	.02	
Caregiving demands	.38	.10**	
Family hardiness	-.08	.00	
Mastery & health	-.21	.02	
Esteem & comm.	-.07	.00	
Coping	-.20	.02	.19
<b>Step 4</b>			
Child age	.07	.00	
Duration diabetes	-.18	.02	
Caregiving demands	.45	.13***	
Family hardiness	-.09	.00	
Mastery & health	-.16	.01	
Esteem & comm.	-.11	.01	
Coping	-.11	.01	
Family support	-.21	.03 <sup>†</sup>	.03

<sup>†</sup>p < .10; \*p < .05; \*\*p < .01; \*\*\*p < .001; \*\*\*\*p < .0001

R<sup>2</sup> model = .45\*\*\*  
R model = .67\*\*\*\*

Table 5

**Summary of Hierarchical Regression Analysis for Variables Predicting Child's Metabolic Control (N = 75)**

Variable	B	sr <sup>2</sup>	R <sup>2</sup> change
<b>Step 1</b>			
Child age	.08	.00	
Duration diabetes	-.02	.00	.004
<b>Step 2</b>			
Child age	.18	.02	
Duration diabetes	-.05	.00	
Caregiving demands	.22	.04	.04
<b>Step 3</b>			
Child age	.06	.00	
Duration diabetes	.02	.00	
Caregiving demands	.17	.02	
Family hardiness	-.18	.02	
Mastery & health	.05	.00	
Esteem & comm.	.03	.00	
Coping	.39	.09*	.11
<b>Step 4</b>			
Child age	-.00	.00	
Duration diabetes	.05	.00	
Caregiving demands	.26	.04 <sup>†</sup>	
Family hardiness	-.20	.02	
Mastery & health	.11	.01	
Esteem & comm.	-.02	.00	
Coping	.52	.14**	
Family support	-.31	.07*	.07

<sup>†</sup>p < .10; \*p < .05; \*\*p < .01; \*\*\*p < .001

R<sup>2</sup> model = .22 (= .05)

R model = .47 (= .05)

sample size was adequate for the number of independent variables for HRA  $n = 76$  for power = .80, significance level of .05, medium effect size and three independent variables; or  $n = 97$  for power = .80, significance level of .05, medium effect size and six independent variables).

The final regression model in this analysis of variables predicting Family Apgar is displayed in Table 3. The overall model was significant ( $R = .64$ ,  $p < .001$ ), with predictors collectively accounting for 41% of the variance in the Family Apgar. Addition of the internal resources of family hardiness, mastery & health, esteem & communication, and coping score in step 3 resulted in a significant change in  $R^2$  ( $R^2$  change = .34,  $p < .001$ ) suggesting that the inclusion of these resources significantly improved the prediction of family apgar. Examination of squared semipartial correlations indicated that child age ( $sr^2 = .05$ ,  $p < .05$ ), duration of diabetes ( $sr^2 = .05$ ,  $p < .05$ ), and coping ( $sr^2 = .10$ ,  $p < .01$ ) made significant contributions to the prediction of the Family Apgar, accounting for 5%, 5%, and 10% of the variance in the variable respectively. Addition of the external resources of family support to the regression model in step 4 did not result in a significant change in  $R^2$ . The overall model, however, was significant. Examination of the squared semipartial correlation coefficients indicates that younger child age ( $sr^2 = .04$ ,  $p < .05$ ), longer duration of diabetes ( $sr^2 = .05$ ,  $p < .05$ ), and coping ( $sr^2 = .38$ ,  $p < .01$ ) made significant unique contributions to the prediction of Family Apgar, accounting for 4%, 5%, and and 7% of the variance in this variable respectively. In addition, esteem & communication demonstrated a trend toward significance accounting for 3% of the variance ( $sr^2 = .03$ ,  $p = .08$ ).

The final regression model for this analysis of variables predicting the Feetham Family Functioning discrepancy score is displayed in Table 4. The overall model was significant ( $R = .67$ ,  $p < .0001$ ) with the predictors collectively accounting for 45% of the variance in satisfaction with family functioning. Child characteristics made no significant contribution to the model. After the second block  $R^2 = .15$ ,  $p < .001$ . Examination of the squared semipartial correlations indicated that caregiving demands made a unique contribution to satisfaction with family functioning accounting for 15% of the variance. Addition of family support scores to the model in the fourth block resulted in a change in  $R^2$  ( $R^2$  change =  $.03$ ,  $p = .08$ ) suggesting that the inclusion of family support may have improved the prediction of greater satisfaction with family functioning. Examination of squared semipartial correlations indicates that caregiving demands ( $sr^2 = .13$ ,  $p < .001$ ) made a significant unique contribution to the prediction of greater satisfaction with family functioning accounting for 13% of the variance in this variable. Family support demonstrated a trend toward significance accounting for 3% of the variance ( $sr^2 = .03$ ,  $p = .08$ ).

The final regression model for this analysis of variables predicting the glycosylated hemoglobin level is displayed in Table 5. The overall model was marginally significant,  $R = .47$ ,  $p = .05$ . Examination of squared semipartial correlations indicates that coping ( $sr^2 = .14$ ,  $p < .01$ ) and family support ( $sr^2 = .07$ ,  $p < .05$ ) made significant unique contributions to the prediction of the glycosylated hemoglobin level above the upper limit, accounting for 14% and 7% of the variance in this variable

respectively. Caregiving demands also demonstrated a trend toward significance ( $sr^2 = .04$ ,  $p = .07$ ) accounting for 4% of the variance.

The following results relate to the study hypotheses.

1. It is expected that there is a negative relationship between caregiving demands (AA) and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that higher caregiving demands will be associated with poorer adaptation.

This hypothesis was supported using the Feetham Family Functioning discrepancy scores, but was not supported using the Family Apgar and the glycosylated hemoglobin level above the upper limit of the laboratory (child's measure of metabolic control). Higher caregiving demands correlated significantly with higher Feetham family functioning discrepancy scores. Higher discrepant scores indicate lower levels of satisfaction with family functioning. Thus, a positive correlation is indicative of higher caregiving demands associated with lower levels of satisfaction with family functioning. Higher caregiving demands correlated significantly with lower levels of satisfaction with family functioning as measured by the Feetham discrepancy score. There was no significant correlation between caregiving demands and the Family Apgar score. Caregiving demands were not significantly correlated with the most recent glycosylated hemoglobin values above the upper limit of the laboratory. However, on the caregiving demands subscale of time demands, there was a trend toward a positive significant relationship with the glycosylated hemoglobin value above the upper limit ( $r = .21$ ,  $p = .08$ ).

**2. It is expected that there is a positive relationship between the family resource (BB) of family hardiness and family adaptation (XX) in families of children with diabetes.**

**Specifically, it is expected that higher levels of family hardiness will be associated with better family adaptation.**

**This hypothesis was supported using the Family Apgar and the Feetham Family Functioning discrepancy score, but not supported using the measure of the child's metabolic control. Higher levels of family hardiness correlated significantly and positively with higher satisfaction with family functioning as measured by the Family Apgar. In addition, higher levels of family hardiness correlated significantly with lower Feetham Family Functioning discrepancy scores. Lower discrepancy scores are reflective of higher satisfaction with family functioning. Thus, higher levels of family hardiness were also significantly correlated with higher satisfaction with family functioning as measured by the Feetham family discrepancy scores. There was no significant correlation between family hardiness and the glycosylated hemoglobin value above the upper limit of the laboratory.**

**3. It is expected that there is a positive relationship between the family resource (BB) of mastery & health and family adaptation (XX) in families of children with diabetes.**

**Specifically, it is expected that higher levels of mastery & health will be associated with better family adaptation.**

**This hypothesis was supported using the Family Apgar and the Feetham Family Functioning discrepancy score, but not supported using the measure of the child's**

metabolic control. Higher levels of mastery & health correlated significantly with higher satisfaction with family functioning as measured by the Family Apgar. In addition, higher levels of mastery & health correlated significantly with lower Feetham Family Functioning discrepancy scores. Lower discrepancy scores are indicative of higher satisfaction with family functioning. Therefore, higher levels of mastery & health were also significantly correlated with higher satisfaction with family functioning as measured by the Feetham family discrepancy scores. There was no significant relationship between mastery & health and the glycosylated hemoglobin value above the upper limit of the laboratory.

4. It is expected that there is a positive relationship between the family resource (BB) of esteem & communication and family adaptation (XX) in families of children with diabetes. Specifically, it is expected that higher levels of esteem & communication will be associated with better family adaptation.

This hypothesis was supported using the Family Apgar and the Feetham Family Functioning discrepancy score, but not using the child's measure of metabolic control. Higher levels of esteem & communication were significantly correlated with higher satisfaction with family functioning as measured by the Family Apgar. In addition, higher levels of esteem & communication correlated significantly with lower discrepancy scores as measured by the Feetham Family Functioning discrepancy score. Lower discrepancy scores indicate higher satisfaction with family functioning. Thus, higher levels of esteem & communication were associated with higher satisfaction with family



functioning as measured by the Feetham Family Functioning discrepancy score. Esteem & communication did not significantly correlate with the glycosylated hemoglobin value above the upper limit of the laboratory.

5. It is expected that there is a positive relationship between the family resource (BB) of family coping (PSC) and family adaptation in families of children with diabetes. Specifically, it is expected that higher coping will be associated with better family adaptation.

This hypothesis was supported using the Family Apgar and the Feetham Family Functioning discrepancy score, but not supported using the child's measure of metabolic control. Higher levels of coping correlated significantly with higher levels of family functioning as measured by the Family Apgar. In addition, higher levels of coping correlated significantly with lower Feetham Family Functioning discrepancy scores. Lower discrepancy scores indicate higher satisfaction with family functioning. Thus, higher levels of coping correlated significantly with higher satisfaction with family functioning as measured by the Feetham Family Functioning discrepancy score. Higher levels of coping correlated significantly with higher glycosylated hemoglobin values above the upper limit of the laboratory.

6. It is expected that there is a positive relationship between the family resource (BB) of family support (BBB) and family adaptation (XX) in families of children with diabetes.

Specifically, it is expected that family support (BBB) will be associated with better family adaptation (XX).

This hypothesis was not supported using the Family Apgar, the Feetham Family Functioning discrepancy score, and the child's measure of metabolic control. There were no significant correlations between family support and scores on the Family Apgar, Feetham Family Functioning discrepancy scores, nor the glycosylated hemoglobin value above the upper limit of the laboratory. However, a correlation between family support and the Family Apgar approached significance in the positive direction ( $r = .19$ ,  $p = .098$ ).

There was a significant correlation between Family Apgar and Feetham Family Functioning discrepancy scores in the expected negative direction. Higher scores on family apgar were associated with lower discrepancy scores, both of which are indicative of higher satisfaction with family functioning.

## CHAPTER FIVE

### DISCUSSION

This study has examined family demands, family resources, and family adaptation in families of children with Type 1 diabetes. In addition, the variables of family demands and family resources were explored to determine the best predictors of family adaptation. The discussion will be focused on the research questions and hypotheses.

The mother was identified as the primary caregiver in most of the families (64.9%) and at least as one of the primary caregivers in most of the remaining families (mother and father 22.1%; mother and child 2.6%). These findings were consistent with other studies findings that the mother assumes most of the responsibility for diabetes management and the ultimate health of the child (Dashiff, 1993; Faulkner, 1996; Gallo, 1991; McCarthy & Gallo, 1992; Moyer, 1989).

Most of the families were in the middle social stratum, and many mothers had completed college or university education. In addition, most of the mothers were employed. Almost half of the sample was employed full-time, and slightly more than 33% was employed part-time. Approximately 20% of the sample was not employed. No significant correlations were found between any of the study variables and the family's social status score as determined by the Hollingshead Four Factor Index of Social Status (1975). This is consistent with findings of U.S. studies in which socioeconomic status did not correlate with metabolic control (Auslander et al., 1993; Goldston, Kovacs, Obrosky, & Iyengar, 1995) and demographic variables did not correlate with metabolic control (Auslander et al., 1993). Few families in this sample were in low social status

groups and all had access to health care so it is not surprising that socioeconomic scores and demographic variables did not correlate with poor metabolic control in the child.

Families reported above average levels of resources including family hardiness, mastery & health, esteem & communication, and coping. Reported satisfaction with family functioning as measured by both the Family Apgar and the Feetham Family Functioning Survey was also above average. However, similar to the findings of Stewart et al. (1994) in a study of families of children with chronic conditions including diabetes, families reported below average family support. This may be due to the relevance of some questionnaire items for this particular group of families. For example, some of the sources of support identified on the questionnaire such as early childhood intervention program and school/day-care centre were not relevant for families of older children. Many of the families identified that not all sources of support were available to them. In addition, as child and parent ages increased, reported family support decreased. Younger children are more dependent upon their parents and therefore, families of younger children may have a greater need for support. Furthermore, older parents may no longer have their own parents available to provide support.

Most of the children were on two insulin injections per day which is the usual prescribed regime. Self blood glucose monitoring ranged from one to six per day. The median glycosylated hemoglobin level above the upper limit of the laboratory indicated that more than half of the children with diabetes were considered to have acceptable metabolic control. Most of the children had not been hospitalized during the previous year. Of those that were hospitalized, most were hospitalized for diagnosis and

subsequent management. This group of children seemed to be fairly well managed and had not required recent hospitalization for management of acute complications.

Mothers of children 13 years of age or younger reported significantly higher caregiving demand scores than mothers of children 14 years of age or older. This likely reflects that older children assume more responsibility for the daily diabetes management such as insulin injections and self blood glucose monitoring. As a result, caregiving demands of mothers of older children with respect to diabetes management were lessened.

The research hypotheses were tested using correlational analyses. For each hypothesis, three outcome variables for family adaptation were used. The Family Apgar score and the Feetham Family Functioning discrepancy score were both measures of satisfaction with family functioning. The third measure was the glycosylated hemoglobin value which was a measure of the child's metabolic control. The ensuing discussion relates to each of the hypotheses.

The first hypothesis of a negative relationship between caregiving demands and family adaptation was supported by the Feetham measure. Higher caregiving demands were associated with poorer adaptation in families of children with diabetes (Feetham score). As reported caregiving demands increased, reported satisfaction with family functioning decreased. This result is consistent with other findings, in which mothers' caregiving demands significantly correlated with family adaptation (McCubbin, personal communication, 1997) and supported the theoretical framework of the study. Caregiving

demands were a measure of stress, and as stress levels increased, it was expected that the measure of adaptation, namely, satisfaction with family functioning, would decrease.

There was no significant relationship between reported caregiving demands and the Family Apgar score. However, the correlation was in the expected negative direction. A possible explanation may be the differences between the Family Apgar and the Feetham Family Functioning Survey, which were both used to measure satisfaction with family functioning. The Family Apgar focused on five aspects of family functioning including adaptation, partnership, growth, affection, and resolve. It is likely that the Family Apgar provided a more global picture of satisfaction with family functioning in the selected areas. The Feetham measure assessed the respondents' discrepancy between their reality and their ideal in areas such as child care, household tasks, and family communication. Thus, the Feetham captures more specifically caregiving demands while the Family Apgar gives a broader overview of satisfaction with family functioning.

The literature has conflicting reports about the influence of family variables and demographic characteristics on metabolic control. No significant relationship was found between caregiving demands and the measure of metabolic control, although this correlation was in the expected direction. These findings are consistent with Vandagriff et al. (1992) who found no relationship between parental worry (as measured by the worry subscale of a modified version of the DCCT's Diabetes Quality of Life measure) and metabolic control, Hauenstein et al. (1989) who found no differences in glycosylated hemoglobin values based on mothers' reported stress levels, and Auslander et al. (1993)

who found that mothers' reports of family stress were not correlated with metabolic control.

The second hypothesis that as family hardiness increased, family adaptation would increase, was supported by both measures of family functioning, but not by the measure of metabolic control. As expected, family hardiness was associated with satisfaction with family functioning in these families. This is consistent with findings of studies of families of children with disabilities (Failla & Jones, 1991; Snowden, Cameron, & Dunham, 1994). These families reported above average levels of family hardiness, which included family commitment to working together to manage problems, seeing difficulties as challenges, and having a sense of internal control.

A positive relationship between the family resource of mastery and health and family adaptation was supported by both indices of family functioning, but not supported by the measure of metabolic control. As expected, higher levels of mastery and health were associated with greater satisfaction with family functioning in these families. This is consistent with findings of a study of families of children with disabilities in which higher levels of mastery & health were also associated with lower family functioning discrepancy scores (Snowdon, Cameron, & Dunham, 1994).

The family resource of esteem and communication also had a positive relationship with both measures of satisfaction with family functioning, but not with the child's metabolic control. Families who reported higher levels of esteem and communication reported higher satisfaction with family functioning. Esteem and communication are family strengths that include respect from others both within and outside of the family,

communication, problem solving, and promotion of autonomy. These resources appear to be important in this group of families.

The hypothesis that coping is related to family adaptation was supported by both measures of satisfaction with family functioning, but not by the measure of the child's metabolic control. Higher reported levels of coping were associated with higher perceived levels of satisfaction with family functioning. This is consistent with findings of a study of families of children with disabilities who reported high levels of coping including the coping pattern of maintaining family unity and cooperation (Failla & Jones, 1991).

Coping was also significantly associated with the child's measure of metabolic control. The correlation was in the positive direction indicating that as coping increased, the glycosylated hemoglobin value increased. In other words, as coping increased, metabolic control decreased indicating poorer blood sugar control. Perhaps as metabolic control worsened, families needed to use more coping strategies in order to manage the diabetes. Faulkner (1996) found that one of the family responses to children with diabetes was coping with the diabetes as well as managing it. Within the conceptual framework, coping behaviours were defined as attempts to decrease or manage demands and to use available resources (McCubbin, Thompson, & McCubbin, 1996).

The hypothesis that as family support increases, family adaptation increases, was not supported by the measures of satisfaction with family functioning or the child's metabolic control. Although not significant, correlations between family support and both measures of satisfaction with family functioning were in the expected directions.



This is consistent with the findings of a study of families of children with disabilities in which total support scores did not correlate with family functioning discrepancy scores (Snowdon, Cameron, & Dunham, 1994). An explanation may be the relevance of some questionnaire items in this instrument for this particular group of families as discussed earlier.

In summary, higher levels of caregiving demands were associated with lower satisfaction with family functioning (Feetham). As mothers reported higher levels of the internal family resources, they reported higher satisfaction with family functioning. These results support the hypotheses drawn from the conceptual framework of the study. Mothers' reports of family support (external resource), however, were not related to satisfaction with family functioning. In addition, mothers' reports of caregiving demands and family resources were not significantly related to the child's metabolic control. These results do not support the hypotheses. Possible explanations may be the relevance of particular questionnaire items on the family support instrument, and the occurrence of other factors impacting on the child's metabolic control.

The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) provided the conceptual framework for this investigation. The focus was on the adaptation phase of the model. The model posits that the level of family adaptation (XX) is determined by interacting variables which include the pileup of demands (AA), the family's resources (BB) including social support (BBB), and the family's problem solving and coping strategies (PSC). The three criterion variables used

as indices of family adaptation (XX) in this study included the Family Apgar score, the Feetham Family Functioning discrepancy score, and the measure of metabolic control.

HRA were conducted using the three outcome measures to determine the most significant predictors of family adaptation (XX) in these families. Based on the literature, the independent variables were entered in four blocks, namely, (1) health characteristics including the child's age and length of time since diagnosis, (2) caregiving demands (AA), (3) internal resources (BB) of family hardiness, mastery & health, esteem & communication, and coping (PSC), and (4) external resources of family support (BBB).

The HRA using the Family Apgar as the outcome measure provided support for particular aspects of the Resiliency Model and explained 41% of the variance in satisfaction with family functioning. Results indicated that younger child age, longer duration of diabetes, and higher levels of mothers' coping each accounted for a significant unique portion of the variance in family functioning. The variable esteem & communication demonstrated a trend toward significance.

Other researchers have also investigated predictors of satisfaction with family functioning. Family hardiness, functional support, family stressors, and parental age were significant predictors of satisfaction with family functioning (Feetham) in families of children with developmental disabilities (Failla & Jones, 1991). Higher levels of mastery and health as well as higher levels of support from spouse and friends were predictors of satisfaction with family functioning (Feetham) in another study of families of children with disabilities (Snowdon, Cameron & Dunham, 1994).

The model in this study provided support for the importance of the family resources of coping and esteem & communication in determining family adaptation (XX) and for the adaptation process, as longer duration of diabetes also emerged as a significant predictor of satisfaction with family functioning. It seems reasonable to find that higher levels of satisfaction with family functioning would be predicted by the use of effective coping strategies. These strategies, by definition, are used to decrease or manage demands and to make use of available resources. Thus, the use of effective coping can be considered to be more important than the other family resources as coping functions to both decrease or manage stress such as caregiving demands, and to access available resources.

The second HRA using the Feetham discrepancy score as the outcome measure provided support for the importance of caregiving demands and family support and explained 45% of the variance in satisfaction with family functioning. Caregiving demands made a significant unique contribution and family support demonstrated a trend toward significance to the prediction of greater satisfaction with family functioning. The regression model did not support the importance of child characteristics, and particular family resources as predictors of family functioning. In a study of families of children with disabilities, child characteristics were not predictors, but higher levels of mastery and health and higher support from spouse and friends predicted higher satisfaction with family functioning (Snowdon, Cameron, & Dunham, 1994).

In this study, higher reported level of caregiving demands was a significant predictor of lower reported levels of satisfaction with family functioning. This was

expected based on the Resiliency Model. Similarly, Failla & Jones (1991) found family stressors to be a significant predictor of satisfaction with family functioning (Feetham). Other studies have identified diabetes management as a major stressor for parents (Hatton et al., 1995; Hodges & Parker, 1987) impacting greatly on family life (Faulkner, 1996). With increased demands which are predominantly assumed by the mother, families may be unable to function as effectively, resulting in lower satisfaction with family functioning.

This regression model did not support the importance of child characteristics or the internal family resources. Conversely the family resources of family hardiness, functional support, (Failla & Jones, 1991) and mastery and health (Snowdon, Cameron, & Dunham, 1994) were predictors of satisfaction with family functioning (Feetham) in families of children with disabilities. The measures of stress in these latter studies differed from the measure used in this study which may account for the variation in findings.

Higher reported levels of family support approached significance as a predictor of satisfaction with family functioning. Questions on the Feetham Family Functioning Survey assess both family demands and family support which may make this instrument more sensitive in these areas than the Family Apgar.

In the third HRA the overall regression model was marginally significant and explained 22% of the variance in the child's metabolic control. This analysis also provided support for some aspects of the Resiliency Model. The measure of caregiving demands approached significance as a predictor while coping and family support made

significant unique contributions to the variance in metabolic control. However, studies have also found that metabolic control was not predicted by mothers' reports of family stress and resources (Auslander et al., 1993), quality of family life or aspects of the parents marriage (Kovacs et al., 1989).

Higher levels of coping and lower levels of family support reported by mothers predicted poorer metabolic control in children with diabetes. These findings are congruent with the theoretical knowledge of coping and family support. Coping strategies are developed in response to stress (McCubbin, Thompson, & McCubbin, 1996). Poor metabolic control can be considered to be stressful to the family, as it can lead to poor health outcomes over time. Thus, it would be expected that mothers with children in poor control would report higher use of coping behaviours. In this study, families reporting lower levels of family support lack an important resource when demands or stress increase. This finding supports the Resiliency Model and highlights the importance of family support on family adaptation (XX) as measured by the child's outcome of metabolic control.

Results also suggest that higher caregiving demands may predict poorer metabolic control. As the overall model was marginally significant, perhaps a larger sample with increased power might have provided more significant results. There may also be other factors that are more important with respect to metabolic control. A recent study found that dietary adherence was the best predictor of metabolic control in adolescents (Burroughs, Pontious, & Santiago, 1993).

Finally, it should be noted that independent variables that are effective predictors should have strong correlations with the dependent variable, but weak correlations with the other independent variables. Findings from the regression analyses may have been weakened due to the significant relationships between the family resources of family hardiness, mastery & health, esteem & communication, and coping. However, these variables were entered as a block. In addition, there were no correlations between the dependent variable of the child's metabolic control and any of the independent variables, which is consistent with the low variance accounted for in this model.

#### **Recommendations for Future Research**

This study contributes to the advancement of nursing knowledge of caregiving demands, family resources, and family adaptation in families of children with diabetes. Support for particular aspects of the Resiliency Model was demonstrated. It also provides some support to research findings that family factors impact on metabolic control.

A strength of this study was the good response rate with sufficient power for the statistical analyses. However, this study used a convenience sample. External validity is therefore limited and the results cannot be generalized to other families of children with diabetes. Therefore, this study should be replicated in other samples of families of children with Type 1 diabetes to determine if similar findings are obtained. The use of multiple sites would increase external validity or generalizability of the findings. Future research could also compare a group of families who have access to a diabetes clinic to a group of families who do not as one would expect that clinic families would be receiving more support.

Significant differences in caregiving demands were found between mothers of older and younger children. Future study could explain if there are differences in caregiving demands between mothers of children of various age groups.

Families in this study reported low levels of family support. Particular questionnaire items from the family support instrument were not relevant for this group of families because parents of older children did not have access to an early childhood intervention program. In addition, some of the sources of support on the measure used were not available to these families. Future research could include the development of an instrument to measure family support that focuses on sources of support that these families find helpful. Qualitative study may provide additional information regarding aspects of family support that are perceived as helpful or not helpful to these families.

This study highlights the differences in findings obtained using different measures of the same variables. Satisfaction with family functioning was operationalized using two measures, both of which yielded different results in the correlational and regression analyses. This acknowledges the differences that are found when a variable is operationalized using two different measures. Future studies could explore this issue further.

Findings supported some aspects of the Resiliency Model. In particular, the correlational analyses supported most of the hypotheses highlighting the importance of family demands and resources to satisfaction with family functioning. HRA supported caregiving demands, coping, and family support as being significant predictors of adaptation.

**This study was cross-sectional and did not examine changes in these variables over time. Longitudinal studies are needed to investigate and document the adaptation process in these families over time. Results of further study may support and enhance the development of the Resiliency Model.**

### **Implications for Nursing Practice**

**The findings of this study provide support for promoting family health and adaptation by assisting families to minimize caregiving demands, and supporting their strengths and resources.**

**Study findings support the need for nursing interventions designed to minimize caregiving demands such as adjusting insulin doses and handling acute illness in all families, but particularly in families of younger children with diabetes. Specifically, nurses could encourage mothers to occasionally delegate some diabetes management tasks to other responsible family members or support persons, so that they can take time for themselves from their busy schedules. The involvement of other family members and support persons in diabetes education classes can be promoted so that they can assist with management activities. The provision of information about new time saving devices for diabetes management may also be helpful.**

**Findings suggest a need for interventions designed to maintain or promote the development of internal resources such as confidence, mastery, and problem solving ability, and the external resource of family support. For example, nurses can support the development of confidence in diabetes management. They can teach families how to respond appropriately to situations such as blood sugar control during exercise and acute**



illness. They can assess family abilities to use problem solving with diabetes management, and support mothers in these endeavours. At times, support groups could be used to encourage sharing of helpful strategies among families. Furthermore, programs may be developed that focus on enhancing coping mechanisms, problem solving strategies, and esteem for family members. Families can be encouraged to seek the help of health care professionals when necessary. Nurses can act as a source of support to these families by their responsiveness to phone inquiries and by their attentiveness during clinic visits and hospitalizations.

The results of this study highlight the importance of family demands and resources and their relationship to adaptation in families of children with diabetes. The nurse can implement interventions that minimize family demands and maximize resources to promote family health and adaptation.

## References

- Almeida, C. M. (1995). Grief among parents of children with diabetes. The Diabetes Educator, 21, 530-532.
- Anderson, J. (1994). Conference news: comments from a recent diabetes symposium. Canadian Journal of Diabetes Care, 18 (2), 11.
- Anderson, B. J., & Auslander, W. F. (1980). Research on diabetes management and the family: A critique. Diabetes Care, 3, 696-702.
- Anderson, B. J., Miller, J. P., Auslander, W. F., & Santiago, J. V. (1981). Family characteristics of diabetic adolescents: Relationship to metabolic control. Diabetes Care, 4, 586-594.
- Auslander, W. F., Bubb, J., Rogge, M., & Santiago, J. V. (1993). Family stress and resources: potential areas of intervention in children recently diagnosed with diabetes. Health and Social Work, 18, 101-113.
- Barnie, A. (1994). The role of the nurse in the implementation of intensive therapy: Lessons from the DCCT. Canadian Diabetes Association, 7 (1), 4-5.
- Banion, C. R., Miles, M. S., & Carter, M. C. (1983). Problems of mothers in management of children with diabetes. Diabetes Care, 6, 548-551.
- Betschart, J. (1987). Parents' understanding of and guilt over their children's blood glucose control. The Diabetes Educator, 13, 398-401.
- Betschart, J. (1993). Children and adolescents with diabetes. Nursing Clinics of North America, 28, 35-44.

Brink, P. J., & Wood, M. J. (1989). Advanced design in nursing research. Newbury Park, CA: Sage.

Burns, N., & Grove, S.K. (1997). The practice of nursing research conduct, critique, & utilization. Philadelphia, PA: W. B. Saunders.

Burroughs, T. E., Pontious, S. L., & Santiago, J. V. (1993). The relationship among six psychosocial domains, age, health care adherence, and metabolic control in adolescents with IDDM. The Diabetes Educator, 19, 396-402.

Canavan, J. (1994). Viewpoint. Canadian Journal of Diabetes Care, 18 (3), 28.

Cohen, J. (1992). A power primer. Psychological Bulletin, 112, 155-159.

Cruickshanks, K. J., LaPorte, R. E., Dorman, J. S., Orchard, T. J., Becker, D. J., Wagener, D., Kuller, L.H., Cavender, D., & Drash, A. L. (1985). The epidemiology of insulin-dependent diabetes mellitus: Etiology and prognosis. In P. I. Ahmed & N. Ahmed., (Eds.), Coping with juvenile diabetes (pp. 332-357). Springfield, Illinois: Charles C. Thomas.

Daneman, D. (1990). Etiology of type 1 diabetes mellitus. Canadian Diabetes Association, 3,(4), 1-2.

Daneman, D. (1994). The control and complications controversy revisited. Canadian Journal of Diabetes Care, 18 (1), 24-25.

Dashiff, C. J. (1993). Parents' perceptions of diabetes in adolescent daughters and its impact on the family. Journal of Pediatric Nursing, 8, 361-369.

Donnelly, E. (1994). Parents of children with asthma: An examination of family hardiness, family stressors and family functioning. Journal of Pediatric Nursing, 9, 398-408.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). Family Support Scale. In Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Enabling and Empowering Families. (pp. 155-157). Cambridge, MA: Brookline Books.

Dunst, C., Trivette, C., & Deal, A. (1988). Enabling and empowering families. Cambridge, MA: Brookline Books.

Edwards, D. R. (1987). Initial psychosocial impact of insulin-dependent diabetes mellitus on the pediatric client and family. Issues in Comprehensive Pediatric Nursing, 10, 199-207.

Failla, S. & Jones, L. C. (1991). Families of children with developmental disabilities: An examination of family hardiness. Research in Nursing and Health, 14, 41-50.

Fantus, I.G., Delovitch, T.L., & Dupré, J. (1997). Prevention of diabetes mellitus: Goal for the twenty-first century: Part two. Canadian Journal of Diabetes Care, 21 (4), 14-20.

Fantus, I. G. & Dupré, J. (1995). Prevention of diabetes: Goal for the twenty-first century: Part one. Canadian Journal of Diabetes Care, 19 (3), 9-17.

Faulkner, M. S. (1996). Family responses to children with diabetes and their influence on self-care. Journal of Pediatric Nursing, 11, 82-93.

Feetham, S. L., & Humenick, S. S. (1982). Feetham Family Functioning Survey. In S. Humenick (Ed.), Analysis of current assessment strategies in the health care of

young children and childbearing families. (pp. 259-268). Norwalk, CT: Appleton-Century Crofts.

Fink, S. V. (1995). The influence of family resources and family demands on the strains and well-being of caregiving families. Nursing Research, *44*, 139-146.

Gallo, A. M. (1991). Family adaptation in childhood chronic illness: A case report. Journal of Pediatric Health Care, *5*, 78-85.

Goldston, D. B., Kovacs, M., Obrosky, D. S., & Iyengar, S. (1995). A longitudinal study of life events and metabolic control among youths with insulin-dependent diabetes mellitus. Health Psychology, *14*, 409-414.

Hatton, D. L., Canam, C., Thorne, S., & Hughes, A. M. (1995). Parents' perception of caring for an infant or toddler with diabetes. Journal of Advanced Nursing, *22*, 569-577.

Hauenstein, E. J., Marvin, R. S., Snyder, A. L., & Clarke, W. L. (1989). Stress in parents of children with diabetes mellitus. Diabetes Care, *12*, 18-23.

Hodges, L. C., & Parker, J. (1987). Concerns of parents with diabetic children. Pediatric Nursing, *13*, 22-24, 68.

Hollingshead, A.B. (1975). Four factor index of social status. Unpublished manuscript, Yale University, New Haven, CT.

Huang, C. (1995). Hardiness and stress: A critical review. Maternal-Child Nursing Journal, *23*, 82-89.

Kobasa, S. C. (1979). Stressful life events, personality and health: An inquiry into hardiness. Journal of Personality and Social Psychology, *37*, 1-11.

Kobasa, S. C., Maddi, S. R., & Courington, S. (1981). Personality and constitution as mediators in the stress-illness relationship. Journal of Health and Social Behavior, 22, 368-378.

Kobasa, S. C., Maddi, S. R., & Kahn, S. (1982). Hardiness and health: A prospective study. Journal of Personality and Social Psychology, 42, 168-177.

Kobasa, S. C., Maddi, S. R., Puccetti, M. C., & Zola, M. A. (1985). Effectiveness of hardiness, exercise and social support as resources against illness. Journal of Psychosomatic Research, 29, 525-533.

Koizumi, S. (1992). Japanese mothers' responses to the diagnosis of childhood diabetes. Journal of Pediatric Nursing, 7, 154-160.

Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paulauskas, S., & Pollock, M. (1985). Initial psychologic responses of parents to the diagnosis of insulin-dependent diabetes mellitus in their children. Diabetes Care, 8, 568-575.

Kovacs, M., Kass, R. E., Schnell, T. M., Goldston, D., & Marsh, J. (1989). Family functioning and metabolic control of school-aged children with IDDM. Diabetes Care, 12, 409-414.

Lawler, M. K., Volk, R., Viviani, N., & Mengel M. B. (1990). Individual and family factors impacting diabetic control in the adolescent: A preliminary study. Maternal-Child Nursing Journal, 19, 331-345.

Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. Psychosomatic Medicine, 55, 234-247.

Lazarus, R. S. & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.

McCarthy, S.M., & Gallo, A. M. (1992). A case illustration of family management style. Journal of Pediatric Nursing, 7, 395-402.

McCubbin, H. I., Comeau, J., & Harkins, J. (1981). Family Inventory of Resources for Management (FIRM). In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (1996). Family assessment: Resiliency, coping and adaptation - Inventories for research and practice. (pp. 307-323). Madison: University of Wisconsin System.

McCubbin, H. I., McCubbin, M. A., Nevin, R., & Cauble, E. (1981). Coping-Health Inventory for Parents (CHIP). In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (1996). Family assessment: Resiliency, coping and adaptation - Inventories for research and practice. (pp. 407-453). Madison: University of Wisconsin System.

McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). Family assessment: Resiliency, Coping, and Adaptation Inventories for Research and Practice. Madison, WI: University of Wisconsin Publishers.

McCubbin, M. A. (1993). Family stress theory and the development of nursing knowledge about family adaptation. In S. L. Feetham, S. B. Meister, J. M. Bell, & C. L. Gillis, (Eds.), The Nursing of Families, 46-58.

McCubbin, M. A. & McCubbin, H. I. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In C. B. Danielson, B. Hamel-Bissel, & P. Winstead-Fry (Eds.), Families, Health, and Illness (pp. 21-63).

McCubbin, M. A., McCubbin, H. I., & Thompson, A. I. (1986). Family Hardiness Index (FHI). In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (1996). Family assessment: Resiliency, coping and adaptation - Inventories for research and practice. (pp. 239-305). Madison: University of Wisconsin System.

McCubbin, M., Oberst, M., Cornwell, S., & Espenshade, E. (1993). Care of My Child (Diabetes).

Mengel, M. B., Lawler, M. K., Volk, R. J., Viviani, N. J., Dees, M. S., & Davis, A. B. (1992). Parental stress response within a family context: Association with diabetic control in adolescents with IDDM. Family Systems Medicine, 10, 395-404.

Menon, R. K., & Sperling, M. A. (1988). Childhood diabetes. Medical Clinics of North America, 72, 1565-1576.

Ministry of Health (1995). Ontario Diabetes Strategy. Taking charge: A new approach to preventing diabetes complications.

Moyer, A. (1989). Caring for a child with diabetes: the effect of specialist nurse care on parents' needs and concerns. Journal of Advanced Nursing, 14, 536-545.

Murphy, H. (1994). Diabetes in childhood. British Journal of Nursing, 3, 892-896.

Norman, G. R. & Streiner, D. L. (1994). Biostatistics The bare essentials. St. Louis, MO: Mosby Year Book.

Papathodorou, N. H. (1985). Diabetes and the family. In P. I. Ahmed & N. Ahmed (Eds.), Coping with juvenile diabetes (pp. 267-292). Springfield, IL: Charles C. Thomas.



Pollock, S. E. (1986). Human responses to chronic illness: Physiologic and psychosocial adaptation. Nursing Research, 35, 90-95.

Radak, J. T. (1990). Who gets diabetes? Diabetes forecast, 12, 38-47.

Sargent, J. (1985). Juvenile diabetes and the family. In P. I. Ahmed & N. Ahmed (Eds.), Coping with juvenile diabetes (pp. 205-233). Springfield, IL: Charles C. Thomas.

Smilkstein, G. (1978). The family Apgar: A proposal for a family function test and its use by physicians. The Journal of Family Practice, 6, 1231-1239.

Snowdon, A. W., Cameron, S., & Dunham, K. (1994). Relationships between stress, coping resources and satisfaction with family functioning in families of children with disabilities. Canadian Journal of Nursing Research, 26, 63-76.

Stewart, M. (1993). Integrating social support in nursing. Newbury Park: Sage.

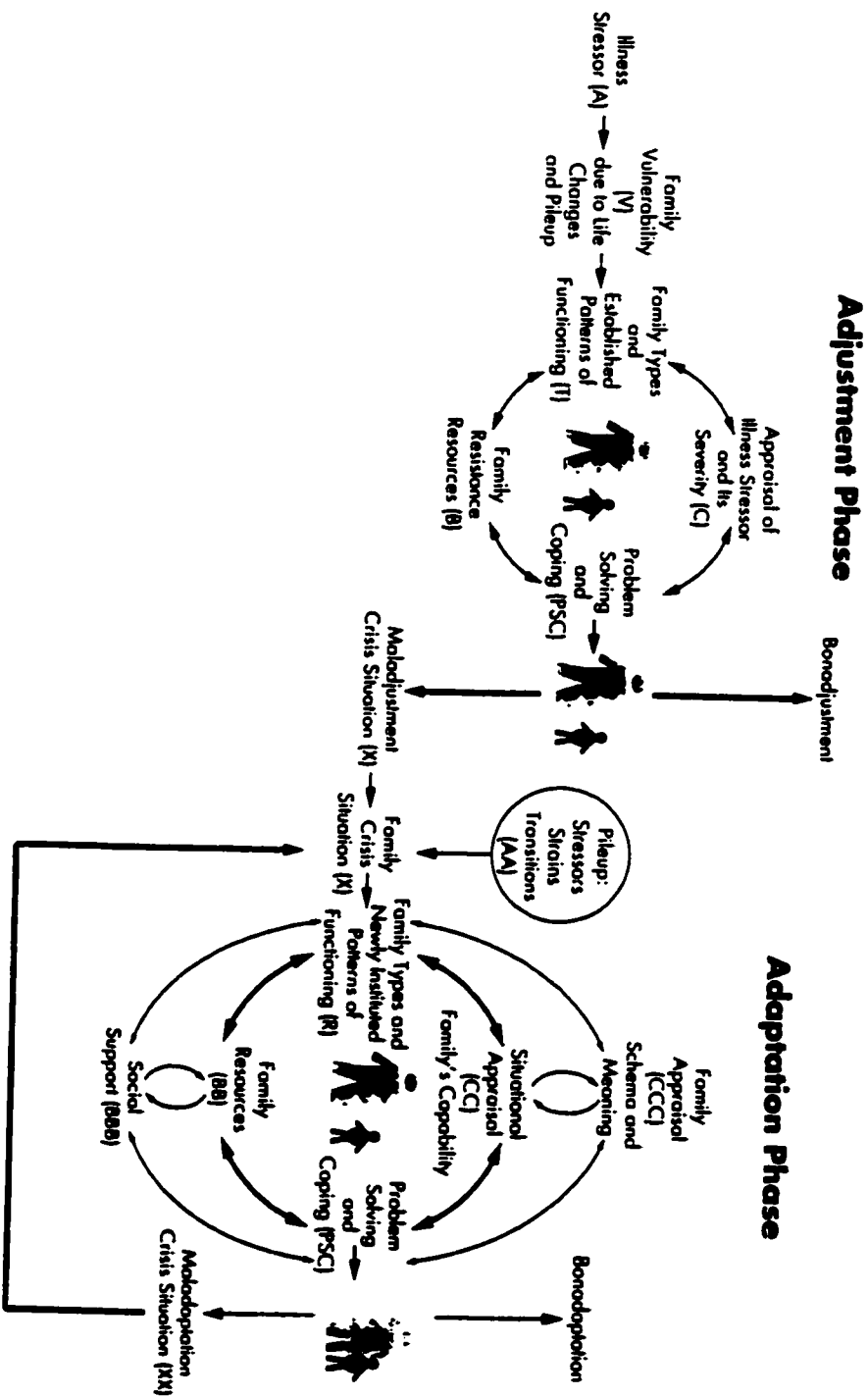
Stewart, M., Ritchie, J., McGrath, P., Thompson, D., & Bruce, B. (1994). Mothers of children with chronic conditions: supportive and stressful interactions with partners and professionals regarding caregiving burdens. Canadian Journal of Nursing Research, 26, 61-82.

Travis, L. B., Brouhard, B. H., Schreiner, B., Johnson, T. A., Guidos, S., McMahon, P., Bingham, S. E., Allen, K., Lovelace, M. (1985). Acute complications of type 1 diabetes: Relationship to coping. In P. I. Ahmed & N. Ahmed (Eds.), Coping with juvenile diabetes (pp. 149-164). Springfield, Illinois: Charles C. Thomas.

Uphold, C. R. & Strickland, O.L. (1989). Issues related to the unit of analysis in family nursing research. Western Journal of Nursing Research, 11, 405-417.

- Vandagriff, J. L., Marrero, D. G., Ingersoll, G. M., & Fineberg, N. S. (1992). Parents of children with diabetes. What are they worried about? The Diabetes Educator, 18, 299-302.
- Warzak, W.J., Ayllon, T., & Delcher, H. K. (1993). Parental versus professional perceptions of obstacles to pediatric diabetes care. The Diabetes Educator, 19, 121-124.
- Wysocki, T. (1993). Associations among teen-parent relationships, metabolic control, and adjustment to diabetes in adolescents. Journal of Pediatric Psychology, 18, 441-452.
- Wysocki, T., Huxtable, K., Linscheid, T. R., & Wayne, W. (1989). Adjustment to diabetes mellitus in preschoolers and their mothers. Diabetes Care, 12, 524-529.
- Wysocki, T. & Wayne, W. (1992). Childhood diabetes and the family. Practical Diabetology, 11 (2), 29-32.
- Zinman, B. (1993). Preventing the complications of diabetes. Beta Release, 17 (1), 25.

**Figure 1 - The Resiliency Model of Family Stress, Adjustment and Adaptation**  
 From M. A. McCubbin & H. I. McCubbin. (1993). In C. B. Danielson, B. Hamel-Bissel, & P. Winstead-Fry (Eds.), *Families, health, & illness: perspectives on coping and intervention*. (p. 23)  
 Used with permission.



## Appendix G

### FAMILY INFORMATION

Date Completed: \_\_\_\_\_

Note: In answering the following questions, please refer to your child with diabetes, unless otherwise indicated.

#### Information pertaining to Child

Date of Birth: \_\_\_\_\_ Male \_\_\_\_\_ Female \_\_\_\_\_ Date of Diagnosis: \_\_\_\_\_

How many insulin injections in one day does your child receive? \_\_\_\_\_

How many finger picks in one day does your child receive? \_\_\_\_\_

Has your child been hospitalized in the past year? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, how many times has your child been hospitalized in the past year? \_\_\_\_\_

Where does your child live? At home with parent(s) \_\_\_\_\_ Other, please specify \_\_\_\_\_

Who is the child's primary caregiver? Mother \_\_\_\_\_ Father \_\_\_\_\_ Other, please specify \_\_\_\_\_

#### Information pertaining to Mother

Date of Birth: \_\_\_\_\_ Country of Birth: \_\_\_\_\_

Highest grade level of education completed: Grade School \_\_\_\_\_

Secondary School \_\_\_\_\_

College \_\_\_\_\_

University \_\_\_\_\_

Marital Status: \_\_\_\_\_ Occupation: \_\_\_\_\_ Employed at present Yes \_\_\_\_\_ No \_\_\_\_\_ if yes

Full-time \_\_\_\_\_ Part-time \_\_\_\_\_

#### Information pertaining to Father

Date of Birth: \_\_\_\_\_ Country of Birth: \_\_\_\_\_

Highest grade level of education completed: Grade School \_\_\_\_\_

Secondary School \_\_\_\_\_

College \_\_\_\_\_

University \_\_\_\_\_

Marital Status: \_\_\_\_\_ Occupation: \_\_\_\_\_ Employed at present Yes \_\_\_\_\_ No \_\_\_\_\_ if yes

Full-time \_\_\_\_\_ Part-time \_\_\_\_\_

Total number of persons living in the home: \_\_\_\_\_

#### Brothers and Sisters

Sex	Date of Birth

#### Brothers and Sisters

Sex	Date of Birth

Family history of diabetes: Yes \_\_\_\_\_ No \_\_\_\_\_

Have your ways of managing your child's diabetes changed over time (since diagnosis to the present time)? If yes, please describe.

---



---



---



---

This form has been completed by \_\_\_\_\_ (mother/father/other, please specify).

If you would like a copy of group results, these will be available at the clinic following completion of the study.

**VITA AUCTORIS**

**NAME** Mary Teresa Lapos Chick

**BIRTH DATE** September 1, 1957

**PLACE OF BIRTH** Windsor, Ontario

**EDUCATION** Centennial Secondary School, Windsor, Ontario  
1971-1976

St. Clair College, Windsor, Ontario  
1978-1980 Diploma in Nursing

University of Windsor, Windsor, Ontario  
1977-1985 B.Sc.N.

University of Windsor, Windsor, Ontario  
1994-1998 M.Sc.